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Contents

Original Papers

Short Paper

Original Paper

Stories From the Field: The Use of Information and Communication Technologies to Address the Health Needs of Underserved Populations in Latin America and the Caribbean

Nasim Farach[1], MA; Gladys Faba[2], PhD; Soroya Julian[3], MSc; Felipe Mejía[4], MSc; Báltica Cabieses[5], PhD; Marcelo D'Agostino[6], MSc; Andrea A Cortinois[7], PhD

[1]Public eHealth, Innovation & Equity in Latin America & the Caribbean (eSAC) project, Tegucigalpa, Honduras
[2]Public eHealth, Innovation & Equity in Latin America & the Caribbean (eSAC) project, Tlayacapan, Mexico
[3]Public eHealth, Innovation & Equity in Latin America & the Caribbean (eSAC) project, Kingston, Jamaica
[4]Public eHealth, Innovation & Equity in Latin America & the Caribbean (eSAC) project, Bogotá, Colombia
[5]Clínica Alemana, Faculty of Medicine, Universidad del Desarrollo, Santiago, Chile
[6]Pan American Health Organization (PAHO), Washington, DC, United States
[7]Dalla Lana School of Public Health, University of Toronto, Toronto, ON, Canada

Corresponding Author:
Nasim Farach, MA
Public eHealth, Innovation & Equity in Latin America & the Caribbean (eSAC) project
Altos de Miraflores Sur, S7
Tegucigalpa,
Honduras
Phone: 504 94573521
Fax: 504 22711357
Email: nfarach@gmail.com

Abstract

Background: As their availability grew exponentially in the last 20 years, the use of information and communication technologies (ICT) in health has been widely espoused, with many emphasizing their potential to decrease health inequities. Nonetheless, there is scarce availability of information regarding ICT as tools to further equity in health, specifically in Latin American and Caribbean settings.

Objective: Our aim was to identify initiatives that used ICT to address the health needs of underserved populations in Latin America and Caribbean. Among these projects, explore the rationale behind the selection of ICT as a key component, probe perceptions regarding contributions to health equity, and describe the challenges faced during implementation.

Methods: We conducted an exploratory qualitative study. Interviews were completed via Skype or face-to-face meetings using a semistructured interview guide. Following participant consent, interviews were audio recorded and verbatim transcriptions were developed. All transcriptions were coded using ATLASti7 software. The text was analyzed for patterns, shared themes, and diverging opinions. Emerging findings were reviewed by all interviewers and shared with participants for feedback.

Results: We interviewed representatives from eight organizations in six Latin American and Caribbean countries that prominently employed ICT in health communication, advocacy, or surveillance projects. ICT expanded project's geographic coverage, increased their reach into marginalized or hard-to-reach groups, and allowed real-time data collection. Perceptions of contributions to health equity resided mainly in the provision of health information and linkage to health services to members of groups experiencing greater morbidity because of poverty, remote place of residence, lack of relevant public programs, and/or stigma and discrimination, and in more timely responses by authorities to the health needs of these groups as a result of the increased availability of strategic information on morbidity and its social determinants. Most projects faced initial resistance to implementation because of lack of precedents. Their financial and technical sustainability was threatened by reliance on external funding and weak transitional structures amidst key staff changes. Projects often experienced challenges in establishing meaningful communication with target audience members, mainly because of divergent motivations behind ICT use between projects and its target audience and the lack of access or familiarity with ICT among the most underserved members of such audiences.

Conclusions: ICT can benefit projects focusing on the health needs of underserved populations by expanding the breadth and depth of target audience coverage and improving data management. Most projects tended to be small, short-term pilot interventions with limited engagement with the formal health sector and did not include health equity as an explicit component. Collaborative projects with government institutions, particularly those with health surveillance objectives, seemed to be the most optimistic about long-term sustainability.

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KEYWORDS

eHealth; Latin America; vulnerable populations; qualitative research

Introduction

It is now widely accepted that social, economic, and environmental conditions are closely linked to health outcomes and that differences in these circumstances among a country's population contribute to persistent and pervasive health inequities [1,2]. This rings particularly true to Latin America and the Caribbean (LAC), regarded as the most persistently unequal region in the world [3]. While certain reductions have been recently noted, LAC countries feature consistently among the most unequal nations [4]. Stark levels of inequality are present in various aspects of everyday life for LAC citizens, including income, housing, education, employment, and health. Differences in health outcomes exist both within and among LAC countries. A regional study in 2010 by the Latin American Center for Rural Development showed that all nations in the region have sub-national territories and lag behind the rest of the country in terms of development indicators and that they tend to have smaller populations, are more rural, and have a larger percentage of indigenous or Afro-descendent inhabitants [5].

Health inequities are closely related to varying levels of power and access to different resources, including information and communication technologies (ICT). As their availability grew exponentially in the last 20 years, the use of ICT in health, often referred to as eHealth, has been widely espoused, with many emphasizing their potential to decrease health inequities [6,7]. The 58th World Health Assembly in May 2005 adopted Resolution WHA58.28, urging member states to develop eHealth strategies and recommending the development of a strategic plan for eHealth; reaching communities, including vulnerable groups; and evaluating and sharing knowledge about eHealth activities to promote equity and equality [8].

Telehealth, in particular, has been at the forefront of the eHealth field. Defined by the World Health Organization (WHO) as the use of ICT by health care professionals for the exchange of information for diagnosis, treatment and prevention of disease and injuries, research and evaluation, and continuing education, telehealth has been one of the most visible, documented, and celebrated applications of ICT in health. Despite this, leading experts in health inequities emphasize the critical importance of addressing social determinants of health (social determinants of health) beyond exclusive clinical settings. For instance, the Strategic Review of Health Inequities in England, chaired by Michael Marmot, unequivocally endorsed the need to address social determinants from a broader perspective to effectively reduce health inequities [9]. Similarly, the Final Report of the WHO Commission on social determinants of health proposed three overarching recommendations that equally highlighted the critical importance of non-clinical factors in health outcomes: improve the conditions of daily life; tackle the inequitable distribution of power, money, and resources; and expand the knowledge base, develop a workforce that is trained in social determinants of health, and raise public awareness about social determinants of health [10].

These calls for action emphasize a need to move beyond purely clinical activities in addressing health inequity by establishing a clear link between social determinants of health and public health activities. As expressed by WHO Director General, Margaret Chan, “in its traditional concern with prevention, public health has much to gain when biomedical approaches to health and disease are extended by a focus on the true root causes of ill-health, suffering and premature death” [11]. ICT may thus have a significant role to play in this extension, beyond a purely telemedical approach, by serving as a channel to effectively address social determinants of health and reduce avoidable inequities in health. This equity-focused public eHealth approach has been described in the literature. Friede, Blum, and McDonald advocated for a greater integration of ICT with public health to enhance disease prevention and health promotion in underserved populations through applications that improve surveillance systems, communication with the public, and service provision [12]. At a political level, the Ministers of Health from LAC highlighted the importance of ICT tools as they incorporated an area of action called Harnessing Knowledge, Science, and Technology for Public Health within the Health Agenda for the Americas in 2007.

With the advent of the Internet and mobile phones, a mounting body of work in the eHealth field has documented reasons for adoption as well as challenges faced by Web-based and mHealth initiatives in diverse settings [13-15]. A large part of this literature focused on clinical applications of eHealth, and recent years have seen an increase in works documenting experiences in developing nations, particularly in Africa—a departure from the initial focus in the developed world [16-19].

Nonetheless, there is currently scarce availability of information regarding ICT as tools to further equity in health specifically in LAC settings. In 2010, the Latin American Economic Commission (CEPAL) highlighted the experiences of six projects in the region that specifically dealt with ICT and inequities, presenting initiatives in six distinct clinical areas: clinical/management systems, unique personal identifiers, remote medical appointments, electronic clinical history, electronic medical prescriptions, and telemedicine. However, the report did not include examples of the use of ICT beyond clinical settings and the impact they could have on social determinants of health [20].

Furthermore, and despite widespread enthusiasm for at least the clinical applications of eHealth in diverse circles, a consensus statement disseminated by thematic experts at the WHO Global eHealth Evaluation Meeting in 2011 urged the continued identification of the barriers to undertaking and using evaluation in eHealth, make recommendations to overcome them, and identify gaps in knowledge where better evidence could increase the appropriate use, scale, and impact of eHealth in resource-limited settings [21].

In response to this knowledge gap, and as part of the Public eHealth, Innovation & Equity in Latin America and the Caribbean (eSAC) project, we conducted an exploratory study among eHealth initiatives in LAC to assess the rationale behind the selection of ICT as a significant project component, probe perceptions regarding contributions to health equity, and describe the challenges these projects faced when conducting their activities. This paper presents the main results of this study in an attempt to capture the experience of projects whose activities dealt with what we considered a particularly understudied purpose (focused on health of vulnerable groups) in a particularly understudied setting (Latin America and the Caribbean). The eSAC project, a joint initiative between the University of Toronto and the Pan American Health Organization (PAHO) and funded by the International Development Research Centre (IDRC), aimed to contribute to the advancement of equity in health in LAC by exploring the intersection of ICT, public health and equity, and fostering the establishment of a virtual community of practice around this intersection.

Methods

Sample Selection

A qualitative research design was selected to allow for an in-depth understanding of the experiences of initiatives that used ICT to address the health needs of underserved populations in LAC. A purposeful sample of projects was selected using specific criteria. To be considered, projects needed to address a public health issue in LAC, have ICT as a key element in project implementation, include an equity component, and be in implementation at the time of the study or completed during the 2 years previous to the interview. For purposes of this study, traditional media, such as radio, television, and landline telephones were not included in our definition of ICT. Because many public health programs did not explicitly mention equity in their objectives or mission statement, we considered the equity criterion to be met if the project addressed a public health need in a traditionally underserved population, such as highly stigmatized groups, rural communities, underprivileged urban areas, youth, or ethnic minorities. Programs that completed projects more than 2 years prior to the time of the interview, but that continued implementing other ICT public health interventions in the region were still considered for inclusion, given the implementing organization´s continuous engagement with public eHealth. In light of the study team’s language skills, only participants fluent in English or Spanish were considered.

Data Collection

Potential participants were identified by a review of the mapping of eHealth projects in LAC conducted by the Public eHealth Equity and Innovation in Latin America and the Caribbean (eSAC) project, publically available at the project’s platform, as well as a scoping review of such interventions conducted in 2012/2013 as part of the eSAC project. This was completed by an expert elicitation process, a structured approach to systematically consult experts on uncertain issues [22]. We contacted four subject-matter experts in the eHealth and equity field in LAC—three with academic backgrounds and one from an international public health agency. We shared study objectives, selection criteria and the preliminary list of participants, and asked for additional potential candidates. As a result of these activities, a list of 18 projects was developed, all of which were contacted via email message or contact request forms at project websites. Out of these, 11 projects responded and 8 agreed to participate in the study.

A semistructured interview guide was developed and piloted with representatives from two projects in Chile and Mexico. Recommendations from the pilot were incorporated into the questionnaire. Interviews were conducted by trained members of the study team using Skype or face-to-face meetings (when the interviewer and participant lived in the same city) and lasted between 45 minutes and 1 hour and 30 minutes. Interviewers followed this guide to address specific topics, including project background, objectives, activities, monitoring and evaluation practices, rationale for ICT tool selection, perception of project’s impact on health inequities, main facilitators, and challenges, and awareness of other eHealth projects. Following participant consent, interviews were audio recorded and verbatim transcriptions were developed.

Analysis

As the interviews were transcribed, a preliminary list of primary themes was identified. These themes became the basis for the first codebook that defined each thematic code. Given transcriptions were developed in participant’s native languages (both Spanish and English), a bilingual study team member was responsible for coding the interviews. All transcriptions were inputted and coded using ATLASti7 software (Scientific Software Development Gmb). During coding, emerging codes were identified and added to the codebook. Memos were written during the process to record our impressions and reflections. Repeated reading of the transcripts facilitated familiarization with the data. Once coding was completed, text was retrieved using ATLASti query functions and analyzed for patterns, shared themes, and diverging opinions. Emerging findings were reviewed by all interviewers and shared with all participants for feedback. While three of them responded thanking the study team for their participation, no technical feedback was received.

Results

Sample Description

A total of 8 participants representing an equal number of projects agreed to participate. Four projects were based in South America (Colombia, n=2, and one each for Chile and Peru), two in the Caribbean (one each from Barbados, Haiti), and two from Central and North America (one each from Mexico, Guatemala). Projects predominantly addressed communicable diseases (n=5): two dealt with HIV/AIDS and one each with water-borne infections (mostly cholera), tuberculosis, and dengue fever. Two projects focused on non-communicable diseases and one dealt with juvenile bullying. While project objectives were more frequently related with health communications (n=5), such as behavior change or health promotion, two projects dealt with public health surveillance and one with advocacy and political incidence. Projects predominantly used mobile phone text messages as their main implementation channel (n=5), but two projects were mainly delivered through social media, particularly Facebook, and one through online games. International agencies constituted the main funding source for most projects (n=5), although one each were primarily supported by a local government, a private business organization or an academic organization. One project was a mixed initiative between an international agency and a private business organization. Table 1 summarizes the characteristics of participating projects, by country, fields of work, ICT channel, and funding source.

Table 1. Profile of participating projects, by country, fields of work, and funding source (N=8).

Characteristics	N
By country	
Barbados	1
Chile	1
Colombia	2
Guatemala	1
Haiti	1
Mexico	1
Peru	1
By morbidity cause	
Communicable diseases	
Dengue fever	1
Water-borne infection (mainly cholera)	1
HIV/AIDS	2
Tuberculosis	1
Non-communicable diseases (NCD)	
General NCD	1
Smoking-related NCD	1
Injury	
Juvenile bullying	1
By technical field of work	
Advocacy and political incidence	1
Health communications	5
Public health surveillance	2
By main ICT channel used	
Mobile phone text messages	5
Gaming (online)	1
Social Media (mainly Facebook)	2
By main funding source	
Academic	1
International agency	5
Mixed (Private/International agency)	1
National government	1
By origin of main funding source	
International	5
Mixed (National and international)	1
National	2

Results are presented around three main themes that convey key aspects of project design and implementation. First, we explore the rationale behind the selection of ICT as the main channel to implement a public health project targeting underserved populations, instead of alternative, non-ICT channels. Second, and in light of projects' focus on underserved populations, we probe perceptions of contribution to health equity. Finally, we analyze the challenges faced by participants during project implementation and discuss the main coping strategies adopted to address these. Table 2 presents the main subthemes identified in each one of these three main themes.

Table 2. Main themes and subthemes: Rationale behind ICT use, perceptions of impact on health equity, and challenges to program implementation.

Main theme	Subthemes
Rationale behind the use of ICT for public health projects targeting underserved populations	
	Expansion of geographic and social reach
	Real time data management
	Interaction enabler
Perceptions of impact on health equity	
	Access to health information and services
	Data for decision making
	Virtual peer support
Challenges	
	Internal
	Lack of precedents
	Technical and financial sustainability
	External
	Lack of meaningful interaction
	Unfamiliarity with ICT
	Data ownership

Rationale Behind the Use of Information and Communication Technologies for Public Health Projects

Expansion of Geographic and Social Reach

The ability to expand geographic or target-audience coverage rates, often with little or no economic investment, featured prominently as a reason to select ICT as a central project component.

> *These powerhouses of platforms [Twitter and Facebook]…are a very effective and cheap form of communication for us because the campaign was spread over many territories. When you look at trying to advertise and communicate with such a wide audience for a small civil society organization that would be very difficult [otherwise].*

ICT also increased the depth of program scope by facilitating connection with stigmatized, hard-to-reach populations—often the most vulnerable, isolated, and who suffer most from health inequities. The selection of a specific ICT varied depending on the characteristics of target audiences. Social media, Facebook in particular, were often selected when the program intended to reach younger audiences, broad national or regional constituencies, or harder-to-reach groups that shared a stigmatized behavior.

> *Overall coverage was minimal in groups like men who have sex with men... you will not find many of them in public venues because of stigma and discrimination. Because they don´t wish to be perceived as gay, they become hermetic, hidden. Social media have helped us most to reach this group.*

The greater availability of mobile phones among economically disadvantaged and rural populations drew many projects to rely on text messages, instead of social media or mobile phone apps. In these cases, target audiences had no or limited access to computers, mobile phones, and/or Internet access.

> *People with tuberculosis are the most vulnerable, the poorest; we assumed that we would be able to reach them through text messages. We could have developed an app, but it would reach the youngest only and would be more complex [for users]. Our idea was to go down to basics, the most commonplace at the time, which I believe is still the text message.*

Some projects adopted a mixed approach. For instance, a project used social media to communicate with members in the capital and other large urban areas, while interventions in rural and other remote regions relied predominantly on text messages.

Real Time Data Management

For health surveillance projects, ICT allowed for more effective survey recruitment and real time data management. This improved data accessibility, facilitated data quality assessments, and allowed for improved monitoring of program activities.

> *SMS text messages were the most efficient and economical way we found for data to flow from the field. The system gives access to first-hand information, directly from the field, from any corner of the country in an almost real time. Public health benefits from access to this data.*
>
> *The real time ability to report and track [text messages] was one of the critical aspects of the project that was able to benefit us and if the project was to be replicated it would be something that we would definitely recommend.*

Interaction Enabler

ICT also brought added value by allowing audience members to become active participants in content creation or communication, beyond mere recipients of information. The dynamic, self-generating characteristic of ICT was highlighted as one of its most valuable and promising features:

> *ICT enables users to produce content. It then becomes an [educational] material that does not end. Our idea is to get to a point where audiences can continue to create material, being a direct player in this construction.*

Participants perceived that eHealth was still in its early development and that projects such as theirs represented the tip of the iceberg in regards to the field´s potential to address other public health concerns. Several participants, while sharing the enthusiasm, stressed the importance of keeping the focus on the project's public health objectives, rather than in the ICT themselves, and stressed the need for further research and evaluation in the field.

> *Many times we think that the project is the technology itself, the act of sending text messages. To be honest, we could have done this [implement the project] in a different way. The good thing is that, since the beginning, we thought about the problem we faced, adherence to treatment, and that this [text messages] was the way in which we could address it in a cheaper, simpler, and more innovative way.*

Perceptions of Impact on Health Equity

Overview

For purposes of this study, we avoided a prescribed definition of equity. Instead, we adopted a more exploratory approach that allowed us to understand the perception of participants regarding their project's contribution to health equity.

Access to Health Information and Services

Perceptions of contributions to health equity resided mainly in the provision of health information and linkage to health services to members of groups experiencing greater morbidity because of poverty, remote place of residence, lack of relevant public programs, and/or stigma and discrimination. In some cases, projects also included a component to effectively link individuals with health services. This was also considered to contribute to health equity, especially considering that many of these individuals faced barriers that had previously prevented their access to health services:

> *Teenagers are not included in any regular program and have no clear alternatives to quit smoking. We are reducing inequity by working with groups with little access to health, but who have a cellular phone.*

Data for Decision Making

Among surveillance projects, participants mentioned that their activities increased the availability of strategic information on morbidity and its social determinants among underserved populations, leading to improved prevention activities and timely responses by Ministries of Health. Perception among participants was that information generated by projects served as a catalyzer for long-overdue health service provision to isolated and marginalized groups:

> *Now, people living in isolated and rural mountain areas are covered by the same system as people in the capital…Before, two days walks were needed to reach some communities, but now the information gets to the central post and the system generates an immediate alert.*

Virtual Peer Support

Another perception of contribution to health equity was the development of virtual self-help groups among people with a specific ailment that eased the psychological burden of disease, created a sense of community, and contributed to improved health outcomes. This was particularly stressed by projects addressing highly stigmatized diseases, like human immunodeficiency virus (HIV):

> *This tool [text-based messages] provided the…confidentiality that many participants sought…Adequate emotional support [through the mHealth group] became a crucial factor in facing daily life.*

Nonetheless, some participants expressed caution in the assessment of contributions to the reduction of health inequities because of the lack of robust evaluations and concerns regarding the exclusion of the most vulnerable:

> *The other obvious bias is that subscribers to our [text message] system are likely more familiar with technology and will perceive it as a more useful tool. This makes us ask ourselves: will we generate a greater gap in relation to the destitute, poorest, or older citizens?*

Challenges to Project Implementation

Overview

Participant narratives revealed both internal and external challenges when implementing eHealth interventions for public health. Internal challenges, referring to obstacles occurring within the organization, were described at different stages of project implementation: resistance to roll out at early phases and uncertainty in project impact and sustainability toward their end. External challenges, on the other hand, refer to barriers arising from projects' interaction with its target audiences, partners and other outside stakeholders, and were experienced mostly during the implementation stage.

Internal Challenges

Lack of Precedents

Many participants faced resistance or skepticism to the introduction of eHealth activities during the initial phases of implementation. In projects operating within organizations where many employees were unfamiliar with ICT, the incorporation of a new ICT element was perceived as an increase in work load that also provided for more intense, unrelenting oversight by off-site supervisors. In other cases, initial tepid responses arose from the lack of precedents:

> *When people don’t understand the benefit [of using ICT] they feel they have one more task to do, that there is one more eye watching over them every day. The perception is that they are now forced to report this new information, that a new inspector is watching them on a daily basis.*

Technical and Financial Sustainability

The lack of sustainability, or project capacity to maintain activities, products and outcomes over time, constantly featured as a significant challenge. Participant narratives described two domains of sustainability challenges: financial and technical. Funding instability loomed as a permanent challenge and became a relentless concern among participants, as international agencies were the most common source of support among sampled projects. From a technical perspective, projects faced the threat of lack of continuity amidst staffing changes, particularly when the person who was more closely linked to project implementation transitioned to another position or organization:

> *An important lesson is that it is important to transmit and share these experiences to give more sustainability in time beyond the people [originally implementing the project].*

Faced rather frequently with these sustainability challenges, projects often recurred to the establishment of partnerships with a diverse set of stakeholders as a strategy to enhance their feasibility. These included collaborations with Ministries of Health, traditional media outlets, mobile phone service providers, community leaders, universities, and existing networks of ICT enthusiasts:

> *I try to invite and involve the private sector, especially those willing to engage in corporate social responsibility…I also try to involve students. I act as a talent hunter among these talented youth, highlighting the opportunity they have to build a name for themselves and showcase their talent.*

Participants working in collaborative projects with government institutions were the most optimistic about long-time sustainability:

> *This system is not expected to end anytime; it does not have a final date. It’s a tool that’s been incorporated into the organization’s management.*

This feeling was even stronger in projects that operated within settings where there was a perception of broader, higher-level support for ICT as part of national policy, instead of the result of a compartmentalized, discrete collaboration between a project and a specific government entity. Such a scenario was described by participants from Colombia:

> *The ICT Ministry and Ministry of Culture are very interested in promoting the use of ICT in different subjects…the stage is set for those interested in working in this, [ICT] when the state is interested in sponsoring.*
>
> *The ICT Ministry has well defined objectives. If one approaches them with an idea, they are very open to it. This facilitated our entry into workplace sites [for the study].*

Beyond the obvious objective of gaining financial sustainability, partnerships were also seen as a strategy to engage with communities, obtain their buy-in, and achieve project objectives. Identifying and partnering with key, local opinion leaders was associated with a greater access to implement project activities and a better response from local audiences.

> *We quickly identified…that the most effective way for the campaign to work is if people on the ground, within the community, take up the campaign. We were able to identify through civil society organizations some team leaders that had the time, the ability and networking to achieve things…Countries where we had strong champions, out there pushing it with their voice and speaking to their communities, we saw a much better response to the campaign.*
>
> *One thing I’ve learned through this pilot is {to understand} the interaction among something new, like technology, and social structures, which tend not to vary. Even if internet is widely available, the community is still in place and is an important factor.*

While partnerships with a myriad of actors featured prominently in the narratives, the establishment of such with other projects implementing public eHealth projects did not surface during the study, despite most participants being aware to some degree of other projects employing ICT in public health, particularly those implemented in the same city or surrounding areas. Very few participants mentioned initiatives beyond their country.

External Challenges

Lack of Meaningful Interaction

For behavior change interventions, the main external challenge was the difficulty of establishing meaningful communication with target audience members through social media channels. Social media was often perceived as a de-personalized channel poorly suited for establishing the often long-term interaction required for successful behavior change:

> *Behavior change is not easy to venture into, even in face-to-face interactions when you have a more human, closer relationship. Let alone through a computer where all sorts of manipulation can take place.*

Further, participants described divergent purposes behind the use of social media among project workers and target audience members. While projects intended to transmit health-related content, the audience mainly used social media for entertainment reasons; projects reported that they could disseminate much information but receive little feedback back. Additionally, projects expressed difficulty transmitting health content in a quantity and format that complied with both project objectives and audience’s needs and interests:

> *The reasons why people use social media are completely different than ours, which are more linked to health, prevention, or education. Many use these*

> *media to meet [sexual partners], interact with friends, or establish relationships.*

Unfamiliarity With Information and Communication Technologies

The lack of familiarity with ICT was an obstacle to reach some of the most vulnerable target audience members, and in some cases required a personalized response to help these individuals join and participate. This rang particularly true for projects that addressed the health needs elderly and economically disadvantaged groups:

> *An older, illiterate woman living with HIV from a very low economic status was very keen in participating [in the virtual support group]…she had difficulties using mobile phones and we had to create a special communication code to ease her use of technology.*

Data Ownership

Projects that established partnerships with private service providers faced issues with mobile phone user data management and ownership, hampering their ability to establish a fluid communication with target audience members. Deficient mobile network and Internet services in remote areas were also reported:

> *The messages went into the different mobile providers systems, into their database, and we then were at the mercy of those providers to push that data back to us.*

Discussion

Principal Results

Among our sample of initiatives, ICT was incorporated as a pivotal element of project implementation for a variety of reasons, most notably the expansion of project geographic coverage, the potential to better access hard-to-reach audiences, perceived low cost, and the improvement of data management and availability. Participant narratives indeed illustrated the edge that ICT can bring to projects addressing the health needs of underserved populations. From improving a country's ability to respond to a water contamination emergency in an isolated rural village, mobilizing large numbers of people to obtain political support for a largely unattended public health problem, or connecting members of a stigmatized group with much-needed prevention services, participants strongly conveyed the critical role played by ICT in addressing public health issues among these vulnerable groups.

Despite these promising accomplishments, participant narratives equally articulated the significant challenges faced during project implementation.

In an environment where pilot projects seemed to be the norm, sustainability was a clear, forefront concern, particularly when activities were primarily supported by international funding or when teams experienced transitions in leadership or key technical staff. As if tagged with an expiry date, projects often operated within a "pilot mode", with a strong commitment to achieve clearly defined outputs but without a clearly defined sustainability plan. With the exception of surveillance focused projects, most interventions did not engage actively with local government structures.

The strong drive among projects to engage with a diverse range of mostly local stakeholders—community leaders, academics, government officials, the private sector—can be interpreted as a clear, concerted effort to enhance sustainability through partnerships. It also seems to reveal an acknowledgement of the significant effect that pre-existing, confounding societal factors can exert in project success or failure. Even when eHealth is touted as an innovative departure from traditional public health approaches and relies on novel channels like social media, apps, and text messages, these projects came to operate into pre-existing social systems already shaped by their own nuanced determinants. Participants described how issues like unequal access to ICT among the most vulnerable (often disguised in thriving ICT penetration rates), persistent stigma and discrimination, or demotivated workforces can inherently affect project capacity to make even the smallest dent in reaching their expected health objectives. For instance, several participants described how the most vulnerable often lacked access or familiarity with ICT and reliable Internet or phone services—the very channels for program implementation. In the case of mHealth interventions, the lack of clearly defined data ownership and access impeded their ability to effectively use customer information for project monitoring and communicating back with consenting target audience members.

Although its benefits were widely acknowledged, the perception of social media and mobile phone apps as exclusionary channels lingered among many participants. This was strongly linked to the understanding that use of both of these required access to a computer or smart phone, as well as Internet service—all of which were limited or unavailable to target audiences. This perception, paired with the ubiquitous nature of mobile phones, prompted several projects to choose text messages as the preponderant delivery channel in their interventions. Even in the case of projects whose target audience was composed by tech-savvy youth, who were purportedly more likely to have access to and familiarity with ICT, their motivation behind using these technologies was often unrelated to health; striking their interest and engagement for health-related purposed thus became a challenge. Regarding networking among these projects, geographical proximity seemed to weigh substantially in the awareness of other interventions, even more than other potentially bonding factors like employment of the same ICT tool or working towards tackling a similar public health issue.

Recommendations

Projects should employ a combination of strategies to overcome the pilot phase where so many currently stumble: addressing sustainability issues from the earliest phases of project design, incorporating program activities into existing government structures, identification of additional sources for renewed funding (including self-generated revenue), and a greater emphasis on capacity building and procedure standardization. mHealth projects establishing partnerships with private service providers should negotiate early on legal issues that could hamper their access to participant data.

Formative research prior to project kick-off and routine monitoring during implementation may help identify potential drawback factors, such as lack of familiarity with ICT or difficulties in establishing meaningful interactions with target audiences. Projects should be ready to design and adapt custom solutions to address these confounding factors.

There seems to be potential for enhanced interaction and collaboration among eHealth practitioners and local stakeholders in close proximity, like policy makers, decision makers, academics, and field enthusiasts. Initiatives promoting public eHealth communities of interest and/or practice could consider a two-tiered approach that stimulates, on the one hand, interaction and potential collaboration with more “local clusters” of eHealth practitioners with a heightened likelihood of some type of face-to-face interaction, while, on the other hand, supporting the integration of these local clusters into a broader, regional network. The likelihood of local clusters emerging and operating regularly would likely be influenced by the context of eHealth support and practice in each city or country.

Limitations

This research paper is based on in-depth interviews with eight projects and results cannot be extrapolated to all interventions of this nature in LAC. Results are based on participant narratives that may include biases of memory selectiveness and attribution. While all organizations that implemented the selected projects were still operating at the time of the interview, two of the projects were completed more than 2 years ago, so there is a possible memory bias in some interviews. Most interviews were conducted in Spanish. Thus, a translation bias may have occurred when citing quotes, which have been translated to English.

Areas for future research include a deeper analysis of eHealth´s potential to reduce health inequities within protractedly unequal societies, the operationalization of equity in ICT-supported health projects, and the exploration of alternative models of sustainability for projects of this nature, including the feasibility of self-generated revenue.

Comparison With Prior Work

The potential and benefits of the use of ICT in health have been extensively touted and helped support the unbridled optimism that has often surrounded the early stages of design and implementation of eHealth initiatives in developing countries [2,6]. Mirroring results from our study, ICT have been credited with increasing reach and raising awareness of health issues among hard to reach groups and offering a more cost-effective way to provide tailored services [23]. From a LAC perspective, most publications have focused on the experience of a specific intervention, particularly in the telehealth field, rather than on a collective perspective on common challenges and perceived impact on equity, which we believe is the main contribution of this paper. While positive short-term outputs and outcomes of eHealth interventions in LAC have been reported in several studies, the analysis of project impact on health inequities and sustainability are still mostly unexplored and additional research on these topics has been strongly advocated [24,25]. The lack of exposure to computer/Internet technology among vulnerable groups and the need for broader partnerships to guarantee project survival beyond pilot phases have also been evidenced earlier and are aspects that need to be addressed in equity-focused health interventions [19,26-28].

Conclusions

ICT may contribute to improved outcomes for projects addressing the health needs of vulnerable populations by expanding geographic coverage, increasing reach into marginalized or hard-to-reach groups, allowing real-time data collection and transforming target audiences from passive recipients into content disseminators and creators. While most projects did not include the concept of health equity as an explicit project component, they clearly perceived their contributions to health equity in the provision of health information and linkage to health services among members of groups suffering from greater morbidity because of poverty, remote place of residence, lack of relevant public programs, and/or stigma and discrimination, and in more timely responses by authorities to the health needs of these groups as a result of the increased availability of strategic information on morbidity and its social determinants. Projects tended to be small pilot interventions with limited engagement with the formal health sector. Their financial and technical sustainability was threatened by reliance on external funding and weak transitional structures within the organizations. Collaborative projects with government institutions seemed most optimistic about sustainability. Projects experienced challenges in establishing meaningful communication with target audience members, mainly because of divergent motivations behind ICT use between projects and its target audience and the lack of access or familiarity with ICT among the most underserved members of such audiences.

Conflicts of Interest

None declared.

References

1. Brennan RLK, Baker EA, Metzler M. Promoting Health Equity: A Resource to Help Communities Address Social Determinants of Health. Atlanta, GA: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention (CDC); 2008.
2. Braveman P, Gruskin S. Defining equity in health. J Epidemiol Community Health 2003 Apr;57(4):254-258 [FREE Full text] [Medline: 12646539]

3. Regional human development report for Latin America and the Caribbean 2010. Acting on the future: breaking the intergenerational transmission of inequality. San Jose, Costa Rica: United Nations Development Program; 2010.
4. Gasparini L, Lustig N. The rise and fall of income inequality in Latin America in Ocampo J, Ros J. editors. Oxford Handbook of Latin American Economics. Oxford: Oxford University Press; 2011.
5. Latin American Center for Rural Development. Poverty and inequality Latin American Report 2011. Santiago, Chile: Latin American Center for Rural Development; 2012.
6. Blaya JA, Fraser HSF, Holt B. E-health technologies show promise in developing countries. Health Aff (Millwood) 2010 Feb;29(2):244-251 [FREE Full text] [doi: 10.1377/hlthaff.2009.0894] [Medline: 20348068]
7. Gerber T, Olazabal V, Brown K, Pablos-Mendez A. An agenda for action on global e-health. Health Aff (Millwood) 2010 Feb;29(2):233-236 [FREE Full text] [doi: 10.1377/hlthaff.2009.0934] [Medline: 20348066]
8. Sinha C, Garro-Strauss D. Research on eHealth across Health Systems: Contributions to Strengthen a Field in Elder, L, Emdon, H, Fuchs, R, Petrazzini, B. In: Connecting ICTs to Development: The IDRC Experience. Ottawa, ON: Anthem Press; 2013.
9. Fair S, Healthy L. Strategic Review of Health Inequities in England. London: The Marmot Review; 2010.
10. Closing the gap in a generation: health equity through action on the social determinants of health. Geneva, Switzerland. 2008. Final Report of the Commission on Social Determinants of Health URL: http://whqlibdoc.who.int/hq/2008/Who_ier_Csdh_08.1_eng.pdf [accessed 2014-12-04] [WebCite Cache ID 6UZUuM3gH]
11. Blas E, Sivasankara-Kurup A. Equity, social determinants and public health programmes. Geneva, Switzerland: Department of Ethics, Equity, Trade and Human Rights, World Health Organization; 2010.
12. Friede A, Blum HL, McDonald M. Public health informatics: how information-age technology can strengthen public health. Annu Rev Public Health 1995;16:239-252. [doi: 10.1146/annurev.pu.16.050195.001323] [Medline: 7639873]
13. Hoffman JA, Cunningham JR, Suleh AJ, Sundsmo A, Dekker D, Vago F, et al. Mobile direct observation treatment for tuberculosis patients: a technical feasibility pilot using mobile phones in Nairobi, Kenya. Am J Prev Med 2010 Jul;39(1):78-80. [doi: 10.1016/j.amepre.2010.02.018] [Medline: 20537846]
14. Chang LW, Kagaayi J, Nakigozi G, Packer AH, Serwadda D, Quinn TC, et al. Responding to the human resource crisis: peer health workers, mobile phones, and HIV care in Rakai, Uganda. AIDS Patient Care STDS 2008 Mar;22(3):173-174 [FREE Full text] [doi: 10.1089/apc.2007.0234] [Medline: 18290750]
15. Mahmud N, Rodriguez J, Nesbit J. A text message-based intervention to bridge the healthcare communication gap in the rural developing world. Technol Health Care 2010;18(2):137-144. [doi: 10.3233/THC-2010-0576] [Medline: 20495253]
16. Aranda C, Mohutsiwa-Dibe N, Loukanova S. Systematic review on what works, what does not work and why of implementation of mobile health (mHealth) projects in Africa. BMC Public Health 2014;14 188 [FREE Full text] [doi: 10.1186/1471-2458-14-188]
17. Rice RE. The Internet and health communication: a framework of experiences. In: Rice R, Katz J, editors. The Internet and Health Communication. Thousand Oaks, CA: Sage; 2001:5-46.
18. Lewis T, Synowiec C, Lagomarsino G, Schweitzer J. E-health in low- and middle-income countries: findings from the Center for Health Market Innovations. Bull World Health Organ 2012 May 1;90(5):332-340 [FREE Full text] [doi: 10.2471/BLT.11.099820] [Medline: 22589566]
19. Gurak L, Hudson B. E-health: Beyond internet searches. In: Murero M, Rice R, editors. The Internet and Health Care: Theory, Research, and Practice. Mahwah, NJ: Lawrence Erlbaum Associates; 2006.
20. Fernandez A, Oviedo E. ICT in the health sector. In: Social policy series Number 165. Santiago, Chile: Latin American Economic Commission (CEPAL); 2010.
21. Bellagio eHealth Evaluation Group. Consensus statement of the WHO Global eHealth Evaluation Meeting, Bellagio. 2011. Call to action on global eHealth evaluation URL: http://www.ghdonline.org/uploads/The_Bellagio_eHealth_Evaluation_Call_to_Action-Release.docx [accessed 2015-03-10] [WebCite Cache ID 6WvyfpR35]
22. Knol AB, Slottje P, van der Sluijs J, Lebret E. The use of expert elicitation in environmental health impact assessment: a seven step procedure. Environ Health 2010;9:19 [FREE Full text] [doi: 10.1186/1476-069X-9-19] [Medline: 20420657]
23. Minichiello V, Rahman S, Dune T, Scott J, Dowsett G. E-health: potential benefits and challenges in providing and accessing sexual health services. BMC Public Health 2013;13:790 [FREE Full text] [doi: 10.1186/1471-2458-13-790] [Medline: 23987137]
24. Glasgow RE, Phillips SM, Sanchez MA. Implementation science approaches for integrating eHealth research into practice and policy. Int J Med Inform 2014 Jul;83(7):e1-11. [doi: 10.1016/j.ijmedinf.2013.07.002] [Medline: 23910896]
25. Schnall R, Travers J, Rojas M, Carballo-Diéguez A. eHealth interventions for HIV prevention in high-risk men who have sex with men: a systematic review. J Med Internet Res 2014;16(5):e134 [FREE Full text] [doi: 10.2196/jmir.3393] [Medline: 24862459]
26. Choi NG, Dinitto DM. The digital divide among low-income homebound older adults: Internet use patterns, eHealth literacy, and attitudes toward computer/Internet use. J Med Internet Res 2013 May;15(5):e93 [FREE Full text] [doi: 10.2196/jmir.2645] [Medline: 23639979]
27. Tomlinson M, Rotheram-Borus MJ, Swartz L. Tsai AC: Scaling Up mHealth: Where Is the Evidence? PLoS Med 2013;10(2).

28. Lemaire J. Scaling up mobile health: Elements necessary for the successful scale up of mHealth in developing countries. Geneva: Advanced Development for Africa; 2010. URL: https://www.k4health.org/sites/default/files/ADA_mHealth%20White%20Paper.pdf [accessed 2015-02-05] [WebCite Cache ID 6W8FqTlwh]

Abbreviations

eSAC: Public eHealth, Innovation & Equity in Latin America and the Caribbean project
ICT: Information and communication technologies
LAC: Latin America and the Caribbean
WHO: World Health Organization

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Original Paper

The Annual American Men's Internet Survey of Behaviors of Men Who Have Sex With Men in the United States: Protocol and Key Indicators Report 2013

Travis Howard Sanchez[1], DVM, MPH; R Craig Sineath[1], MPH; Erin M Kahle[1], PhD, MPH; Stephen James Tregear[2], DPhil; Patrick Sean Sullivan[1], DVM, PhD

[1]Emory University, Atlanta, GA, United States

[2]Manila Consulting Group, McLean, VA, United States

Corresponding Author:
Travis Howard Sanchez, DVM, MPH
Emory University
1518 Clifton Road NE
Atlanta, GA, 30322
United States
Phone: 1 404 727 8403
Fax: 1 404 727 8737
Email: Travis.Sanchez@emory.edu

Abstract

Background: Men who have sex with men (MSM) are disproportionately affected by human immunodeficiency virus (HIV) and there is evidence that this population is participating in increasingly risky sexual behavior. These changes are occurring in the context of new modes of online social interaction—many MSM now report first meeting their sex partners on the Internet. Better monitoring of key behavioral indicators among MSM requires the use of surveillance strategies that capitalize on these new modes of interaction. Therefore, we developed an annual cross-sectional behavioral survey of MSM in the United States, the American Men's Internet Survey (AMIS).

Objective: The purpose of this paper was to provide a description of AMIS methods. In addition we report on the first cycle of data collection (December 2013 through May 2014; AMIS-2013) on the same key indicators used for national HIV behavioral surveillance.

Methods: AMIS-2013 recruited MSM from a variety of websites using banner advertisements or email blasts. Adult men currently residing in the United States were eligible to participate if they had ever had sex with a man. We examined demographic and recruitment characteristics using multivariable regression modeling (*P*<.05) stratified by the participants' self-reported HIV status.

Results: In the AMIS-2013 round, 79,635 persons landed on the study page and 14,899 were eligible, resulting in 10,377 completed surveys from MSM representing every US state. Participants were mainly white, 40 years or older, living in the US South, living in urban areas, and recruited from a general social networking website. Self-reported HIV prevalence was 10.73% (n=1113). Compared to HIV-negative/unknown status participants, HIV-positive participants were more likely to have had anal sex without a condom with any male partner in the past 12 months (72.24% versus 61.24%, respectively; *P*<.001) and more likely to have had anal sex without a condom with their last male sex partner who was discordant/unknown HIV status (42.95% versus 13.62%, respectively; *P*<.001). Illicit substance use in the past 12 months was more likely to be reported by HIV-positive participants than HIV-negative/unknown status participants (39.17% versus 26.85%, respectively; *P*<.001). The vast majority of HIV-negative/unknown status participants (84.05%) had been previously HIV tested, but less than half (44.20%) had been tested in the past 12 months. Participants 18-24 years of age were more likely than those 40 years or older to have had anal sex without a condom with a discordant/unknown HIV status partner, were more likely to report substance use, and were less likely to have been HIV tested. Compared to general social networking, those from a geospatial social networking website were more likely to have reported all risk behaviors but were more likely to have been HIV tested.

Conclusions: The first round of AMIS generated useful behavioral measures from more than 10,000 MSM Internet users. Preliminary findings identified some subgroups of MSM Internet users that are at potentially higher risk of HIV acquisition/transmission. AMIS will provide an ongoing data source for examining trends in sexual risk behavior of MSM. This will help to plan and monitor the impact of programs to improve this population's health.

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KEYWORDS

MSM; gay; homosexual; bisexual; HIV; STD; Internet; survey; surveillance

Introduction

Men who have sex with men (MSM) continue to be disproportionately affected by human immunodeficiency virus (HIV). In the United States in 2012, more than 30,000 MSM were newly diagnosed with HIV infection, representing 66% of all diagnoses that year [1]. In contrast, gay/bisexual-identifying men account for <2% of the total US population [2]. There is also evidence that risky sexual behavior among MSM has increased in the past decade; data from the Centers for Disease Control and Prevention’s National HIV Behavioral Surveillance system (NHBS), that collects data on MSM in major US cities every three years, show a significant increase in the proportion of MSM who reported having anal sex without a condom between their 2005 and 2011 surveys [3]. From 2002-2011, MSM were also the only risk group for whom new HIV diagnoses did not decline [4], and HIV incidence among young MSM is estimated to have increased in recent years [5].

Contemporary to these increased HIV risks are new advances in HIV prevention for MSM. The past 5 years has seen new research proving the efficacy of antiretroviral medication to prevent HIV acquisition (pre-exposure prophylaxis or PrEP) and treatment of HIV positive persons that can reduce transmission [6,7]. Modeling has shown that implementing these biomedical interventions as part of an overall package of HIV prevention services could avert at least one quarter of HIV transmissions among MSM [8]. There are also now more sensitive tests that can detect HIV as early as 1 week after infection and a self-administered rapid HIV test [9,10].

All of these changes are occurring in a new context of social interaction. There are growing numbers of social networking website users and mobile application users [11]. MSM frequently report that they first met their sex partners online and spend considerable time looking for new partners this way [12-15]. This pattern of changing social context for MSM has been capitalized upon by many previous researchers who have successfully conducted entire cross-sectional research studies with MSM online [12-31].

There has also been progress made in large-scale behavioral surveys of MSM designed to monitor key risk behaviors over time. An example of such a system is the Gay Men's Sex Survey that has been conducted with Internet-recruited MSM in the United Kingdom every year since 2001 [32]. The Internet component of the survey now comprises the majority of the more than 10,000 annual survey respondents [33]. The largest ever Internet survey of MSM, the European MSM Internet Survey, was conducted in 2010 and collected data from 180,000 MSM in 38 European countries [34]. This study proved that the Internet is a viable and useful approach for large-scale behavioral surveillance.

In the United States, there has also been exploration of methods for routine monitoring of HIV-related risk behaviors among MSM. There was a one-time feasibility pilot of the Web-based HIV behavioral surveillance system (WHBS) conducted by the Centers for Disease Control and Prevention as supplement to NHBS [3,15,35]. The primary purpose of WHBS was to conduct behavioral surveillance with a standardized survey to compare to other data collections of MSM and estimate prevalence of risk behaviors among MSM Internet users. The pilot was successful at garnering a large sample of MSM.

There remains a need for establishing a system that can produce data for timely and large-scale monitoring of the behavior trends among MSM. In response to this need, we developed a new annual cross-sectional Internet survey of MSM in the United States, the American Men's Internet Survey (AMIS). The goal of AMIS is to collect surveys from 10,000 MSM each year in the United States in order to generate annual snapshots of relevant behaviors. In this paper, we provide the detailed description of our methods/materials, and report recruitment outcomes and some key indicators from our first round of data collection. To help with comparisons, the key indicators and the analytic approach were designed to mirror those used by NHBS’s most recent report on MSM risk behavior [3].

Methods

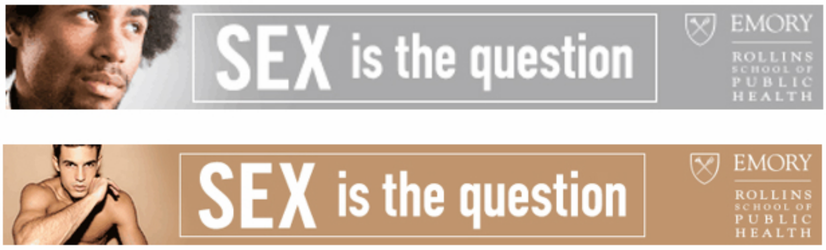
Recruitment and Enrollment

AMIS participants were recruited through convenience sampling from a variety of websites using banner advertisements or email blasts to website members (hereafter referred to generically as "ads"). Ads depicted male models of various races and ethnicities (Figure 1). Men who clicked on the ads were taken directly to the survey website. Two survey platforms were used, depending on the recruitment website. Men recruited through ads posted to a geospatial social networking application were taken to our mobile-optimized survey hosted on a secure server administered by SurveyGizmo (Boulder, Colorado). Men recruited through ads posted elsewhere were taken to our survey hosted on a custom-designed survey website, also hosted on a secure server. Both survey websites used the same study content, used the same security standards, and were compliant with the Health Information Portability and Accountability Act.

The first page that men encountered on the study website contained a brief description of the study. Those who were interested in participating clicked a "begin survey" button that took them to the study's informed consent page which contained standard information regarding the study purpose, procedures, risks, benefits, protections, and investigator contact information.

Those who consented to participate in the study were asked to check a box affirming this decision before continuing. Men who consented were then taken to a page with a brief eligibility screening questionnaire. To be eligible for the survey, participants had to be 18 years of age or older, consider themselves to be male, and report that they had oral or anal sex with a man at least once in the past. As is standard in behavioral research with MSM, transgender persons were excluded from the study because they are not MSM and recruitment approaches and behavioral risk measures should be specifically designed for this group. Persons who reported being <18 years of age or refused to provide their age were not asked any other screening questions. Persons who reported any gender identity other than male were not asked the sex behavior screening questions.

Figure 1. Example Banner Advertisements Used for the American Men’s Internet Survey, 2013.



Survey Administration

MSM who met the eligibility criteria started the online survey immediately. The survey consisted of a core questionnaire administered to all participants, 3 different subset questionnaires to which participants were randomized at the start of the survey, and an additional set of questions that were asked only of participants recruited through geospatial social networking ads. The subset questionnaires were of similar lengths. The intent of the randomization was to reduce overall survey response burden while still generating useful information on some additional behaviors. Participants were blind to this randomization and the randomized subset questions were interspersed with the core questions. The core questions were comprised of the following domains: demographics, sexual behavior, HIV testing history, drug and alcohol use, and HIV prevention services exposure. The randomized question subsets were comprised of the following domains: Subset A—knowledge and use of antiretrovirals for HIV prophylaxis and sexually transmitted disease testing/vaccination; Subset B—disclosure of sexual identity and experiences of stigma; and Subset C—additional details about most recent male sex partner. The participants recruited from the geospatial social networking website received an additional set of questions about a potential mobile HIV prevention app and about acute HIV infection. The core and subset questions were derived from those validated and used by NHBS and used the same timeframes for behaviors [3,36]. The full questionnaire is presented in Multimedia Appendix 1.

To maximize the efficiency of the survey, questions were presented adaptively using a participant's previous responses to determine the path of questioning or auto-filling responses into the text of follow-up questions. On average there were 5 questions per survey webpage. Participants could decline to answer any question. Participants were not asked to correct, verify, or complete responses at the end of their survey. A participant who left their survey would not be able to see any of their previous responses on returning and would have to start the whole survey over again. We did not use cookies to minimize information on a participant's computer that could potentially identify them as an AMIS participant. We did collect Internet protocol (IP) address to allow us to determine residency and identify potential duplicate respondents.

Human Subjects Protections

The study was conducted in compliance with federal regulations governing protection of human subjects and was reviewed and approved by our institution's human subjects research review board. No incentive was provided to the participants. Datasets for analyses are stored on secure data servers with access only granted to study staff. The study data are protected under a federal certificate of confidentiality that prevents legal action to force data release.

Measures and Analyses

Recruitment outcomes for the study are reported as screening, eligibility, unduplicated responses, survey success and reporting sex with a man in the past 12 months. Screening was defined as those who started the screening questionnaire. Overall survey eligibility and individual criteria for ineligibility are presented and were based on survey responses for age, gender and sexual behavior. US residency was determined by either a response of a valid US ZIP code of residence or, for those with no valid ZIP code response, an IP address assigned to a location in the US. Unduplicated responses were determined based on the de-duplication algorithm using IP address, response matching and survey success (see Multimedia Appendix 2 for details). If an observation had a missing value for the first question of at least two consecutive sections, their response was considered incomplete and was not included in the final dataset. All other surveys were considered a "success". Sex with a man in the past 12 months was determined by reporting of one or more partners in response to the question, "In the past 12 months, with how many different men have you had oral or anal sex?"

In addition to standard individual demographic characteristics, we categorized participants based on recruitment source, self-reported HIV status, and geography. The embedded links in the ads were unique and allowed us to determine from which website participants were recruited. We categorized these based on target audience and purpose: gay social networking (n=2), gay general interest (n=3), general social networking (n=1), and geospatial social networking (n=1). We do not provide the names of the websites to preserve operator/client privacy, particularly where a website category has only one operator. Gay social networking websites are those designed for gay or bisexual men to connect with one another, including those attempting to connect for sex. Gay general interest websites are those designed specifically for gay or bisexual men's general interests, such as news stories, public policy advocacy, and travel. The general social networking website is one designed for the general public to connect with others and is not specifically focused on connecting sexual partners. The geospatial social networking website runs on smart cellular telephones and is designed for gay and bisexual men to connect to other men who are near their current location, including those attempting to connect for sex. Self-reported HIV status was determined from responses to questions about having ever had an HIV test, results of the most recent HIV test, and having ever had a positive HIV test. Participants were categorized as HIV-positive, HIV-negative, or unknown status.

We used a combination of county and ZIP code of residence to determine state, US Census-based region, NHBS city residency, and population density. Cities included in the NHBS as of 2011 were as follows: Atlanta, Georgia; Baltimore, Maryland; Boston, Massachusetts; Chicago, Illinois; Denver, Colorado; Houston, Texas; Los Angeles, California; Miami, Florida; Newark, New Jersey; New York City, New York; Philadelphia, Pennsylvania; San Diego, California; San Francisco, California; San Juan, Puerto Rico; Washington, DC; Dallas, Texas; Detroit, Michigan; New Orleans, Louisiana; Nassau-Suffolk, New York; and Seattle, Washington.

The participants who were eligible, unduplicated, successful, and reported male-male sex in the past 12 months were included in analyses of participant characteristics and behavior. Overall chi-square tests were used to identify whether participant characteristics significantly differed between recruitment website types and between question subsets. Following the format used by NHBS in the most recent report of MSM behaviors [3], the prevalence of sex and substance-using behaviors were stratified by self-reported HIV status as either HIV-positive or HIV-negative/unknown. Sexual behaviors were assessed with male partners for either the past 12 months (anal intercourse without a condom with any partner) or for the last partner (anal intercourse without a condom with a discordant or unknown status partner) [3]. HIV serostatus discordance was based on the participant’s HIV status and the status of their sex partner. Discordance was defined as either the participant or partner having unknown status or when one was HIV-negative and the other was HIV-positive. Sexually transmitted infection (STI) testing and diagnosis in the past 12 months was only assessed for one-third of randomized participants and included gonorrhea, Chlamydia and syphilis [37]. Illicit substance use in the past 12 months was assessed as the use of any type of illicit substance by any means of delivery, including injection [37]. Binge alcohol drinking in the past 12 months was assessed as having at least once had 5 or more alcoholic drinks in one sitting [38].

Prevalence of sexual behaviors with male partners, substance use and HIV testing were also presented by race/ethnicity, age group, NHBS city residency, and website recruitment type within the HIV status categories. To determine whether there were significant differences in reported behaviors of different participant subgroups, we conducted multivariable modeling stratified by self-reported HIV status in which each behavior was modeled as the dependent variable and including the following independent variables: race/ethnicity, age group, NHBS city residency, and recruitment website type. We also conducted multivariable logistic regression modeling to determine significant differences in behaviors based on self-reported HIV status while controlling for race/ethnicity, age group, NHBS city residency, and recruitment website type. HIV testing behaviors were only examined among those who did not report that they were HIV-positive and were also presented by participant characteristics. Multivariable logistic regression results are presented as Wald chi-square P values to denote an independently significant difference in the behavior for each sub-group compared to a referent group. Statistical significance was determined at $P<.05$.

Results

Recruitment, Enrollment, and Survey Completion

The 2013 data collection round of AMIS (AMIS-2013) ran from December 2013 through May 2014, and resulted in 79,635 persons clicking on the ads and landing on the study's recruitment page (Table 1). Most were from a general social networking website (36,281/79,635, 45.56%) or a geospatial social networking website (27,720/79,635, 34.81%). About a quarter of those who landed on the study's page (18,669/79,635, 23.44%) consented to take part in it. The proportion providing consent varied by recruitment website, with the highest proportion consenting among those recruited from gay general interest websites (36.97%) and the lowest proportion among recruits from the geospatial social networking website (14.18%). Most who were screened were eligible (79.81%). The most common reasons for ineligibility were not being male or reporting not having male-male sex. This was true even of the websites that were specifically marketed to gay persons.

There were 709 (4.76%) surveys determined to likely be from duplicate participants. Among unduplicated surveys, most were considered successful (12,369/14,190, 87.17%). Most successful surveys were among men who reported having sex with another man in the past 12 months (10,377/12,369, 83.90%). The median duration of completion for successful surveys from MSM participants was 14 minutes. AMIS-2013 was managed, implemented, and analyzed by 4 part-time staff (2 faculty, 1 post-doctoral fellow, and 1 program associate). The total cost to implement the survey was approximately 150,000 USD or 15 USD per successful survey.

Table 1. Recruitment outcomes with different recruitment website types for the American Men's Internet Survey, United States, 2013.

Recruitment outcomes	Total		Gay social networking (n=2)		General gay interest (n=3)		General social networking (n=1)		Geospatial social networking (n=1)	
	n	(%)	n	(%)	n	(%)	n	(%)	n	(%)
Clicked ad	79,635		6889		8745		36,281		27,720	
Consented[a]	18,669	(23.44)	1404	(23.38)	3233	(36.97)	10,100	(27.84)	3932	(14.18)
Ineligible [b]	3770		223	(15.88)	632	(19.55)	2304	(22.81)	611	(15.54)
Not 18+ years of age[c]	636	(16.87)	54	(24.22)	109	(17.25)	311	(13.50)	162	(26.51)
Not male[c]	2132	(56.55)	175	(78.48)	450	(71.20)	1052	(45.66)	455	(74.47)
Not ever MSM[c]	3628	(96.23)	223	(100)	631	(99.84)	2304	(100.00)	470	(76.92)
Not a resident[c]	1408	(37.35)	119	(53.36)	369	(58.39)	732	(31.77)	188	(30.77)
Eligible[b]	14,899	(79.81)	1181	(84.12)	2601	(80.45)	7796	(77.19)	3321	(84.46)
Unduplicated[d]	14,190	(95.24)	1130	(95.68)	2516	(96.73)	7373	(94.57)	3171	(95.48)
Success[e]	12,369	(87.17)	987	(87.35)	2270	(90.22)	6735	(91.35)	2377	(74.96)
MSM[f] past 12 months[g]	10,377	(83.90)	802	(81.26)	1958	(86.26)	5336	(79.23)	2281	(95.96)

[a] Proportion is of total who clicked ad

[b] Proportion is among consented

[c] Proportion is among total ineligible

[d] Proportion is among eligible. Unduplicated removes participants who were marked as duplicates using IP address and demographic data.

[e] Proportion is among unduplicated. Success removes participants who did not pass the survival analysis test for survey completeness.

[f] MSM: Men who have sex with men

[g] Proportion is among successes

Participant Characteristics

Of the 10, 377 participants in AMIS-2013 who had a successful survey and had male-male sex in the past 12 months, more than three-quarters were white, non-Hispanic (Table 2). Nearly half of the participants were ≥ 40 years of age; others were distributed almost equally between younger age groups. The most common region of residence was the South followed by the West. AMIS-2013 had participants from all US states and at least 100 participants from each of 27 states (Figure 2). There were approximately twice as many participants from urban areas as there were from rural areas, and about one-third of participants lived in NHBS cities. Overall, 1113 (10.73%) participants reported being HIV positive and 9264 (89.27%) reported being HIV negative or having an unknown HIV serostatus. Most participants were recruited from a general social networking website. The second most common recruitment site was the geospatial social networking website.

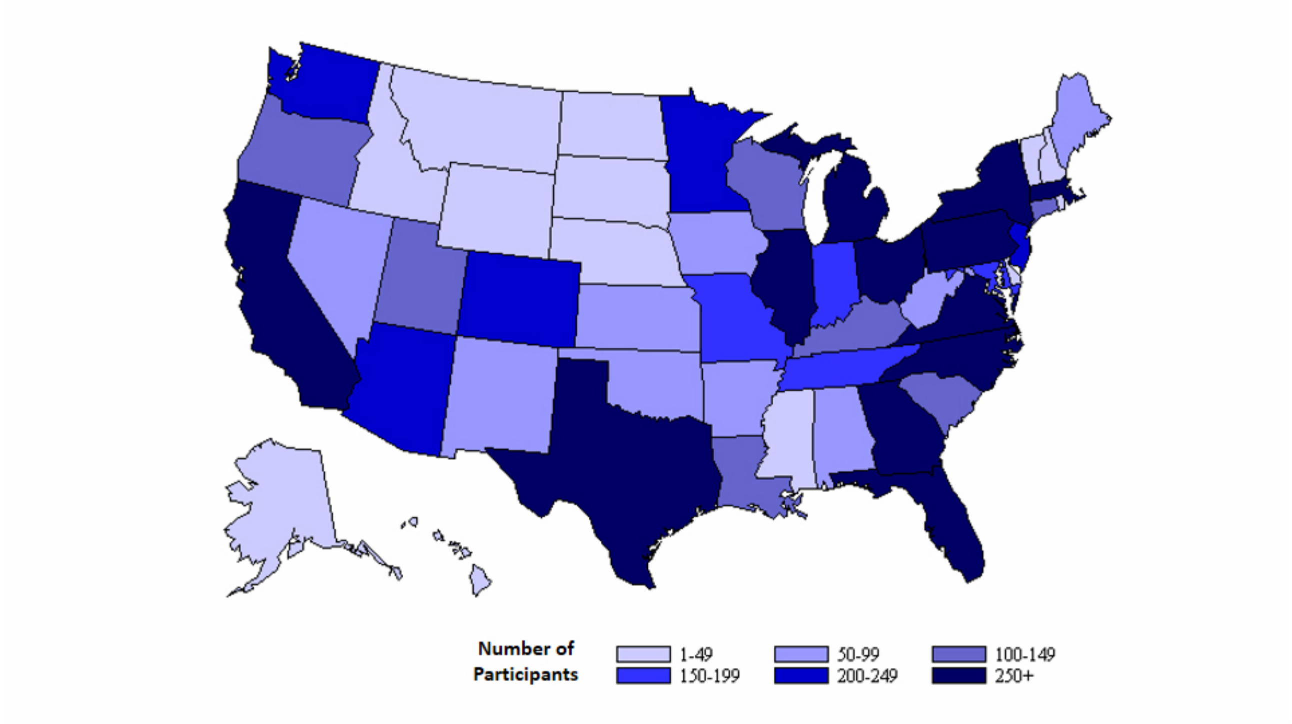
There were significant differences in participant characteristics based on where they were recruited (Table 2, all *P*<.001). Most of those differences were observed among participants recruited from the geospatial social networking website, who were less likely be white, less likely be 40 years or older, less likely to live in an NHBS city, more likely to live in the South, more likely to live in urban areas, and more likely to report being HIV positive. There were no significant differences in the characteristics of survey sub-samples that received the 3 different randomized questionnaires (see Multimedia Appendix 3).

Table 2. Characteristics of MSM participants in the American Men's Internet Survey by recruitment website type, United States, 2013.

Participant characteristics	Total		Gay social networking (n=2)		General gay interest (n=3)		General social networking (n=1)		Geospatial social networking (n=1)	
	n	(%)	n	(%)	n	(%)	n	(%)	n	(%)
Race/Ethnicity										
Black, non-Hispanic	354	(3.41)	37	(4.61)	48	(2.45)	119	(2.23)	150	(6.58)
Hispanic	1084	(10.45)	66	(8.23)	127	(6.49)	417	(7.81)	474	(20.78)
White, non-Hispanic	8076	(77.83)	645	(80.42)	1638	(83.66)	4351	(81.54)	1442	(63.22)
Other or multiple races	863	(8.32)	54	(6.73)	145	(7.41)	449	(8.41)	215	(9.43)
Age (years)										
18-24	1982	(19.10)	96	(11.97)	246	(12.56)	1067	(20.00)	573	(25.12)
25-29	1515	(14.60)	76	(9.48)	256	(13.07)	693	(12.99)	490	(21.48)
30-39	1918	(18.48)	80	(9.98)	398	(20.33)	881	(16.51)	559	(24.51)
40 or older	4962	(47.82)	550	(68.58)	1058	(54.03)	2695	(50.51)	659	(28.89)
Region										
Midwest	2078	(20.03)	203	(25.31)	347	(17.72)	1147	(21.50)	381	(16.70)
Northeast	2050	(19.76)	176	(21.95)	444	(22.68)	1119	(20.97)	311	(13.63)
South	3558	(34.29)	279	(34.79)	648	(33.09)	1681	(31.50)	950	(41.65)
West	2503	(24.12)	144	(17.96)	518	(26.46)	1382	(25.90)	459	(20.12)
US dependent areas	8	(0.08)	0	(0.00)	1	(0.05)	7	(0.13)	0	(0.00)
NHBS[a] City Resident										
Yes	3268	(31.49)	244	(30.42)	858	(43.82)	1750	(32.80)	416	(18.24)
No	7109	(68.51)	558	(69.58)	1100	(56.18)	3586	(67.20)	1865	(81.76)
Population Density										
Rural	3833	(36.94)	360	(44.89)	626	(31.97)	2129	(39.90)	718	(31.48)
Urban	6544	(63.06)	442	(55.11)	1332	(68.03)	3207	(60.10)	1563	(68.52)
Self-reported HIV Status										
Positive	1113	(10.73)	50	(6.23)	155	(7.92)	439	(8.23)	469	(20.56)
Negative	7657	(73.79)	535	(66.71)	1556	(79.47)	4018	(75.30)	1548	(67.86)
Unknown	1607	(15.49)	217	(27.06)	247	(12.61)	879	(16.47)	264	(11.57)
Total	10,377		802		1958		5336		2281	

[a] NHBS: National HIV Behavioral Surveillance System

Figure 2. Number of MSM Participants in the American Men's Internet Survey by State, 2013.



Sexual Behaviors

Most participants had anal sex without a condom with another man in the past 12 months (Table 3). The proportion who had anal sex without a condom was significantly higher among HIV-positive participants compared to HIV-negative/unknown status participants (72.24% versus 61.24%, respectively; *P*<.001). Compared to HIV-negative/unknown status participants, a larger proportion of HIV-positive participants had anal sex without a condom with their last male sex partner who was discordant/unknown status (13.62% versus 42.95%, respectively; *P*<.001).

Among those who were HIV-positive, Hispanic participants were less likely than white participants to report anal sex without a condom in the past 12 months and black participants were less likely than white participants to report anal sex without a condom with an HIV-negative/unknown status partner (Table 3). Participants 18-24 years of age were more likely to report anal sex without a condom with an HIV-negative/unknown status partner compared to participants ≥40 years of age. Nearly two-thirds of HIV-positive participants 18-24 years reported anal sex without a condom with a partner who was either HIV-negative or of unknown status. HIV-positive participants who lived in NHBS cities were also more likely than those living elsewhere to report anal sex without a condom in the past 12 months. Compared to HIV-positive participants from a general social networking website, those recruited from a geospatial social networking website were also significantly more likely to report anal sex without a condom and anal sex without a condom with an HIV-negative or unknown status partner.

Among those who were HIV-negative or unknown status, those 25-39 years of age were significantly more likely to report anal sex without a condom compared to participants ≥40 years of age (Table 3). Participants 18-24 years of age were more likely to report anal sex without a condom with an HIV-positive or unknown status partner compared to participants ≥ 40 years of age. Compared to participants recruited from the general social networking website, those from other websites had significant differences sexual behaviors. Participants from gay social networking websites were less likely to report anal sex without a condom, but those from a geospatial social networking website were more likely to report this behavior. Participants from gay social networking and geospatial social networking websites were more likely to report anal sex without a condom with an HIV-positive/unknown status partner.

Among MSM participants who were HIV-positive, 3.05% (34/1113) also had sex with a woman and 1.17% (13/1113) of those participants reported vaginal sex without a condom in the past 12 months (data not presented in a table). Among those who were HIV-negative or unknown status, 10.29% (953/9264) also had sex with a woman and 6.50% (602/9264) had vaginal sex without a condom in the past 12 months. Both behaviors were significantly more likely among HIV-negative or unknown status participants than among HIV-positive participants (both *P*<.001).

Table 3. Sexual Behaviors with Male Partners of MSM Participants in the American Men's Internet Survey, United States, 2013.

Participant characteristics	n in sample	Anal intercourse without a condom in the past 12 months			Anal intercourse without a condom with last sex partner of discordant or unknown HIV status		
		n	(%)	*P* value[a]	n	(%)	*P* value[a]
HIV-positive overall	1113	804	(72.24)	<.001[b]	478	(42.95)	<.001[b]
Race/Ethnicity							
Black, non-Hispanic	63	46	(73.02)	.580	21	(33.33)	.009
Hispanic	162	110	(67.90)	.032	74	(45.68)	.780
White, non-Hispanic	810	590	(72.84)	REF	343	(42.35)	REF
Other or multiple races	78	58	(74.36)	.335	40	(51.28)	.027
Age (years)							
18-24	90	78	(86.67)	.060	56	(62.22)	.033
25-29	124	104	(83.87)	.085	66	(53.23)	.504
30-39	201	148	(73.63)	.041	94	(46.77)	.244
40 or older	698	474	(67.91)	REF	262	(37.54)	REF
NHBS city resident[c]							
Yes	311	232	(74.60)	.016	119	(38.26)	.793
No	802	572	(71.32)	REF	359	(44.76)	REF
Recruitment website type							
Gay social networking	50	35	(70.00)	.987	25	(50.00)	.122
General gay interest	155	103	(66.45)	.139	57	(36.77)	.108
General social networking	439	291	(66.29)	REF	139	(31.66)	REF
Geospatial social networking	469	375	(79.96)	.001	257	(54.80)	.002
HIV-negative or unknown overall	9264	5673	(61.24)	REF	1262	(13.62)	REF
Race/Ethnicity							
Black, non-Hispanic	291	179	(61.51)	.297	55	(18.90)	.578
Hispanic	922	592	(64.21)	.934	183	(19.85)	.125
White, non-Hispanic	7266	4408	(60.67)	REF	901	(12.40)	REF
Other or multiple races	785	494	(62.93)	.651	123	(15.67)	.998
Age (years)							
18-24	1892	1217	(64.32)	.813	323	(17.07)	.001
25-29	1391	937	(67.36)	.019	193	(13.87)	.157
30-39	1717	1218	(70.94)	<.001	241	(14.04)	.613
40 or older	4264	2301	(53.96)	REF	505	(11.84)	REF
NHBS city resident[c]							
Yes	2957	1784	(60.33)	.596	370	(12.51)	.737
No	6307	3889	(61.66)	REF	892	(14.14)	REF
Recruitment website type							
Gay social networking	752	365	(48.54)	<.001	95	(12.63)	.275
General gay interest	1803	1113	(61.73)	.134	205	(11.37)	.002
General social networking	4897	2926	(59.75)	REF	533	(10.88)	REF
Geospatial social networking	1812	1269	(70.03)	<.001	429	(23.68)	<.001

[a] Wald chi-square from multivariable logistic regression comparing behavior (yes versus no) among group with some characteristic compared to a

referent (REF) group.

[b] Wald chi-square from multivariable logistic regression comparing behavior (yes versus no) among HIV-positive participants compared to HIV-negative or unknown serostatus particiants. Model controlled for race/ethnicity, age, NHBS residency, and website type.

[c] NHBS = National HIV Behavioral Surveillance System

Substance Use Behaviors

Illicit substance use in the past 12 months was more likely to be reported by HIV-positive participants than HIV-negative/unknown status participants (39.17% versus 26.85%, respectively; *P*<.001; Table 4). Approximately half of participants reported binge drinking alcohol in the past 12 months, and there was no difference by participants' HIV status (55.53% for HIV-positive and 58.27% for HIV-negative/unknown; *P*=.681).

Among participants who were HIV-positive, those 25-29 years of age were more likely to report using illicit drugs and binge drank alcohol compared with those ≥40 years of age (Table 4). More than half of those 25-29 years of age reported using illicit substances and more than three-quarters reported binge drinking alcohol in the past 12 months. Compared to participants recruited from a general social networking website, those from gay general interest websites were less likely to report binge drank alcohol.

Among participants who were HIV-negative or unknown status, Hispanic participants were more likely and black or other/multiracial participants were less likely than white participants to report binge drinking alcohol (Table 4). Compared to participants ≥40 years of age, those 18-29 were more likely to report using illicit substances and binge drinking alcohol. Approximately one-third of these younger participants reported using illicit substances and three-quarters reported binge drinking alcohol in the past 12 months. Participants who resided in NHBS cities were also more likely to report using illicit substances and binge drinking. Compared to participants from the general social networking website, those from gay social networking websites were less likely to report substance use and those from a geospatial social networking website were more likely to report substance use.

Table 4. Substance using behaviors of MSM participants in the American Men's Internet Survey, United States, 2013.

Participant characteristics	n in sample	Substance use behaviors in the past 12 months					
		Used illicit drug			Binge drank alcohol		
		n	(%)	*P* value[a]	n	(%)	*P* value[a]
HIV-positive overall	1113	436	(39.17)	<.001[b]	618	(55.53)	.681[b]
Race/Ethnicity							
Black, non-Hispanic	63	27	(42.86)	.722	42	(66.67)	.434
Hispanic	162	68	(41.98)	.529	102	(62.96)	.981
White, non-Hispanic	810	304	(37.53)	REF	430	(53.09)	REF
Other or multiple races	78	37	(47.44)	.210	44	(56.41)	.435
Age (years)							
18-24	90	37	(41.11)	.360	66	(73.33)	.195
25-29	124	67	(54.03)	.007	100	(80.65)	<.001
30-39	201	94	(46.77)	.404	132	(65.67)	.502
40 or older	698	238	(34.10)	REF	320	(45.85)	REF
NHBS city resident							
Yes	311	131	(42.12)	.050	163	(52.41)	.625
No	802	305	(38.03)	REF	455	(56.73)	REF
Recruitment website type							
Gay social networking	50	15	(30.00)	.309	18	(36.00)	.025
General gay interest	155	57	(36.77)	.809	78	(50.32)	.271
General social networking	439	159	(36.22)	REF	227	(51.71)	REF
Geospatial social networking	469	205	(43.71)	.121	295	(62.90)	.131
HIV-negative or unknown overall	9264	2487	(26.85)	REF	5398	(58.27)	REF
Race/Ethnicity							
Black, non-Hispanic	291	75	(25.77)	.075	165	(56.70)	.007
Hispanic	922	275	(29.83)	.960	612	(66.38)	.007
White, non-Hispanic	7266	1912	(26.31)	REF	4187	(57.62)	REF
Other or multiple races	785	225	(28.66)	.336	434	(55.29)	.018
Age (years)							
18-24	1892	686	(36.26)	<.001	1349	(71.30)	<.001
25-29	1391	452	(32.49)	.006	1069	(76.85)	<.001
30-39	1717	521	(30.34)	.466	1143	(66.57)	.326
40 or older	4264	828	(19.42)	REF	1837	(43.08)	REF
NHBS [c] city resident							
Yes	2957	828	(28.00)	.002	1788	(60.47)	<.001
No	6307	1659	(26.30)	REF	3610	(57.24)	REF
Recruitment website type							
Gay social networking	752	118	(15.69)	<.001	339	(45.08)	<.001
General gay interest	1803	474	(26.29)	.176	1033	(57.29)	.773
General social networking	4897	1255	(25.63)	REF	2773	(56.63)	REF
Geospatial social networking	1812	640	(35.32)	<.001	1253	(69.15)	<.001

[a] Wald chi-square from multivariable logistic regression comparing behavior (yes versus no) among group with some characteristic compared to a

referent (REF) group.

[b] Wald chi-square from multivariable logistic regression comparing behavior (yes versus no) among HIV-positive participants compared to HIV-negative or unknown serostatus particiants. Model controlled for race/ethnicity, age, NHBS residency, and website type.

[c] NHBS = National HIV Behavioral Surveillance System

HIV and STI Testing Behaviors

HIV testing behaviors were only examined among those who did not report being HIV-positive. Most of those participants (84.05%) had been previously tested for HIV infection, but less than half (44.20%) reported being tested in the past 12 months (Table 5). Compared to white participants, black participants were more likely to report ever having been tested. Compared to participants ≥40 years of age, those 18-24 years were less likely to report ever having been tested or having been tested in the past 12 months. Those 30-39 years were more likely to have been tested ever or in the past 12 months. Compared to participants recruited from the general social networking website, those from other websites had significant differences in reported HIV testing behaviors. Participants from gay social networking websites were less likely to report having been tested ever or in the past 12 months. Participants from general gay interest websites and from a geospatial social networking website were more likely to report having been tested ever or in the past 12 months.

Among participants who were HIV-positive and got the randomized STI testing and diagnosis questions, 56.54% (216/382) had an STI test in the past 12 months and 19.89% (76/382) had any STI diagnosis: 9.16% (35/382) were diagnosed with gonorrhea, 7.07% (27/382) with Chlamydia and 9.69% (37/382) with syphilis. Among participants who were HIV-negative or unknown status, 24.48% (758/3096) had an STI test in the past 12 months and 4.98% (154/3096) had any STI diagnosis: 2.68% (83/3096) were diagnosed with gonorrhea, 2.62% (81/3096) with Chlamydia and 1.26% (39/3096) with syphilis. Compared to participants who were HIV-negative or of unknown status, those who were HIV-positive were significantly more likely to have been tested for and to have had any diagnosis of an STI (both *P*<.001).

Table 5. HIV testing behaviors of HIV-negative or unknown status MSM participants in the American Men's Internet Survey, United States, 2013.

Participant characteristics	n in sample	Testing behaviors HIV tested ever			HIV tested past 12 months		
		n	(%)	*P* value[a]	n	(%)	*P* value[a]
Race/Ethnicity							
Black, non-Hispanic	291	256	(87.97)	.009	160	(54.98)	.133
Hispanic	922	763	(82.75)	.541	458	(49.67)	.285
White, non-Hispanic	7266	6117	(84.19)	REF	3073	(42.29)	REF
Other or multiple races	785	649	(82.68)	.146	374	(47.64)	.786
Age (years)							
18-24	1892	1224	(64.69)	<.001	815	(43.08)	<.001
25-29	1391	1176	(84.54)	.295	688	(49.46)	.076
30-39	1717	1571	(91.50)	<.001	878	(51.14)	<.001
40 or older	4264	3814	(89.45)	REF	1684	(39.49)	REF
NHBS [b] city resident							
Yes	2957	2599	(87.89)	<.001	1403	(47.45)	<.001
No	6307	5186	(82.23)	REF	2662	(42.21)	REF
Recruitment website type							
Gay social networking	752	542	(72.07)	<.001	236	(31.38)	<.001
General gay interest	1803	1570	(87.08)	.008	730	(40.49)	<.001
General social networking	4897	4084	(83.40)	REF	1933	(39.47)	REF
Geospatial social networking	1812	1589	(87.69)	<.001	1166	(64.35)	<.001
Total	9264	7786	(84.05)		4095	(44.20)	

[a] Wald chi-square from multivariable logistic regression comparing behavior (yes versus no) among group with some characteristic compared to a referent (REF) group.

[b] NHBS = National HIV Behavioral Surveillance System

Discussion

Principal Findings

The first round of data collection for AMIS was successfully implemented and resulted in more than 10,000 surveys from a diverse sample of Internet using MSM residing in all US states. There were notable differences in key behavioral indicators sorted by recruitment website type. In particular, the geospatial social networking website produced a sample made up of participants with significantly different demographic characteristics and self-reported HIV status. Participants recruited from that site were also substantially more risky but also more likely to have been HIV tested. Future samples for AMIS and other analyses with this data will have to take these differences into consideration in study and analysis design.

One purpose of AMIS was to generate useful annual behavioral data to compare to NHBS-MSM which is only conducted every 3 years [3]. Understanding the differences between MSM recruited in the “in-person” NHBS surveys and our Internet-recruited surveys will allow correlation of NHBS and AMIS results and evaluation of trends in years between NHBS surveys. Compared to the most recent NHBS-MSM data from 2011, our study found a higher prevalence of all of the assessed risk behaviors, including for our sub-sample that lived in NHBS cities. Data from our study do not explain this difference, because where the few significant differences exist, AMIS participants that lived in NHBS cities were more likely than those that lived elsewhere to report risky behaviors. This risk difference between the two samples could be partially explained by differences between the demographic composition of the AMIS and NHBS samples, where NHBS had more participants who were younger and black. Our own study has shown that older participants were less likely to report risky behavior and other research has shown black MSM tend to report less unprotected sex and drug use [39]. Demographic differences between online and real-world samples have also been previously reported even where the geographic areas are the same, though unlike our study, most have found Internet surveys to have a higher proportion of younger participants than their comparison surveys [15,18,40]. The demographic characteristics of the AMIS sample and the WHBS pilot sample were more similar to one another than to NHBS also indicating that these differences in behaviors may be due less to geographic differences and more to sampling approach [35].

Regardless of those differences, our findings emphasize how annual AMIS data may complement those from the 3-year NHBS samples, providing timely and useful information for prevention program planning for MSM in many US states. In addition, the complementary data from AMIS may come at considerably reduced cost compared to the venue-recruited NHBS sample. The entire AMIS data collection and analysis support costs approximately $15 per survey whereas NHBS costs at least $1000 per survey based only on federal funding to local jurisdictions and not including CDC management or analysis costs [41]. NHBS is rightfully more expensive than AMIS because it involves a more comprehensive and detailed survey approach that requires full survey teams in each city to conduct the in-person method, participant incentives, and laboratory expenses for rapid HIV testing.

Substantial proportions of AMIS participants reported sexual behaviors that may potentially pose a risk of HIV transmission. Over 40% of HIV-positive participants had anal sex without a condom with a potentially serodiscordant male partner. More than half of HIV-negative/unknown status participants also had anal sex without a condom, though most reported that they perceived their partners to be HIV-negative. Serostatus discussions between sex partners are an important part of HIV prevention, but previous studies have shown that those discussions may be based on inaccurate information because of high rates of undiagnosed HIV infection among MSM [39,42-44]. HIV-positive persons who are taking antiretroviral medications and have their HIV virus suppressed are also significantly less likely to transmit HIV to their sex partners, but we do not have this information for our participants [7]. Younger MSM were also significantly more likely to have had anal sex without a condom, a pattern also seen in the NHBS data [3]. For the youngest group in our study, 18-24 years of age, this is combined with a significantly increased likelihood that they are substance users and a reduced likelihood that they have ever been HIV tested. This presents a potentially heightened risk for HIV transmission in this group.

Compared to AMIS, NHBS had similar proportions who reported anal sex without a condom, but NHBS reported a substantially lower proportion of HIV-positive participants who had serodiscordant anal sex without a condom than our study (13% versus 43%, respectively) [3]. This may be explained by other differences in the samples/procedures (eg, demographics, self- versus interviewer-administered survey) or may be due to some fundamental difference in how sexual encounters are negotiated by HIV-positive MSM who were recruited from the internet. This indicator did not substantially differ between the HIV-negative/unknown status participants in the two studies. Similar to our findings, the EMIS study also found a significantly higher risk of non-concordant unprotected anal intercourse among HIV-positive participants compared to HIV-negative participants, but reported a substantially higher proportion of their participants overall had engaged in this behavior compared to our study (30% versus 17%, respectively) [34]. The timeframes for this behavior between our study and EMIS were not the same and may explain at least part of this difference; we examined behavior with last male sex partner and EMIS examined behavior with any male sex partner in the past 12 months. Collaborations should be explored to allow comparisons of non-concordant anal intercourse without condoms between these studies.

Limitations

Several limitations to the AMIS methods and these analyses should be noted. First, AMIS data are not generalizable to all MSM in the US or to all MSM online. AMIS used a convenience sampling approach online and we cannot determine the degree or direction of response bias. Though we included several different types of websites to increase sample diversity, the websites still represent a small fraction of those that MSM likely use. Second, there was under-representation of black or African

American MSM in the AMIS sample, a problem common to Internet research [23]. This group is disproportionately impacted by HIV infection and the small AMIS sample size limits our ability to do more detailed analyses with these data. Third, the survey only involved self-report of behaviors. Though anonymous self-administered surveys such as AMIS may be less prone to obsequiousness bias [45-47], it is possible that less socially desirable responses may be under-reported (eg, anal sex without a condom) and more socially desirable responses may be over-reported (eg, recent HIV testing). Finally, the analyses presented here were only preliminary to illustrate the success of the AMIS method in generating key behavioral indicators. Although we report statistical tests in our behavioral analyses that controlled for some demographic characteristics, there were relatively few factors in the model which may not have resolved all confounding. Therefore interpretation regarding the independence of statistical relationships should be made with caution until more detailed modeling can be conducted and reported.

Future Directions

We are nearing completion of our second round of data collection of 10,000 surveys and intend to conduct the third round in the summer of 2015. The data we have collected to-date have been shared with state health departments in standardized reports to enable better planning for public health interventions (see Multimedia Appendix 4 for an example report). We have also made individual state AMIS datasets available to each state's public health authorities so they can conduct further analyses for their own MSM residents. We have developed and deployed what will eventually become the largest ongoing Internet survey of MSM in the United States, and we envision that AMIS will become a useful tool in our joint endeavors to improve the health and wellbeing of this population.

Acknowledgments

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Conflicts of Interest

Authors Sanchez and Sullivan are members of the Editorial Board of JMIR Public Health and Surveillance. However, they had no involvement in the editorial decision for this manuscript. It was reviewed and handled by an independent editor.

Multimedia Appendix 1

AMIS 2013 questionnaire.

[PDF File (Adobe PDF File), 214KB - publichealth_v1i1e3_app1.pdf]

Multimedia Appendix 2

AMIS deduplication algorithm.

[PPTX File, 102KB - publichealth_v1i1e3_app2.pptx]

Multimedia Appendix 3

Characteristics of MSM participants in the American Men's Internet Survey by randomization to different question subsets, United States, 2013.

[PDF File (Adobe PDF File), 48KB - publichealth_v1i1e3_app3.pdf]

Multimedia Appendix 4

AMIS 2013 sample state report.

[PDF File (Adobe PDF File), 226KB - publichealth_v1i1e3_app4.pdf]

References

1. Centers for Disease Control and Prevention. 2014. Diagnoses of HIV Infection in the United States and Dependent Areas, 2012 URL: http://www.cdc.gov/hiv/library/reports/surveillance/2012/surveillance_Report_vol_24.html [accessed 2015-02-03] [WebCite Cache ID 6W4bEeOFn]
2. Ward BW, Dahlhamer JM, Galinsky AM, Joestl SS. National Health Statistics Reports.: Centers for Disease Control and Prevention; 2014 Jul 15. Sexual orientation and health among US adults: national health interview survey, 2013 URL: http://www.cdc.gov/nchs/data/nhsr/nhsr077.pdf [accessed 2015-04-13] [WebCite Cache ID 6Xm0UMOxp]
3. Centers for Disease Control and Prevention. HIV testing and risk behaviors among gay, bisexual, and other men who have sex with men - United States. Morbidity and Mortality Weekly Report 2013;62(47):958-962.

4. Johnson AS, Hall HI, Hu X, Lansky A, Holtgrave DR, Mermin J. Trends in diagnoses of HIV infection in the United States, 2002-2011. JAMA 2014;312(4):432-434. [doi: 10.1001/jama.2014.8534] [Medline: 25038362]
5. Centers for Disease Control and Prevention. 2012. CDC Fact Sheet: New HIV Infections in the United States URL: http://www.cdc.gov/nchhstp/newsroom/docs/2012/HIV-Infections-2007-2010.pdf [WebCite Cache ID 6VsLlm07w]
6. Grant RM, Lama JR, Anderson PL, McMahan V, Liu AY, Vargas L, et al. Preexposure chemoprophylaxis for HIV prevention in men who have sex with men. N Engl J Med 2010 Dec 30;363(27):2587-2599 [FREE Full text] [doi: 10.1056/NEJMoa1011205] [Medline: 21091279]
7. Cohen MS, Chen YQ, McCauley M, Gamble T, Hosseinipour MC, Kumarasamy N, Pilotto Jose H S, HPTN 052 Study Team. Prevention of HIV-1 infection with early antiretroviral therapy. N Engl J Med 2011 Aug 11;365(6):493-505 [FREE Full text] [doi: 10.1056/NEJMoa1105243] [Medline: 21767103]
8. Sullivan PS, Carballo-Diéguez A, Coates T, Goodreau SM, McGowan I, Sanders EJ, et al. Successes and challenges of HIV prevention in men who have sex with men. Lancet 2012 Jul 28;380(9839):388-399 [FREE Full text] [doi: 10.1016/S0140-6736(12)60955-6] [Medline: 22819659]
9. Centers for Disease Control and Prevention. 2014. Laboratory testing for the diagnosis of HIV infection : updated recommendations URL: http://www.cdc.gov/hiv/pdf/HIVtestingAlgorithmRecommendation-Final.pdf [accessed 2015-02-03] [WebCite Cache ID 6W4bW0D9q]
10. Centers for Disease Control and Prevention. 2014. Rapid HIV tests suitable for use in non-clinical settings URL: http://www.cdc.gov/hiv/pdf/testing_nonclinical_clia-waived-tests.pdf [accessed 2015-02-03] [WebCite Cache ID 6W4bZao2M]
11. Pew Research Internet Project. Social Media Update 2014 URL: http://www.pewinternet.org/2015/01/09/social-media-update-2014/ [accessed 2015-01-20] [WebCite Cache ID 6VjXjUHqX]
12. Bolding G, Davis M, Hart G, Sherr L, Elford J. Where young MSM meet their first sexual partner: the role of the Internet. AIDS Behav 2007 Jul;11(4):522-526. [doi: 10.1007/s10461-007-9224-9] [Medline: 17347876]
13. Grosskopf NA, Harris JK, Wallace BC, Nanin JE. Online sex-seeking behaviors of men who have sex with men in New York City. Am J Mens Health 2011 Sep;5(5):378-385. [doi: 10.1177/1557988310372801] [Medline: 20798150]
14. Horvath KJ, Rosser B R Simon, Remafedi G. Sexual risk taking among young internet-using men who have sex with men. Am J Public Health 2008 Jun;98(6):1059-1067. [doi: 10.2105/AJPH.2007.111070] [Medline: 18445804]
15. Sanchez T, Smith A, Denson D, DiNenno E, Lansky A. Internet-based methods may reach higher risk men who have sex with men not reached through venue-based sampling. Open AIDS 2012;6(Supplement 1):99-105.
16. Rhodes SD, DiClemente RJ, Cecil H, Hergenrather KC, Yee LJ. Risk among men who have sex with men in the United States: a comparison of an Internet sample and a conventional outreach sample. AIDS Educ Prev 2002 Feb;14(1):41-50. [Medline: 11900109]
17. Bull SS, Lloyd L, Rietmeijer C, McFarlane M. Recruitment and retention of an online sample for an HIV prevention intervention targeting men who have sex with men: the Smart Sex Quest Project. AIDS Care 2004 Nov;16(8):931-943. [doi: 10.1080/09540120412331292507] [Medline: 15511725]
18. Elford J, Bolding G, Davis M, Sherr L, Hart G. Web-based behavioral surveillance among men who have sex with men: a comparison of online and offline samples in London, UK. J Acquir Immune Defic Syndr 2004 Apr 1;35(4):421-426. [Medline: 15097159]
19. Chiasson MA, Hirshfield S, Remien RH, Humberstone M, Wong T, Wolitski RJ. A comparison of on-line and off-line sexual risk in men who have sex with men: an event-based on-line survey. J Acquir Immune Defic Syndr 2007 Feb 1;44(2):235-243. [doi: 10.1097/QAI.0b013e31802e298c] [Medline: 17179769]
20. Berg RC. Barebacking among MSM Internet users. AIDS Behav 2008 Sep;12(5):822-833. [doi: 10.1007/s10461-007-9281-0] [Medline: 17676278]
21. Rosser B R Simon, Miner MH, Bockting WO, Ross MW, Konstan J, Gurak L, et al. HIV risk and the internet: results of the Men's INTernet Sex (MINTS) Study. AIDS Behav 2009 Aug;13(4):746-756 [FREE Full text] [doi: 10.1007/s10461-008-9399-8] [Medline: 18512143]
22. Gilbert LK, Levandowski BA, Scanlon KE, Peterson RS. A comparison of hepatitis A and hepatitis B measures among vaccinated and susceptible online men who have sex with men. Int J STD AIDS 2010 Jun;21(6):400-405. [doi: 10.1258/ijsa.2009.009010] [Medline: 20606219]
23. Sullivan PS, Khosropour CM, Luisi N, Amsden M, Coggia T, Wingood GM. Bias in online recruitment and retention of racial and ethnic minority men who have sex with men. Journal of Medical Internet Research 2011;13(2).
24. Krakower DS, Mimiaga MJ, Rosenberger JG, Novak DS, Mitty JA, White JM. Limited Awareness and Low Immediate Uptake of Pre-Exposure Prophylaxis among Men Who Have Sex with Men Using an Internet Social Networking Site. PloS One 2012;7(3).
25. Rosenberger JG, Reece M, Schick V, Herbenick D, Novak DS, Van Der Pol Barbara, et al. Condom use during most recent anal intercourse event among a U.S. sample of men who have sex with men. J Sex Med 2012 Apr;9(4):1037-1047. [doi: 10.1111/j.1743-6109.2012.02650.x] [Medline: 22353190]
26. Berg RC, Tikkanen R, Ross MW. Barebacking among men who have sex with men recruited through a Swedish website: associations with sexual activities at last sexual encounter. European Communicable Disease Bulletin 2013;18(13):06.

27. Greacen T, Friboulet D, Blachier A, Fugon L, Hefez S, Lorente N, et al. Internet-using men who have sex with men would be interested in accessing authorised HIV self-tests available for purchase online. AIDS Care 2013;25(1):49-54. [doi: 10.1080/09540121.2012.687823] [Medline: 22670681]
28. Yu G, Wall MM, Chiasson MA, Hirshfield S. Complex drug use patterns and associated HIV transmission risk behaviors in an Internet sample of U.S. men who have sex with men. Arch Sex Behav 2015 Feb;44(2):421-428. [doi: 10.1007/s10508-014-0337-8] [Medline: 25104104]
29. Dasgupta S, Vaughan AS, Kramer MR, Sanchez TH, Sullivan PS. Use of a Google Map Tool Embedded in an Internet Survey Instrument: Is it a Valid and Reliable Alternative to Geocoded Address Data? JMIR Res Protoc 2014;3(2):e24 [FREE Full text] [doi: 10.2196/resprot.2946] [Medline: 24726954]
30. Sineath RC, Finneran C, Sullivan P, Sanchez T, Smith DK, Griensven FV, et al. Knowledge of and interest in using preexposure prophylaxis for HIV prevention among men who have sex with men in Thailand. J Int Assoc Provid AIDS Care 2013;12(4):227-231. [doi: 10.1177/2325957413488184] [Medline: 23708677]
31. Santos GM, Do T, Beck J, Makofane K, Arreola S, Pyun T, et al. Syndemic conditions associated with increased HIV risk in a global sample of men who have sex with men. Sex Transm Infect 2014 May;90(3):250-253. [doi: 10.1136/sextrans-2013-051318] [Medline: 24431183]
32. Hickson F, Bonell C, Hargreaves J, Reid D, Weatherburn P. HIV Testing and HIV Serostatus-Specific Sexual Risk Behaviour Among Men Who Have Sex with Men Living in England and Recruited Through the Internet in 2001 and 2008. Sex Res Soc Policy 2012 Dec 2;10(1):15-23. [doi: 10.1007/s13178-012-0106-1]
33. Sigma Research. The Gay Men's Sex Survey. 2015. Sample Sizes URL: http://www.sigmaresearch.org.uk/gmss/survey/sample [accessed 2015-01-27] [WebCite Cache ID 6VsiSRKo6]
34. The EMISN. Findings from 38 countries. EMIS 2010: The European Men-Who-Have-Sex-With-Men Internet Survey URL: http://www.emis-project.eu/sites/default/files/public/publications/emis-2010_european_msm_internet_survey_38_countries_v5.pdf [accessed 2015-01-21] [WebCite Cache ID 6VjZO8w7m]
35. Sanchez T, Smith A, Denson D, Dinenno E, Lansky A. Developing a Web-Based HIV Behavioral Surveillance Pilot Project Among Men Who Have Sex with Men. Open AIDS J 2012;6:224-231 [FREE Full text] [doi: 10.2174/1874613601206010224] [Medline: 23091580]
36. Centers for Disease Control and Prevention. 2011. National HIV Behavioral Surveillance System Round 3 Questionnaire URL: http://www.cdc.gov/hiv/pdf/NHBS_Round3_OMBApprovedQuestionnaire-508remediated.pdf [accessed 2015-01-21] [WebCite Cache ID 6VjZqrbd0]
37. Sanchez T, Finlayson T, Drake A, Behel S, Cribbin M, Dinenno E, Centers for Disease ControlPrevention (CDC). Human immunodeficiency virus (HIV) risk, prevention, and testing behaviors--United States, National HIV Behavioral Surveillance System: men who have sex with men, November 2003-April 2005. MMWR Surveill Summ 2006 Jul 7;55(6):1-16 [FREE Full text] [Medline: 16826162]
38. National Institute of Alcohol Abuse and Alcoholism. 2004. NIAAA Council Approves Definition of Binge Drinking URL: http://pubs.niaaa.nih.gov/publications/Newsletter/winter2004/Newsletter_Number3.pdf [accessed 2015-03-11] [WebCite Cache ID 6WxahUEAA]
39. Maulsby C, Millett G, Lindsey K, Kelley R, Johnson K, Montoya D, et al. HIV among Black men who have sex with men (MSM) in the United States: a review of the literature. AIDS Behav 2014 Jan;18(1):10-25. [doi: 10.1007/s10461-013-0476-2] [Medline: 23620241]
40. Evans AR, Wiggins RD, Mercer CH, Bolding GJ, Elford J. Men who have sex with men in Great Britain: comparison of a self-selected internet sample with a national probability sample. Sex Transm Infect 2007 Jun;83(3):200-5; discussion 205 [FREE Full text] [doi: 10.1136/sti.2006.023283] [Medline: 17135330]
41. Centers for Disease Control and Prevention. Division of HIV/AIDS Prevention Awards by State, 2012 URL: http://www.cdc.gov/hiv/pdf/policies_funding_awards2012.pdf [accessed 2015-03-11] [WebCite Cache ID 6WxF9BeJe]
42. Winter AK, Sullivan PS, Khosropour CM, Rosenberg ES. Discussion of HIV status by serostatus and partnership sexual risk among internet-using MSM in the United States. J Acquir Immune Defic Syndr 2012 Aug 15;60(5):525-529 [FREE Full text] [doi: 10.1097/QAI.0b013e318257d0ac] [Medline: 22549381]
43. Sullivan PS, Wall KM, O'Hara B, Jones J, Barnes J, DiClemente R, et al. The prevalence of undiagnosed HIV serodiscordance among male couples presenting for HIV testing. Arch Sex Behav 2014 Jan;43(1):173-180 [FREE Full text] [doi: 10.1007/s10508-013-0214-x] [Medline: 24233391]
44. Millett GA, Ding H, Marks G, Jeffries WL, Bingham T, Lauby J, et al. Mistaken assumptions and missed opportunities: correlates of undiagnosed HIV infection among black and Latino men who have sex with men. J Acquir Immune Defic Syndr 2011 Sep 1;58(1):64-71. [doi: 10.1097/QAI.0b013e31822542ad] [Medline: 21654500]
45. Langhaug LF, Sherr L, Cowan FM. How to improve the validity of sexual behaviour reporting: systematic review of questionnaire delivery modes in developing countries. Trop Med Int Health 2010 Mar;15(3):362-381 [FREE Full text] [doi: 10.1111/j.1365-3156.2009.02464.x] [Medline: 20409291]
46. Hewett PC, Mensch BS, Ribeiro Manoel Carlos S de A, Jones HE, Lippman SA, Montgomery MR, van de Wijgert Janneke H H M. Using sexually transmitted infection biomarkers to validate reporting of sexual behavior within a randomized,

experimental evaluation of interviewing methods. Am J Epidemiol 2008 Jul 15;168(2):202-211 [FREE Full text] [doi: 10.1093/aje/kwn113] [Medline: 18525081]

47. Metzger DS, Koblin B, Turner C, Navaline H, Valenti F, Holte S, et al. Randomized controlled trial of audio computer-assisted self-interviewing: utility and acceptability in longitudinal studies. HIVNET Vaccine Preparedness Study Protocol Team. Am J Epidemiol 2000 Jul 15;152(2):99-106 [FREE Full text] [Medline: 10909945]

Abbreviations

AMIS: American Men’s Internet Survey
CDC: Centers for Disease Control and Prevention
EMIS: European MSM Internet Survey
HIV: human immunodeficiency virus
IP: Internet protocol
MSM: men who have sex with men
NHBS: National HIV Behavioral Surveillance System
STI: sexually transmitted infection
WHBS: Web-based HIV Behavioral Surveillance System

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Short Paper

Using Social Media to Perform Local Influenza Surveillance in an Inner-City Hospital: A Retrospective Observational Study

David Andre Broniatowski[1], PhD; Mark Dredze[2], PhD; Michael J Paul[3], PhD; Andrea Dugas[4], MD, PhD

[1]Department of Engineering Management and Systems Engineering, The George Washington University, Washington, DC, United States

[2]Human Language Technology Center of Excellence, Johns Hopkins University, Baltimore, MD, United States

[3]Department of Computer Science, Johns Hopkins University, Baltimore, MD, United States

[4]Department of Emergency Medicine, Johns Hopkins University, Baltimore, MD, United States

Corresponding Author:
David Andre Broniatowski, PhD
Department of Engineering Management and Systems Engineering
The George Washington University
Science and Engineering Hall
800 22nd Street NW, #2700
Washington, DC, 20052
United States
Phone: 1 2029943751
Fax: 1 2029943751
Email: broniatowski@gwu.edu

Abstract

Background: Public health officials and policy makers in the United States expend significant resources at the national, state, county, and city levels to measure the rate of influenza infection. These individuals rely on influenza infection rate information to make important decisions during the course of an influenza season driving vaccination campaigns, clinical guidelines, and medical staffing. Web and social media data sources have emerged as attractive alternatives to supplement existing practices. While traditional surveillance methods take 1-2 weeks, and significant labor, to produce an infection estimate in each locale, web and social media data are available in near real-time for a broad range of locations.

Objective: The objective of this study was to analyze the efficacy of flu surveillance from combining data from the websites Google Flu Trends and HealthTweets at the local level. We considered both emergency department influenza-like illness cases and laboratory-confirmed influenza cases for a single hospital in the City of Baltimore.

Methods: This was a retrospective observational study comparing estimates of influenza activity of Google Flu Trends and Twitter to actual counts of individuals with laboratory-confirmed influenza, and counts of individuals presenting to the emergency department with influenza-like illness cases. Data were collected from November 20, 2011 through March 16, 2014. Each parameter was evaluated on the municipal, regional, and national scale. We examined the utility of social media data for tracking actual influenza infection at the municipal, state, and national levels. Specifically, we compared the efficacy of Twitter and Google Flu Trends data.

Results: We found that municipal-level Twitter data was more effective than regional and national data when tracking actual influenza infection rates in a Baltimore inner-city hospital. When combined, national-level Twitter and Google Flu Trends data outperformed each data source individually. In addition, influenza-like illness data at all levels of geographic granularity were best predicted by national Google Flu Trends data.

Conclusions: In order to overcome sensitivity to transient events, such as the news cycle, the best-fitting Google Flu Trends model relies on a 4-week moving average, suggesting that it may also be sacrificing sensitivity to transient fluctuations in influenza infection to achieve predictive power. Implications for influenza forecasting are discussed in this report.

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KEYWORDS

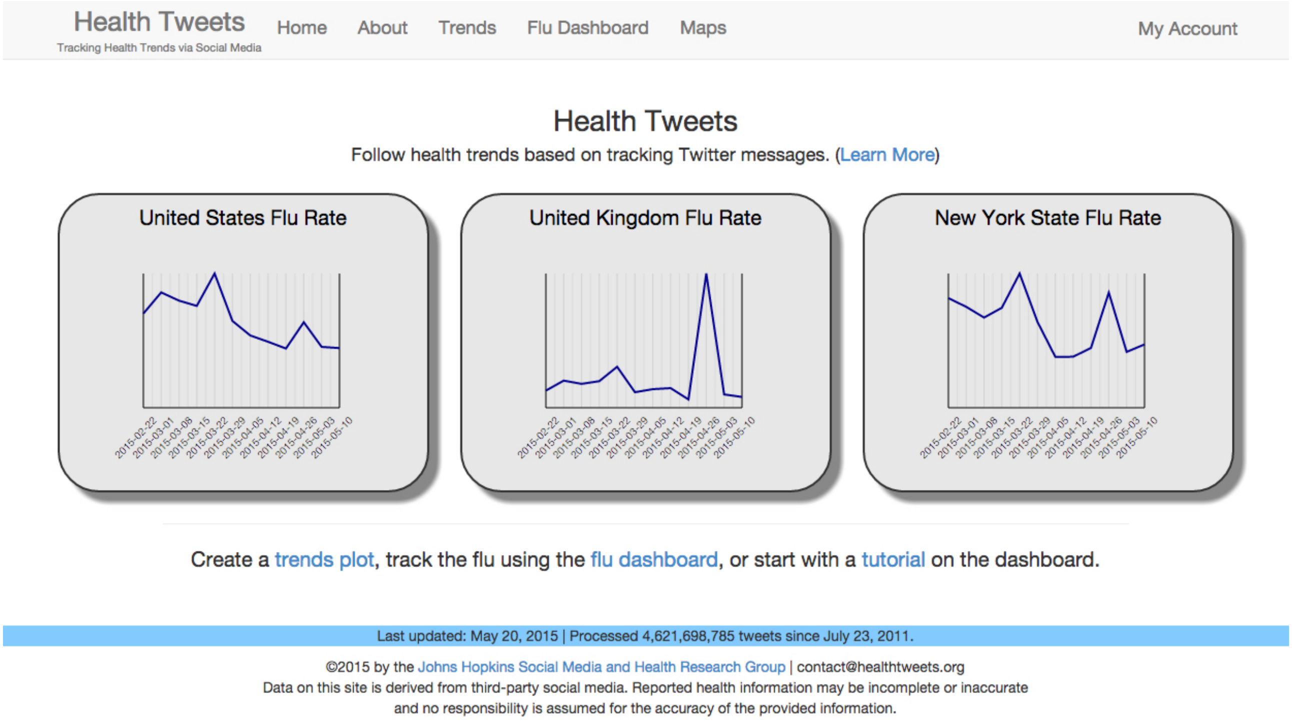
Web mining; social computing; time series analysis

Introduction

Public health officials and policy makers rely on influenza infection rate information to make important decisions during the course of an influenza season. Whereas influenza surveillance has traditionally been conducted using laboratory data, hospitalizations, and physician visits for influenza-like illness (ILI), web and social media data sources have emerged as attractive alternatives to supplement existing practices. While traditional surveillance methods take 1-2 weeks, and significant labor, to produce an infection estimate in each locale, web and social media data are available in near real-time for a broad range of locations. Studies have demonstrated that web queries [1-3], Twitter messages [4-12], and other sources (eg, Wikipedia [13], mobile app reporting [14]) may be productively mined for influenza surveillance data. New resources like Google Flu Trends [1], HealthTweets [15,16](Figure 1), and Flu Near You [14] deliver near-real time estimates of infection rates.

However, few have examined the efficacy of local surveillance [12,17,18]. In this study, we analyzed the efficacy of local flu surveillance from Google Flu Trends and HealthTweets. Whereas previous studies that considered either Google or Twitter in isolation, we evaluated multiple trends available from both. Furthermore, instead of restricting our study to hospitals designated as ILI sentinels, or emergency department ILI rates, we considered both emergency department ILI and laboratory-confirmed influenza cases for a single hospital in the city of Baltimore. This enabled us to evaluate the impact on specific care centers when making influenza response decisions, such as staffing and resource allocation.

Figure 1. Screenshot of HealthTweets.



Health Tweets

Follow health trends based on tracking Twitter messages. (Learn More)

Create a trends plot, track the flu using the flu dashboard, or start with a tutorial on the dashboard.

Last updated: May 20, 2015 | Processed 4,621,698,785 tweets since July 23, 2011.

©2015 by the Johns Hopkins Social Media and Health Research Group | contact@healthtweets.org
Data on this site is derived from third-party social media. Reported health information may be incomplete or inaccurate
and no responsibility is assumed for the accuracy of the provided information.

Methods

Study Population and Setting

This was a retrospective observational study comparing estimates of influenza activity from Google flu trends and Twitter to actual counts of individuals with laboratory-confirmed influenza, and counts of individuals presenting to the emergency department with ILI. Each parameter was evaluated on the municipal, regional, and national scale.

Data Collection and Methods of Measurement

Data were collected from November 20, 2011 through March 16, 2014. All measurements were recorded weekly to allow for direct comparison between data sources. Following the Centers for Disease Control (CDC) Convention, each week summed the data points from Sunday through the following Saturday. The number of municipal- (city) level subjects was estimated by evaluating the number of patients presenting to an urban academic emergency department in Baltimore, Maryland with an annual volume of over 60,000 adult and 24,000 pediatric visits. The number of confirmed influenza cases was determined by summing the number of emergency department visits with laboratory-confirmed influenza that occurred during each week. Similarly, the number of patients with ILI was determined by summing the number of emergency department patients who reported fever with cough or sore throat each week. Regional data were collected via the CDC surveillance reports for health and Human Services (HHS) Region 3, including both the percentage of patients reporting ILI and the percentage of tests positive for influenza. National data were collected from the CDC surveillance report of the nationwide percentage of patients reporting ILI and the total percentage of patients testing positive for influenza.

Google Flu Trends data for the United States, the state of Maryland, and the city of Baltimore were downloaded directly from the Google Flu Trends website [19]. Twitter data for the same three locations was obtained from the HealthTweets website [15], an online platform for public health surveillance aimed at sharing the latest research results on Twitter data with the scientific community and public officials. The underlying data were generated using a sequence of supervised machine-learning algorithms [10,12], namely logistic regression classifiers, the first of which identified tweets that were relevant to health. Next, tweets that were about influenza were isolated. The final classifier separated tweets that were about reported influenza infection from those that only reported awareness of the flu. The tweets indicating influenza infection constituted our dataset. Message locations were identified using Carmen [20], a software package that infers tweet locations using Global Positioning System (GPS) coordinates and self-reported locations from the free text of the user biographic profiles.

Statistical Analysis

Data were analyzed by evaluating weekly trends over time using the Box-Jenkins procedure [21] applied to each data source (influenza tests at our medical center, ILI at our medical center, % reported flu cases in HHS region 3 and the USA, and % reported ILI in HHS region 3 and the USA) in order to control for autocorrelation in the corresponding time series. We next fit an autoregressive integrated moving average model with exogenous covariates (ARIMAX) to each data time series, X_t, where p, d, and q, are the respective autoregressive, differencing, and moving average orders of the model (Figure 2 , part a). The $\phi_i$and $\theta_i$are the autoregressive and moving average parameters, respectively, $\varepsilon_t$is a normally distributed error term with a mean of 0, L is a lag operator defined as in Figure 2 , part b, and $m_t$is defined as in Figure 2 , part c, where $y_t$is a series of predictors (eg, Twitter and/or Google Flu Trends data), the $\eta_i$are a series of predictor weights, and b is the total number of predictor time series.

We chose the autoregressive, differencing, and moving average terms of each model that minimized each its Aikake Information Criterion (AIC) subject to the constraint that each model used the same degree of differencing for each data source. This constraint was imposed to enable comparison across social media predictors (ie, Twitter, Google Flu Trends, or both). All statistics were conducted using the R Project for Statistical Computing, version 3.0.2 (The R Foundation for Statistical Computing). Specifically, we used the "arima()" function in the forecast package [22]. Parameter selection was informed by the "auto.arima()" function, using the Hyndman and Khandakar algorithm [23]. Deviations from the algorithm's output were then examined by hand and parameters that deviated from algorithm output were chosen if they minimized AIC.

Figure 2. Equations defining the ARIMAX model.

$$\left(1-\sum_{i=1}^{p}\phi_i L^i\right)(1-L)^d(X_t-m_t)=\left(1+\sum_{i=1}^{q}\theta_i L^i\right)\varepsilon_t, \qquad \text{(a)}$$

$$L^k X_t = X_{t-k}\ , \qquad \text{(b)}$$

$$m_t = c+\sum_{i=0}^{b}\eta_i y_{t,i} \qquad \text{(c)}$$

Results

Table 1 summarizes the results of each ARIMA model incorporating Twitter and Google Flu Trends data. Our results show that Baltimore-area Twitter data provided a better estimate of actual influenza cases reported in the Baltimore metropolitan area when compared to state- and national-level Twitter data (see Figure 3). Furthermore, a combination of Twitter and Google Flu Trends data sources outperformed either Twitter or Google Flu Trends individually when predicting actual influenza outbreaks at municipal and regional levels.

Table 1. Log-likelihood (AIC[a]) for each surveillance method.

		Laboratory-confirmed influenza			Influenza like illness (ILI)		
		City	Region	US	City	Region	US
Twitter [b]							
	US[c]	-311 (627)^{0,1,0}[e]	-317[g](653)^{5,1,3}	-235[g](484)^{0,1,5}	-502[g](1009)^{0,2,1}	-66[g](143)^{0,1,0}	-27[g](61)^{1,1,1}
	MD[d]	-310 (624)^{0,1,0}	-321 (661)^{5,1,3}	-236 (486)^{0,1,5}	-503 (1012)^{0,1,0}	-70 (144)^{0,1,0}	-30 (68)^{1,1,1}
	Baltimore	-308[g](620)^{0,1,0}	-323 (666)^{5,1,3}	-235 (484)^{0,1,5}	-504 (1013)^{0,2,1}	-74 (158)^{0,1,3}	-32 (74)^{1,1,1}
Google Flu Trends							
	US	-291[g](596)^{1,1,4}	-313[g](648)^{5,1,4}	-230[f,g](475)^{0,1,5}	-494[f,g](1002)^{1,2,4}	-49[f,g](110)^{0,1,4}	-1[f,g](15)^{1,1,4}
	MD	-299 (612)^{1,1,4}	-318 (656)^{5,1,3}	-236 (486)^{0,1,5}	-498 (1010)^{1,2,4}	-58 (129)^{0,1,4}	-27 (61)^{1,1,1}
	Baltimore	-295 (604)^{1,1,4}	-320 (660)^{5,1,3}	-236 (486)^{0,1,5}	-495 (1005)^{1,2,4}	-60 (132)^{0,1,4}	-23 (56)^{1,1,2}
Both							
	US	-289[f,g](594)^{1,1,4}	-312[f,g](646)^{5,1,3}	-230[g](477)^{0,1,5}	-495[g](1003)^{0,1,4}	-49[g](112)^{0,1,4}	-0[g](17)^{1,1,4}
	MD	-299 (613)^{1,14}	-318 (657)^{5,1,3}	-235 (485)^{0,1,5}	-498 (1011)^{1,2,4}	-58 (130)^{0,1,4}	-27 (68)^{1,1,1}
	Baltimore	-294 (604)^{1,1,4}	-319 (659)^{5,1,3}	-235 (486)^{0,1,5}	-500 (1007)^{0,2,1}	-60 (134)^{0,1,4}	-22 (55)^{1,1,2}

[a] AIC=Aikake Information Criterion

[b] Twitter data from the HealthTweets website.

[c] US=United States

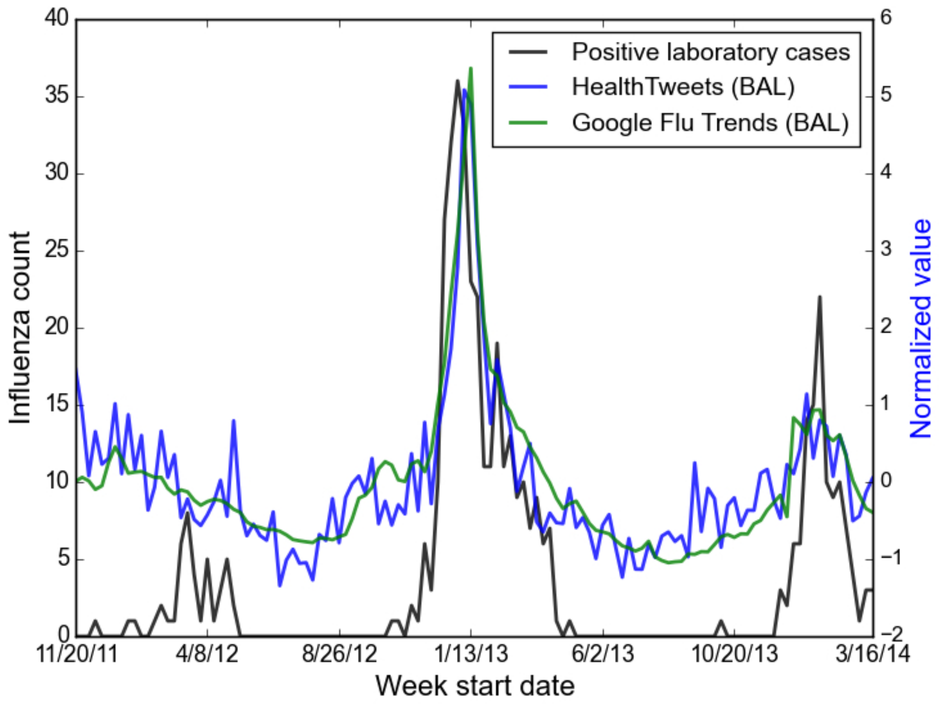
[d] MD=Maryland

[e] Superscript numerals indicate the autoregressive order, the order of differencing, and the moving average order, respectively. Models were chosen to minimize AIC, guided by examinations of autocorrelation and partial autocorrelation values.

[f] The best predictor across all data sources.

[g] The best predictor within each data source (HealthTweets website, Google, or a linear combination of both).

Figure 3. Plot of weekly confirmed influenza cases (right axis) as compared to standardized Baltimore social media data (left axis).



When directly comparing models that rely only on one data source (ie, Twitter or Google Flu Trends but not both), we found that the best-fitting Twitter models were simple whereas the best-fitting Google Flu Trends models generally required more parameters. For example, at the municipal level, the best-fitting Twitter model did not require any autoregressive or moving average terms, whereas the best-fitting Google Flu Trends model required a 4-week moving average of Google Flu Trends data and an autoregressive term. In general, these more complex Google Flu Trends models outperformed the best-fitting Twitter models. Although these Google Flu Trends models were significantly more complex (ie, one must fit more parameters), they had a lower AIC, indicating that they were also more informative.

Discussion

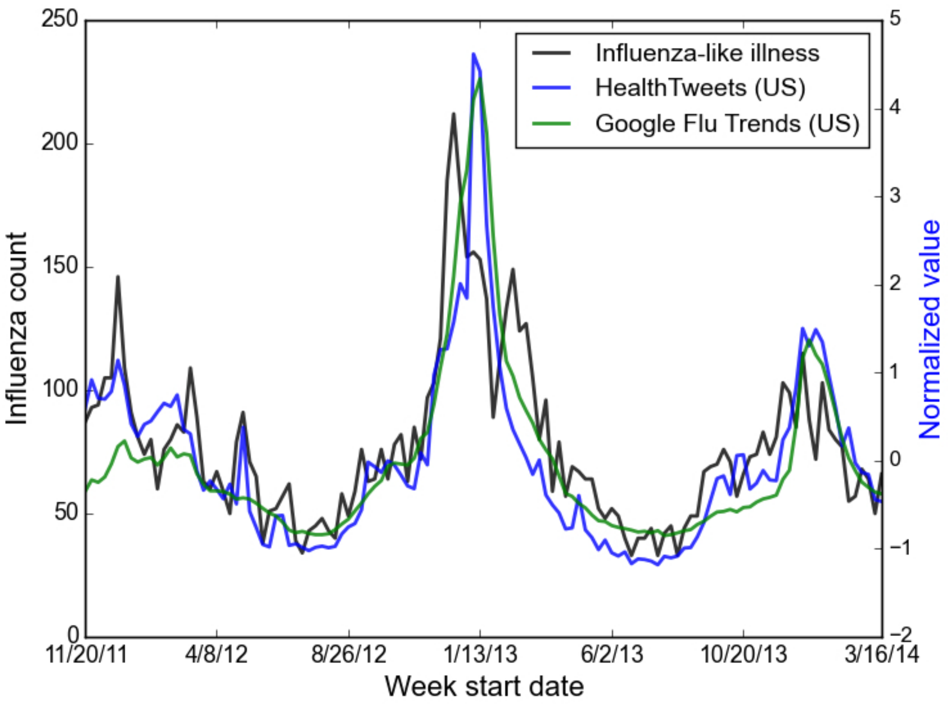
Principal Findings

Consistent with prior work [18], we found that national-level Google Flu Trends data may be used to track actual influenza cases in the Baltimore area. The fact that a combination of Twitter and Google Flu Trends data at the national (US) level outperformed all other data sources for local and regional confirmed influenza cases indicates that these data sources are not redundant and that Twitter data are contributing information useful to influenza surveillance that are not captured by the corresponding Google Flu Trends data.

Comparison With Prior Work

Whereas prior work using Google Flu Trends data has largely focused on US ILI data, we extended this finding to multiple levels of geographic granularity by examining social media surveillance at the regional and city levels as well. We found that US Google Flu Trends data best explained ILI rates at all levels (including the municipal level, see Figure 4). This contrasts with prior research, which found that Google Flu Trends data conflated signals of influenza awareness (eg, media attention) with signals of actual infection - overestimating the flu season’s peak prevalence. In addition, this prior work found that there was insufficient control for temporal autocorrelation and a lack of analysis of Google Flu Trends data at local, rather than national, levels [24].

Figure 4. Plot of weekly influenza-like illness cases (right axis) as compared to standardized US social media data (left axis).



In this study, we controlled for autocorrelation and exogenous temporal factors using an ARIMAX model. The improved performance of this model might be an indication that the 4-week moving average terms are smoothing out fluctuations due to the news cycle. Nevertheless, because Google Flu Trends data do not explicitly differentiate between signals of influenza awareness and actual infection, this relatively complicated model may buy accuracy at the cost of sensitivity to transient phenomena. Thus, temporary spikes in media coverage are smoothed out, but so would temporary spikes in influenza infection.

Elsewhere, we have shown that our Twitter data overcome the limitations identified in prior Google Flu Trends studies by filtering out signals of influenza awareness from signals of actual infection and enabling analysis at multiple levels of geographic granularity [12,25]. Furthermore, the fact that the Twitter model is more lightweight means that it is more able to correctly track transient increases in infection when they occur [12]. Finally, municipal-level Twitter data provided a better account of actual influenza cases in Baltimore than did state- or national- level data. This finding is consistent with prior work [12] showing that local Twitter data does contribute information that is useful for municipal surveillance. In contrast, state- and local-level Google Flu Trends data did not improve surveillance when compared to national GFT data.

Limitations

One limitation of our approach is that it only relies upon one municipality. Furthermore, our analysis only examined three seasons of influenza data, one of which (the 2012-2013 season) is known to have been anomalous. Future work should therefore focus on incorporating data from multiple influenza seasons.

Conclusions

Overall, our results motivate the need for future work examining how social media may be used to track measures relevant to influenza surveillance in multiple different locations and seasons.

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Conflicts of Interest

M Dredze and MJ Paul serve on the advisory board of SickWeather. There are no other conflicts of interest.

References

1. 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]
2. 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]
3. Yuan Q, Nsoesie EO, Lv B, Peng G, Chunara R, Brownstein JS. Monitoring influenza epidemics in china with search query from baidu. PLoS One 2013;8(5):e64323 [FREE Full text] [doi: 10.1371/journal.pone.0064323] [Medline: 23750192]
4. Culotta A. Towards detecting influenza epidemics by analyzing Twitter messages. 2010 Presented at: Proc First Workshop on Social Media Analytics : 115-122; 2010; New York, NY, USA. [doi: 10.1145/1964858.1964874]
5. Paul MJ, Dredze M. You are what you Tweet: Analyzing Twitter for public health. 2011 Presented at: ICWSM; 2011; Barcelona, Spain p. 265-272.
6. Lampos V, Cristianini N. Nowcasting events from the social web with statistical learning. ACM Transactions on Intelligent Systems and Technology (TIST) 2012;3(4):72. [doi: 10.1145/2337542.2337557]
7. Dredze M. How Social Media Will Change Public Health. IEEE Intell. Syst 2012 Jul;27(4):81-84. [doi: 10.1109/MIS.2012.76]
8. 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] [Medline: 21124761]
9. Salathé M, Khandelwal S. Assessing vaccination sentiments with online social media: implications for infectious disease dynamics and control. PLoS computational biology 2011;7(10). [doi: 10.1371/journal.pcbi.1002199]
10. Lamb A, Paul MJ, Dredze M. Separating Fact from Fear: Tracking Flu Infections on Twitter. In: HLT-NAACL. 2013 Presented at: HLT-NAACL; 2013; Atlanta, Georgia, USA p. 789-795.
11. Gesualdo F, Stilo G, Agricola E, Gonfiantini MV, Pandolfi E, Velardi P, et al. Influenza-like illness surveillance on Twitter through automated learning of naïve language. PLoS One 2013;8(12):e82489 [FREE Full text] [doi: 10.1371/journal.pone.0082489] [Medline: 24324799]
12. Broniatowski DA, Paul MJ, Dredze M. National and local influenza surveillance through Twitter: an analysis of the 2012-2013 influenza epidemic. PLoS One 2013;8(12):e83672 [FREE Full text] [doi: 10.1371/journal.pone.0083672] [Medline: 24349542]
13. McIver DJ, Brownstein JS. Wikipedia usage estimates prevalence of influenza-like illness in the United States in near real-time. PLoS computational biology 2014;10(4). [doi: 10.1371/journal.pcbi.1003581]
14. Chunara R, Aman S, Smolinski M, Brownstein JS. Flu near you: an online self-reported influenza surveillance system in the USA. Online Journal of Public Health Informatics 2013;5(1). [Medline: PMC3692780]
15. Dredze M, Cheng R, Paul MJ, Broniatowski DA. HealthTweets. org: A Platform for Public Health Surveillance using Twitter. In: Workshops at the Twenty-Eighth AAAI Conference on Artificial Intelligence. 2014 Presented at: AAAI Conference on Artificial Intelligence; 2014; Quebec City, Quebec, Canada.
16. HealthTweets.org. URL: http://www.healthtweets.org/accounts/login/?next=/ [accessed 2015-05-22] [WebCite Cache ID 6YhoN4Fak]
17. Nagel AC, Tsou MH, Spitzberg BH, An L, Gawron JM, Gupta DL, et al. The complex relationship of realspace events and messages in cyberspace: Case study of influenza and pertussis using tweets 2013. JMIR 2013;15(10). [doi: 10.2196/jmir.2705] [Medline: PMC3841359]
18. Dugas AF, Jalalpour M, Gel Y, Levin S, Torcaso F, Igusa T, et al. Influenza forecasting with Google Flu Trends. PLoS One 2013;8(2):e56176 [FREE Full text] [doi: 10.1371/journal.pone.0056176] [Medline: 23457520]
19. Google Flu Trends. URL: https://www.google.org/flutrends/us/#US [WebCite Cache ID 6YhoaMjpP]

20. Dredze M, Paul MJ, Bergsma S, Tran H. Carmen: A twitter geolocation system with applications to public health. 2013 Jun Presented at: AAAI Workshop on Expanding the Boundaries of Health Informatics Using AI (HIAI); 2013; Bellevue, WA p. 20-24.
21. Box GEP, Jenkins GM, Reinsel GC. Time series analysis: forecasting and control. Hoboken, NJ: John Wiley; 2008.
22. Hyndman RJ, Khandakar Y. Automatic Time Series Forecasting: The forecast Package for R. Journal of Statistical Software 2008;27(3) [FREE Full text]
23. Hyndman RJ, Khandakar Y. No 6/07 2007. Monash University, Department of Econometrics and Business Statistics. 2007. Automatic time series for forecasting: The forecast package for R URL: http://webdoc.sub.gwdg.de/ebook/serien/e/monash_univ/wp6-07.pdf [accessed 2015-05-19] [WebCite Cache ID 6Yeg6094h]
24. Lazer D, Kennedy R, King G, Vespignani A. The Parable of Google Flu: Traps in Big Data Analysis. Science 2014 Mar. [doi: 10.1126/science.1248506]
25. Broniatowski DA, Paul MJ, Dredze M. Twitter: big data opportunities. Science 2014 Jul 11;345(6193):148. [doi: 10.1126/science.345.6193.148-a] [Medline: 25013052]

Abbreviations

AIC: Aikake information criterion
ARIMA: Autoregressive integrated moving average
CDC: Centers for Disease Control
HHS: Health and Human Systems
ILI: Influenza-like illness

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Original Paper

Geosocial-Networking App Usage Patterns of Gay, Bisexual, and Other Men Who Have Sex With Men: Survey Among Users of Grindr, A Mobile Dating App

William C Goedel[1,2,3*]; Dustin T Duncan[1,2,4,5,6*], ScD

[1]School of Medicine, Department of Population Health, New York University, New York, NY, United States
[2]Global Institute of Public Health, New York University, New York, NY, United States
[3]College of Arts and Science, Department of Sociology, New York University, New York, NY, United States
[4]Center for Drug Use and HIV Research, College of Nursing, New York University, New York, NY, United States
[5]Population Center, New York University, New York, NY, United States
[6]Center for Data Science, New York University, New York, NY, United States
[*]all authors contributed equally

Corresponding Author:
William C Goedel
School of Medicine
Department of Population Health
New York University
227 East 30th Street, Room 628A
New York, NY, 10016
United States
Phone: 1 646 501 2715
Fax: 1 646 501 2706
Email: wcg219@nyu.edu

Abstract

Background: Geosocial-networking apps like Grindr have been used increasingly among men who have sex with men (MSM) to meet anonymous partners. These mobile dating apps employ global positioning system technology to facilitate connections with other users based on their current location. These new technologies have generated quicker and easier modes for men who have sex with men to meet potential partners based on attraction and physical proximity.

Objective: The aim of this study is to describe geosocial-networking app use and recent sexual behaviors of MSM in the Atlanta metropolitan statistical area.

Methods: Our sample was recruited from Grindr, the most commonly used of these mobile apps among MSM, using broadcast advertising. Advertisements were displayed over the course of a 72-hour period and participants were directed to a Web-based survey.

Results: In total, 604 men clicked through the advertisement, and 92 users completed the survey. One-third (38.0%) of the men reported using these mobile apps to meet new sexual partners, and one-fifth (18.5%) used them to “kill time” when bored. Men reporting currently being in a relationship were less likely to report using these mobile apps to meet other MSM to date or to find a boyfriend or romantic partner, but more likely to report using these mobile apps to meet other MSM to have sex, $X^2_{24}=12.1$, $P=.016$. Respondents had current accounts on 3.11 mobile apps (SD 1.84) on average, with Grindr being the most common (100%), followed by Scruff (52.5%), and Jack’d (45.7%). Most men were most active in the late night (40.2%), and on weekdays (64.1%). Each day, on average, men reported opening these mobile apps 8.38 times (SD 8.10) and spent 1.31 hours (SD 1.15) on these mobile apps. The age respondents began using these mobile apps was associated with the age at their first instance of insertive anal sex ($r_{80}=.527$, $P<.001$) and receptive anal sex ($r_{76}=.527$, $P<.001$).

Conclusions: These findings suggest that MSM use multiple mobile apps and spend significant time on them. For these reasons, HIV prevention interventions could be delivered on these mobile apps.

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KEYWORDS

homosexuality; MSM; men who have sex with men; male; mobile apps; dating apps; mobile phones; HIV; AIDS prevention

Introduction

Gay, bisexual, and other men who have sex with men (MSM) represent only 2% of the male population in the United States, yet comprised the majority (63%) of all new human immunodeficiency virus (HIV) infections diagnosed in adults and adolescents in the United States in 2010 [1]. The region commonly referred to as the Deep South (Alabama, Georgia, Louisiana, Mississippi, North Carolina, and South Carolina) is disproportionately affected by the HIV/AIDS epidemic. From 2000 to 2003, the number of newly reported acquired immune deficiency syndrome (AIDS) cases increased by 36.5% in this region, while the number of newly reported AIDS causes increased by only 4.0% in the other states in the Southern United States. (Delaware, Maryland, West Virginia, Virginia, Florida, Arkansas, Tennessee, Kentucky, Texas, and Oklahoma) and by 5.2% in the remaining portion of the country [2]. Although only 37% of the US population resides in the South, about half (49%) of individuals living with HIV in 2010 were diagnosed in the South [3,4]. In 2010, Georgia ranked sixth highest in the nation for the total number of adults and adolescents living with HIV. In 2012, among all HIV infections and cases of AIDS in male adults and adolescents in Georgia, 63% of HIV infections and 76% of cases of AIDS were seen in MSM [5].

The Internet is one of the most popular venues for sexual partner seeking among MSM [6,7]. Sexual partner seeking on the Internet encourages the use of partner selection criteria in profiles and these specifications often include the preferred age, race/ethnicity, and body type of a partner as well as the desired sexual practices of the individual [8-12]. Studies suggest that compared to men who do not seek sex on the Internet, Internet sex-seekers tend to have more frequent anal intercourse, more previously diagnosed sexual transmitted infections (STIs), more sexual exposure to men, greater numbers of sexual partners, and greater numbers of sexual partners known to be HIV-positive [13]. Prior research demonstrates that time spent online looking for casual sexual partners may increase the odds of having anal intercourse without a condom [14].

Geosocial-networking apps (mobile dating apps) like Grindr, Jack'd, and Scruff have been used increasingly among MSM to meet anonymous partners [15]. In 2013, Grindr, the most popular of these apps, reported that it had six million users in 192 different countries around the world with 2.5 million new users added in the previous year [15]. These apps employ global positioning system technology to facilitate connections with other users based on their current location [16] and enable their users to scan for nearby users, chat with them, and meet, sometimes for sexual encounters. These new mobile technologies have generated quicker and easier modes for MSM to meet potential partners based on attraction and physical proximity [17].

Use of these apps is commonplace among MSM. In a sample of 379 MSM in Washington, DC, 63.6% of men reported having used an app to meet a sexual partner in the past year [18]. The use of these apps enables an expansion of an individual's sexual and social networks. Individuals integrating app-met sexual partners into their social networks were nearly twice as likely to have engaged in anal intercourse without a condom compared to individuals who did not integrate these partners into their social networks as seen in a sample of 295 MSM in Los Angeles [19]. Previous research also found that 75.0% of respondents had a sexual encounter with partners they met on Grindr, and reported significantly higher rates of condom use with partners met on Grindr (59.8%) compared to partners met elsewhere (41.9%) [17,19,20].

Despite the increased popularity of these apps, little is known about the behaviors among their users. As such, the purpose of the current study is to describe the use of these apps and the sexual behaviors of MSM in Atlanta, Georgia as they represent a high-risk group for acquiring HIV. Almost two-thirds (64%) of persons living with HIV in Georgia reside in the Atlanta metropolitan statistical area [5] -an area that included twenty-eight counties and 4.9 million people in 2005. To our knowledge, this is the first study to investigate app use and sexual behaviors of geosocial-networking app-using MSM in Atlanta and in the Southern United States as a whole.

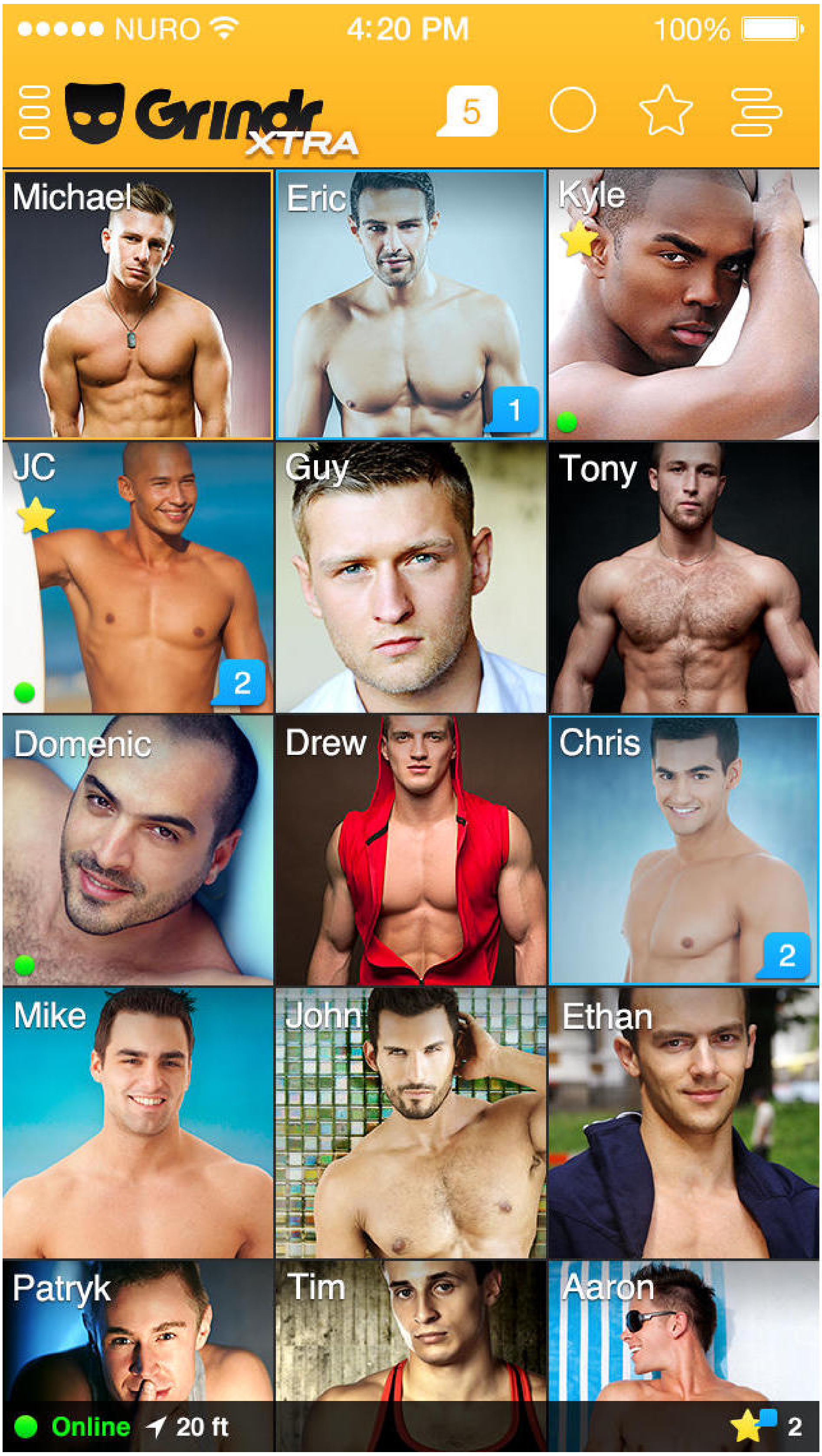
Methods

Recruitment

Figure 1 displays a simulated user interface on Grindr. During a three-day period in January 2015, we advertised on Grindr, utilizing a pop-up advertisement encouraging users to click through to take our survey, a method previously used to recruit MSM into cross-sectional and longitudinal studies of sexual risk taking behavior and substance use [21]. This advertisement was shown the first time that users logged on to the app within a 24-hour period, and was displayed three times during three consecutive 24-hour periods. This advertisement was only shown to Grindr users who logged in to their account in the Atlanta metropolitan area. Participants were alerted that completing the survey entered them for a chance to win one of six $50.00 Amazon gift cards.

The survey took, on average, 25 minutes to complete. All men reported being 18 years of age at survey completion. All procedures were approved by the New York University Committee on Activities Involving Human Subjects. Data were collected anonymously. In total, 604 users clicked through the advertisement and reached the survey, 148 (24.5%) continued to the consent page, 143 (23.7%) provided informed consent, and 92 (15.2%) completed the questionnaire. IP addresses were used to identify potential duplicate entries from the same user over the course of the 72-hour period, but no potential duplicate entries were identified.

Figure 1. Screenshot of the Grindr user interface.



Study Measures

Demographic Characteristics

Demographic characteristics were assessed in fourteen items. Age was measured continuously. Sex assigned at birth included male or female. Gender was measured as male, female-to-male transgender, female, male-to-female transgender, and other. Sexual orientation was categorized as gay or homosexual, bisexual, straight or heterosexual, and other. Relationship status was identified as reporting currently being in a relationship or not currently being in a relationship. Race/ethnicity was measured in two items, “Are you Hispanic or Latino?” and “Which of the following best describes your race?” and participants were later categorized as White (non-Hispanic/Latino), Black or African American (non-Hispanic/Latino), Hispanic or Latino (any race), Asian/Pacific Islander, and Multiracial/other based on their responses to these items. National origin was categorized as either being born in the United States or being born outside the United States. Highest educational attainment was categorized as less than twelfth grade, high school or equivalent, some college, trade or vocational training, Associates degree, Bachelor’s degree, Master’s degree, or Doctoral degree. Employment status was categorized as working full time, working part time, not working, currently a student, retired, or unable to work. Individual income in the past year was categorized as under $10,000; $10,000 to $24,999; $25,000 to $39,999; $40,000 to $54,999; $55,000 to $69,999; $70,000 to $84,999; $85,000 to $99,999; and $100,000 or more.

Geosocial-Networking App Use Patterns

App use behaviors were assessed in three items. The age at which the respondent started using apps to meet other men was measured continuously. The number of years spent using these apps was calculated for each participant by subtracting the age at which the respondent reported beginning to use these apps from the participant’s self-reported age. Motivation for using these apps was asked, “Which best describes your reason for using these apps?” with five options informed by prior work [17,19,20]: “I want to ‘kill time’ when bored,” “I want to make friends with other gay and bisexual men,” “I want to meet other gay and bisexual men to date,” “I want to find a boyfriend or other romantic partner,” and “I want to meet other gay and bisexual men to have sex with.” While we acknowledge that it is possible for transgender individuals to utilize these apps, we estimate, based on prior work assessing MSM-targeted apps and their use, that individuals using these apps were assigned male at birth and identify as male and are seeking others who were assigned male at birth and identify as male [17]. Respondents were asked to check off which apps they currently had profiles or accounts on from a list including nineteen options: Bender, Boy Ahoy, Distinc.tt, DowneLink, Gay Thug Dating, Grindr, GROWLr, Guy Spy, Hornet, Hunters BBS, Jack’d, Maleforce, MISTER, Planet Romeo, Scruff, Skout, u2nite, u4Bear, and VGL, and a space to indicate others not listed. The number of apps a respondent currently had a profile or account on was calculated for each participant.

Average daily activity was assessed in six items. The time of day an individual was most active on these apps was categorized as early morning (2:31am to 6:30am), morning (6:31am to 12:00pm), afternoon (12:01pm to 5:00pm), evening (5:01pm to 9:30pm), and late night (9:31pm to 2:30am). The part of week an individual was most active on these apps was categorized as weekdays (Monday through Thursday) and weekends (Friday through Sunday). The day of week an individual was most active on these apps included Sunday, Monday, Tuesday, Wednesday, Thursday, Friday, or Saturday. The average number of times an individual opens or logs on was measured continuously in response to: “On average, how many times do you open or log on to these apps each day?” The average number of hours spent on these apps each day was measured continuously in response to: “On average, how many minutes or hours do you spend on these apps each day?” The average number of messages sent each day was measured continuously in response to: “On average, how many messages do you send on these apps each day?”

HIV Status and Recent Sexual Behaviors

HIV status was categorized as positive, negative, or unknown/never tested and based on participant self-report. The individual’s age at his first instance of insertive anal intercourse and receptive anal intercourse respectively were measured continuously. Sexual behaviors were assessed in eight items. Participants were asked for the number of partners they had met through apps and engaged in anal intercourse (regardless of position) and in anal intercourse without a condom (regardless of position). Respondents were asked whether or not they engaged in insertive and receptive anal intercourse in the past six months. If insertive or receptive anal intercourse was indicated, the respondent was asked about the number of partners he engaged in the particular behavior with, in the past six months (measured continuously), and the number of partners he engaged in the particular behavior without a condom in the past six months (measured continuously).

Partner Characteristics

Information was also collected on sexual partners met using apps and was assessed in three items. Relative age of the majority of sexual partners met using apps was categorized as a lot older (>4 years older), slightly older (2-4 years older), approximately the same age, and younger. Race/ethnicity of the majority of sexual partners met on apps was categorized as White (non-Hispanic/Latino), Black or African American (non-Hispanic/Latino), Hispanic or Latino (any race), and Asian/Pacific Islander. Perceived HIV status of the majority of sexual partners met on apps was categorized as positive, negative, or unknown.

Sexual Sensation Seeking Scale

The Sexual Sensation Seeking Scale was used to gauge an individual’s propensity to seek out novel or risky sexual stimulation [22-25]. This ten-item instrument employs a four-point Likert-type response format that has an acceptance internal consistency (Cronbach alpha=.75) in gay men [22,23]. Scores on this scale range from 10 to 40, where higher scores indicate a higher propensity to seek out novel or risky sexual stimulation. In this sample, the instrument displayed moderate internal consistency (Cronbach alpha=.68).

Statistical Analysis

Statistical Package for the Social Sciences (SPSS) version 21 (SPSS IBM, New York, USA) was used to perform all statistical analysis. Descriptive statistics (eg, means, standard deviations) were calculated for demographic characteristics and behavioral characteristics. Differences in these behavioral characteristics by demographic characteristics were examined using analyses of variance (ANOVA) for associations between continuous behavioral variables and categorical demographic variables, chi-square tests of independence for associations between categorical behavioral variables and categorical demographic variables, and Spearman correlations for associations between continuous behavioral variables and continuous demographic variables. Statistical significance was determined by *P*<.05. No post-hoc statistical analyses were conducted.

Results

Sample Characteristics

The demographic characteristics of the sample (N=92) are listed in Table 1. The mean age was 31.73 years old (SD 10.77) and ranged from 18 to 66. A majority of the sample identified as non-Hispanic White (63.0%), while 19.6% of the sample identified as non-Hispanic Black, 9.8% identified as Hispanic or Latino of any racial background, 3.3% identified as Asian or Pacific Islander, and 4.3% identified as multiracial. The vast majority of the sample (93.5%) was born in the United States. The majority of the sample identified their sexual orientation as gay (77.2%) or bisexual (21.7%). More than half of the sample (51.2%) graduated college or completed more graduate education. Nearly three-quarters of the sample (72.8%) was employed either on a full-time or part-time basis.

Geosocial-Networking App Use Patterns

Table 2 shows the geosocial-networking app use behaviors of the sample. The average age at which respondents began using these apps was 26.61 years old (SD 9.80) and ranged from 14 to 55, and on average, they had been using these apps for 4.83 years (SD 3.50). Over one-third of the men reported using these apps to meet other men for sexual encounters (38.0%), and the second most common reason was using these apps to “kill time” when bored (18.5%), following by using these apps to make friends with other men (17.4%), to find a boyfriend or romantic partner (14.1%), and to meet other gay and bisexual men to date (10.9%). Men reporting currently being in a relationship were less likely than men not currently in a relationship to report using these apps to meet other men who have sex with men to date (0.0% vs 14.7%) or to find a boyfriend or other romantic partner (0.0% vs 19.1%), but more likely to report using these apps to meet other men who have sex with men to have sex (60.9% vs 30.9%), χ^2_4=12.1, *P*=.02.

Respondents, on average, reported having current accounts or profiles on 3.11 apps (SD 1.84), with Grindr being the most common (100%), followed by Scruff (52.5%), Jack’d (45.7%), Hornet (21.8%), and GROWLr (18.5%). Most men were active in the evening (34.8%) or late night (40.2%), and on weekdays (64.1%)—compared to early morning (6.5%), morning (8.7%), and afternoon (9.8%) hours, and weekends (35.9%). Being active on weekdays was associated with having a lower individual income in the past year, χ^2_7=23.5, *P*=.001, and being currently unemployed, χ^2_4=13.9, *P*=.008. Each day, on average, men logged on or opened these apps 8.38 times (SD 8.10), spent 1.31 hours (SD 1.15), and sent 21.03 messages (SD 25.62).

Table 1. Sample Demographics.

Demographics	Frequency	Percentage (%)[a]
Sex assigned at birth (Male)	90	97.8
Gender identity (Male)	92	100.0
Sexual orientation		
Gay	71	77.2
Bisexual	20	21.7
Other	1	1.1
Current relationship		
Yes	23	25.0
No	69	75.0
Race/ethnicity		
White (non-Hispanic/Latino)	58	63.0
Black (non-Hispanic/Latino)	18	19.6
Hispanic/Latino (any race)	9	9.8
Asian/Pacific Islander	3	3.3
Multiracial	4	4.3
National origin		
United States	86	93.5
Outside United States	6	6.5
Education		
Less than 12th Grade	2	2.2
High School, or equivalent	11	12.0
Some college	21	22.8
Technical or vocational training	4	4.3
Associates degree	7	7.6
Bachelors’ degree	33	35.9
Masters’ degree	11	12.0
Doctoral degree	3	3.3
Employment status		
Working full time	52	56.5
Working part time	15	16.3
Not working	12	13.0
Student	11	12.0
Unable to work	2	2.2
Individual yearly income		
Under $10,000	16	17.4
$10,000 to $24,999	17	18.5
$25,000 to $39,999	17	18.5
$40,000 to $54,999	20	21.7
$55,000 to $69,999	8	8.7
$70,000 to $84,999	6	6.5
$85,000 to $99,999	4	4.3
$100,000 or more	2	2.2

[a] Percentages may not add to 100 in cases of missing data.

Table 2. Geosocial-networking app use (categorical variables).

App use	Frequency	Percentage (%)[a]
Current accounts/profiles		
Grindr	92	100.0
Scruff	48	52.2
Jack'd	42	45.7
Hornet	20	21.7
GROWLr	17	18.5
Guy Spy	10	10.9
MISTER	8	8.7
Boy Ahoy	7	7.6
Skout	7	7.6
Bender	4	4.3
Planet Romeo	3	3.3
U4BEAR	3	3.3
VGL	3	3.3
Most active time of day		
Early morning (2:31am to 6:30am)	6	6.5
Morning (6:31am to 12:00pm)	8	8.7
Afternoon (12:01pm to 5:00pm)	9	9.8
Evening (5:01pm to 9:30pm)	32	34.8
Late night (9:31pm to 2:30am)	37	40.2
Most active part of week		
Weekdays (Monday through Thursday)	59	64.1
Weekends (Friday through Sunday)	33	35.9
Most active day of week		
Sunday	6	6.7
Monday	16	17.4
Tuesday	6	6.7
Wednesday	12	13.0
Thursday	8	8.7
Friday	21	22.8
Saturday	21	22.8

[a] Percentages may not add to 100 in cases of missing data.

Recent Sexual Behaviors

Table 3 displays the self-reported HIV statuses and recent sexual behaviors of all respondents in the sample. HIV-negative individuals constituted 84.8% of the sample, while HIV-positive individuals constituted 8.7% of the sample, and 6.5% reported an unknown HIV status or had never been tested. The average age at the individual's first instance of insertive anal intercourse (IAI) was 20.64 years old (SD 6.90), ranging from 13 to 56, and at first instance of receptive anal intercourse (RAI) was 20.14 years old (SD 7.14), ranging from 12 to 58. The respondents who were sexually active in the last six months, on average, had 4.28 app-met partners (SD 5.68) in the last six months who they engaged in either anal intercourse (irrespective of role as an insertive or receptive partner). Additionally, these respondents had 2.19 app-met partners (SD 4.72) in the last six months who they engaged in anal intercourse (irrespective of role as an insertive or receptive partner) without a condom. HIV-positive respondents, on average, had 8.00 partners who they met on apps and had anal intercourse without a condom in the last six months, while HIV-negative respondents had anal intercourse without a condom in the last six months with 1.68 app-met partners, $F_{2,86}$=7.800, P=.001.

Table 3. HIV status and recent sexual behaviors.

	Frequency	Percentage (%)[a]
HIV status		
Negative	78	84.8
Positive	8	8.7
Unknown/never tested	6	6.5
Engaged in Insertive Anal Intercourse (IAI) in past 6 months		
Yes	65	70.7
No	27	29.3
Engaged in Receptive Anal Intercourse (RAI) in past 6 months		
Yes	54	58.7
No	38	41.3

[a] Percentages may not add to 100 in cases of missing data.

Partner Characteristics

Table 4 reports the characteristics of the majority of the respondent's app-met partners. Most respondents reported meeting partners that were younger than themselves (34.1%) on these apps; however, 27.5% reported meeting partners greater than four years older than themselves, 25.3% reported meeting partners approximately the same age as themselves, and 13.1% reported meeting partners two to four years older than themselves. Asian and Black respondents were more likely to report pairing with partners who are greater than four years older than themselves, while White and Hispanic/Latino respondents were more likely to report pairing with partners who are about the same age as or younger than themselves, χ^2_{12}=28.6, P=.005.

Table 4. App-met partner characteristics.

Characteristics	Frequency	[a]Percentage (%)
Relative age		
Younger	31	34.1
Approximately same age	23	25.3
2-4 Years older	12	13.2
>4 Years older	25	27.5
Race/ethnicity		
White (non-Hispanic/Latino)	64	69.6
Black (non-Hispanic/Latino)	15	16.3
Hispanic/Latino (any race)	10	10.9
Asian/Pacific Islander	1	1.1
Perceived HIV status		
Negative	77	84.6
Positive	3	3.3
Unknown/never tested	11	12.1

[a] Percentages may not add to 100 in cases of missing data.

Most respondents reported a majority of their partners met on these apps being White (69.6%), and 16.3% reported a majority of their app-met partners being Black. Also, 10.9% reported a majority of their app-met partners being Hispanic/Latino, and 1.1% reported a majority of their app-met partners being Asian. White respondents were more likely to report pairing with White partners (82.1%), compared to Hispanic/Latino, Black/African American, and Asian/Pacific Islander partners, χ^2_{12}=45.9, P<.001. Most respondents believed a majority of their partners to be HIV-negative (84.6%) or HIV-unknown (12.1%) compared to those believing a majority of their partners to be HIV-positive (3.3%). HIV-negative respondents were more likely to pair with

HIV-negative partners (90.9% vs 37.5%) and HIV-positive respondents were more likely to pair with HIV-positive partners (37.5% vs 0.0%), χ^2_4=37.8, P<.001.

Sexual Sensation Seeking Scale

The average Sexual Sensation Seeking Scale score was 30.32 (SD 4.52), ranging from 16 to 40. A higher propensity to seek out novel or risky sexual stimulation was positively associated with the number of partners an individual met on apps and had anal intercourse with (r_{84}=.269, P=.012), the number of partners an individual met on apps and had anal intercourse without a condom (r_{85}=.362, P=.001), the number of partners an individual engaged in anal intercourse in the receptive position (r_{50}=.457, P=.001), and the number of partners an individual engaged in anal intercourse in the receptive position without a condom (r_{48}=.427, P=.002).

Discussion

Principal Findings

The purpose of the current study was to describe the usage of geosocial-networking apps among a sample of MSM in Atlanta, Georgia on Grindr. To our knowledge, this is the first study to investigate app use and sexual behaviors of geosocial-networking app users in Atlanta and in the Southern United State as a whole. Most men involved in the study currently had an account or profile on more than one app other than Grindr, with the most common being Scruff, Jack'd, Hornet, and GROWLr. In addition, we found that most men were active in the evening (34.8%) or late night (40.2%), and on weekdays (64.1%). Each day, on average, men logged on or opened these apps 8.38 times, spent 1.31 hours, and sent 21.03 messages. Similarly frequent use of these apps was observed in a sample of 195 Grindr users in Los Angeles, where approximately half (49.7%) reported using Grindr more than five times per day [17].

Individuals indicating being in a relationship were less likely to report using these apps for dating or finding a romantic partner, but more likely to use these apps to find other sexual partners. Among gay couples, agreements about sex with outside partners, whether closed (monogamous) or open, are common, and these agreements serve as a framework for the couples' decisions regarding sexual behaviors that heighten risk of acquiring HIV. Open agreements may permit a variety of acceptable sexual behaviors with outside partners, such as "being safe" (ie, using a condom) with outside partners [26].

In addition, we found that the age respondents began using these apps was associated with the age at their first instance of insertive anal sex and receptive anal sex. Young MSM often rely on organizations, social events, and the Internet to assist in developing their sexual identity, but in cities with limited community-based organizations, they may rely on informal role models, such as older men and individuals on geosocial-networking apps, to learn about cultural norms in MSM [27,28]. However, little research has directly assessed the age an individual begins to use these geosocial-networking apps and associated sexual behaviors. Thus, our study provides a new contribution to the literature. It is possible that earlier access to other MSM in nearby areas provided by these apps may lead to earlier sexual debut. Sexual debut earlier than 16 years old has been associated with more frequent exchange sex, substance use, emotional and psychological problems related to substance use, and a history of suicide attempts, compared to MSM with later sexual debuts [29].

Many prior studies have compared sexual behaviors, HIV/STI testing and diagnoses, and substance use of app users and non-app users. Psychosocial characteristics, including sensation seeking and self-control, have been compared between MSM who meet partners through apps and MSM who meet partners through other methods. However, no significant differences between the two groups were observed [30]. To our knowledge, this is the first investigation assessing sexual sensation seeking specifically as a correlate of sexual behaviors in MSM who meet partners through apps. However, without a sample of MSM who meet partners through other methods to serve as a control, the significance of findings associated with higher propensities to seek sexual sensation is uncertain and worthy of further investigation.

Study Implications

This investigation on the usage patterns of geosocial-networking apps has substantial implications for utilizing these apps for HIV prevention efforts—as we show that many men use apps for meeting anonymous sexual partners and that the age respondents began using these apps was associated with the age at their first instance of anal intercourse with another man. While many studies have examined the effectiveness of app-based intervention strategies, these are only effective if downloaded and used by the population at risk [31-33]. Due to their wide use by MSM, it may be best to leverage the use of popularly used and established apps like Grindr, Jack'd, and Scruff for HIV prevention and sexual health promotion. One such app, Hornet, has begun its "Know Your Status" campaign, where HIV status and date of most recent test are featured on profiles. Keeping with this wider pattern of apps targeting MSM promoting sexual health, apps could utilize measures of sexual sensation seeking and recent sexual behavior prior to creating a profile on the app for targeted HIV prevention messages. For example, individuals with a higher propensity to seek sexual sensations may have more frequent sexual encounters and need more frequent reminders for HIV testing.

Previous research among MSM found that 64% of the sample found these apps to be acceptable sources of sexual health information [34], which suggests that these existing tools can be effective intervention targets. Understanding when users are most active, as this work presents, for example, may inform optimal timing for broadcast advertisements used for health promotion services, including information regarding new forms of prevention such as pre-exposure prophylaxis (PrEP), and ways to locate nearby free, confidential HIV testing locations. For example, our work suggests that men are most active on these apps on weekday nights, and health promotion messages could appear more frequently at these higher-use times.

Future Research

Future research into app use patterns could be conducted in MSM in the Deep South and elsewhere. Such investigations should examine app use in MSM from multiple geographies to enable comparison of use by location—which may have implications for targeted intervention strategies. Indeed, such research would benefit from large population-based samples, not just highly select samples of MSM using only one particular app such as Grindr. We are not aware of any other research on other popular apps, such as Scruff and Jack'd. Additionally, differences in use among various apps should be studied cross-sectionally to investigate variations in behavior and demographics based on the use of specific apps. We recognize different geosocial-networking apps may be popular among different subgroups (eg, Jack'd might be more popular among Black MSM).

In addition, longitudinal research studies could be conducted to examine app use patterns overtime. Longitudinal studies should be conducted to better understand the associations between connecting with potential partners via apps and sexual risk behaviors, with a focus on the impact of varying durations and frequencies of use with age, as young MSM have been found to heavily utilize Internet search engines, gay-friendly chat rooms, pornography websites, and apps targeted to MSM to gain information on sexual behavior, identity, and health [35-38].

Limitations

The results of this study should be considered in light of their limitations. First, our sample is a relatively small sample of MSM who use geosocial-networking app in Atlanta recruited exclusively from Grindr. A substantial percentage of individuals (83.9%) who saw the advertisement and clicked on it did not complete the survey; as a result, the sample is likely to be biased by some degree of self-selection. For this reason, and given the small sample size, these findings may not be representative of the population of Grindr users in Atlanta or non-Grindr app users in Atlanta.

Furthermore, the behaviors in this study were assessed with self-report measures. While there can be some misclassification (eg, inaccurate reporting) in self-report measures, the survey was conducted anonymously by MSM over their mobile phone or tablet computers, so they may be more likely to answer accurately and honestly. Finally, this was a cross-sectional study app use patterns at one point in time. It is possible that MSM can vary their use patterns over time, perhaps due to seasonality and current relationship status. For example, it is possible that men might be more active on apps during the winter months when they may be more likely to be in their homes, and may be inactive on these apps throughout the course of a monogamous relationship.

Conclusions

Despite these limitations, this study has a number of strengths and provides meaningful insights for HIV prevention among MSM. These findings suggest that MSM have accounts on multiple apps simultaneously and spend significant time on these apps each day. For these reasons, HIV prevention interventions for MSM could be delivered through a wide range of apps with a potentially large reach to a high-risk subset of MSM.

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Conflicts of Interest

None declared.

References

1. Centers for Disease Control. HIV Surveillance Supplemental Report 2012;17(No. 4). 2012. Estimated HIV Incidence in the United States, 2007-2010 URL: http://www.cdc.gov/hiv/pdf/statistics_hssr_vol_17_no_4.pdf [accessed 2015-04-28] [WebCite Cache ID 6Y6edPqQa]
2. Reif S, Geonnotti KL, Whetten K. HIV Infection and AIDS in the Deep South. Am J Public Health 2006 Jun;96(6):970-973. [doi: 10.2105/AJPH.2005.063149] [Medline: 16670228]
3. Reif S, Pence BW, Hall I, Hu X, Whetten K, Wilson E. HIV Diagnoses, Prevalence and Outcomes in Nine Southern States. J Community Health 2014 Dec 19 (forthcoming). [doi: 10.1007/s10900-014-9979-7] [Medline: 25524210]
4. Reif SS, Whetten K, Wilson ER, McAllaster C, Pence BW, Legrand S, et al. HIV/AIDS in the Southern USA: a disproportionate epidemic. AIDS Care 2014;26(3):351-359. [doi: 10.1080/09540121.2013.824535] [Medline: 23944833]
5. HIV Surveillance Fact Sheet, Georgia, 2012. 2013. Georgia Department of Health; 2013 URL: https://dph.georgia.gov/sites/dph.georgia.gov/files/HIV_EPI_Fact_Sheet_Surveillance_2012_updated.pdf [accessed 2015-04-28] [WebCite Cache ID 6Y6eVtNtX]

6. Liau A, Millett G, Marks G. Meta-analytic examination of online sex-seeking and sexual risk behavior among men who have sex with men. Sex Transm Dis 2006 Sep;33(9):576-584. [doi: 10.1097/01.olq.0000204710.35332.c5] [Medline: 16540884]
7. Benotsch EG, Kalichman S, Cage M. Men who have met sex partners via the Internet: prevalence, predictors, and implications for HIV prevention. Arch Sex Behav 2002 Apr;31(2):177-183. [Medline: 11974643]
8. Paul JP, Ayala G, Choi KH. Internet sex ads for MSM and partner selection criteria: the potency of race/ethnicity online. J Sex Res 2010 Nov;47(6):528-538 [FREE Full text] [doi: 10.1080/00224490903244575] [Medline: 21322176]
9. Kaufman G, Phua VC. Is Ageism Alive in Date Selection among Men? Age Requests among Gay and Straight Men in Internet Personal Ads. The Journal of Men's Studies 2003 Jan 1;11(2):225-235. [doi: 10.3149/jms.1102.225]
10. Phua VC, Kaufman G. The Crossroads of Race and Sexuality: Date Selection among Men in Internet “Personal” Ads. Journal of Family Issues 2003 Nov;24(8):981-994. [doi: 10.1177/0192513x03256607]
11. Wilson PA, Valera P, Ventuneac A, Balan I, Rowe M, Carballo-Dieguez A. Race-based sexual stereotyping and sexual partnering among men who use the internet to identify other men for bareback sex. J Sex Res 2009;46(5):399-413 [FREE Full text] [doi: 10.1080/00224490902846479] [Medline: 19337934]
12. Green AI. Health and sexual status in an urban gay enclave: an application of the stress process model. J Health Soc Behav 2008 Dec;49(4):436-451. [Medline: 19181048]
13. Landovitz RJ, Tseng CH, Weissman M, Haymer M, Mendenhall B, Rogers K, et al. Epidemiology, sexual risk behavior, and HIV prevention practices of men who have sex with men using GRINDR in Los Angeles, California. J Urban Health 2013 Aug;90(4):729-739 [FREE Full text] [doi: 10.1007/s11524-012-9766-7] [Medline: 22983721]
14. Bauermeister JA, Leslie-Santana M, Johns MM, Pingel E, Eisenberg A. Mr. Right and Mr. Right Now: romantic and casual partner-seeking online among young men who have sex with men. AIDS Behav 2011 Feb;15(2):261-272 [FREE Full text] [doi: 10.1007/s10461-010-9834-5] [Medline: 20953689]
15. Beymer MR, Weiss RE, Bolan RK, Rudy ET, Bourque LB, Rodriguez JP, et al. Sex on demand: geosocial networking phone apps and risk of sexually transmitted infections among a cross-sectional sample of men who have sex with men in Los Angeles County. Sex Transm Infect 2014 Nov;90(7):567-572 [FREE Full text] [doi: 10.1136/sextrans-2013-051494] [Medline: 24926041]
16. Grosskopf NA, LeVasseur MT, Glaser DB. Use of the Internet and mobile-based "apps" for sex-seeking among men who have sex with men in New York City. Am J Mens Health 2014 Nov;8(6):510-520. [doi: 10.1177/1557988314527311] [Medline: 24658284]
17. Rice E, Holloway IW, Winetrobe H, Rhoades H, Barman-Adhikari A, Gibbs J, et al. Sex Risk among Young Men who have Sex with Men who use Grindr, a Smartphone Geosocial Networking Application. J AIDS Clinic Res 2012;01(S4). [doi: 10.4172/2155-6113.S4-005]
18. Phillips G, Magnus M, Kuo I, Rawls A, Peterson J, Jia Y, et al. Use of geosocial networking (GSN) mobile phone applications to find men for sex by men who have sex with men (MSM) in Washington, DC. AIDS Behav 2014 Sep;18(9):1630-1637. [doi: 10.1007/s10461-014-0760-9] [Medline: 24682866]
19. Holloway IW, Pulsipher CA, Gibbs J, Barman-Adhikari A, Rice E. Network Influences on the Sexual Risk Behaviors of Gay, Bisexual and Other Men Who Have Sex with Men Using Geosocial Networking Applications. AIDS Behav 2015 Jan 9 (forthcoming). [doi: 10.1007/s10461-014-0989-3] [Medline: 25572832]
20. Holloway IW, Rice E, Gibbs J, Winetrobe H, Dunlap S, Rhoades H. Acceptability of smartphone application-based HIV prevention among young men who have sex with men. AIDS Behav 2014 Feb;18(2):285-296 [FREE Full text] [doi: 10.1007/s10461-013-0671-1] [Medline: 24292281]
21. Rendina HJ, Jimenez RH, Grov C, Ventuneac A, Parsons JT. Patterns of lifetime and recent HIV testing among men who have sex with men in New York City who use Grindr. AIDS Behav 2014 Jan;18(1):41-49 [FREE Full text] [doi: 10.1007/s10461-013-0573-2] [Medline: 23925515]
22. Kalichman SC, Johnson JR, Adair V, Rompa D, Multhauf K, Kelly JA. Sexual sensation seeking: scale development and predicting AIDS-risk behavior among homosexually active men. J Pers Assess 1994 Jun;62(3):385-397. [doi: 10.1207/s15327752jpa6203_1] [Medline: 8027907]
23. Kalichman SC, Rompa D. Sexual sensation seeking and Sexual Compulsivity Scales: reliability, validity, and predicting HIV risk behavior. J Pers Assess 1995 Dec;65(3):586-601. [doi: 10.1207/s15327752jpa6503_16] [Medline: 8609589]
24. Berg RC. Barebacking among MSM Internet users. AIDS Behav 2008 Sep;12(5):822-833. [doi: 10.1007/s10461-007-9281-0] [Medline: 17676278]
25. Gaither GA, Sellbom M. The sexual sensation seeking scale: reliability and validity within a heterosexual college student sample. J Pers Assess 2003 Oct;81(2):157-167. [doi: 10.1207/S15327752JPA8102_07] [Medline: 12946922]
26. Hoff CC, Beougher SC. Sexual agreements among gay male couples. Arch Sex Behav 2010 Jun;39(3):774-787 [FREE Full text] [doi: 10.1007/s10508-008-9393-2] [Medline: 18686027]
27. Bruce D, Harper GW, Adolescent Medicine Trials Network for HIV/AIDS Interventions. Operating without a safety net: gay male adolescents and emerging adults' experiences of marginalization and migration, and implications for theory of syndemic production of health disparities. Health Educ Behav 2011 Aug;38(4):367-378 [FREE Full text] [doi: 10.1177/1090198110375911] [Medline: 21398621]

28. Jamil OB, Harper GW, Fernandez MI, Adolescent Trials Network for HIV/AIDS Interventions. Sexual and ethnic identity development among gay-bisexual-questioning (GBQ) male ethnic minority adolescents. Cultur Divers Ethnic Minor Psychol 2009 Jul;15(3):203-214 [FREE Full text] [doi: 10.1037/a0014795] [Medline: 19594249]
29. Outlaw AY, Phillips G, Hightow-Weidman LB, Fields SD, Hidalgo J, Halpern-Felsher B, Young MSM of Color SPNS Initiative Study Group. Age of MSM sexual debut and risk factors: results from a multisite study of racial/ethnic minority YMSM living with HIV. AIDS Patient Care STDS 2011 Aug;25(Suppl 1):S23-S29. [doi: 10.1089/apc.2011.9879] [Medline: 21711140]
30. Lehmiller JJ, Ioerger M. Social networking smartphone applications and sexual health outcomes among men who have sex with men. PLoS One 2014;9(1):e86603 [FREE Full text] [doi: 10.1371/journal.pone.0086603] [Medline: 24466166]
31. Rosser B R Simon, Oakes JM, Konstan J, Hooper S, Horvath KJ, Danilenko GP, et al. Reducing HIV risk behavior of men who have sex with men through persuasive computing: results of the Men's INTernet Study-II. AIDS 2010 Aug 24;24(13):2099-2107 [FREE Full text] [doi: 10.1097/QAD.0b013e32833c4ac7] [Medline: 20601853]
32. Muessig KE, Pike EC, Fowler B, LeGrand S, Parsons JT, Bull SS, et al. Putting prevention in their pockets: developing mobile phone-based HIV interventions for black men who have sex with men. AIDS Patient Care STDS 2013 Apr;27(4):211-222 [FREE Full text] [doi: 10.1089/apc.2012.0404] [Medline: 23565925]
33. Goldenberg T, McDougal SJ, Sullivan PS, Stekler JD, Stephenson R. Preferences for a Mobile HIV Prevention App for Men Who Have Sex With Men. JMIR Mhealth Uhealth 2014;2(4):e47 [FREE Full text] [doi: 10.2196/mhealth.3745] [Medline: 25355249]
34. Sun CJ, Stowers J, Miller C, Bachmann LH, Rhodes SD. Acceptability and Feasibility of Using Established Geosocial and Sexual Networking Mobile Applications to Promote HIV and STD Testing Among Men Who Have Sex with Men. AIDS Behav 2015 Mar;19(3):543-552. [doi: 10.1007/s10461-014-0942-5] [Medline: 25381563]
35. Kingdon MJ, Storholm ED, Halkitis PN, Jones DC, Moeller RW, Siconolfi D, et al. Targeting HIV prevention messaging to a new generation of gay, bisexual, and other young men who have sex with men. J Health Commun 2013;18(3):325-342. [doi: 10.1080/10810730.2012.727953] [Medline: 23320963]
36. Kubicek K, Carpineto J, McDavitt B, Weiss G, Iverson EF, Au CW, et al. Integrating professional and folk models of HIV risk: YMSM's perceptions of high-risk sex. AIDS Educ Prev 2008 Jun;20(3):220-238 [FREE Full text] [doi: 10.1521/aeap.2008.20.3.220] [Medline: 18558819]
37. Kubicek K, Carpineto J, McDavitt B, Weiss G, Kipke MD. Use and perceptions of the internet for sexual information and partners: a study of young men who have sex with men. Arch Sex Behav 2011 Aug;40(4):803-816 [FREE Full text] [doi: 10.1007/s10508-010-9666-4] [Medline: 20809373]
38. Mustanski B, Lyons T, Garcia SC. Internet use and sexual health of young men who have sex with men: a mixed-methods study. Arch Sex Behav 2011 Apr;40(2):289-300 [FREE Full text] [doi: 10.1007/s10508-009-9596-1] [Medline: 20182787]

Abbreviations

AIDS: Acquired Immune Deficiency Syndrome
HIV: Human Immunodeficiency Virus
MSM: men who have sex with men
PrEP: Pre-Exposure Prophylaxis
STIs: Sexually Transmitted Infections

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Original Paper

The Digital Distribution of Public Health News Surrounding the Human Papillomavirus Vaccination: A Longitudinal Infodemiology Study

L Meghan Mahoney[1], PhD; Tang Tang[2], PhD; Kai Ji[3], MA; Jessica Ulrich-Schad[4], PhD

[1]West Chester University, West Chester, PA, United States

[2]University of Akron, Akron, OH, United States

[3]University of New Hampshire, Durham, NH, United States

[4]Purdue University, West Fayette, IN, United States

Corresponding Author:
L Meghan Mahoney, PhD
West Chester University
511 Main Hall
West Chester, PA, 19383
United States
Phone: 1 3022998475
Fax: 1 6104361000
Email: mmahoney@wcupa.edu

Abstract

Background: New media changes the dissemination of public health information and misinformation. During a guest appearance on the *Today Show*, US Representative Michele Bachmann claimed that human papillomavirus (HPV) vaccines could cause “mental retardation”.

Objective: The purpose of this study is to explore how new media influences the type of public health information users access, as well as the impact to these platforms after a major controversy. Specifically, this study aims to examine the similarities and differences in the dissemination of news articles related to the HPV vaccination between Google News and Twitter, as well as how the content of news changed after Michele Bachmann’s controversial comment.

Methods: This study used a purposive sampling to draw the first 100 news articles that appeared on Google News and the first 100 articles that appeared on Twitter from August 1-October 31, 2011. Article tone, source, topics, concerns, references, publication date, and interactive features were coded. The intercoder reliability had a total agreement of .90.

Results: Results indicate that 44.0% of the articles (88/200) about the HPV vaccination had a positive tone, 32.5% (65/200) maintained a neutral tone, while 23.5% (47/200) presented a negative tone. Protection against diseases 82.0% (164/200), vaccine eligibility for females 75.5% (151/200), and side effects 59.0% (118/200) were the top three topics covered by these articles. Google News and Twitter articles significantly differed in article tone, source, topics, concerns covered, types of sources referenced in the article, and uses of interactive features. Most notably, topic focus changed from public health information towards political conversation after Bachmann’s comment. Before the comment, the HPV vaccine news talked more often about vaccine dosing ($P<.001$), duration ($P=.005$), vaccine eligibility for females ($P=.03$), and protection against diseases ($P=.04$) than did the later pieces. After the controversy, the news topic shifted towards politics ($P=.01$) and talked more about HPV vaccine eligibility for males ($P=.01$).

Conclusions: This longitudinal infodemiology study suggests that new media influences public health communication, knowledge transaction, and poses potential problems in the amount of misinformation disseminated during public health campaigns. In addition, the study calls for more research to adopt an infodemiology approach to explore relationships between online information supply and public health decisions.

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KEYWORDS

new media; public health dissemination; health communication; social media; HPV vaccination; infodemiology; infoveillance

Introduction

The dissemination of health communication has undergone dramatic changes as digital distribution and social media transfer considerable power to users and enhance opportunities for asynchronous mass delivery. According to the Pew Internet & American Life Project [1], 72% of Internet users seek health information online. Thus, a critical public health concern is the quality of health information consumed and disseminated on the Web [2,3]. This study examines how digital distribution and social media impact the diversity of the public health information gathering and dissemination process. Through an investigation of a specific public health initiative—the human papillomavirus (HPV) vaccination—a better understanding is gained of how online health news is presented, as well as the influence that structure has on information dissemination.

HPV represents one of the most common sexually transmitted infections linked to cancer. Researchers found that an underestimated 93% of invasive cervical cancers worldwide contain HPV [2]. The Food and Drug Administration (FDA) approved vaccinations that prevent certain HPV infections and reduce the incident of cervical cancer and other anogenital cancers. Medical organizations and professionals, including the World Health Organization and Advisory Committee on Immunization Practices (ACIP), praise this HPV vaccination and encourage coverage for all females [3-5]. It is also important to note that although the HPV vaccination was originally recommended for young females, the ACIP has begun recommending it for boys as well in 2011 [5]. Nonetheless, since its introduction, dialogue surrounding the HPV vaccination has raised concerns due to its recommended administration to young girls, making it a highly controversial public health debate.

While health professionals argue for stronger public health campaigns to promote the HPV vaccination, communication efforts have been challenged on political platforms by US Representative Michele Bachmann. During a guest appearance on the *Today Show* on September 13, 2011, after criticizing Texas Governor Rick Perry, GOP Presidential candidate, for mandating HPV vaccines for school girls, Bachmann claimed that a crying woman had recently approached her and said that her daughter received the HPV vaccine and consequently developed “mental retardation” [6]. The American Academy of Pediatrics (AAP) responded by saying “There is absolutely no scientific validity to this statement”. Nonetheless, online news and dialogue surrounding the topic of HPV vaccination began linking to the misinformation in Bachmann’s comment.

The distribution of this type of public health misinformation is unclear and proves especially difficult to track due to unlimited diverse online news sources and the ability of social media users to participate and negotiate the information-exchange process. Public health specialists suggest that new media, such as social networking sites and online news aggregators, may have the potential to impact the public’s understandings and their adoption decisions of the HPV vaccination [3,5]. There is clearly a need to understand Internet dialogue and dissemination surrounding public health issues further, particularly ones that are surrounded by such a public health controversy.

Eysenbach [7,8] suggests that an infodemiology approach can help measure information diffusion and knowledge transaction and provide valuable insights to health professionals when misinformation happens. Infodemiology 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 [8]”. Thus, this study uses the infodemiology approach to explore the usage of online media as a new space of public health information gathering and dissemination. Specifically, it examines news diffusion of the HPV vaccination by comparing stories distributed on Google News and “retweets” distributed on Twitter, before and after Bachmann’s controversial comment.

Challenges of the Human Papillomavirus Vaccination Initiative

The Centers for Disease Control (CDC) reports that as of June 2011, more than 35 million doses of the HPV vaccination had been distributed in the United States. Nonetheless, the introduction of HPV vaccination has come with its own unique set of challenges. One key challenge in the promotion of the HPV vaccination program is the recommended age of immunization. The recommendation is to vaccinate young girls prior to sexual debut, with the recommendation of ages starting at 11-12 years [9]. Additionally, the social stigma attached to HPV as a sexually transmitted disease may prevent the highest risk population from receiving vaccinations [10]. Parents have voiced concerns over the sexual implications of HPV vaccination leading towards earlier or higher-risk sexual activities [9-11]. Moreover, the HPV vaccination requires a round of three shots for vaccination protection. Research shows that just 38.2% of girls who received the first vaccination complete all three vaccine doses in the recommended timeframe of 365 days [12]. This suggests that even if a patient understands the benefits and opts in to the HPV vaccination, the majority will not complete the immunization process. There is a need for increasing health communication regarding the dosing and duration of the vaccination. Furthermore, the target population for the HPV vaccination program is difficult to reach through traditional public health messages [3]. For these reasons, innovative efforts are needed to educate parents and young women about the benefits of cervical cancer prevention.

New technologies allow greater opportunities for difficult-to-reach patients to receive health information and make personal health care decisions [13]. However, the frequency of misinformation online may actually negatively impact the public’s health decisions. Indeed, controversies about vaccine’s side effects have long been a challenge for public health professionals. As early as in the 1990s, incorrect dialogue linked autism disorders and the measles-mumps-rubella (MMR) vaccine, which caused significant drops in vaccination rates and increased incidence of disease [14]. It is evident that such a controversy about the side effects of a vaccine may prevent treatment. Levine [11] demonstrates how much of the public dialogue surrounding the HPV vaccination focuses on common misconceptions regarding HPV, specifically that it causes Guillain-Barré Syndrome and leads to muscle weakness and paralysis. This misnomer can then be repeated and shared across unlimited media platforms without scientific sources or credible information. Therefore, it is important to use infodemiology metrics to follow the online dialogue and news dissemination surrounding the HPV vaccination.

News Coverage of the Human Papillomavirus Vaccination

Many scholars have examined the news coverage of the HPV vaccination when it was first released [10,11,14-17]. Johnson et al [15] examined newspaper articles on the HPV vaccination for 19 months after the FDA approved the first HPV vaccine and found the press coverage lacked detailed health information. Few mentioned the dosing, duration, effectiveness, and/or side effects of the vaccination. Wardle et al [16] examined the news coverage of the HPV vaccination in the United Kingdom and found British newspapers had a positive tone towards the vaccine in general. However, increasing risky sexual behavior has been a major topic discussed by the press. CDC researchers [10] also found that vaccine affordability was the most often-mentioned concern about the HPV vaccination among 250 search engine articles that they analyzed. Online news stories disseminated a more balanced tone regarding the vaccine. Nakada et al [17] found that the national agreement on HPV vaccination in Japan positively contributed to the advocacy of vaccine beneficiaries through media coverage online and in print.

While scholars provided important insights on how media first disseminate information related to the HPV vaccination, little scholarly attention has been given to social media dissemination reports, which could be crucial to the vaccination promotion today.

This type of follow-up research becomes even more necessary when additional news surrounding the vaccination has little to do with the public health initiative itself. For example, in September 2011, US Representative Michele Bachmann brought the side effects of the HPV vaccines into the political discussion. Her controversial comment that HPV vaccination could cause mental retardation soon fueled online debate between scientific, political, and family communities [6,14,18]. Even though the AAP issued an official response, reiterating that Bachmann’s assertion was false, media coverage of this response was not as widely disseminated as Bachmann’s controversial comment itself [14].

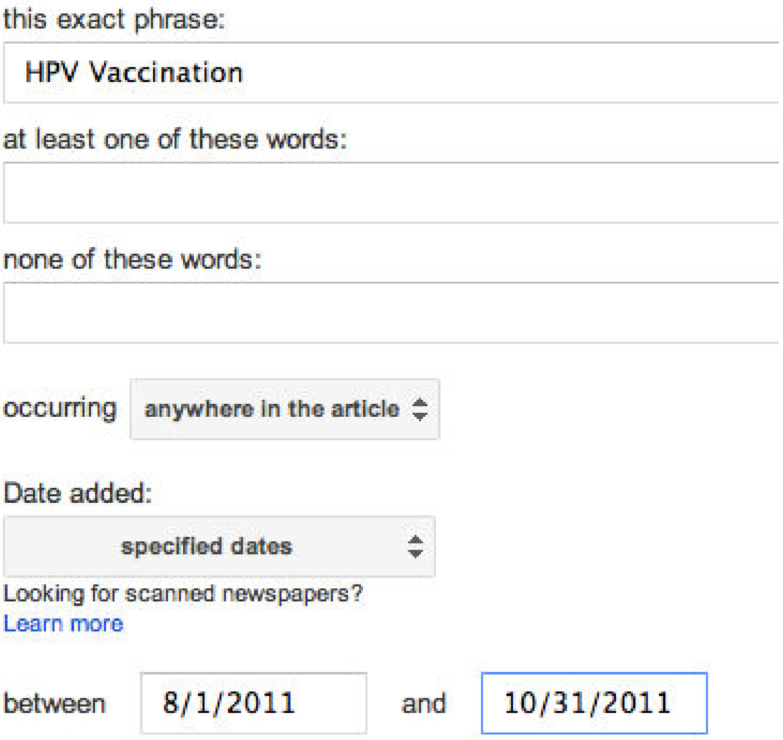
While it is challenging to examine how much influence this type of public health misinformation has on personal health care decisions, it is valuable to investigate information shared through online public forums. “Although few would argue that spreading blatant misinformation should be a punishable offense, false claims about vaccine risk can have deadly consequences when they discourage vaccination” [14]. This calls for a more thorough longitudinal infodemiology study of how controversy impacts online information dissemination surrounding the HPV vaccination.

The purpose of this study is to compare aggregated news stories shared on Google News and retweets shared on Twitter both before and after Bachmann’s comment to help understand the public health information dissemination through both social media and news aggregates. A snapshot of the Google News search criteria is illustrated in Figure 1; a sample of this search is found in Figure 2. A snapshot of the Twitter search criteria and results is found in Figure 3. Specifically, this research aims to answer the following research questions:

RQ1: What are the similarities and differences in the HPV vaccination coverage between Google News and Twitter?

RQ2: How did the content of news articles centered on the HPV vaccination change after Bachmann’s 2011 interview on the *Today Show*?

Figure 1. Google News criteria.



this exact phrase:

HPV Vaccination

at least one of these words:

none of these words:

occurring anywhere in the article

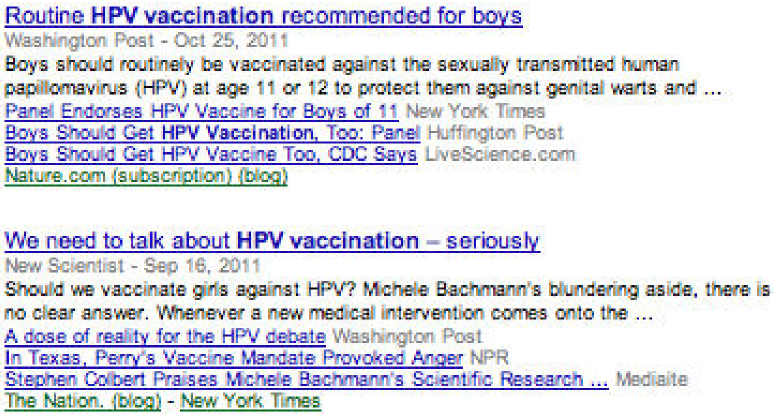
Date added:

specified dates

Looking for scanned newspapers?
Learn more

between 8/1/2011 and 10/31/2011

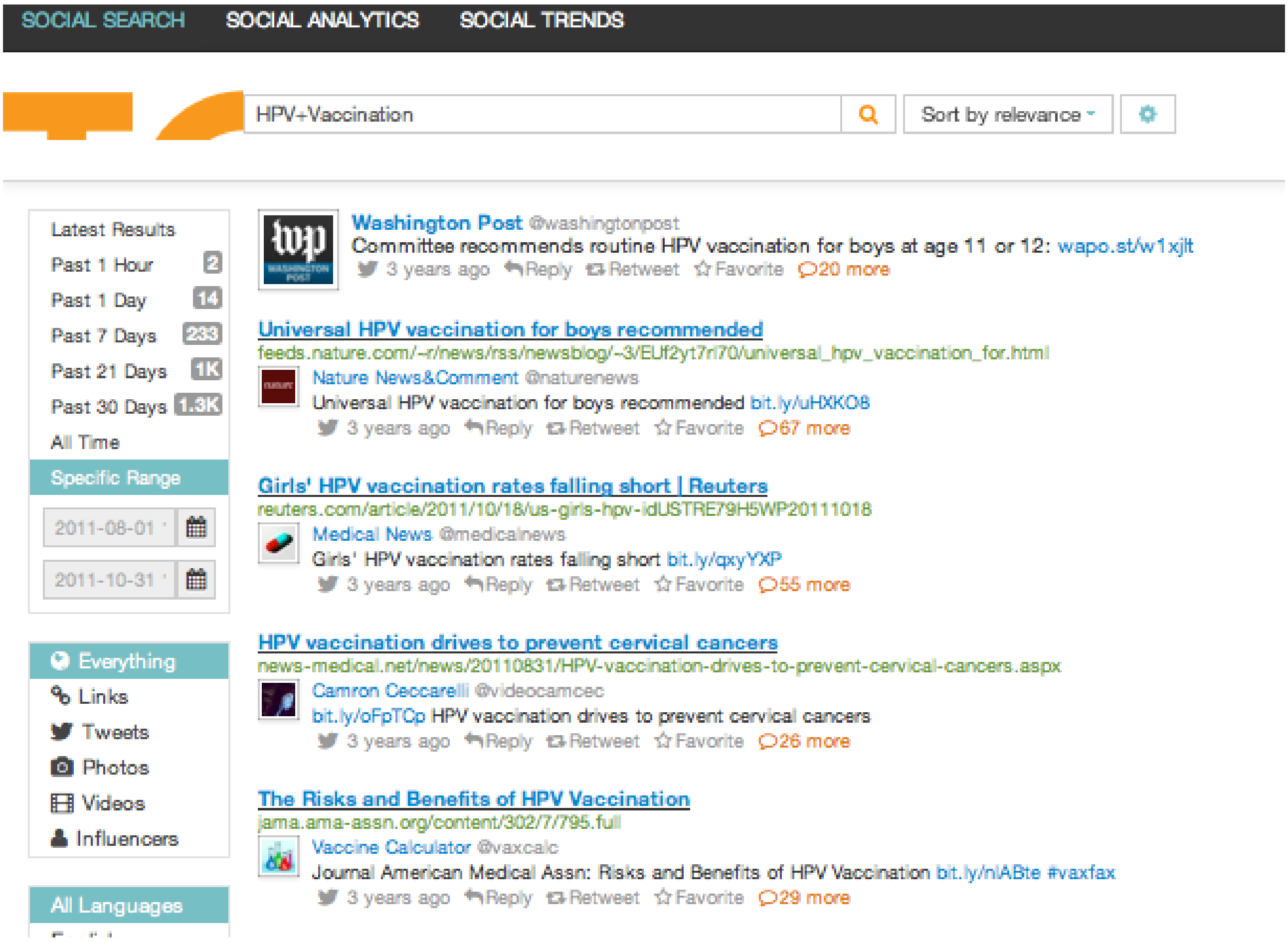
Figure 2. Google News sample articles.



Routine **HPV vaccination** recommended for boys
Washington Post - Oct 25, 2011
Boys should routinely be vaccinated against the sexually transmitted human papillomavirus (HPV) at age 11 or 12 to protect them against genital warts and ...
Panel Endorses HPV Vaccine for Boys of 11 New York Times
Boys Should Get **HPV Vaccination**, Too: Panel Huffington Post
Boys Should Get HPV Vaccine Too, CDC Says LiveScience.com
Nature.com (subscription) (blog)

We need to talk about **HPV vaccination** – seriously
New Scientist - Sep 16, 2011
Should we vaccinate girls against HPV? Michele Bachmann's blundering aside, there is no clear answer. Whenever a new medical intervention comes onto the ...
A dose of reality for the HPV debate Washington Post
In Texas, Perry's Vaccine Mandate Provoked Anger NPR
Stephen Colbert Praises Michele Bachmann's Scientific Research ... Mediaite
The Nation. (blog) - New York Times

Figure 3. Topsy search criteria and sample articles.



Washington Post @washingtonpost
Committee recommends routine HPV vaccination for boys at age 11 or 12: wapo.st/w1xjlt
3 years ago Reply Retweet Favorite 20 more

Universal HPV vaccination for boys recommended
feeds.nature.com/~r/news/rss/newsblog/~3/EUf2yt7rl70/universal_hpv_vaccination_for.html
Nature News&Comment @naturenews
Universal HPV vaccination for boys recommended bit.ly/uHXKO8
3 years ago Reply Retweet Favorite 67 more

Girls' HPV vaccination rates falling short | Reuters
reuters.com/article/2011/10/18/us-girls-hpv-idUSTRE79H5WP20111018
Medical News @medicalnews
Girls' HPV vaccination rates falling short bit.ly/qxyYXP
3 years ago Reply Retweet Favorite 55 more

HPV vaccination drives to prevent cervical cancers
news-medical.net/news/20110831/HPV-vaccination-drives-to-prevent-cervical-cancers.aspx
Camron Ceccarelli @videocamcec
bit.ly/oFpTCp HPV vaccination drives to prevent cervical cancers
3 years ago Reply Retweet Favorite 26 more

The Risks and Benefits of HPV Vaccination
jama.ama-assn.org/content/302/7/795.full
Vaccine Calculator @vaxcalc
Journal American Medical Assn: Risks and Benefits of HPV Vaccination bit.ly/nlABte #vaxfax
3 years ago Reply Retweet Favorite 29 more

Methods

Sample and Unit Analysis

Google News and Twitter are among the primary sources that researchers use to study news media and information dissemination [19-21]. Google News is a computer-generated news aggregator that provides readers news articles from over 4500 sources, making it one of the most popular sources for online news [22,23]. Google News offers links to the news articles based on the criteria provided by the users (eg, subject, timeline), as well as the characteristics of news content such as relevance and "how often and on what sites a story appears online" [22]. Through Google News Archive Advanced Search, users are able to find news articles on any subject during any time period.

Twitter, on the other hand, is a social media site that provides information, news, and communication about what users are interested in [24,25]. On Twitter, individuals disseminate information or news via "tweets", which are short messages each within 140-character limit. Twitter users are able to tweet about any topic and to provide links to full stories via abbreviated dialogue. One of the most popular features of Twitter is the ability for users to "retweet" stories they find in other users' feeds. Research points to this retweeting option as a primary tool for disseminating information about important news topics [21].

While it may be argued that the structure and purpose of news dissemination on Twitter differs from that on Google News, it is appropriate to analyze and compare articles disseminated through both platforms. Social media research demonstrates how Twitter is being used primarily as a resource for individuals to access and communicate on recent news issues [19,20]. Furthermore, public health literature examines Twitter as a platform to investigate important health care news dissemination [21- 23]. Thus, this research used news articles disseminated by Google News and news articles linked to "retweets" on Twitter as materials to study information dissemination of HPV vaccination.

Google News Archive database was used to identify Google News articles on HPV vaccination from August 1-October 31, 2011. The 3-month time period was chosen because it includes 1.5 months before and 1.5 months after Bachmann's comment about the HPV vaccines on September 13, 2011. In addition, a 3-month period is a common timeframe used by content analysis studies on information dissemination [26,27]. Topsy database was used to identify news articles linked to retweets on Twitter regarding HPV vaccination. Topsy is a partner of Twitter that analyzes billions of tweets on a daily basis and provides one of the largest public indexes of social media posts [28]. Similar to Google News search, Topsy users can find news articles retweeted on Twitter on any subject during any time period. The same time period (ie, August 1-October 31, 2011) was used in the Topsy search. The search term "HPV vaccination" was entered into both Google News search and Topsy search.

A purposive sampling was used to draw the first 100 news articles that appeared on the Google News search results pages and the first 100 news articles that appeared on the Topsy search results pages. This represents a sample that audiences are likely to access and read, as previous research suggests that users typically start from the top of search results/tweets and read only the first few pages of search results/tweets [8,29]. Duplication was not used in this research. Duplicated articles were recorded only once to increase variety and the degree of representativeness within the sample.

Coding

Each news article was coded for seven key variables: (1) date (ie, before or after Bachmann's comment), (2) tone of the article (ie, positive, neutral, or negative), (3) article source (ie, government website, health organization website, newspaper/magazine, portal site, radio program transcript, scientific journal, TV program transcript, user-generated content, or other), (4) topics covered in the article (ie, vaccine efficacy, dosing, duration, protection against diseases, side effects, cost, politics, vaccine eligibility for females, and vaccine eligibility for males), (5) concerns raised in the article (ie, increasing sexual risk behavior, mandatory school vaccination, importance of continued Pap smears, age concern, safety, accessibility, and affordability), (6) types of sources referenced in the article (ie, medical doctors, political and government officials/organizations, CDC, vaccine manufacturer representatives, cancer organizations, research community, personal accounts, and other), and (7) interactivity (ie, hyperlink, search function, comment, and share). All the coding categories are based on previous literature [30,31].

Two researchers carried out the coding independently. Coders were trained using a preliminary subset of news stories. The training process continued until the coders were comfortable with the various coding categories [32]. Detailed definitions of categories were provided for coding. All of the selected news articles were downloaded to a computer hard drive for the purpose of coding and conducting an intercoder reliability test, as Google News and Twitter frequently update their pages.

Approximately 20% of the total sample was randomly selected to assess intercoder reliability, including news articles disseminated by both Google News and Twitter. A Cohen's kappa test was run on all seven variables that required a judgment call from the coders. The measure of agreement was as follows: date=1.0, tone of the article=.85, article source=.98, topics covered in the article=.90, concerns raised in the article=.80, types of sources referenced in the article=.78, and interactivity=1.0. The total agreement was .90, which indicates a high level of reliability on the coding instrument and across coders.

Results

A total of 100 Google News articles and 100 Twitter articles were coded to examine the similarities and differences in information gathering and diffusion of HPV vaccination. Overall, 37.5% articles (75/200) were published before Bachmann's comment, and 62.5% (125/200) appeared after her interview. Specifically, among the 100 articles from Google News, 45.0% (45/100) were published before Bachmann's comment, and 55.0% (55/100) were after. Among the Twitter articles coded in this study, 30.0% (30/100) were published before Bachmann's interview, while 70.0% (70/100) were after.

Among the news articles analyzed in this study, 44.0% (88/200) had a positive tone towards HPV vaccination, 32.5% (65/200) a neutral tone, and 23.5% (47/200) presented a negative tone. The top three topics covered by these articles were protection against diseases (82.0%, 164/200), vaccine eligibility for females (75.5%, 151/200), and side effects (59.0%, 118/200). Safety (68.5%, 137/200), mandatory school vaccination (44.5%, 89/200), and age concern (30.0%, 60/200) were the most frequently mentioned concerns related to the vaccine. In addition, CDC (46.5%, 93/200) was the most-cited reference in these articles, followed closely by the research community (45.0%, 90/200), and medical doctors (40.5%, 81/200). Most of the news articles disseminated by Google News and Twitter were newspaper/magazine articles (44.0%, 88/200), articles appearing on health organizations' websites (17.0%, 34/200), and user-generated content (14.5%, 29/200). Furthermore, this analysis found that increased interactivity became a trend during this public health dialogue. The majority of the news articles coded in this study included more than one type of interactive feature, such as hyperlinks and search functions.

To answer RQ1, this study found that Google News and Twitter articles significantly differed in tone, source, topics, concerns raised, types of sources referenced, and uses of interactive features. First, results indicate that news articles presented by Google News and linked to Twitter presented different tones when diffusing information about the HPV vaccination. Among the Twitter articles coded in this study, 54.0% (54/100) had a positive tone, 29.0% (29/100) a neutral tone, while only 17.0% (17/100) had a negative tone. On the other hand, Google News had an equal distribution in terms of the article tone towards HPV vaccination, that is, positive (34.0%, 34/100), neutral (36.0%, 36/100), negative (30.0%, 30/100). The chi-square test result was significant (χ^2_2=8.895, P=.01; see Table 1). Findings suggest that Twitter disseminated more "positive" articles related to the HPV vaccines compared to its Google counterparts, while Google News presented more "neutral" and "negative" pieces than did Twitter.

Table 1. Article tones used by Twitter and Google News HPV vaccination articles.

Tones	Twitter (n=100)		Google News (n=100)	
	n	%	n	%
Positive	54	54.0	34	34.0
Neutral	29	29.0	36	36.0
Negative	17	17.0	30	30.0

In addition, this study found that Google News and Twitter were significantly different in their coverage about vaccine eligibility for females (χ^2_1=9.758, *P*=.002; see Table 2), politics (χ^2_1=7.788, *P*=.005), protection against diseases (χ^2_1=6.640, *P*=.01), side effects (χ^2_1=4.051, *P*=.04), and vaccine efficacy (χ^2_1=3.945, *P*=.047). Specifically, Google News articles covered topics of vaccine eligibility for females, protection against diseases, and vaccine efficacy significantly more frequently than its Twitter counterparts. On the contrary, news articles linked to Twitter-reported topics around politics and side effects significantly more often than did Google News. No statistically significant differences were found in coverage about vaccine cost, duration, dosing, and eligibility for males between news articles disseminated by Google News and Twitter. Protection against diseases (89.0%, 89/100) was the most frequently covered topic by Google News, followed by vaccine eligibility for females (85.0%, 85/100) and vaccine efficacy (53.0%, 53/100). The top three topics for Twitter articles were protection against diseases (75.0%, 75/100), side effects (66.0%, 66/100), and vaccine eligibility for females (66.0%, 66/100).

Vaccine accessibility was the only concern expressed significantly differently between Google News and Twitter articles. Articles linked to Twitter addressed the accessibility of the HPV vaccination more frequently than did Google News (χ^2_1=14.624, *P*<.001). No statistically significant differences were found regarding any other concerns coded in this study. Safety (63.0%, 63/100), mandatory school vaccination (38.0%, 38/100), and age concerns (32.0%, 32/100) were the most frequently mentioned concerns regarding the HPV vaccination in Google News articles. Similarly, safety (74.0%, 74/100), mandatory school vaccination (51.0%, 51/100), and affordability (30.0%, 30/100) were the top three concerns raised by articles linked to Twitter.

Table 2. Topics covered by Twitter and Google News HPV vaccination articles.

	Twitter (n=100)		Google News (n=100)		χ^2	df	*P* value
Topics	Freq.	%	Freq.	%			
Protection against diseases	75	75.0	89	89.0	6.640[b]	1	.01
Side effects	66	66.0	52	52.0	4.051[a]	1	.04
Vaccine eligibility for females	66	66.0	85	85.0	9.758[b]	1	.002
Duration	48	48.0	41	41.0	0.992	1	.32
Politics	46	46.0	27	27.0	7.788[a]	1	.005
Dosing	39	39.0	33	33.0	0.781	1	.38
Vaccine efficacy	39	39.0	53	53.0	3.945[b]	1	.047
Vaccine cost	33	33.0	29	29.0	0.374	1	.54
Vaccine eligibility for males	31	31.0	27	27.0	0.389	1	.53

[a] Covered more frequently by the Twitter articles (*P*<.05).

[b] Covered more frequently by the Google News articles (*P*<.05).

As shown in Table 3, this study found that Google News and Twitter significantly differed in the references they used when disseminating news regarding HPV vaccination. Twitter articles used personal accounts (χ^2_1=16.860, *P*<.001), medical doctors (χ^2_1=5.996, *P*=.01), and political and government officials/organizations (χ^2_1=4.119, *P*=.04) as reference sources significantly more often than its Google counterparts; while Google News cited the research community more frequently than did Twitter (χ^2_1=5.172, *P*=.02). No statistically significant differences were found in the quotations from CDC, vaccine manufacturers, and cancer organizations. CDC (52.0%, 52/100), medical doctors (49.0%, 49/100), and political officials (46.0%, 46/100) were the most frequently used references in Twitter articles, while the research community (53.0%, 53/100) was the major reference for Google News articles, followed by CDC (41.0%, 41/100). It is also important to note that while 31.0% (31/100) of the Twitter articles used personal accounts as a reference source, only 8.0% (8/100) of the articles from Google News did the same.

Table 3. Types of sources referenced by Twitter and Google News HPV vaccination articles.

	Twitter (n=100)		Google News (n=100)		χ^2	df	*P* value
Reference sources	Freq.	%	Freq.	%			
CDC	52	52.0	41	41.0	2.432	1	.12
Medical doctors	49	49.0	32	32.0	5.996[a]	1	.01
Political/Government officials	46	46.0	32	32.0	4.119[a]	1	.04
Research community	37	37.0	53	53.0	5.172[b]	1	.02
Personal accounts	31	31.0	8	8.0	16.860[a]	1	<.001
Cancer organizations	28	28.0	27	27.0	0.025	1	.87
Vaccine manufacturer	8	8.0	10	10.0	0.244	1	.62
Other	4	4.0	5	5.0	0.116	1	.73

[a] Used more frequently by the Twitter articles ($P<.05$).

[b] Used more frequently by the Google News articles ($P<.05$).

Moreover, newspapers/magazines (33.0%, 33/100), user-generated content (28.0%, 28/100), and health organizations' websites (19.0%, 19/100) were the top three sources for articles linked to Twitter, while newspapers/magazines (55.0%, 55/100), health organizations' websites (15.0%, 15/100), and scientific journals (11.0%, 11/100) were the major sources for Google News articles. Interestingly, while 4.0% (4/100) of the Twitter articles used government websites as the source to disseminate information about the HPV vaccines, zero Google News articles came from government websites. While 28.0% (28/100) of the Twitter articles about the vaccination came from user-generated content, only one Google News article (1.0%, 1/100) used this source. The chi-square test suggests a significant difference in article source used by Google News and Twitter ($\chi^2_8=39.997$, $P<.001$; see Table 4).

Table 4. Article sources used by the Twitter and Google News HPV vaccination articles.

Information sources	Twitter (n=100)		Google News (n=100)	
	Freq.	%	Freq.	%
Newspapers/Magazines	33	33.0	55	55.0
User-generated content	28	28.0	1	1.0
Health organization websites	19	19.0	15	15.0
Scientific journals	7	7.0	11	11.0
TV	6	6.0	10	10.0
Government websites	4	4.0	0	0.0
Other sources	2	2.0	4	4.0
Portal sites	1	1.0	2	2.0
Radio	0	0.0	2	2.0

While this study found that both articles from Google News and those linked to Twitter encouraged the interactivity between content providers and consumers during this public dialogue about HPV vaccination, significantly more Twitter articles allowed users to leave comments, compared to its Google News counterparts ($\chi^2_1=16.262$, $P<.001$; see Table 5). On the other hand, articles from Google News included search functions and hyperlinks significantly more often than did the Twitter ones ($\chi^2_1=19.175$, $P<.001$; and $\chi^2_1=6.133$, $P=.01$ respectively).

Table 5. Interactive features used by Twitter and Google News HPV vaccination articles.

	Twitter (n=100)		Google News (n=100)				
Interactivity	Freq.	%	Freq.	%	χ^2	df	*P* value
Comments	89	89.0	65	65.0	16.262[a]	1	<.001
Share	88	88.0	92	92.0	0.889	1	.35
Hyperlinks	77	77.0	90	90.0	6.133[b]	1	.01
Search functions	67	67.0	92	92.0	19.175[b]	1	<.001

[a] Used more frequently by the Twitter articles (*P*<.05).

[b] Used more frequently by the Google News articles (*P*<.05).

To answer RQ2, this study tests the similarities and differences in news articles regarding HPV vaccination before and after Michele Bachmann's *Today Show* interview. Topic shift was the major change that happened. As shown in Table 6, the news articles covered six out of the nine topics coded in this study significantly differently before and after Bachmann's remark. Before Bachmann's comment, the news surrounding HPV vaccination focused on vaccine dosing (χ^2_1=13.333, *P*<.001), duration (χ^2_1=8.002, *P*=.005), vaccine eligibility for females (χ^2_1=4.687, *P*=.03), and protection against diseases (χ^2_1=4.372, *P*=.04) significantly more often than did the later pieces. After Bachmann's *Today Show* appearance, not surprisingly, the news topics shifted towards politics (χ^2_1=6.456, *P*=.01), and interestingly, news articles talked about HPV vaccine eligibility for males more frequently (χ^2_1=6.223, *P*=.01).

Specifically, Twitter articles covered information regarding the HPV vaccine dosing (before: 67%, 20/30; after: 27%, 19/70; χ^2_1=13.789, *P*<.001), duration (before: 73%, 22/30; after: 37%, 26/70; χ^2_1=11.020, *P*=.001), eligibility for females (before: 83%, 25/30; after: 59%, 41/70; χ^2_1=5.738, *P*=.02), and protection against diseases (before: 90%, 27/30; after: 69%, 48/70; χ^2_1=5.143, *P*=.02) significantly more often before Bachmann's interview than did the later pieces. Nonetheless, after Bachmann's *Today Show* appearance, Twitter linked to more HPV news articles focused on politics than before (before: 23%, 7/30; after: 56%, 39/70; χ^2_1=8.864, *P*=.003). It is important to note that this study found no significant topic changes in Google News articles before and after Bachmann's comment.

Table 6. Topics covered by the HPV vaccination articles before and after Bachmann's comment.

	Before (n=75)		After (n=125)				
Topics	Freq.	%	Freq.	%	χ^2	df	*P*
Protection against diseases	67	89.3	97	77.6	4.372[a]	1	.04
Vaccine eligibility for females	63	84.0	88	70.4	4.687[a]	1	.03
Side effects	44	58.7	74	59.2	0.006	1	.94
Duration	43	57.3	46	36.8	8.002[a]	1	.005
Dosing	39	52.0	33	26.4	13.333[a]	1	<.001
Vaccine efficacy	37	49.3	55	44.0	0.537	1	.46
Vaccine cost	21	28.0	41	32.8	0.505	1	.48
Politics	19	25.3	54	43.2	6.456[b]	1	.01
Vaccine eligibility for males	14	18.7	44	35.2	6.223[b]	1	.01

[a] Covered more often by the articles published before the Bachmann's comment (*P*<.05).

[b] Covered more often by the articles published after Bachmann's comment (*P*<.05).

In addition, this study found that the articles focused on HPV vaccination used cancer organizations as a reference source significantly more often after Bachmann's comment than before (χ^2_1=7.960, *P*=.005). However, no statistically significant differences were found in uses of other types of reference sources in these articles before and after the controversy. The top three reference sources used before Bachmann's comment were CDC (49%, 37/75), the research community (47%, 35/75), and medical doctors (45%, 34/75); while afterwards, the top three were CDC (45%, 56/125), the research community (44%, 55/125), and political and government officials/organizations (43%, 54/125).

Specifically, Google News articles cited cancer organizations significantly more often after Bachmann's comment than before (before: 9%, 4/45; after: 42%, 23/55; χ^2_1=13.616, *P*<.001).

Nonetheless, Twitter articles used government and political officials/organizations as reference sources significantly more frequently after Bachmann's comment than before (before: 23%, 7/30; after: 56%, 39/70; χ^2_1=8.864, P=.003). In terms of concerns raised in these HPV vaccine news, Twitter articles expressed concerns related to accessibility of the vaccine (before: 50%, 15/30; after: 20%, 14/70; χ^2_1=9.179, P=.002) and the importance of continued Pap smears (before: 13%, 4/30; after: 3%, 2/70; χ^2_1=4.086, P=.04) significantly more often before the comment than the later pieces. Articles from Google News mentioned concerns related to mandatory school vaccination significantly more before Bachmann's *Today Show* appearance than its later pieces (before: 49%, 22/45; after: 29%, 16/55; χ^2_1=4.118, P=.04). This study did not find significant differences in terms of article tone, interactivity, and article source between news disseminated before and after Bachmann's comment.

Discussion

Principal Findings

This longitudinal infodemiology study examined the similarities and differences in the dissemination of news articles related to the HPV vaccination between Google News and Twitter, as well as how the content of news changed after Bachmann's controversial 2011 appearance on the *Today Show*. Overall, this study found that protection against diseases, vaccine eligibility for females, and side effects were the topics most often covered by the coded HPV vaccination articles, while safety, mandatory school vaccination, and age concern were the most widely expressed concerns. This is an alarming trend, as health communication research calls for a more focused diffusion of detailed treatment-related information about the HPV vaccines rather than concerns that may drive the public dialogue in a non-health related direction [15]. While participation in health-related websites advances personal empowerment and user satisfactions [3,30], more needs to be done to promote public health facts, not just public dialogue.

Additionally, this study found that increased interactivity became a trend during this public dialogue. Both Google News and Twitter allowed users to share the articles, leave comments, and included links and search functions, though Twitter encouraged more comments, while Google News provided more links and search functions. These interactive functions serve as tools for interpersonal communication and recommendation, which should continue to be encouraged, since personal networks are one of the most influential factors for behavior change [31].

Through a comparison of the information disseminated between Google News and Twitter, this research found that Google News had a more balanced tone towards the HPV vaccination, while Twitter had a positive tone towards the vaccine in general. Given the function that each medium serves (Google News as a search engine and Twitter as a popular social media), this result is consistent with expectations. Nonetheless, findings suggest that Twitter took on the role of a "soap box" for users to voice outrage against Bachmann's misinformed comment after her appearance on the *Today Show* and provided an opportunity that individuals may not have received if not for social media, especially since the articles disseminated on Google News continued taking a neutral stance regarding the vaccination. This neutral tone models a more traditional role of news in the United States, as it presented two sides of an issue, American Pediatric Society versus Michele Bachmann, even if there was no scientific evidence to support one side's claims.

This research also compared how Bachmann's controversial comment impacted the online public dialogue about the HPV vaccination. Interestingly, the study found no differences in overall article tones, concerns raised by the news and reference sources used before and after her appearance. According to our research, topic change was the only major shift happened after Bachmann's comment. Results indicate a turn towards a political discussion after Bachmann's comment. Fewer news articles talked about the important treatment information about the HPV vaccines, such as vaccine dosing, duration, and protection against diseases after the controversy. This finding demonstrates that misinformation not only pushed forth an increase in articles that contained false public health information, but transformed dialogue from a public health initiative to a political debate.

It is important to note that the content of news articles disseminated through Twitter were highly impacted by Bachmann's misinformed comment while Google News articles remained more consistent. After the controversy, Twitter had many more articles related to politics, while Google News was able to maintain the same or even increased the amount of articles centered on the science and the vaccine itself. This finding is interesting, as it points to a key difference between a strictly news aggregate (Google News) search and an aggregator within a social media platform (Twitter). While Twitter does allow for users to "retweet" news stories that they find in other users' feeds, they are also given the option to add on to these conversations with their own viewpoints or experiences. This suggests that Twitter provides a structure that allows for users to lead public dialogue in any direction that they choose, or in this case, politics. Google News, however, served as more of a top-down dissemination of "expert" information. While there are certainly opportunities and challenges of each of these structures, in regards to misinformation, Twitter allows for users to fight back against, or increase the spread of, misinformation. This proves a much more egalitarian medium, as the everyday user is able to trend the same manner as an expert.

If more physicians utilized Twitter and/or other social media (eg, Facebook, social support groups) as a platform to both disseminate and gather news with their patients, more could be done to minimize the misinformation shared, without diluting the participatory process for individual users. For example, if an individual heard Bachmann's comment on the *Today Show* and immediately became concerned about HPV vaccines causing mental retardation, they would likely share that concern with their social network so that they could become informed and engage in dialogue. If their physician was a part of their online social network, he or she could also add to the conversation and help facilitate the dialogue by filtering out misinformation.

Limitations

Although this research provides valuable insights into the dissemination of public health information via new media, it is important to note the limitations of a content analysis study. This research cannot provide accurate insights into the influence or effect that this dissemination has on users. In addition, this research examined only the top news that appeared on Twitter and Google News. Future studies may consider examining all articles within the timeframe. Nonetheless, such a purposive sample (instead of studying the entire population or drawing a probability sample) represents a practical frame of the articles audiences read, which can be more valuable when seeking an understanding of how public opinion is formed. Moreover, this study focused on the news articles 1.5 months before and 1.5 months after Bachmann's comment, which captures the short-term differences between Twitter and Google News coverage. Future research may consider gathering data within a longer timeframe to better understand how online sources impact public opinion about important health issues.

Conclusions

Overall, this infodemiology study suggests that new media is influencing public health communication and the patient's role in today's dynamic communication environment [30,33]. While this shift from physician-centered treatment towards patient-centered treatment does lead to an increase in personal empowerment and user satisfaction, it also poses potential problems in the amount of misinformation disseminated during public health campaigns. By understanding how users negotiate the structures of gathering information, medical professionals, researchers, and communication specialists will be better able to understand how mainstream media and social media reproduce a consensual public information dialogue, potentially optimizing the personal health care management process. This study also calls for more research to adopt an infodemiology approach to further explore relationships between online information supply and public health decisions.

Conflicts of Interest

None declared.

References

1. Pew Internet Research. Washington, DC: Pew Internet and American Life Project; 2001. URL: http://www.pewinternet.org/ [accessed 2014-09-08] [WebCite Cache ID 6SRCcP9uh]
2. Walboomers JM, Jacobs MV, Manos MM, Bosch FX, Kummer JA, Shah KV, et al. Human papillomavirus is a necessary cause of invasive cervical cancer worldwide. J Pathol 1999 Sep;189(1):12-19. [doi: 10.1002/(SICI)1096-9896(199909)189:1<12::AID-PATH431>3.0.CO;2-F] [Medline: 10451482]
3. Saslow D, Castle PE, Cox JT, Davey DD, Einstein MH, Ferris DG, Gynecologic Cancer Advisory Group, et al. American Cancer Society Guideline for human papillomavirus (HPV) vaccine use to prevent cervical cancer and its precursors. CA Cancer J Clin 2007;57(1):7-28. [Medline: 17237032]
4. World Health Organization (2007). URL: http://whqlibdoc.who.int/hq/2007/WHO_IVB_07.05_eng.pd [accessed 2014-09-08] [WebCite Cache ID 6SRCmCSGf]
5. Advisory Committee on Immunization Practices. 2011. Recommendations on the use of quadrivalent Human Papillomaviru Vaccine in males URL: http://www.immunize.org/acip/acipvax_hpv.asp [accessed 2014-09-08] [WebCite Cache ID 6SRD3O0Gi]
6. Mulcahy N. Medscape Today. 2011. Bioethicists offer $11,000 for proof of HPV vaccine story URL: http://www.medscape.com/viewarticle/749775 [accessed 2011-09-29] [WebCite Cache ID 6SRCxCyIP]
7. Eysenbach G, Köhler C. How do consumers search for and appraise health information on the world wide web? Qualitative study using focus groups, usability tests, and in-depth interviews. BMJ 2002 Mar 9;324(7337):573-577 [FREE Full text] [Medline: 11884321]
8. Eysenbach G, Powell J, Kuss O, Sa ER. Empirical studies assessing the quality of health information for consumers on the world wide web: a systematic review. JAMA 2002;287(20):2691-2700. [Medline: 12020305]
9. Adams M, Jasani B, Fiander A. Human papilloma virus (HPV) prophylactic vaccination: challenges for public health and implications for screening. Vaccine 2007 Apr 20;25(16):3007-3013. [doi: 10.1016/j.vaccine.2007.01.016] [Medline: 17292517]
10. Garnett GP, Waddell HC. Public health paradoxes and the epidemiological impact of an HPV vaccine. J Clin Virol 2000 Oct;19(1-2):101-111. [Medline: 11091153]
11. Levine S. Washington Post. 2008. Parents question HPV vaccine: Push to mandate shots rapidly creates backlash URL: http://www.washingtonpost.com/wpdyn/content/article/2007/03/03/AR2007030301 356.html [accessed 2015-03-15] [WebCite Cache ID 6X33qXIV2]
12. Cowen L. Medwire News. 2012. HPV vaccine completion rate more than halved since its introduction URL: http://www.farma.bg/ [accessed 2015-03-15] [WebCite Cache ID 6X33wse5E]
13. Gerber BS, Eiser AR. The patient physician relationship in the Internet age: future prospects and the research agenda. J Med Internet Res 2001;3(2):E15 [FREE Full text] [doi: 10.2196/jmir.3.2.e15] [Medline: 11720957]

14. Intlekofer KA, Cunningham MJ, Caplan AL. The HPV vaccine controversy. Virtual Mentor 2012 Jan;14(1):39-49 [FREE Full text] [doi: 10.1001/virtualmentor.2012.14.1.msoc1-1201] [Medline: 23116916]
15. Quintero JJ, Sionean C, Scott AM. Exploring the presentation of news information about the HPV vaccine: a content analysis of a representative sample of U.S. newspaper articles. Health Commun 2011 Sep;26(6):491-501. [doi: 10.1080/10410236.2011.556080] [Medline: 21469005]
16. Forster A, Wardle J, Stephenson J, Waller J. Passport to promiscuity or lifesaver: press coverage of HPV vaccination and risky sexual behavior. J Health Commun 2010 Mar;15(2):205-217. [doi: 10.1080/10810730903528066] [Medline: 20390987]
17. Nakada H, Yuji K, Tsubokura M, Ohsawa Y, Kami M. Development of a national agreement on human papillomavirus vaccination in Japan: an infodemiology study. J Med Internet Res 2014;16(5):e129 [FREE Full text] [doi: 10.2196/jmir.2846] [Medline: 24834471]
18. Hensley S. Pediatricians Fact-Check Bachmann's Bashing Of HPV Vaccine. 2011. URL: http://www.npr.org/blogs/health/2011/09/13/140445104/pediatricians-fact-check-bachmanns-bashing-of-hpv-vaccine [accessed 2015-03-15] [WebCite Cache ID 6X34UGBki]
19. Ahmad A. Is Twitter a useful tool for journalists? Journal of Media Practice 2010 Aug;11(2):145-155 [FREE Full text] [doi: 10.1386/jmpr.11.2.145_1]
20. Choudhury M, Lin Y, Sudaram H. How does the data sampling strategy impact the discovery of information diffusion in social media?. 2012. URL: http://research.microsoft.com/en-us/um/people/munmund/pubs/icwsm_10.pdf [accessed 2015-03-15] [WebCite Cache ID 6X34hQsTN]
21. Kwak H, Lee C, Park H, Moon S. The 19th World-Wide Web (WWW). 2011. What is Twitter, a social network or a news media? URL: http://an.kaist.ac.kr/traces/WWW2010.html [accessed 2015-03-15] [WebCite Cache ID 6X34q7TcB]
22. Das A, Datar M, Garg A, Rajaram S. Google news personalization: Scalable online collaborative filtering. 2007. URL: http://www2007.org/papers/paper570.pdf [accessed 2015-03-15] [WebCite Cache ID 6X34zi8Wz]
23. Lloyd L, Kechagias D, Skiena S. SPIRE. 2005. Lydia: A system for large-scale news analysis URL: http://www3.cs.stonybrook.edu/~skiena/lydia/37720161.pdf [accessed 2015-03-15] [WebCite Cache ID 6X35QPm0J]
24. Hermida A. From TV to Twitter: How ambient news became ambient journalism. M/C Journal 2010;13(2):-.
25. Lerman K, Ghosh R. Information Contagion: An Empirical Study of the Spread of News on Digg and Twitter Social Networks. ICWSM 2010;10:90-97.
26. Jackson D. Strategic news frames and public policy debates: Press and television news coverage of the euro in the UK. European Journal of Communication Research 201;36(2):169-193.
27. Josey C, Dixon T, Hurley R, Hefner V. Online news and race: A content analysis of the portrayal of racial stereotypes in a new media environment. 2008 Presented at: National Communication Association Annual Conference; 2008; San Diego, CA.
28. Topsy Social Media Analytics. 2015. URL: http://topsy.com/ [accessed 2015-03-15] [WebCite Cache ID 6X361na68]
29. Habel MA, Liddon N, Stryker JE. The HPV vaccine: a content analysis of online news stories. J Womens Health (Larchmt) 2009 Mar;18(3):401-407. [doi: 10.1089/jwh.2008.0920] [Medline: 19281323]
30. Warner D, Procaccino JD. Women seeking health information: distinguishing the web user. J Health Commun 2007 Dec;12(8):787-814. [doi: 10.1080/10810730701672090] [Medline: 18030642]
31. West J, Hall P, Thackerey R, Hanson C. Using Social Networking Sites to Support Online Individual Health Behavior Change Projects. Journal of Online Learning and Teaching 2010;6(3):686-691.
32. Holsti OR. Content analysis for the social sciences and humanities. Reading, MA: Addison-Wesley; 1969.
33. Hong T. Contributing factors to the use of health-related websites. J Health Commun 2006 Mar;11(2):149-165. [doi: 10.1080/10810730500526679] [Medline: 16537285]

Abbreviations

AAD: American Academy of Pediatrics
CDC: Centers for Disease Control
FDA: Food and Drug Administration
HPV: human papillomavirus

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Original Paper

Using Twitter to Measure Public Discussion of Diseases: A Case Study

Christopher Weeg[1], MSLS; H Andrew Schwartz[2], PhD; Shawndra Hill[3], PhD; Raina M Merchant[4], MD MSHP; Catalina Arango[5], BS; Lyle Ungar[2], PhD

[1]Positive Psychology Center, Department of Psychology, University of Pennsylvania, Philadelphia, PA, United States
[2]Department of Computer and Information Science, University of Pennsylvania, Philadelphia, PA, United States
[3]Operations and Information Management, Wharton School, University of Pennsylvania, Philadelphia, PA, United States
[4]Social Media and Health Innovation Lab, Department of Emergency Medicine, University of Pennsylvania, Philadelphia, PA, United States
[5]Wharton School, University of Pennsylvania, Philadelphia, PA, United States

Corresponding Author:
Christopher Weeg, MSLS
Positive Psychology Center
Department of Psychology
University of Pennsylvania
Solomon Laboratories
3720 Walnut St.
Philadelphia, PA, 19104-6241
United States
Phone: 1 206 412 1689
Fax: 1 215 573 2188
Email: mr.weeg@gmail.com

Abstract

Background: Twitter is increasingly used to estimate disease prevalence, but such measurements can be biased, due to both biased sampling and inherent ambiguity of natural language.

Objective: We characterized the extent of these biases and how they vary with disease.

Methods: We correlated self-reported prevalence rates for 22 diseases from Experian's Simmons National Consumer Study (n=12,305) with the number of times these diseases were mentioned on Twitter during the same period (2012). We also identified and corrected for two types of bias present in Twitter data: (1) demographic variance between US Twitter users and the general US population; and (2) natural language ambiguity, which creates the possibility that mention of a disease name may not actually refer to the disease (eg, "heart attack" on Twitter often does not refer to myocardial infarction). We measured the correlation between disease prevalence and Twitter disease mentions both with and without bias correction. This allowed us to quantify each disease's overrepresentation or underrepresentation on Twitter, relative to its prevalence.

Results: Our sample included 80,680,449 tweets. Adjusting disease prevalence to correct for Twitter demographics more than doubles the correlation between Twitter disease mentions and disease prevalence in the general population (from .113 to .258, $P < .001$). In addition, diseases varied widely in how often mentions of their names on Twitter actually referred to the diseases, from 14.89% (3827/25,704) of instances (for stroke) to 99.92% (5044/5048) of instances (for arthritis). Applying ambiguity correction to our Twitter corpus achieves a correlation between disease mentions and prevalence of .208 ($P < .001$). Simultaneously applying correction for both demographics and ambiguity more than triples the baseline correlation to .366 ($P < .001$). Compared with prevalence rates, *cancer* appeared most overrepresented in Twitter, whereas *high cholesterol* appeared most underrepresented.

Conclusions: Twitter is a potentially useful tool to measure public interest in and concerns about different diseases, but when comparing diseases, improvements can be made by adjusting for population demographics and word ambiguity.

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KEYWORDS

bias; data mining; demographics; disease; epidemiology; prevalence; public health; social media

Introduction

Background

Word-use patterns in Twitter, Facebook, newsgroups, and Google queries have been used to investigate a wide array of health concerns. Twitter is perhaps the most popular online data source for such studies, due in part to its relative accessibility. It has been used to monitor health issues including influenza [1,2], cholera [3], H1N1 [4-6], postpartum depression [7], concussion [8], epilepsy [9], migraine [10], cancer screening [11], antibiotic use [12], medical practitioner errors [13], dental pain [14], and attitudes about vaccination [15].

Such research has demonstrated the utility of mining social media for public health applications despite potential methodological challenges, including the following: (1) Twitter users form a biased sample of the population [16-18], and (2) their word usage within tweets can be highly ambiguous. For example, focusing just on the medical domain, “stroke” has many nonmedical uses (“stroke of genius” or “back stroke ”); most mentions of “heart attack” are metaphorical, not literal (just had a heart attack and died the power went out while I was in the shower); and although doctors associate “MI” with myocardial infarction, on Twitter it refers more often to the state of Michigan.

Study Objectives

This paper quantifies, and provides a framework for partially correcting, the error arising when using sources such as Twitter as a proxy for measuring disease prevalence. We investigate the relationship between the frequency of disease mentions on Twitter in the United States and the prevalence of the same diseases in the US population. Understanding this relationship could be useful for a variety of applications, including health care messaging and disease surveillance. We use Twitter as the venue for measuring discussion largely because it has already received substantial attention as an inexpensive proxy for tracking disease prevalence [19,20].

Our key contribution is to demonstrate that it is possible to better align Twitter disease-mention statistics with actual disease-prevalence statistics by correcting for ambiguous medical language on Twitter, and by correcting for the difference between the demographics of Twitter users and the general US population. We observe that a slight correlation exists between general population disease-prevalence statistics (sourced from existing survey data) and the number of times each disease is mentioned on Twitter (according to our own counts). We find that we can significantly increase this correlation (1) by restricting the disease-prevalence population specifically to Twitter users (ie, by correlating with existing prevalence data focused specifically on that group), and (2) by adjusting our disease-mention counts to correct for word-sense ambiguity.

Methods

Overview

We first identified a list of diseases; then for each disease, we constructed a list of terms that refer to it (ie, a disease-specific lexicon). We also collected a large number of tweets and compiled them into a tweets corpus. Next, we retrieved a random sample of tweets from our corpus that contained any of our disease terms. We then determined the relative frequencies (percentage) of medical uses of the disease terms (ie, valid positives) versus nonmedical uses (ie, false positives due to ambiguity), using human annotation on the random sample. This allowed us to compute corrected counts of the number of tweets in the corpus that mention each disease (we call this a disease’s “validated tweet count,” whereas an uncorrected count is termed a “raw tweet count”).

We correlated the corrected disease-mention frequencies with the US disease-prevalence statistics from the Simmons National Consumer Study [21]. The resulting correlation serves as a measure of the relationship between the quantity of disease mentions in the corpus, and the quantity of disease cases in the US population (for either the general population or the Twitter-using population). Comparing the correlations with and without correction demonstrates the size of our corrections.

Data Collection

Selection of Diseases

We used the following criteria for selecting diseases for this research: (1) diseases that could be paired with both US population prevalence data and Twitter-use data; and (2) diseases deemed by previous literature to be most impactful for the health care community. Each criterion is satisfied by a different dataset.

The first dataset comes from Experian, a global information services company. Experian also conducts consumer surveys on a variety of topics, including health care. For this study, we used data from Experian’s Simmons National Consumer Study and focused on survey questions pertaining to general demographics, health status, and social media use.

Results from the various Experian surveys are combined into a database and released both quarterly and annually. Experian conducts poststratification on its survey data to create demographically representative estimates for its measured variables. We queried this database to obtain a dataset for the year 2012 that crosstabulates disease prevalence for all available diseases (n=52) with both general demographics and Twitter use. For the estimated English-speaking or Spanish-speaking US adult population (n=230,124,220), we were able to find the estimated number of individuals who suffer from a disease (eg, backache, n=42 million), and the subset of those disease sufferers who use Twitter (in the case of backache, n=2.6 million). This dataset, then, provides us with parallel sets of disease-prevalence statistics for the general US population and for US Twitter users.

The second dataset is from a RAND study designed to broadly measure the quality of health care delivery in the United States

[22]. Through reviews of the literature and of national health care data, and through consultation with panels of medical experts, 46 “clinical areas” were identified in this report that represent the leading causes of illness, death, and health care utilization in the United States.

The list of 24 diseases (see Multimedia Appendix 1) used in this study is composed of the overlap between the diseases represented in the Experian dataset (n=52) and in the RAND study (n=46). This overlap may be explicit (eg, “asthma” appears on both lists) or implicit (eg, two separate Experian entries, “stomach ulcers” and “acid reflux disease/GERD,” are both suggested by the single RAND entry “peptic ulcer disease and dyspepsia”). The focus in this task was not pinpointing exact matches between the two lists, but rather finding areas of general agreement between them, to identify high-impact diseases from the Experian dataset.

Compilation of Disease Terms

For each disease on our list, we constructed a lexicon of disease terms that are used to refer to that disease. For example, the lexicon for *diabetes* used in this study contains three disease terms, namely, “diabetes,” “diabete,” “niddm.” All lexica in this study are derived from terms found in Consumer Health Vocabulary (CHV) [23], an online open source thesaurus that associates medical concepts (including diseases, medical procedures, drugs, anatomy, etc) with a mix of colloquial and technical terms. At the time of this study, the CHV contained 158,519 entries, covering 57,819 unique (but often closely related) concepts. Each entry collects (along with other data) at least three term elements: (1) a CHV term, (2) a descriptive phrase, and (3) a related term from a medical vocabulary called the “Unified Medical Language System (UMLS).” A CHV term can have multiple entries in the thesaurus, thereby associating the CHV term with any number of descriptive phrases or UMLS terms. Each CHV term can then be seen as a key-value pair, where the CHV term is the key and a network of associated terms (consisting of descriptive phrases and UMLS terms) is the value.

For each of the 24 diseases included in the study, we processed the CHV to retrieve an entire key-value network of associated terms if *any one* of the terms (in the key or the value) seemed to refer to the target disease. Multiple networks could be (and often were) collected for any disease. Together, these results constituted a disease’s list of candidate disease terms (these were then vetted, according to the process described in the “Vetting Disease-Term Candidates” section). A term was judged to be a potential reference to a target disease (thereby triggering the retrieval of all associated terms) primarily if it contained a search string derived from the target disease’s name (including both abbreviated and spelled-out forms). For example, “attention deficit” is a search string for *attention deficit disorder/attention deficit hyperactivity disorder (ADD/ADHD)* ; “heart disease” is a search string for *heart disease* ; and “GERD” is a search string for *acid reflux disease/GERD*. Also included among the search strings were some common disease synonyms, such as “zit” for *acne* and “tumor” for *cancer*. The number of search strings varied for each disease, ranging from 1 to 7.

Tweet Text Corpus

The tweets used in our analysis were taken from a random sample of 1% of all available tweets in 2012, as collected through the Twitter “1% random public stream” application programming interface (API) [24]. To align our data more closely with the American and mostly English-speaking Experian Simmons sample, we filtered our Twitter corpus to keep only English tweets originating in the United States. To filter for English, we only considered tweets with at least 50% of their words found in the Hunspell English dictionary [25]. Tweets were then further restricted to the United States by finding tweets with “United States” or nonambiguous US cities in their location field (city names were taken from [26]). For example, “Chicago” would match the United States, whereas “London,” even though there is a London in Texas, would not. This resulted in a corpus of 80,680,449 tweets.

Vetting Disease-Term Candidates

Grammatical

In this research, we focused on finding tweets that specifically *name* our target diseases. Broadening this focus to include related concepts, such as symptoms and treatments, was desirable but was not possible for the scope of this paper. Because of our focus on terms that name diseases (as opposed to terms that describe or suggest them), we dropped all candidate disease terms that were not nouns (eg, adjectives such as “depressed” or “arthritic”). We then manually expanded the list, adding plural forms where grammatically appropriate.

Medical

We mined the CHV using a keyword search strategy inclined toward inclusiveness. For example, a search on “acne” retrieved terms for medical concepts that might be at best tenuously related to *acne*. One of these concepts was *acne rosacea* , whose network of associated terms contains the terms “acne rosacea,” “disorders rosacea,” “rosacea,” and “rosacea acne.”

Because the concept *acne rosacea* incorporates at least one term containing the text string “acne,” its entire network of terms automatically became candidates for the *acne* lexicon. This inclusiveness raises the question of whether “rosacea,” “acne rosacea,” “disorders rosacea,” etc denote *acne*. To solve this problem, a physician on the research team vetted the candidate terms. For each disease, she dropped candidates that did not denote the disease, ensuring that only medically appropriate terms were admitted into any disease lexicon.

Structural

We produced a list of text strings for each disease that we could use to search the Twitter corpus for mentions of that disease. To achieve this goal we took into account two realities. First, many CHV term elements use constructions that are uncommon in natural language (eg, “fever hay” as in *nasal allergies/hay fever*), “attack heart,” “attacks hearts,” or “attacking heart” as in *heart attack* , and “pain, back, radiating” as in *back pain*). Second, during execution of searches within the Twitter corpus, only the shortest element of a search phrase is required; if a compound search phrase contains a shorter search phrase, the longer one is implied by the shorter (eg, “asthma” retrieves *asthma* , *allergic asthma* , *pollen asthma* , etc; “diabetes” retrieves *diabetes mellitus* , *insulin-dependent diabetes* , *diabetes screening* , etc).

Because of these two facts, we were able to significantly shorten the candidate disease-term lists that were produced by the semiautomated CHV search procedure. All reverse-order candidates (eg, “fever hay”) and compound candidates (eg, “allergic asthma”) were dropped.

After these three vetting procedures, the 24 disease lexica contained a combined 488 disease terms (see Multimedia Appendix 1).

Manual Tweet Appraisal

We determined how often each of the 488 disease terms referred to its associated disease when included in a tweet. This began with a basic count for each disease term of the number of tweets in the corpus in which the term appears (before any language ambiguity corrections were applied). This is a disease term’s raw tweet count. Note that we allow a single tweet to be counted two times if it contains multiple disease terms (regardless of whether the two terms refer to the same or a different disease). Throughout this study, we consider random instances of disease terms as they appear in tweets, without consideration for other terms that co-occur with them.

We then performed manual appraisal. For each disease term, we randomly selected 30 tweets containing the term from our tweet corpus for manual analysis. This number was chosen to balance research needs and time constraints. Some disease terms occurred in 30 or fewer tweets in the tweet corpus. When this occurred, all available tweets were retrieved.

Two English-speaking research assistants independently read each tweet and made a simple appraisal, answering, “For each tweet, in your judgment does the disease term that flagged the tweet’s retrieval refer to a medical meaning of that term?” Each tweet required a Yes or No judgment, as shown in Table 1 . The two raters each compiled a complete collection of Yes/No judgments, held in secret from the other rater.

Table 1. Example of rating whether each tweet does or does not refer to a medical meaning of the selected term. Here the term is “heart attacks.”

Rater 1	Rater 2	Tweet
Yes	Yes	Visited a man who has had 2 heart attacks who feels privileged to be in circumstances that allow him to share his trust in God. #realdeal
Yes	No	Got room for 1 more? RT @pjones59: Sausage balls, heart attacks on a stick, dip, chips, wings and cheese, cream cheese/pickle/ham wraps
No	No	I still can't believe I saw Kris at work the other day. Talk about mini heart attacks. U_U

After these tweet-level appraisals were completed, we aggregated the scores at the disease-term level (independently for each rater’s collection of judgments). For each rater and each disease term (n=488), we calculated the percentage of tweets from the sample that were appraised as referring to a medical meaning. The Cohen’s kappa for inter-rater reliability was .77.

The disease-term percentages of the two raters were then averaged, resulting in a correction factor for each disease term. We multiplied this coefficient by the disease term’s raw tweet count (*rcount*), to arrive at an estimated disease-term *validated tweet count*(*vcount*).

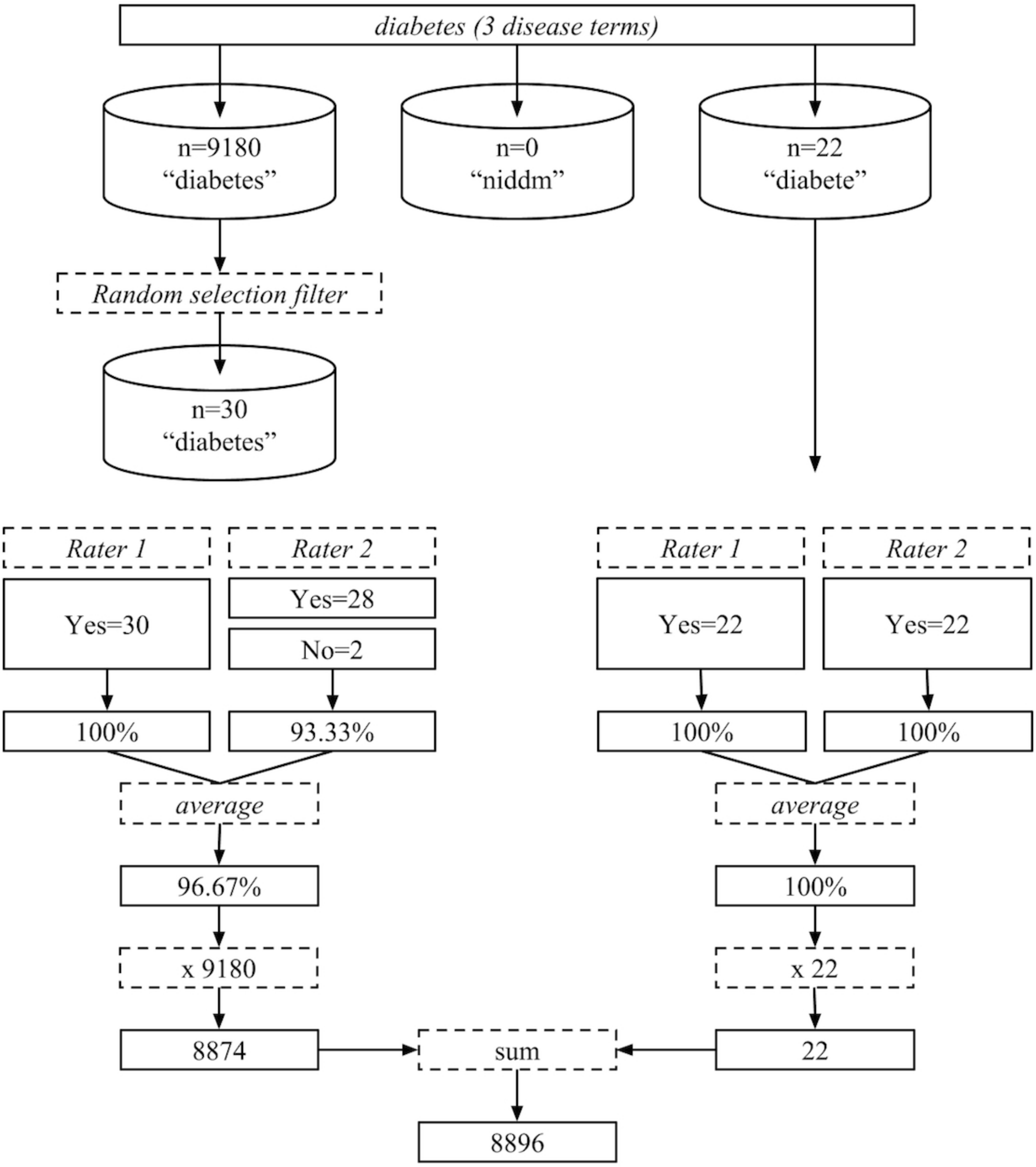
Once this estimate was completed for each disease term in a disease lexicon, the disease term estimates were summed, producing our ultimate metric, a validated tweet count for each disease lexicon (Figure 1). The validated tweet count for a disease lexicon is the estimated number of tweets in our corpus that are a valid reference to the disease in question, that is, correcting for the ambiguity error present in the disease lexicon’s raw tweet count.

As an example, manual appraisal for the *diabetes* disease lexicon (Figure 2) illustrates the evolution from a raw tweet count of 9202 to a validated tweet count of 8896.

Figure 1. Equation for deriving a disease lexicon's correction factor.

$$vcount(d) = \sum_{t \in terms(d)} rcount(t) * cf_t$$

Figure 2. Disease terms from the diabetes lexicon that were subjected to manual appraisal. Each term receives appraisal on up to 30 instances. The term-level appraisals are then summed to reach the final lexicon-level diabetes-validated tweet count (8896).



Results

Preliminary Findings

Of the 2824 tweets containing disease terms that we manually reviewed, the averaged judgments of our 2 human raters indicate that 2276.5 (80.61%) actually referred to diseases, with validity rates that were highly variable across different diseases. For example, *stroke* terms rarely referred to the medical emergency (only 22% of the time, or 55/252), whereas *diabetes* terms almost always referred to the medical condition (98% of the time, or 102/104). Note that the percentages we report in Table 2 (14.89%, 3827/25,704, for stroke; 96.67%, 25,104/25,704, for diabetes) weight the manually derived percentages according to the term frequency in the Twitter corpus of the different terms that comprise a disease lexicon.

The raw tweet counts and validated tweet counts for the 24 diseases are compared in Table 2 , along with a correction factor (an adjustment according to the percentage of evaluated tweets that were judged as valid). Table 2 also includes disease-prevalence data (for both the general US population and among US Twitter users), which come directly from Experian’s Simmons National Consumer Study. We noted high levels of heterogeneity for all five measurements across diseases. This probably reflects the heterogeneity among the diseases themselves: among them are acute viral infections (eg, *flu*), general maladies (eg, *backache* , *nasal allergies/hay fever*), chronic disorders (eg, *arthritis* , *osteoporosis*), test measures (eg, *high cholesterol* , *hypertension/high blood pressure*), medical emergencies (eg, *heart attack* , *stroke*), and psychological disorders (eg, *depression* , *ADD/ADHD*). Some of the diseases are transitory (eg, *urinary tract infection*) and others are long term (eg, *diabetes*). Some are causes of mortality (eg, *cancer* , *congestive heart failure*), whereas others are relatively superficial (eg, *acne*). Given such variety, it is no surprise to see a wide range of values for tweet counts, correction factor, and prevalence across the list of diseases.

Table 2. Raw and validated tweet counts, correction factor, and US and Twitter disease prevalence for each disease.

Disease	Raw tweet count	Validated tweet count	Correction factor[a]	Prev US (millions)[b,d]	Prev US Twitter (millions)[c,d]
Acid reflux disease/gastroesophageal reflux disease	743	631	84.98	32.4	2.40
Acne	6936	6027	86.89	11.2	2.00
Attention deficit disorder/attention deficit hyperactivity disorder	2794	2660	95.19	4.9	0.90
Arthritis	2524	2522	99.92	34.4	1.30
Asthma	3952	3754	95.00	12.4	1.00
Backache	3035	3028	99.77	42.0	2.60
Cancer	110,760	63,647	57.46	5.0	0.46
Congestive heart failure	928	313	33.76	—	—
Heart disease	2741	2410	87.91	—	—
Congestive heart failure/heart disease[e]	3669	2723	74.21	5.9	0.46
Chronic obstructive pulmonary disease	226	188	83.37	5.5	0.86
Depression	14,294	10,459	73.17	18.7	2.20
Diabetes	9202	8896	96.67	20.8	1.20
Flu	10,139	8810	86.90	17.2	1.80
Genital herpes	76	66	86.84	1.8	0.33
Heart attack	15,027	2311	15.38	—	—
Stroke	12,852	1914	14.89	—	—
Heart attack/stroke[f]	27,879	4225	15.15	3.0	0.11
High cholesterol	225	218	96.67	37.9	1.70
Human papilloma virus	636	545	85.73	1.5	0.12
Hypertension/high blood pressure	1630	1491	91.49	43.5	1.50
Migraine headache	5958	5615	94.24	16.4	1.80
Nasal allergies/hay fever	481	473	98.27	18.2	1.30
Osteoporosis	316	306	96.68	6.0	0.13
Stomach ulcers	80	73	91.25	3.3	0.03
Urinary tract infection	880	479	54.40	10.0	1.00

[a] Correction factor is the percentage of tweets that were appraised as valid.

[b] Prev US (millions) represents a disease's prevalence in the US.

[c] Prev US Twitter (millions) represents a disease's prevalence among US Twitter users.

[d] The source for both Prev US (millions) and Prev US Twitter (millions) is the Experian Simmons National Consumer Study.

[e] In the Experian dataset, congestive heart failure and heart disease are collapsed into a single data point. We mined Twitter for these diseases separately, and we applied our evaluation method to tweets containing disease terms for each one separately. However, because Experian was our source for prevalence statistics, we can only report on the prevalence of these two diseases in a combined state.

[f] Note "e" is true for the diseases heart attack and stroke.

Statistical Analysis

We determined the Spearman correlation coefficients (all *P* <.001) between both raw and validated tweet counts and disease prevalence among both the general US population and among US Twitter users (Table 3). Correcting just for Twitter use more than doubles the correlation between tweet count and prevalence (from .113 to .258). Correcting only for word ambiguity has a similar but slightly smaller effect (.208). Correcting for both more than triples the baseline correlation (.366).

Table 3. Spearman correlation coefficients between both raw and validated tweet counts and US population and Twitter-user disease prevalence (all *P* <.001).

	Prevalence	
	US population	US Twitter users
Raw tweet count	.113	.258
Validated tweet count	.208	.366

Discussion

Overview

The correlation improvements we found due to ambiguity correction may seem unsurprising. However, the improvements due to demographic correction are less straightforward, particularly because no effort was made to restrict our tweet analysis to first-person self-report mentions of diseases. It is easy to assume that there must be a causal connection between disease prevalence and disease mentions. Indeed, we interpret an increased correlation due to demographic correction as supporting this assumption: it means the signal we measure (ie, disease mentions on Twitter) demonstrates positive correspondence to a plausible source of that signal (ie, disease sufferers who use Twitter). However, we find that for certain individual diseases, disease prevalence and disease mentions are wildly out of sync. For the time being just what causes someone to tweet (or not tweet) about a disease remains an open question, particularly because many people mentioning the disease are not suffering from it. In any case, methods utilizing social media to estimate disease prevalence do not need to explain a causal connection. They only demand that social media reliably captures the variance of disease prevalence. We have shown that such measurement can be improved by adjusting for demographic differences between disease sufferers and Twitter users.

Bias Correction

We found that naïvely counting mentions of disease terms in tweets produces results that are biased (in terms of correlation with known disease-prevalence statistics) due to both demographic pattern of Twitter users and the ambiguity of natural language. These biases can be at least partially corrected, resulting in a threefold increase in the correlation between counts of disease terms in tweets and known prevalence statistics for the 24 diseases we studied.

The observation that the Twitter population is a biased sample of the United States is relatively easily corrected using standard stratified sampling methods, given the known demographics of the Twitter population. We identified this using data from an Experian survey, but other studies of Twitter demographics could also be used. We demonstrated that the demographic corrections roughly doubled the correlation between disease mentions and disease prevalence.

Types of Ambiguity

The intrinsic ambiguity of language requires more work to correct. We observed that language ambiguity varies significantly across diseases. The fraction of mentions of a disease term that actually refer to the disease ranged from highly specific terms such as arthritis (99.92%, or 5044/5048) to less specific terms such as stroke (14.89%, or 3827/25,704). This language ambiguity takes 2 major forms.

The first is “lexical ambiguity.” Some diseases such as arthritis, diabetes, and high cholesterol are in practice referred to by terms that almost always refer to their associated disease concepts. In our analysis, tweeters rarely used words from the arthritis lexicon to refer to anything other than the disease “arthritis.” There are, however, a number of disease terms that are often used to refer to concepts that are not diseases (or not the intended diseases). Frequently occurring example words include “cancer” (the astrological sign), “depression,” “stroke” (nonmedical usages and also heat stroke), and “flu” (as in stomach flu, versus “influenza”). Abbreviations are particularly ambiguous. For example, “copd” (ie, chronic obstructive pulmonary disease) is a popular variant spelling of “copped” (as in the verb “took”); “uti” (*urinary tract infection*), “hpv” (*human papillomavirus*), and “zit” (*acne*) show up in Internet addresses (particularly in short links using URL redirection); and “CHF” (*congestive heart failure*) is an abbreviation for the Swiss Franc. Or conversely, “Gerd” is a masculine first name that coincides with an abbreviation for the disease gastroesophageal reflux disease (part of the *acid reflux disease/GERD* lexicon). Lexical ambiguity also arises from metaphorical and slang usages of disease terms. “Heart attack” and “heart failure” are used to mean surprise and “ADHD” to mean distracted.

The second type of ambiguity could be considered “disease ambiguity.” Some of the 24 diseases included in this study are less clearly delineated than others. One aspect of this problem is intensity. Is it medical depression if a Twitter user reports being depressed about her favorite sports team losing a game? What if she ends a seemingly grave tweet with “LOL?” A second aspect of disease ambiguity is specificity or accuracy. Some Twitter users may use the word migraine for other types of headache or say hay fever when actually they are allergic to cats. A third aspect of disease ambiguity is complexity. A prime example is the range of cardiovascular diseases in this study (ie, *congestive heart failure* , *heart disease* , *heart attack* , *high* *cholesterol* , *hypertension* , possibly *stroke*), whose inter-relations and exact boundaries are difficult or impossible to draw.

Both types of ambiguity can affect a disease's validation coefficient. The first type, lexical ambiguity (eg, homographs or metaphorical word usage), is likely to affect the "back end" of the methodology, requiring corrections to the observed term counts (ie, using the method described in this paper). The second type, disease boundary ambiguity, presents problems on the "front end" and it makes tailoring the disease lexica difficult. This type of ambiguity raises the question of whether the potentially hierarchical relationship between congestive heart failure and heart disease, or the potentially causal relationship between high cholesterol and either heart attack or stroke, could or should somehow be encoded in the disease lexica.

In this research, we treated each disease lexicon as a stand-alone entity, and the effects of that decision are necessarily written into the results we derived. We can expect that diseases of a more "stand-alone" quality (ie, those that are relatively self-contained like *osteoporosis* , rather than part of a complex like *heart disease*) will naturally be better represented by their respective disease lexica than are diseases that potentially harbor a complex relationship with other diseases. It is intuitive that mismatch between a disease's representation on Twitter and its representation within its disease lexicon is essentially what causes the disease's validation coefficient to drop below 100%.

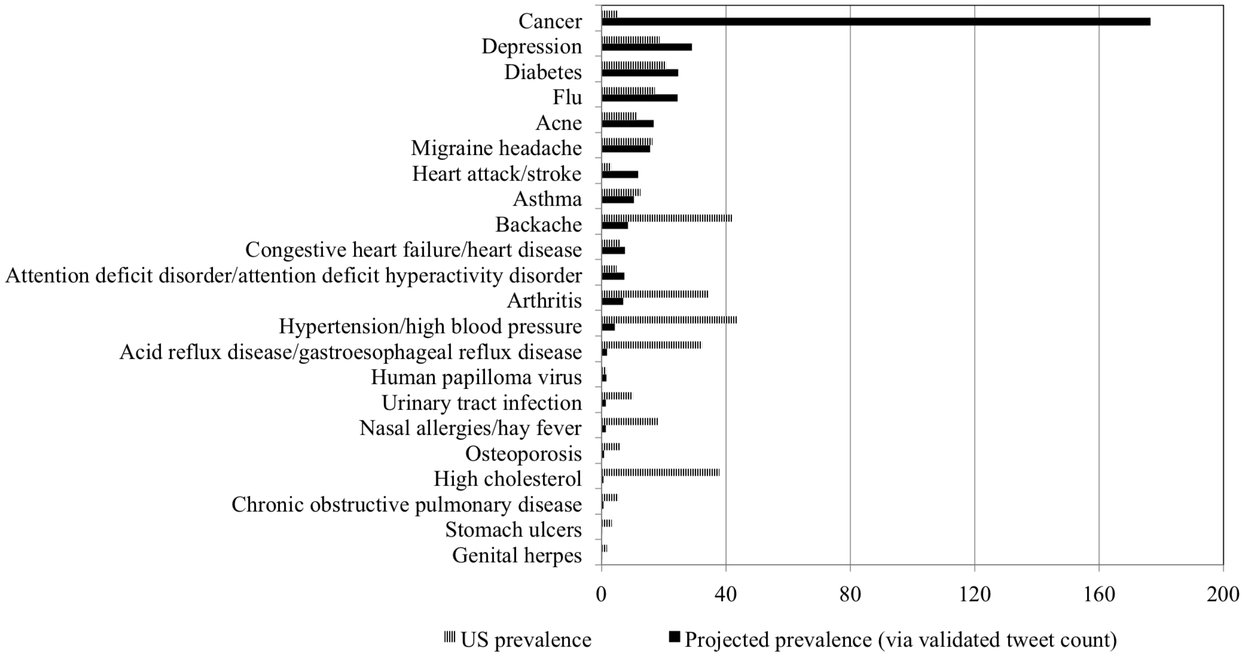
Correlation of Validated Tweet Count With Prevalence

Just as validity rates proved highly variable across diseases, the levels of Twitter discussion relative to disease prevalence also varied. Some diseases were discussed at levels outstripping their prevalence in the population, whereas others received little relative attention. The relationship between validated tweet count and US prevalence across diseases has a correlation of .208 (Table 3 , P <.001). To provide a more detailed picture of this relationship, we calculated validated tweet count for each disease as a function of prevalence. The following formula is used for this purpose: for each disease d , projected prevalence = (validated tweet count of d /sum of all validated tweet counts) × sum of all disease prevalence. This can be understood as the prevalence that validated tweet count (inaccurately) projects for each disease.

We compare this projected prevalence with actual prevalence in Figure 3 . The sum of prevalence across all diseases (351,939,580) is identical for both the projected and the actual cases, but the distributions are quite different. We see that *cancer* is a major outlier, "taking up" over 50% of projected prevalence (176,605,210), whereas it accounts for less than 2% of actual prevalence (5,031,120). Clearly, *cancer* receives far more attention than merely prevalence warrants. Projected prevalence is more than 35 times as great as actual prevalence. Conversely, *high cholesterol* is on the extreme end of underrepresentation. Projected prevalence (604,898) is only 1.60% of actual prevalence (37,861,070). These figures demonstrate that other unknown factors besides prevalence influence the amount of discussion a disease receives on Twitter.

One hypothesis is that Twitter demographics skew discussion levels upward for diseases that are of high concern to the population of users and downward for diseases that are of less concern. Given the generalization that Twitter users tend to be young, this could explain why *arthritis* seems to be drastically under-tweeted, and why *acne* and *ADD/ADHD* are over-tweeted. However, demographics alone cannot explain the extraordinary projected prevalence of *cancer*. Nor are they likely to explain the over-tweeting of *flu* and *diabetes*. We assume that demographics do influence these results (notice the over-projection of *acne* , a disease of youth, and the under-projection of *hypertension/high blood pressure* , a disease of aged, in Figure 3), but that multiple other factors also play roles. Likely candidates include the intensity and history of disease awareness and advocacy campaigns (see *cancer* , *diabetes* , and *human papilloma virus*); and disease stigma or body-part stigma (see *genital herpes* and *urinary tract infection*). Investigation into these and other possible factors is an area for future research.

Figure 3. Projected prevalence (as a function of validated tweet count) versus actual US prevalence for 22 diseases, in millions (sorted by projected prevalence). Some diseases are "over-tweeted" (in particular, cancer), whereas others are "under-tweeted" (eg, backache and arthritis).



Limitations

It remains unclear precisely what is the nature of the relationship between disease discussion (on Twitter or even just in general) and disease prevalence. Twitter disease discussion is likely driven by many more factors than disease prevalence. People tweet about diseases for many reasons, and for the purposes of this paper, we do not attempt to disentangle such reasons. We do demonstrate, though, that Twitter disease mentions correlate with disease prevalence, and that this correlation improves after our demographic and word ambiguity corrections have been applied. This lesson can and should be incorporated into other research or tools that would seek to mine the language found on Twitter (or similar venues) for information about broader populations.

Despite our best efforts, the demographics of our Twitter corpus and of the Experian dataset do not entirely match. Most significantly, the Experian dataset includes disease-prevalence estimates for both English-speaking and Spanish-speaking US residents, whereas our tweet corpus was restricted to English language tweets. This research was conducted in English; future work should extend a similar analysis to other languages.

We did not account in this research for all possible variables that could influence the interplay of disease prevalence and tweets about diseases. Some of these missed variables are disease centric. For example, some diseases may actually be more "tweet-able" than others due to any number of disease factors, including intensity, duration, stigma, social salience, and so on, or possibly even due to formal considerations (is the disease easy or quick to spell?). A less tweet-able disease might be expected to have fewer associated tweets, outside of any prevalence-based influence on tweet counts.

We only account for mentions of diseases that specifically name a (properly spelled) disease in a tweet. On the one hand, relying on correct noun-form disease names that are sourced from a recognized health vocabulary such as the CHV helps push this study toward semiautomation, objectivity, and reproducibility. However, on the other hand, this decision leaves an unknown, but possibly large, quantity of disease-relevant tweets unmined, and so unaccounted for in our analysis. We miss mentions that are slang terms (eg, "diabeetus") or are misspelled (eg, "ashtma," "hi cholesterol"). On a strictly formal level, our current approach is tuned to precision at the expense of recall. Furthermore, people may discuss health concerns on Twitter by mentioning symptoms, sequelae, locations (such as a hospital), drugs, or treatments, etc. Our focus on disease names is unable to capture this broader domain of health-related tweets. Improving recall is left for future work.

Other missed variables are Twitter centric. It is well documented that Twitter does not reveal what sampling procedures are used in their APIs [27,28]. Therefore, it is unclear how representative the tweeters (whose tweets were captured for this study) are of the US population of Twitter users. This is unavoidable, and it is a shortcoming common to all research using Twitter APIs.

We also did not discriminate in this research between tweeters. A Twitter "user" may not be an individual person. Many health-related or even disease-related organizations mention diseases on Twitter. Factors related to such organizations (their quantity, their social media strategies, etc) may be relevant to counts of disease-naming tweets. Other researchers have addressed the problem of distinguishing tweets authored by health organizations [29], but this study did not make that distinction.

Comparison With Prior Work

In the normal course of life or business, individuals and organizations generate vast amounts of text that can be mined. Much of it is shared or published online in one form or another, and these data are attractive to researchers, including those interested in epidemiology and public health.

Several “infodemiology” studies (eg, many in the long list cited in the “Introduction” section) correlate word use in Twitter with prevalence of a disease or medical condition. Beyond Twitter, Web search activity has also been used, for example to monitor Lyme disease [30] and dengue [31], as well as risk behaviors associated with dietary habits [32] and with suicide [33]. Blog posts have been used to predict influenza outbreaks [34]. Facebook has been used to predict “gross national happiness,” that is, well-being across the United States [35].

These studies primarily correlate word use in some medium (eg, Twitter or Google search) over some period (eg, day or week) and in some region (eg, US county or state) with a disease-prevalence level. Such correlational approaches rely on certain assumptions about the homogeneity of the populations they study, which often go unstated and so presumably untested and uncorrected. It is not clear whether demographic or word ambiguity biases are typically accounted for. We suppose that researchers implicitly assume that these factors will be handled automatically by the statistical regression methods they use. If demographic and ambiguity biases are constant over time and space, this will be true. However, if populations vary in their usage of the target medium (eg, Twitter), prediction accuracy can vary, and this variation may be significant.

Google Flu Trends is perhaps the “poster child” for the correlational approach to prediction. It is a widely cited online tool that uses statistical correlations between a broad set of Google search terms and historical flu levels to predict regional changes in US flu levels [36]. Google Flu Trends was initially highly accurate. However, it has also been used as a case study of how “big data” predictions can go awry when the statistical patterns upon which they are based are descriptively inaccurate (either from the start or due to drift over time) [37,38], with claims that at one point predictions became exaggerated by nearly a factor of 2 [39].

A limited number of studies have emphasized concerns about validity in social media analyses [40]. There has also been some work on selecting “high-quality” disease-related tweets, mostly achieving high specificity at the cost of poor sensitivity. For example, [41] uses regular expressions and machine-learning methods to filter out all but first-person self-report tweets. We strive for higher coverage, including all “real” mentions of a disease, and then we seek out previously established data (ie, disease prevalence) against which we validate our findings. In a previous study [42], researchers identified known sick persons, then study their Twitter data to characterize a kind identifying fingerprint for Twitter users who have the flu (utilizing their tweets and their Twitter profile metadata). They then use that model to “diagnose” individual Twitter users with influenza, an approach that the authors imply could be directed toward population-level disease surveillance.

In the near term, we think that the major use of social media for public health may be to understand attitudes toward health, disease, and treatment. Effective public policy depends on subjective inquiries into what people know and care about. Why do they seek or avoid treatment? How do they reveal disease status? What risk behaviors do they shrug off? Predictions about a phenomenon that one can measure, such as disease prevalence, may have limited utility, especially if the measurements are timely and accurate. Although traditional ground truth measurements have been questioned [43], the Centers for Disease Control and Prevention flu estimates appear to be better than Google Flu Trends estimates [44]. Nevertheless, online disease detection and prediction is a rapidly growing research area, and as work continues in this field, our collective ability to make these types of estimates will likely increase.

Conclusions

Several types of research using social media to study public health will benefit from corrections for demographic variation and language ambiguity of the type that are outlined in this paper. Social media datasets are biased convenience samples, and word ambiguity is endemic. Nevertheless, social media provide a relatively cheap way to monitor countless domains, including public health and attitudes toward health and health care.

In this study, we began with a large, “poor-quality,” nonrandom dataset (ie, Twitter), and compared it with a small, “high-quality,” random (achieved via poststratification) dataset (ie, the Simmons National Consumer Study from Experian). We filtered the Twitter dataset so that its demographics would match that of the Experian dataset. We then performed both naïve and ambiguity-corrected counts of Twitter disease mentions. Finally, we compared both of these counts with prevalence data found in the Experian survey. We found that the corrected Twitter counts correlated much more strongly than the naïve Twitter counts with the “high-quality” Experian data.

We think that this demonstrates both the need and the capacity for other studies using nonrandom convenience samples (eg, social media data or Google queries) to take demographic and word ambiguity factors explicitly into account, for example, using our method or other related or novel methods.

Conflicts of Interest

None declared.

Multimedia Appendix 1

This study focuses on a list of 24 diseases. Each of these diseases is represented by a disease lexicon composed of one or more disease terms. There are 24 lexica, comprising 488 disease terms. The first row in this appendix holds lexica names, subsequent rows hold disease terms. Each column represents a different disease.

[XLSX File (Microsoft Excel File), 14KB - publichealth_v1i2e6_app1.xlsx]

References

1. Collier N, Son NT, Nguyen NM. OMG U got flu? Analysis of shared health messages for bio-surveillance. J Biomed Semantics 2011;2 Suppl 5:S9 [FREE Full text] [doi: 10.1186/2041-1480-2-S5-S9] [Medline: 22166368]
2. Paul MJ, Dredze M. You are what you tweet: Analyzing Twitter for public health. Menlo Park, CA: Association for the Advancement of Artificial Intelligence; 2011 Jul 17 Presented at: Fifth International AAAI Conference on Weblogs and Social Media (ICWSM); Jul 17-21, 2011; Barcelona, Spain.
3. Chunara R, Andrews JR, Brownstein JS. Social and news media enable estimation of epidemiological patterns early in the 2010 Haitian cholera outbreak. Am J Trop Med Hyg 2012 Jan;86(1):39-45 [FREE Full text] [doi: 10.4269/ajtmh.2012.11-0597] [Medline: 22232449]
4. Chew C, Eysenbach G. Pandemics in the age of Twitter: Content analysis of tweets during the 2009 H1N1 outbreak. PLoS One 2010 Nov;5(11):e14118 [FREE Full text] [doi: 10.1371/journal.pone.0014118] [Medline: 21124761]
5. 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 May;6(5):e19467 [FREE Full text] [doi: 10.1371/journal.pone.0019467] [Medline: 21573238]
6. Szomszor M, Kostkova P, De Quincey E. #Swineflu: Twitter predicts swine flu outbreak in 2009. Heidelberg, Germany: Springer; 2012 Presented at: 3rd International ICST Conference on Electronic Healthcare for the 21st Century (eHEALTH2010); Dec 13-15, 2010; Casablanca, Morocco p. 18-26.
7. De Choudhury M, Counts S, Horvitz E. Predicting postpartum changes in emotion and behavior via social media. New York, NY: ACM; 2013 Presented at: SIGCHI Conference on Human Factors in Computing Systems; Apr 27-May 2, 2013; Paris, France p. 3267-3276. [doi: 10.1145/2470654.2466447]
8. Sullivan SJ, Schneiders AG, Cheang C, Kitto E, Lee H, Redhead J, et al. 'What's happening?' A content analysis of concussion-related traffic on Twitter. Br J Sports Med 2012 Mar;46(4):258-263. [doi: 10.1136/bjsm.2010.080341] [Medline: 21406451]
9. McNeil K, Brna PM, Gordon KE. Epilepsy in the Twitter era: A need to re-tweet the way we think about seizures. Epilepsy Behav 2012 Feb;23(2):127-130. [doi: 10.1016/j.yebeh.2011.10.020] [Medline: 22134096]
10. Nascimento TD, DosSantos MF, Danciu T, DeBoer M, van HH, Lucas SR, UMSoD (Under)Graduate Class of 2014, et al. Real-time sharing and expression of migraine headache suffering on Twitter: A cross-sectional infodemiology study. J Med Internet Res 2014 Apr;16(4):e96 [FREE Full text] [doi: 10.2196/jmir.3265] [Medline: 24698747]
11. Lyles CR, López A, Pasick R, Sarkar U. "5 mins of uncomfyness is better than dealing with cancer 4 a lifetime": An exploratory qualitative analysis of cervical and breast cancer screening dialogue on Twitter. J Cancer Educ 2013 Mar;28(1):127-133. [doi: 10.1007/s13187-012-0432-2] [Medline: 23132231]
12. Scanfeld D, Scanfeld V, Larson EL. Dissemination of health information through social networks: Twitter and antibiotics. Am J Infect Control 2010 Apr;38(3):182-188 [FREE Full text] [doi: 10.1016/j.ajic.2009.11.004] [Medline: 20347636]
13. Nakhasi A, Passarella R, Bell S, Paul M, Dredze M, Pronovost P. Malpractice and malcontent: Analyzing medical complaints in Twitter. Menlo Park, CA: Association for the Advancement of Artificial Intelligence; 2012 Presented at: 2012 AAAI Fall Symposium Series; Nov 2-4, 2012; Arlington, VA p. 84-85.
14. Heaivilin N, Gerbert B, Page JE, Gibbs JL. Public health surveillance of dental pain via Twitter. J Dent Res 2011 Sep;90(9):1047-1051 [FREE Full text] [doi: 10.1177/0022034511415273] [Medline: 21768306]
15. Salathé M, Khandelwal S. Assessing vaccination sentiments with online social media: Implications for infectious disease dynamics and control. PLoS Comput Biol 2011 Oct;7(10):e1002199 [FREE Full text] [doi: 10.1371/journal.pcbi.1002199] [Medline: 22022249]
16. Brenner J, Smith A. 72% of Online Adults Are Social Networking Site Users. Washington, DC: Pew Research Center; 2013. URL: http://www.pewinternet.org/files/old-media/Files/Reports/2013/PIP_Social_networking_sites_update_PDF.pdf [accessed 2014-09-01] [WebCite Cache ID 6SGvEVQFj]
17. Duggan M, Smith A. Social Media Update. Washington, DC: Pew Research Center; 2014. URL: http://www.pewinternet.org/files/2014/01/Social_Networking_2013.pdf [accessed 2014-09-01] [WebCite Cache ID 6SGvMaF2d]
18. Mislove A, Lehmann S, Ahn Y, Onnela J, Rosenquist J. Understanding the demographics of Twitter users. Menlo Park, CA: Association for the Advancement of Artificial Intelligence; 2011 Presented at: Fifth International AAAI Conference on Weblogs and Social Media (ICWSM); Jul 17-21, 2011; Barcelona, Spain p. 554-557.
19. 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]
20. 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 Jul;15(7):e147 [FREE Full text] [doi: 10.2196/jmir.2740] [Medline: 23896182]
21. Experian Marketing Services. Simmons National Consumer Study. Dublin, Ireland: Experian Marketing Services; 2014. URL: http://www.experian.com/simmons-research/consumer-study.html [accessed 2014-09-01] [WebCite Cache ID 6SGtWFNi5]
22. Kerr E, Asch S, Hamilton E, McGlynn E. Quality of care for general medical conditions: A review of the literature and quality indicators. Santa Monica, CA: RAND; 2000.

23. Consumer Health Vocabulary. Salt Lake City, UT: Open Access, Collaborative Consumer Health Vocabulary Initiative, University of Utah URL: http://consumerhealthvocab.org/ [accessed 2014-09-01] [WebCite Cache ID 6SGtoLBel]
24. Twitter Public Streams API Documentation. URL: https://dev.twitter.com/docs/streaming-apis/streams/public [accessed 2014-09-01] [WebCite Cache ID 6SGu2qB7Z]
25. Hunspell Dictionary. URL: http://hunspell.sourceforge.net/ [accessed 2014-09-01] [WebCite Cache ID 6SGuCquNN]
26. US Cities List. URL: http://www.uscitieslist.org/ [accessed 2014-09-01] [WebCite Cache ID 6SGuPqocl]
27. González-Bailón S, Wang N, Rivero A, Borge-Holthoefer J, Moreno Y. Assessing the bias in samples of large online networks. Soc Networks 2014 Jul;38:16-27. [doi: 10.1016/j.socnet.2014.01.004]
28. Morstatter F, Pfeffer J, Liu H, Carley K. Is the sample good enough? Comparing data from TwitterÃ¢â‚¬â„¢s streaming API with TwitterÃ¢â‚¬â„¢s firehose. Menlo Park, CA: Association for the Advancement of Artificial Intelligence; 2013 Presented at: Seventh International AAAI Conference on Weblogs and Social Media (ICWSM); Jul 8-11, 2013; Cambridge, MA p. 400-408.
29. Dumbrell D, Steele R. Twitter and health in the Australian context: What types of information are health-related organizations tweeting? New York: IEEE; 2013 Presented at: 46th Annual Hawaii International Conference on System Sciences (HICSS); Jan 7-10, 2013; Wailea, HI p. 2666-2675. [doi: 10.1109/HICSS.2013.578]
30. Seifter A, Schwarzwalder A, Geis K, Aucott J. The utility of "Google Trends" for epidemiological research: Lyme disease as an example. Geospat Health 2010 May;4(2):135-137. [doi: 10.4081/gh.2010.195] [Medline: 20503183]
31. Chan EH, Sahai V, Conrad C, Brownstein JS. Using web search query data to monitor dengue epidemics: A new model for neglected tropical disease surveillance. PLoS Negl Trop Dis 2011 May;5(5):e1206 [FREE Full text] [doi: 10.1371/journal.pntd.0001206] [Medline: 21647308]
32. West R, White RW, Horvitz E. From cookies to cooks: Insights on dietary patterns via analysis of Web usage logs. Geneva, Switzerland: International World Wide Web Conferences Steering Committee; 2013 Presented at: 22nd International World Wide Web Conference; May 13-17, 2013; Rio de Janeiro, Brazil p. 1399-1410.
33. McCarthy MJ. Internet monitoring of suicide risk in the population. J Affect Disord 2010 May;122(3):277-279 [FREE Full text] [doi: 10.1016/j.jad.2009.08.015] [Medline: 19748681]
34. Corley CD, Cook DJ, Mikler AR, Singh KP. Text and structural data mining of influenza mentions in web and social media. Int J Environ Res Public Health 2010 Feb;7(2):596-615 [FREE Full text] [doi: 10.3390/ijerph7020596] [Medline: 20616993]
35. Kramer A. An unobtrusive behavioral model of gross national happiness. 2010 Presented at: 28th International Conference on Human Factors in Computing Systems (CHI 2010); Apr 10-15, 2010; Atlanta, GA p. 287-290. [doi: 10.1145/1753326.1753369]
36. 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]
37. Lazer D, Kennedy R, King G, Vespignani A. Big data. The parable of Google Flu: Traps in big data analysis. Science 2014 Mar 14;343(6176):1203-1205. [doi: 10.1126/science.1248506] [Medline: 24626916]
38. Olson DR, Konty KJ, Paladini M, Viboud C, Simonsen L. Reassessing Google Flu Trends data for detection of seasonal and pandemic influenza: A comparative epidemiological study at three geographic scales. PLoS Comput Biol 2013 Oct;9(10):e1003256 [FREE Full text] [doi: 10.1371/journal.pcbi.1003256] [Medline: 24146603]
39. Butler D. When Google got flu wrong. Nature 2013 Feb 14;494(7436):155-156. [doi: 10.1038/494155a] [Medline: 23407515]
40. Kass-Hout TA, Alhinnawi H. Social media in public health. Br Med Bull 2013 Oct;108:5-24. [doi: 10.1093/bmb/ldt028] [Medline: 24103335]
41. Prieto VM, Matos S, Álvarez M, Cacheda F, Oliveira JL. Twitter: A good place to detect health conditions. PLoS One 2014 Jan;9(1):e86191 [FREE Full text] [doi: 10.1371/journal.pone.0086191] [Medline: 24489699]
42. Bodnar T, Barclay V, Ram N, Tucker C, Salathé M. On the ground validation of online diagnosis with Twitter and medical records. 2014 Presented at: 23rd International Conference on World Wide Web; Apr 7-11, 2014; Seoul, Korea p. 651-656.
43. Reed C, Angulo FJ, Swerdlow DL, Lipsitch M, Meltzer MI, Jernigan D, et al. Estimates of the prevalence of pandemic (H1N1) 2009, United States, April-July 2009. Emerg Infect Dis 2009 Dec;15(12):2004-2007 [FREE Full text] [doi: 10.3201/eid1512.091413] [Medline: 19961687]
44. Ortiz JR, Zhou H, Shay DK, Neuzil KM, Fowlkes AL, Goss CH. Monitoring influenza activity in the United States: A comparison of traditional surveillance systems with Google Flu Trends. PLoS One 2011 Apr;6(4):e18687 [FREE Full text] [doi: 10.1371/journal.pone.0018687] [Medline: 21556151]

Abbreviations

ADD/ADHD: attention deficit disorder/attention deficit hyperactivity disorder
API: Application Programming Interface
CHV: Consumer Health Vocabulary
UMLS: Unified Medical Language System

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