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Twitter and Public Health (Part 1): How Individual Public Health Professionals Use Twitter for Professional Development

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Abstract

Background: The use of social networking sites is increasingly being adopted in public health, in part, because of the barriers to funding and reduced resources. Public health professionals are using social media platforms, specifically Twitter, as a way to facilitate professional development.

Objective: The objective of this study was to identify public health professionals using Twitter and to analyze how they use this platform to enhance their formal and informal professional development within the context of public health.

Methods: Keyword searches were conducted to identify and invite potential participants to complete a survey related to their use of Twitter for public health and professional experiences. Data regarding demographic attributes, Twitter usage, and qualitative information were obtained through an anonymous Web-based survey. Open-response survey questions were analyzed using the constant comparison method.

Results: "Using Twitter makes it easier to expand my networking opportunities" and "I find Twitter useful for professional development" scored highest, with a mean score of 4.57 (standard deviation [SD] 0.74) and 4.43 (SD 0.76) on a 5-point Likert scale. Analysis of the qualitative data shows the emergence of the following themes for why public health professionals mostly use Twitter: (1) geography, (2) continuing education, (3) professional gain, and (4) communication.

Conclusions: For public health professionals in this study, Twitter is a platform best used for their networking and professional development. Furthermore, the use of Twitter allows public health professionals to overcome a series of barriers and enhances opportunities for growth.

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KEYWORDS

Twitter; social media; public health; technology transfer; blogging

Introduction

Facebook, YouTube, Instagram, and Twitter are well-known social networking sites (SNS) that 69% of adults use daily in the United States [1,2]. On a global scale, as of January 2017, over 2.7 billion people, or 37% of the planet's population, are characterized as active social media users [1]. As the use of SNS has grown in popularity, its applications have expanded beyond personal communication [3]. In particular, one field is increasing its use of social media specifically for professional development is public health.

The practice and discipline of public health focuses on a broad range of tasks to accomplish its ultimate goal of disease and injury prevention among an entire community or population [4]. These preventative measures derive from 10 essential public health services listed by the Centers for Disease Control and

Prevention [4]. The final essential public health service listed states that research is key to providing "new insights and innovative solutions to health problems" [4]. This service is completed through collaboration among public health researchers and public health workers and through sufficient funding [5]. Unfortunately, public health funding is continually being cut from health departments and from research purposes, which in turn significantly reduces and eliminates funding for collaboration and networking among public health professionals [5,6].

To bypass the barriers of funding, public health professionals have turned to technology and social media for professional development, using sites such as LinkedIn and Twitter [7,8]. Most SNS share common features, including the ability of users to create public profiles within websites that connect people through common interests and personal relationships, which exponentially grow as more information is provided. Whereas many of the sites have similar features, users often stratify the sites based on different usage patterns; for example, Facebook is often used for friends and family, and LinkedIn is used for employment purposes [8]. Twitter, with 313 million active users, is unique in its function of communicating in 140 characters or less and the use of the hashtags, thus allowing public health professionals to connect and communicate quickly and efficiently [9]. Twitter is used worldwide, allowing communication through numerous languages and can connect users of vastly different geographical and socioeconomic areas. The public space Twitter provides also allows public health workers to network within their specialties, ultimately allowing for better understanding and initiation of the 10 public health essential services.

This use of Twitter, connected with the theoretical framework of social media functionality, shows professional development functions specifically in the constructs of conversation and groups, by not only providing networking for future employment opportunities but also a pool of professional associates fostering learning experiences [10]. During conferences and other important public health meetings, public health organizations are tweeting updates while attending as well as reporting on current research being conducted [7]. Public health organizations are also using Twitter as a form of journal club by choosing an paper and then letting public health professionals tweet discussions and questions with other professionals in real time [8]. Whereas research has explored how public health organizations have adjusted to a financial crisis by overcoming barriers through social media, research has yet to explore how individual public health professionals use social media, specifically Twitter, to enhance their formal and informal professional development [8].

Methods

Participants

Using Twitter's keyword search, the phrases "public health practitioner," "MPH" (Master's in Public Health), "public health," and "APHA" (American Public Health Association) were used to identify potential participants. The researchers sifted through the results to achieve the sample of 200 public health–affiliated Twitter users. Inclusion criteria comprised Twitter users with active accounts and minimums for number of tweets and followers (over 150 followers). Active accounts were defined as users who had posted content on their Twitter page in the past 3 weeks. Additionally, omitted from the sample were users who primarily were not engaged in general public health topics, public health organizations, and those who were identified as working solely in academia. Practicing public health professionals were the target population. The 200 public health professionals identified were asked through a direct Twitter message whether they would participate in a survey asking questions on their Twitter usage related to public health and their professional experiences. Those responding affirmatively were sent a direct link for our survey housed on an encrypted direct server, which was available for 1 month; ultimately, 49 people participated.

Materials

The first 5 survey items asked for demographic characteristics and the following 5 items specifically asked about Twitter usage. A modified version of an existing scale assessing perceived usefulness and ease of use regarding technology was applied [11]. The following questions asked participants to rate the following questions on a 1 (strongly disagree) to 5 (strongly agree) Likert scale: (1) using Twitter improves my job performance; (2) using Twitter increases my productivity; (3) using Twitter enhances my effectiveness on the job; (4) using Twitter makes it easier to expand my networking opportunities; and (5) I find Twitter useful for professional development. The last 3 questions were open-response questions providing a participant the opportunity to not only address personal meaningful practices but also gather insight on how Twitter has been used to advance professional development. Open-ended questions specifically asked included the following: (1) How has Twitter affected your standing within the field of public health? (2) How has Twitter affected your work in the field of public health? and (3) What advice would you give to other public health professionals considering the use of Twitter?

Procedure

Through the use of a college departmental Twitter account, specifically set up for this study, a single tweet briefly linked individuals to the electronic questionnaire on Qualtrics (Qualtrics, Provo, UT, USA). Interested participants were routed to a consent webpage before proceeding with the survey. All responses were confidential, and researchers were blind to which public health professionals responded from the 200 participants who were sent the initial direct message. Respondents did not receive any compensation for their participation. All research was approved by the institutional review board of the University of Florida.

Data Analyses

Frequency counts were used to determine the demographics of the survey respondents (Table 1). Mean, variance, and standard deviation were used to calculate the usefulness and ease of Twitter (Table 2). All quantitative data were analyzed using Statistical Package for the Social Sciences (SPSS). The constant comparison method was used to analyze the open-response

survey questions. This method is specifically used to reduce the text (data) into manageable units and, in turn, coded information [12-14]. The process began with 2 trained researchers (SI and NS) open-coding the responses to discover themes and subthemes [12-14]. After open-coding, specific themes were chosen, with both researchers (SI and NS) separately coding the responses by themes [12-14]. After the final coding, the 2 researchers checked to ensure that the responses matched, and discrepancies were decided by a third party who was also a trained researcher in the constant comparison method (MH) [12-14].

Results

Participants

Overall, 49 participants responded and completed the survey (response varied by question). Of those, 51% were females (n=25), 47% were males (n=23), and 2% did not identify with a gender (n=1). The majority of participants were aged between 25 and 34 years (45%, n=22). The second majority of participants were aged between 35 and 44 years (24%, n=12; Table 1). Whereas 59% (n=27) of the participants were located in the United States, 41% (n=19) were located outside the United States. The majority of the participants have worked in the field of public health for more than 10 years (43%, n=21), followed by 5 to 9 years (20%, n=10), and 0 to 4 years (37%, n=18). The majority of participants had obtained their master's degree (52%, n=25; Table 1).

Usefulness and Ease

The scale asked 5 questions about the usefulness and ease of Twitter on a 5-point Likert scale. "Using Twitter improves my job performance" has a mean of 3.80 (standard deviation [SD] 0.82, n=49), "Using Twitter increased my productivity" has a mean of 3.35 (SD 0.86, n=49), "Using Twitter enhances my effectiveness on the job" has a mean of 3.80 (SD 0.89, n=49), "Using Twitter makes it easier to expand to my networking opportunities" has a mean of 4.57 (SD 0.74, n=49), and "I find Twitter useful for professional development" has a mean of 4.43 (SD 0.76, n=49; Table 2, modified from Davis [11]). Overall, results show that public health professionals find Twitter the most useful and easiest to use for networking and professional development over job performance, productivity, and effectiveness.

Table 1. Demographics of survey respondents.

Characteristics	Frequency, n (%)
Gender (n=49)	
Female	25 (51)
Male	23 (47)
Unspecified	1 (2)
Age in years (n=49)	
18-24	2 (4)
25-34	22 (45)
35-44	12 (24)
45-54	8 (16)
55-64	5 (10)
Location (n=46)	
United States	27 (59)
Outside United States	19 (41)
Years worked in public health (n=49)	
0-4	18 (37)
5-9	10 (20)
More than 10	21 (43)
Education level (n=48)	
Some college	1 (2)
Bachelor's degree	8 (17)
Master's degree	25 (52)
Professional degree	5 (10)
Doctorate degree	9 (19)

Table 2. Usefulness and ease of use of Twitter on a 5-point Likert scale.

Survey questions	Mean	Variance	Standard deviation	Total responses, n
Using Twitter improves my job performance	3.80	0.67	0.82	49
Using Twitter increased my productivity	3.35	0.73	0.86	49
Using Twitter enhances my effectiveness on the job	3.80	0.79	0.89	49
Using Twitter makes it easier to expand my networking opportunities	4.57	0.54	0.74	49
I find Twitter useful for professional development	4.43	0.58	0.76	49

Open-Response Questions

Qualitative inquires comprised the last 5 items on the electronic survey. Common across sections emerged from the data, resulting in 4 major themes: (1) geography, (2) continuing education, (3) professional gain, and (4) communication.

Geography

A significant number of free responses emphasized the absence of locational factors that would otherwise present limitations in meeting other professionals and colleagues, as is evident from the following responses:

> *Twitter has enabled me to connect to colleagues across all professions and geography. That would not have been possible without the use of Twitter.* [Respondent #8]

> *I have had conversations with people all across the world who I would normally have no opportunity to meet. This has been everyone from prominent professors, presidents of royal colleges, journalists, to patient advocates and medical students. Notably, I have met quite a few of these people at conferences, after meeting them electronically; it always smooths the introduction for a face to face meeting.* [Respondent #23]

> *I've reached out to and/or interacted with professionals who I wouldn't have known about or have been able to contact otherwise.* [Respondent #9]

Through the elimination of traditional barriers to travel and location, the use of Twitter allows for outreach and network building to be carried out more efficiently than conventional means. This inclusion of networked professionals outside the original user's geographical area also increases diversity of ideas and experiences shared.

Continuing Education

The majority of public health professionals are required to have formal continuing education units (CEUs) to ensure that they are up to date with current practices in their field. The following open responses show that public health professionals engage in an informal type of CEU when engaging with other public professionals:

> *It is interesting to see their perspective on different issues and it challenges me to look at things from a different angle, with lenses that I may not have. It has certainly challenged my perspective on a number of issues.* [Respondent #18]

> *To keep up to date with recent developments. Get an impression of the broader public/Twitter users' feeling on issues.* [Respondent #26]

> *It provides learning opportunities in terms of expanding my ideas, knowledge and perspectives by reading others' ideas.* [Respondent #39]

This type of informal CEU is important to ensure that public health professionals are staying up to date on the latest news and research in the field, especially in a time with diminishing funding for formal CEU.

Professional Gain

A large part of professional development is networking to make connections and strengthening one's profile as a public health professional. More and more professionals are blogging, using coordinated efforts on sites such as LinkedIn, YouTube, Pinterest, and so on, to create their own brand as an expert in a specific field or topic. The following open responses show that individuals specifically use Twitter as a way to increase their career profile:

> *I originally started using Twitter in 2010 to promote my blog, Pop Health. Twitter led to many great connections and opportunities (eg, being asked to guest blog on other public health sites).* [Respondent #4]

> *Learning, networking, sharing knowledge, and gaining a bigger profile in the PH (Public Health) community.* [Respondent #15]

Twitter provides a unique platform for public health professionals to put themselves, and their work, out into a large portion of the public health community all at once, while also quantifying their reach through followers and analytics. This use of Twitter circumvents traditional methods of professional gain often occurring at conferences, other professional gatherings, and through formal writing.

Communication

Another significant aspect of professional development is communication, which allows public health professionals to exchange ideas and to collaborate efficiently among the various fields in public health.

> *However, Twitter allows me to converse with colleagues all day. We discuss current events, professional development opportunities, and I often ask my followers for specific resources/references relevant to a paper or project I am working on. I get lots of responses.* [Respondent #25]

> *Twitter has made it easier to tune into conversations taking place near and far and discover individuals and organizations with similar interests. Twitter has made my tasks easier by making these interactions possible and accessible in a public forum.* [Respondent #19]

Open responses show Twitter is being used to communicate ideas and collaborate while eliminating time and response barriers usually experienced through email and other forms of communication. More specifically, as seen in these examples, many public health professionals are using Twitter as a means for conducting informal research and crowdsourcing ideas for work or branding. Furthermore, Twitter not only allows users to search for those working in similar subfields, it also allows them to follow whoever they want, thus allowing for a custom interdisciplinary approach to their feed and connections.

Discussion

Principal Findings

Along with being a social media outlet to connect to peers, Twitter has become a digital platform for public health professionals to enhance their professional development in a time of continual budget cuts and lack of funding. Whereas many public health workers are still receiving formal professional development to satisfy continuing education credits or certification needs, budget cuts have often resulted in lower staffing, which does not allow for as much informal learning that used to occur more naturally among colleagues in a work location. Twitter specifically eliminates geographical and locational boundaries; it provides informal continuing education, opportunities for growing career profiles, and a space to converse and collaborate with other public health professionals, often by connecting those in the same field or in other subspecialties of public health through avatar biographies and hashtags. Furthermore, Twitter is often an integral information conduit for many followers, as new notifications are often alerted to them through their electronic devices in real time.

A consistent use of the words “connect” and “connected” was found in the open-response section of the survey. Users also characterize the sharing of information in an outward direction, with many respondents discussing building their “brand,” blogs, websites, and so on, as well as an inward direction, where it is obvious that many of these public health workers are using Twitter as a major source of obtaining news and current events, often to gain different perspectives. One respondent’s claim of seeking “Twitter users’ feelings on issues” shows that users are not only seeking information and current events through the SNS but also allowing the collective voice help shape how they feel about certain issues. The real-time global expanse of Twitter also appeals to many in public health as they seek the perspective of witnessing a potential health crisis in real time from those “on the ground.” To see an edited news package on, perhaps, an Ebola outbreak is different than reading how people are dealing with the issue in the moment, at the center of the outbreak. Public health workers often compromise our first line of defense for a health emergency; therefore, using Twitter allows workers to see a health crisis from a new perspective. Twitter can provide a timeline of an event and allows users to read the collective voice of the response, often providing opportunities for learning what the most critical issues are and observing how those present there are trying to coordinate services.

Through the elimination of traditional boundaries, Twitter encourages public health professionals to be more creative in their work and research, as they can receive instant feedback and new ideas from public health professionals around the globe through informal interdisciplinary teamwork. Interdisciplinary teamwork among public health professionals could promote better health outcomes and more successful behavior change interventions as interdisciplinary teamwork in medicine has been shown to improve overall health outcomes and patient quality of care [15]. This study reflects the specific areas in which public health workers are using Twitter and how it can have value for their work and professional development. This work, however, is often done in their free time, or on their personal devices, as many local health departments and organizations block SNS through their Internet filters. This study should further the discussion on the value of removing these blocks to allow public health professionals to truly connect and collaborate with others working in the field of public health, or even those in the community they serve.

Limitations

This study’s sample comprised active Twitter users, making it likelier that their feedback would overall be more positive. The aim, however, focused on how Twitter could potentially be beneficial for public health professionals, and an engaged group of users was critical in acquiring this information. The second limitation was the small sample size. Although only 49 of the 200 participants were recruited, this study was exploratory and did not seek to discover trends emerging among all public health professionals. The small sample size limits our study’s generalizability. Looking at the research of how public health organizations are using Twitter, however, parallels how individual public health professional use Twitter, making findings more generalizable.

Conclusions

Overall, Twitter provides a unique platform for professional development, enhancing the work and research being conducted in the field. This study shows how public health professionals self-reported the potential benefits of using Twitter, whereas future research can focus on content analysis of how they are actually using the tool.

Conflicts of Interest

None declared.

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Abbreviations

APHA: American Public Health Association
CEU: continuing education units
MPH: Master's in Public Health
SD: standard deviation
SNS: social networking site
SPSS: Statistical Package for the Social Sciences

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Viewpoint

Vulnerable Youth as Prosumers in HIV Prevention: Studies Using Participatory Action Research

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Abstract

Background: Stigma, voicelessness, and legislative and rights barriers, coupled with top-down decision making, are the common experiences of vulnerable youth populations that limit their opportunities to participate in vital health promotion efforts such as HIV prevention.

Objective: To consider new opportunities arising from a digital society for youth to creatively shape HIV prevention.

Methods: Drawing on research with vulnerable youth in Busoga, Uganda; Bulawayo, Zimbabwe; Bangkok, Thailand; and Bali, Indonesia, we explore current youth participation, in theory and practice, while considering new opportunities arising from a digital society for youth to creatively shape HIV prevention.

Results: Collaborative commons and prosumer models are defined as people employing new technology to codesign toward a common goal. Within the context of a diminishing role of the traditional institution and the rise of digitized networks, such models offer exciting new directions for youth as electronic health promotion prosumers to participate in difficult challenges such as HIV prevention in the 21st century.

Conclusions: It is time for institutions to embrace such opportunities, especially in areas where access to technology is widening, while continuing to champion youth and advocate for supportive social environments.

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KEYWORDS

community participation; social environments

Introduction

The HIV prevention agenda remains a vital health promotion challenge across the globe in the 21st century. A major focus of HIV prevention is to address the needs of key and vulnerable populations, which include youth who live in a context of inequity, poverty, stigma, and lack of rights. Participation of such youth populations in HIV prevention programs is considered essential to maximize positive outcomes. However, multiple vulnerabilities pose a challenge in meeting such outcomes and create barriers to participation in HIV prevention programs [1].

Community participation in health has been of significance for decades. From Arnstein's urban citizenry model [2] to community-based primary health care [3,4], the focus has largely centered on decision makers consulting communities in recognition of the value of their knowledge and the need for buy-in from communities to ensure effective health programs. In the 1990s, "new public management" was influential with governments and donors [5]. With an emphasis on *consumer participation* within a managerialist and accountable public service, statutory entities incorporated community representatives. These, however, are primarily institution-led models.

Alternatively, *activist participation* is about communities self-mobilizing to take a lead on issues that affect them [2,4,6-8]. There are celebrated examples of this type of participation in HIV prevention. In Thailand, Service Workers in Group, a community of sex workers, mobilized the media and powerful forces against stigma, raised awareness, and attracted resources to support their needs in addressing HIV [9]. Treatment Action Campaign in South Africa has been effective in establishing an activist lobby by, and for, young women drawing the support of important allies such as the media and funders [10]. Thus, the major benefits of activist participation in HIV prevention are that the initiatives are likely to be more relevant to the target group, and they aim to tackle the social conditions of vulnerability that contribute to the risk of HIV. In the context of a fast-changing global digital society, new participation opportunities are opening up as a result of widening access to mobile phones and Internet technology [11,12]. Collaborative commons and prosumer models, defined as people employing technology to codesign toward a common goal, resonate with activist- or empowerment-type participation in that they are about people taking action independently of traditional institutions [13]. This in turn reflects the definitions of eHealth that refer to technology enabling empowerment of communities, partnership between communities and providers, and promotion of health equity [14,15].

However, institutions have often neglected the needs and views of vulnerable youth communities; instead, participation by adults and elites dominates [16]. In HIV prevention, notably in Africa, donors and governments have typically set agendas based on powerful interest groups (such as faith-based groups providing support for proabstinence messages) rather than the needs of populations [17,18]. Drawing on four cases of research from Africa and South East Asia, the aim of this paper is to discuss the possibilities for youth prosumerism as a participation mechanism in HIV prevention in the context of widening access to technology and enduring harmful social environments.

Methods

Studies of Participation, Vulnerable Youth and HIV Prevention

The studies, conducted between 2006 and 2015, took place in two sub-Saharan Africa locations in the context of generalized HIV epidemics and two locations in South East Asia in the context of epidemics concentrated in key populations. These studies are underpinned by a critical paradigm of social change and youth empowerment, mainly using participatory and action methodologies [19,20]. Such methodologies actively seek to position participants as coresearchers who shape the choice of study methods and help analyze data to develop research findings and recommendations. This was considered appropriate, given the need to make the voices of the youth heard. Ethics approval was provided by the University of Leeds for the Uganda study and the Auckland University of Technology Ethics Committee for the other three studies. Whereas only the Bali study explored the use of the Internet, all the studies focused on youth views of participation in HIV prevention; their voices contribute to the following discussion on technology-enabled participation.

Young Women of Busoga, Eastern Uganda: Their Lives and HIV Prevention

In this study, 15 young women of Busoga, aged between 15 and 19 years, used narrative tools—drawing, drama, and written stories—to depict their life experiences and views in relation to the challenges of HIV [21]. Straight Talk Foundation, a prominent Uganda HIV communication nongovernmental organization (NGO), initiated the research, as they were concerned about the voicelessness of young women in the space of programs, schools, and communities. Young women's voicelessness related to gender norms of dropping out of school because of early marriage and pregnancy, underpinned by appropriate behaviors of submissiveness and deference to authority. These young women were recipients of HIV prevention messages that did little to address the vulnerability and gender inequality contributing to their risk of HIV such as not being in a position to negotiate for safe sex. Yet, they expressed a desire for greater engagement and empowerment in all aspects of their lives. The study called for intensifying efforts to involve young women in HIV prevention. As a prerequisite, it stressed the need for a change in the gender environment. Recommendations included promotion of girl-friendly schools, more women teachers, symbols of equity and empowerment positioning young women differently, and involving allies such as media in the social change agenda.

Youth Perceptions of School-Based HIV Prevention Sex Education in Bulawayo, Zimbabwe

A participatory action research partnered with 8 women and 8 men aged between 18 and 24 years from Bulawayo [20]. Young coresearchers participated in 10 action-oriented focus groups to explore their personal experiences of HIV prevention sex education and design a perfect lesson. The coresearchers depicted autocratic and nonparticipatory models of HIV prevention sex education in school based on standardized proabstinence curricula. Young people noted a lack of openness and opportunity for discussion and dialogue, especially exploring themes of sexual relations. Youth aspired to different styles of HIV prevention sex education characterized by an ability to voice their queries and concerns openly, even where these are taboo subjects. The study showed the potential of youth for creativity and enthusiasm as designers of HIV prevention sex education lessons. Recommendations centered on the need for change in the educational environment of schools, along with the need to be more student driven, and to support creative and relational HIV prevention sex education.

Young Women Sex Workers and Participation in HIV Programs in Bangkok, Thailand

Using semistructured interviews, this study explored the participation views and strategies of 5 young women sex workers and 2 community support workers from Bangkok [22]. Barriers to participation included the illegality of sex work, fear of authorities, and widespread social stigma. In the context of significant vulnerabilities faced by young women sex workers, they valued their involvement in peer education and were

supportive of greater involvement in HIV programs. Participants expressed a need for such involvement to be safe and private, as they feared exposure to families and authorities. Recommendations were for a more comprehensive empowerment approach to participation by young women sex workers by positioning young women as more than experts and peer educators, taking into consideration their need for safety as leaders and codecision makers within accountable programs. As with the other studies presented here, the social environment that creates the conditions of vulnerability and risk was highlighted as an area for urgent attention.

Young Men Who Have Sex With Men and Internet-Based HIV Prevention in Bali, Indonesia

Participatory action research was used for a study that partnered with 9 young men who have sex with men (YMSM) living and working in Bali [23]. YMSM used mobile phones and the Internet to a great extent in their lives for friendship and social and sexual relationships. Thus, the research aimed to create a space for YMSM to explore and develop ideas for Internet-based HIV prevention. The research comprised a series of eight action-oriented focus group discussions, moving from scoping to design using mapping and video. YMSM described the need to feel safe, yet they feared stigma and physical violence from the community. They wished to be able to express and share their identity but recognized that this had to be done in private Web-based spaces. Current HIV prevention messages had little relevance or relationship to their sense of self, and therefore they tended to ignore them. Recommendations included an Internet-based HIV prevention more relevant to YMSM, shaped by them in terms of design and delivery, with a clear need to address a social environment characterized by the lack of sexual rights, stigma, and discrimination.

Results

Three common themes relevant to this paper emerged from these studies. First, all the studies found that youth aspired to have a say in HIV prevention through creative and empowering ways relevant to their lives. For example, in Zimbabwe, youth designed lively interactive lessons tackling difficult and forbidden subjects of sexual relations. In Bali, YMSM designed 2 videos for Web-based viewing, promoting condom use using forthright, taboo-based language and ideas that had personal meaning. In Uganda and Thailand, young women aspired to greater empowerment and safety in relation to their sexual health and lives. This reflects findings from similar studies within technology-enabled settings, where youth favored the use of computers and being involved in design of content specifically for them. However, they also qualified this with concerns about the role of adults and issues of privacy and safety [24-26].

Second, the studies showed that there are significant institution-related barriers to youth involvement. HIV prevention initiatives were found to be didactically delivered, with standardized designs and mass media developed and delivered with little or no participation from youth. HIV prevention largely lacked relevance for youth, as it did not reflect their lives, identities, or preferences. In Zimbabwean and Ugandan schools, youth described being recipients of standardized curricula within overcrowded classes. Experiencing poorly trained and overburdened teachers meant that there was a lack of safe and appropriate spaces for openly discussing sexuality. In Bali, older MSM were shown to be involved in NGO-led HIV prevention but not the young. Third, besides nonparticipatory institutional practices, harmful social environments were key to the vulnerability of youth in relation to HIV, as observed in Uganda, Thailand, and Bali, where issues of significant inequality and stigma surround gender, youth, and sexual identity. In Thailand, young women sex workers entering sex work at a young age were particularly vulnerable, being subject to multiple vulnerabilities, including poverty, low levels of education, and gender inequality. In relation to their occupation and HIV risk, they face dangers as a result of the illegality of sex work; trafficking for sex work; and violence, stigma, drug use, and unsafe workplaces are common experiences [27-29]. In Bali, YMSM are increasingly vulnerable as attitudes toward gay men harden. Social environments, which create many of the conditions of vulnerability, limit opportunities for participation, including the ones which might involve technology. There was little evidence from the studies of institutions suggesting their role as contributors to change in the social environment.

Discussion

Ways Forward for Participation by Youth in HIV Prevention in a Digital Society

Toffler first coined the term “prosumer” to reflect the blurring of lines between the consumer and producer [30]. In the 21st century, growing access to the mobile phone-Internet nexus across the globe opens up opportunities both functionally and creatively for participation by youth as prosumers in HIV prevention. The studies presented here are from areas where youth face challenges in the social environment, with two studies being from locations with limited access to technology. These provided indications of youth aspirations and creativity as collaborators, designers, and advocates sharing their ideas and preferences with others. Studies from other settings have shown that new technologies can enable such youth prosumerism [31,32].

Access to mobile phones and the Internet is still limited, in terms of infrastructure and cost, including in much of Africa [33]. This is set to change, with the opening up of opportunities to use technology in that region. Overburdened African schools, a focus of the studies in Uganda and Zimbabwe, have the potential to take advantage of this significant change [34]. In the context of large class sizes and overburdened teachers, increased access to affordable mobile phones or tablets, could have an impact for students with new ways of technology-enabled sexuality education, using innovations such as serious games and empowerment-based storytelling [32,35] or other fun and collaborative tools sharing ideas and opinions in the space of school. However, students will increasingly be able to access information on sexuality education and networks outside of school. They will be in a strong position to choose content, dismiss what they do not like, or even create their own content. Instead of standard messages, they will be able to access diverse information relating to sexual and social relationships

and share or reproduce these using their own style of communication as observed in the studies presented above. Thus, in the context of these changes, HIV prevention programs and institutions must seek alternative roles and ways of partnering with youth to harness creativity in these new styles of programs and initiatives.

Furthermore, technology also offers the potential to go beyond codesign and information sharing to the youth utilizing the Internet to develop their own initiatives, including advocacy and entrepreneurship for HIV prevention. Service Workers in Group and Treatment Action Campaign, both initiated for and by young women from Thailand and South Africa, respectively, relied on the availability of social media and the Internet for their HIV prevention campaigns [36]. Yet, schools and other institutions will still have an important role to play in supporting young people by creating opportunities for digital literacy; creating spaces to discuss challenging issues; sharing opinions in a safe environment; and advocating for the rights of young people, including those relating to gender and sexuality.

In the studies from South East Asia, the issue is less that of poor access to the Internet. The Bali study certainly showed that youth were comfortable and avid users of the Internet. In both the Bali and Thailand studies, the major barrier to extending participation was a lack of safety indeed, with youth experiencing multiple vulnerabilities, including stigma, illegality, and violence. In such cases, the challenge is how to empower and involve youth but without exposing them to harm and while providing strategies to challenge harmful norms. For these reasons, privacy, safety and anonymous collaboration through private Internet-based networks will be important in future, given the sensitive nature of the subject of sex and sexuality and the significant stigma existing in many contexts [37]. YMSM in Bali mentioned the importance of this function; they referred to private Web-based networks as a means of making HIV prevention attractive to them. Similarly, young women sex workers of Bangkok expressed the need for private means of communication and sharing. Flexible spaces and funding for youth-driven HIV prevention would be valued, moving away from standard messages to those which are more specific to the diverse youth contexts, thereby offering greater scope for privacy and being less bounded by institutional agendas. In a fast-changing society, institutions could take advantage of new opportunities to become the early adopters of empowerment-type prosumer models [38,39]. Institutions, given their resources and power, continue to have a strategic role to play in making this happen. Policy makers and practitioners are encouraged to rise to the challenge by taking more risks and by being more visionary and less concerned with the status quo.

Conclusions

There is a need for a continuing and strong participation agenda with regard to HIV prevention by supporting condom use and normalizing and integrating HIV into health systems as part of wider changes in attitudes toward sexual rights [40]. Yet, as highlighted in this study, barriers to such attitudinal changes exist in social environments around the world. This paper explored the possibilities offered by widening access to technology for vulnerable youth to participate in HIV prevention as prosumers, that is, as being active in seeking empowerment and change; as codesigners of educational tools; and as collaborators and networkers sharing stories and views. These go beyond the consumer and consultation models of participation typically found journeying into new and exciting spaces.

From a weakening of the traditional role of HIV prevention institution and the rise of digitized collaborations, information flow is no longer dependent on the program and service. Future participation is likely to embrace different paradigms and language, thereby facilitating the emergence of different actions and actors; innovation and creativity will become as important as information, which is readily accessed. Further research is necessary in this growing field, especially relating to codesign and empowerment approaches creating new spaces to prototype vulnerable youth-driven HIV prevention but at the same time, contributing to social change.

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Abbreviations

YMSM: young men who have sex with men

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Original Paper

Evaluation of Sampling Recommendations From the Influenza Virologic Surveillance Right Size Roadmap for Idaho

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Abstract

Background: The Right Size Roadmap was developed by the Association of Public Health Laboratories and the Centers for Disease Control and Prevention to improve influenza virologic surveillance efficiency. Guidelines were provided to state health departments regarding representativeness and statistical estimates of specimen numbers needed for seasonal influenza situational awareness, rare or novel influenza virus detection, and rare or novel influenza virus investigation.

Objective: The aim of this study was to compare Roadmap sampling recommendations with Idaho's influenza virologic surveillance to determine implementation feasibility.

Methods: We calculated the proportion of medically attended influenza-like illness (MA-ILI) from Idaho's influenza-like illness surveillance among outpatients during October 2008 to May 2014, applied data to Roadmap-provided sample size calculators, and compared calculations with actual numbers of specimens tested for influenza by the Idaho Bureau of Laboratories (IBL). We assessed representativeness among patients' tested specimens to census estimates by age, sex, and health district residence.

Results: Among outpatients surveilled, Idaho's mean annual proportion of MA-ILI was 2.30% (20,834/905,818) during a 5-year period. Thus, according to Roadmap recommendations, Idaho needs to collect 128 specimens from MA-ILI patients/week for situational awareness, 1496 influenza-positive specimens/week for detection of a rare or novel influenza virus at 0.2% prevalence, and after detection, 478 specimens/week to confirm true prevalence is ≤2% of influenza-positive samples. The mean number of respiratory specimens Idaho tested for influenza/week, excluding the 2009-2010 influenza season, ranged from 6 to 24. Various influenza virus types and subtypes were collected and specimen submission sources were representative in terms of geographic distribution, patient age range and sex, and disease severity.

Conclusions: Insufficient numbers of respiratory specimens are submitted to IBL for influenza laboratory testing. Increased specimen submission would facilitate meeting Roadmap sample size recommendations.

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KEYWORDS

influenza; sample size; public health surveillance

Introduction

Influenza illness in the United States produces a significant burden in terms of morbidity, mortality, and economic influence. An average of >200,000 influenza-associated hospitalizations and >23,600 influenza-associated deaths with underlying respiratory and circulatory causes have been estimated to occur in the United States annually [1,2]. The total economic burden

of annual influenza epidemics by using projected statistical life values has been estimated at US $87.1 billion [3]. Whereas hospitalization costs are important contributors, lost productivity from missed work and lost lives comprise the bulk of the economic burden. During October 2008 to May 2014 in Idaho, according to Influenza-like Illness National Surveillance Network (ILINet), the mean annual proportion of outpatient visits for influenza-like illness (ILI) was 20,834 (2.3%) out of 905,818 total outpatient visits. ILINet is a national network maintained by the Centers for Disease Control and Prevention (CDC) that consists of more than 2800 enrolled outpatient health care providers reporting patient visits due to ILI. The Idaho Division of Public Health (DPH), Bureau of Vital Records and Health Statistics reports that 103 influenza and influenza-related deaths occurred in Idaho during this period.

National influenza virologic surveillance is conducted by 60 National Respiratory and Enteric Virus Surveillance System (NREVSS) laboratories and approximately 85 US World Health Organization (WHO) collaborating laboratories located throughout the United States [4]. The DPH Idaho Bureau of Laboratories (IBL) participates as a US WHO collaborating laboratory. IBL conducts influenza virologic surveillance to identify circulating strains, identify antiviral resistance, and detect novel strains in Idaho. Novel influenza is reportable in Idaho, but seasonal influenza is not reportable except during outbreak settings, therefore specimen submission in support of seasonal surveillance is voluntary and is based on convenience sampling. IBL engages ILINet sites and other health care providers and laboratories around the state, including hospital laboratories, to voluntarily submit respiratory specimens from those with medically attended ILI (MA-ILI), prescreened for influenza or not, for reverse-transcription polymerase chain reaction testing for influenza A and B, and subtypes AH1, AH1N1, AH3, and AH5. Isolates, including untypeable isolates, are sent to the CDC for genotyping. Specimen collection is year-round; however, solicitation efforts are heightened during influenza season, which runs from *Morbidity and Mortality Weekly Report* (*MMWR*) epidemiologic week 40 through *MMWR* epidemiologic week 20, typically from the beginning of October through mid-May.

During 2013, the Association of Public Health Laboratories and CDC developed the Influenza Virologic Surveillance Right Size Roadmap (Roadmap) [5]. The Roadmap is a resource to assist state health departments in optimizing virologic surveillance system by helping to identify the number of specimens to be tested to ensure ample confidence in influenza surveillance and detection of novel viruses. Sampling recommendations are included with the Roadmap for improved influenza virologic surveillance. Sample size calculators [6] were developed to systematically establish virologic sample size goals on the basis of minimum detection thresholds and acceptable confidence levels for 3 different surveillance objectives as follows: (1) situational awareness—to determine the beginning and end of the influenza season and monitor the prevalence and spread of influenza viruses throughout the year; (2) rare or novel influenza event detection—to detect a rare or novel influenza virus among influenza-positive specimens tested in the United States at a low enough threshold for effective intervention and control measures; and (3) rare or novel influenza event investigation—to determine the prevalence of the rare or novel influenza virus and confirm it does not exceed a specific percent positivity, within a state (eg, Idaho) after the initial detection of a rare or novel influenza virus. Components of the sampling recommendations include using "a statistical, systematic approach to collect an appropriate, adequate number of specimens" representative of virus type and subtype, entire year, geographic and age diversity of the population, and influenza disease severity [5]. Moreover, the Roadmap recommends ensuring a timely information flow, through the 5 tiers of influenza virus surveillance from point-of-care settings to CDC's laboratories. We compared the Roadmap sampling recommendations with Idaho's influenza virologic surveillance to determine implementation feasibility. That is, the comparison was made to see whether any gaps between them might help determine whether it would be feasible for Idaho's influenza virologic surveillance to meet the recommended sampling goals.

Methods

We included the previous 5 years' worth of available data to capture any unusual fluctuations in sample collection, as shown in 2009-2010 due to the H1N1 pandemic. Additionally, 5 years of data allow for the possibility of noting sample collection trends. We calculated MA-ILI proportion by using data from Idaho's outpatient ILI surveillance during October 2008 to May 2014. Data regarding outpatient visits for ILI were collected through CDC's ILINet, which defines ILI as fever (≥100°F) and a cough or sore throat without a known cause other than influenza. Eleven health care sites from Idaho participated in this surveillance by providing weekly the total number of patients who sought outpatient care specifically for ILI and the number of patients treated for any reason. We used the latest available estimates from the US Census Bureau for Idaho [7] to determine population age and sex distribution in the state. We obtained the total number of respiratory specimens tested for influenza at IBL during October 2008 to May 2014 from the influenza virologic surveillance system in Idaho.

We used the calculated proportion of baseline MA-ILI and the preestablished estimated Idaho population size as a starting point in the 3 Roadmap sample size calculators, and compared these calculations with actual numbers of specimens tested for influenza by IBL. We assessed representativeness of the tested specimens in terms of submission month and year, virus type and subtype, patient's county of residence and health district, patient age and sex, and patient hospitalization status. We compared the proportion of females and the proportion of patients aged <5 years or >65 years among tested specimens with the proportion of females and the proportion of persons aged <5 years or >65 years from Idaho residents, respectively. We assessed flow of specimens in terms of timeliness and determined whether they were prescreened at the health care-provider level before submission. Calculations were done by using Microsoft Excel 2010 (Microsoft Corporation, Redmond, Washington).

This study underwent CDC human subjects review and was deemed not to involve human subject research.

Results

According to ILINet, the mean baseline annual proportion of MA-ILI in Idaho during October 2008 to May 2014 was 2.3%. At this proportion, for influenza situational awareness in Idaho, IBL would need test results for 128 specimens from MA-ILI patients/week to determine that the prevalence of influenza-positive specimens is 10% (considered the start of the influenza season; seasonal baseline setting recommended by the Roadmap, page 58) at a 95% confidence level and 5% error rate (situational awareness setting recommended by the Roadmap, page 52) (Table 1) [5]. At the peak of influenza seasons, based on an annual proportion of MA-ILI of 5%, IBL would need to test results for 297 specimens from MA-ILI patients/week to determine that the prevalence of influenza-positive specimens is 30% at a 95% confidence level and 5% error rate. For rare or novel influenza event detection, IBL would need test results from 1496 influenza-positive specimens/week to allow the Idaho surveillance system to detect a rare or novel influenza virus at 0.2% prevalence at a 95% confidence level (Table 1). For rare or novel influenza event investigation after a rare or novel influenza virus is detected, IBL would need test results from 478 MA-ILI specimens/week to confirm that the true prevalence does not exceed 2% of influenza-positive within the state at a 95% confidence level (Table 1). If surveillance is done at the national rather than state level, the minimum number of influenza-positive specimens that Idaho would need to meet the second 2 surveillance objectives decreases from 1496 to 8 for detection of a rare or novel influenza event nationally at a 0.2% threshold, and from 478 to 3 for a 95% confidence level that the actual national prevalence of the novel virus does not exceed 2% of the influenza-positive specimens (Table 1).

During October 2008 to May 2014, 4984 respiratory specimens were tested for influenza at IBL. In 5 of 6 influenza seasons included in the study period, the pattern of specimen submission coincided with typical influenza seasons; during the 2009-2010 influenza A (H1N1) pandemic there was an uncharacteristic increase in specimen submission (Figure 1). The average number of respiratory specimens tested for influenza/week, excluding the 2009-2010 influenza season, ranged from 6 to 24 (Table 2). During the 2009-2010 pandemic influenza season, this increased to 47 samples/week.

IBL received specimens during 64 (94%) of 68 months evaluated; however, during 31 (46%) months, ≤10 samples were submitted. Sample test results represented nationally circulating virus types and subtypes, including influenza A (H1 and H3) and influenza B. Specimen submission sources were geographically diverse, with 37 of 44 counties of residence and all 7 public health districts *represented*. Patient age ranged from 1 to 101 years. Persons aged <5 years or >65 years comprised 21.5% of the state population [7], and 23.9% of patients from whom specimens were submitted. Females comprised 49.9% of the Idaho population according to the 2015 US Census Bureau estimates [7], and 53.5% of patients from whom specimens were submitted. Hospitalization status of patients was used to assess representativeness regarding disease severity and was available for 89.2% of specimens: 47.9% and 41.3% of tested specimens came from hospitalized and nonhospitalized patients, respectively.

Table 1. Recommended number per week of respiratory specimens to be tested for influenza per Roadmap surveillance objective in Idaho.

Objective	Number of recommended specimens to sample per week
Objective 1[a]	128
Objective 2[b]	1496 (8 if National surveillance)
Objective 3[c]	478 (3 if National surveillance)

[a]To determine that the prevalence of influenza-positive specimens is 10% at a 95% confidence level and 5% error rate.

[b]To allow the Idaho surveillance system to detect a rare or novel influenza virus at 0.2% prevalence at a 95% confidence level.

[c]To confirm that the true prevalence does not exceed 2% of influenza-positive within the state at a 95% confidence level.

Figure 1. Number of influenza specimens tested at Idaho Bureau of Laboratories by month, October 2008 to May 2014 (N=4984). Shading denotes months outside of traditional influenza seasons. Seasonal influenza activity is illustrated by the sinusoidal shape of the bar graph.

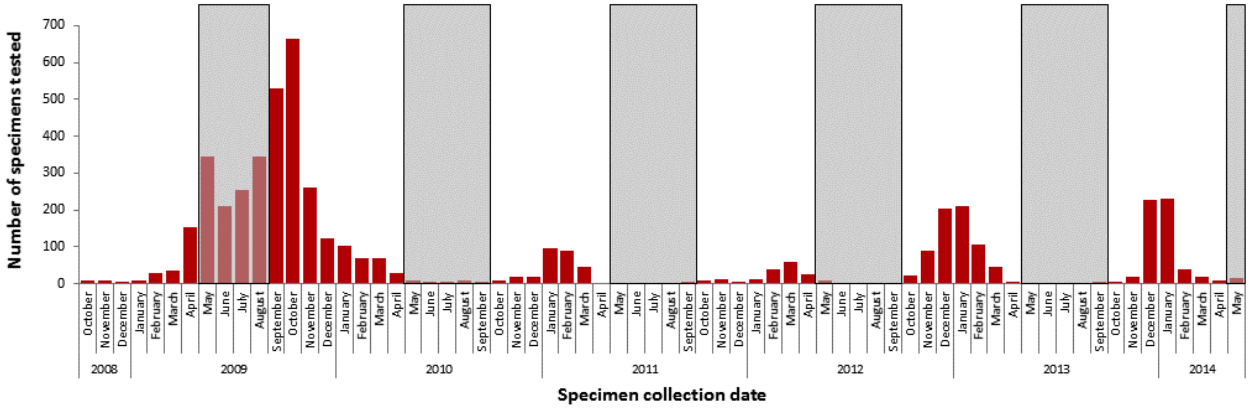

Table 2. Total number and average per week of respiratory specimens tested for influenza per influenza season at the Idaho Bureau of Laboratories, by influenza season in Idaho, 2008-2014.

Year of influenza season (October 1 to May 1)	2008-2009	2009-2010	2010-2011	2011-2012	2012-2013	2013-2014
Total number of specimens tested	243	1317	278	160	677	545
Average number of specimens/week	9	47	10	6	24	20

The flow of respiratory specimens seemed timely. CDC recommends that influenza specimens should be submitted as they are collected and not batched, and be tested within 72 hours of collection for optimal virus recovery [8,9]. IBL received specimens an average of 2.4 days after collection, tested 80.6% within the first week postreceipt, and uploaded results into the Laboratory Information Managing System immediately. Test result summaries were sent to CDC weekly. Approximately 97% of respiratory specimens were prescreened for influenza at the health care-provider level before IBL submission, with the majority (85.8%) being influenza rapid test-positive.

Discussion

Although Idaho's virologic surveillance system fails to meet all Roadmap sampling recommendations for chosen parameters used in this study, DPH has the ability to meet the sample size recommendation for situational awareness if it were able to supplement data from IBL, a public health laboratory, with virologic surveillance data from other sources, such as clinical or commercial laboratories, including participating Idaho NREVSS sites or other points of care in Idaho as recommended by the Roadmap to supplement (Roadmap, page 78). Additionally, IBL alone would be able to meet sample size recommendations if testing specimens received in formats other than in viral transport media were approved for diagnostic use. CDC's interim guidance on testing, collecting, and processing specimens for influenza surveillance indicates that the preferred respiratory specimens for submission should be placed into sterile viral transport media and immediately placed on refrigerant gel-packs or at 4°C for transport [8,9]. Unfortunately, submission of leftover clinical samples such as those from a rapid test done at a clinical setting is not approved or recommended as an optimal specimen for diagnostic testing. However, there is evidence that influenza infection cannot be ruled out by negative rapid test results due to potential low sensitivity of the diagnostic test; researchers have successfully been able to quantify influenza viral loads from false-negative viral suspensions left over from influenza rapid tests [10]. For that reason, we envisaged this specimen type as a suitable alternative for virologic influenza surveillance testing and suggest it as one way to augment sample submission numbers. Moreover, if surveillance is done at the national rather than state level, number of specimens recommended by the Roadmap to be tested from Idaho for both detection and investigation of a rare or novel influenza event decreases substantially. However, system sensitivity to detect and investigate a rare or novel influenza event at the national level relies on the contribution of all states to submit proportionate numbers of specimens and data to their population size.

Roadmap calculators are subjected to arbitrarily chosen parameters, including influenza positivity, confidence levels, error rates, and detection thresholds. This flexibility allows states to adjust their target number of influenza virologic specimens to be tested to the realities of sample collection and time frame during the influenza season or outbreak. While selecting higher margins of error allows for a wider tolerance for error in sampling recommendations, in a practical situation, a surveillance system might find that meeting such relaxed sampling sizes could result in miscalculating the start of influenza season or the detection of a rare or novel influenza event. Convenient, precalculated tables for situational awareness and for rare or novel influenza event detection are available in the Roadmap Appendix B for quick reference, and offer the user a range of arbitrarily chosen parameters to determine the variability of recommended target sample sizes based on a few different population sizes. Using the Roadmap calculators with user-specified inputs provides an increased precision and allows the user to understand the weight of each parameter by visually noting the effect of altering each during calculations. Calculators also allow the user to work backwards by inputting actual sample sizes obtained by their state and determining confidence levels regarding the true influenza prevalence in their state. No precalculated tables for rare or novel influenza event investigation are available.

During October 2008 to May 2014 in Idaho, respiratory specimens collected were representative in terms of virus type and subtype (eg, influenza A [H1 and H3] and influenza B), time (eg, 94% of the 68 months evaluated), geography (eg, all of Idaho's public health districts, including 37/44 Idaho counties), age diversity of the population (eg, 1-101 years), and influenza disease severity, measured by hospitalization status (eg, 47.9% hospitalized versus 41.3% nonhospitalized). Respiratory specimens were also processed within a timely manner, ensuring a timely flow from the patient level to the CDC level of virologic surveillance. A substantial portion of specimens submitted to IBL were initially screened positive with a rapid test for influenza by submitters, likely altering the positivity rate and biasing prevalence calculations upward. Although realistically difficult to do under a resource-limited, voluntary submission system, submitters should be encouraged to submit specimens from both influenza-positive and -negative tests when possible.

During October 2008 to May 2014, the number of respiratory samples submitted to IBL for influenza testing was below Roadmap recommendations. Implementing an incentive program to increase specimen submission might be beneficial. Additional incentives for further collaboration among health care entities and state public health laboratories would be helpful. Agreements with hospitals for sharing data from implemented multiplex respiratory panels that include influenza types and subtypes might be helpful in determining the proportion of

influenza-positive and influenza-negative specimens from the total tested, and in meeting Roadmap surveillance objectives.

States can benefit from using the Web-based sample size tools [6] provided in the Roadmap, because of the ease with which they can determine their capacity to attain situational awareness and detect and investigate the occurrence of a rare or novel influenza strain. Moreover, states can assess how their contributions add to the collaborative effort needed to perform national influenza virologic surveillance.

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Conflicts of Interest

None declared. The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.

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Abbreviations

CDC: Centers for Disease Control and Prevention
DPH: Division of Public Health
IBL: Idaho Bureau of Laboratories
ILI: influenza-like illness
ILINet: Influenza-like Illness National Surveillance Network
MA-ILI: medically attended influenza-like illness
MMWR: Morbidity and Mortality Weekly Report
NREVSS: National Respiratory and Enteric Virus Surveillance System
WHO: World Health Organization

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Original Paper

Effect of Viewing Smoking Scenes in Motion Pictures on Subsequent Smoking Desire in Audiences in South Korea

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Abstract

Background: In the modern era of heightened awareness of public health, smoking scenes in movies remain relatively free from public monitoring. The effect of smoking scenes in movies on the promotion of viewers' smoking desire remains unknown.

Objective: The study aimed to explore whether exposure of adolescent smokers to images of smoking in films could stimulate smoking behavior.

Methods: Data were derived from a national Web-based sample survey of 748 Korean high-school students. Participants aged 16-18 years were randomly assigned to watch three short video clips with or without smoking scenes. After adjusting covariates using propensity score matching, paired sample *t* test and logistic regression analyses compared the difference in smoking desire before and after exposure of participants to smoking scenes.

Results: For male adolescents, cigarette craving was significantly higher in those who watched movies with smoking scenes than in the control group who did not view smoking scenes ($t_{307.96}$=2.066, P<.05). In the experimental group, too, cigarette cravings of adolescents after viewing smoking scenes were significantly higher than they were before watching smoking scenes ($t_{161.00}$=2.867, P<.01). After adjusting for covariates, more impulsive adolescents, particularly males, had significantly higher cigarette cravings: adjusted odds ratio (aOR) 3.40 (95% CI 1.40-8.23). However, those who actively sought health information had considerably lower cigarette cravings than those who did not engage in information-seeking: aOR 0.08 (95% CI 0.01-0.88).

Conclusions: Smoking scenes in motion pictures may increase male adolescent smoking desire. Establishing a standard that restricts the frequency of smoking scenes in films and assigning a smoking-related screening grade to films is warranted.

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KEYWORDS

film; smoking; craving; South Korea

Introduction

Media exposure might detrimentally affect health behavior by influencing short- and long-term attitudes and beliefs [1]. In particular, movies can have a strong exposure effect. Smoking scenes that are included in the development of a plot can induce smoking behavior because they have a strong ripple effect [2-4]. Scenes of actors smoking in movies can contribute to the view that smoking is a positive, socially acceptable act [5].

Different theories have been proposed to explain how media exposure can alter health behavior. The cognitive priming theory proposes that particular stimuli provided by the media can activate related behavior in viewers [6]. The theory explains that the media can remind viewers of already acquired behavior. For example, if smokers see smoking scenes through the media,

they are likely to have a stronger desire to smoke. A second theory is the theory of social learning, which posits that social people can engage in vicarious learning after witnessing reinforcements acquired through a particular behavior [7]. Learning in adolescents occurs through the indirect experience of imitating others in their social environment and the direct experience of trial and error. Mass media exposure can be a source of imitative learning. For example, a movie in which an actor smokes and receives a positive reward can instill a smoking-positive memory in viewers, which can influence future real-life behavior. A third theory is the contextual effect theory. It states that individuals may perform a particular behavior because of social contexts, not because of a desire for the behavior [8]. In other words, a particular behavior may become socially normal when presented in the media [9]. As an example, if the media portray adolescent smoking as a quotidian phenomenon, viewers are likely to have a positive context for smoking. However, the specific effects of media exposure on adolescents have not been fully studied. In particular, sensation-seeking and information-seeking behaviors on adolescents' smoking desire as a result of media exposure are influential. Even if other conditions are equal, the desire to smoke in an adolescent who views smoking scenes in films can be stimulated or restrained significantly, depending on whether or not the person is a sensation seeker or a health-information seeker [10-12].

In 2008, the United States National Cancer Institute (NCI) reported a strong causal relationship between smoking scenes in movies and initiation of smoking by adolescents [5,13]. The Hollywood movie industry has spent millions of dollars to stage smoking scenes in movies [14]. A study on movies released in the United States from 2002-2010 chronicled that 80% of all R-rated movies and nearly 70% of all PG-13-rated movies featured smoking scenes [5,15]. Consequently, the NCI's warning has important implications. Smoking scenes are relatively free from public health monitoring even though movies are viewed worldwide. The fact that smoking scenes can promote viewers' smoking has not been widely disseminated [5,16,17].

In 2005, South Korea ratified the Framework Convention on Tobacco Control (FCTC) legislated by the World Health Organization (WHO) [18]. Article 13 of the FCTC recommends the inclusion of warning messages or labels in the advertisement, promotion, and support of tobacco products and restricts the use of incentives to encourage their purchase. Yet, active measures have not been instituted in South Korea. Movies rated for viewers 15 years of age or older frequently feature smoking scenes [19]. While viewing motion pictures is regarded as a popular leisure activity in contemporary culture, the presentation of smoking scenes in films and their effects on audiences have not been fully studied.

Using a large Web-based panel, we investigated whether exposure of adolescent smokers to images of smoking in movies could stimulate their smoking desire after adjusting for the factors related to smoking desire, which included their attitudes and beliefs regarding smoking, its health effects, and whether or not their parents indulged in smoking.

Methods

Sample

Data were derived from a survey of respondents drawn from a nationally representative Web-based sample of 748 Korean high school students (376 males and 372 females) who participated in the Hankook Research Master Sample Panel. Respondents were recruited using a dual sampling frame. A combination of random digit dial and address-based sampling allowed for the selection of a sample of individuals without using telephone land lines. Respondents received a nominal cash incentive (US $2.50) to participate when they completed both the baseline and post-movie surveys. The final response rate was 81.0%. Missing values of survey questions for key analytical variables were excluded using the pairwise method.

Study Design

The students (aged 16-18 years) were randomly assigned to watch three professionally edited short (40-120 seconds) video clips of representative popular Korean films with smoking scenes (exposure group, n=374) or without smoking scenes (non-exposure group, n=374). Before the participants started the Web-based survey, the statistician randomly assigned each of them to two different study groups (exposure/non-exposure), according to a table of computational random numbers. The random assignment was blocked by gender to distribute males and females equally in each group. The video clips were professionally edited versions of representative hit films from among 51 films that played in Korean cinemas from 2000-2013 [19]. We defined a hit film as a movie that had been viewed by at least 5 million people [19]. The participants watched the three video clips in a row by themselves while completing the Web-based survey. The participants were unable to skip watching certain videos. In the exposure group, all scenes presented contained images of smoking. Participants' desire to smoke was gauged immediately after viewing the clips. We examined whether smoking scenes in motion pictures could increase adolescents' smoking desire. We also examined whether adolescents' smoking desire could be promoted or restrained by predisposing conditions, such as sensation-seeking or health information-seeking behavior. After adjusting covariates using propensity score matching (PSM), we conducted a paired-sample *t* test to compare the smoking desire of respondents before and after viewing smoking scenes.

Measures

Survey questions were based on previous reports on the effects of social context, including mass media use and social capital, on health [17,19,20]. The questionnaire included topics adapted from the Health Information National Trends Survey of validated measures developed through a series of health communication studies in Korea [12,21]. Sensation-seeking behavior was defined as an individual's innate propensity to seek out novel, strong, and intricate experiences and feelings and to willingly take physical and socioeconomic risks to have such experiences and feelings [22,23]. Sensation-seeking is strongly associated with a variety of illegal and risky behaviors, such as smoking, among adolescents [24]. The Cronbach alpha

values of all individual subscales ranged from .60 to .87 in this study.

Dependent Variable

The dependent variable of cigarette craving was measured using two questions. This was the first question: "What is your current smoking desire on a scale of 0 to 100 score?" A 0-100 Likert scale was used to evaluate responses. This was the second question: "Do you wish to take a puff on a cigarette now?" Response options to the second question were "not at all" (including non-smokers), "somewhat," "considerably," and "very strongly." The first continuous question was used for *t* test analysis. The second nominal question was used for the logistic regression, with answers grouped into two categories as dependent variables by calculating the change in smoking desire before and after watching the smoking scenes using these two questions. Responses indicating an increase in smoking desire after watching the smoking scenes were coded 1 and decreased or no change in smoking desire after watching the smoking scenes was coded 0.

Independent Variable

We considered viewing smoking scenes in motion pictures as the baseline independent variable for the *t* test. For logistic regression, we used three independent variables (mass media, impulsivity, and information-seeking behavior) to identify related factors with difference in smoking desire before and after watching the movie clips. General mass media usage was assessed by querying how much time was estimated to have been spent each day in the prior 7 days watching television, searching for information with a smartphone, and reading news on the Internet using a personal computer. Responses ranged from 0 to ≥5 hours. Media usage was divided into four categories: ≤30 minutes, 30 minutes to 1 hour, 1-2 hours, and >2 hours (Cronbach alpha=.60). To assess the sensation-seeking behavior (ie, impulsivity) of the adolescent respondents, we used the validated and reliable Korean version of the Sensation Seeking Scale [25], which queried the responses to the following, with responses rated on a four-point Likert scale: (1) I want to try rock climbing, I want to try thrilling things even if they're scary, I want to try thrilling sports like water skiing and surfboarding, I want to jump off an airplane with a parachute on, I want to slide down fast on skis from a high slope, I want to try bungee jumping, I want to go on roller coasters or thrilling rides at amusement parks, and I want to hang out with motorcycle gangs who look like they're around my age (Cronbach alpha=.87); (B) I want to make out with someone of the opposite sex, I want to go to bars or clubs and have fun all night, I want to try drinking or smoking without having to mind other people, I want to laugh and be rowdy at gatherings or parties full of people, I want to go crazy at standing seats at concerts, I want to try outlandish hairstyles or clothes, I want to zoom down big roads in a sports car, and I want to sing or yell loudly in the street in the middle of the night (Cronbach alpha=.82). For information-seeking behavior, the respondents were asked "Have you ever actively searched for health-related information?" The five possible responses were as follows: "very actively," "actively," "average," "inactively," and "very inactively."

Covariates

We considered covariates in accordance with previous studies [26,27]. Respondents were queried on their attitudes and beliefs with regard to smoking and its health effects. Attitude toward smoking was assessed by asking "What are your thoughts on smoking?" and responses were categorized as "very positive," "positive," "so-so," "negative," or "very negative." Belief in the effect of smoking on health was assessed based on the question "What do you think that how much smoking will affect your health?" and responses were categorized as "no effect," "has somewhat effect," "considerable effect," or "fatal effect." Respondents were also asked "Who is a smoker among your parents?" The response options were "father only," "mother only," "both," or "neither of them." We grouped these answers into two categories: "neither of them" and "more than one."

Statistical Analyses

We expected that the two groups (with exposure to smoking scenes or without such exposure) were different in a range of characteristics. Such a difference might artificially inflate the effect of smoking desire when using traditional statistical techniques [28]. PSM is a statistical tool to create matched sets of treated and untreated participants who show similar values of propensity scores (PS) for covariates [29,30]. Therefore, PSM was used in this study to compare the smoking desire of the treatment group that viewed smoking scenes with the comparison group that did not view those scenes, according to the smoking-related risk factors of attitude to smoking, belief in the effect of smoking on health, and parental smoking. PS was calculated for each gender using a non-parsimonious multiple logistic regression model to ensure that the balancing property of the covariates was satisfied. Subsequently, PS was used to match using the Mahalanobis nearest-neighbor matching algorithm without caliper. We performed a series of statistical analyses to determine the effect of viewing smoking scenes in motion pictures on audiences' subsequent smoking desire. First, as a manipulation check, chi-square tests were conducted to evenly compare the distribution of covariates between the control group and the treatment group after matching the scores. Second, the two matched patient groups were compared using a paired *t* test to identify the difference between the two groups. Third, logistic regression was performed to explore the influential factors on audiences' smoking desire.

Ethics Statements

Approval for the study was granted by the Korea National Institute for Bioethics Policy Institutional Review Board (Approval Date: March 8, 2016; Approval No.: P01-201603-22-003). All participants gave written informed consent to participate in this study. The Ethics Committee of the Demographic Health Survey approved the consent procedure. Any information that could distinguish individual participants was not collected during the data collection process.

Results

Baseline Characteristics Related to Smoking Desire

Results of a cross-tabulation analysis conducted to verify whether the experimental group and the control group were well

matched are shown in Tables 1 and 2. For male respondents, the multivariate imbalance measure was 0.162 before matching and decreased to 0.111 after matching, indicating good matching. Male respondents with a "very negative" opinion of smoking comprised 60.5% of the control group and 56.8% of the experimental group. Concerning the effect of smoking on health, 67.3% of respondents in the control group and 59.3% of respondents in the experimental group believed smoking was fatal. Similar percentages of both groups responded that one or both of their parents smoked or that both were non-smokers.

For female respondents, the multivariate imbalance measure decreased from 0.246 before matching to 0.209 after matching. The proportion of females with a very negative attitude to smoking was 63.4% in both the control group and the experimental group. Similar percentages of females believed that smoking is fatal (66.0% and 68.6% in the control and experimental group, respectively). Concerning parental smoking, 54.9% of the control group responded that both parents were non-smokers with 56.2% of the experimental group responding that one or both smoked.

Smoking Desire According to Exposure to Smoking Scenes After Propensity Score Matching

Table 3 presents the data concerning cigarette cravings between the experimental and control groups based on independent sample *t* tests. Cigarette craving was significantly higher in the experimental group than that in the control group among male adolescents ($t_{307.96}$=2.066, P<.05; Table 3). In the experimental group, cigarette cravings of adolescents after viewing smoking scenes were significantly higher than they were before watching the video clips ($t_{161.00}$=2.867, P<.01; Table 4). Figure 1 depicts the results graphically.

Table 1. Baseline characteristics related to smoking desire (men).

Characteristics	Before matching			After matching		
	Control (n=189), n (%)	Experiment (n=187), n (%)	*p*	Control (n=162), n (%)	Experiment (n=162), n (%)	*p*
Attitude to smoking						
Very positive	0 (0.0)	4 (2.2)	.04	0 (0.0)	1 (0.6)	.58
Positive	4 (2.1)	3 (1.6)		2 (1.2)	3 (1.9)	
So-so	28 (14.8)	38 (20.3)		21 (13.0)	29 (17.9)	
Negative	48 (25.4)	40 (21.4)		41 (25.3)	37 (22.8)	
Very negative	109 (57.7)	102 (54.5)		98 (60.5)	92 (56.8)	
Belief in the effect of smoking on health						
Not effective	2 (1.1)	2 (1.1)	.22	2 (1.2)	2 (1.2)	.45
Somewhat effective	19 (10.1)	17 (9.1)		11 (6.8)	17 (10.5)	
Considerably effective	52 (27.5)	48 (25.7)		40 (24.7)	47 (29.0)	
Fatal	116 (61.4)	120 (64.2)		109 (67.3)	96 (59.3)	
Parental smoking						
Neither of them	97 (51.3)	99 (52.9)	.42	80 (49.4)	80 (49.4)	>.99
More than one	92 (48.7)	88 (47.1)		82 (50.6)	82 (50.6)	
Multivariate Imbalance Measure	0.162			0.111		

Effects of Mass Media Usage, Impulsivity, and Information-Seeking Behavior on Smoking Desire Among Male Adolescents

Logistic regression was performed through PSM to determine factors associated with changes in cigarette cravings among the male high school students following viewing of smoking scenes in motion pictures. Results are summarized in Tables 5 and 6. Table 5 provides descriptive statistics of the sample. According to Model III, the video clips did not significantly influence cigarette craving (Table 6). However, more impulsive adolescents had significantly higher cigarette cravings than less impulsive adolescents: adjusted Odds Ratio (aOR) 3.40 (95% CI 1.40-8.23). On the contrary, cigarette cravings did not significantly increase in adolescents who habitually engaged in health information-seeking. In particular, those who very actively sought health information had considerably lower cigarette cravings than the group who did not engage in such information-seeking: aOR 0.08 (95% CI 0.01-0.88).

Table 2. Baseline characteristics related to smoking desire (women).

Characteristics	Before matching			After matching		
	Control (n=185), n (%)	Experiment (n=187), n (%)	*p*	Control (n=153), n (%)	Experiment (n=153), n (%)	*p*
Attitude to smoking						
Very positive	0 (0.0)	2 (1.1)	.01	0 (0.0)	0 (0.0)	>.99
Positive	6 (3.2)	3 (1.6)		3 (2.0)	3 (2.0)	
So-so	21 (11.4)	15 (8.0)		15 (9.8)	15 (9.8)	
Negative	60 (32.4)	38 (20.3)		38 (24.8)	38 (24.8)	
Very negative	98 (53.0)	129 (69.0)		97 (63.4)	97 (63.4)	
Belief in the effect of smoking on health						
Not effective	0 (0.0)	0 (0.0)	.05	0 (0.0)	0 (0.0)	.23
Somewhat effective	7 (3.8)	10 (5.3)		4 (2.6)	9 (5.9)	
Considerably effective	59 (31.9)	40 (21.4)		48 (31.4)	39 (25.5)	
Fatal	119 (64.3)	137 (73.3)		101 (66.0)	105 (68.6)	
Parental smoking						
Neither of them	98 (53.0)	99 (52.9)	.54	84 (54.9)	67 (43.8)	.07
More than one	87 (47.0)	88 (47.1)		69 (45.1)	86 (56.2)	
Multivariate Imbalance Measure	0.246			0.209		

Table 3. Smoking desire according to exposure to smoking scenes by gender after propensity score matching.

Control (exposure to smoking scenes) versus treatment group	Control		Experiment		Degrees of freedom	*t*	*p*
	Mean	SD	Mean	SD			
Men	1.58	1.76	2.04	2.19	307.96	2.066	.04
Women	1.20	1.08	1.22	1.04	304.00	0.054	.96

Table 4. Smoking desire according to before and after exposure to smoking scenes by gender after propensity score matching.

Before exposure to smoking in movies versus after exposure to smoking in movies	Before exposure to smoking in movies		After exposure to smoking in movies		Degrees of freedom	*t*	*p*
	Mean	SD	Mean	SD			
Men	1.76	1.86	2.04	2.19	161.00	2.867	.01
Women	1.30	1.33	1.22	1.04	152.00	1.088	.28

Figure 1. Difference in cigarette cravings between the control group and the experimental group or between before and after viewing smoking scenes in motion pictures in the experimental group.

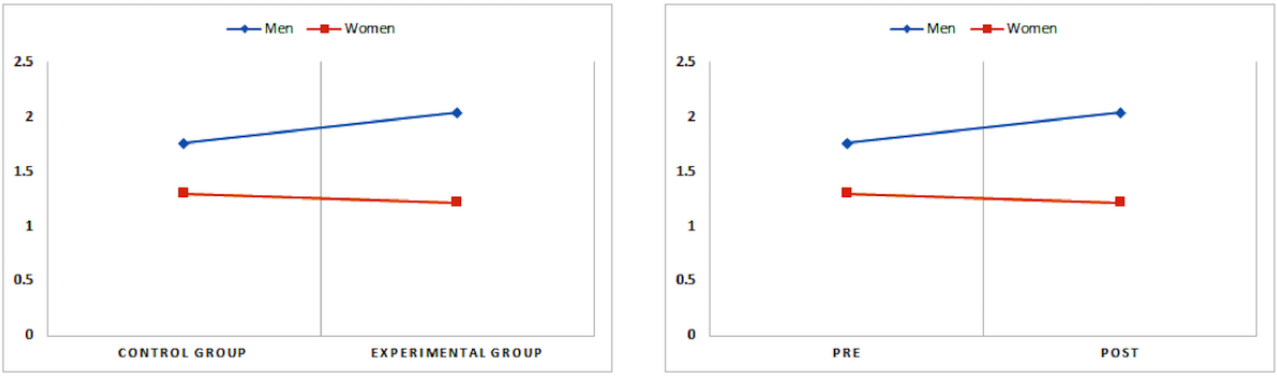

Table 5. Characteristics of mass media usage, impulsivity, and information-seeking behavior in 162 subjects.

Characteristics	n	%
Watch television per day on average		
<30 minutes	89	54.94
30 minutes-1 hour	39	24.07
1 hour-2 hours	22	13.58
>2 hours	12	7.41
Search information with a smartphone		
<30 minutes	48	29.63
30 minutes-1 hour	36	22.22
1 hour-2 hours	46	28.40
>2 hours	32	19.75
Read news on the Internet		
<30 minutes	68	41.98
30 minutes-1 hour	38	23.46
1 hour-2 hours	33	20.37
>2 hours	23	14.20
Impulsivity [mean, SE (range)]	2.38	0.73 (1-4)
Information-seeking behavior		
Very inactively	6	3.70
Inactively	20	12.35
Average	92	56.79
Actively	23	14.20
Very actively	21	12.96

Discussion

Principal Findings

This study revealed a direct link between viewing smoking scenes and immediate subsequent smoking desire. In particular, male adolescents who watched smoking scenes were more likely to have the desire to smoke than those who watched scenes that did not contain smoking. This is consistent with findings in the literature that people 18 to 25 years of age are influenced by smoking scenes in movies and are more apt to initiate smoking [31,32]. Presently, cigarette cravings in male high-school students were markedly increased in those displaying impulsive behavior, which is a known risk factor for smoking. The urge to smoke following viewing of the smoking scenes was considerably less in those who habitually engaged in health information-seeking behavior. The former group perceived tobacco as a substance of curiosity. In contrast, the latter group had negative attitudes and beliefs regarding tobacco, which were reinforced by information-seeking.

One-third of smokers start smoking when they are adolescents. Failure to quit smoking during adolescence considerably increases the chance of becoming a long-term smoker [33]. Smoking scenes frequently appear in movies rated PG-15. This makes it very likely that Korean adolescents will view the scenes. In impressionable individuals, the exposure could be an important factor in their decision to smoke. One factor could be a reinforcement of their burgeoning positive attitude towards cigarettes. Appropriate regulations and management are necessary to curb this influence. Banning smoking scenes in films is seemingly an obvious option. However, filmmakers counter that dramatic necessity and freedom of expression can allow for depiction of smoking, especially when it is deemed essential in the storyline [34].

Table 6. Effects of mass media use, impulsivity, and information-seeking behavior on smoking desire of male adolescents.

Characteristics	Model 1		Model 2		Model 3	
	aOR[a]	95% CI	aOR	95% CI	aOR	95% CI
Watch television per day on average (ref: <30 minutes)	1		1		1	
30 minutes-1 hour	1.64	0.52-5.17	1.45	0.43-4.94	1.13	0.34-4.50
1 hour-2 hours	1.6	0.41-6.22	1.70	0.42-6.93	1.76	0.41-7.55
>2 hours	2.08	0.36-11.90	1.87	0.29-11.94	1.70	0.23-12.68
Search information with a smartphone (ref: <30 minutes)	1		1		1	
30 minutes-1 hour	1.46	0.32-6.64	1.63	0.34-7.71	1.64	0.33-8.21
1 hour-2 hours	3.16	0.72-11.75	2.79	0.60-10.39	3.03	0.64-10.47
>2 hours	3.28	0.62-15.47	2.61	0.43-12.04	2.01	0.29-10.32
Read news on the Internet (ref: <30 minutes)	1		1		1	
30 minutes-1 hour	0.58	0.16-2.09	0.64	0.17-2.35	0.64	0.17-2.49
1 hour-2 hours	0.46	0.11-1.88	0.53	0.12-2.33	0.44	0.09-2.08
>2 hours	0.49	0.11-2.26	0.66	0.13-3.42	0.69	0.12-4.10
Impulsivity			3.13[b]	1.35-7.28	3.40[b]	1.40-8.23
Information-seeking behavior (ref: Very inactively)					1	
Inactively					0.19	0.02-1.86
Average					0.12[c]	0.02-0.92
Actively					0.11[c]	0.01-0.89
Very actively					0.08[c]	0.01-0.88

[a]aOR=adjusted attitude to smoking, belief in the effect of smoking on health, and parental smoking. Dependent variable: increasing smoking desire after exposing to smoking scenes (1), decreasing or no change in smoking desire after exposing to smoking scenes (reference: 0).

[b]Significance at 1% significance level.

[c]Significance at 5% significance level.

Some countries, such as the United Kingdom, have banned the promotion and advertisement of tobacco. However, they still allow movies with positive messages towards tobacco to be viewed. Many R-rated movies produced in the United States from 2001 to 2006 had smoking scenes and 90% of viewers of such movies reported that they had a greater urge to smoke after watching these movies [35,36]. However, more people agree that regulations against smoking scenes in movies are needed. Positive changes to regulate smoking scenes in movies are being made. In the United States, Hollywood film companies are practicing self-regulatory rules to ban scenes where protagonists smoke in G, PG, and PG-13 movies [37]. This decision was based on research suggesting that the more R-rated movies a minor watches, the more likely it is that this person will smoke in the future [32]. India, another country with a robust film industry ("Bollywood") is also strengthening regulations on smoking. Tobacco brands were frequently shown in Bollywood films made in Hindi until the early 2000s [38]. However, as the government espoused the reduction of smoking scenes in movies, vetting of films to decide whether the smoking scene is necessary has been instituted [39]. To increase the effectiveness of the ban on smoking scenes, the Indian government is allowing smoking scenes but only if the scene is out-of-focus and accompanied by a 30-s message in the film warning of the danger of smoking [40].

Establishing a standard that restricts the frequency of smoking scenes in films and assigning a smoking-related screening grade to films are warranted. Our findings suggest that adolescents who attempt to quit smoking should lessen or refrain from viewing motion pictures that contain smoking scenes.

Limitations

Some study limitations should be noted. First, the number of friends who smoke is an important covariate, but this study was not able to include any type of information on social networks among adolescents in the questionnaire due to ethical problems. However, regarding adolescent smoking, the significance of viewing smoking scenes in motion pictures may be amplified by social networks rather than attenuated [8]. Second, data on smoking desire were collected via a self-reported questionnaire. So, the results may have been subject to recall bias. In addition, the Hawthorne effect may have occurred because participants knew the purpose of the study. Future research needs to develop a longitudinal study and an investigation and management system to conclusively establish the reliability and validity of the data.

Public Health Implications

This study reveals a direct link between viewing smoking scenes and immediate subsequent smoking desire. In particular, male

adolescents who watched smoking scenes were more likely to have the desire to smoke than those who watched scenes without smoking and were more apt to commence smoking. Cigarette craving increased considerably in male high-school students with an impulsive, risk taking personality. However, the desire to smoke cigarettes was considerably decreased in those who habitually engaged in health information-seeking behavior. Thus, a comprehensive effort involving dissemination of information is needed to promote global health. Effort is especially needed to prevent adolescents from being exposed to smoking scenes in movies. First, we need to identify the more vulnerable adolescents who are being exposed to smoking scenes in films. At the same time, we need to consider a targeted approach by finding predisposing conditions, such as sensation-seeking or impulsivity. Health campaigns that foster health information-seeking among young people are a good idea. Second, rather than implementing downstream and selective protection plans targeting adolescent viewers and their parents, an upstream approach is needed. For example, if the movie industry is genuinely interested in this project, civil servants, movie creators, and academics can talk together to understand the necessity of rules against smoking scenes and find ways to come up with appropriate solutions.

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Conflicts of Interest

None declared.

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Abbreviations

aOR: adjusted odds ratio
PSM: propensity score matching
FCTC: Framework Convention on Tobacco Control
WHO: World Health Organization

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Original Paper

Point-of-Sale Tobacco Advertising and Display Bans: Policy Evaluation Study in Five Russian Cities

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Abstract

Background: The tobacco industry uses point-of-sale (POS) advertising, promotion, and product display to increase consumption of its products among current users, to attract new consumers, and to encourage former customers to resume tobacco use. As part of a comprehensive tobacco control effort, Russia—having one of the highest tobacco use prevalence rates in the world—enacted legislation that banned tobacco POS advertising, effective November 15, 2013, and banned the display of tobacco and the sale of cigarettes in kiosks, effective June 1, 2014.

Objective: The objective of the study was to evaluate the implementation of the national law by assessing the state of POS advertising, promotion, and product display, and sales in kiosks across Russia.

Methods: Two waves of observations were conducted to measure compliance with the POS restrictions: wave 1 took place in April-May 2014 after the advertising ban was in effect and again in August-September 2014 after the display ban and elimination of tobacco sales in kiosks came into effect. Observations were conducted by local trained staff that traveled to 5 populous cities in different regions of Russia (Moscow, St. Petersburg, Kazan, Ekaterinburg, and Novosibirsk). Staff followed a published POS evaluation protocol and used mobile phones to collect data. Observations were conducted in a roughly equal number of supermarket chains, convenience stores, and kiosks. Observed items included advertising at POS, product displays, and cigarette sales in kiosks.

Results: Observations were made in 780 venues in wave 1 and in 779 revisited venues in wave 2. In wave 1, approximately a third of supermarkets and convenience stores (34.2%, 184/538) were advertising cigarettes using light boxes, and over half of observed venues (54.3%, 292/538) had signage such as banners or shelf liners that used colors or images related to cigarette brands. Product displays were common in wave 1. In wave 2, compliance with advertising restrictions was very good: there were virtually no light boxes (1.0%, 5/489); banners or shelf liners were observed in 30.5% (149/489) of supermarkets/convenience stores; approximately 7.4% (36/489) of venues were still displaying products in a powerwall. In wave 2, 41.3% (100/242) of kiosks continued to sell tobacco.

Conclusions: Russia's compliance with POS bans was excellent. Remaining compliance issues are largely with the use of cigarette brand colors or images used in banners or shelf liners; this type of infraction is more difficult to enforce as inspectors need to be deeply familiar with tobacco industry products and marketing practices. A sizable proportion of kiosks continue to sell tobacco post restrictions.

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KEYWORDS

tobacco; marketing; public health; public policy; evaluation; Russia

Introduction

Tobacco Use in Russia

Tobacco use is a worldwide problem exacerbated by a global tobacco industry that works to promote and sell a product that kills nearly half of its long-term users [1]. The health burden of tobacco use is borne heavier in certain countries and regions due in part to higher prevalence of use. One of the countries most affected in the world is the Russian Federation (Russia). The World Health Organization (WHO) estimates that just over 60% of adult males and almost 22% of adult females smoke cigarettes (a total of approximately 43.9 million adults) [2]. Every year, it is estimated that 400,000 Russians are killed by tobacco-caused disease [2].

Russia represents the world's second largest tobacco market by volume of sales, worth an estimated US $28 billion in 2014 [2,3]. It is well documented that the tobacco industry works to increase sales of its products using a variety of tobacco advertising, promotion, and sponsorship (TAPS) activities [4,5], and that these activities increase tobacco consumption among current users, attract new consumers, and encourage former customers to resume tobacco use [4-7]. The tobacco industry spends tens of billions of US dollars globally each year on TAPS [2,5]. In Russia, it is estimated that the tobacco industry invests approximately US $1 billion annually on TAPS [8,9].

Tobacco Promotion in Russia

Before the 1970s, consistent with a centralized economy, not much commercial advertising took place in Russia [10]. This began to change in the 1970s when Western-made cigarette brands were introduced to Russia. In 1980, the Soviet government adopted a regulation that banned the advertising of cigarettes in mass media and on outdoor billboards; the regulation was largely followed until the end of the decade [10,11]. However, by the mid-1990s, tobacco advertising in Russia was ubiquitous; ads were on television and radio, and cigarette products were promoted on billboards, in public transit spaces, and at point-of-sale (POS), including brightly colored kiosks that replaced "gloomy grey tobacco kiosks" [10]. It was noted that in the 1990s, the most prominent product being sold in kiosks was cigarettes [12]. In the mid-1990s, foreign cigarette companies were reported as being the largest advertisers on television and radio—accounting for up to 40% of Russia's national advertising [13].

Tobacco Control in Russia

The Russian Ministry of Health was actively working to develop tobacco prevention and control programs during the 1990s [9]. Earlier versions of the Federal Law No. 87-FZ of July 10, 2001, on the "Imposition of Restrictions on Tobacco Smoking" included limitations on tobacco advertising; however, these limitations were removed from the actual law that was passed [9]. A federal law regulating all commercial advertising was passed in the Duma in 2006 (Federal Law No. 38-FZ); Article 23 of the advertising law provided key provisions governing the advertising of tobacco products, including banning tobacco advertising in TV and radio programs and in videos and movies. The law further banned advertising in printed publications intended for minors, and newspapers and magazines could not print tobacco advertisements on the first and last pages [14]. Although this law represented significant progress for tobacco control, the tobacco industry continued to sponsor events, and advertise and promote its products in public spaces and on billboards, and, importantly, at POS [9].

In 2003, to address the global problem of tobacco use, an international treaty was negotiated under the auspices of the World Health Organization (WHO): the Framework Convention on Tobacco Control (FCTC) [15]. The FCTC outlines effective policy responses and implementation guidelines to support tobacco control including measures against TAPS [4]. Comprehensive bans on TAPS have proven to be the most effective in reducing tobacco consumption [16-18], particularly product displays at POS [19-21]. There is evidence that although a country restricts tobacco product advertising in media, tobacco companies will increase their marketing efforts through other channels including POS promotions [22]. The WHO reported in 2013 that 50% of adult Russians notice POS promotions for tobacco products [23], suggesting that this was an important marketing strategy for the tobacco industry.

Russia acceded to the FCTC on 3 June, 2008, and, on February 23, 2013, passed the Federal Law N 15-FZ, "Protecting the Health of Citizens From the Effects of Second Hand Tobacco Smoke and the Consequences of Tobacco Consumption" (tobacco control law) [24]. The tobacco control law was implemented in two phases. The first phase, outlined in Article 16, bans all forms of tobacco advertising, promotion, and sponsorship, and came into effect on November 15, 2013. This included banning marketing at POS such as promotional signage, price discounts, and free product giveaways. The second phase, outlined in Article 19, prohibits the display of tobacco products at trade sites and regulates retail product listings; these restrictions came into effect on June 1, 2014. The tobacco industry quickly identified a possible loophole during the implementation of Article 16, determining that enhanced forms of product displays could be considered compliant with advertising restrictions. This perceived loophole was exploited by employing tactics such as light boxes (see Figure 1) and enlarged cigarette packages. There was no legal decision made in Russia to determine whether such product displays could be classified as advertising or promotion or whether they would be considered product display. Article 19 also restricted the sale of tobacco to only stores and pavilions, which were defined in part using various physical characteristics including having a door for customers to enter. Kiosks, which generally sell items through a window, do not match the definition of a store or a pavilion and therefore were not permitted to sell tobacco after June 1, 2014. The Federal Department of Health has argued that kiosk vendors often sold cigarettes to minors [25]. As described earlier, kiosks also prominently display cigarettes in their windows and often include bright colorful advertisements for cigarette products.

This two-phase policy implementation approach presents an important opportunity to understand how retailers achieve compliance with different types of advertising, promotion, and display restrictions and a ban on sales in a specific vendor type. Policy evaluations are useful to inform policy implementation

and enforcement and to identify any policy development needed to close loopholes that undermine the spirit of the legislation.

This aim of this study is to use a policy design to evaluate the implementation and compliance of the national law, before and after it was enacted, by assessing the state of POS advertising, promotion, and product display, and sales in kiosks across Russia. This study design captured industry activities between the implementation of product advertising and promotion and product displays, which provides insight into the tobacco industry's marketing efforts and optimal policy design. Finally, the study measured the sale of other non-cigarette products including alcohol, e-cigarettes, and gasoline to understand, in part, if this tobacco control legislation is associated with unintended consequences such as a change in the availability of other consumer products with potential public health impacts.

Figure 1. Cigarette packs displayed in a lightbox, Moscow, April 17, 2014. (photo credit: Ashley Grant).

Methods

Groups Involved in the Study

This work was conducted by researchers based at the Institute for Global Tobacco (IGTC) at Johns Hopkins Bloomberg School of Public Health in Baltimore, Maryland (USA) referred to in this paper as the investigator team. IGTC worked closely with partners of the Campaign for Tobacco Free Kids, an international public health nongovernmental organization based at Washington, DC (USA), which includes policy experts and a legal team. IGTC also partnered with Russian tobacco control experts based in Moscow, who worked as data collectors. These experts were familiar with the tobacco control law and industry marketing practices.

This study was observational in nature; it did not include human subjects and therefore did not require approval from an institutional review board.

Study Overview

The study details are described in detail below. As a summary, the compliance measures relevant in each wave of data collection are detailed in Table 1, including the dates of data collection and details of the tobacco control law.

Table 1. Study overview.

Study domains	Wave 1 Data collected April-May 2014	Wave 2 Data collected Aug-Sept 2014
Tobacco control law details	Article 16, bans all forms of tobacco advertising, promotion and sponsorship, Restrictions entered into effect on November 15, 2013.	Article 19, prohibits the display of tobacco products at trade sites and regulates retail product listings; Restrictions entered into effect on June 1, 2014.
POS (point-of-sale) compliance	All cigarette promotions and advertisements are banned including: Use of signs/ posters/ banners/ shelf liners/ backgrounds (not in light box) Use of light boxes Use of enlarged packs Promotional discounts Sale or distribution of non-tobacco products with a tobacco brand name Signage or brand representative offering gifts (free or with purchase) Free product distribution	All cigarette product displays are banned including: Cigarette pack/product display visible from street (kiosk or storefront window) Cigarette pack/product display in cashier zone Cigarette pack/product display on power wall Cigarette pack/product display in other locations Product sales of cigarettes only permitted in stores or pavilions (not permitted to be sold in Kiosks); Product list required to be available upon request.
Other products sold or displayed (unintentional consequences of the law)	Gasoline, e-cigarettes, alcohol, smokeless tobacco	Gasoline, e-cigarettes, alcohol, smokeless tobacco

The protocol used in this study is detailed extensively elsewhere [26], but in brief, the study was conducted in the cities of Moscow, St. Petersburg, Novosibirsk, Ekaterinburg, and Kazan. These cities were selected for data collection based on their population size and geographical dispersion. Each of the 5 cities is located in separate and distinct federal subjects (constituent members of the federation) and is among the top 10 most populous cities in Russia. POS venues included in the study were located in neighborhoods with varying property values across each city; roughly equal number of observations were conducted in neighborhoods with above-average, average, and below-average housing value (used as a proxy for socioeconomic status). The Russian based data collectors acquired a near-comprehensive list of supermarkets and their addresses, but did not have access to comprehensive lists of other tobacco retailers. POS venues included in the study were identified by randomly selecting supermarkets where data collectors began recording observations, and by using a walking protocol to identify nearby convenience stores and kiosks. Data collectors were trained to follow the walking protocol (which was designed to be sufficiently random while also expedient) to identify POS venues and to collect observational data by completing an observation checklist. The observation checklist was developed following a thorough review of the tobacco control law and was reviewed by in-country partners including a public health lawyer.

Four data collectors from Russia were trained over 3 days in Moscow in April 2014 and retrained for 2 days before wave 2 in August 2014. Initial training included an introduction to the tobacco control law and different POS marketing or product display practices. The data collectors spent 2 supervised days in Moscow practicing data collection including how to identify POS venues following the walking protocol, how to use the mobile technology, and how to conduct the observations in retail settings. Initially, data collectors practiced conducting observations in pairs under the direct supervision of the investigator team. Each pair of data collectors visited a minimum of 6 POS venues in Moscow to practice conducting observations and uploading data. Then a set of 8-10 POS venues were double-coded by data collectors to ensure consistent and reliable observations. The field team experienced minimal differences in observations. In wave 2, similar practice field work was conducted to reacquaint the data collectors to the mobile technology. Venues were revisited in wave 2, so no walking protocol was needed; photos taken and GPS (Global Positioning System) coordinates collected in wave 1 were used by data collectors to help identify venue locations in wave 2.

Data collectors used mobile phones equipped with a customizable mobile data collection software app to complete observations and, when possible, took digital photos of observed marketing including signage and product displays [26]. Data were uploaded in real time when the phones were connected to a cellular network. Data included the aforementioned specific instrument observations and photos as well as metadata (such as time stamp, GPS-based location coordinates, and device identification number). Data collectors primarily relied on the cellular network, but did occasionally use Wi-Fi capabilities to enhance the accuracy of study site geolocation. The real-time data upload allowed the investigator team in Baltimore, Maryland, to oversee the field work.

Data collectors were required to take photos of the POS entrance, which was particularly important to ensure that the wave 2 data collection occurred at the same venue. The data collectors were also asked to take photos of product displays and advertising or promotional activities. However, these were optional because data collectors were occasionally reprimanded by store clerks or security guards; therefore, data collectors prioritized collecting observational data and took photos when

it was possible. Data collectors could also add in specific notes to each POS observation, and were required to complete daily field reports highlighting any data collection issues or questions along with the number of POS venues visited that day. The Baltimore-based investigator team could function as a remote field supervisor and review uploaded data in real time, and in some cases was able to respond to any questions related to observation classifications or the walking protocol within 24 hours. Time differences made immediate response challenging, but data sharing occurred automatically without the need to wait for data collectors to share files. Members of the investigator team could check for data accuracy or possible inconsistencies such as GPS coordinates corresponding with POS location, or review images collected in POS environments and ensure the details in the images matched the recorded observations.

Data were collected at two points in time: wave 1 was conducted in April-May of 2014 (5 months after the tobacco control law banned all forms of advertising and promotion), and wave 2 was conducted in August-September 2014, 3 months after Article 19 (the second phase of Russia's tobacco control law) was implemented, which banned all product displays and sales of tobacco products in kiosks. Before wave 2, data collectors underwent similar training and pilot testing as in wave 1. The data collectors in wave 2 of this study included 2 staff members who participated in wave 1 and 2 staff members who were new to the study.

Physical details about kiosks (the presence of a door for customers to enter or exit) were also collected in order to distinguish them from stores and pavilions.

Sample

The study measured compliance with the tobacco control law in different types of retail settings, including: (1) supermarket chains, (2) independently owned markets/convenience stores (including gas stations), and (3) kiosks. These POS types were selected for inclusion based on their prominence as tobacco retailers in Russia. Kiosks were also included because Article 19 permits the sale of tobacco only in stores and pavilions. See Figure 2 for an image of a kiosk in Moscow with cigarette packs on display before the product display ban took effect.

The data collectors had a goal to visit 810 POS in wave 1—162 POS in each city (54 in each high, medium, and low property value neighborhoods, with 18 venues from each type of retail setting). A goal was more suitable than a quota, because the availability of some types of retailers is not uniformly distributed in each neighborhood. A list of supermarkets in each of the 5 cities was created using a variety of mapping tools including 2GIS, Google Maps, and Yandex. Data collectors would begin data collection at a supermarket, exit the store, and follow a prescribed walking protocol to identify a convenience store and a kiosk (for which there were no lists and addresses available). The protocol had a provision that if no convenience store or kiosk was found after 30 minutes of walking, data collectors could proceed to the next supermarket on their list [26]. In wave 2, data collectors returned to the same venues to repeat observations.

Figure 2. Kiosk selling tobacco in Moscow, April 17, 2014 (photo credit, Ashley Grant).

Observations

In wave 1, data collectors visited retail venues and noted (yes/no) *cigarette product advertisements* including signs, posters, banners, shelf liners or backgrounds, a light box, and the presence of oversized cigarette packs. Tobacco companies provide some retailers with signage or display cases that use tobacco brand colors or images that can convey the brand. Data collectors also noted (yes/no) *cigarette product promotions* including coupons, discounts or vouchers, brand stretching, gifts with purchase, and the presence of brand representatives and free product giveaway promotions. Data collectors noted the brands of cigarettes being promoted if any of the above tactics were being used. Data collectors also recorded the presence of *cigarette product displays*. Data collectors noted (yes/no) if cigarettes were visible from the street, in the cashier zone, on a powerwall, and in any another area of the retail venue (area recorded).

Additional consumer product displays, not regulated through the national tobacco control law, were also noted (yes/no) including displays for e-cigarettes and smokeless tobacco and the presence of candy or sweet snacks on display in the cashier zone. Furthermore, the sale (yes/no) of alcohol and e-cigarettes was also noted. If e-cigarettes were not on display, data collectors asked the staff at the venue if these products were available.

In wave 2, data collectors noted any changes in the status of the POS, for example, whether the business had closed or ceased selling cigarettes. If a POS continued to sell cigarettes, in lieu of product displays, the retailer was allowed by the tobacco control law to have a list of tobacco products sold, the text of which is in letters of the same size in black font against a white background and which is composed in alphabetical order, with indication of the price of tobacco products sold without the use of any graphics and images [25]. Data collectors recorded if the POS had a *product list* (yes/no), and if it was in compliance (yes/no) with the law's requirements including being printed on plain white paper with text in a black font.

In both waves 1 and 2, data collectors could also record general comments or notes about a venue. At the end of each day, data collectors completed a log summarizing the number and type of venues they visited and any issues with data collection.

Data Quality Checks

Data collected in Russia were reviewed, generally within hours, by the Baltimore-based investigator team who routinely checked time stamps and GPS locations to ensure data collectors were in the correct locations and that their daily logs matched the uploaded files.

Analysis

Observations are reported as proportions of noncompliance with the tobacco control law; analysis was conducted by the lead author (RDK) and coauthor (AG), members of the Baltimore-based investigator team. Analysis was conducted using SPSS statistical software version 23.0 (IBM Corp). Some of the recorded observations, including brand of cigarettes advertised or on display, were manually counted. Additional observation notes were reviewed and reported.

Results

Sample

The study team conducted observations and recorded data at a total of 780 POS in wave 1; the number of POS observed by city, relative property value zone, and retail type are detailed in Table 1. During wave 2 of data collection, data collectors revisited 779 POS venues (one location, a kiosk, could not be located); data collected and uploaded successfully in wave 2 (n=720) are also detailed in Table 2.

Table 2. Cigarette POS (point-of-sale) venues where observations took place during wave 1 and wave 2.

City	Supermarket chains		Independent market or convenience store		Kiosk		Total per city	
	Wave 1	Wave 2	Wave 1	Wave 2	Wave 1	Wave 2	Wave 1	Wave 2
Moscow	59	54	54	50	54	46	167	150
St. Petersburg	53	52	54	51	49	45	156	148
Novosibirsk	55	53	53	50	54	49	162	152
Ekaterinburg	53	54	54	49	55	45	162	148
Kazan	51	50	52	49	30	23	133	122
Total per venue type	271	263	267	249	242	208	780	720

In wave 1, sample goals were achieved or nearly achieved in each city. In wave 2, one venue could not be relocated and thus was not observed. Data from 7 venues were not successfully uploaded due to failure of mobile devices. When visited, 52 POS venues were closed, and observers determined the retail venues were unlikely to reopen in the near future, and therefore observations were not possible. The majority of venues that were closed were kiosks (63%, n=33), followed by convenience/stores (29%, n=15) and supermarket chains (8%, n=4). In total, 720 venues were revisited by data collectors in wave 2 and observations were conducted.

Of the 720 POS venues visited in wave 2, it was determined that 589 were still selling cigarettes. Of the 131 venues that had stopped selling cigarettes, the majority were kiosks (82.4%, n=108), followed by supermarket chains (10.7%, n=14) and independent convenience stores (6.9%, n=9).

Observations

Observed noncompliance with the tobacco control law in supermarkets and independent convenience stores is detailed in Table 3. Observations conducted at kiosks are reported in Table 4; kiosks are reported separately because in wave 2 no kiosk was permitted to sell cigarettes and was therefore inherently noncompliant.

During wave 1, all product promotions and advertisements were banned; during wave 2, all product display activities were also banned and sales of cigarettes were limited to stores and pavilions (ie, banned at kiosks). Cigarettes displayed in light boxes and enlarged packs are presented in Tables 3 and 4 as product promotions and advertisements; however, as described earlier, the industry preferred to consider these marketing tactics as product displays.

Table 3. Noncompliance with POS (point-of-sale) restrictions at supermarkets and convenience stores.

Observation item	Wave 1 (N=538), n (%)	Wave 2 (N=489)
Product promotions and advertisements		
ANY cigarette promotion or advertisement	367 (68.2)	150 (30.7)
Use of signs/posters/banners/shelf liners/backgrounds (not in light box)	292 (54.3)	149 (30.5)
Use of light boxes	184 (34.2)	5 (1.0)
Use of enlarged packs	31 (5.8)	1 (0.2)
Promotional discounts	9 (1.7)	0
Sale or distribution of non-tobacco products with a tobacco brand name	17 (3.2)	Data not available
Signage or brand representative offering gifts (free or with purchase)	22 (4.1)	0
Free product distribution	21 (3.9)	2 (0.4)
Product display		
ANY display of cigarette pack/product	510 (94.8)	109 (22.3)
Cigarette pack/product display visible from street (storefront window)	18 (3.3)	2 (0.4)
Cigarette pack/product display in cashier zone	492 (91.4)	104 (21.3)
Cigarette pack/product display on a powerwall	181 (33.6)	36 (7.4)
Cigarette pack/product display in other locations	30 (5.6)	6 (1.2)
Smokeless tobacco products on display anywhere in store	23 (4.3)	1 (0.2)
Cigarette product list—noncompliant or no list	N/A	259 (53.0)

Table 4. POS (point-of-sale) promotions and product displays observed at kiosks.

Observation item	Wave 1 (n=242)	Wave 2 Open and selling tobacco (n=100)
Product promotions and advertisements		
Venue has a door	52 (21.5)	67 (67.0)
ANY cigarette promotion or advertisement		12 (12.0)
Use of signs/ posters/banners/shelf liners/backgrounds (not in light box)	121 (50.0)	12 (12.0)
Use of light boxes	67 (27.7)	0
Use of enlarged packs	11 (4.5)	0
Promotional discounts	2 (0.8)	0
Sale or distribution of non-tobacco products with a tobacco brand name	6 (2.5)	Data not available
Signage or brand representative offering gifts (free or with purchase)	6 (2.5)	0
Free product distribution	4 (1.7)	0
Product display		
ANY display of cigarette pack/product	242 (100.0)	24 (24.0)
Cigarette pack/product display visible from street (kiosk or storefront window)	206 (85.1)	0
Cigarette pack/product display in cashier zone	234 (96.7)	22 (22.0)
Cigarette pack/product display on a powerwall	90 (37.2)	9 (9.0)
Cigarette pack/product display in other locations	4 (1.6)	1 (1.0)
Smokeless tobacco products on display anywhere in store	20 (8.3)	2 (2.0)
Cigarette product list—noncompliant or no list	N/A[a]	78 (78.0)

[a]N/A: not applicable.

In wave 1, the overwhelming majority of POS venues were compliant with restrictions related to price discounts, sales of non-cigarette products with cigarette branding (brand stretching), signage, or a brand representative present offering gifts (free or with purchase) or distributing free product. Approximately 5.8% (31/538) of supermarkets and convenience stores and 4.5%, (11/242) of kiosks had enlarged packs on display; brands of oversized packs included Marlboro, Lucky Strike, Bond, Chesterfield, and Kent. Approximately one-third (34.2%, 184/538) of supermarkets and convenience stores and about a quarter of kiosks (27.7%, 67/242) had a light box advertising or displaying a brand of cigarette. The most offending brand by far was Kent (present in 16.4% of all POS venues (128/780), as well as several other brands including Camel, Chesterfield, Davidoff, Marlboro, Parliament, and Winston.

The most common noncompliance issue in wave 1, observed in over half the POS venues, was the presence of signs, shelf liners, or backgrounds that used colors or symbols from a tobacco brand.

Product displays were not banned at the time of wave 1 data collection, and the vast majority of all POS venues had products visible in the cashier zone including 91.4% (492/538) of supermarkets and convenience stores and 96.7% (234/242) of kiosks. Products were visible from the street for most kiosks (85.1%, 206/242), compared with only 3.3% (18/538) of supermarkets and convenience stores.

In wave 2, cigarette advertising and promotions decreased. The use of light boxes and oversized packs had largely ceased: approximately 1% of POS venues had light boxes (5/489) and only one POS had an enlarged pack (Marlboro). Free product distribution was observed in 2 POS venues. Due to a glitch in the mobile data collection software, observations of the sale or distribution of non-tobacco products with a tobacco brand name were lost during the upload of data, although very few supermarkets or convenience stores (3.2%, 17/538) and fewer kiosks (2.5%, 6/242) were noncompliant in wave 1, and observer photos and notes did not include evidence of this brand stretching in wave 2. Almost one-third of POS venues (30.5%,149/489) continued to have signs/posters/shelf liners, or backgrounds that used colors or symbols from a tobacco brand. The brand colors used included Bond, Chesterfield, Kent, Marlboro, Parliament, and Rothmans.

In wave 2, 2 supermarket/convenience stores POS had a pack visible from the street. Some of these venues continued to have packs visible on a powerwall (7.4%, 36/489) or in the cashier zone (21.3%,104/489); it was noted by data collectors that some products were visible in the cashier zone or on a powerwall because staff had improperly or incompletely covered cigarette packs with curtains or because the curtains were not sufficiently opaque. One data collector noted during a visit to a supermarket in Ekaterinburg that a cashier reminded their colleague on two occasions to close the door to a cupboard that was displaying cigarettes.

In wave 2, it was observed that 100 kiosks remained open and sold tobacco. Data collectors observed that the majority of these venues, two-thirds (67/100), had a door, and approximately half of these venues (29/67) had added the door since wave 1.

In wave 2, more than half of supermarkets and convenience stores and more than three-quarters of kiosks selling tobacco neither had a cigarette product list nor had a list that was noncompliant because it was not printed on the correct style of paper or with the correct font or other design issues.

In wave 1 and wave 2, almost all venues displayed candy or sweets in the cashier zone (approximately 95% in both waves). In wave 1, smokeless tobacco was on display in the cashier area of some supermarkets and convenience stores (4.3%, 23/538); however, in wave 2, only one convenience store displayed smokeless tobacco. In wave 1, e-cigarettes were on display in about a quarter of venues (26.3%, 205/780) and for sale in 31.0% of venues (242/780). Over 90% of supermarkets and convenience stores sold alcohol in each wave. In wave 1, 14.0% (34/242) of kiosks sold alcohol; of the kiosks still selling tobacco in wave 2, 25.0% (25/100) also sold alcohol.

Compliance with product display restrictions in wave 2 differed across cities. In Ekaterinburg, approximately half of POS venues (51.2%, 66/129) were noncompliant, compared with 10.7% in Kazan (11/103), 13.8% in Novosibirsk (15/109), 15.0% in St. Petersburg (20/133), and 15.7% in Moscow (18/115).

During data collection in wave 2, recorded observations about the sale or distribution of non-tobacco products with a tobacco brand name were not properly uploaded and those fields were left blank. During wave 1, these forms of promotion were observed in 2.9% (23/780) of venues.

Discussion

Policy Implementation

The results of this study demonstrate that the tobacco control law in Russia that banned tobacco advertising, promotion, and product display has been well implemented, with the vast majority of retailers compliant with these restrictions. The multiphase aspect of the POS restrictions demonstrate that the tobacco industry took advantage of some ambiguity in the law, and continued to use tactics such as light boxes and enlarged packs after the implementation of product advertising and promotional restrictions; however, these tactics almost vanished after the product display bans were implemented, pointing to the need for clear and comprehensive policy language. There was a notable difference in compliance between retail venues in Ekaterinburg and the venues in the other 4 cities. The reasons for this are unknown, but do suggest that implementation of the law was not uniform across the country. The study also revealed that there were only minor changes in the display and sale of products including alcohol, e-cigarettes, and candy in the venues studied. It does not appear that kiosks replaced sales of cigarettes, for example, with alcohol or e-cigarettes. The results of this study are similar to other POS studies before and after the ban that found tobacco retailers were almost universally compliant following the implementation of comprehensive laws [20,27,28].

This study also found that the majority of kiosks achieved compliance with the tobacco control law by no longer selling tobacco (51.9%, n=108). About 1 in 7 kiosks were closed at the time of wave 2 data collection, although some supermarkets and convenience stores were also closed between waves, suggesting that there is a rate of retail closure independent of this legislation. The tobacco control law requires tobacco retailers to provide a product list, and the law sets out very specific criteria for that list in terms of font size and paper color. Many POS venues were not compliant with this aspect of the law; however, the impact on public health from this aspect of noncompliance is likely negligible.

In wave 2, some POS venues (less than a third) had signage or cabinets (formerly display cases) that included brand colors or images that are associated with cigarette brands. This type of infraction is difficult to enforce as inspectors need to be deeply familiar with tobacco industry products and marketing. Light boxes and, to a lesser extent, oversized cigarette packs were common after the implementation of the national ban on tobacco promotion and advertising; however, virtually none were observed following the product display ban.

Approximately a quarter of venues had cigarettes visible in the cashier zone. This can be partially explained by cupboard doors and curtains not being fully closed. Display bans that require tobacco products be kept under a counter do not have these staff-related compliance issues because the products are more likely to be out of view of the customers.

Kiosks were a common place to purchase cigarettes before the implementation of Article 19 of the tobacco control law, and almost all kiosks included in this study had cigarette packs visible from their storefront. Kiosks arguably were not just a place to purchase cigarettes, but would have greatly impacted the visual landscape of the cities included in this study. It is uncommon globally for a specific type of retailer to be banned from selling cigarettes. Although some supermarkets and convenience stores closed between the waves, a greater proportion of kiosks were closed at the time of wave 2 data collection. Presumably, this can be explained in part by the fact that some kiosks in our sample likely relied primarily on cigarette sales and would clearly have been impacted deeply by the tobacco control law. At the time of wave 2, it was unclear if some kiosks were closed permanently or if they were closed while reconfiguring to sell different products. Some data collector notes suggested that some kiosks were now selling shoes or ice cream although our data collection methods did not allow us to measure changes in product offerings. Despite some possible closures, many kiosks remained open and achieved compliance with the law by ceasing to sell cigarettes. The facades of these outlets were transformed as a direct result of the ban on the display of cigarette packs, which were, when collectively displayed in kiosk windows, essentially acting as large advertisement for the products. As noted, most of the kiosks still selling cigarettes had a door (and many added a door between waves). Presumably kiosk owners or managers had added a door in an effort to achieve compliance with the law; however, it is unclear if this simple physical change would be sufficient to reclassify the POS venue as a store or a pavilion.

There was little change between the waves in the proportion of POS venues selling e-cigarettes, a class of products that was excluded from the definition of tobacco products in the tobacco control law. Moving forward, it will be important to monitor e-cigarette displays and advertising in Russia. In wave 2, the proportion of kiosks selling alcohol was slightly greater than in wave 1. It will also be important to understand if kiosks have transitioned from the sale of cigarettes to the sale of alcohol, as this may trade one public health issue for another.

Lessons and Opportunities for Future Mobile Data Collection

Russia is a large country, both in geography and in population. These factors can present challenges for tobacco control policy implementation and evaluation. The mobile data collection method followed by this study was effective and presented few problems. Observational data, including photos as well as metadata such as including the time when data were logged, and the GPS coordinates worked well and permitted the research team in the United States to monitor work as it was conducted, ensuring that the team's data were collected in the proper locations and that observational data corresponded with the image content. The field team did experience an issue with uploading data from 7 POS venues, and it was determined that this was due to a network connectivity issue. In wave 2, one variable related to the sale or promotion of non-tobacco products with a tobacco brand name (brand extension) was not uploaded properly, and that variable was not reported. Finally, there was one location (a kiosk) that could not be found in wave 2—one probable explanation was that the kiosk was physically removed and therefore it was impossible to find. These issues, related to methods, were small with respect to the use of these novel protocols and demonstrate that this method should be considered by other jurisdictions to evaluate similar policies related to POS policy restrictions.

The protocol, designed for expediency as well as rigor, did not include a step where a subset of venues was visited by multiple data collectors. This decision results in limitations to the study. First, data collectors may have missed or incorrectly recorded certain important observations. Using double-coding may have reduced the likelihood of something being missed. Second, without double-coding venues, there is less certainty that data collectors did not fraudulently fabricate observations. There are several reasons to believe that these are not deep concerns, including the fact that data collectors were observing the presence of promotional materials such as posters, which are, by nature, visible. Second, the data collectors were aware that data were being checked as they were uploaded. The metadata include time and location; their in-store observations, however, could have been fabricated. The protocol required data collectors to take pictures where possible, inside venues, which allows for some secondary checks to ensure accuracy with data collection. Although most POS venues included at least one photo, not all photos were taken with sufficient resolution or appropriate in-frame content to confirm all data collection details. It is suggested that future studies consider including a subset of venues to be visited by multiple data collectors to improve the rigor of findings.

Implications for Public Health and Policy

This study found higher compliance in wave 2, when product displays were banned in addition to product advertisement and promotion; in particular, there was a decrease in product displays including light boxes, which were present at approximately one-third of venues during wave 1 but almost nonexistent during wave 2. This highlights the benefit of comprehensive policies where there is little opportunity for ambiguity in the law.

Comprehensive policy evaluations provide evidence of policy compliance and can help measure unintended consequences from the policy. This study did not examine implementation strategies related to how the Russian government implemented the tobacco control law provisions regarding tobacco advertising, promotion, and product display. Understanding these approaches and strategies can be helpful for other jurisdictions preparing to implement similar policies. Other researchers have focused on the challenges related to implementing other aspects of the tobacco control law in Russia, including the high demands the law places on Russia's health care system and the need to establish smoking cessation services to comply with the tobacco control law [9].

The results of this study are important for the preservation of tobacco control policies in Russia and to support the development and implementation of similar policies in other jurisdictions. Globally, there was deep skepticism when jurisdictions such as Ireland and France went smoke-free [29,30]. The results of the present evaluation may support the maintenance of the current ban because tobacco control experts can highlight the success of the policy implementation and highlight that there has not been a significant increase in the sale of other products that present challenges to public health such as alcohol or e-cigarettes. This study's findings may support the development and implementation of similar policies in other jurisdictions.

Conflicts of Interest

None declared.

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Abbreviations

FCTC: Framework Convention on Tobacco Control
GPS: global positioning system
IGTC: Institute for Global Tobacco Control
POS: point-of-sale
TAPS: tobacco advertising, promotion, and sponsorship
WHO: World Health Organization

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Original Paper

Attitudes of Crohn's Disease Patients: Infodemiology Case Study and Sentiment Analysis of Facebook and Twitter Posts

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Abstract

Background: Data concerning patients originates from a variety of sources on social media.

Objective: The aim of this study was to show how methodologies borrowed from different areas including computer science, econometrics, statistics, data mining, and sociology may be used to analyze Facebook data to investigate the patients' perspectives on a given medical prescription.

Methods: To shed light on patients' behavior and concerns, we focused on Crohn's disease, a chronic inflammatory bowel disease, and the specific therapy with the biological drug Infliximab. To gain information from the basin of big data, we analyzed Facebook posts in the time frame from October 2011 to August 2015. We selected posts from patients affected by Crohn's disease who were experiencing or had previously been treated with the monoclonal antibody drug Infliximab. The selected posts underwent further characterization and sentiment analysis. Finally, an ethnographic review was carried out by experts from different scientific research fields (eg, computer science vs gastroenterology) and by a software system running a sentiment analysis tool. The patient feeling toward the Infliximab treatment was classified as positive, neutral, or negative, and the results from computer science, gastroenterologist, and software tool were compared using the square weighted Cohen's kappa coefficient method.

Results: The first automatic selection process returned 56,000 Facebook posts, 261 of which exhibited a patient opinion concerning Infliximab. The ethnographic analysis of these 261 selected posts gave similar results, with an interrater agreement between the computer science and gastroenterology experts amounting to 87.3% (228/261), a substantial agreement according to the square weighted Cohen's kappa coefficient method (w2K=0.6470). A positive, neutral, and negative feeling was attributed to 36%, 27%, and 37% of posts by the computer science expert and 38%, 30%, and 32% by the gastroenterologist, respectively. Only a slight agreement was found between the experts' opinion and the software tool.

Conclusions: We show how data posted on Facebook by Crohn's disease patients are a useful dataset to understand the patient's perspective on the specific treatment with Infliximab. The genuine, nonmedically influenced patients' opinion obtained from Facebook pages can be easily reviewed by experts from different research backgrounds, with a substantial agreement on the classification of patients' sentiment. The described method allows a fast collection of big amounts of data, which can be easily analyzed to gain insight into the patients' perspective on a specific medical therapy.

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KEYWORDS

health information systems; public health informatics; consumer health information; social networking

Introduction

Patient opinions are highly valued in many medical studies for the assessment of their well-being. However, it is not always easy to collect patients' feedbacks for clinical studies. Interestingly, the advent of means of one-to-many communication, including the Web and social media, support peer-to-peer and one-to-many exchanges and comparisons of patients' experiences and feelings. Such Web-based tools have also radically changed the scenario in front of caregivers; patients are set in front of many more stimuli and sources of information than before (one-third of adult American citizens consider the Web a diagnostic tool), although no guarantee is granted on the quality of the retrieved information [1-3].

Nonetheless, Web-based anonymity may boost frankness and sincerity, as its privacy is often perceived as absolute, also when compared with the direct patient-doctor interactions. Sharing their experiences on the Web, patients provide a very useful knowledge base of insights to both rookies and medical researchers [4]: the former could learn how to handle given situations, and the latter could gather more sincere and unbiased feedback or even acquire further knowledge in their field of clinical study.

Although the reasons for understanding what is shared on the Web in relation to a given disease are clear, no well-established method exists today. Challenges, in fact, may be found and are not limited to (1) data gathering, (2) filtering of any unwanted or unnecessary information, (3) key topics individuation and interpretation, and (4) comparison to any related state-of-the-art in medical research.

An open question amounts to understand what the medical community could learn from the information that is shared on the Web [5-8]. Such new interesting area of research is part of the novel infoveillance and infodemiology fields. A few studies have considered such a problem in relation to different chronic diseases [9-16]. However, to the best of our knowledge, a general approach to this class of problems, based on the use of a combination of different technologies, is missing. This requires expertise that cannot stop to the medical or statistical fields but must also include techniques developed in computer science in addition to others from econometrics, ethnographic research, and psychometrics areas of study.

We borrowed the techniques from the aforementioned scientific areas to investigate a well-defined community of chronic illness patients affected by Crohn's disease. The choice of such a community is motivated by the following important fact: Crohn's disease is a chronic illness with increasing incidence, especially in western countries where it is often diagnosed in young people (in the age range of 15-30 years) who typically spend a lot of time on the Web [17]. Crohn's disease is therefore a good study model for our purposes.

The method that we present builds upon steps that we have previously developed [18,19]. In an initial analysis [18], computer science and econometrics techniques led us to find that (1) Crohn's disease patients share more frequently information on Facebook pages rather than in Twitter streams, and (2) the pharmaceutical treatment that is most often cited, in both positive and negative terms for Crohn's disease, is Infliximab. Further contributions have been made [19], where we put our findings in relation with small and large scale medical trials.

Now, the logic and contribution of this paper is to present a method on how Web-based patient information could be obtained and evaluated. To this aim, the following research questions (RQs) are considered:

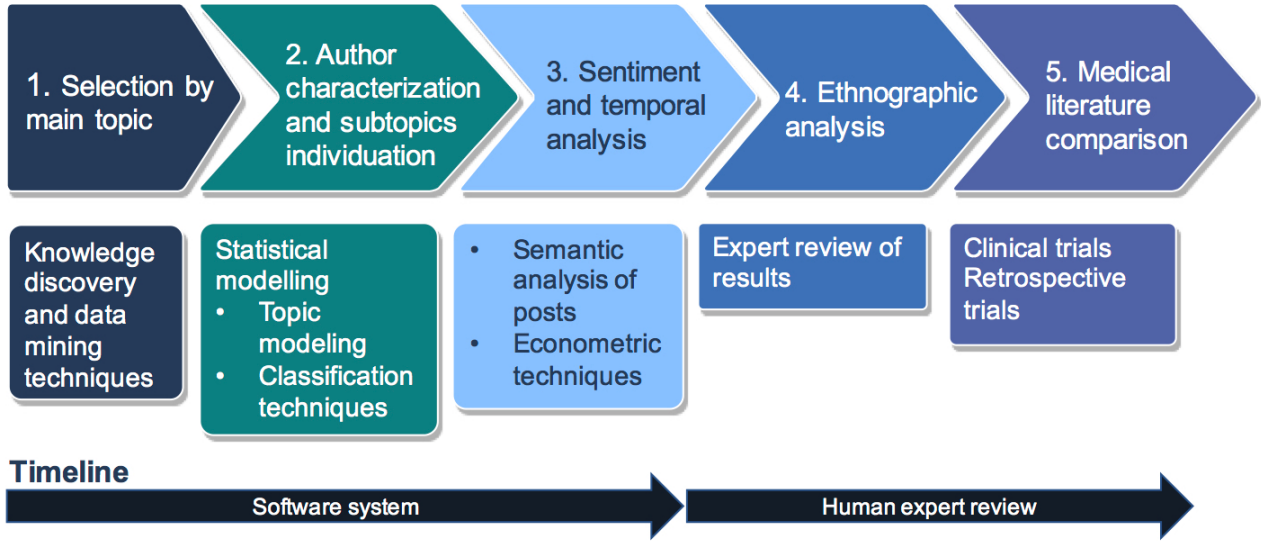
1. Between Twitter and Facebook, which social media platform do people post on most frequently?
2. Which topics trigger the most patient reactions (eg, medical therapy satisfaction or dissatisfaction)?
3. What kind of attitude do patients have toward the most debated topic (eg, positive, neutral, or negative)?

The results of this study should be integrated with traditional research approaches to help clinicians understand patients' perspectives.

Methods

Answers to RQ1, RQ2, and RQ3 were obtained following the methods delineated in Figure 1, where the problem of finding and analyzing Web-based data involves two steps. The first one (leftmost part of the timeline) relies completely on software components, whereas the second includes the intervention of human operators. Why this architectural choice has been made will become clear in the following subsections.

Figure 1. Web-based patient feedback analysis.



Topic Selection

To understand where patients share their experiences, we implemented a selection procedure (selection by main topic in Figure 1), a well-known operation in data mining and knowledge discovery [20,21]. In fact, no a priori knowledge may be available regarding where patients prefer sharing their experiences. Often the burden of such discovery process is very limited, as many forums and social media pages are often entirely dedicated to the discussion of given diseases. Hence, it is often simple to carry out this step accessing a great quantity of relevant data.

However, often posts are not written by patients (ie, many report scientific news or drug advertisements). Such a problem requires the implementation of mechanisms capable of identifying sites where patients publish their experiences. In our analysis of Crohn's disease patients, this has been done resorting to two different techniques known for the uncovering of social spammers [22,23].

The first technique simply amounts to identify nonhuman Web-based posts from the number of duplicate ones that may be associated to a single user account. In fact, duplicates are frequently associated to those accounts which are dedicated to post news or advertisements [22]. The second amounts to analyze the behaviors of single writers [23]. To this aim, we performed an additional test, assessing the role of the most prolific users on both social media (please note that this test could be performed automatically by a computer program) to determine whether they were patients or not.

Subtopic Individuation

The second step of interest is that of shaping the corpus of acquired data, characterizing and modeling it in terms of subtopics of interest. Four different subtopics have been individuated: lifestyle, symptoms, treatments, and side-effects, used to define four corresponding dictionaries. Such approach is consistent with previous works on medical data mining [24-26]. Within the lifestyle subtopic, we included all those terms that are related to the behavior of a patient (eg, food consumption habits and smoker or nonsmoker). Symptoms, treatments, and side-effects contain, instead, the words representing the distinctive signs of a disease (eg, fever and high pressure), the names of the medications utilized to contrast it (eg, tylenol and paracetamol), along with any related side-effect (eg, dizziness), respectively.

For the sake of completeness, we note that the number of subtopics, in general, may be any. The area of topic individuation and modeling is an active area of research whose developments may prove to be very useful in such context, to reveal the topics treated in a corpus of posts [27]. In text data mining, the creation of dictionaries is called feature selection. A wide variety of feature selection methods exist. One of the most common methods for quantifying the discrimination level of a feature is the use of a measure known as the Gini-index [28]. In essence, let $p_i(w)$ be the conditional probability that a document belongs to class i, given the fact that it contains the word w. The Gini-index for word w, denoted by $G(w)$, is defined as $G(w)=\sum p_i(w)^2$ where k amounts to the number of classes. The value of $G(w)$ always lies in $(1/k, 1)$, with higher values of $G(w)$ associated to a higher discriminative power of the word w. Such an approach is very general, however. For the very specific situations, say a situation where we are interested at selecting those posts where users mention a specific medication, setting w=medication name results a reliable indicator of an ongoing exchange regarding this topic.

Sentiment Analysis

After a topic has been identified and posts containing words pertaining to that topic selected, an additional step is performed to determine the relationship of a patient with the given topic. To this aim, sentiment analysis techniques have been exploited, as their performance is progressively becoming more accurate and reliable [29-33]. In this work we used University of Pittsburgh's OpinionFinder, but additional resources are freely available for the assessment of sentiment values in posts [34]. For example, the Apache OpenNLP framework could be utilized to classify text into predefined categories resorting to the maximum entropy algorithm [35]. Standford's StanfordNLP,

in addition, is a tool trained with 215,154 phrases with fine grained sentiment labeling [36].

Subsequently, in order to verify the correlation between given topics and given sentiment values, econometric approaches (eg, Granger causality) have been employed. Notably, we borrowed such an approach from social media data mining applied to stock exchange analysis [37]. Logistic regression approaches also appear viable for such a domain [38]. Simpler approaches could also be employed to verify the co-occurrence of negative or positive expressions with given key terms. In essence, various statistical analysis methodologies can be utilized to evaluate the importance of a given topic within post sentiment values.

Ethnographic Analysis

The use of software components in the chart shown in Figure 1 ends with the sentiment analysis step. After individuating the topic of greatest interest for patients, we analyzed, by ethnographic approach, the qualitative feeling of the patients on the specific issue. Since the use of the Infliximab therapy was the most discussed topic (see below), we adopted a 3-valued Likert scale to assess the sentiment value of a patient toward Infliximab [39]. A value of 1 was attributed to positive, 0 to neutral, and −1 to negative feelings. Because we wanted to investigate the reliability of such manual assessment, we compared the ethnographic analysis performed by a computer science researcher and a senior gastroenterologist. We then analyzed the concordance of such assessments using the square weighted Cohen's kappa coefficient method. Additionally, we also assessed the patients' feelings according to the 3-point Likert scale using our software system, which relied on OpinionFinder.

Results

Topics, Subtopics, and Sentiment Analysis

In 2014, 71% and 23% of adults on the Web used Facebook and Twitter, respectively [40]. Because of this fact, our attention focused on the posts that could be found on these two social networks. In fact, such two social networks have the potential of providing spontaneous and uncontrolled patients' opinions differently from thematic and moderated Web-based platforms specifically designed for patients.

To begin our analysis (RQ1), we searched for the "crohn" keyword to select relevant tweets on Twitter and to individuate Crohn's Facebook public pages from their title. By these means, we found over 26,000 tweets and almost 56,000 posts on Facebook published from October 2011 to August 2015. A further analysis of such posts let us conclude that the feedback of real patients is more easily found on Facebook rather than on Twitter (such result corroborates similar findings) [18].

Concentrating on Facebook, we found the terms that belonged to the four subtopics of interest, and we selected those that appeared at least 50 times (Table 1). Such dictionaries include both specific terms (eg, diarrhea or abdomen) but also generic ones that are related to the subtopic (eg, suffer or symptom). Please note that our results are consistent with the findings obtained using a different methodology based on metadata analysis from PubMed [24].

The analysis of such subtopics produced three terms (RQ2), namely Adalimumab, Azathioprine, and Infliximab, which triggered the longest and most vibrant discussions among people. We then adopted Granger and sentiment analysis to investigate which one of these three terms was more strictly related to the patients' feelings. Infliximab was the most sentiment-related term, with a statistical significance association to either positive or negative feelings (P=.04 and P=.01, for positive and negative feeling, respectively).

Ethnographic Analysis of Posts Related to Infliximab

Inspired by ethnographic approaches [41], we performed an expert review of the threads of 261 posts containing the keyword Infliximab (such posts are available in the study by Roccetti M. et al [42]). Two different groups of experts read all the posts containing the term Infliximab (or alternative trade names such as Remicade) to either confirm or deny the positive or negative evaluations assigned to those posts by the employed software system.

The classification performed by both groups (computer scientist and senior gastroenterologist) confirmed that a relevant fraction of patients treated with Infliximab were not fully satisfied. The outcome (RQ3) is portrayed in Figure 2.

Table 1. Subtopic dictionaries.

Subtopics	Dictionary
Lifestyle	Alcohol, bacteria, butter, cake, cell, chocolate, coffee, drink, eggs, food, gene, honey, lactose, map, meat, milk, pasta, smoke, sugar, tnf, virus, vitamin, and wine.
Symptoms and body parts	Abdomen, abscess, agony, anal, anxiety, appetite, arthritis, attack, belly, bladder, bleed, blood, bone, bowel, butt, colitis, constipation, cramp, damage, deficiency, depression, diabetes, diarrhea, digestion, disorder, exhausted, fever, fistula, flare, flu, gastro, grow, hurt, infection, inflamed, intestine, liver, mouth, muscle, nausea, pain, psoriasis, rectum, scar, severe, sleep, stress, suffer, symptom, tired, toilet, ulcer, and vomit.
Treatments	Adalimumab, aloe, antibiotic, asacol, azathioprine, budesonide, calcium, cannabis, capsule, certolizumab, cimzia, colectomy, colonoscopy, colostomy, diagnosis, diet, doctor, dose, drain, entocort, enzyme, fda, ferment, ginger, gp, health care, hospital, humira, ileostomy, imuran, infliximab, infusion, injection, kefir, marijuana, medication, medicine, mercaptopurine, methotrexate, morphine, mri, natural, nutrition, operation, oral, organic, paleo, pentasa, powder, prednisolone, prescribed, prescription, probiotic, rafton, remedy, remicade, resection, reversal, scd, solution, specialist, steroid, surgeon, surgery, test, therapy, transplant, treat, and visit.
Side-effects	Complications, effect, lupus, reaction allergy, and skin.

Figure 2. Computer scientist (red bars), senior gastroenterologist (green bars), and software classification (blue bars).

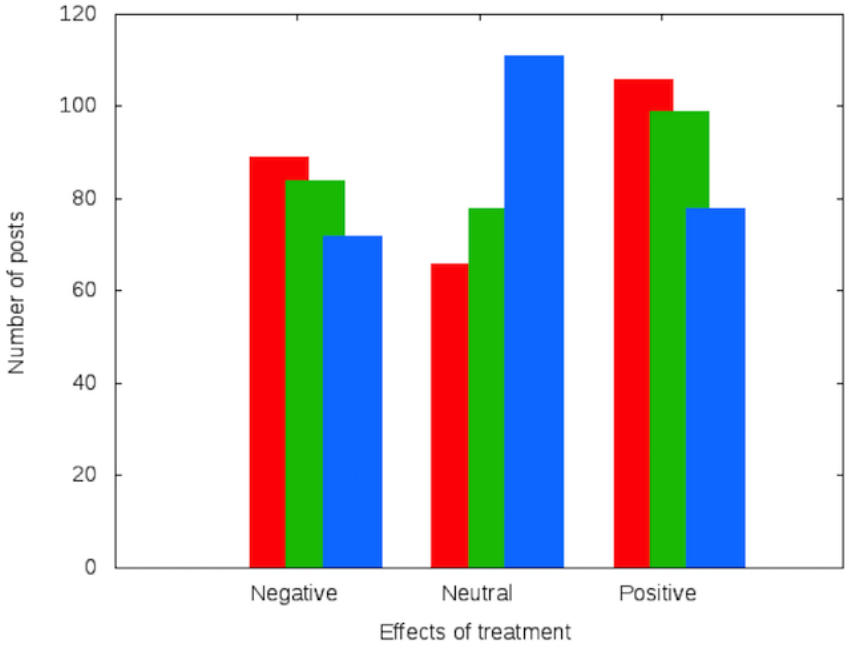


Table 2. Square weighted Cohen's kappa coefficient (w2K) for the interrater agreement. The number of patients corresponding to the attributed score (−1, 0, 1) is indicated for each different observer (senior gastroenterologist vs computer science expert). The interobserver agreement was substantial: 87.36% (w2K: 0.6470).

	Computer science expert score			
Senior gastroenterologist score	−1	0	1	Total
−1	62	17	5	84
0	22	40	16	78
1	11	13	75	99
Total	95	70	96	261

Both expert reviews point to the same conclusions, as confirmed by interrater agreement statistical analysis (data reported in Table 2). The interrater agreement was performed using a square weighted Cohen's kappa coefficient (w2K). A substantial agreement (w2K=0.6470, corresponding to 87.36%) was found comparing the computer scientist versus the senior gastroenterologist evaluation of patients' global sentiment. This result indicates that the evaluation of the feeling that was communicated by a post was independent of the scientific background of the reader, although the senior gastroenterologist tended to classify as neutral a slightly larger share of posts, as not deemed relevant from a clinical point of view.

The classification performed by our software system, instead, provides a different outcome than those given by the computer science expert and by the senior gastroenterologist. In fact, the number of posts classified as neutral increase, as the sentiment analysis algorithm was evidently unable to determine with a precision similar to a human being the underlying meaning of a piece of text. Nonetheless, the proportion between positive and negative posts remains comparable, showing that the algorithmic tool could be useful to determine the existence of situations where positive and negative remarks concerning Infliximab were made.

Discussion

The availability of big data from social networks may be seen as an important source of information in medical research, alternative to the traditional sources of information [43,44]. Obviously, there are limitations, as patient characteristics (eg, age and sex) are often unknown.

We used social networks to analyze the perception of therapies by Crohn's disease patients. Crohn's disease has been chosen because of its well-defined features of chronic and sometimes disabling disease, with a strong impact on the quality of life of patients. Additionally, Crohn's disease is typically diagnosed in young patients (in the age range of 15-30 years), an age group of frequent social network users.

This work expands our previous studies, to propose a method to analyze the information posted on the Web. An important point of this work is that we use data derived from external observation of patients' spontaneous opinions during their daily lives. From this perspective, this study is a meticulous observation of the big data that a social network like Facebook may supply.

Our previous analyses revealed that Facebook (RQ1), with respect to Twitter, is the social network in which it is easier to find Crohn's disease information [18]. Our further studies individuated Infliximab as the most debated drug (RQ2), with both positive and negative sentiments among Crohn's disease patients [19]. This result was justifiable considering that Infliximab has been the first biological treatment (ie, monoclonal antibody) capable of strongly improving Crohn's disease management, with a rapid diffusion in the clinical setting. In addition, social networks usage started a few years after the 1998 approval of the Infliximab therapy for Crohn's disease patients, and this chronological coincidence possibly boosted the discussion on sites such as Facebook. Notably, a good match was found between the sentiment assessments in relation to Infliximab obtained, with the ethnographic analyses performed by either computer science or gastroenterology experts (RQ3). This indicates that a data mining approach provided material of simple interpretation, regardless of the analysts' scientific and professional background. This represents a good starting point to provide a completely automated approach for the analysis of such data, in substitution of the final ethnographic step performed in this work. Another important finding is that our ethnographic results are in substantial agreement with the medical literature. In fact, medical trials involving large numbers of patients (large-scale retrospective trials) exhibit a percentage of those who experienced a negative reaction to Infliximab falling between 20-40% [45,46].

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Authors' Contributions

The authors declare an equal contribution to this manuscript in all of its phases. These include the design of the research activities, experimental studies, and the writing of the manuscript. In particular, MR, GM, PS, and CP have collaborated on ideating, designing, and developing the computer application that has been utilized to gather and classify data. Additionally, RMZ, FLGK, FB, and MM have contributed to the analysis of the supplied data from a medical and statistical viewpoint.

Conflicts of Interest

None declared.

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Original Paper

Classification of Twitter Users Who Tweet About E-Cigarettes

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Abstract

Background: Despite concerns about their health risks, e-cigarettes have gained popularity in recent years. Concurrent with the recent increase in e-cigarette use, social media sites such as Twitter have become a common platform for sharing information about e-cigarettes and to promote marketing of e-cigarettes. Monitoring the trends in e-cigarette–related social media activity requires timely assessment of the content of posts and the types of users generating the content. However, little is known about the diversity of the types of users responsible for generating e-cigarette–related content on Twitter.

Objective: The aim of this study was to demonstrate a novel methodology for automatically classifying Twitter users who tweet about e-cigarette–related topics into distinct categories.

Methods: We collected approximately 11.5 million e-cigarette–related tweets posted between November 2014 and October 2016 and obtained a random sample of Twitter users who tweeted about e-cigarettes. Trained human coders examined the handles' profiles and manually categorized each as one of the following user types: individual (n=2168), vaper enthusiast (n=334), informed agency (n=622), marketer (n=752), and spammer (n=1021). Next, the Twitter metadata as well as a sample of tweets for each labeled user were gathered, and features that reflect users' metadata and tweeting behavior were analyzed. Finally, multiple machine learning algorithms were tested to identify a model with the best performance in classifying user types.

Results: Using a classification model that included metadata and features associated with tweeting behavior, we were able to predict with relatively high accuracy five different types of Twitter users that tweet about e-cigarettes (average F_1 score=83.3%). Accuracy varied by user type, with F_1 scores of individuals, informed agencies, marketers, spammers, and vaper enthusiasts being 91.1%, 84.4%, 81.2%, 79.5%, and 47.1%, respectively. Vaper enthusiasts were the most challenging user type to predict accurately and were commonly misclassified as marketers. The inclusion of additional tweet-derived features that capture tweeting behavior was found to significantly improve the model performance—an overall F_1 score gain of 10.6%—beyond metadata features alone.

Conclusions: This study provides a method for classifying five different types of users who tweet about e-cigarettes. Our model achieved high levels of classification performance for most groups, and examining the tweeting behavior was critical in improving the model performance. Results can help identify groups engaged in conversations about e-cigarettes online to help inform public health surveillance, education, and regulatory efforts.

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KEYWORDS

electronic cigarettes; social media; machine learning

Introduction

E-cigarettes have gained popularity among adults and youth in recent years. Following sustained increases in the use of e-cigarettes by adults from 2010 to 2013 [1], the prevalence of adult e-cigarette use plateaued at 3.7% in 2014 and was reported to be much higher among current cigarette smokers (15.9%) [2]. Despite the slight decline in the use of e-cigarettes by youth from 2014 to 2015, e-cigarettes remain the most commonly used tobacco product among the middle and high school students in the United States, with 16.0% reporting current use in 2015 [3,4]. Although the long-term health effects of e-cigarette use are largely unknown, e-cigarettes commonly contain nicotine, which has negative effects on the adolescent brain [5], along with a range of other chemicals that are harmful to human health [6-10]. In addition, youth who initiate nicotine use with e-cigarettes may transition to combustible tobacco use [11-14], which has been identified as the leading preventable cause of death in the United States [15].

Concurrent with the rapid rise in e-cigarette use, advertising and sharing of information about e-cigarettes have proliferated in recent years. Although advertisements for tobacco products have been banned on television since 1971 in the United States, e-cigarette advertising via television, magazines, outdoor, radio, and Web-based channels has increased dramatically between 2010 and 2013. Approximately 24 million adolescents were exposed to e-cigarette advertising in 2014 [16]. In addition to traditional advertising platforms, e-cigarette–related information and promotional material are widely available through e-cigarette user forums, Web-based marketing, branded websites, and user-generated content on social media sites such as Twitter and YouTube [17,18].

Social media has become a particularly important platform for sharing information about e-cigarettes. The majority of youth (81%) and adults (74%) in the United States use some form of social media [19-21], and the microblog, Twitter, has more than 316 million active users creating more than 500 million brief posts (called *tweets*) daily [22]. Twitter's pervasiveness makes it a convenient tool for e-cigarette manufacturers, enthusiasts, and advocates to promote e-cigarettes actively to a wide audience. Some studies of the content of e-cigarette–related tweets suggest that the overwhelming majority is commercial or promotional in nature [23-25], and many of these tweets offer discounts or free samples [24]. However, recent research suggests that many tweets reflect discussion of policies, personal experiences, and risks and benefits associated with e-cigarette use among individuals and e-cigarette proponents [26]. Another study found that although the majority of Twitter users engaged in social media conversations about e-cigarettes are not affiliated with the e-cigarette industry, e-cigarette proponents (ie, e-cigarette marketing or manufacturing representatives, advocates, and enthusiasts) tweet more frequently and are more likely to highlight favorable aspects of e-cigarette use [27].

Monitoring trends in e-cigarette–related social media activity requires timely assessment of the content of posts and the types of users generating the content to inform regulatory and surveillance efforts. In 2016, the Food and Drug Administration (FDA) finalized a rule extending the agency's authority to regulate e-cigarettes, which includes federal provisions requiring companies that sell e-cigarettes to include warning statements about nicotine on advertising and promotional materials, including content on digital/social media. To ensure that e-cigarette companies are complying with these advertising and labeling restrictions, FDA will need to identify and monitor websites and social media accounts maintained by these companies. Furthermore, as public health researchers continue to use social media data to track and understand emerging issues concerning e-cigarettes, they will need to be able to distinguish between the content from individuals who may be the target of Web-based e-cigarette advertising (eg, young adults) and the content from e-cigarette companies, marketers, or spammers who may be posting content for commercial purposes. Such information could also be useful in the development and targeting of social media campaigns to prevent e-cigarette use.

The proliferation and variety of Web-based information sharing about e-cigarettes presents challenges in differentiating content from different types of social media users. Previous studies have used a range of techniques to identify Twitter accounts that are purely automated (*robots*), human-assisted automated (*cyborgs*), or organic (ie, individuals) [28] and to distinguish between promotional and nonpromotional tweets [25,29]. Less is known about identifying the diversity of user types responsible for generating e-cigarette–related content on Twitter, including vape proponents, promotional marketers, automated spammers, public health agencies, news organizations, and individuals. In a recent study of tweets about e-cigarettes, Lazard and colleagues [26] analyzed clusters of e-cigarette topics (eg, marketing-focused personal experience) to categorize tweets as being generated by marketers, individual users, or e-cigarette proponents. However, this assessment was based on a review of the topics being discussed (eg, personal experience about e-cigarette use must be posted by individual users) and was not informed by analysis of user handles that were tweeting the content. Thus, Lazard and colleagues' attribution of message source may be limited. For example, Lazard and colleagues reported that tweets about e-cigarette policy bans (a common topic cluster identified in the study) were posted by e-cigarette proponents opposing the ban, but these tweets could have been posted by policy makers announcing or promoting the ban. Examining the topic of tweets may not be sufficient for attributing the source of the message. A more detailed assessment of Twitter users' profile and tweet metadata, in addition to the content of their tweets, could provide better insights into the types of users posting the content.

This study demonstrates a novel methodology for automatically classifying Twitter users who tweet about e-cigarette–related topics into five categories of users—individuals, vaper enthusiasts, informed agencies, marketers, and spammers. We used a supervised machine learning approach to predict different types of Twitter users based on their metadata and tweeting behavior. We tested different models, evaluated model performance, and discussed features that are most predictive of each user type. This study expands on previous research studying the content and the types of users who tweet about e-cigarettes [23-25,27] by providing a greater level of granularity

in the classification of users. Findings from this study provide insight into the composition and the characteristics of social media users posting about e-cigarettes, which can help inform future regulatory action.

Methods

Using a supervised machine learning approach, we developed models to predict different types of Twitter users who tweet about e-cigarettes. First, a random sample of Twitter handles that have tweeted about e-cigarettes was obtained, and our trained human coders examined the handles' profiles and manually labeled a specific user type for each handle. Next, Twitter metadata and a sample of tweets for each labeled user were gathered, and features that reflect users' metadata and tweeting behavior were created. In the final steps, multiple machine learning algorithms to identify a model with the best classification performance were tested. Figure 1 illustrates our approach to developing the classification model, which we describe further in the sections below. This study was exempt from the institutional review board (IRB) review because it used publicly available Twitter data. Our approach to obtaining and analyzing the Twitter data was in compliance with Twitter's terms of service at the time of the study, such as removing tweets that were deleted or made private by the user.

Phase 1: Twitter Data Source and Manual Annotation of User Types

Using Twitter's enterprise application programming interface (API) platform, Gnip, we collected e-cigarette–related tweets posted between November 2014 and October 2016. A comprehensive search syntax was developed with 158 keywords, including terms such as *ecig*, *vape*, and *ejuice*, as well as popular e-cigarette brands and hashtags, which resulted in approximately 11.5 million e-cigarette–related tweets from 2.6 million unique users. Next, a random sample of the users associated with these tweets was reviewed, and the content of their posts was examined to identify the range of entities tweeting about e-cigarettes. Using a grounded theory approach informed by literature review and guidance from subject matter experts, a protocol was developed for categorizing Twitter users who tweet about e-cigarettes according to the following types: (1) individual, (2) vaper enthusiast, (3) informed agency, (4) marketer, and (5) spammer (see Table 1).

Six coders were trained using the protocol and practice data to classify the user types manually. For each user, the coders reviewed the user's profile page on Twitter, which included a profile description and a sample of recent tweets on their timeline, which may have included e-cigarette and non-e-cigarette topics. Random samples of Twitter users were double coded until at least 300 labeled cases were obtained per user type. Coding discrepancies were resolved by an adjudicator. In total, 4897 users were manually classified according to the user type definitions (see Table 1 for coding results).

Figure 1. Approach to classifying Twitter users who tweet about e-cigarettes.

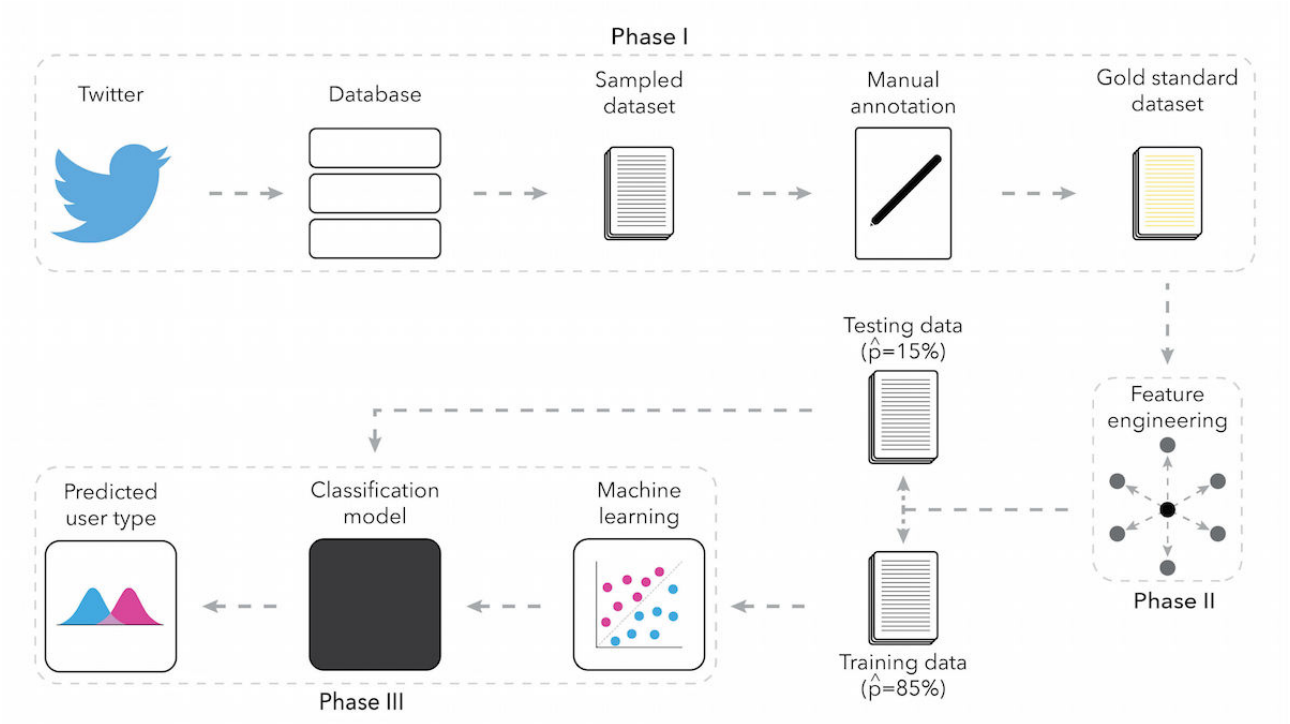


Table 1. Manual classification of Twitter users who tweet about e-cigarettes: user type definitions and proportion of each type in manually labeled sample.

Type	Definition	Sample, N
Individual	The account of a real person whose Twitter profile information and tweets reflect their individual thoughts and interests. An individual is someone whose primary post content is not about vaping.	2168
Vaper enthusiast	The account of a person or organization whose primary content is related to promoting e-cigarettes but is not primarily trying to sell e-cigarettes or related products.	334
Informed agency[a]		622
News media	The account of a newspaper, magazine, news channel, etc. News media does not include vaping-specific news sources.	
Health community	The account of a public health organization, coalition, agency, or credible individual affiliated with an organization. These may also be the accounts of organizations with authority on a topic that should be thought of as *trusted sources*.	
Marketer[a]		752
Marketer	An account marketing e-cigarette or vaping products. These accounts can belong to a Web-based or brick-and-mortar retailer or an individual who is an affiliate marketer.	
Information aggregator	An account that primarily aggregates information about e-cigarettes/vaping and where most or all tweets are news articles related to e-cigarettes/vaping. This account could also aggregate vaping coupons or deals.	
Spammer	An account that does not fall into one of the other coding categories. These accounts often post on a broad range of topics unrelated to this project, and their content can be nonsensical. Anecdotally, it was observed that many of these accounts exhibited *bot* behaviors.	1021

[a]During manual annotation of data, we initially categorized subtypes of informed agency (ie, news media and health community) and marketer (ie, marketer and information aggregator) user types, but we did not identify sufficient numbers of user handles for these subtypes to conduct meaningful analyses. Thus, during the feature selection and modeling phases, we collapsed across user subtypes to define five total user types.

Phase 2: User Metadata Features and Derived Behavioral Features

Next, we built out the feature space for 4897 labeled users, extracting the metadata provided by the Twitter API and engineering our own features that were derived from the users' tweet text (see Multimedia Appendix 1).

User Metadata Features

The Twitter API provides basic profile information about a user such as screen name, location, bio, number of friends, number of followers, and total number of tweets. The API also provides the actual tweet text and underlying metadata associated with tweet text that was used in this study to characterize the tweeting behavior (eg, retweet) of the users. These types of metadata features have a demonstrated utility in characterizing different types of users [30,31]. Using the Twitter API, 15 metadata features were obtained for each labeled user. Examples of metadata features include number of followers and the number of tweets favorited by the user (see Multimedia Appendix 1).

Derived Tweeting Behavior Features

In addition to the metadata, the users' tweet text data were also examined to capture their tweeting behavior. It was hypothesized that tweeting behaviors would vary across different user types (eg, individuals are likely to tweet about more diverse topics than marketers). Studies have shown that linguistic content of social media posts is particularly useful because it illustrates the topics of interest to a user and provides information about their lexical usage that may be predictive of certain user types [32,33]. For each Twitter handle, the 200 most recent publicly available tweets were collected using the Twitter REST API. Previous studies have shown that 100 to 200 tweets are typically sufficient for predicting Twitter user characteristics [34,35]. These 200 tweets included tweets about e-cigarettes as well as non-e-cigarette–related topics. The non-e-cigarette–related tweets were included because most of the user types examined in this study (eg, news media agency, individuals, and public health agencies) do not tweet about e-cigarettes alone.

To capture the users' tweeting behavior, 58 features derived from the behavioral and linguistic content of the account profile and the tweet text were generated; summary statistics of sets of users' tweets were also created. To generate these features, a variety of text mining techniques were used to capture the distribution characteristics of the users' tweeting behavior and word usage. For example, the minimum, maximum, median, mean, and mode for how many times an e-cigarette keyword was used per tweet was calculated. A term frequency-inverse document frequency matrix of each user's corpus of tweets (up to 200 tweets) was also created, and the pair-wise cosine similarity between each tweet was calculated. For each user, the mean and standard deviation of the set of cosine similarity values, which provided a sense of the semantic diversity and consistency of a user's vocabulary, was calculated. After generating the behavioral features, we dropped nine features in our dataset that had more than 10% missing data. Then, a mean imputation was performed on the derived features that had 10% or less missing data.

Phase 3: Predictive Models

To determine the best model for classifying the user types, several different algorithms were built and compared using the features described in phase 2. Before modeling, the data were split into a training set (85%) and a test set (15%), using stratified sampling to preserve the relative ratio of classes across sets. To construct our models, a stratified 10-fold cross-validation on the training set was first run and eight different classifiers as well as a *dummy classifier* were evaluated. The dummy classifier—which makes random guesses based on the known distributions of user types in the training data—served as a benchmark for evaluating the performance of our other models. The results from these analyses showed that F_1 scores were highest (82.5%) for the Gradient Boosting Regression Trees (GBRT) classifier and lowest for the dummy classifier (28.6%) (see Multimedia Appendix 2 for results of all classifiers).

On the basis of these results, the GBRT algorithm was used to classify the testing dataset. The GBRT approach builds an additive model in a forward stage-wise fashion [36]. The *boosting* technique combines an ensemble of many weak predictive models—in this case, shallow trees—into a single strong one [37]. Each weak model is weighted and trained to be an *expert* on the residuals of the preceding model [38,39] (see Multimedia Appendix 3 for additional information about GBRT and the other algorithms examined).

To determine the best tuning values for the hyperparameters in our model, a fourfold grid-search cross-validation on the training dataset was run (see Multimedia Appendix 3). Then, to evaluate the performance of our tuned GBRT model and the marginal impact of our derived features in improving class differentiation, two separate models were run—one composed of metadata features alone and the other composed of both metadata and derived features. These two separate models were used to evaluate the marginal impact of adding derived features as metadata features for user profile and tweets are easily obtainable, whereas derived features are more labor intensive to create. Finally, the extent of misclassification and the most important features for user types were examined.

Results

User Classification Model Results

Table 2 presents the GBRT model results for predicting different types of Twitter users who have tweeted about e-cigarettes. When the complete dataset (metadata + derived features) was tested, the model achieved an average F_1 score of 83.3% across all user types. The F_1 score was highest for predicting individuals (91.1%) and progressively lower for informed agencies (84.4%), marketers (81.2%), spammers (79.5%), and vaper enthusiasts (47.1%).

The metadata-only model (72.7%) achieved lower F_1 scores than the full model (83.3%) (Table 2). Including derived features in the full model improved classification results for each user type, with improvements in F_1 scores ranging from 7.5% for individuals to 30.9% for vaper enthusiasts.

Table 2. Classification of Twitter users who tweet about e-cigarettes: Gradient Boosting Regression Trees (GBRT) results comparing full model and metadata-only model.

User type	Full model (metadata + derived data)			Metadata-only model		
	F_1 score, %	Recall, %	Precision, %	F_1 score, %	Recall, %	Precision, %
Individual	91.1	92.3	89.8	83.6	86.2	81.2
Vaper enthusiast	47.1	40.0	57.1	16.2	12.0	25.0
Informed agency	84.4	78.5	91.3	70.0	67.7	72.4
Marketer	81.2	85.9	77.0	65.6	72.6	59.9
Spammer	79.5	81.1	78.0	74.8	71.9	78.0
Average	83.3	83.7	83.3	72.7	73.7	72.3

Misclassification

To further examine variations in the predictive performance across user types, a confusion matrix illustrating predicted and actual user types was generated. Figure 2 shows the distribution of predicted user types on the horizontal axis and actual user types from the manual coding on the vertical axis. To aid in interpretation, the predicted sample proportion for each user type is shaded from light (low proportion) to dark (high proportion). Darker shading in the cells along the diagonal indicates correct classification, whereas darker shading elsewhere indicates misclassification. For example, of the 325 users manually coded as individuals, 300 (92.3%) were correctly predicted to be individuals. In contrast, there was a high level of misclassification of vaper enthusiasts; only 20 of the 50 vaper enthusiasts (40.0%) were correctly predicted to be vaper enthusiasts, whereas 22 (44.0%) were misclassified as marketers.

A two-dimensional (2D) plot of the feature space was also constructed to better understand the extent to which the user types fall into naturally separated clusters (see Figure 3). To accomplish this, a dimensionality reduction method called t-distributed stochastic neighbor embedding (t-SNE) [40] was used to create a 2D representation of the 78-dimensional feature space (see Figure 3). The results of the t-SNE plot indicate that individuals, marketers, and informed agencies fall into fairly discrete clusters, with some users in each class falling closer to other clusters. The plot also shows that whereas spammers are also fairly distinct from other user types, this user type appears to comprise two to three clusters, perhaps suggestive of different subtypes of spammers. Vaper enthusiasts also comprise a distinct

cluster, but there appears to be a substantial overlap between vaper enthusiast and marketer clusters.

Figure 2. Distributions of manually labeled versus model-predicted classification of Twitter users who tweet about e-cigarettes.

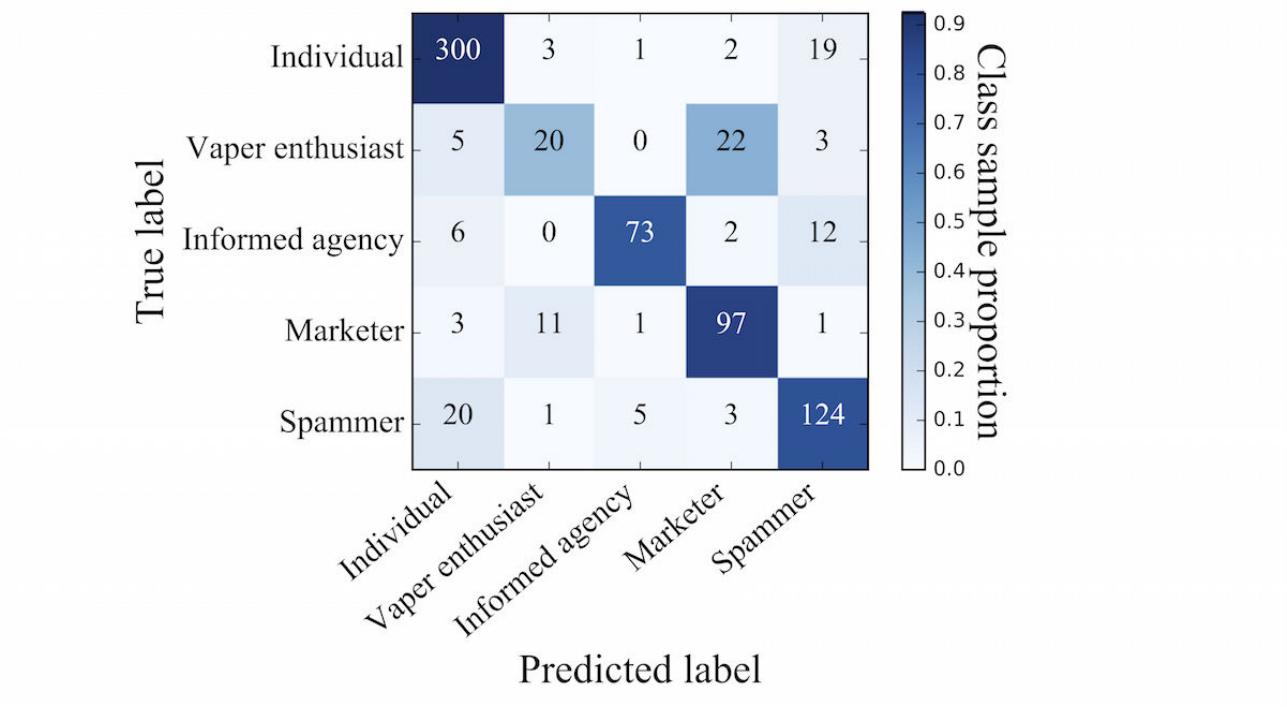


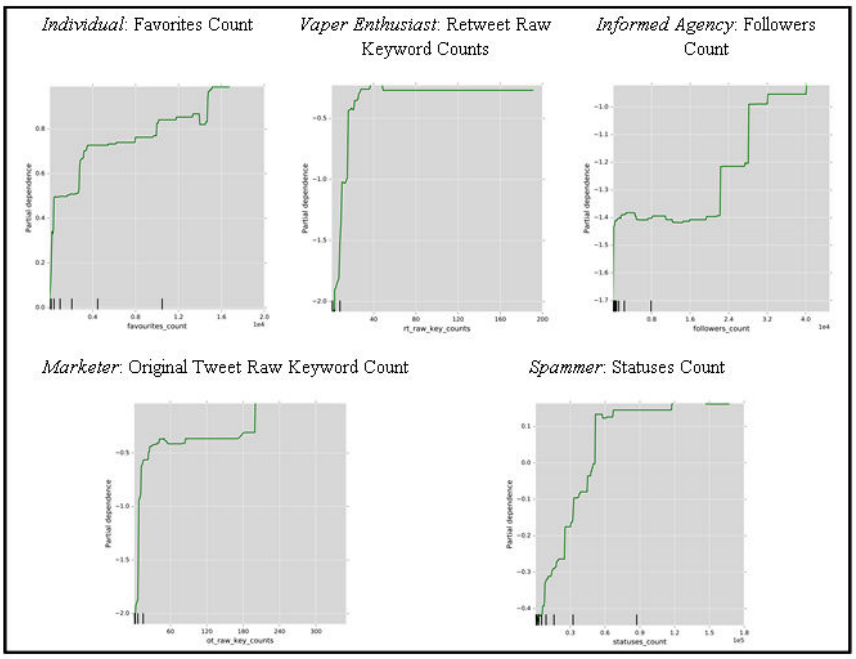
Figure 3. Two-dimensional t-SNE visualization of Twitter users who tweet about e-cigarettes.

Table 3. Ten most important features in predicting Twitter users who tweet about e-cigarettes across all user types.

Features[a]	Proportion of feature importance among all variables, %
Statuses count	5.1
Followers count	4.1
Original tweet raw keyword count	3.7
Profile description keyword count	3.3
Original tweet cosine similarity mean	3.2
Retweet cosine similarity mean	3.0
Friends count	3.0
Retweet raw keyword count	3.0
Listed count	2.9
Original tweet URL count mean	2.7
Favorites count	2.7

[a]Most important feature among each user type—Individual: favorites count (4.9%); Vaper enthusiast: retweet raw keyword count (8.3%); Informed agency: followers count (6.5%); Marketer: original tweet raw keyword counts (8.9%); Spammer: statuses count (8.1%).

Figure 4. Partial dependence plots of top features by user type for users who tweet about e-cigarettes.



Feature Importance

To better understand the contribution of each variable in our modeling outcome, each variable was evaluated using Gini Importance, which is commonly used in ensembles of decision trees as a measure of a variable's impact in predicting a label that also takes into account estimated error in randomly labeling an observation according to the known label distributions [41]. Table 3 shows the top 10 most important features, ranked by the proportion of feature importance among all variables in the full model. Results show that two profile metadata features—statuses count and followers count—represent the most important features in the model, with values of 5.1% and 4.1%, respectively. Several derived data features were also important, including original tweet raw keyword counts (3.7%), profile description keyword count (3.3%), and original tweet cosine similarity mean (3.2%). The single most important feature varied among the user types. For individuals, the most important feature was favorites count (4.9%); for vaper enthusiasts, it was retweet raw keyword count (8.3%); for informed agencies, it was followers count (6.5%); for marketers, it was original tweet raw keyword count (8.9%); and for spammers, it was statuses count (8.1%). Feature importance scores for all features examined is available in Multimedia Appendix 4.

Partial dependence plots (PDPs) illustrate the dependence between a target function (ie, user type) and a set of target features. Figure 4 shows PDPs for each user type, illustrating the association between user type and the most important feature for that particular group. Figure 4 shows the most important

features for each user type, whereas Table 3 summarizes the most important features across all user types. For individuals, as the number of tweets the user has liked increases, a given user is more likely to be classified as an individual. For informed agencies, as the number of followers increases, a given user is more likely to be classified as an informed agency. For marketers, as the number of raw keyword counts increases in a given user's set of original tweets, that user is more likely to be classified as a marketer. This indicates that marketers tend to create original content using e-cigarette terms. For spammers, as the total number of statuses (original tweets and retweets) count increases, a given user is more likely to be classified as a spammer. For vaper enthusiasts, as the number of raw keyword counts increases in a given user's set of retweets, that user is more likely to be classified as a vaper enthusiast. This indicates that vaper enthusiasts tend to retweet content with e-cigarette terms.

Discussion

Principal Findings

In summary, we developed algorithms with relatively high performance in predicting different types of Twitter users that tweet about e-cigarettes. The rates of precision and recall for *most* user types ranged from 78% to 92%, which was well above the baseline dummy classification and serves as a new baseline for the future user type classification of users who tweet about e-cigarette content on Twitter. Although using metadata features alone in user classification demonstrates performance gains over dummy classification, the results of this study suggest that including additional tweet-derived features that capture tweeting behavior significantly improves the model performance—an overall F_1 score gain of 10.6%—beyond metadata features alone. Previous studies have shown that tweet linguistic patterns are strong predictors of social media user demographics [42]. This is the first study to show the predictive utility of tweeting behavior in classifying different types of users who tweet about e-cigarettes.

We achieved the best performance in predicting individuals, informed agencies (news media and health agencies), and marketers. In contrast, vaper enthusiasts were challenging to predict and were commonly misclassified as marketers. There are several reasons why this may be the case. First, it is possible that there were not enough labeled cases of vaper enthusiasts for the machine learning models; there were only 334 labeled cases of vaper enthusiasts (6.8% of all labeled users) compared with 622 to 2168 cases for the other classes. Second, vaper enthusiasts are an evolving group of individuals, and their tweeting behavior may therefore vary more than other established user types such as informed agencies (eg, news media and health agencies). Third, our definition of vaper enthusiasts may not have been distinct enough from marketers; a vaper enthusiast was defined as a user whose primary objective is to *promote but not sell* e-cigarette/vaping products, whereas a marketer was defined as a user whose primary objective is to *market and sell* e-cigarette/vaping products. The distinction of promoting but not selling may have been too subtle to pick up, as vaper enthusiasts promote e-cigarettes by using similar strategies that marketers employ to sell products, such as sharing information about new products, promoting giveaways, and posting product reviews. It is possible that having more labeled cases and extracting more than 200 tweets per handle could improve model performance and better discriminate vaper enthusiasts from marketers. Alternatively, not being able to distinguish vaper enthusiasts from marketers may signal that they share common interests and possible affiliations. With the rise of *social influencer marketing*, where brands incentivize influencers to promote products or subcultures on social media, it is possible that vaper enthusiast messaging may represent commercial marketing interests. The vagueness and ambiguity that was observed between the feature spaces of the vaper enthusiast and marketer classes warrants additional research that examines potential relationships between vaper enthusiasts and e-cigarette commercial entities.

Given the overlap between vaper enthusiasts and marketers, a possible strategy to improve predictive performance might be to combine the two groups. In fact, in their study, Kavuluru and Sabbir [27] classified e-cigarette proponents as "tweeters who represent e-cigarette sales or marketing agencies, individuals who advocate e-cigarettes, or tweeters who specifically identify themselves as vapers in their profile bio." They achieved a high level of accuracy in predicting these e-cigarette proponents (97% precision, 86% recall, and 91% F-score). Although combining these groups may help improve model performance, from a public health perspective, these are distinct groups whose Web-based behaviors have different implications for regulatory agencies. For example, FDA has the authority to regulate claims made by e-cigarette companies and will need to monitor e-cigarette brand social media handles to ensure that they are being compliant with regulatory policies (eg, not making cessation claims, posting warning statements about the harmful effects of nicotine) [43]. In contrast, FDA cannot regulate claims made by vaper enthusiasts because they are individuals and not companies selling e-cigarette products. Therefore, distinguishing vaper enthusiasts from marketers is critical to informing FDA compliance and enforcement efforts. Being able to distinguish vaper enthusiasts from marketers is also important with regard to public health education efforts because vaper enthusiasts have been known to undermine e-cigarette education campaigns. For example, when the California Department of Public Health launched its *Still Blowing Smoke* campaign to educate consumers about the potential harmful effects of e-cigarette use, vaper advocates launched a countercampaign (*Not Blowing Smoke*). By using both hashtags and creating new accounts, the countercampaign attacked the credibility of messages of the California Department of Public Health and effectively controlled the messaging on social media [44]. We would argue that classifying marketers and vaper enthusiasts separately is important for informing e-cigarette surveillance, regulatory, and education efforts; thus, future studies should build on our results and examine methods to improve classification of vaper enthusiasts.

In this study, the top features that were most predictive of each user type were also examined. Individuals like more tweets than nonindividuals; informed agencies have more followers than their counterparts; marketers use more e-cigarette words in their

original tweets than nonmarketers; vaper enthusiasts retweet e-cigarette content more than nonvaper enthusiasts; and more frequent tweeting behavior is indicative of spammers. Given the infancy of this research, the findings of this study should be viewed as an initial inquiry into classifying different types of users who tweet about e-cigarettes. Future studies should build on this work and examine other features that may be predictive of these classes of users. For example, other researchers have examined features such as sentiment of tweets [27] to classify certain subgroups of users who tweet about e-cigarettes.

Limitations

Our study has several limitations. First, because of resource constraints, we only collected the 200 most recent tweets for the users in our dataset, and some users had less than 200 tweets in total. Previous studies examining Twitter metadata and linguistic features to predict sociodemographic characteristics of users (eg, gender and age) have extracted up to 3200 tweets per handle, but other researchers have also found that having more than 100 tweets per handle did not necessarily improve the model performance [34]. Additional studies are needed to determine whether increasing the number of tweets for each user would increase the importance of the behavioral features in our classification of user types. Second, the methodology involved manual feature engineering, which can be time intensive and is limited to researcher-defined categories. A neural network approach could enable more automated construction of other text-based features that may help in distinguishing user types. Whereas computational text mining methods make it easy to create a multitude of different features, having more features may not necessarily yield information that is useful for classification tasks [31]. Furthermore, issues about scalability and reproducibility should be considered. As social media data are increasingly being used in applied fields such as public health, we need to consider how to balance the resources to conduct this type of analysis with a high level of accuracy and methodological rigor against timeliness and usefulness of the data to inform surveillance and regulatory efforts. Third, the definitions used to classify Twitter users who tweet about e-cigarettes may not be generalizable. Some of the methodologies would be applicable in other contexts (eg, identifying marketers in other domains), but results may not generalize readily across domains.

Comparison With Prior Work

This is the first study we are aware of that has examined methods to predict a broad set of different types of users tweeting about e-cigarettes. Previous studies have examined either the topic of e-cigarette tweets [23,24] or a single user type (eg, proponents of e-cigarettes vs nonproponents) [27]. In this study, five different categories of users who were involved in public discourse about e-cigarettes and groups that are of interest to inform public health surveillance, education, and regulatory efforts were examined. Second, multiple machine learning algorithms were tested and GBRT was used, which has not been used previously for this purpose. This is important, given the limited work in this area and the lack of existing methodology to build on. Third, in addition to analyzing Twitter metadata features, as prior studies have done, behavioral features that are shown to be important in performance gains were also examined. Finally, by using PDPs, evidence for how important features relate to a given user type was also provided.

Conclusions

In conclusion, this study provides a method for classifying five different types of users who tweet about e-cigarettes. Our model achieved high levels of classification performance for most groups; examining tweeting behavior was critical in improving the model performance. The results of our approach can help identify groups engaged in conversations about e-cigarettes online to help inform public health surveillance, education, and regulatory efforts. Future studies should examine approaches to improve the classification of certain user groups that were more challenging to predict (eg, vaper enthusiasts).

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Authors' Contributions

AK conceptualized the study, secured funding, directed study implementation, and led the writing of the manuscript and the revisions. TM led the analysis, implemented the machine learning methods, interpreted the results, produced figures, wrote the Methods and Results sections, and revised the manuscript. RC contributed to the study design, data collection, analysis, and manuscript review. ME assisted with the writing of the manuscript. JN provided feedback on the analysis and the manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1

List of Twitter metadata features and derived behavioral features used in models to classify Twitter users who tweet about e-cigarettes.

[PDF File (Adobe PDF File), 20KB - publichealth_v3i3e63_app1.pdf]

Multimedia Appendix 2

Modeling results of different machine learning algorithms to classify Twitter users who tweet about e-cigarettes.

[PDF File (Adobe PDF File), 16KB - publichealth_v3i3e63_app2.pdf]

Multimedia Appendix 3

Overview of machine learning algorithms examined.

[PDF File (Adobe PDF File), 214KB - publichealth_v3i3e63_app3.pdf]

Multimedia Appendix 4

Importance of features in models to predict Twitter users who tweet about e-cigarettes.

[PNG File, 196KB - publichealth_v3i3e63_app4.png]

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Abbreviations

API: application programming interface
FDA: Food and Drug Administration
GBRT: Gradient Boosted Regression Trees
IRB: institutional review board
PDPs: partial dependence plots
t-SNE: t-Distributed Stochastic Neighbor Embedding
2D: two-dimensional

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Original Paper

The Use of Facebook Advertising for Communicating Public Health Messages: A Campaign Against Drinking During Pregnancy in New Zealand

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Abstract

Background: Social media is gaining recognition as a platform for delivering public health messages. One area attracting attention from public health researchers and professionals is Facebook's advertising channel. This channel is reported to have a broad reach and generate high user engagement with the disseminated campaign materials. However, to date, no study has examined the communication process via this channel which this study aimed to address.

Objective: The specific objectives of the study were to (1) examine user engagement for a public health campaign based on the metadata provided by Facebook, (2) analyze comments generated by the campaign materials using text mining, and (3) investigate the relationship between the themes identified in the comments and the message and the sentiments prevalent in the themes that exhibited significant relationships.

Methods: This study examined a New Zealand public health pilot campaign called "Don't Know? Don't Drink," which warned against drinking alcohol during pregnancy. The campaign conveyed the warning through a video and three banner ads that were delivered as news feeds to women aged 18-30 years. Thematic analysis using text mining performed on the comments (n=819) identified four themes. Logistic regression was used to identify meaning-making themes that exhibited association with the message.

Results: The users' engagement was impressive with the video receiving 203,754 views. The combined likes and shares for the promotional materials (video and banner ads) amounted to 6125 and 300, respectively. The logistic regression analysis showed two meaning-making themes, namely, risk of pregnancy (P=.003) and alcohol and culture (P<.001) exhibited association with the message. The sentiment analysis carried out on the two themes revealed there were more negative than positive comments (47% vs 28%).

Conclusions: The user engagement observed in this study was consistent with previous research. The numbers reported for views, likes, and shares may be seen as unique interactions over the fixed period of the campaign; however, survey research would be required to find out the true evaluative worth of these metadata. A close examination of the comments, employing text mining, revealed that the message was not accepted by a majority of the target segment. Self-identity and conformity theories may help to explain these observed reactions, albeit warrant further investigations. Although the comments were predominantly negative, they provide opportunities to engage back with the women. The one-way communication format followed in this campaign did not support any two-way engagement. Further investigation is warranted to establish whether using a two-way communication format would have improved the acceptability of such public health messages delivered via social media. The

findings of this study caution using a one-way communication format to convey public health messages via Facebook's advertising channel.

(JMIR Public Health Surveill 2017;3(3):e49) doi:10.2196/publichealth.7032

KEYWORDS

social media; health promotion; alcohol; pregnancy; New Zealand

Introduction

Background

Social media websites accumulate a vast amount of user-generated content [1,2]. Of interest to public health researchers is health information placed on social media by individuals with health conditions and their families [3]. For example, people with diabetes voluntarily share diabetes management strategies on Facebook for the benefit of others enduring that condition [4]. Likewise, the narratives of cancer patients on YouTube offer valuable health messages to current and future patients [5]. Farmer et al [6] identified 757 dedicated health groups on Facebook comprising 290,962 individuals. The content generated by these health groups is readily available to individuals seeking health information. These networked systems allow participants to add value, correct misconceptions, and generate credible information within any given conversation [7]. Thus, social media platforms (Facebook in particular) are recognized as valuable sources for information on health topics [8-11].

Use of Social Media in Public Health

The use of social media as an information source for health topics has opened channels of communication between health care providers and their patients. Both individual health care providers [12] and institutions [13,14] use social media to communicate with their clients. The notion that social media could operate like mass media [15] is also drawing the interest of public health researchers [16]. Whether social media can effectively communicate messages to better facilitate public health interventions requires investigation [17,18]. To date, literature on the effectiveness of social media to communicate public health messages is sparse but emerging, as evidenced by recent publications [19]. Early indications from randomized controlled trials (RTCs) [20-23] investigating social media's effectiveness at communicating public health messages show promising results. One study [22] showed communication via Facebook to effectively sustain modified alcohol consumption behavior for up to 3 months, postintervention.

Use of Facebook Advertising for Delivering Public Messages

Although support for using social media to communicate public health messages is gaining momentum, there are still areas that warrant further investigation. One such area is social media's advertising channel. Social media sites are set up with the right to communicate with their users. Owners of these websites lease out this right to contact users within their system. Individuals and organizations lease out the right to disseminate messages, as news feed, to the accounts of their target audience. Researchers have successfully tested Facebook's advertising channel for recruiting specific subjects to participate in health studies [24] (eg, women who are 8-10 weeks pregnant). This study [24] found Facebook's advertising channel to be cost-effective and efficient for recruitment. The channel is valuable for communicating public health messages because of its broad reach. For example, a campaign to raise awareness for a newborn screening and bio-banking program used Facebook's advertising channel to reach 1.88 million users from the US state of Michigan [25]. The campaign generated 9186 likes, 452 shares, and 642 comments. Whereas the engagement reported in Platt et al [25] was impressive, what remains unknown is how much of that translated into acceptance of the program.

This paper reports the findings of a study that examined the use of Facebook's advertising channel as a vehicle for health promotion. The study was on a New Zealand public health campaign called "Don't Know? Don't Drink" [26], which is part of the New Zealand Health Promotion Agency's (HPA's) wider alcohol harm reduction program that aims to reduce the prevalence of alcohol-exposed pregnancies. This campaign aimed to convey the following message: "A woman who thinks there is a chance she may be pregnant should stop drinking alcohol until she knows she is not pregnant."

The campaign targeted women aged 18-30 years, based on evidence that these women are at risk for drinking during pregnancy [27]. A video and three banner advertisements, carrying the message, were piloted from June to September 2015 using Facebook's advertising channel.

The aim of this study was to better understand the communication process of Facebook's advertising channel for conveying public health messages. The specific objectives of the study were to (1) examine user engagement for the video and banner ads based on metadata provided by Facebook, (2) analyze comments generated by the campaign materials using text mining, and (3) investigate the relationship between the themes identified in the comments and the message and the sentiments prevalent in the themes that exhibited significant relationships.

Methods

Metadata

The metadata provided by Facebook are designated as counts of likes, shares, and views. Likes and shares are provided for all postings, whereas views are provided for videos only. By clicking the like button, Facebook users convey their approval of a posting. Facebook displays the total number of likes received for a posting. The share button allows users to share a posting with others within their network. The total number of shares for a posting is also displayed. Views indicate the number of times a video was run. Although it is hard to assign specific

evaluative worth, metadata does help more generally to assess the audience's level of engagement with a campaign.

Thematic Analysis

The comments made on postings contain textual information that, when classified and analyzed, indicate how and to what extent the target audience made meaning of and reflected the campaign's embedded message. This study used text mining to reveal the meaning-making and message reflecting themes within the comments. As all the promotional materials were designed to convey a single message, the comments received for all the postings (both the video and banner ads) were combined and analyzed. The number of comments (n=819) was sufficient for conducting a thematic analysis. The methodology employed for the thematic analysis comprised first defining the corpus of words and then carrying out text parsing, stemming, filtering, and dimensional reduction via unsupervised and supervised classification of terms into topics or themes for meaning-making and message reflection, respectively.

Definition of the Corpus of Words

The extraction of comments from Facebook required expanding the conversation threads to make all the comments visible. Following this, an exact copy of the comments was captured by maintaining the format of the Facebook pages. The raw data was scrubbed down to remove all meta-information attached to the comments (eg, time stamps and likes) and redundant formats (eg, extra carriage returns, horizontal tabs, and empty rows). At the end of this scrubbing, the Facebook usernames and their comments were left in separate rows. Each row was converted into a text file containing only the name and the comment. There were as many text files as there were comments, forming the corpus of terms analyzed. The text files were imported into SAS Enterprise Miner 12.3 (SAS Institute Inc) for thematic analysis. The identifiable names attached to the comments were replaced by codes to ensure that the confidentiality of the data was maintained throughout the analyzing and reporting process so as to minimize any unintentional harm to the participants.

Text Mining of the Themes

The aim of the text mining was to discover underlying themes in the corpus of words. The text mining steps included text parsing, text filtering, and theme generation [28]. Text parsing broke down the comments into root words (or stemming), parts-of-speech, and term definition. By stemming, words containing the same root word were made into that root word (eg, "drink" and "drinking" were stemmed to "drink"). By defining the parts-of-speech, the role of each word in a sentence was identified, and, by term identification, a term-by-frequency matrix was created for the corpus of terms. The terms were assigned information weights using the inverse document frequency (IDF) method [29]. IDF assigns high weights (implying greater importance) to words that appear less frequently and low weights to those that appear more often (implying lesser importance). Text filtering reduced the number of terms to a more manageable number while minimizing the loss of information. This step removed words that carried little or no meaning according to their information weight while maintaining a minimum document incidence threshold of four. Themes were generated using the data reduction technique of singular value decomposition (SVD) [28] to identify and quantify the meaning-making that took place. SVD reduced the corpus into orthoginal dimensions to reveal the underlying themes in the data. The terms in the themes were assigned a "theme-term-weight." The cut-off for inclusion in the theme was computed using the formula: "mean theme-term-weight plus one standard deviation" [28]. The terms with weights greater than the cut-off value formed the "keywords," and they conveyed an approximated essence of the theme. Likewise, comments within a theme were assigned a "theme-comment-weight." The cut-off point for inclusion of comments was calculated using the formula: "mean theme-comment-weight plus one standard deviation" [28]. The comments that received the highest weights formed the archetypes of that theme. By reviewing the keywords and the corresponding theme archetype comments, meaningful labels were then assigned to the themes.

The presence of the reflective message in the themes was identified using a supervised classification via a user-supplied topic-term-role based on the terms and grammar roles derived from the sponsoring stakeholder's message. Each comment document was assigned a "message reflection theme information weight" using this method. The interval scale message measurement variable for the message reflection theme was then modified to produce a binary value based on the message reflection topic weight threshold, where "one" represented a strong evidence of the theme being present in the comments and "zero" represented otherwise. The dependent variable for this analysis was thus derived using the keywords of the message (see Textbox 1).

The information weight threshold and binary coding modifications explained above were applied to each of the comments to produce the dependent message reflection theme variable and the independent or predictor meaning-making theme variables. The critical alpha for inferential statistics for the predictive model used was .05, for the evidence of an association to be deemed to be strongly apparent.

Textbox 1. Keywords of the message.

Message

- "A woman who thinks there is a chance she may be pregnant should stop drinking alcohol until she knows she is not pregnant."

Keywords

- woman, think, chance, pregnant, stop, drink, know, not

Logistic Regression

On social media, users express their ideas voluntarily. and the bias of social desirability has a surprisingly minimal influence. Such free-flowing comments convey what is on the users' minds more honestly [1]. Using logistic regression, an investigation was carried out to find out whether the contents of the message were related to, or predicted by the comments. A stepwise method of predictor variable selection in the logistic regression model framework was used with a critical "stay" alpha value of .05. This value helped to identify the themes extracted from the comments in the unsupervised classification text mining phase which strongly exhibited associations with the desired supervised classification message theme. The approach, which comprises of identifying themes in the comments and using them in a logistic regression model to investigate for predictive associations, is gaining increasing recognition (eg, [30]). This study used logistic regression in the context of dependent and independent variables dervived from the unsupervised and supervised classification of the text mining phase.

Sentiment Analysis

Sentiment analysis was used to explain the outcome of the logistic regression. The themes meeting the logistic regression threshold for strong evidence for the presence of the reflective message retained in the stepwise selection process were subjected to sentiment analysis using Mathematica 10.3 (Wolfram Research, Inc., Mathematica, version 10.3) [31]. The comments of the themes retained that met the message evidence threshold were categorized as positive, negative, and neutral. The authors reviewed the comments to verify the categorization was accurate, particularly for the comments that used negative words to convey a positive idea and vice versa.

Results

Analysis of the Metadata

The metadata reported are for the four promotional materials used in the campaign, which included a video and three banner advertisements. The total number of likes, shares, and views were obtained from the promotional materials' respective Facebook pages. Table 2 presents this information along with the number of comments for each posting. The video had 203,754 views and together the promotional materials generated 819 comments, 6125 likes, and 300 shares.

Thematic Analysis

After several iterations over the number of unsupervised classification themes extracted, the best theme clarity was obtained for the singular value decomposition that extracted four themes. By using the cut-off weights, the keywords and archetypes for the themes were established. The comments above the cut-off weight formed the archetypes and the numbers for each of the theme are shown in Table 3. The archetype comments were reviewed and the four themes were labeled as risk of pregnancy, alcohol and culture, credibility of the campaign, and contraception failure (Table 3).

Table 2. Metadata for the campaign posting.

Posting	Number of comments	Likes	Shares	Views
Don't Know? Don't Drink (video)	146	1281	92	203,754
Missed a pill? Maybe? (ad #1)	330	2127	101	N/A[a]
You used a condom, right? (ad #2)	250	1714	69	N/A
Definitely, definitely not pregnant? (ad #3)	86	1003	38	N/A
Don't Know? Don't Drink profile thumbnail	7	0	0	N/A
Total	819	6125	300	203,754

[a]N/A: not applicable.

Table 3. Themes and their corresponding keywords.

Labels	Term cut-off	Keywords	Comment cut-off	Number of archetypes[a]	Exemplar[b]
Risk of pregnancy	0.317	sex, pregnancy, woman, mean, contraception	0.318	67	"...No contraception is 100%. What a dumb ad"
Alcohol and culture	0.320	wine, eat, raw, fish, pregnancy,	0.331	69	"Explain all the European pregnant women who drink wine on a daily basis because it's a cultural habit...?"
Credibility of the campaign	0.288	stop, stupid, risk, drink, problem	0.278	49	"What a stupid campaign, everything has 'risks' but this just seems like a big fat waste of time."
Contraceptionfailure	0.319	pill, miss, condom, time, period	0.352	35	"...The ad should be 'missed a pill? wear a condom'(or probably get him to wear one hahaha)"

[a]The number of comments with meaning-making theme information weight above a critical level.

[b]Exemplars are snippets of the archetypes with the highest information weight for that meaning-making theme.

Logistic Regression Analysis

Using logistic regression, we investigated whether the contents of the message were related to, or predicted by, the comments. The stepwise regression retained coefficient estimates for two of the themes, namely, "risk of pregnancy" and "alcohol and culture" using the critical alpha value of .05 (Table 4). The −2log-likelihood ratio statistics showed that adding the two themes improved the model substantially (Intercept only=196.233; intercept and covariates=157.873). The chi-square test statistics for adding the two themes into the model (Risk of pregnancy: Wald χ^2=8.7591, P=.003; culture and drinking: Wald χ^2=18.5995, $P \leq .001$) were supported with evidence at the critical alpha level (Table 4), confirming their inclusion in the model was supported.

The baseline odds for strong evidence in the comments that the message was received and reflected in the themes was one in three (0.33). The odds of this message reflection approximately doubled when the first meaning-making theme (risk of pregnancy) was included (see Table 4). When evidence for the second meaning-making theme (alcohol and culture) was included, the odds increased by about three times (see Table 4).

Based on the odds ratio, the probability of finding evidence for the message being received and reflected in the two themes is shown in Table 5. The other themes showed no strong evidence of association with the supervised classification message reflection theme. The authors inspected the exemplars for these other two themes and were satisfied that the meaning-making was not related to the message but rather to unrelated topics.

Sentiment Analysis of the Themes in the Model

Sentiment analysis was conducted to further illuminate the interpretation of the regression model results. Using Mathematica [31], qualifying comments containing strong evidence of the two meaning-making themes in the model ("risk of pregnancy" and "alcohol and culture") were categorised as positive, neutral, and negative. The validity of this categorization was then checked in the qualifying comments by the authors and found to be satisfactory. Table 6 presents the results of the sentiment analysis. As the results show, this campaign evoked all three sentiment valences: positive, neutral, and negative. For both the unsupervised classification meaning-making themes extracted, the proportions of negative comments were higher than the positive and neutral comments (Table 6).

Table 4. Association between the meaning-making themes and message.

Parameter	Degrees of freedom	Estimate	Standard error	Wald χ^2	$Pr>\chi^2$	Exp (Est)
Intercept	1	−1.1058	0.2693	16.86	<.001	0.331
Risk of pregnancy	1	0.7782	0.2629	8.76	.003	2.177
Alcohol and culture	1	1.1161	0.2588	18.60	<.001	3.053

Table 5. Probability of the message provoking a message-reflective response.

Parameter	Probability
Without any meaning-making	0.25 (0.331/1+0.331)
Risk of pregnancy cognition	0.42 (0.331×2.177/1+0.331×2.177)
Alcohol and culture cognition	0.50 (0.331×3.053)/1+(0.331×3.053)
All related cognition	0.69 (0.332×2.177×3.053)/1+(0.332×2.177×3.053)

Table 6. Sentiment analysis of comments in the two themes.

Meaning making themes	Positive comments n (%)	Neutral comments n (%)	Negative comments n (%)
Risk of pregnancy	15 (23)	18 (27)	33 (50)
Alcohol and culture	23 (34)	15 (22)	30 (44)
Total	38 (28)	33 (25)	63 (47)

Discussion

Principal Findings

Despite the lack of empirical evidence, observed in the literature, the use of Facebook for communicating health messages is gaining popularity [19]. The RTCs that attempted to develop social media as vehicles for health promotion have tested and reported favorable results [20-23]. All the same, these studies were on specific features of Facebook, such as the messaging system, and the authors implicitly advocated Facebook as a platform for health promotion. The findings of such studies have provided the impetus for public health researchers and professionals to use Facebook and other social media as a format for delivering health promotion messages. This study aimed to investigate the use of Facebook's advertising channel for health promotion to generate hypotheses for the systematic development of this platform. The findings of this study confirm high levels of engagement, as observed in previous research [25]. When examining the level of engagement, the findings were based on the metadata Facebook provided for the campaign. The overall number of likes (6125), shares (300), and comments (819) achieved in a short time (June to September 2015) suggests the promotional material stimulated reasonable engagement within the target audience. The evaluative worth of the metadata is hard to establish. All the same, the high level of engagement suggests that this channel was successful, both in presenting materials to a target audience and for facilitating engagement. This observation confirmed the earlier reporting of Platt et al [25], suggesting that this channel encouraged user engagement.

The video used in this campaign produced an impressive number of views (203,754). However, it is hard to reach a conclusion on how the message was received based on this metadata alone. Going by the definition of likes, the number of people who approved the video was less than one percent (0.63%), that is, 1281 likes given by 203,754 individuals who viewed the video (see Table 2). The reaction of the remaining 99% remains unknown. The same can be claimed for shares, which was 0.05%, that is, the proportion of the number of shares from those who viewed the video (see Table 2). Whereas sharing expanded the campaign's reach to other audiences, the context in which they were shared remained unknown. As such, whether the message was supported or rejected could not be ascertained based on the measures of engagement observed in this and a previous study [25].

This study goes further than the previously reported study [25] to investigate the association between the meaning-making themes generated by the comments and the reflected message in the themes. The exemplars in Table 3 suggest that the comments seemingly dismissed the campaign (the carrier of the message) as "a big waste of time" (see exemplar for credibility of the campaign in Table 3) and as a "dumb ad" (see exemplar for risk of pregnancy in Table 3). Consequent to such dismissal, the likelihood of the message being communicated "as intended" is small. Falomir & Invernizzi [32] observed similar reactions to antismoking messages. A key factor responsible for the dismissal was the "smoker identity," reenforced by the social categorization of individuals into smokers and nonsmokers. When such caegorization becomes a defining trait of oneself, people tend to be defensive of their self-identity [33,34]. Like smoking, drinking alcohol is common practice for many people and hence, may contribute to defining their self-identity.

The findings from the logistic regression indicated the base level likelihood of the message being featured in the comments was comparatively small (1 in 3; see in the column Exp [Est] for the intercept in Table 4). The odds increased by a combined factor of about six when the two themes were included in the equation (odds ratio of 2.177 for risk of pregnancy; odds ratio of 3.053 for alcohol and culture). The overall probability of the message receiving any reaction was about seven in ten (0.69, Table 5). The sentiment analysis performed for the two themes returned neutral, positive, and negative, with the latter, unfortunately for the sponsoring stakeholder and the public health of the target population, trending higher (47%) than the former two (28% for positive and 25% for neutral comments, Table 6). As discussed above, if self-identity is a contributing factor for drinkers to react negatively to the message of abstinence if they are unsure of pregnancy, then it is even more likely that the message will not receive the endorsement of those giving negative comments. It is possible that the overly negative reaction from women for the Don't Know? Don't Drink campaign may well be in defense of their self-identity. However, as evidence to support this is currently lacking, future research to test the self-identity theory for women who drink alcohol is warranted (H1).

Negative comments can influence subsequent viewers' evaluations, as Walther et al [35] observed for antimarijuana messages disseminated via YouTube. Walther and colleagues found that the messages with negative comments were perceived as less effective than those with positive. Shi et al [36] reported a similar pattern in the evaluation of antitobacco messages, showing how negative comments dissuaded effectiveness. Identification with the previous commenter influenced the direction of the perceived effectiveness [35,36], as explained by Conformity Theory [37]. According to this theory, people conform to the behavior of their peers to gain social approval. In a virtual context, conformity to an identity is conveyed via commenting. With a large number of the target population

identifying themselves as drinkers (75%) [38], the accumulation of negative comments directed at this campaign could progressively render it ineffective. Whether or not peer pressure to conform was the underlying cause for the large proportion of negative comments observed in this study, needs further investigation (H2). It could be argued that the individuals whose comments were neutral could swing either way. However, it is highly likely that peers providing negative comments loaded with anecdotal evidence can convince the neutral commenters who identify themselves as "drinkers" to reject the message, albeit this premise needs to be investigated (H3).

Sentiment analysis was carried out for the two themes included in the logistic regression equation. The proportion of positive comments (28%— total for risk of pregnancy and alcohol and culture in Table 6) was small compared with the negative ones (47%—total for risk of pregnancy and alcohol and culture in Table 6). Whether the women who made positive comments knew the dangers of drinking during pregnancy or whether their position was modified by the campaign can only be confirmed using a cross-sectional survey design. Therefore, a future study is required to investigate whether the campaign produced attitudinal change among those who gave positive comments (H4). Nevertheless, their presence in the current data suggests the campaign reached a broad cross-section of women.

The Don't Know? Don't Drink campaign adopted a one-way communication format. That is, the message, encoded in promotional materials, was disseminated in one direction via Facebook's advertising channel. The line of communication was unidirectional with no further interaction between the sender and the receivers. Evaluation of such social campaigns is carried out separately, usually by an independent agency. In the current instance, the comments provided are a first-hand assessment of the acceptability of the message. The findings from the logistic regression and the sentiment analysis revealed that the message was mostly "not" received "as intended" by those most vulnerable to an alcohol-exposed pregnancy. This study cautions the use of a one-way communication model for conveying such warning messages via Facebook's advertising channel. At most, it could be said that the communication process was initiated. The communication effectiveness could be enhanced using a two-way communication format, which enables the promoter to respond to the negative comments. Thus, the negative comments could be seen as opportunities, both to provide scientific evidence and reinforce the message. To understand the communication process further, the testing of Facebook's advertising channel using a two-way communication format is warranted (H5).

Facebook offers the option to moderate the comments by hiding or deleting them to prevent derogatory comments being viewed by others. The temptation to moderate the negative comments by managers of such public campaign needs to be recognized as it can impact negatively on the findings. However, in this study, as the number of negative comments was greater than the positive ones for the campaign, it is very unlikely that this was the case.

In a two-way communication, such negative comments open the channel of communication to engage back with the commenters with additional explanation and information. In doing so, concrete evidence is placed in the domain of the target audience. Hence, negative comments must be viewed as a means to an end, which is to make the current information available to the target population, thereby alleviating the knowledge gaps. Therefore, we suggest that public campaigns using social media include a protocol against moderating the comments solely based on sentiment valence so as to maximize the intervening opportunities and maintain the completeness and quality of the raw data.

Conclusions

The user engagement observed in this study was consistent with previous research. The examination of the comments revealed that the message was not received favorably by a majority of women. The observations made in this study provided a direction for future research, to both understand the target audience (traits of women who drink alcohol) and enhance the effective use of Facebook's advertising channel for health promotion activities. Future investigations are required to find out whether the self-identity and conformity theories can explain why the abstinence in a pregnancy message was largely unaccepted. Although the positive comments were fewer in number compared with the negative, they also need to be studied to find out whether that attitude resulted from the campaign or they preexisted. The negative comments should be seen as an opportunity for engagement with the target population.

The one-way communication format used in the current campaign could only observe the commencement of the communication process. Future investigation is needed to find out whether a two-way communication format would help both promoters and researchers to engage back, which might improve the acceptability of public health messages delivered via social media. Finally, the observations made in this study caution against using a one-way communication format in conjunction with Facebook advertising to convey warning messages.

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Conflicts of Interest

None declared.

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Original Paper

Informing the Development of a Mobile Phone HIV Testing Intervention: Intentions to Use Specific HIV Testing Approaches Among Young Black Transgender Women and Men Who Have Sex With Men

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Abstract

Background: Regular human immunodeficiency virus (HIV) testing of persons at risk is critical to HIV prevention. Infrequent HIV testing and late diagnosis of HIV infection have been observed among young black men who have sex with men (MSM) and transwomen (transgender women)—two groups overrepresented in the HIV epidemic.

Objective: The objective of this study was to inform the development of a brief mobile phone intervention to increase HIV testing among young black MSM and transwomen by providing a tailored recommendation of an optimal HIV testing approach. We identified demographic, behavioral, psychosocial, and sociostructural factors associated with intentions to use three specific HIV testing approaches: self-testing, testing at a clinic or other provider, and couples HIV testing and counseling (CHTC).

Methods: Individuals were eligible for a Web-based survey if they were male at birth; were between the ages of 16 and 29 years; self-identified as black, African American, Caribbean black, African black, or multiethnic black; were not known to be HIV-infected; and reported insertive or receptive anal intercourse with a man or transwoman in the last 12 months. Recruitment occurred via banner advertisements placed on a range of social and sexual networking websites and apps in New York City and nationally, and via events attended by young black MSM and transwomen in New York City. Intention to test by each testing method was analyzed using logistic regression with best subset models and stepwise variable selection.

Results: Among 169 participants, intention to use a self-test was positively associated with comfort in testing by a friend or a partner at home (Adjusted odds ratio, AOR, 2.40; 95% CI 1.09-5.30), and stigma or fear as a reason not to test (AOR 8.61; 95% CI 2.50-29.68) and negatively associated with higher social support (AOR 0.48; 95% CI 0.33-0.72) and having health insurance (AOR 0.21; 95% CI 0.09-0.54). Intention to test at a clinic or other provider was positively associated with self-efficacy for HIV testing (AOR 2.87; 95% CI 1.48-5.59) and social support (AOR 1.98; 95% CI 1.34-2.92), and negatively associated with a lifetime history of incarceration (AOR 0.37; 95% CI 0.16-0.89). Intention to test by CHTC was negatively associated with higher educational

level (Some college or Associate's degree vs high school graduate or less [AOR 0.81; 95% CI 0.39-1.70]; Bachelor's degree or more vs high school graduate or less [AOR 0.28; 95% CI 0.11-0.70]).

Conclusions: Unique factors were associated with intention to test using specific testing approaches. These data will be critical for the development of a tailored intervention that shows promise to increase comfort and experiences with a variety of testing approaches among young black MSM and transwomen.

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KEYWORDS

HIV infections; African American; homosexuality, male; transgender persons; cell phones

Introduction

Men who have sex with men (MSM) comprised the largest proportion (67%) of new human immunodeficiency virus (HIV) diagnoses in the United States in 2014. Black MSM are affected at greatly disproportionate rates, overall and by age, comprising two-thirds of new diagnoses in the age group of 15 to 29 years [1]. Though national HIV surveillance data are unavailable for transgender women (transwomen) [2], multiple studies report high HIV prevalence and incidence rates, with black transwomen disproportionately affected [3-5].

The Centers for Disease Control and Prevention (CDC) recommends that individuals test every 3 to 6 months if they have additional HIV risk factors [6,7], and recent data from National HIV Behavioral Surveillance (NHBS) found that 65% of HIV-negative men report condomless anal sex with male partners in the prior 12 months [8]. NHBS also reported that HIV testing in the prior 12 months increased among young black MSM from 2008 to 2011 [9]. Nevertheless, infrequent HIV testing and late diagnosis of HIV infection continue to be prevalent among young black MSM and transwomen [3,10,11]. Increasing the uptake of testing is critical to identifying young black MSM and transwomen with undiagnosed HIV infection, linking to them to care, and thereby, lowering HIV transmission in this group.

Delayed HIV testing (eg, not testing in the prior 6 months) among young black MSM and transwomen has been found to be associated with behavioral factors such as condomless sex and substance use [12,13] and psychosocial factors such as stigma associated with HIV and testing [13]. Research into peer norms and social support suggests that stronger social support is associated with a lower risk of delayed HIV testing [12,14]. Socio-structural factors have also been found to be important, such as lack of health insurance, cost of tests and visits, lower income, as well as racism and homophobia experienced at clinic visits [15-18].

Several HIV testing approaches are now available, in addition to traditional clinic-, doctor-, or community-based testing. The Orasure's OraQuick In-Home HIV Test, approved in 2012, is available via the Internet and at local drug stores and uses an oral swab, providing results to the user in 20 minutes [19]. In addition, couples HIV testing and counseling (CHTC) [20-22] is becoming more prevalent as an important approach, with the given data suggesting that a significant proportion of transmissions among MSM may be attributed to sex with main partners [23,24].

Targeted, tailored, and culturally appropriate HIV testing interventions for young black MSM and transwomen are urgently needed. A number of Web-based and text messaging HIV prevention interventions have been developed for adolescent and young adult MSM [25-31] and a few have targeted uptake of HIV testing as an outcome [30-33]. One intervention, *Get Connected!*, demonstrated an increase in HIV testing through the use of a tailored intervention based on a baseline assessment [30]. Only a limited number of these interventions have been developed specifically for young black MSM or transwomen [27,28].

The overall goal of our study was to develop a brief mobile phone intervention to increase HIV testing by providing young black MSM and transwomen with a tailored recommendation of their optimal HIV testing approach. The development of our intervention is based on theory and results from a multistage process, including formative research [14], the survey reported in this study, community and focus group input, and a pilot study. The formative research and survey were framed broadly within social cognitive theory [34,35] assessing relevant determinants of testing behavior at the personal, behavioral, and socio-structural levels. Within this broad framework, we nested several mid-range theories, including the theory of planned behavior [36], stigma theory [37], social identity theory [38] and social norms theory [35]. These guided our qualitative and quantitative inquiries, resulting in assessments of cognitions; beliefs; behavioral intentions, attitudes, and perceived behavioral control; internalized HIV stigma; personal identity and sense of community; and subjective norms.

In this study, we report on a comprehensive Web-based assessment of demographic, behavioral, psychosocial, and sociostructural factors associated with intentions to use three specific HIV testing approaches (self-testing, testing at a clinic or other provider, and CHTC). The factors found to be associated with HIV testing by specific approaches will be used to construct the HIV testing algorithm, which would provide a tailored recommendation of a person's optimal testing approach.

Methods

Recruitment

Individuals were eligible if they were male at birth; were between the ages of 16 and 29 years; self-identified as black, African American, Caribbean black, African black, or multiethnic black; were not known to be HIV-infected (including those who had never tested for HIV); reported insertive or receptive anal intercourse with a man or transwoman in the last

12 months; and resided in the New York City metropolitan area (for national component described below: resided in the United States). Individuals were ineligible if they were enrolled in any other research study involving HIV testing and/or participating in an HIV vaccine trial. Recruitment for this convenience sample occurred via banner advertisements placed on a range of social and sexual networking websites and apps and by recruitment at local New York City events attended by young black MSM and transwomen. A wide range of images and texts were used to engage potential participants (Multimedia Appendix 1). Persons who clicked on a study banner ad were transferred to the study survey that contained a brief eligibility assessment. Persons who did not meet inclusion criteria were skipped to an exit page, thanked for their interest, and provided a link to locate local HIV testing places. Eligible participants were sent to the Web-based consent form that required acknowledgment of having been read by clicking a Consent button. The consent form presented the purpose of the survey, estimated time needed to complete the survey, and type of questions asked. It also provided assurances of confidentiality and secure data storage, and the name of the principal investigator. Participants were then sent to the Web-based survey, hosted on Health Insurance Portability and Accountability Act–compliant, password-protected servers at Survey Gizmo. At the end of the survey, first name, mobile phone number, and email were collected to facilitate distribution of gift codes for the incentive. Internet Protocol (IP) addresses were collected only for the purpose of prohibiting more than one survey per IP address.

The survey was administered from October 2014 to August 2015 for the New York City metropolitan area initially, with no compensation and then, with a US $10 gift code for survey completion. From June 2015 to July 2015, surveys were completed at New York City events with a US $10 gift card for survey completion. Due to the need to increase the number of responses, we opened the survey nationally for approximately 1 month, from July 2015 to August 2015 with no gift code. Only 7 respondents in the national survey resided in the State of New York. The study was approved by the Institutional Review Boards of the New York Blood Center, Public Health Solutions, and the Binghamton University.

Measures

The selection of assessment questions was based on our theoretical framework, the literature [39-41] and in-depth interviews with the target populations [14]. Specifically, we report on associations of sociostructural factors, HIV risk factors (sexual risk and substance use), peer norms and social support, and stigma with intention to test by each HIV testing approach. In addition, we describe associations of HIV testing variables such as awareness of testing approaches, comfort levels with different approaches, reasons for not testing, HIV testing self-efficacy, and access to testing with intention to test by each HIV testing approach.

The survey was tested for usability, correct skip patterns, and other functionality prior to launching. The number of items per page and the number of screens varied with participants due to skip patterns. All survey items were required and had an "I would prefer not to answer" response option. Participants were not allowed to review and change answers via a Back button.

Outcomes

Three outcomes related to intention to test were defined. Intention to test by a self-test was asked by "In the next 6 months, how likely are you to test using a home HIV test?" with responses of very likely, somewhat likely, somewhat unlikely, and very unlikely. Intention to test at a clinic or other provider was asked by "In next 6 months, how likely are you to test *by yourself* at a clinic, doctor's office, community-based organization or mobile van?" with the same response categories. Finally, intention to test by CHTC was asked by "In the next 6 months, how likely are you to test *with a partner* at a clinic, doctor's office, community-based organization or mobile van?" with the same response categories.

Sociostructural Variables

Measures of *socioeconomic status* included level of education, employment, and occurrence of financial insecurity: "In the past 3 months, how often was there not enough money in the household for rent, food, or utilities (for example, gas, electric, phone)?" Participants were also asked whether they had *health insurance* and what was their *usual place for medical care*. *Perceived sexual discrimination* was measured by the question: "How often in your life have you been made fun of, picked on, pushed, shoved, hit, or threatened with harm because of being gay, transgender, bisexual or man who had sex with men?" with responses of never, once in a while, sometimes, or a lot. History of *incarceration* was assessed by the question: "Have you ever spent one or more nights in a jail, prison, or detention facility?"

HIV Testing Variables

Measures included *awareness* of the self-test and CHTC. The questions about awareness were prefaced with a description of each test: "A home HIV test is one you can buy at a store or online and use to test yourself." and "Testing Together or Couples Testing is when 2 people talk with a counselor together, get tested together, and get their HIV test results together." HIV testing self-efficacy was measured with a scale of 7 items such as "I feel confident I could test myself using the home HIV test kit" and "I feel confident I could ask a doctor or health-care provider for HIV testing" and a 4-point Likert response scale from strongly disagree to strongly agree (Cronbach alpha=.81) [42]. *Comfort* with specific testing approaches was asked with 6 different questions such as "How comfortable are you being tested at a clinic outside my community?" with a 3-point Likert response scale of not comfortable, somewhat comfortable, and comfortable [13]. Individuals who had never tested or had not tested in the last year were asked to indicate which of the 11 *reasons they had not tested* such as "I think I'm at low risk for HIV" or "I did not want other people to know that I got a test," adapted from the CDC's NHBS System [43]. The reasons were grouped into four categories of reasons for not testing: low risk, stigma or fear, lack of access to testing, and beliefs about treatment/other reason. *Access to testing* was measured with the item "I know where I can get an HIV test" with a 4-point Likert response scale of strongly disagree to strongly agree [44].

HIV Risk Behaviors

Questions about *sexual behaviors* in the prior 3 months included number of anal or vaginal sex partners, having a primary partner ("someone who is your boyfriend, girlfriend, lover, life partner, who you live with or see a lot or to whom you feel special emotional commitment"), insertive and receptive anal sex, condom use, and HIV status of partners. Questions on use of *substances* in the prior 3 months included marijuana and stimulants (powder cocaine, crack cocaine, methamphetamine). Occurrence of a *sexually transmitted infection* (STI) in the past year was asked as well. *Risk perception* was measured by 2 questions: "How likely do you think you are to get (HIV/a sexually transmitted disease [STD] other than HIV) in the next year?" with 4-point responses ranging from very unlikely to very likely.

Peer Norms, Social Support and Stigma

Peer norms for HIV testing were asked using two questions: "Most of my friends would approve of me getting an HIV test" and "My friends would probably think less of me if they knew I got an HIV test" with a 4-point Likert response scale of strongly disagree to strongly agree [45]. *Social support related to HIV and sex* was asked with a scale of 3 items, including "How often do you have someone to share concerns about HIV/AIDS" with a 4-point Likert response scale of never to all the time (Cronbach alpha=.92) [46]. *HIV stigma* was measured with a scale of 8 items such as "If you talk too much about HIV, people will think that you have HIV" with a 4-point response scale of strongly disagree to strongly agree (Cronbach alpha=.88).

Statistical Analysis

Consistent with best practices in Web-based survey research [47] and due to the high eligibility rate in the New York City survey with compensation, a systematic review was made of all completed surveys to identify potentially invalid survey entries by identifying surveys with the following characteristics and patterns among multiple records: (1) survey completion in less than 10 minutes; (2) female first name (and not self-identified as a transwoman); (3) IP address outside of the United States; (4) email address that was similar to others or made up of many consonants (eg, xyzztp); (5) mobile phone numbers with same first 7 digits (eg, 212-568-4xxx); (6) IP addresses that matched on 3 of the 4 quadrants; and (7) repeated identical answers. Through this process, we identified 251 invalid responses in the New York City metropolitan area survey, which had compensation. No invalid surveys were identified in the national survey, which did not have compensation.

A comparison was made between participants from the local survey to those from the national survey. Those from the national survey who indicated that they resided in the New York City metro area were classified as local survey respondents. Age group, ethnicity, educational level, financial insecurity, living situation, being a transwoman, and intent to test in the next 6 months by self-test, by clinic/other provider, and by CHTC were all not significantly associated with national/local survey status (data not shown). Only one demographic variable, employment, was found to be significantly associated with national/local survey status, with 60% (36/60) of respondents from the national survey employed full-time compared with 34.6% (37/107) of respondents from the local survey. Given the limited differences between the national and local survey respondents, analyses were conducted on the survey data as a whole.

Survey responses for the outcome measures were recoded into binary variables that maintained similar distributions across the outcomes. As such, intention to test by a self-test and intention to test by CHTC were classified as very likely and somewhat likely versus somewhat unlikely and very unlikely. Intention to test at a clinic or other provider was classified as very likely versus all other categories. In this manner, we had sufficient sample size in each category to conduct analyses to identify factors associated with each outcome.

For survey scales, a mean score of the scale items was generated based on complete cases. Separate bivariate analyses were conducted for each of the three intention-to-test outcomes. Chi-square tests for binary and categorical measures and nonparametric Kruskal-Wallis tests for continuous measures were conducted to test significant associations between intention to test by a specific testing approach and socio-structural variables, HIV testing variables, HIV risk behaviors, peer norms, social support, and stigma at $P<.05$.

The three testing method outcomes then were analyzed individually in two stages. Due to the comprehensive list of HIV risk behaviors and HIV testing feature variables, in the first stage, we implemented logistic regression modeling with best subset models (Best=4) [48] on these measures. In the second stage, we conducted stepwise variable selection [48] adding the peer norms and social support, stigma, and sociostructural factors to the variables identified in the best subset from the first stage. For the intention to test by CHTC outcome, we forced primary partner status into the final model.

Results

Study Sample

Figure 1 presents the number of responses through the recruitment process. The final sample was 169 completed surveys: 98 from the New York City survey, 61 from the national survey, and 10 from the local New York City events.

The mean age of respondents was 24.1 years (Standard deviation, SD=3.0); the majority ethnicity was African American (Table 1). About 1 in 7 respondents had never tested for HIV and over one-quarter had their last HIV test over 6 months ago. Awareness of self-testing and CHTC was relatively high, with 70.4% of participants indicating that they knew about self-tests, and 55.0% indicating that they knew about CHTC. However, only 11.1% (16/144) of those who previously tested had ever used an HIV self-test and 13.2% (19/144) had ever tested using CHTC. Almost all (133/140; 95.0%) tested at a clinic for their last test.

Table 1. Demographic characteristics and intention to test, All About Me Study, N=169.

Characteristics	n (%)
Age, years	
16-19	12 (7.1)
20-24	82 (48.5)
25-29	75 (44.4)
Ethnicity	
African American	137 (81.1)
Caribbean	34 (20.1)
Afro-Latino	17 (10.1)
African	3 (1.8)
Other	7 (4.1)
Transwoman	14 (8.3)
Recent HIV testing	
In last 3 months	57 (33.9)
4-6 months ago	41 (24.4)
7-12 months ago	25 (14.9)
More than 1 year ago	21 (12.5)
Never	24 (14.3)
Region of survey respondents[a]	
New York City	108 (63.9)
South	33 (19.5)
Northeast	12 (7.1)
Midwest	12 (7.1)
West	4 (2.4)

[a]based on US Census Bureau regional divisions.

With regard to specific testing approaches, 40.9% and 47.0% were very or somewhat likely to test in the next 6 months by self-test and CHTC, respectively (Figure 2). Over half (55.4%) of participants were very likely to test in the next 6 months at a clinic or other provider. Participants who had not tested in the last 6 months were significantly more likely to be very likely or somewhat likely to test by self-test in the next 6 months (40/70; 57.1%) compared with participants who had tested in the prior 6 months (29/98; 29.6%; *P*=.001). In contrast, participants who had not tested in the last 6 months were significantly less likely to be very likely to test at a clinic or other provider in the next 6 months (28/67; 41.8%) compared with those who had tested recently (63/98; 64.3%; *P*=.007). No significant differences in intention to test by CHTC were observed by recent testing.

Correlates of Intention to Test by Specific Testing Approaches: Sociostructural Variables

Intention to test by self-test was significantly higher among those without health insurance and for those whose usual place of care was a community health center/clinic (Table 2). Intention to test at a clinic or other provider was significantly lower for participants with a lifetime history of incarceration. Intention to test by CHTC was significantly higher with lower educational levels.

Figure 1. Response rates and analysis dataset.

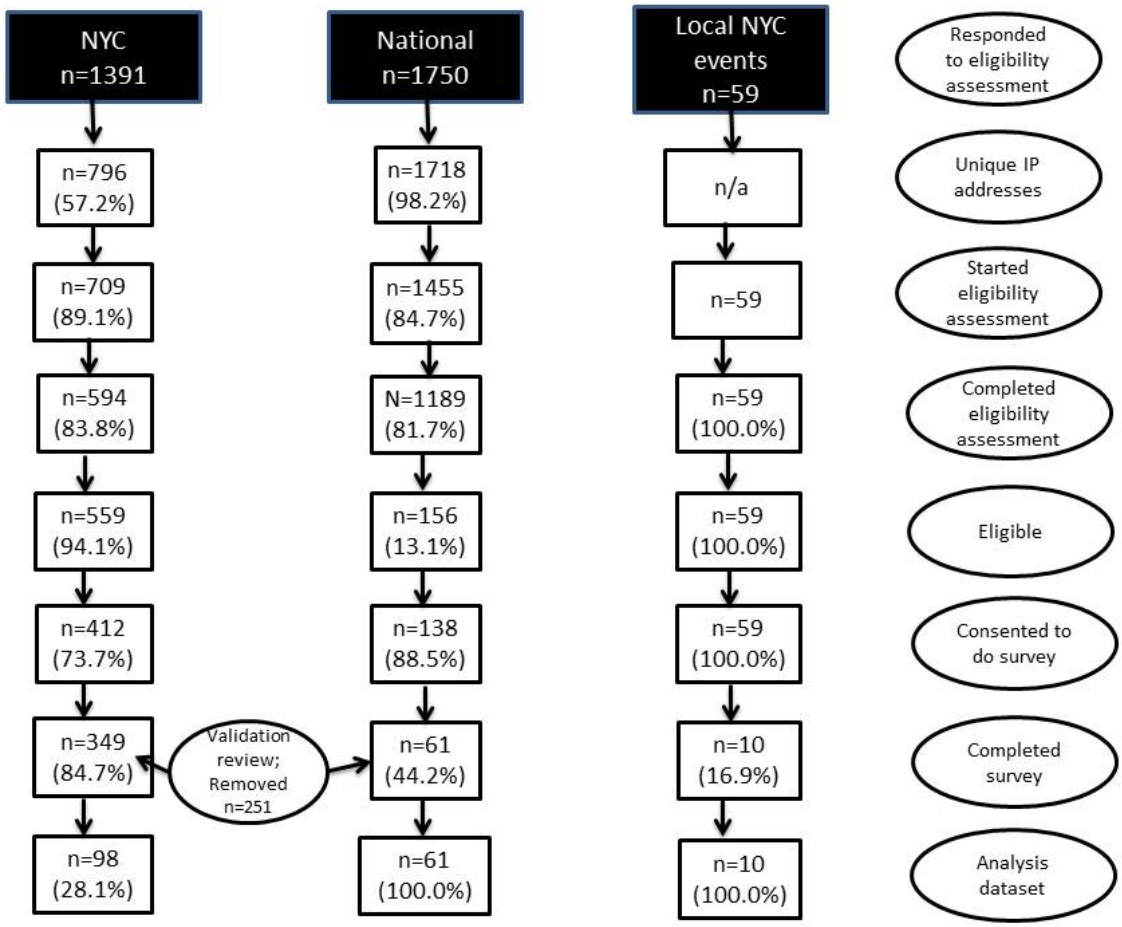

Figure 2. Intention to test by specific testing approaches.

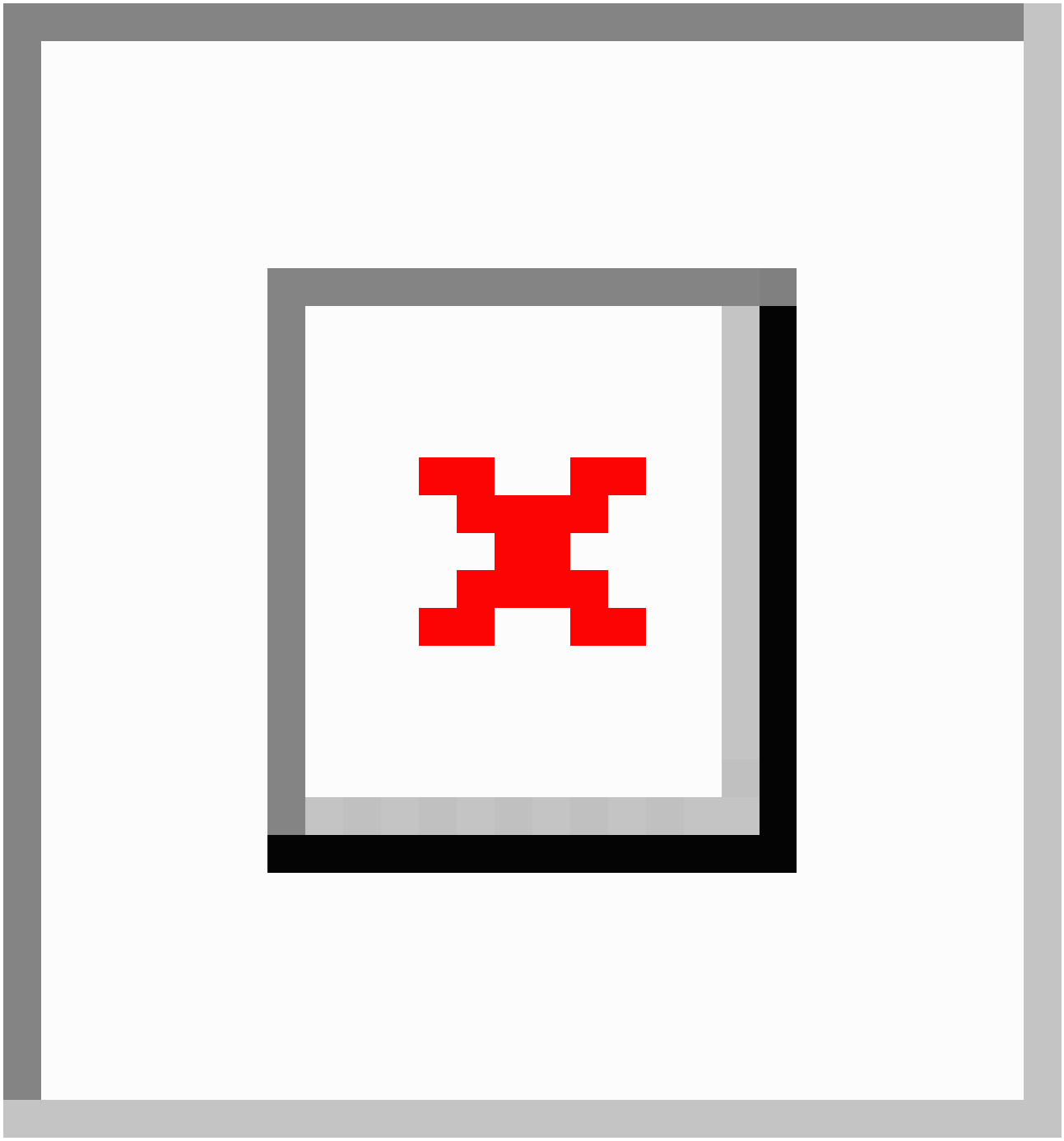

Table 2. Correlates of intention to test by specific testing approaches: Sociostructural variables, All About Me Study, N=169.

Sociostructural variables	Intention to test by...					
	Self-test[a]		Clinic or other provider[b]		CHTC[a,c]	
	%	*P*	%	*P*	%	*P*
Education		.13		.43		.008
High school graduate or less, vocational	20 (40.8)		24 (51.1)		27 (56.3)	
Some college	38 (47.5)		42 (53.2)		41 (52.6)	
College degree or more	11 (28.2)		25 (64.1)		10 (25.6)	
Financial insecurity		.14		.19		.93
Very often	9 (39.1)		12 (54.6)		11 (47.8)	
Fairly often	14 (56.0)		9 (36.0)		10 (40.0)	
Once in a while	18 (50.0)		20 (58.8)		16 (48.5)	
Never	27 (33.3)		49 (60.5)		37 (45.7)	
Employment		.48		.91		.11
Full-time	33 (45.2)		39 (54.2)		38 (53.5)	
Part-time	18 (42.9)		23 (54.8)		14 (33.3)	
Off the books/not working/other	18 (34.6)		29 (58.0)		24 (47.1)	
Health insurance		.02		.93		.31
No	20 (58.8)		18 (54.6)		18 (54.6)	
Yes	48 (36.4)		72 (55.4)		58 (44.6)	
Usual place for medical care		.001		.38		.58
Community health center/clinic	27 (64.3)		19 (46.3)		22 (53.7)	
Private MD/student health center	22 (28.6)		47 (61.8)		33 (42.9)	
Emergency room/urgent care	14 (35.9)		21 (55.3)		18 (48.7)	
Alternative practitioner/nowhere	5 (55.6)		4 (44.4)		3 (33.3)	
Perceived sexual discrimination (lifetime)		.15		.77		.10
Never	22 (38.6)		30 (55.6)		30 (55.6)	
Once in a while	17 (32.7)		29 (55.8)		26 (50.0)	
Sometimes	17 (58.6)		14 (48.3)		13 (44.8)	
A lot	12 (41.4)		18 (62.1)		8 (27.6)	
Incarceration (lifetime)		.39		.008		.38
No	51 (39.5)		78 (60.9)		57 (44.5)	
Yes	18 (47.4)		13 (36.1)		19 (52.8)	

[a]Self-test and CHTC outcomes: Very likely/somewhat likely versus somewhat unlikely/very unlikely.

[b]Clinic outcome: Very likely versus somewhat likely/somewhat unlikely/very unlikely.

[c]CHTC: couples HIV testing and counseling.

Correlates of Intention to Test by Specific Testing Approaches: HIV Testing Variables

Intention to test by self-test was significantly higher for participants who were previously unaware of the self-test and among those somewhat comfortable testing at a clinic inside the community (but not comfortable testing outside the community), by their health care provider, on a mobile van, and by a friend or partner at home (Table 3). Participants who indicated stigma/fear or lack of access to testing as reasons not to test were significantly more likely to indicate an intention to test by self-test.

Table 3. Correlates of intention to test by specific testing approaches: HIV testing variables, All About Me Study, N=169.

HIV testing variables	Intention to test by...					
	Self-test[a]		Clinic or other provider[b]		CHTC[a,c]	
	%	*P*	%	*P*	%	*P*
Aware of self-test		.001		.001		.18
No	30 (60.0)		17 (34.7)		27 (55.1)	
Yes	39 (32.8)		75 (64.1)		51 (43.6)	
Aware of CHCT		.06		.09		.83
No	37 (48.7)		35 (48.0)		35 (48.0)	
Yes	32 (34.4)		57 (61.3)		43 (46.2)	
Comfort getting tested…						
At clinic in my community		.009		<.001		.01
Not comfortable	12 (42.9)		8 (29.6)		7 (25.9)	
Somewhat comfortable	21 (63.6)		10 (30.3)		21 (63.6)	
Comfortable	36 (33.6)		74 (69.8)		50 (47.2)	
At clinic outside my community		.04		.002		.55
Not comfortable	13 (61.9)		5 (23.8)		8 (40.0)	
Somewhat comfortable	17 (48.6)		17 (48.6)		19 (54.3)	
Comfortable	39 (34.8)		70 (63.6)		51 (46.0)	
By my health care provider		.004		<.001		.18
Not comfortable	5 (38.5)		4 (30.8)		4 (30.8)	
Somewhat comfortable	22 (66.7)		8 (24.2)		19 (59.4)	
Comfortable	42 (34.7)		79 (66.4)		55 (45.8)	
On a mobile van		.02		.001		.67
Not comfortable	12 (30.8)		22 (56.4)		16 (41.0)	
Somewhat comfortable	25 (59.5)		14 (33.3)		21 (50.0)	
Comfortable	32 (37.7)		56 (67.5)		41 (48.8)	
By myself at home		.13		.43		.45
Not comfortable	10 (27.0)		23 (62.2)		20 (54.1)	
Somewhat comfortable	14 (43.8)		15 (46.9)		12 (38.7)	
Comfortable	45 (45.9)		54 (56.8)		46 (47.9)	
By a friend or partner at home		.007		.22		.05
Not comfortable	23 (31.1)		44 (59.5)		28 (38.4)	
Somewhat comfortable	21 (63.6)		14 (42.4)		21 (63.6)	
Comfortable	25 (43.9)		33 (58.9)		28 (50.0)	
With a sex partner		.26		.009		.001
Not comfortable	19 (45.2)		17 (40.5)		10 (23.8)	
Somewhat comfortable	21 (51.2)		20 (48.8)		22 (55.0)	
Comfortable	29 (36.3)		53 (68.0)		46 (58.2)	
Reasons for not testing						
Low risk		.06		.32		.30
No	58 (38.4)		85 (56.7)		68 (45.6)	
Yes	11 (61.1)		7 (43.8)		10 (58.8)	
Stigma/fear		<.001		.004		.38

HIV testing variables	Intention to test by...					
	Self-test[a]		Clinic or other provider[b]		CHTC[a,c]	
	%	*P*	%	*P*	%	*P*
No	53 (35.8)		87 (59.6)		70 (48.3)	
Yes	16 (76.2)		5 (25.0)		8 (38.1)	
Lack of access to testing		.04		.01		.03
No	57 (38.0)		87 (58.8)		74 (50.0)	
Yes	12 (63.2)		5 (27.8)		4 (22.2)	
Belief about treatment/other		.47		.41		.82
No	67 (41.6)		90 (56.3)		75 (47.2)	
Yes	2 (25.0)		2 (33.3)		3 (42.9)	
Know where to test		.79		.03		.12
Strongly disagree/disagree	5 (35.7)		4 (30.8)		3 (25.0)	
Strongly agree/agree	57 (39.3)		88 (61.1)		70 (48.3)	

[a]Self-test and CHTC outcomes: Very likely/somewhat likely versus somewhat unlikely/very unlikely.

[b]Clinic outcome: Very likely versus somewhat likely/somewhat unlikely/very unlikely.

[c]CHTC: couples HIV testing and counseling.

Intention to test at a clinic or other provider was significantly higher for those who were aware of the self-test, were comfortable testing at a clinic inside and outside the community, by their health care provider, on a mobile van or with a sex partner, and reported knowing where to test for HIV. Participants who indicated stigma/fear or lack of access to testing as reasons not to test were significantly less likely to indicate an intention to test at a clinic or other provider. The mean score for HIV testing self-efficacy was significantly higher for participants who indicated an intention to test at a clinic or other provider compared with those who did not indicate an intention to test at a clinic or other provider (Table 4).

Participants who were somewhat comfortable testing at a clinic inside the community or somewhat comfortable or comfortable testing with a sex partner had a significantly higher intention to test by CHTC (Table 3). Participants who indicated lack of access to testing were significantly less likely to indicate an intention to test by CHTC compared with those who did not.

Correlates of Intention to Test by Specific Testing Approaches: HIV Risk Behaviors

Participants with a primary partner and reporting an STI in the prior year were significantly more likely to indicate an intention to test by self-test (Table 5). Marijuana users were significantly less likely to indicate an intention to test by self-test compared with non-users, whereas stimulant users were more likely to indicate an intention to test by self-test compared with non-stimulant users. The mean score for risk perception was significantly higher for participants who indicated an intention to test by self-test compared with those who did not indicate an intention (Table 4).

Stimulant users were less likely to indicate an intention to test at a clinic or other provider compared with non-stimulant users (Table 5). Participants who reported having a primary partner were more likely to indicate an intention to test by CHTC compared with those not in a primary partnership (40.4%), although this was of borderline significance (Table 5).

Correlates of Intention to Test by Specific Testing Approaches: Peer Norms, Social Support and Stigma

Mean scores for peer norms for testing and social support were significantly lower for those with an intention to test by self-test compared with those who did not (Table 4). Conversely, mean scores for peer norms for testing and social support were significantly higher for those with an intention to test at a clinic or other provider test compared with those who did not. The mean score for peer norms for testing was significantly lower for those with an intention to test by CHTC compared with those who did not.

Table 4. Correlates of intention to test by specific testing approaches: HIV testing self-efficacy, risk perception, peer norms, social support and stigma, All About Me Study, N=169.

Self-efficacy, risk perception, norms, support and stigma	Intention to test by...					
	Self-test[a]		Clinic or other provider[b]		CHTC[a,c]	
	Mean (SD)	*P*	Mean (SD)	*P*	Mean (SD)	*P*
HIV testing self-efficacy		.45		<.001		.08
Intention	3.2 (0.6)		3.3 (0.5)		3.2 (0.6)	
No intention	3.1 (0.7)		2.9 (0.7)		3.0 (0.7)	
Risk perception		.002		.14		.79
Intention	2.2 (0.9)		1.8 (0.9)		2.0 (0.9)	
No intention	1.7 (0.8)		2.0 (0.9)		1.9 (0.9)	
Peer norms for testing		<.001		<.001		.01
Intention	3.3 (0.7)		3.7 (0.7)		3.4 (0.8)	
No intention	3.7 (0.6)		3.4 (0.7)		3.7 (0.6)	
Social support		<.001		<.001		.93
Intention	2.4 (0.8)		3.2 (0.9)		2.8 (1.0)	
No intention	3.0 (1.0)		2.4 (0.9)		2.8 (1.0)	
HIV stigma		.09		.09		.83
Intention	17.9 (5.6)		19.8 (5.7)		19.0 (5.6)	
No intention	19.7 (6.4)		17.9 (6.2)		18.8 (6.4)	

[a]Self-test and CHTC outcomes: Very likely/somewhat likely versus somewhat unlikely/very unlikely.

[b]Clinic outcome: Very likely versus somewhat likely/somewhat unlikely/very unlikely.

[c]CHTC: couples HIV testing and counseling.

Multivariable Analysis for Intention to Test by Specific Approaches

In multivariable analysis (Table 6), intention to use a self-test remained independently associated with comfort in testing by a friend or partner at home and stigma or fear as a reason not to test and negatively associated with higher social support and having health insurance. Intention to test at a clinic or other provider remained independently associated with self-efficacy for HIV testing and higher social support and negatively associated with a lifetime history of incarceration. Intention to test by CHTC remained negatively associated with higher educational level and having a primary partner was of borderline significance.

Table 5. Correlates of intention to test by specific testing approaches: HIV risk behaviors, All About Me Study, N=169.

HIV risk behaviors in the last 3 months	Intention to test by...					
	Self-test[a]		Clinic or other provider[b]		CHTC[a,c]	
	%	*P*	%	*P*	%	*P*
Number of anal/vaginal partners		.47		.96		.24
0-1	24 (40.0)		32 (55.2)		31 (52.5)	
2-3	25 (48.1)		30 (58.8)		26 (52.0)	
4-5	10 (35.7)		15 (53.6)		10 (35.7)	
>5	8 (30.8)		14 (53.9)		9 (34.6)	
Primary partner		.01		.22		.05
No	33 (32.7)		59 (59.6)		40 (40.4)	
Yes	35 (52.2)		33 (50.0)		37 (56.1)	
Condomless anal intercourse (insertive or receptive)		.18		.09		.16
No	29 (47.5)		28 (46.7)		33 (54.1)	
Yes	40 (37.0)		64 (60.4)		45 (42.9)	
Anal intercourse with positive or unknown status partner		.16		.78		.56
No	52 (38.2)		73 (54.9)		64 (48.1)	
Yes	17 (51.5)		19 (57.6)		(14) 42.4	
STI[d] in past year		.04		.33		.31
No	43 (35.8)		62 (53.0)		52 (44.4)	
Yes	26 (53.1)		30 (61.2)		26 (53.1)	
Marijuana use		.03		.19		.46
No	39 (49.4)		39 (50.0)		39 (50.0)	
Yes	30 (33.3)		53 (60.2)		39 (44.3)	
Stimulant use		.009		.03		.35
No	56 (37.3)		86 (58.5)		71 (48.3)	
Yes	13 (68.4)		6 (31.6)		7 (36.8)	

[a]Self-test and CHTC outcomes: Very likely/somewhat likely versus somewhat unlikely/very unlikely.

[b]Clinic outcome: Very likely versus somewhat likely/somewhat unlikely/very unlikely.

[c]CHTC: couples HIV testing and counseling.

[d]STI: Sexually transmitted infection.

Table 6. Multivariable analysis for intention to test by specific testing approaches, All About Me Study, N=169.

Variables	Intention to test by...					
	Self-test[a]		Clinic or other provider[b]		CHTC[a,c]	
	AOR[d]	95% CI	AOR	95% CI	AOR	95% CI
Comfort in testing by a friend or partner at home	2.4	1.1-5.3				
Stigma or fear as a reason not to test	8.6	2.5-29.7				
Social support (per point higher)	0.5	0.3-0.7	2.0	1.3-2.9		
Health insurance	0.2	0.1-0.5				
Self-efficacy for HIV testing (per point higher)			2.9	1.5-5.6		
Lifetime history of incarceration			0.4	0.2-0.9		
Some college/Associate's degree vs high school graduate or less					0.8	0.4-1.7
Bachelor's degree or higher vs high school graduate or less					0.3	0.1-0.7
Have a primary partner					1.8	1.0-3.5

[a]Self-test and CHTC outcomes: Very likely/somewhat likely versus somewhat unlikely/very unlikely.

[b]Clinic outcome: Very likely versus somewhat likely/somewhat unlikely/very unlikely.

[c]CHTC: couples HIV testing and counseling.

[d]AOR: adjusted odds ratio.

Discussion

Principal Findings

With multiple options available to test for HIV, but low uptake of testing among black MSM and transwomen, data from this study serve as the basis for development of a computerized algorithm that provides a tailored recommendation of an optimal HIV testing approach for individuals. Young MSM and transwomen completed a Web-based comprehensive assessment regarding HIV testing history and related experiences, awareness and comfort levels with specific testing modalities, sociostructural factors, behavioral risk, peer norms, social support and stigma. The main outcomes of the assessment centered on intentions to test using specific HIV testing approaches. We sought to identify correlates of intention to test by three specific HIV testing methods in order to inform the basis of the testing algorithm. Using equations from the multivariable models generated from these analyses, we have calculated the probability of intention to test for each specific testing approach. We developed decision rules for choosing the recommended HIV testing approach. Thus, from a short series of questions, we can provide a tailored recommendation of an optimal testing approach and are currently pilot testing this intervention algorithm among young black MSM and transwomen. One example is a young black MSM with some college education and health insurance. He is not comfortable testing at home with a friend or partner. He has a high level of social support and HIV testing self-efficacy. He does not cite stigma/fear as a reason not to test. Using the algorithm and the decision rules, this individual would receive a recommendation of "Based on your answers, a good option for your next HIV test is going to an HIV testing site, clinic or doctor." Another example is someone with some college education and health insurance. He has a primary partner. He has a history of incarceration. He is comfortable testing at home with a friend or partner. He is on the lower range of social support but in the medium range of HIV testing self-efficacy. He cites stigma/fear as a reason not to test. This individual would receive a recommendation of "Based on your answers, a good option for your next HIV test is an HIV self-test."

We found that over half of the participants (55%) were very likely to test at a clinic or other provider in the next 6 months. These results are similar to those found in an national Web-based survey of mostly white and Latino MSM conducted in 2012, with 56% indicating that they would be extremely likely to test at a physician's office [49]. A small proportion of participants indicated that they were very likely to test by self-test (17%) or CHTC (19%). These are considerably lower than the 58% and 30% found to be extremely likely to test by self-test or CHTC, respectively, in the national Web-based survey [49]. Although a high percentage of participants knew about these approaches, the lower intention to test using these methods may reflect a generalized reluctance to adopt newer approaches [14]. Alternatively, there may be unique aspects of each testing approach that appeal, either by design or otherwise, to select members of the population.

In support of this notion, we found in multivariable analysis that specific variables were associated with intention to test using specific testing approaches. For example, those who cited stigma or fear as a reason not to test were more likely to express an intention to use a self-test. Other studies have found that perceived stigma is negatively associated with recent HIV testing among young MSM [50-52] and among young black MSM [13,53]. The privacy associated with self-testing may address the stigma and fear associated with HIV testing at a clinic site or in front of another person. Our results support the idea that the HIV self-test may be effective in increasing HIV testing uptake among those for whom stigma or fear forms a barrier to HIV testing. Our previous qualitative work with young black MSM and transwomen found that privacy was an

important part of the appeal of self-testing, in addition to how self-testing reduced the anxiety of going to a clinic [14]. In our analysis, we also found that having higher social support was negatively associated with intention to test by self-test. Thus, self-testing may provide an option for those who are not well-linked with a supportive social network. Our qualitative work suggested that lower social support could reflect the need for autonomy or control over the testing experience [14].

As expected, we found that a higher level of comfort with testing by a friend or partner at home was also associated with intention to test by self-test. In addition, lack of health insurance was also associated with a higher intention to test by self-test. Others have found structural barriers to testing, such as lack of health insurance, to be higher among black MSM compared with white MSM [54], whereas others have found no difference [55]. Perhaps such individuals are unaware that HIV testing is available for free at many clinics, or health insurance may be a marker for other issues such as inadequate access to health care or having experienced discrimination in health care settings [13,15,56]. Attempts to increase access to self-test kits have been conducted by local health departments such as a recent public health initiative in New York City, which provided a limited number of free self-test kits [57].

Intention to test at a clinic or other provider was more likely with higher HIV testing self-efficacy and social support. We are not aware of other studies among young black MSM and transwomen, which provide data on the role of self-efficacy and social support in intention to test by specific HIV testing approaches. Recent studies examining the role of social network and individual-level characteristics in HIV testing behaviors found that some social network characteristics and functions such as network-mediated information acquisition about HIV/AIDS was associated with ever and repeat testing, but HIV-specific social support from network members was not associated with ever, repeat, or recent HIV testing [52]. We also found that those who had a lifetime history of incarceration were less likely to have an intention to test at a clinic or other provider. It is possible such intentions are low because they were HIV tested while incarcerated; alternatively, they may have had negative experiences testing in the criminal justice system [58,59].

Finally, only lower educational level was found to be associated with intention to test by CHTC. Sharma et al [49] also found that lower educational level was associated with the likelihood to test by CHTC among MSM in a national Web-based survey. Perhaps these findings are explained by partnering patterns and duration of relationships by educational level or whether CHTC is available at community clinics versus private practices.

Limitations

This study has several limitations. Due to the limited sample size, especially among transwomen, we may not have detected some associations of importance. A large number of invalid cases were detected from the Web-based New York City survey; a dilemma that researchers face when conducting Web-based studies is whether or not to provide monetary incentives, which can help to attract potential participants but also invites opportunities for fraudulent data [60]. In addition, even with fraud detection protocols in place (eg, reCAPTCHA codes, blocking duplicate IP addresses, verifying email and phone numbers) with Web-based recruitment, many participants can enroll during a short time frame, or an individual can attempt to participate numerous times [61], making it difficult to prevent duplicate respondents and invalid data in real time.

Addressing and removing suspicious and invalid cases is critical, as those cases may differ from valid cases, potentially affecting study outcomes and implications [62,63]. Finally, recruitment occurred through a range of social and sexual networking websites and apps and at local events. It is likely that we missed some individuals who do not visit the specific websites or attend local events, or who do not publicly identify as MSM or transgender.

Conclusions

It is a crucial public health goal to increase the proportion of young black MSM and transwomen who get tested for HIV and test consistently. Multiple websites and apps are rapidly becoming available to maximize user choice to increase levels of intervention uptake, such as contraceptives, pre-exposure prophylaxis, and STI testing (eg, Nurx app, “Which Method,” “I want the Kit”). Given the need to increase regular HIV testing among young black MSM and transwomen, the data presented here provide information on the important factors that are associated with intentions to test using these different approaches. These data will be critical for the development of a tailored intervention that shows promise to increase comfort and experiences with a variety of testing approaches among young black MSM and transwomen.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Sample recruitment ads and sources.

[PDF File (Adobe PDF File), 442KB - publichealth_v3i3e45_app1.pdf]

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Abbreviations

AOR: adjusted odds ratio
CDC: Centers for Disease Control and Prevention
CHTC: couples HIV testing and counseling
HIV: human immunodeficiency virus
IP: Internet Protocol
MSM: men who have sex with men
NHBS: National HIV Behavioral Surveillance
SD: standard deviation
STD: sexually transmitted disease
STI: sexually transmitted infection

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Original Paper

Developing a Web-Based Geolocated Directory of HIV Pre-Exposure Prophylaxis-Providing Clinics: The PrEP Locator Protocol and Operating Procedures

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Abstract

Background: Human immunodeficiency virus (HIV) pre-exposure prophylaxis (PrEP) is highly effective in preventing HIV transmission, yet patients interested in learning more about PrEP or in getting a PrEP prescription may not be able to find local medical providers willing to prescribe PrEP.

Objective: We sought to create a national database of PrEP-providing clinics to allow for patients to have access to a unified, vetted source of PrEP providers in an easily accessible database.

Methods: To develop the protocol and operating procedures for the PrEP Locator, we conducted a series of 7 key informant interviews with experts who had organized PrEP or other HIV service directories. We convened an external advisory committee and a collaborators board to gain expert and community-situated perspectives.

Results: At its public release in September 2016, the database included 1,272 PrEP-providing clinics, including clinics in all 50 states and in Puerto Rico. Web searches, referrals, and outreach to state health departments identified 58 unique lists of PrEP-providing clinics, with 33 from state health departments, 6 from government localities, 2 from professional medical organizations, and 19 from nongovernmental organizations. Out of the 2,420 clinics identified from the lists and Web searches, we removed 798 as duplicate entries, and we determined that 350 were ineligible for listing. The most common reasons for ineligibility were not having the appropriate medical licensure to prescribe PrEP (67/350) or not prescribing PrEP, based on self-report (192/350). Key informant interviews shaped important protocol decisions, such as listing clinics instead of individual clinicians as the primary data element and streamlining data collection to facilitate scalability. We developed a Web interface to provide public access to the data, with geolocated data display, search filter functionality, a webform for public suggestions of new clinics, and a publicly available directory Web tool that can be embedded in websites. In the 6 months following release, preplocator.org and hosting websites had received over 35,000 unique views and 300 clinic additions, and 5 websites had initiated hosting of the widget.

Conclusions: Directories exist for many preventive and treatment services. As new medical applications become available, there will be a corresponding need to develop new directories for service provision. Geolocated directories can assist patients in accessing care and have the potential to increase demand for and access to newer, more efficacious medical interventions. Early choices in the development of service directories have long-lasting impact, because once data collection begins, it can be challenging to reverse course. The PrEP Locator protocol may inform early decisions in the development of future service directories. Additionally, the case study on developing the PrEP Locator demonstrates the importance of formative work in identifying service-specific factors that can guide decisions on directory development.

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KEYWORDS

HIV prevention, service directory, geolocated database, PrEP

Introduction

HIV pre-exposure prophylaxis (PrEP) is highly efficacious in preventing HIV, preventing between 56% and 100% of new infections across several effectiveness studies [1-3]. Additionally, bringing PrEP to scale would have a substantial impact on the overall HIV epidemic, with one mathematical model indicating that scaling PrEP use to 40% of eligible men who have sex with men (MSM) based on US Centers for Disease Control and Prevention (CDC) eligibility criteria would reduce the number of new HIV infections in this group by 33% [4]. Moreover, this intervention is cost-effective for at-risk MSM [5-7]. MSM are not the only group for whom PrEP is appropriate; the CDC estimates that substantial numbers of women (468,000) and injection drug users (115,000) are eligible for PrEP [8]. Given the effectiveness and cost-effectiveness of PrEP, it is an essential public health priority to bring PrEP to scale as rapidly as possible. However, PrEP uptake has been limited, even in the highest-risk groups [9-12].

To better characterize the ways in which PrEP uptake occurs, we have previously specified a PrEP care continuum that includes awareness and willingness, access to health care, the likelihood of receiving a prescription, and adherence and efficacy [13]. PrEP awareness estimates among MSM in the United States vary widely (11%-68%), in part according to region [14-18] but also according to time, as studies with more recent data collection indicate higher awareness estimates [14-18]. Willingness to take PrEP and intention to take PrEP are not synonymous, however, with one study identifying a substantial gap between PrEP willingness and intention [19].

Individuals who are aware of PrEP and intend to initiate it need to find a clinician prepared to prescribe PrEP. Any clinician licensed to prescribe medication can prescribe PrEP, but only 7% of primary care providers in one national survey reported ever prescribing PrEP [20]. Moreover, less than 1% of the 1500 clinicians correctly answered a series of four true-or-false questions regarding PrEP, with “don’t know” being the most commonly selected answer for each question [20]. Encouragingly, however, 22% reported reading CDC clinical practice guidance regarding PrEP. Difficulty in identifying PrEP providers has been described as a “purview paradox”, in which neither specialists (viewing PrEP as needing broad provision and therefore being the domain of primary care doctors) nor primary care doctors (feeling a lack of experience, particularly in prescribing antiretroviral medication) feel that they are the appropriate group to prescribe PrEP [21,22]. Despite the purview paradox, a substantial number of primary and specialist clinicians, found in local lists of PrEP-providing clinics, are willing to prescribe PrEP.

There has previously been no single place for patients to look for a clinician willing to prescribe PrEP. A panoply of local resources have been developed to serve as directories of PrEP clinicians, including clinic lists furnished by states, local health departments, community-based organizations, and even medical provider associations such as the HIV Medicine Association. However, such a fragmented system has a number of limitations. First, accessibility is limited because there is no single place for those interested in PrEP to look; rather, the information is dispersed, and the burden is on the patient to identify the appropriate resource. Second, and related, the ease of accessing and sorting through current lists is mixed. A few directories are location-based lists with accessible, map-based interfaces [23-25], but the majority either are published in list form on the Web or require a telephone call to the relevant agency. Third, the lists have varying quality; some lists have no discernable vetting criteria, and others are not up to date. Fourth, in absence of a single and thorough system to identify where PrEP-providing clinics are located, there is no way to identify pockets where PrEP services are least accessible. Identifying areas of low PrEP service access would allow for targeted recruitment and training of clinicians who could prescribe PrEP. Last, few of the lists identify important services at or features of particular clinics. With a unified national database, it is possible to track and publish searchable lists of services that patients might want to be able to access. For instance, patients might want to be able to identify clinics that prescribe services for patients without insurance or clinics that provide PrEP financial “navigation” services that help patients enroll in manufacturer or state medication assistance or copayment programs [26].

This protocol describes the creation of a national database of PrEP-providing clinics. We conducted developmental planning work, including forming advisory boards and conducting key informant interviews with those experienced in developing HIV and PrEP service directories. We then populated the database by gathering and collating PrEP clinic data from existing resources. We added new data fields, including data to allow for eligibility determination and data that we could present to the public, and conducted data collection to furnish information for these new data fields. While populating the database, we developed an accessible tool for patients to search for clinics in a geolocated fashion, hosted at preplocator.org. To maximize accessibility, we also made the database available through an open-source widget interface that can be added to any website. The goal of this protocol is to document the process used to create a geolocated service directory of PrEP-providing clinics, informing interpretation of the data and serving as a foundation for future efforts to develop PrEP or other health service directories.

Methods

To develop the protocol and operating procedures for the PrEP Locator, we had several sources of data and advisement, including convening an external advisory committee and a collaborators board and conducting of a series of key informant interviews. The purpose of the External Advisory Committee was to provide guidance regarding the goals of the PrEP Locator project and included representatives from the CDC, community-based organizations, and the activist community.

We convened quarterly meetings to receive advice from this group. The purpose of the Collaborators Board was to provide detailed input on implementation of the PrEP Locator and included key community representatives and nongovernmental partners. The Collaborators Board convened monthly at project initiation and biweekly in the months preceding public release of the PrEP Locator, in September 2016.

By conducting a series of key informant interviews, we sought to build on the experiences of those who have previously developed service directory resources. The 7 interviews were with experts who have organized PrEP or other HIV service directories at the local or national level. Participants included representatives from community-based organizations, city and state health departments, and federal HIV prevention efforts. The interviews topics were (1) strategies for identifying and recruiting clinics for inclusion in a database, (2) eligibility criteria for clinics, (3) areas of data collection, (4) methods of managing a database, (5) maintaining and updating clinic data, and (6) lessons learned in running local and national service clinic directories. Because the recommendations and lessons learned were largely mechanistic in nature, the data did not require in-depth textual analysis, with analysis instead via a review of interview notes. We also recorded the interviews, and for areas in which further detail was needed, we reviewed the source material.

Results

Advisory Boards

Based on early meetings of the External Advisory Committee and Collaborators Board, we came to several consensus decisions regarding database accessibility and development. First, the database would be easily available for hosting on any site through a simple, location-based widget interface. Second, we settled on an ethos of including as many PrEP-providing clinics as possible by minimizing eligibility criteria. Eligibility criteria would be restricted to either (1) the information necessary for database operation or (2) the information required to allow for determination of appropriate patient access. Operationalizing this ethos meant that eligible clinics only needed (1) a correct address and contact information and (2) verbal or electronic verification that the clinic prescribes PrEP, using state licensure databases to ensure that the clinic has at least one provider with appropriate and up-to-date licensure to prescribe medication such as PrEP. We would not perform more advanced vetting, such as by performing secret shopper calling, determining minimum clinic hours (and even making such hours available), or performing dedicated PrEP scheduling or service navigation. The rationale was that the External Advisory Committee and Collaborators Board were concerned that overly stringent eligibility criteria could exacerbate low numbers of PrEP-providing clinics in resource-poor and rural areas. Third, each collaborating organization agreed to provide specific input within its relative domain of expertise. This feedback covered topics including marketing, graphical design, database design, clinical expertise, and promotional strategy. These areas of feedback substantially informed diverse yet key project components, such as strategies for vetting clinics, the PrEP Locator logo and branding, details of the website graphical interface, and engagement with community partners to ensure reaching those most in need of access to the service.

Key Informant Interviews

There was substantial consensus across key informant interviews regarding how the PrEP Locator database should identify and recruit clinics, maintain and update clinic data, and manage data. Interview participants recommended that we have a maximally inclusive process, identifying clinics by including all publicly available clinic and clinician lists (governmental and nongovernmental groups included), contacting health departments and medical organizations for unpublished lists, and conducting keyword Web searches state by state.

To update clinic data, participants recommended that we have a webform located on a “front-end” (publicly visible) website and that we also set up regular automatic distribution of this form (eg, biannually) to clinics in the directory along with a request to update any information that has changed. Similarly, informants recommended a front-end accessible webform to add new clinics to the database. To manage webform updates and new clinic entries, participants recommended a “holding pen” system on the database back-end (visible only through rights-based access), allowing database administrators to fact-check information prior to it being added to the publicly available dataset. Regarding database management, a single, cloud-based relational database was recommended, with import and export functionality, an administrative interface to edit data, and rule functions for each database variable or object to ensure data quality.

Interview participants had more divergent views regarding how the PrEP Locator database should determine clinic eligibility criteria. There was a substantial range of eligibility criteria for PrEP clinics across different databases. The minimum threshold used by some was to have the clinics self-complete a brief electronic or paper survey or even a single, opt-in item in a larger clinician survey. One directory used “mystery calling”, a process in which staff would call each clinic and claim to be a patient searching for PrEP. Key informants used the mystery calling system as a point to start discussions with clinics in their database that failed to provide a minimum level of care access. However, after a certain period of attempting to improve outcomes, repeat failures could result in removal of a clinic from the list. Features explored in “mystery” calls included front desk staff indicating awareness of PrEP and knowledge of where to connect the calls or which clinicians at the institution prescribe PrEP, a reasonable wait time for clinic visits, and reasonable access to appointment scheduling. All PrEP clinic directories using more rigorous eligibility criteria served urban areas with a high density of PrEP clinics. At the state level and among local efforts with less funding, directories used substantially fewer eligibility criteria. For the vast majority of PrEP clinic lists, the only inclusion criterion was self-report that a clinic prescribed PrEP.

Across interviews, key informants agreed that certain basic data fields should be included in the database: clinic address, clinic name, clinic contact information (telephone number, email address, and website), and provider name. There was less

agreement regarding other domains of data collection, including types of PrEP services offered, hours of operation, and more extensive clinic vetting criteria. Some noted personal experiences with building databases with too many fields, noting that with each additional field, the time required for initial collection and subsequent updating might substantially increase. Some interviewees told stories of users who relied on incorrectly listed hours for a clinic, resulting in delays in obtaining appropriate care. However, other key informants thought that data fields such as hours, PrEP services for those without insurance, or language availability would provide an important service to database users. PrEP services generally require a clinician appointment, so one participant noted that any errors in clinic hours would be unlikely to negatively impact users. Others suggested the possibility of including additional data fields but not making their completion a requirement for a clinic to be included in the public display of PrEP-providing clinics.

Interviewees preferred listing clinics, rather than individual clinicians within each clinic, as a database entry. Some directory developers had initially listed individual clinicians but found it logistically infeasible to maintain an up-to-date list. Individual providers not only frequently changed clinic affiliation but also often shared their times across different offices or clinics. Therefore, it was considered too resource intensive to maintain an individual list of clinicians. Furthermore, interviewees indicated that an individual provider-based system was problematic because it would clutter any geolocated interface, resulting in an unwieldy interface for potential users.

Based on this input from advisory boards and key informants, we developed a protocol for the PrEP Locator database. For areas without consensus, we returned to seek further input from our advisory boards, with the project's principal investigator being responsible for final decisions. In decisions regarding database development and feature inclusion, we weighed resource availability and the costs and benefits to end users.

PrEP Locator Protocol

Purpose

Emory University, supported by the MAC AIDS Fund, developed a national directory of clinics providing HIV PrEP. The national directory of PrEP-providing clinics, along with its public-facing website, preplocator.org, is termed the PrEP Locator. The PrEP Locator's goal is to serve as a common repository for information regarding clinics that prescribe PrEP. The directory is an open resource for those who are managing existing directories, allowing them to share their resources in a common format so that patients can access a national, integrated PrEP clinic location service that includes both public and private-practice PrEP providers. The database is easily accessible at preplocator.org or through a public-facing widget that allows distribution through existing websites and mobile apps.

Procedures

Eligibility criteria

The PrEP Locator database includes both public and private health care clinics that are willing to prescribe PrEP. For all clinics listed in the database, Emory staff verify that at least one provider has current licensure to prescribe medication such as PrEP based on publicly available licensure information posted by state medical boards. Appropriate professional licensure includes an M.D., D.O., N.P., or P.A. degree, which would allow for a clinician to prescribe PrEP. To identify a provider at each clinic to allow for state licensure searching, we rely on either publicly available information or the clinic's self-report. Publicly available information comes from organizational websites that list providers as part of their staff and from inference for eponymous clinics (eg, for Dr. Jane Doe's Clinic, we consider Jane Doe to be the provider). Organizations may also self-report to Emory staff that a provider at the organization can prescribe PrEP. Self-report data come from email, webforms, or telephone calls. Regardless of source, staff then enter clinician names into state licensure databases as search criteria to determine appropriate and up-to-date licensure. Pharmacies prescribing PrEP through collaborative drug therapy agreements are eligible for inclusion, with vetting conducted based on the name and credentials of the clinician overseeing the agreement. Prior to being included in the database, pharmacies must submit relevant information to allow for standard eligibility determination. Due to privacy concerns for providers and to organizations' internal vetting, Planned Parenthood clinics and other public clinics known for offering birth control prescriptions are exempt from this vetting process. For all other organizations, if we are unable to verify a licensed provider on staff, the organization is not eligible for inclusion in the directory.

Another eligibility criterion is that clinics must have complete data for four variables: *clinic name*, *address* (street address, county and/or city, state, and zip code), and *telephone number* and *provider name* (to verify licensure). If these data fields are not available from the data used to populate the database, Emory staff contact the clinic or provider electronically or with a telephone call. If unable to establish contact, Emory staff make connections through use of Web-based keyword searches to correct potentially incorrect contact information. If Emory staff are still unable to make contact after 3-7 additional telephone calls, they consider the clinic or provider not eligible for database inclusion. Eligible clinics must also serve the general public, so some student health clinics and Veterans Administration clinics are not included in the database. The call script used for clinic eligibility determination and additional data collection, when available, is in Multimedia Appendix 1.

Procedure for Database Population

Development of the PrEP Locator dataset, conducted from October 2015 to September 2016, used Web searches, referrals, and outreach to state health departments to identify PrEP-providing clinics. Emory staff entered all PrEP-providing clinics into a single database. For the majority of clinics, information was not available in database-friendly electronic format, therefore requiring manual data entry by Emory staff. During the process of data entry, staff removed duplicate entries. To develop the final dataset, we then made a case-by-case eligibility determination for each clinic. For clinics with insufficient data available from the original data source to determine eligibility, we either called the clinic or used

information available on the Web, based on a clinic's website, to collect sufficient data to make a determination.

To identify sources of PrEP-providing clinics, we first identified state health department lists by using Web searches and by referral from our advisory boards. Next, Emory staff conducted keyword searches by state, between January 2016 and August 2016, for each of the following terms: "(PrEP OR pre-exposure prophylaxis) providers (state)", "(PrEP OR pre-exposure prophylaxis) HIV providers (state)", "clinics that prescribe (PrEP OR pre-exposure prophylaxis) (state)", and "(PrEP OR pre-exposure prophylaxis) HIV prevention (state)". For all states without publicly available clinic lists, Emory staff contacted the state health department director or the state director of HIV prevention to request lists, if available. Our searches further identified other governmental sources that list PrEP-providing clinics, such as city, county, and regional directories. We included clinician lists from professional organizations, the HIV Medicine Association and the American Academy of HIV Medicine, and we identified nongovernmental lists, such as lists of community-based organizations, social media groups (eg, PrEP Facts), and foundations, through similar means and included these as well. Last, we included individual PrEP-providing clinics identified during the Web search process.

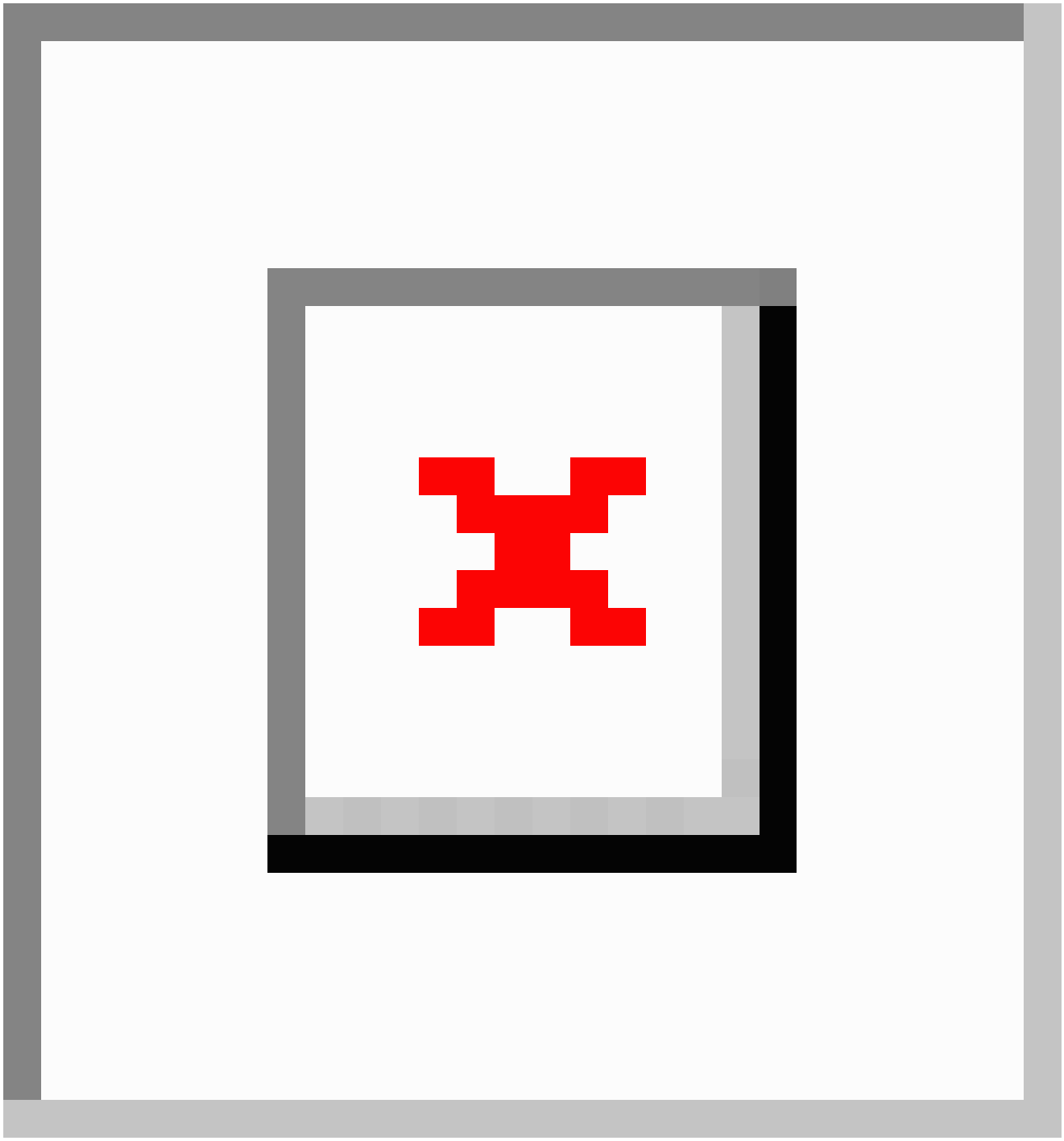
Database Release

At database release in September 2016, we had identified a total of 58 unique lists of PrEP-providing clinics, including 33 from state health departments, 6 from government localities (city or county), 2 from professional medical organizations, and 19 from nongovernmental organizations. Prior to screening and deduplication, PrEP-providing clinics across these lists totaled 2346, and we added an additional 74 clinics based on Web searches.

From this group of 2420, we determined 1272 clinics to be eligible for inclusion, comprising the final set of clinics publicly listed in the database at the release of preplocator.org (Figure 1). We removed one-third of clinics (798/2420) because these were duplicate entries. Of the remaining unique clinics, 22% (350/1622) were ineligible. Common reasons for ineligibility included self-report as not prescribing PrEP (55%, or 192/350), not having current medical licensure to prescribe PrEP (19%, or 67/350), and not serving members of the general public (eg, student-only clinics) (15%, or 54/350). The final dataset of eligible clinics included PrEP-providing clinics in all 50 states and in Puerto Rico.

In the 6 months following release, preplocator.org and hosting websites had received over 35,000 unique views and over 45,000 views in total. The sites attracted this traffic without a substantial advertising campaign, instead relying on advertisements donated by a geosocial networking app company and by websites hosting the Web tool. Over 300 new clinics had been added to the PrEP Locator database, mostly through webform additions by clinics seeking to join the database. Five websites had initiated hosting of the Web tool by embedding it into their websites, allowing for their site users to have real-time access to the PrEP Locator database. Web tool users include a local health department campaign, a foundation, and community-based organizations.

Figure 1. Data sources for clinics populating the PrEP Locator database at project release, September 2016.



Adding New Clinics to the Database

New entries in the database are added through two mechanisms. In the first, participating state and local health departments are asked to add any clinics newly added to their local databases to the PrEP Locator database at minimum biannually, with a goal of monthly information updates. Updates are communicated through webform entries or through electronic communication. Emory staff update the directory with information for new clinics after appropriate vetting to determine eligibility. Similarly, Emory staff make any corrections needed for previous entries, as the information is received from webform entries. State or local directories willing to participate in more real-time mechanisms to update their information will be accommodated.

The second method for the addition of new clinics to the database is based on crowdsourcing. Both the widget display and the PrEP Locator website have links to a webform (Multimedia Appendix 2) for the addition of new clinics. The database can accommodate requests directly from clinics that wish to join the database and also any clinic suggestions from the public. The webform version presented to those identifying as staff at a clinic includes all major data elements for the database. The webform for those identifying as members of the public not affiliated with a particular clinic only has data categories that would be publicly available, such as address and clinic contact information. For all new clinics, we conduct our standard vetting procedures. When members of the public external to the organization suggest an organization, we conduct

standard eligibility assessment and also ensure, through a telephone call or electronic communication, that the organization wishes to opt into the database, and we verify that the organization prescribes PrEP.

New clinics added to the database enter a "holding pen", a part of the database dedicated to non-publicly listed clinic data to be stored. Emory staff review data in the holding pen for eligibility prior to finalization and public listing of the information in the database. Emory maintains a list of clinics previously determined to be ineligible for the database and checks any newly added data against the ineligible list. Emory staff generally complete determination of clinic eligibility within 2 weeks. Once this is complete, the person or organization responsible for completing the webform entry receives an email describing the eligibility determination.

Directory Editing or Removal

Clinics and the public can edit the details of any listing by searching on preplocator.org or the widget for the address of a particular clinic. Clicking on the clinic name or pin will result in display of more detailed information that includes a link labeled "Notify Us of Information Update". Clinic staff and the public can fill out this information update webform, and their corrections enter an update "holding pen". Emory staff determine whether the update is accurate and properly sourced within 2 weeks of the information being submitted and send an update determination email to the clinic as well as the member of the public, if applicable. If a clinic or provider wants to remove themselves from the directory, the same steps as above can be followed for the information update webform. Emory maintains records for clinics opting out of the database to ensure that staff do not mistakenly add these clinics back into the database.

Data Fields

The database core areas of data collection include contact information, address, PrEP service information, clinic hours, database management information, and system auto-generated variables (Table 1). The database contains a single entry per unique physical address, rather than including multiple entries representing each medical provider at a shared practice or clinic. This approach mirrors that of previous databases, such as the CDC National Prevention Information Network [27]. Having only a single entry per address is beneficial for a location-based interface, as it simplifies the user's view. Additionally, it increases the long-term feasibility of keeping the database up to date so that provider changes within a clinic do not need tracking over time. For implementation purposes, a single entry is made, with the *title* variable being the clinic or organization's name. Practitioners without affiliation with a named clinic or practicing outside of a named clinic, at a separate address, are permitted to use their name as the *title* variable in the database.

Address information is collected to allow for geolocation of each clinic, including street information (*streetAddress*), city and/or county (*locality*), zip code (*postalCode*), and state (*region*). Contact information, collected to allow the public to communicate with the facility, includes the clinic telephone number (*telephone*), email address (*clinicEmail*), and website (*link*).

Based on guidance from the project's steering committee, the database includes information on four key services: (1) *Spanish* language: "Do you have Spanish-speaking clinic staff?" (2) services for the *uninsured*: "Do you offer PrEP if a patient does not have insurance?" (3) PrEP *coordinator*: "Do you have a PrEP coordinator in your clinic or practice?" and (4) PrEP *navigation*: "Does your practice help patients navigate paying for PrEP (eg, reviewing insurance, identifying coverage and deductible gaps, and assisting with enrollment in appropriate programs)?" Each of these service offerings is assessed based on clinic self-report, with binomial (Yes or No) responses. If a clinic has a PrEP coordinator, additional questions are asked to collect contact information, and this information becomes an object in the database.

Additional areas of data include clinic hours (captured as a single database object), data entry management variables, and system-generated variables. Data entry management variables are used to manage the system and include the *status* of the entry (active, pending, or excluded (ineligible)), whether an entry has been *vetted* by Emory staff for proper licensure to prescribe PrEP, and *notes* regarding eligibility determination for each clinic. Certain read-only, system-generated variables are automatically generated by the system based on predefined rules: unique *id* number, latitude (*lat*) and longitude (*long*) of each clinic based on the clinic's address and a Google application programming interface (API) callout, and date and time variables to indicate when each clinic entry was *created* and/or most recently *updated*.

Table 1. PrEP Locator database system domains, variables, variable definitions, and variable examples.

Domain and variable name	Variable definition	Variable example
Contact information		
Title[a]	Name of the clinic or provider	Empowerment Resource Center
Telephone[a]	Clinic telephone number object, containing a number that must be 10 digits or empty and an extension field without an enforced format	404-999-9999
Telephone2	Second clinic telephone number object	404-999-5555
ClinicEmail	Email address of the clinic, which must be a valid email address	info@preplocator.org
Link	Website of the clinic, which must be a valid URL beginning with http:// or https://	https://www.preplocator.org
Address		
StreetAddress[a]	Street address	1518 Clifton Rd.
Locality[a]	City and/or county	Decatur
Region[a]	State	GA
PostalCode[a]	5-digit zip code	30322
PrEP service information		
Spanish	Whether the clinic offers services in Spanish; false by default	False
Uninsured	Whether the clinic accepts uninsured patients; false by default	True
Navigation	Whether the clinic offers PrEP navigation services; false by default	True
Coordinator	PrEP coordinator for the clinic, an object containing the clinic coordinator's information, with name, email address, and telephone number fields	Jane Doe, janedoe@healthcare.com, 404-727-9999
Clinic hours		
Schedule	Schedule for the clinic, an object containing the hours of operation, with objects for each day of the week; each day's object contains status (open, closed, or empty), openTime, and closeTime	Monday, open 8:00AM to 5:00PM
Entry management		
Status[a]	Active, pending, or excluded, as determined by Emory staff	Active
Vetted[a]	State licensure verification by Emory staff	True
Eligible	Rationale for eligibility determination	Does not prescribe PrEP
Notes	Contact notes for each clinic, including information such as the number of contact attempts and the results of contact	Contacted by email and telephone 5 times.
System-generated variables		
Id	ID of the clinic, auto-incremented from 1	1428
Lat	Latitude in decimal format, generated from a Google API using the clinic address	33.798258
Long	Longitude in decimal format, generated from a Google API using the clinic address	-84.323467
Created	RFC 3339 timestamp for when the clinic was added to the database	2016-04-12T23:20:50.52Z
Updated	RFC 3339 timestamp for when the clinic was added to the database	2016-04-12T23:20:50.52Z

[a]Indicates a required variable; an entry cannot be processed without this information.

For all non-required variables, information may not be available for each clinic for all data fields. In the case of incomplete information, each variable is set to empty.

Data Validation

Emory staff conduct data validation checks to ensure the accuracy of the information in the directory. Website links are checked to ensure that they link to active websites. For clinics that list a Facebook page as their primary website, Emory staff check to ensure that the Facebook page has been updated in the last 6 months. If Facebook websites have not been recently updated or if we are unable to locate an active and functioning link for a standard website, we set the *link* variable to empty.

We developed a function for duplicate identification via an algorithm that uses distance, address, and name similarity. Emory staff manually review potential duplicates identified through the algorithm to determine whether a follow-up call with the clinic(s) is merited for clarification. Staff then determine whether no change is needed, a duplicate entry needs to be determined to be ineligible, or fields from an entry need to be edited for one or both clinics.

PrEP Locator Access

A location-based search widget that can be easily embedded into any website allows organizations or individuals to place the PrEP Locator on their website and have real-time access to the PrEP Locator's database using an API. There are no restrictions on use of the PrEP Locator widget. Information necessary to embed the tool is available at https://preplocator.org/publicly-available-tools/. The widget can auto-detect user location, via permission to use the device's location option, or users can enter their address or zip code. Using a Google API, the widget lists PrEP clinics by nearest location. Implementation of the widget can be seen at https://preplocator.org/ and also is hosted at https://www.greaterthan.org/get-prep/. The PrEP Locator currently has several features, including search filtering options for the uninsured and navigator variables. It also uses an algorithm to automatically expand the search area if there are no PrEP clinics or providers proximal to a given search location. Therefore, if there are no clinics within 25 miles of the user-determined location, the widget will automatically expand the search area outward, with a maximum search area of 100 miles. The widget is compatible with desktop (screenshot in Multimedia Appendix 3) and mobile (screenshot in Multimedia Appendix 4) devices.

Database Information

Database Specifications

The database is a RESTful API service programmed in Go and hosted on Amazon Web Services (AWS EBS). The database uses Amazon Relational Database (AWS RDS) with the open-source, object-relational database PostgreSQL engine. Locations can be queried individually (by ID) or with search parameters (including geography) and can be added (POST), updated (PUT), or deleted (DELETE). Authentication is done via basic HTTP authentication over SSL with per-client credentials that will be provided. Clients are listed, added, or deleted, and clients have read, write, and/or admin permissions.

Database Compatibility

In order to facilitate ease of use and data access, the data fields of the PrEP Locator have name and format conventions that are in line with existing databases, such as the National Prevention Information Network presented by the CDC. Additionally, staff will continue to seek to provide functionality for other partners wishing to access the data.

Database Management

For security purposes, database access will be role based and limited to Emory staff working on this project, who have each completed appropriate training regarding the data system and its management and operation. Rights-based permissions will be used to allow database updating and changes.

Records for all clinics, including those deemed ineligible, will be maintained in the database to facilitate screening of clinics suggested for inclusion. The records of clinics determined to be ineligible will be kept internal to Emory; their records will not be shared with or viewable by external partners unless the listings maintained by database partners, such as state health departments, need to be updated.

Database Updating

Above, we describe our system for regular information updates from state and health department databases and options for crowdsourced, clinic staff, or public updating of individual clinic entries. To further maintain the accuracy of the information in the directory, an email will be sent biannually to each clinic that provided a contact email address. The update email asks clinic staff to verify that the information in the directory is correct. Any edits are vetted through the process described above. For clinics or providers without electronic contact information, we will attempt to make calls annually to ensure that information in the database is current.

Collaborations

The Collaborators Board for the project is responsible for making recommendations for addressing the challenges of this project throughout its development as well as for long-term strategies for the successful distribution and utilization of the PrEP Locator database. The Collaborators Board includes staff representatives from the University of California – San Francisco, the National Alliance of State and Territorial AIDS Directors (NASTAD), Gilead Sciences, and the Greater Than AIDS (represented by the Kaiser Family Foundation). The External Advisory Committee for the project is responsible for providing guidance regarding the development of the PrEP Locator. The desired result of this input is to maximize the acceptability of the resource to clinics, current directory owners, and end users. It includes participants affiliated with the CDC and with AIDS.gov (see Multimedia Appendix 5 for the full list of Collaborators Board and External Advisory Committee members as well as for the charters for each group).

Legal

Attorneys in the Emory legal department guided the process of addressing the copyright ownership issues related to the data,

the development of the database, and the distribution of the widget. The Emory legal team also suggested or reviewed language regarding disclaimers of use. Additionally, the Emory legal department developed the Terms of Use for the contents of the directory, seen in Multimedia Appendix 6, and informed our development of a privacy policy, seen in Multimedia Appendix 7.

Discussion

Patients often need to locate a clinician, such as when they are seeking a new service or seeking services after moving to a new geographic area. Clinic and clinician directories facilitate appropriate identification of clinicians for a broad array of health services, such as services for traumatic stress [28]; transgender or LGBT health [29]; obesity [30]; pediatric autism spectrum disorder [31]; or HIV, sexually transmitted diseases, or hepatitis [32,33]. As new treatment and prevention modalities are developed, there will be a corresponding need to develop new clinic directories. Early choices in the development of service directories have a long-lasting impact due to the labor-intensive nature of conducting the initial database population. The PrEP Locator protocol may inform decisions in the development of future service directories.

Key informant interviews and advisory board input shaped a number of important decisions regarding database development and dissemination, particularly by emphasizing project feasibility and end-user perspectives. The use of clinics as the unit of data, instead of individual clinicians, was key to the project's feasibility because the total number of data lines requiring manual review, 2420, would have been substantially larger if individual clinicians were enumerated. Similarly, suggestions to reduce eligibility criteria to a few key variables and to minimize other areas of data collection to those most relevant to the patient end users facilitated streamlined creation and future management of the database.

Our use of a patient-centered approach served as a useful framework to inform many of the directory development decisions. We collected data on PrEP financial navigation services and on clinics that serve patients without insurance because our advisory boards identified these as important and because making the information publicly available could remove access barriers. Concepts regarding our targeted user-interface design informed our database design. As anticipated, the majority of Web traffic came from mobile phones. For mobile devices with smaller screens, a simplified interface was required (Multimedia Appendix 4), with active links that could facilitate use. Data should be collected to allow for a mobile-relevant interface; a tap on the telephone number, email address, or mailing address of the clinic should lead to opening of the appropriate functionality (dialer, mail, or navigation map). Similarly, database variables should be questions with binomial or categorical answers as often as possible, as this answer type easily translates into check-box search filters.

Management of data entry and verification is essential, so database construction requires building back-end functionality. The public can suggest new data, consisting of either corrections of existing listings or suggestions for new listings, through webforms, and these data must be managed. Including a "holding pen" where data are stored prior to public availability requires additional staff effort to maintain but ensures that the public can contribute to the database and that staff can vet data. Building an efficient back-end (not publicly facing) system for data entry and management provides substantial benefit, allowing for efficient and accurate data entry by staff, facilitating adherence to directory protocols, and aiding project oversight and management. Additionally, building a back-end system with appropriate data formatting and data management can serve to facilitate potential future integration with complementary external databases for other services. For instance, adding a PrEP services database to a sexually transmitted infection services database could benefit users by allowing them to search services in a single hub.

Geolocated directories for service provision have the potential to assist patients in seeking needed health services. Such directories have the potential to maximize the ease of patient access by incorporating electronic and Web-based design components as well as appropriate database structure and design to support the patient-facing interface. Gathering information from key stakeholders and those with database development experience provides substantial utility. This protocol may serve as a starting point for future directory development.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Script for calls to clinics/ health centers/providers that prescribe PrEP.

[PDF File (Adobe PDF File), 48KB - publichealth_v3i3e58_app1.pdf]

Multimedia Appendix 2

Clinic addition webform.

[PDF File (Adobe PDF File), 122KB - publichealth_v3i3e58_app2.pdf]

Multimedia Appendix 3

Desktop widget interface.

[PDF File (Adobe PDF File), 152KB - publichealth_v3i3e58_app3.pdf]

Multimedia Appendix 4

Mobile widget interface screenshots.

[PDF File (Adobe PDF File), 238KB - publichealth_v3i3e58_app4.pdf]

Multimedia Appendix 5

PReP locator.

[PDF File (Adobe PDF File), 11KB - publichealth_v3i3e58_app5.pdf]

Multimedia Appendix 6

Terms of use.

[PDF File (Adobe PDF File), 11KB - publichealth_v3i3e58_app6.pdf]

Multimedia Appendix 7

Privacy policy.

[PDF File (Adobe PDF File), 12KB - publichealth_v3i3e58_app7.pdf]

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Abbreviations

API: application programming interface
CDC: Centers for Disease Control and Prevention
MSM: men who have sex with men
NASTAD: National Alliance of State and Territorial AIDS Directors
PrEP: pre-exposure prophylaxis

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Original Paper

Facebook Recruitment of Vaccine-Hesitant Canadian Parents: Cross-Sectional Study

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Abstract

Background: There is concern over the increase in the number of "vaccine-hesitant" parents, which contributes to under-vaccinated populations and reduced herd immunity. Traditional studies investigating parental immunization beliefs and practices have relied on random digit dialing (RDD); however, this method presents increasing limitations. Facebook is the most used social media platform in Canada and presents an opportunity to recruit vaccine-hesitant parents in a novel manner.

Objective: The study aimed to explore the use of Facebook as a tool to reach vaccine-hesitant parents, as compared with RDD methods.

Methods: We recruited Canadian parents over 4 weeks in 2013-14 via targeted Facebook advertisements linked to a Web-based survey. We compared methodological parameters, key parental demographics, and three vaccine hesitancy indicators to an RDD sample of Canadian parents. Two raters categorized respondent reasons for difficulties in deciding to vaccinate, according to the model of determinants of vaccine hesitancy developed by the World Health Organization's Strategic Advisory Group of Experts on Immunization.

Results: The Facebook campaign received a total of 4792 clicks from unique users, of whom 1696 started the Web-based survey. The total response rate of fully completed unique Web-based surveys was 22.89% (1097/4792) and the survey completion rate was 64.68% (1097/1696). The total cost including incentives was reasonable (Can $4861.19). The Web-based sample yielded younger parents, with 85.69% (940/1097) under the age of 40 years as compared with 23.38% (408/1745) in the RDD sample; 91.43% (1003/1097) of the Facebook respondents were female as compared with 59.26% (1034/1745) in the RDD sample. Facebook respondents had a lower median age of their youngest child (1 year vs 8 years for RDD). When compared with the RDD sample, the Web-based sample yielded a significantly higher proportion of respondents reporting vaccines as moderately safe to not safe (26.62% [292/1097] vs 18.57% [324/1745]), partially or not at all up-to-date vaccination status of youngest child (22.06% [242/1097] vs 9.57% [167/1745]), and difficulty in making the decision to vaccinate their youngest child (21.06% [231/1097] vs 10.09% [176/1745]). Out of the Web-based respondents who reported reasons for the difficulties in deciding to vaccinate, 37.2% (83/223) reported lack of knowledge or trust due to conflicting information and 23.8% (53/223) reported the perception of the risk of the adverse effects of vaccines being higher than the risk of disease acquisition.

Conclusions: We successfully recruited a large sample of our target population at low cost and achieved a high survey completion rate using Facebook. When compared with the RDD sampling strategy, we reached more vaccine-hesitant parents and younger parents with younger children—a population more likely to be making decisions on childhood immunizations. Facebook is a promising economical modality for reaching vaccine-hesitant parents for studies on the determinants of vaccine uptake.

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KEYWORDS

immunization; vaccination; social media; Canada; parents

Introduction

Background

Immunization is one of the most important accomplishments in the global fight against infectious diseases. In Canada, vaccines have saved more lives than any other public health intervention [1]. Despite this success, a 2011 Canadian national survey on immunization coverage reported sub-optimal coverage rates for recommended childhood vaccinations [2]. This low coverage among Canadian children is of concern as vaccine-preventable diseases (VPDs) endemic in other parts of the world could be imported into Canada and lead to outbreaks due to transmission among unvaccinated or under-vaccinated individuals in low coverage areas [3]. Measles is still common in developing countries and remains one of the leading causes of death in young children [4]. The import of measles into Canada was made evident with several recent outbreaks [3]. For example, in 2011, the province of Québec reported the largest North American outbreak of measles since 2002, with 776 cases as compared with the usual annual average of 0 to 2 cases [5,6]. In 2013, there were nine measles outbreaks in Canada with more than half of the cases (42/71) linked to one outbreak in a non-immunizing community in Alberta [7]. In March 2014, the Public Health Agency of Canada (PHAC) released a public health notice, warning Canadians of unusually high numbers of measles cases in five Canadian provinces [8,9]. In 2015, another notice was released because of outbreaks in Ontario and Quebec and the multi-state measles outbreak in the United States [10]. Outbreaks of VPDs such as measles are an imminent threat to Canadians, and experts have suggested that lower vaccine coverage rates are an “impending crisis” [11].

Vaccine hesitant individuals are a “heterogeneous group in the middle of a continuum ranging from total acceptors to complete refusers” [12]. These individuals are of interest as they are undecided about vaccination and may decide to accept, refuse, or delay all or some vaccines for themselves or their children [12]. A recent systematic review by Larson et al (2014) on vaccine hesitancy found that factors affecting vaccine hesitancy include confidence in the vaccine or the provider, complacency regarding the need for or effectiveness of the vaccine, and convenience in terms of access to health care or vaccines [12]. The Strategic Advisory Group of Experts Working Group (SAGE WG) on Immunization recently built on this definition by organizing vaccine hesitancy around three domains: contextual influences such as socio-economic barriers or communications via media/social media, individual/social group influences such as personal knowledge or perceptions of risk, and vaccinations and vaccination-specific issues such as vaccination schedules or characteristics of the vaccines [12-14].

There is a critical need to better understand the factors underlying vaccine hesitancy in Canada in order to implement interventions to help parents in their decision to vaccinate and increase vaccine coverage. Random digit dialing (RDD) surveys have historically been the “Gold Standard” in the collection of Canadian immunization study data. However, Statistics Canada reports that more Canadian households are abandoning their traditional landline telephones; the number of households with landlines has fallen from 66% of households in 2010 to 56% in 2013 [15]. In the province of Quebec, only 43% of households reported having a landline [15]. In contrast, Internet use has been steadily increasing over the years and as of 2010, 80% of Canadians 16 years of age and older use the Internet at home at least once per day [16]. In 2012, this increased to 83% [17]. In addition, the majority (58%) of Internet users are using social media, including over 86% of those under the age of 35 [16], that is, those in their peak reproductive, childbearing, and small-child-rearing years. Concerns have been emerging in the public health community that parental fears regarding childhood vaccines are growing, largely due to rapid sharing of misinformation and the increasing expression and empowerment of anti-vaccine communities and activists on social media [11,18]. Therefore, recruiting via social media platforms for Web-based surveys should be investigated as a viable alternative or complement to RDD to reach self-selecting higher risk populations, such as vaccine-hesitant parents. Alshaikh et al (2013) conducted a systematic review of articles using social media for health research and reported that despite the risk of sampling bias, social media platforms are a useful tool in health research [19]. Furthermore, several recent studies have reported the success of Facebook as a viable, rapid, and cost-effective platform for targeted recruitment of specific populations such as pregnant women, unvaccinated women, parents, young adults and smokers [20-24].

Objective

This study aims to explore the effectiveness of Canada’s most popular social media platform, Facebook, as a tool to reach vaccine-hesitant parents, and it will explore the differences in key parental demographics and vaccine hesitancy indicators between a Facebook survey of recruits and the most recent RDD survey of the Canadian population [25]. To date no study has investigated the value of social media recruitment versus traditional RDD household recruitment in the study of parental immunization practices and beliefs.

Methods

Study Design

In this observational study, we used two datasets that included data on parental immunization beliefs and practices collected from Canadian parents via two different cross-sectional methods. The inclusion criteria for both populations were as follows: (1) over 18 years of age, (2) having at least one child under 18 years, (3) living in Canada, and (4) able to respond to questions in English or French.

Population-based data were de-identified and extracted from a survey collected by a research company contracted by PHAC. During a period of three weeks in March 2011, the researchers randomly selected a sample of Canadian households with a landline via RDD and administered a telephone survey in French or English. The telephone survey consisted of questions on demographics and Canadian parents' knowledge, awareness, attitudes, and behaviors related to immunization [25]. The researchers attempted contact with each household in the sample 8 times prior to retiring the phone number [25]. The average time to complete the survey was 18 minutes and 30 seconds [25]. Researchers of the RDD sample reported a participation rate of 23.43% (7898/33,698) and a total cost of Can $163,398. The average cost per completed survey was Can $93.64.

The Web-based survey comprised primary data collected from self-selected respondents recruited via the social media platform, Facebook. Facebook has been reported as the most popular social media platform in Canada, with more than half of the population logging into Facebook at least once per month, and daily Facebook usage reported as higher than global and US averages [26,27]. The Web-based semistructured survey was available in French and English and contained questions similar to the RDD survey on demographics, parents' knowledge, awareness, attitudes, and behaviors related to immunization. Trusted website links with reliable information on childhood immunizations appeared immediately after terminating or completing the survey to ensure there was no prior influence on the respondents. We piloted the survey with a convenience sample of the primary researcher's "Facebook friends" and a snowball sample of the friends' "Facebook friends" who met the inclusion criteria.

The Web-based survey was set to automatically terminate if the respondents did not provide informed consent or did not meet eligibility criteria. We used a Canadian Web-based survey company (now owned by an American company), Fluid Surveys, to capture the survey data. Fluid Surveys stored all of its data in Canada and used the latest in firewall and encryption technology to protect private information. We exported, encrypted, and password protected the survey responses and did not collect any identifying information on respondents. Upon completion of the survey, respondents were eligible to participate in a draw with an estimated 1 in 90 chance (based on an estimated sample size of 800 respondents participating in the draw) to win an iPad mini (value of Can $375). We kept all email addresses of participating respondents confidential and destroyed them at the end of the draw. We obtained ethical approval from University of Toronto's Office of Research Ethics (REF# 29309).

Recruitment

We displayed Facebook advertisements on the News Feeds of Facebook users whose profiles matched the following inclusion criteria: (1) located in Canada, (2) 18 years or older, (3) parent of a child aged 0 to 15 years, and (4) displaying a profile in English or French. Our advertisements did not target parents with children aged 16-19 years as they are self-consenting to immunization and their inclusion would significantly increase the target audience and dilute our advertisements; however, they would be included if they had younger children. Facebook determines users' location based on information in their timeline, verified by their Internet Protocol (IP) address and by examination of the user's friends' locations [28]. A user's age was determined by their year of birth, required by Facebook for all personal accounts [28]. Parents were identified based on activity or information on their timelines and language was determined from the language used in their profiles [28].

The optimal delivery mechanism of advertisements on Facebook is determined by many factors such as the target audience, the marketplace competition, the bid, and the advertisement's performance history [29]. Facebook provides the option of being charged each time the advertisement is displayed, that is, cost per thousand impressions (CPM) or each time the advertisement is clicked (CPC) [29]. We chose to pay based on CPM as Facebook ensures the advertisement will be optimized to the people most likely to click on your advertisement (eg, most active and engaging users) and remains in the optimal bid range. In addition, Facebook paces the rate at which the advertisement is displayed based on the budget, goal, and period of time specified [29]. We set a goal to reach a minimum of 800 participants based on power calculations and our budget for survey incentives. We began with a lifetime budget of Can $1500 over a period of one month, as this would grant us access to a Facebook consultant. At the time of our advertisement launch, there was a potential to reach 300,000 Canadian parents on Facebook (260,000 English users and 40,000 French users). Therefore the money was allocated based on this distribution with approximately 85% of the budget allocated to the English campaign. Fifty dollars (Can $) gifted by Facebook was later added to the French campaign budget. The Facebook advertisement campaign was launched on December 12, 2013, at 14:00 and ended on January 11, 2014, at 14:00. Three different images were used in our advertisement (Figures 1-3).

Facebook provided several advertisement statistics such as the number of clicks (eg, likes, comments, click for our Facebook page, and click for our Web-based survey), the number of impressions (placements on users' News Feeds), the CPM, and the CPC. Based on these statistics, Facebook optimized the advertisements with the highest click-through rate (CTR) (the number of clicks received/number of impressions) to serve the most users. We removed advertisements that fell below the Facebook average CTR of 1-1.5 % from the campaign.

The objective of the campaign was for targeted Facebook users to click on the advertisement linked to our secure Web-based survey. Users could also be directed to our Facebook page titled

"Parents, tell us what you think about vaccines" by clicking on the advertisement's profile user as opposed to the link. We provided further information on the study and links to the survey on our official Facebook Page.

Statistical Analysis

Campaign and Recruitment

We investigated methodological parameters on the number of impressions, the number of clicks, demographics of users who clicked the advertisement, timelines of data collection, and the costs for both the English and French campaigns. The response rate calculation for the Web-based sample is a derivation from definitions provided by the American Association for Public Opinion Research [30] and is the number of completed surveys divided by the total number of surveys (completed, partially completed, and terminated), plus the remaining unique clicks of unknown eligibility.

Respondent Characteristics and Vaccine Hesitancy

We validated Web-based sample data for single questionnaire response and accuracy of eligibility criteria by verifying IP addresses and demographic information. We conducted univariate analyses for the Web-based and the RDD samples on individual level variables for respondent characteristics and vaccine hesitancy indicators. Respondent characteristics included age group, sex, income and education level, median age of youngest child, birthplace, and place of residence. We investigated vaccine hesitancy using three indicators: perception of safety of childhood vaccinations, measured on a 7-point scale from "Not safe" (1) to "Moderately Safe" (4) to "Extremely Safe" (7); vaccination status of youngest child was classified as "Completely up-to-date" or "Partially or Not at all up-to-date;" and difficulty in making the decision to vaccinate (or not vaccinate) their youngest child, measured as "Very Easy," "Easy," "Difficult," or "Very Difficult." We conducted all descriptive analyses using Microsoft Office Excel 2007 and SAS Version 9.3 (SAS Institute Inc.).

A primary and secondary rater independently coded qualitative data from the Web-based survey on the difficulties in deciding to vaccinate youngest child according to the SAGE model of determinants of vaccine hesitancy [13]. Two raters independently coded all responses with a high level of agreement (percent agreement>90%). Discrepancies were resolved via consensus to reach 100% agreement. The raters could not code the pre-categorized open-ended responses from the RDD data. However, the raters classified the pre-coded categories according to best fit in the SAGE model. The raters conducted all qualitative analyses with NVivo 10 software (QSR International).

Figure 1. Facebook advertisement A in the English campaign.

Figure 2. Facebook advertisement B in the English campaign.

Figure 3. Facebook advertisement C in the English campaign.

Results

Campaign and Recruitment

During the one-month campaign, our advertisements made 280,485 impressions yielding 8557 total clicks on our advertisements. The overall campaign CTR was 3.05% (8557/280,485), with the English campaign yielding a higher click rate of 3.57% (7981/223,637) as compared with 1.01% (576/56,848) for the French campaign. Over 75% (215,770/280,485) of the impressions were among women. Women aged 25-34 years were reached the most, with 39.15% (109,808/280,485) of the overall impressions. Thus, the majority (87.05% [7449/8557]) of the clicks on the advertisements were also women, with the highest average CTR of 2.82% (159/12,410 in the French campaign and 1818/41,804 in the English campaign) among women aged 35-44 years, followed closely by an average CTR of 2.59% among women aged 45-54 years (45/3008 in the French campaign and 261/7080 in the English campaign) and 2.53% among women aged 25-34 years (107/13,212 in the French campaign and 4111/96,596 in the English campaign). In terms of unique Facebook users, our campaign reached 32.53% (97,598/300,000) of our target population on Facebook, with 4.91% (4792/97,598) clicking on the advertisement. Out of the 4792 unique clicks on our advertisements, 35.41% (1697/4792) started the survey. Only fully completed surveys were counted as part of our sample, resulting in 1097 unique respondents. Thus, the response rate was 22.89% (1097/ 4792) and the survey completion rate was 64.68% (1097/1696), with very little missing data (Figure 4). The average time taken to complete the survey was 17 minutes.

Advertisement success varied by language and image displayed. All advertisements produced clicks; however, advertisement A (Figure 1) produced the highest reach and click-through rate and had the lowest cost (Table 1). The CTR was consistently higher over time and the CPC consistently lower for the English campaign as compared with the French campaign. CTRs and CPCs were variable over time for both campaigns; however, the English campaign experienced a substantial drop in the CTR during the holidays from December 23 to 25, 2013. In periods of CTR decrease, there was a corresponding increase in CPC (Figure 5). For the English campaign, the average cost per 1000 impressions (CPM) was Can $5.59 and Can $5.28 for the French campaign. Translated into CPC, the English campaign cost an average of Can $0.16 and the average for the French campaign was Can $0.52. The total research cost was Can $4,861.19 (Can $1500 campaign cost – Can $50 Facebook credit + Can $3361.19 incentives cost).

Table 1. Facebook advertisement statistics.

Campaign		Reach (No. of unique Facebook users)	No. of impressions	No. of clicks	CTR[b] (%)	No. of unique clicks	Unique CTR (%)	Average cost per CPM[c] (Can $)	Average CPC[d] (Can $)	Average cost per unique click (Can $)
English advertisements										
	A	74,572	153,217	5767	3.76	3346	4.49	5.39	0.14	0.25
	B	38,643	51,647	1778	3.44	1189	3.10	6.05	0.18	0.26
	C	16,919	18,773	436	2.32	368	2.18	5.98	0.26	0.30
French advertisements[a]										
	A	15,767	36,327	393	1.08	338	2.14	5.18	0.48	0.56
	B	9178	15,891	150	0.94	128	1.40	5.39	0.57	0.67
	C	3811	4630	33	0.71	33	0.87	5.63	0.79	0.79

[a]French advertisements B and C were removed from the campaign on January 3, 2014.

[b]CTR: click-through rate.

[c]CPM: cost per impression.

[d]CPC: cost per click.

Figure 4. Facebook advertisement recruitment.

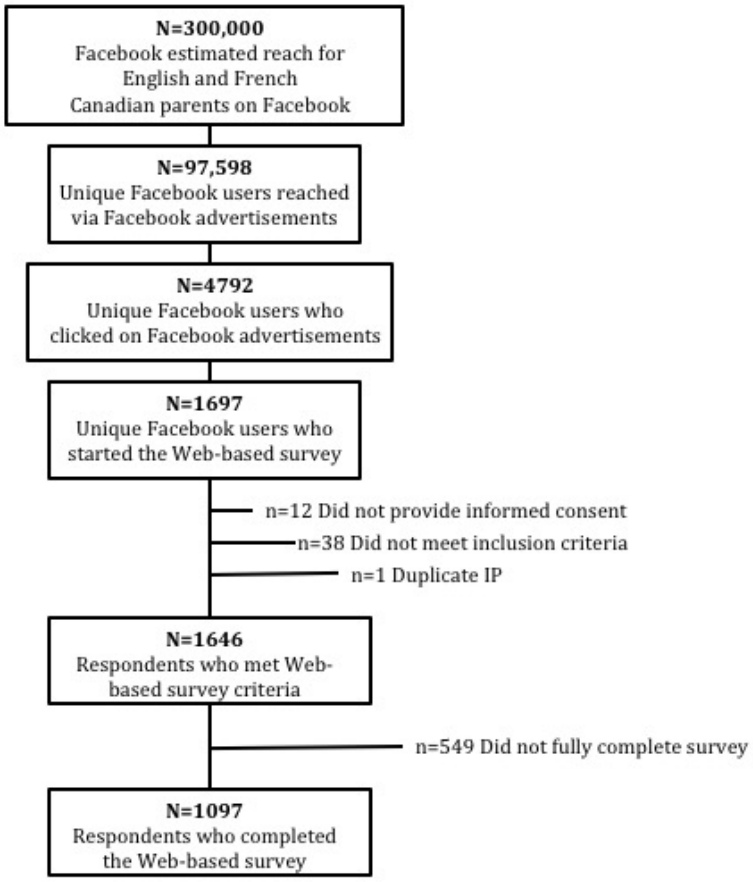
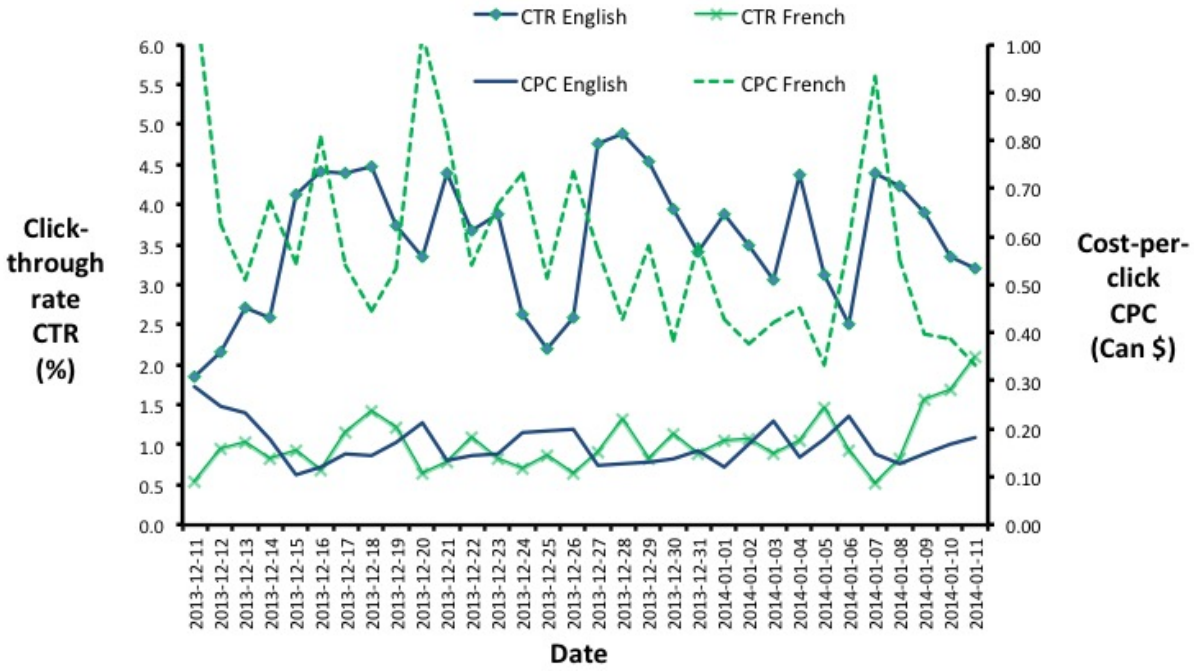


Figure 5. Daily click rates as compared with the cost per click for all campaigns from December 11, 2013, to January 11, 2014.



Respondent Characteristics

Of the respondents in the Web-based survey and the population-based RDD survey, 91.89% (1008/1097) and 83.61% (1459/1745), respectively were born in Canada. The distribution across place of residence was similar, except that the Web-based sample had a lower proportion of respondents from Québec as compared with the RDD sample (10.94% [120/1097] vs 24.47% [427/1745) and a higher proportion of respondents from Alberta (23.61% [259/1097] vs 11.46% [200/1745]). The age distribution differed, with 85.69% (940/1097) of the Web-based survey respondents under the age of 40 years as compared with 23.38% (408/1745) in the RDD sample; however, the age for 37.99% (663/1745) of the RDD respondents is not known. For both samples, the median number of children was two (IQR 1.0) with the median age of the youngest child at 1 year (IQR 1.50) in the Web-based sample and 8 years (IQR 10.0) in the RDD sample. The Web-based sample had 91.43% (1003/1097) female respondents as compared with 59.26% (1034/1745) in the RDD sample. Both samples had similar distribution of education and income level, with almost half of the respondents completing some level of higher education, following the education distribution of Canadian adults [31], and the majority lying close to or above the 2012 median total household income for Canadian families of $74,540 [32] (Table 2).

Vaccine Hesitancy

Of the respondents from the Web-based survey, 26.62% (292/1097) perceived childhood immunizations to be not safe to moderately safe as compared with 18.57% of the RDD sample (324/1745), 22.06% (242/1097) reported the vaccination status of their youngest child to be not up-to date compared to 9.57% (167/1745) in the RDD sample, and 21.1% (231/1097) of the Web-based sample reported the decision to vaccinate their youngest child to be difficult or very difficult as compared with 10.09% (176/1745) in the RDD sample. In the Web-based sample, more than half of those not up-to-date reported that their youngest child had not received any vaccinations (126/242), with 6.3% (n=8/126) reporting the child was too young for vaccinations (Table 3). In total, 20.2% (49/242) of the respondents with their youngest child not up-to-date in terms of vaccinations reported concerns over autism or sudden infant death syndrome as important reasons for deciding not to vaccinate their youngest child.

Of those who found the decision difficult or very difficult, 54.8% (125/228) of the Web-based sample and 36.4% (64/176) of the RDD sample reported their youngest child to be not-up-to date. No significant trends were found when stratifying by parental age, parity, and sex.

In the Web-based sample, 79.8% (178/223) of the reasons for difficulty in their decision making were reported as individual and group influences with knowledge/awareness of vaccination information reported as the most important determinant for 35.4% (40/113) of those with their youngest child up-to-date and 39.1% (43/110) of those who reported their child as not-up-to-date (Table 4). In terms of knowledge, the majority reported difficulties with too much controversial or contradicting information and not enough unbiased or trustworthy information. The second highest determinant reported was the perception of the risks/benefits of vaccination, reported by 23.9% (27/113) of parents with an up-to-date child and 23.6% (26/110) of those whose children were not up-to-date. Most struggled with the risk of adverse effects or side effects versus the risk of acquiring the disease, where 23% (12/53) specifically expressed concern over the risk of autism. Approximately 6.0% (7/113) in the up-to-date and 9.1% (10/110) in the not-up-to-date group reported pressure from society, family/friends, or physicians to vaccinate or not. To a lesser extent, other individual or group influences included personal experience or knowledge of someone who subsequently experienced side effects or developed autism after vaccination, distrust of the government, and belief that vaccines are not necessary for health. Vaccine or vaccination specific issues were reported as reasons in 12.1% (27/223) of the sample. The majority in both groups reported issues with the vaccination schedules in terms of multiple vaccines or age of vaccination, followed by issues with lack of research or testing of new vaccines. Approximately 8% (18/223) of the reasons were reported as contextual, with respondents reporting distrust of the pharmaceutical industry, controversial coverage or fear mongering by the media, and forced vaccination as a result of mandatory vaccination policies in schools. Based on the pre-coded categories in the RDD sample, the majority of both up-to-date and not up-to-date parents also reported perception of risks/benefits and knowledge/awareness as the most important reasons why their decision to vaccinate was difficult or very difficult.

Table 2. Respondent demographic characteristics.

Characteristic	Web-based survey (N=1097)			Population-based RDD survey, un-weighted (N=1745)		
	n	%	95% CI	n	%	95% CI
Age group (years)						
Under 30	395	36.01	33.20-38.88	57	3.27	2.51-4.18
30-34	356	32.45	29.73-35.27	129	7.39	6.23-8.69
35-39	189	17.23	15.08-19.55	222	12.72	11.22-14.35
40-44	96	8.75	7.19-10.53	244	13.98	12.41-15.67
45 and over	56	5.10	3.92-6.53	430	24.64	22.66-26.71
Unknown	5	0.46	0.17-1.01	663	37.99	35.74-40.29
Sex						
Male	80	7.29	5.86-8.95	711	40.74	38.46-43.06
Female	1003	91.43	89.66-92.98	1034	59.26	56.94-61.54
Unknown	14	1.28	0.73-2.08	-	-	
Education level						
Did not graduate high school	25	2.28	1.51-3.30	83	4.76	3.83-5.83
High school diploma	147	13.40	11.48-15.51	275	15.76	14.11-17.53
Trade or vocational school	286	26.07	23.54-28.73	514	29.46	27.35-31.63
Some university	110	10.03	8.35-11.91	144	8.25	7.02-9.61
Bachelor’s degree	277	25.25	22.75-27.89	404	23.15	21.22-25.17
Professional certification	123	11.21	9.45-13.18	97	5.56	4.56-6.71
Graduate degree	101	9.21	7.60-11.03	221	12.66	11.17-14.29
Unknown	28	2.55	1.74-3.62	7	0.40	0.18-0.86
Income level (Can $)						
Under $30,000	85	7.75	6.27-9.44	157	9.00	7.22-10.41
$30,000-$70,000	236	21.51	19.16-24.02	522	29.91	27.80-32.09
$70,000-$79,999	92	8.39	6.85-10.14	125	7.16	6.02-8.45
$80,000-$119,999	316	28.80	26.18-31.54	381	21.83	19.94-23.82
Over $120,000	256	23.34	20.90-25.91	374	21.43	19.56-23.41
Unknown	112	10.21	8.52-12.11	186	10.66	9.28-12.17
Province or Territory of residence						
British Columbia	160	14.59	12.59-16.77	175	10.03	8.68-11.51
Alberta	259	23.61	21.17-26.19	200	11.46	10.03-13.02
Saskatchewan	95	8.66	7.10-10.44	101	5.79	4.76-6.96
Manitoba	42	3.83	2.80-5.09	96	5.50	4.50-6.65
Ontario	336	30.63	27.95-33.41	486	27.85	25.79-29.99
Québec	120	10.94	9.19-12.89	427	24.47	22.50-26.53
New Brunswick	26	2.37	1.59-3.40	62	3.55	2.76-4.50
Nova Scotia	31	2.83	1.96-3.94	70	4.01	3.16-5.01
Prince Edward Island	5	0.46	0.17-1.01	30	1.72	1.18-2.42
Newfoundland	16	1.46	0.87-2.31	46	2.64	1.96-3.47
Yukon	3	0.27	0.07-0.74	15	0.86	0.50-1.38
Northwest Territories	2	0.18	0.03-0.60	23	1.32	0.86-1.94

Characteristic		Web-based survey (N=1097)			Population-based RDD survey, un-weighted (N=1745)		
		n	%	95% CI	n	%	95% CI
	Nunavut	-	-	-	14	0.80	0.46-1.31
	Unknown	2	0.18	0.03-0.60	-	-	-
Birthplace							
	Canada	1008	91.89	90.16-93.39	1459	83.61	81.82-85.29
	Outside of Canada	61	5.56	4.32-7.04	286	16.39	14.71-18.18
	Unknown	28	2.55	1.74-3.62	-	-	-

Table 3. Respondent perception of safety of childhood vaccination, vaccination status of youngest child, and difficulty in making the decision to vaccinate youngest child.

Characteristic		Web-based survey (N=1097)			Population-based RDD survey, Un-weighted (N=1745)		
		n	%	95% CI	n	%	95% CI
Perception on safety of childhood immunizations							
	1-Not at all safe	49	4.47	3.36-5.82	43	2.46	1.81-3.28
	2	48	4.38	3.28-5.71	24	1.38	0.90-2.01
	3	64	5.83	4.56-7.34	50	2.87	2.16-3.73
	4-Moderately safe	131	11.94	10.12-13.96	207	11.86	10.41-13.44
	5	134	12.22	10.38-14.25	275	15.76	14.11-17.53
	6	338	30.81	28.13-53.59	500	28.65	26.57-30.81
	7-Extremely safe	327	29.81	27.16-32.57	630	36.10	33.87-38.38
	Unknown	6	0.55	0.22-1.13	16	0.92	0.54-1.45
Vaccination status of youngest child							
	Completely up-to-date	851	77.58	75.03-79.97	1552	88.94	87.40-90.35
	Somewhat-up-to-date or not at all up-to-date	242	22.06	19.68-24.59	167	9.57	8.26-11.02
	Unknown	4	0.36	0.12-0.88	26	1.49	0.99-2.15
Difficulty in making the decision to vaccinate youngest child							
	Very easy	624	56.88	53.94-59.79	642	36.79	34.55-39.07
	Easy	234	21.33	18.98-23.83	914	52.38	50.03-54.72
	Difficult	152	13.86	11.91-16.00	131	7.51	6.34-8.82
	Very difficult	79	7.20	5.78-8.85	45	2.58	1.91-3.41
	Unknown	8	0.73	0.34-1.38	13	0.74	0.42-1.24

Table 4. Web-based survey respondent reasons for difficulty in deciding to vaccinate youngest child by youngest child vaccination status.

SAGE Model determinant of vaccine hesitancy	Vaccination status of youngest child					
	Up-to-date		Not up-to-date			
	n	%	n	%	Total	Total %
Contextual influences						
Communication and media environment	3	2.7	1	0.9	4	1.8
Influential leaders, gatekeepers, and anti- or pro-vaccination lobbies	1	0.9	-	-	1	0.5
Pharmaceutical industry	3	2.7	4	3.6	7	3.1
Politics, policies	3	2.7	3	2.7	6	2.7
Total	10	8.9	8	7.3	18	8.1
Individual and group influences						
Experience with past vaccination	6	5.3	5	4.6	11	4.9
Beliefs and attitudes about health and prevention	4	3.6	2	1.8	6	2.7
Knowledge/awareness	40	35.4	43	39.1	83	37.2
Health system and providers—trust and personal experience	3	2.7	5	4.6	8	3.6
Risk/benefit (perceived, heuristic)	27	23.9	26	23.6	53	23.8
Immunization as a social norm versus not needed/harmful	7	6.2	10	9.1	17	7.6
Total	87	77.0	91	82.7	178	79.8
Vaccine/vaccination specific issues						
Risk/Benefit (scientific evidence)	-	-	1	0.9	1	0.5
Introduction of a new vaccine or new formulation	6	5.3	5	4.6	11	4.9
Mode of administration	2	1.8	-	-	2	0.9
Vaccination schedule	8	7.1	3	2.7	11	4.9
Costs	-	-	1	0.9	1	0.9
Role of healthcare professionals	-	-	1	0.9	1	0.9
Total	16	14.6	11	10.0	27	12.1
Grand Total	113	100.0	110	100.0	223	100.0

Discussion

Principal Findings

Overall, Facebook was a successful recruitment method for parents to complete a Web-based survey on vaccination. Out of the three advertisements posted in French and English, the English advertisements were the most successful with the highest CTR and subsequently lowest CPC and Advertisement A producing the highest CTR and lowest CPC. We were able to exceed our ideal sample size within a short timeframe, at low cost, and with one researcher running the campaign and data collection. The cost (Can $4,861), timeliness, and sample size of this study achieved comparable or better results than other recent health studies using targeted recruitment via Facebook [20-24,33]. For both the Web-based and RDD survey methods, data collection spanned the same time frame and individual surveys took approximately the same amount of time; however, the costs were 97% lower with Web-based recruitment. The quality of the data was evident with a rich pool of qualitative and quantitative data, a high completion rate, and little missing data. Although both monetary figures represent the total research costs, there are some notable differences as the Web-based recruitment costs also include incentives (no incentives were utilized in the RDD survey), but does not include the supplementary research costs associated with the use of an outside agency (eg, salaries and resources for implementation and deliverables). Notwithstanding, a typical RDD phone survey of 1000 participants might cost approximately Can $70,000 [34], and as demonstrated in this study, external contractual services would not necessarily be needed using Facebook targeted recruitment as it is a less labor-intensive process.

This study solely recruited from one social media platform, Facebook. However, respondents could have also been recruited from other social media platforms such as Twitter. Although Twitter users are typically younger and in childbearing/childrearing years [35], Twitter does not permit targeted recruitment via paid advertisement. Thus, it was considered as a supplementary sampling strategy should we not reach our pre-determined sample size of completed surveys via targeted recruitment on Facebook. Furthermore, Quach et al (2013) reported less success using a social network strategy (as opposed to a paid advertisement) in the recruitment of Canadian parents via Facebook and Twitter [36].

In both populations, the majority of the respondents were Canadian born, followed similar distribution patterns in terms of province/territory of residence, had mostly higher education levels and higher household income levels than the median total household income. We did not compare our data to census data as we were not trying to generalize to the Canadian population. In addition, census data is not available specifically for Canadian parents, our target population. The high response from residents of Alberta in the Web-based sample could be the result of higher engagement due to a large measles outbreak in Alberta that occurred in the month before our campaign launch [7]. The lower number of Québec responses was surprising as Québec has the second highest Facebook usage next to Ontario [27] and experienced a large measles outbreak in 2011. Moreover, we specifically targeted French Facebook users. Based on the lower success of our French campaigns, it is possible that the advertisements were not as attractive to French-speaking Québec users or that Québec users do not interact on the Internet in the same manner as Ontario users or that a higher percentage of the budget needed to be allocated to the French campaign to reach more French-speaking Facebook users.

The Web-based sample demographics differed because we recruited a majority of female respondents and a younger population with younger children compared to the RDD sample that had fairly equal representation of males and females, an older population (even if we assumed all of the unknowns were below 35 years), and older median age of the youngest child. As evidenced by the impression demographics, the Facebook campaign biased the recruitment toward a younger and female population, however the advertisements were intended to target parents with younger children as this would be the demographic interacting on the Internet and making decisions on childhood immunizations. Furthermore, Dubé et al (2012) reported no difference between mothers and fathers in intentions to vaccinate [37]. Combined, both methods produce the greatest spectrum of respondents; however, the Facebook campaign recruited more parents with young children at the most important stage of the vaccination process. Some of the differences we observed may be due to cohort effects, as vaccine hesitancy may have been increasing and been more prevalent in the younger parents recruited through Facebook.

According to our indicators, the Web-based strategy was successful in recruiting a higher number of vaccine-hesitant parents: more respondents perceived childhood immunizations to be not safe to moderately safe, more reported their youngest child's vaccination status as not-up-to-date and more had difficulty in making the decision to vaccinate their youngest child. In addition, out of those reporting difficulty in the decision to vaccinate, more than half in the Web-based sample reported their youngest child's vaccination status as not up-to-date. Moreover, one-fifth of the respondents who reported their child as not-up-to-date reported concerns over autism or sudden infant death syndrome as important reasons for deciding to not vaccinate their youngest child, even though it has been proven that neither disorder is associated with vaccination [38-40]. No significant contributions were observed when stratifying by age, sex, or parity; however, low numbers in some categories prevented reliable comparisons from being made. The factors associated with parental decisions to not vaccinate have been well studied [12,41,42], but no study has focused on vaccine-hesitant Canadian parents. We found that the main reasons reported for difficulty in decision-making were the inability to decipher or trust all the information available and the difficulties in weighing the risks and benefits of immunization with concerns over side effects and adverse effects. The contextual influence of media, social media, or other sources of communication may have played an important role in contributing to respondent concerns regarding their own knowledge or risk perception. However, this could not be further probed because of the inherent limitations of Web-based surveys.

Limitations

As more people abandon landlines, the validity of traditional population telephone surveys is compromised with low response rates and potentially non-representative samples [43]. Representativeness and validity concerns are also relevant for Web-based surveys as research relies on the collection of self-reported data by self-selected participants [44]. However, there are more and more people on popular social media platforms such as Facebook and possibly different people than those reached by RDD. For example, active social media users may be mostly represented by educated females in higher income brackets [17,45,46], which is also the demographic most often looking for health information on the Internet [18]. Furthermore, active social media users may be potentially viewing an abundance of anti-vaccination sentiment on the Internet and may be the people that need to be reached most to combat vaccine hesitancy [47,48].

Both sampling techniques produced low response rates of 23%, which could produce biased samples. The reasons for the low response rate in the RDD sample include invalid numbers, unresolved callbacks, ineligibility, and refusals [25]. In the Web-based survey, there was no direct communication with the potential respondents; thus, it is not clear why certain Facebook users did not click on the advertisement or why those who clicked on the advertisement did not participate in the Web-based survey. This could be an important area for future study.

However, purposive Facebook targeted recruitment of self-selected respondents was not intended to provide a sample representative of the RDD sample or the Census population, but to determine whether we could recruit more "at risk" vaccine-hesitant parents as compared with the standard sampling

technique. Reaching a higher proportion of vaccine-hesitant respondents proved successful; however, there are several inherent biases in using Facebook as a recruiting platform and in targeted sampling to self-selectors. For example, the low recruitment of male respondents could be the result of Facebook's targeting criteria, the visuals, or the content of the advertisements. Selection bias is inevitable as Facebook identifies your desired target population, targets the most active and engaged users, and the number of impressions depends on factors such as the amount spent, the CTR, and market competition. However, for the purpose of our research, this proved to be a strength as this was the group we intended to target and would likely reach with any Web-based intervention. There is potential for volunteer bias and without a sampling frame we cannot calculate a true participation rate, nor can we characterize users who did not see the advertisement or did not engage. The timing of the advertisement (December) may have affected the type of respondents. However, this could not be verified without data from Facebook on who may be more likely to respond at different periods in time. Duplicate responses and gaming are also an important concern in Web-based recruitment [36]. Although difficult to prevent, safety measures as recommended in the Checklist for Reporting Results of Internet E-Surveys (CHERRIES) [49], were implemented to prevent and evaluate repeat respondents. Furthermore, it is possible that we attracted participants who were more likely to click on the advertisement because of strong views (anti or pro) on vaccination. However, based on our results, we were also able to reach an important proportion of participants who did not fall on the very extreme ends of the vaccination spectrum and reached a higher proportion of vaccine-hesitant parents when compared with the RDD.

As with any Web-based recruitment strategy, there are concerns about the "digital divide." Statistics Canada recently reported that Canadians over the age of 65 years are responsible for the lag in Internet use in lower income households [17]. This population is not expected to represent a large proportion of our target population of vaccine-hesitant parents. In addition, the Web-based sample neglected to recruit many foreign-born parents or children. Yet, nearly 20% of Canadians were born outside of Canada. This might represent a significant bias that is difficult to quantify, as the Facebook activity of foreign-born residents is not known. Moreover, recent immigrants may not be a priority group to address for vaccine-hesitancy as they are more likely to arrive with immunity due to previous infections and more likely to become immunized as citizens [50,51]. Notwithstanding the inherent biases, we were able to obtain a large sample size for the recruitment period at a low cost, and we achieved a high survey completion rate with very little missing data. Furthermore, we reached younger Canadian mothers with younger children and more vaccine-hesitant parents when compared with the RDD sample.

Conclusions

Targeted recruitment via Facebook was successful in reaching a population more likely to be engaging in health discussions on the Internet and making decisions on childhood immunizations. Thus, this recruitment strategy was superior to the RDD methodology in reaching "at-risk" vaccine-hesitant parents. Engaged respondents also provided us with insights into the most important determinants of vaccine hesitancy, providing valuable information in directing any future intervention efforts. With more Canadians abandoning landlines and interacting on the Internet with potential exposure to an abundance of anti-vaccination sentiment, popular social media platforms should be considered as part of any recruitment strategy or study on the determinants of vaccine-hesitant parents but also in the implementation of interventions to address these determinants. Future research should consider studies to investigate data reliability and to better examine the relative importance of contextual influences, such as the Internet, as determinants of vaccine hesitancy.

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Conflicts of Interest

None declared.

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Abbreviations

CPC: cost per click
CPM: cost per impression
CTR: click-through rate
IQR: interquartile range
IP: Internet Protocol
PHAC: Public Health Agency of Canada
RDD: random digit dialing
SAGE WG: Strategic Advisory Group of Experts Working Group
VPD: vaccine preventable disease

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Original Paper

Body Weight Misperception and Dissatisfaction Among Overweight and Obese Adult Nigerians

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Abstract

Background: The increase in the prevalence of overweight and obesity in low- and medium-income countries has a negative impact on overall health. Correct perception of one's body weight is a step in seeking healthy help toward weight reduction in overweight and obese individuals.

Objective: This study was carried out to assess the body weight misperception and dissatisfaction among overweight and obese adults in an urban African setting.

Methods: This study was part of a larger cross-sectional study that was designed to plan an intervention for overweight and obese adults in an urban African setting. For this study, we randomly selected only overweight and obese adults (≥18 years old) who consented to participate in the study from 15 enumeration areas in Alimosho Local Government Area of Lagos State, Nigeria. We followed the World Health Organization guidelines for conducting community surveys in recruiting overweight and obese participants. We assessed body weight perception and dissatisfaction through their responses to the following: "How do you describe your weight?" and "I feel bad about myself because of my weight." Data for this study were collected between November 2012 and March 2013.

Results: We recruited 567 participants, of whom more than half (n=304, 53.6%) misperceived their weight as either underweight or normal weight, and 61.2% (n=186) of whom were women. The strength of agreement between the actual body mass index and weight perception was very poor (κ=.032, SE .015, *P*=.04). The strongest predictor of weight perception was sex (female) with an odds ratio of 1.63 (95% CI 1.13-2.35). About 41.1% (n=233) of the participants were dissatisfied with their weight, of whom 30.0% (n=70) were men. Age (young adult) was a predictor of weight dissatisfaction with an odds ratio of 2.37 (95% CI 1.62-3.46).

Conclusions: More than half of the participants misperceived their body weight as either underweight or normal weight, and the majority of them were women. More men were not happy with their body weight, and participants in the young adult age group were more dissatisfied with their body weight.

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KEYWORDS

overweight; obesity; misperception; Nigeria; adult

Introduction

Weight perception is a concept of how an individual perceives his or her weight appropriateness. Self-perceived weight has been documented to have positive associations with effective weight control and weight loss behaviors in adults [1]. Appropriate weight perception is of utmost importance, as this would stimulate the need to reduce weight by individuals who are either overweight or obese [2]. Some overweight and obese individuals do misperceive their body weight. This misperception of weight can hinder the prevention, control, and management of overweight and obesity [2,3]. Weight misperception is the disagreement between an individual's actual weight status and the person's perception of his or her weight [4], which can be categorized into body weight underestimation and body weight overestimation. Weight underestimation is a situation in which overweight individuals consider themselves to be underweight whereas they are overweight, while weight overestimation is when individuals with normal or underweight considers themselves to be overweight as determined by body mass index (BMI) [5].

Weight misperception has been a public health concern, since it can result in large numbers of overweight and obese individuals failing to understand the need for weight control or losing weight [6]. This will eventually affect interventions toward overweight prevention, control, and management. It has been hypothesized that weight misperception among overweight and obese individuals might deter their adoption of healthy weight reduction behaviors [7]. Subjective evaluation of health has been shown to have a link with misperception [8]. The discordance between actual body weight and perceived body weight is associated with depression [8,9], inappropriate weight control practices [8,9], and negative body image [9], which are precursors of health-related quality of life impairments [10]. Weight misperception has been reported in the literature among the youths and adults of different countries. A high prevalence of weight misperception has been reported among youth in Pakistan, a developing country, with 42.4% overall weight misperception seen in the total youth population [11]. High prevalences of weight misperception have also been reported in Spain [12], the United States [5], and China [13].

Little is known about weight misperception among overweight and obese individuals in the urban setting of sub-Saharan Africa. Ethnic and racial differences in body weight perception have been reported in the literature. Non-Hispanic blacks and Mexican Americans who are overweight or obese have been found to view themselves as underweight and incorrectly perceived themselves to be at the recommended weight [14]. Duncan et al [4] also reported that nearly one-quarter of the US sample of overweight and obese adults misperceived their body weight. Also, it has been reported that body weight misperception among overweight individuals was more common among blacks than among whites and less common in women than in men [15]. Among rural dwellers in Nigeria, Akinpelu et al [16] reported that a large proportion of participants in their study could not perceive their weight accurately. Appreciating the issues of weight misperception might increase the awareness of the need to reduce body weight among overweight and obese persons [14], thereby enhancing healthy life behavior and successful weight reduction. We carried out this study to determine the prevalence of weight misperception among overweight and obese Nigerians.

Methods

Participants

This was part of a cross-sectional study carried out at Alimosho Local Government Area of Lagos State, Nigeria. Alimosho Local Government Area has a population of over 1,277,714 (2006 National Population Census) [17]. Using the World Health Organization (WHO) [18] guidelines for conducting community surveys, we randomly chose 5 of 11 political wards into which Alimosho area is divided. We randomly selected 3 census enumeration areas in each of the 5 chosen political wards in Alimosho Local Government Area through National Population Commission 2006 census enumeration areas. We selected houses with odd numbers for survey in each census enumeration area and recruited participants who were 18 years of age and older. The participants for this study were overweight or obese individuals who gave written informed consent to participate in the whole cross-sectional study.

We administered the WHO STEPS Questionnaire to each of the participants [19]. Not all of the data gathered from the STEPS Questionnaire were relevant for this study; we used a section of the STEPS Questionnaire pertaining to demographic information. The demographic data we collected were sex, age, years spent at school, highest educational level attained, racial group, marital status, work status, number of people in the household, and income. To measure height, we instructed each participant to stand barefoot with feet together on a level cemented floor, buttocks and heels touching the wall, head held erect, and eyes looking forward so that the lower margin of the external auditory canal was in the Frankfurt horizontal plane. The point of greatest height to the nearest 0.1 cm was marked off on the wall with a stretch - resistant tape. For weight measurement, we encouraged each participant to put on minimal clothing material prior to measurement. The participant's weight was measured using a Tanita BC-549 Plus Ironman body composition monitor (Tanita Europe BV, Amsterdam, the Netherlands). The weight was recorded to the nearest 0.5 kg. To ensure reliability of these measurements, we took 3 measurements of the participant's height and weight and used the average of the 3 measurements.

Body Weight Perception and Dissatisfaction Measurement

We assessed body weight perception and dissatisfaction mainly through 2 questions in the baseline survey using the protocol of Wang et al [20]. Responses to "How do you describe your body weight? were scored as follows: underweight=1; normal weight=2; a little overweight=3; very overweight=4. Responses to "I feel bad about myself because of my weight" were scored as follows: very true=1; little true=2; not true=3; can't say=4.

We obtained permission and ethical clearance from the University of the Western Cape Research Ethics Committee

(12/9/15) and Lagos State University Health Research and Ethics Committee (LREC/10/06/261).

Statistical Analysis

We recorded frequencies and percentages for categorical variables. For ease of analysis, we recoded the sociodemographic variables age (young adults, middle-aged adults, and older adults), educational status (primary school completed, secondary education completed, tertiary education completed, and postgraduate education), employment (employed, unemployed, and pensioner), and marital status (married and single). We assessed the relationship between independent (sociodemographic) variables and weight perception and weight dissatisfaction using chi-square analysis, and subjected only the variables that showed a significant relationship to logistic regression. We assessed the predictors of the relationship between independent (sociodemographic) variables and weight perception and weight dissatisfaction using logistic regression. Kappa statistics were used to determine the strength of agreement between weight perception and actual body weight (BMI). We set the level of significance at .05. We analyzed the data using IBM SPSS version 23 (IBM Corporation).

Results

We administered the body weight perception questionnaires to a total of 567 overweight and obese Nigerians. Of these, 193 (34.04%) were men and 374 (65.96%) were women. The strength of the agreement between BMI and weight perception was very poor among our participants (κ=.032, SE .015, *P*=.04).

Weight Misperception by Overweight and Obese Nigerians

Table 1 shows the weight status of our sample. As Table 2 shows, of all respondents misperceiving their weight as normal, 38.6% (112/290) were men and 61.4% (178/290) were women. Also, among those who misperceived their weight as a little overweight, 72.7% (141/194) were women and 27.3% (53/194) were men. It should be noted that the participants in these studies were overweight and obese adults. Those participants who classified themselves as either underweight or normal weight actually misperceived their actual weight status. There was no significant difference between male and female weight perception ($\chi^2_{3,n=567}$=7.24, *P*=.07).

Predictors of Weight Perception by Overweight and Obese Nigerian Adults

We carried out a binomial logistic regression to determine which of the sociodemographic variables predicted weight perception. Our model contained sex, age, marital status, employment status, and educational status as predictors. We observed that the full model containing all sociodemographic predictors was statistically significant ($\chi^2_{9,n=567}$=25.60, *P*<.001), showing that our model was able to distinguish between weight perception respondents. However, only 3 of these predictors (female, middle-aged adult, and unemployed) made a statistically significant input to our model, as Table 3 shows. The strongest predictor of weight perception was sex (female), with an odds ratio of 1.63, indicating that women were 1.63 times more likely to misperceive their weight. The odds ratio of 0.39 (which is less than 1) for unemployed participants shows that they were less likely by 0.39 times to misperceive their weight (Table 3).

Table 1. Body mass index (BMI) status of the study population.

BMI category	Men n (%)	Women n (%)	Total n (%)
Overweight	142 (73.6)	165 (44.1)	307 (54.1)
Obese	51 (26.4)	209 (55.9)	260 (45.9)
Total	193 (34.0)	374 (66.0)	567 (100)

Table 2. Weight misperception by overweight and obese Nigerians.

Response	Men n (%)	Women n (%)	Total n (%)
Underweight	6 (42.9)	8 (57.1)	14 (100)
Normal weight	112 (38.6)	178 (61.4)	290 (100)
A little overweight	53 (27.3)	141 (72.7)	194 (100)
Very overweight	22 (31.9)	47 (68.1)	69 (100)
Total	193	374	567

Table 3. Relationship between body weight misperception and demographic variables.

Sociodemographic characteristics	B	SE	Wald	*df*	*P* value	Odds ratio	95% CI
Sex							
Male (reference)							
Female	0.490	0.186	6.962	1	.008[a]	1.633	1.134-2.350
Age							
Young adult (reference)							
Middle-aged adult	–0.667	0.191	12.219	1	.001[a]	0.513	0.353-0.746
Older adult	–0.467	0.353	1.750	1	.19	0.627	0.314-1.252
Educational status							
Primary school completed (reference)							
Secondary school completed	–0.277	.366	0.573	1	.45	0.758	0.370-1.553
Tertiary education completed	–0.125	.357	0.123	1	.73	0.882	0.439-1.776
Postgraduate education	0.023	.369	0.004	1	.95	1.023	0.497-2.107
Employment status							
Employed (reference)							
Unemployed	–0.937	.446	4.409	1	.04[a]	0.392	0.164-0.940
Pensioner	–0.877	.841	1.086	1	.30	0.416	0.080-2.164
Marital status							
Single (reference)							
Married	–.147	.254	0.335	1	.56	.863	0.525-1.420
Constant	0.124	0.397	0.097	1	0.76	1.132	

[a]Significant at $P<.05$.

Weight Dissatisfaction Among Overweight and Obese Nigerian Adults

Table 4 shows how dissatisfied our participants were regarding their weight. Descriptive statistics show that 233 (41.1%) of all participants were not happy with their weight, of whom 70 (30.0%) were men and 163 (70.0%) were women. However, there was a significant difference between how men and women felt about their weigh ($\chi^2_{3,n=567}=16.53$, $P=.001$).

Predictors of Weight Dissatisfaction Among Overweight and Obese Nigerian Adults

We performed logistic regression to assess the impact of sociodemographic variables on weight dissatisfaction among the overweight and obese adult Nigerians in our study population. The model contained sex, age, highest educational level, employment status, and marital status as independent variables, with weight dissatisfaction as the dependent variable. The model explained between 4.7% (Cox and Snell R^2) and 6.4% (Nagelkerke R^2) of the variance in weight dissatisfaction and correctly classified 62.4% of cases. Logistic regression also showed that the independent variable age made a unique statistically significant contribution to the regression model ($\chi^2_{9,n=567}=27.40$, $P=.001$), which implies that the model was able to distinguish between overweight and obese adults who were able to show dissatisfaction with their weight correctly and incorrectly. The main predictor of weight dissatisfaction was age (young adult) with an odds ratio of 2.37. This can be interpreted as overweight and obese young adults being 2.37 times more dissatisfied with their body weight.

Table 4. Weight dissatisfaction among the overweight and obese Nigerian adult study population.

Description	Men n (%)	Women n (%)	Total n (%)
Dissatisfied	70 (30.0)	163 (70.0)	233 (42.9)
Satisfied	123 (37.9)	211 (65.1)	324 (57.1)
Total	193 (34.0)	374 (66.0)	567 (100)

Discussion

Principal Findings

This study sought to determine the prevalence of weight misperception and dissatisfaction among Nigerian overweight and obese adults, as well as those factors that would predict weight perception and dissatisfaction. The outcome of this study shows that more than half of our participants perceived their BMI as either underweight or normal, and the majority of them were women, although we found no difference between male and female weight perception. The level of agreement between BMI and weight perception was actually very poor, which accounts for why more than half perceived their weight to be underweight or normal. Of the participants, 41.1% displayed dissatisfaction toward their body weight (BMI).

Weight reduction success depends on a few factors, among which are weight control practice and behavior acquired by the individual. Recognition and appreciation of one's body weight once it is compromising health is an important factor in reducing excess weight. This can be achieved through accurate body weight perception. Weight control behaviors and practices have been shown to be caused by body weight perception [20].

Weight misperception was reported among overweight and obese Sri Lankan adults in a study in which more than two-thirds of overweight and one-third of obese Sri Lankan adults misperceived their weight to be normal or underweight [21]; the majority of them were women. This is in line with the findings of our study. Although this study was carried out among Nigerian adults, similar results were reported among adolescents in Hong Kong [22]. While looking at differences in perceived weight and attractiveness among overweight black or white America women, Chithambo and Huey [23] found that black women reported lower perceived weight than did white women. Our study showed very poor agreement between actual body weight (BMI) and perceived body weight. Since self-perception of body weight is a major determinant of nutritional practices and weight management [24], health care professionals and public health physicians should step up awareness campaigns regarding the importance of accurate body perception.

The predictors of weight misperception were sex (female), young adult age, and being employed. This is contrary to the finding of Jayawardena et al [21], who reported that older age was a significant predictor of underperception of body weight. This difference might arise from their use of self-reported weight and height to arrive at their participants' BMI, which had been earlier reported to be unreliable and inconsistent [25]. Also, the weight perception questionnaire administered to our participants was different from that used by Jayawardena et al [21], whose body weight perception question contained 5 options, whereas ours contained 4 options. Furthermore, the participants in the Jayawardena et al [21] study had participated previously in the Sri Lankan Diabetes Cardiovascular Study (SLDCS), whereas the participants in our study had never participated in this type of study. Findings from Jayawardena et al [21] might have been influenced by recall or learning effects, since they had participated previously in a similar study [26]. However, the findings in our study were similar to those of Chang and Christakis [12] who reported that age, sex, and income were independently associated with self-evaluation of weight status in an American population. Furthermore, age and sex (female) were also reported to be associated with weight misperception among overweight and obese adults in Pakistan [27].

The extent of body weight satisfaction or dissatisfaction hinges on self-assessment of one's body, the knowledge of which is personal and cannot be assessed or determined by someone else [28]. Body weight dissatisfaction might play a role in healthy weight behaviours and practices. Less than half of the participants in our study reported body weight dissatisfaction, and age is a predictor of body weight dissatisfaction. Similar results were reported among Israeli Arab women by Niskar et al [29] and among overweight and obese adult women in the United States [30]. Body weight dissatisfaction might be influenced by racial and cultural affiliations, especially among the black population in sub-Saharan Africa [31]. There is an unconfirmed belief that a bigger and plumper body size attracts respect and indicates the absence of diseases in some cultural settings. A cross-cultural perspective study to determine the weight control behaviour among women of diverse ethnic affiliations, however, reported that larger body size is more acceptable to women of ethnic minorities, and hence mitigates weight reduction behaviour [32]. In Nigeria, the social and cultural acceptability of overweight and obesity has been reported in the literature [33]. Marital preference is given to individuals who are bigger because it connotes affluence and healthiness. This might hinder healthy weight and weight reduction practices and behaviors. In view of these, the need arises to change cultural orientations and perceptions of plumpness as a sign of affluence to being a sign of ill health by public health and medical practitioners.

Conclusion

This study has shown that the majority of participants misperceived their body weight (BMI) and less than half of the participants were dissatisfied with their body weight. These results should be interpreted and generalized with caution because we obtained the responses subjectively. Another limitation is that the 2 questions that assessed weight perception and dissatisfaction were not validated and their reliability was not determined. However, the strength of this study lies in the fact that it was conducted on only overweight and obese adults of both sexes. We recommend, therefore, that further studies should be carried out using a validated measure to assess weight misperception and dissatisfaction. We also recommend that various weight reduction steps and attempts being made by overweight and obese individuals should be assessed.

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Conflicts of Interest

None declared.

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Abbreviations

BMI: body mass index
SLDCS: Sri Lankan Diabetes Cardiovascular Study
WHO: World Health Organization

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Original Paper

A Platform for Crowdsourced Foodborne Illness Surveillance: Description of Users and Reports

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Abstract

Background: Underreporting of foodborne illness makes foodborne disease burden estimation, timely outbreak detection, and evaluation of policies toward improving food safety challenging.

Objective: The objective of this study was to present and evaluate Iwaspoisoned.com, an openly accessible Internet-based crowdsourcing platform that was launched in 2009 for the surveillance of foodborne illness. The goal of this system is to collect data that can be used to augment traditional approaches to foodborne disease surveillance.

Methods: Individuals affected by a foodborne illness can use this system to report their symptoms and the suspected location (eg, restaurant, hotel, hospital) of infection. We present descriptive statistics of users and businesses and highlight three instances where reports of foodborne illness were submitted before the outbreaks were officially confirmed by the local departments of health.

Results: More than 49,000 reports of suspected foodborne illness have been submitted on Iwaspoisoned.com since its inception by individuals from 89 countries and every state in the United States. Approximately 95.51% (42,139/44,119) of complaints implicated restaurants as the source of illness. Furthermore, an estimated 67.55% (3118/4616) of users who responded to a demographic survey were between the ages of 18 and 34, and 60.14% (2776/4616) of the respondents were female. The platform is also currently used by health departments in 90% (45/50) of states in the US to supplement existing programs on foodborne illness reporting.

Conclusions: Crowdsourced disease surveillance through systems such as Iwaspoisoned.com uses the influence and familiarity of social media to create an infrastructure for easy reporting and surveillance of suspected foodborne illness events. If combined with traditional surveillance approaches, these systems have the potential to lessen the problem of foodborne illness underreporting and aid in early detection and monitoring of foodborne disease outbreaks.

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KEYWORDS

foodborne illness surveillance; crowdsourced surveillance; foodborne diseases; infectious diseases; outbreaks; food poisoning; Internet; mobile; participatory surveillance; participatory epidemiology

Introduction

The World Health Organization estimates that each year roughly 1 in 10 people worldwide experience illness after consuming contaminated food [1]. In the United States, an estimated 48 million people experience foodborne illness each year [2], resulting in costs of at least US $15.5 billion annually [3]. A majority of cases are unreported due to mild illness, limited public knowledge of reporting procedures, or absence of laboratory confirmation of disease [4]. Underreporting of foodborne illness makes foodborne disease burden estimation,

timely outbreak detection, and evaluation of policies toward improving food safety challenging.

To augment traditional approaches (via phone, email, forms on department of health websites, fax, etc) to foodborne illness reporting, illness complaints submitted on social media and business review sites have been used by local departments of health for targeted restaurant inspections and foodborne disease outbreak surveillance [5-7]. Furthermore, foods implicated in foodborne illness reports on the business review site Yelp.com have also been shown to correlate with foods identified as the source of foodborne outbreaks by the US Centers for Disease Control and Prevention (CDC) [8]. These studies used passively collected information from social media and business review sites.

Alternatively, these data can be collected via crowdsourcing, which refers to the collection of information or completion of tasks by a large public audience [9]. Crowdsourcing or participatory surveillance has been used for public health monitoring of infectious diseases such as influenza and dengue [10,11]. These systems use mobile apps and the Internet to recruit and collect data on disease-specific symptoms. Examples include systems for monitoring influenza-like illness activity in Europe (eg, Influenzanet [12]) and the United States (eg, FluNearYou [13]); systems for identifying viruses causing acute respiratory infections at the community level (eg, GoViral [14]); and systems for reporting dengue and other mosquito-borne pathogens (eg, Kidenga [15]). Some of these systems have shown that participatory surveillance can enable timely ascertainment of susceptible and diagnosed cases of disease and has the potential to augment traditional disease surveillance systems [13,16].

Crowdsourced surveillance of foodborne illness can be useful in several ways. First, crowdsourced reporting of foodborne illness complaints is useful for general monitoring to enable targeted restaurant inspection [5] and identification of safety issues in the food production chain. Food can be contaminated at any point in the food production chain, and only a small proportion of foodborne illnesses are linked to outbreaks [17]. Early detection of food safety problems can prevent outbreaks. Second, information submitted through these platforms can aid in the early identification of unsafe food products, which can lead to product recall. Products can be unsafe due to contaminants or mislabeling that can result in illness or allergic reactions. Third, data submitted through these platforms can aid in detection and monitoring during foodborne disease outbreaks.

The objective of this paper was to present an efficient and easy-to-use data submission platform—Iwaspoisoned.com—for crowdsourced surveillance of foodborne illness.

Methods

Iwaspoisoned.com (Figure 1) is a freely accessible crowdsourcing system launched in 2009. Persons experiencing symptoms of a foodborne illness can submit information on the implicated foodservice business, foods consumed, date of visit, date of symptom onset, and number of affected individuals.

Data Collection

A report can be submitted on Iwaspoisoned.com using the form displayed on the left in Figure 1. Upon clicking, "Report Now," users will be directed to a second page where they are asked whether they saw a doctor and to provide additional details on their experience. Once the complaint (or report) is submitted, the unstructured data is formatted and stored in a database with each data element segregated into unique fields. The data fields include date, product details, restaurant details, description of experience, contact information (optional), and Internet Protocol (IP) address. Each report is assigned a unique identification number, and new reports default to the status of "Pending Review."

To ensure data quality, human curators review reports for tone and accuracy of restaurant information. The restaurant details, which consist of the restaurant name and location, are validated using the Google search engine. If the restaurant name or location is missing or incorrect, the report is held for further review. We attempt to contact the user to obtain the missing details if the contact information is provided. In the event that we cannot validate the business location, the report is deemed invalid and is not published. Additionally, each description of a foodborne illness experience is carefully read to detect obscene or abusive language or language that suggests an attack on the business. Two examples of the 1700 submitted reports that have been excluded are presented.

> *Ate a piece of Trident Layers strawberry gum that my friend bought, felt a small (very tiny) trace of fever (mild headache, sore throat, mild loss of appetite) 1 hour later. Ilovehorseyrides.* [Example 1]

> *Location: Bikini Bottom I went to the Krusty Krab a few days ago. I ordered a Krabby Patty that shut was expensive n*gga. I got home and everything was all gucci. Next morning I saw dookie stains all over.my bed sheets and it smelled like ASS nigguh. Damn that sh*t was off chain. I suffered a Fever and I puked on my wifes lap and she bitch slapped me. F*ck Mr Krabs, Krusty Krab? More Like Krusty Crap. People, buy at the Chum Bucket, I hear their new human hot dog is a.must eat.* [Example 2]

Example 1 was excluded because of the inclusion of the nonsensical text—"ilovehorseyrides"—in this report and several other reports from the same IP address. All reports containing the nonsensical text were excluded. In Example 2, the restaurant cited was fictional, so the content was deemed inauthentic.

Furthermore, to eliminate spam, we verify IP addresses through IP lookup tools and identify suspicious patterns using a combination of automated and human review. We also consider a combination of timestamp, contact email, IP address, restaurant details, and description to identify multiple submissions of similar reports by the same user. If the duplicate reports are about the same incident and the details do not change, we assume the multiple submissions are because of user error. In such cases, only one report is published.

A report is only posted to the site and considered in review of larger trends after the authentication process. Food poisoning

complaints posted on Iwaspoisoned.com are reviewed and compared with other reports to identify patterns in reported symptoms and geography. As foodborne diseases have varying incubation periods, there's a possibility of individuals implicating the wrong foodservice business; therefore, surveillance is focused on identifying case clusters within a single report or across multiple reports rather than a single case. Some users submit reports while or right after experiencing illness, making it easier to identify and track disease clusters for timely outbreak control. Whenever a potential emerging or ongoing food safety issue is identified, the appropriate health department is contacted via email or phone and provided with details on the implicated business, symptoms, and contact information, if included in the report. The health department is contacted when two or more reports stating that multiple people experienced illness after eating at the same location are received within a span of 7 days.

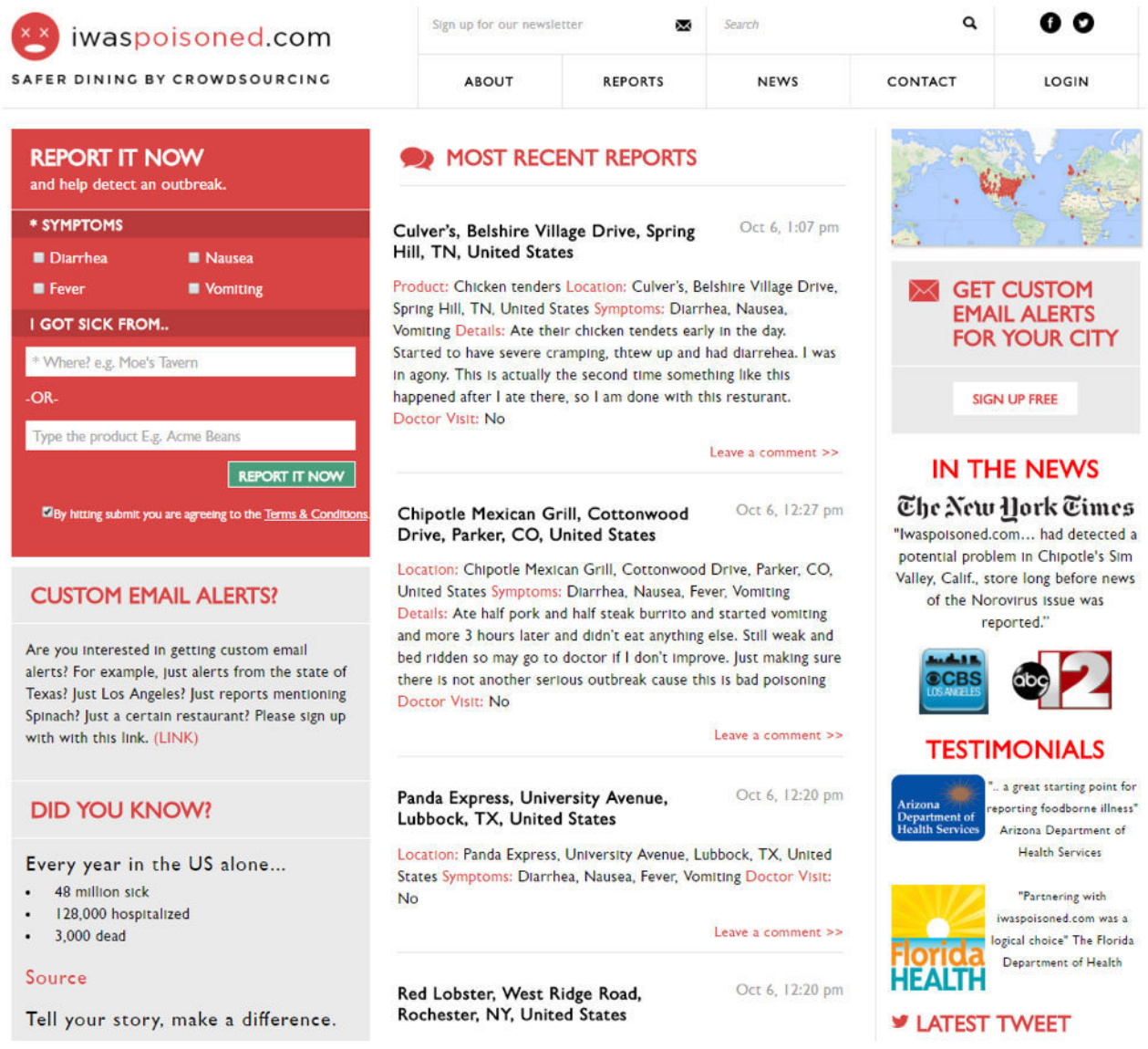
Survey

To better understand user demographics, we developed a survey that asked users about their gender (male/female) and age (under 18, 18-24, 25-34, 35-44, 45-55, 55+). The optional survey ran from February 6, 2016 to August 12, 2016, and was presented to every person who submitted a complaint. A second survey that focused on doctor visits and disease diagnosis was run from Feb 28, 2016 to July 10, 2016. The survey asked two questions: (1) Did you see a doctor? (Yes/No), and (2) If yes, was there a diagnosis? If there was a diagnosis, was the user diagnosed with a foodborne disease or another disease?

Case Studies

In the last two years, the system has assisted in the detection and monitoring of outbreaks associated with at least three major food chains. Our knowledge on early detection involving communication with a health department is limited to outbreaks that were reported in the news. We present three examples: two local outbreaks and one of national attention because there were multiple outbreaks associated with the same chain across the United States. Note that these examples are meant to demonstrate the potential utility of this system and do not in any way suggest that foodborne outbreaks are limited to these restaurants.

Figure 1. Screenshot of the Iwaspoisoned.com website.



Results

Data Collected

As of October 6, 2016, 49,934 unique reports have been collected. Most reports originated from the United States (44,524/49,934, 89.17%), Canada (1070/49,934, 2.14%), United Kingdom (1050/49,934, 2.10%), and Australia (178/49,934, 0.36%). In the United States, the highest number of reports were received for California, accounting for 16.95% (7547/44,524) of all reports, followed by Texas with 7.10% (3161/44,524), Florida with 5.80% (2581/44,524), and New York with 4.24% (1886/44,524; Figure 2). In contrast, the lowest volume of reports was observed in Mississippi and South Dakota. Factors that could explain the low volume of reports in these states include low Internet access, low population density, and an absence of big cities.

Of the 44,119 users with precise information on the suspected business, 95.51% (42,139/44,119) and 2.63% (1159/44,119) attributed their illness to restaurants and grocery stores, respectively. The remainder were distributed across other business categories (Table 1). According to the most recent outbreak report from the US CDC for 2014, the most reported foodborne outbreaks associated with a single location were attributed to foods prepared in a restaurant: 485 (65%) outbreaks and 4780 (44%) associated illnesses [18].

Survey Responses

The demographics survey had 4616 respondents. Approximately 67.5% (3118/4616) of respondents were under the age of 34, and 60.1% (2776/4616) of respondents were female (Table 2).

There were 7141 respondents to the doctor visit survey and 88.4% (6315/7141) did not see a doctor. Of those who saw a doctor, approximately 24.3% (201/826), 22.4% (185/826), and 5% (37/826) received a general diagnosis, no diagnosis, or other diagnosis (ie, not a pathogen associated with foodborne diseases), respectively. Approximately 7% (58/826) were either still awaiting results or did not want to share results. Of the remaining 41.8% (345/826), 32.8% (113/345) received a diagnosis of *Salmonella*, 27.5% (95/345) were diagnosed with *Norovirus*, 25.2% (87/345) with *Escherichia coli* (E coli), and 14.5% (50/345) with *Listeria*, *Campylobacter*, Colitis, Ciguatera toxin, Trichinosis, *Shigella*, *Clostridium*, and *Giardia lamblia*. According to the US CDC, *Norovirus* and *Salmonella* were the leading cause for confirmed foodborne disease outbreaks with a single etiology in the United States in 2014 [18].

Figure 2. (A) heat map illustrating the distribution of foodborne reports by state with the legend from red to green, representing most to least. (B) heat map showing the most populous states in red, and the least populous in light green. (C) heat map showing per capita food poisoning reports per state. This is the population of the state divided by the number of reports received. The highest number of reports received per capita is in bright red at 1 for every 5200 people, the least number of per capita reports is in white at 1 for every 18,300 people.

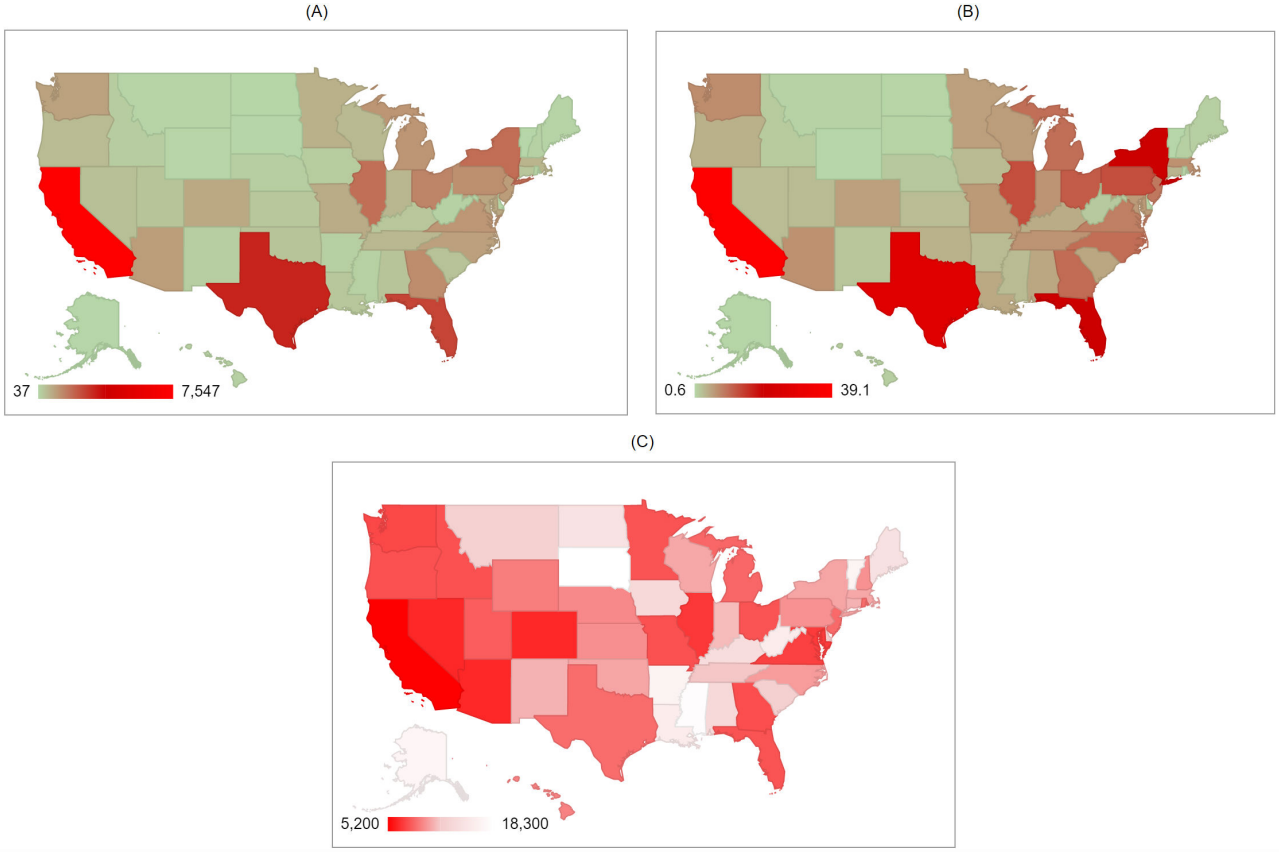


Table 1. Distribution of reports across businesses.

Business	n (%)
Restaurant	42,139 (95.51)
Grocery/Supermarket/Warehouse	1159 (2.63)
Retail host	419 (1.0)
Convenience store/Gas station	130 (0.3)
Hotel/Resort/Casino	67 (0.2)
Packaged food product	57 (0.1)
Entertainment/Theme park/Festival	49 (0.1)
Airline	35 (0.1)
Airport	18 (0.0)
Shopping mall	11 (0.0)
University/School	11 (0.0)
Train station	6 (0.0)
Stadium	6 (0.0)
Hospital	5 (0.0)
Food truck	4 (0.0)
Community service/Church	2 (0.0)
Cruise	1 (0.0)
Total	44,119 (100.00)

Table 2. Survey of 4616 Iwaspoisoned.com users.

Age group in years	Female, n (%)	Male, n (%)	Total, n (%)
Under 18	281 (6.09)	158 (3.42)	439 (9.51)
18-24	772 (16.72)	519 (11.24)	1291 (27.97)
25-34	832 (18.02)	556 (12.05)	1388 (30.07)
35-44	453 (9.81)	304 (6.59)	757 (16.40)
45-55	251 (5.44)	164 (3.55)	415 (8.99)
55+	187 (4.05)	139 (3.01)	326 (7.06)
Total	2776 (60.14)	1840 (39.86)	4616 (100.00)

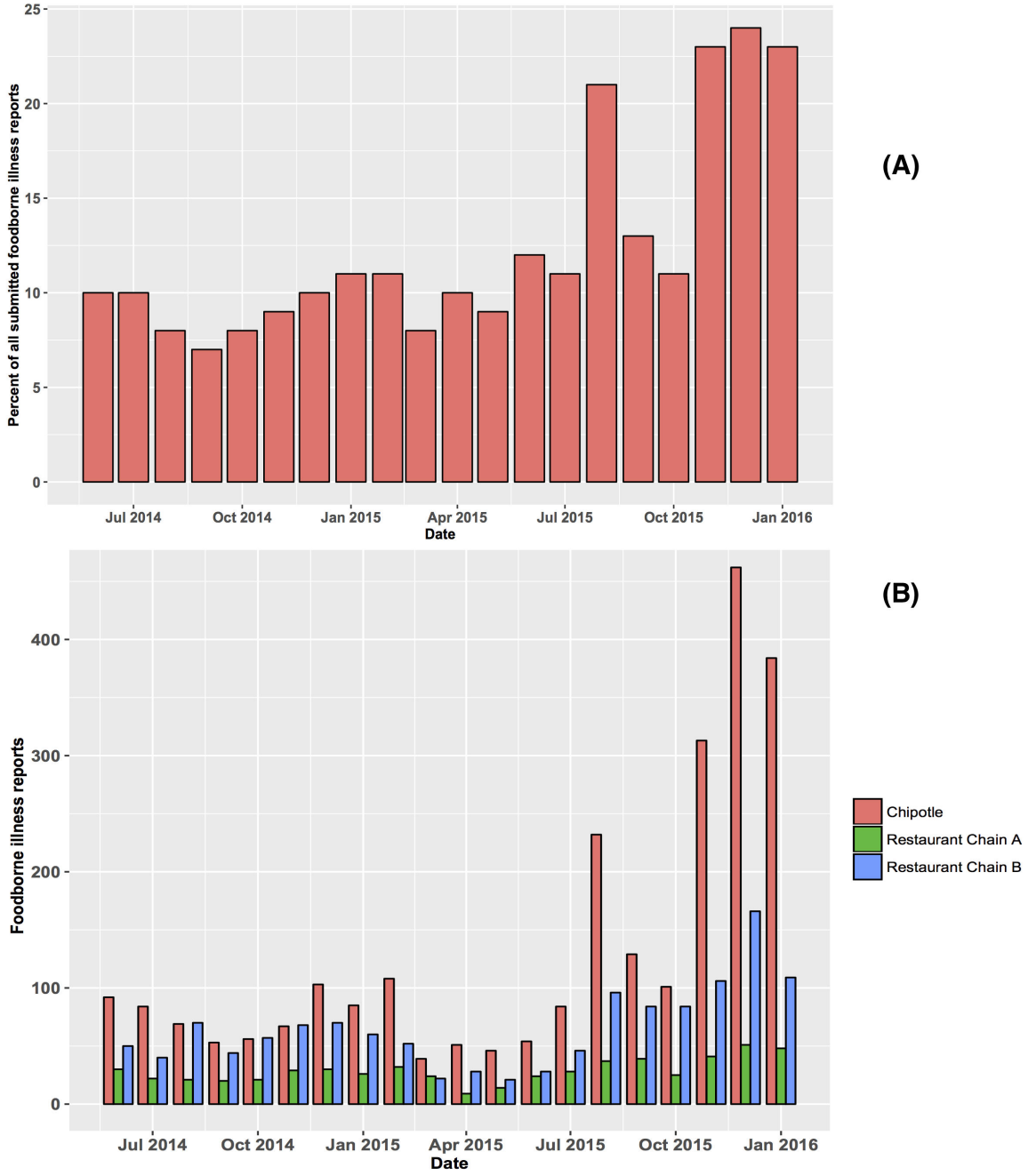
Case Studies: Restaurant Outbreaks

We present three examples in which Iwaspoisoned.com detected clusters of similar illness linked to a restaurant before an official press release by the local health departments. Note, the case studies are meant to illustrate the potential of using this system to supplement state and local public health foodborne disease surveillance systems and in no way suggest that foodborne outbreaks are limited to these restaurants. See the US CDC and Surveillance Food Safety website [19] for more information on handling food and foodborne outbreaks.

First, in 2015, Chipotle, a major fast food company was identified as the source of several foodborne disease outbreaks across the United States. Between August and December of 2015, single- and multistate outbreaks were reported in California, Massachusetts, Minnesota, Wisconsin, Delaware, Illinois, Maryland, Kansas, New York, Oklahoma, Ohio, Oregon, and Washington.

On August 21, 2015, three reports citing a total of 7 people experiencing illness after consuming food at a Chipotle restaurant in Simi Valley, California, were submitted on Iwaspoisoned.com. On August 22, 6 new reports were submitted mentioning 23 sick individuals, and on August 23, 37 reports were submitted mentioning multiple sick persons; all implicating the same restaurant. Additional reports were submitted over the next several days, averaging approximately 5 to 10 per day. The persons mentioned in these additional reports experienced illness during the time frame of the outbreak; however, the individuals were either too sick to report in real time or discovered the website a few days post illness. The number of reports implicating Chipotle in Simi Valley increased from 1 to 30 within 2 days. On September 4, approximately 2 weeks after the initial report, the Ventura County Department of Health, California, confirmed a Norovirus outbreak linked to Chipotle.

Figure 3. (A) The monthly percentage of suspected foodborne illness reports implicating Chipotle relative to all reports submitted to the system. Peaks in reporting are noted during the period when multiple outbreaks were reported. (B) Number of suspected foodborne illness reports implicating Chipotle, and Restaurant Chain A and Chain B, which have similar and greater than five times more store locations compared with Chipotle, respectively. The number of foodborne illness reports implicating Chipotle is significantly higher.



Data submitted to Iwaspoisoned.com suggested that as early as 2014, foodborne illness linked to Chipotle represented a significant proportion of reports submitted to the site (see Figure 3). The first peak in Figure 3 a is noted in August 2015 during the outbreak in California. Additional peaks in the foodborne illness reports implicating Chipotle were noted in November, December, and January. During this time, a multistate outbreak that began in October 2015 was reported in California, Illinois, Maryland, Minnesota, New York, Ohio, Oregon, Pennsylvania, and Washington. The CDC reports that 55 people were sickened with E coli O26 being the responsible pathogen; however, the contaminated food item was not identified [20]. In another outbreak that was reported in Boston in December 2015, Norovirus was implicated. Foodborne illness complaints implicating Chipotle were also higher during the outbreaks when compared with two other major food chains with similar or more locations across the United States (see Figure 3 b). Since then, Chipotle has taken several steps to improve sanitation at its facilities to prevent future outbreaks.

Second, on March 13, 2016, Iwaspoisoned.com received four reports citing 20 people becoming sick after eating at an Applebee's in Corunna, Michigan, and alerted the Shiawassee County Health Department. On March 22, approximately a

week after the initial report, the health department confirmed a Norovirus outbreak linked to that Applebee's restaurant.

Third, in late December 2016, Iwaspoisoned.com contacted the Tacoma-Pierce County Health Department about a potential foodborne outbreak after receiving multiple foodborne illness reports associated with a Melting Pot franchise in Tacoma, Washington. Tacoma-Pierce County Health Department conducted an investigation and subsequently shut down the franchise for 24 hours.

Discussion

The integration of social media and other digital data sources with traditional foodborne illness surveillance systems has the potential to improve foodborne illness surveillance in the United States. Data submitted on Iwaspoisoned.com can alert public health officers to clusters of foodborne illness reports as noted in the three case studies presented. Similar participatory surveillance systems developed for influenza-like illness have been shown to be useful in assessing influenza-like illness trends, risk factors, estimating attack rates, and care-seeking behavior [10-12,16,21,22].

Limitations

Though crowdsourced surveillance has many advantages, there are some limitations to the use of these systems for public health surveillance. First, recruiting and maintaining participants is a major challenge. A study comparing different methods for recruiting participants suggested that offline enrollment is more effective than Internet-based campaigns [23]. However, Iwaspoisoned.com does not require enrollment and mainly requires responsiveness by the public. Potential approaches for increasing awareness include advertising and promotion, especially during disease outbreaks and collaboration with public health departments to increase the public's understanding of the importance of reporting illness. Reports on Iwaspoisoned.com are accessed by state and local health departments in 90% (n=45) of US states to supplement existing programs on foodborne illness reporting. State food inspectors also use these data to generate alerts that focus on specific issues such as shellfish poisoning. Distributors can also monitor complaints associated with specific products or their foodservice business customers.

A second limitation is building a nationally representative sample. The demographics of users in the Iwaspoisoned.com system are skewed toward younger age groups; 67.5% are under the age of 34. We do not have data on the proportion of individuals who experience and report foodborne illness in each age category, therefore we cannot quantify representativeness. Younger and older persons who are at risk of more severe reactions to foodborne diseases might be underrepresented. Furthermore, studies suggest that representativeness in Internet-based systems and data sources for disease surveillance are influenced by factors such as gender, education, and income [24-26].

A third limitation involves the influence of news on disease reporting on social media and similar platforms. Though social media can aid in the early detection of disease outbreaks, it can also lead to over- and underreporting during outbreaks, which in some cases correlates with trends in news coverage during an outbreak [27,28]. Additionally, in the case of mild illness, individuals might be more likely to report suspected illness associated with an outbreak after public knowledge of the outbreak. Therefore, crowdsourced data might not always allow for early detection of outbreaks but can still enable monitoring of trends during outbreaks.

A fourth limitation is the validity of reports. Although there are several processes in place to assess the validity of foodborne illness complaints, these are not ensured to be completely effective. Therefore, Iwaspoisoned.com continues to refine the validation process and emphasize a focus on clusters of reports in the same locality or implicating the same business.

Advantages

Despite these limitations, there are several advantages to using crowdsourcing for foodborne illness monitoring. Data from Iwaspoisoned.com suggests that the main pathogens reported by users with an official diagnosis of a foodborne disease are the same as those reported as major causes of foodborne illness in the United States. By enabling real-time reporting of illness, public health departments can encourage affected individuals to seek medical care and diagnosis.

Additionally, data from other platforms such as Yelp.com and Twitter.com can be integrated with data from Iwaspoisoned.com to track trends in reporting, identify changes in trends that are common across platforms, and correct for limitations in the individual sources. Furthermore, integrating data from these systems with traditional approaches to disease surveillance has the potential for mitigating the underreporting problem and aiding in timely reporting during outbreaks and disease burden estimation.

Conclusions

Anyone can submit a report on Iwaspoisoned.com; however, the platform currently operates only in English. Future iterations would include additional languages. Additionally, the system will be updated to enable real-time geo-positioned location-based alerts for public health officers. Crowdsourced disease surveillance through systems such as Iwaspoisoned.com uses the ease and familiarity of social media to create an infrastructure for easy reporting and surveillance of foodborne illness events. Collaborations with local public health departments and the food service industry can improve data collection through such systems and create opportunities for educating the public regarding the importance of food safety and disease reporting.

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Conflicts of Interest

Patrick Quade is the founder of Iwaspoisoned.com

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Abbreviations

CDC: Centers for Disease Control and Prevention IP: Internet Protocol

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Letter to the Editor

Effectivity of Awareness Months in Increasing Internet Search Activity for Top Malignancies Among Women

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Letter

In a recent article, Ling et al. hypothesized that following the launch of a campaign for a medical condition, information seeking behavior pertaining to the condition would increase as well [1]. They used data from Google Trends (Google Inc., CA) on 4 different diseases (including Colon Cancer) to conclude that the use of infoveillance (type of public health surveillance based on online content analysis),shows promise as an alternative and inexpensive solution for disease surveillance and health care campaign evaluation. While a number of health campaigns are rolled out by the government and professional societies, there are limited means and tools to evaluate the effectivity of these campaigns. Using infoveillance, the 'digital impact' of various health- and disease-related campaigns can be assessed.

Cancer awareness has massively benefited from rapid growth of internet and mass media and the evolution of social marketing strategies around the promotion of healthcare [2,3]. This has resulted in the development of cancer oriented societies, websites, public campaigns and specifically earmarked Cancer Awareness Months (CAMs) directed at changing public attitudes towards prevention, screening, treatment and informed decision making. However, despite the significant impact of cancer awareness on screening of preventable cancers [3], the impact of CAMs on cancer-related internet search activity has not been well studied. Breast (BC), Lung (LC) and Colorectal Cancers (CRC) are the leading causes of cancer incidence and mortality among women [4] and have their respective CAMs during October, November and March [5].

Using Google Trends, a public web facility of Google Inc. based on Google Search, we compared the relative frequency of search of terms 'Breast Cancer','Lung Cancer' and 'Colon Cancer' between 1st January 2004 and 31st January 2017 (n=158 months). The program assigns a reference value of 100 for the point of maximum popularity from among the search terms, and provides relative monthly scores for all terms, which we termed interest scores (IS). IS were then compared among cancers for the overall period (n=158 months) and specifically during their CAMs (n=13 months). Within each cancer, IS were then compared during the CAMs (n=13 months) as compared to the remaining months (n=145 months). Parametric and non-parametric analyses were carried out (wherever applicable) using ANOVA and Kruskal-Wallis tests respectively. A *P*-value of <.05 was considered significant.

We found that BC had higher IS (mean± S.D) than LC and CRC for the entire study period (38.83±14.46 vs14.71 ±4.56 and 11.98±2.13 respectively, *P*<0.001*), including a peak IS of 100

in October, 2004. BC also had significantly higher IS during its CAM (October) than the CAMs for LC (November) and CRC (March); 69.92±11.75 vs 15.38±4.54 and 13.53±2.43 respectively, $P<0.001$*. While BC (69.92±11.02 vs 36.04±11.02; $P<0.001$*) and CRC (13.53±11.84 vs 11.85 ± 2.06; $P=0.036$*) had higher IS during their CAMs as compared to other months, LC did not (15.38 ±4.53 vs 14.65±4.57; $P=0.3019$) (Table 1).

We concluded that ongoing campaigns for BC awareness are very effective at driving internet search activity, not only at baseline (2.5-3 times) but even more so also during its CAM (4-5 times) as compared to the other two leading malignancies among women (CRC and LC). Despite having a higher mortality than CRC, the campaign for LC was unable to significantly impact internet search activity during its CAM. Reasons behind the success of the BC awareness campaign in driving internet search activity should be further explored and applied to those for other malignancies such as LC and CRC, which also continue to have high mortality. Therefore, as highlighted by Ling et al [1], the use of infoveillance can serve as a cost-effective solution to evaluate the effects of health campaigns. However, further research is needed to definitively establish Google Trends as a valid and reliable tool for this purpose.

Conflicts of Interest

None declared.

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Original Paper

Feasibility of Establishing HIV Case-Based Surveillance to Measure Progress Along the Health Sector Cascade: Situational Assessments in Tanzania, South Africa, and Kenya

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Abstract

Background: To track the HIV epidemic and responses to it, the World Health Organization recommends 10 global indicators to collect information along the HIV care cascade. Patient diagnosis and medical record data, harnessed through case-based surveillance (CBS), can be used to measure 8 of these. While many high burden countries have well-established systems for monitoring patients on HIV treatment, few have formally adopted CBS.

Objective: In response to the need for improved strategic HIV information and to facilitate the development of CBS in resource-limited countries, we aimed to conduct situational assessments of existing data collection systems in Tanzania, South Africa, and Kenya.

Methods: We developed a standardized protocol and a modularized data collection tool to be adapted for the particular focus of the assessments within each country. The three countries were selected based on their stage of readiness for CBS. The assessment included three parts: a desk review of relevant materials on HIV surveillance and program monitoring, stakeholder meetings, and site visits.

Results: In all three countries, routine HIV program monitoring is conducted, and information on new HIV diagnoses and persons accessing HIV care and treatment services is collected. Key findings from the assessments included substantial stakeholder support for the development of CBS, significant challenges in linking data within and between systems, data quality, the ability to obtain data from multiple sources, and information technology infrastructure. Viral load testing capacity varied by country, and vital registry data were not routinely linked to health systems to update medical records.

Conclusions: Our findings support the development of CBS systems to systematically capture routinely collected health data to measure and monitor HIV epidemics and guide responses. Although there were wide variations in the systems examined, some of the current program and patient monitoring systems can be adapted to function effectively for CBS, especially if supported by an improved patient registration system with shared unique health identifiers.

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KEYWORDS

HIV; surveillance; case reports; continuum of care; epidemiologic surveillance

Introduction

The World Health Organization (WHO) released consolidated guidelines in 2015 recommending ten global indicators to track the HIV epidemic and responses to it and measure progress and drive action toward the 90-90-90 targets of the United Nations Joint Program on AIDS (UNAIDS) [1,2]. To provide high-quality, timely, and reliable data by population characteristics and across the different levels of a health care system, it is recommended to develop a comprehensive strategic HIV information system [2-7]. Case-based surveillance (CBS) is such a system, and it is a key element of HIV Second Generation Surveillance, which is recommended by the WHO [8].

Case-based surveillance has three characteristics that differentiate it from most HIV program monitoring systems. The main distinctive characteristic is that at all levels (facility, subnational, and national health agencies or ministries), CBS systems obtain and retain *individual-level data* for each person diagnosed with HIV. The second characteristic is *within-system record linkage* that is facilitated by the collection of a unique identification number (eg, a national or regional health care identification number) or unique personal identifiers (eg, full or part date of birth, sex, full or part name, and a marker of residence). Individual record linkage at the national level enables the identification and removal of duplicate records and the tracking of cases over time, thereby providing a more accurate number of cases than can be obtained through aggregate data from facilities. The third characteristic is that CBS data are gathered and retained from *multiple data sources* (eg, from testing laboratories and facilities and from care facilities). This aspect of CBS serves two important purposes: it improves the completeness of case ascertainment, and it provides critical information on the key events that concur with global indicators [1]. These events include HIV diagnosis, entry into care, initiation of antiretroviral therapy (ART), disease progression or treatment success (as measured by CD4 (T-helper) cell and viral load tests), and death.

By developing a linked database, CBS data can contribute information to all but two (*domestic finance and prevention by key population*) of the ten global indicators described in the consolidated guidelines [1]. Table 1 presents how CBS data may be utilized to measure the eight indicators [1].

Table 1. The use of case-based surveillance data in measuring indicators along the HIV care cascade.

Indicator	CBS[a] data
People living with HIV	Directly provide national or regional specific estimates of people living with diagnosed HIV and indirectly provide national or regional specific estimates of undiagnosed HIV by fitting statistical models to data (eg, back-calculation analysis of CD4 count at the time of diagnosis)
Knowing HIV status	Indirectly provide estimate of denominator (all living with HIV) and directly provide estimate of numerator (cumulative diagnoses minus deaths or number of people currently in care)
Linkage to care	Directly measured based on the report of a CD4 cell or viral load test
Currently on ART[b]	Indirectly provide estimate of denominator (all living with HIV) and directly provide estimate of numerator (number of people currently on ART)
ART retention	Directly measure denominator (initiated ART) and numerator (number of people retained on ART according to an applied-time criteria)
Viral suppression	Directly calculate denominator (on ART) and numerator (virally suppressed)
AIDS deaths	Directly measure through reporting (the provision of data from source) and follow-up of cases, and indirectly measure through linkage with vital statistics for deaths and cause of death
New HIV infections	Provide a framework for conducting recency testing or for incidence estimation through back-calculation analysis of CD4 count at the time of diagnosis

[a]CBS: case-based surveillance.

[b]ART: antiretroviral therapy.

Although HIV CBS is conducted in many high, middle, and low income countries, it has not been implemented in sub-Saharan Africa, where the burden of the disease has been greatest [9]. In an environment where donors are increasingly insisting on cost-sharing assurances from the governments of low- and middle-income countries, and for more cost-effective use of funds [1], HIV CBS presents a cost-effective method for collecting strategic information in sub-Saharan Africa to improve patient and program management. To identify systems that are context appropriate, feasible, scalable, and sustainable for CBS, the Measurement and Surveillance of HIV Epidemics (MeSH) Consortium facilitated situational assessments in Tanzania, South Africa, and Kenya between August 2015 and February 2016.

Methods

In our assessments, we focused on the feasibility of implementing CBS, including the availability of individual-level data, the ability to uniquely identify and link cases, and the capacity to capture key events along the HIV care cascade from multiple sources. We developed a protocol and data collection tool to promote a standardized approach to our situational assessments [10]. Our assessment included three parts: (1) desk review of materials relevant for HIV surveillance, (2) meetings

with stakeholders knowledgeable about HIV strategic information, (3) site visits to understand human resource capacity and the availability and quality of data. For the meetings and site visits, the data collection tool was used and notes were taken by between two and four assessors while on-site. In Kenya and South Africa, all meetings were conducted in English. In Tanzania, the majority of the meetings where conducted in English, with a couple conducted in Kiswahili with the aid of a translator.

The data collection systems assessed include patient monitoring systems (PMS), which maintain individual patient health information at the facility, and laboratory information management systems (LIMS), which maintain individual-level data from laboratory tests. Information held by PMS may be paper-based (consisting of a standard medical chart) or electronic—referred to as an electronic medical record (EMR)—and may be completed either by clinical or clerical staff after clinical staff complete the paper records.

Our assessment team had experience in the implementation and management of PMS and CBS systems and data. Prior to each assessment, we met with national and international stakeholders to confirm the focus of the appraisal, to develop a list of documents to obtain and review (eg, on policies concerning disease reporting, medical record privacy, and data security), to identify further relevant stakeholders for engagement, and to agree on sites to visit.

Kenya, Tanzania, and South Africa were selected for assessment based on having high HIV prevalence, partial or fully implemented electronic data systems, and being a MeSH Consortium focus country. The focus of our assessment differed in each country (see below). In all 3 countries, there was engagement with regional and national stakeholders, including Ministry of Health representatives, and results with recommendations were presented back to stakeholders in the form of a country specific detailed assessment report.

In Tanzania, we assessed the feasibility and acceptability of developing a HIV CBS system. As the HIV care and treatment clinic (CTC) PMS has greatest coverage of individual-level data in Tanzania, the system was a major focus of our assessment. To include both urban and rural areas with substantial disease burden, the assessment was conducted in the Dar-es-Salaam and Mwanza regions. Site visits were made to nine health facilities and laboratories providing HIV services in these areas at various levels (regional and district hospitals, health centers, and dispensaries). A total of 23 stakeholders were engaged with at the national, regional, district, and facility levels.

Our assessment in South Africa considered how existing multi-facility-based integrated HIV data systems and various patient identifiers could be used for CBS. We focused on the Three Interlinked Electronic Registers system (TIER.Net) and the National Health Laboratory System (NHLS). The Western Cape Province was selected as a region where the TIER.Net system and identifiers could be explored. The NHLS is based in Johannesburg. Seven stakeholders were engaged at the national and regional (Western Cape) level and two health facilities offering HIV care and treatment and one regional laboratory were visited.

In Kenya, in 2015, a pilot of CBS was performed in a high-burden region in order to inform the development and implementation of a national CBS system. Cases were identified and reported by surveillance officers and by facility staff who received a monetary stipend for their CBS work. Among other findings, the human resource costs associated with the pilot methods called into question the sustainability of this CBS model. The goal of our assessment was to explore reporting options that might be less demanding of human resources. In Nairobi and Kisumu counties, we examined the potential for reporting from EMRs, laboratories, and providers (clinical and HIV testing counselors) without additional compensation and met with six national and regional stakeholders. We also visited three regional laboratories and 8 health facilities at various levels (sub-district hospitals, health centers, and dispensaries).

We present results and recommendations from the three components of our assessments in each country and by a framework based on the three distinctive characteristics of CBS. In addition, we assess the commonalities and differences in the ability of the three countries to measure the care cascade indicators and the feasibility of implementing CBS under current conditions.

Results

United Republic of Tanzania

Collecting Individual-Level Data

Currently, in Tanzania, the most comprehensive mechanism for reporting clinical HIV data is aggregate reporting of routine program monitoring activities to the District Health Information System (DHIS-2). In addition to this, HIV programs led by the Ministry of Health and Social Welfare (MoHSW) have their own reporting mechanisms. Primary among these is the HIV CTC program, which is the PMS for HIV care and treatment that collects individual-level data for both adult and pediatric cases. At the time of the assessment, 637 CTC sites reported individual-level data to the national CTC system, providing information on 67% of all persons receiving ART [11].

Uniquely Identifying and Linking Records

Names are collected when patients enter HIV care, but are not made available outside of a health facility. Names are not universally collected at HIV testing and counseling (HTC) facilities. The recording of names of persons receiving HTC services in a paper registry was observed at one facility, although the purpose of this was not clear. While information on age and sex are collected at testing and care facilities, the absence of names at testing sites presents challenges for linking records to obtain an accurate estimate of the number of people diagnosed or to monitor linkage to care.

Each CTC facility records personal identifiable information and assigns a unique number to new attendees, thereby facilitating within-site data linkage. Although this CTC number is unique within the country, it is often not transferred from one facility to the next, resulting in patients being assigned an additional number when obtaining care at a subsequent CTC site. Multiple assignments of CTC numbers, coupled with the absence of a

national identifier in Tanzania, make data linkage between sites to monitor individuals who receive care at two or more sites consecutively or over time, challenging.

Capturing Key Events From Multiple Data Sources

A number of variables required for CBS to produce key indicators along the care cascade are available through the CTC. These include the number of patients in care, the number of patients on ART, and ART retention. As identifying data are not routinely collected at HTC facilities, individual-level data are only captured for those who seek care. Tanzania has not yet adopted routine viral load monitoring for patients on ART.

Most CTC facilities enter data into an electronic database. However, various information technology issues were observed, including smaller facilities not having computers, inconsistent connectivity and power outages, and a lack of interoperability between the PMS and other data systems at the health facility. It is likely that the observed shortcomings of the health facility staff members in the area of information technology compromises the completeness and quality of the data. Neither new diagnoses nor vital statistics data are linked with CTC data, and although regional laboratories and pharmacies have electronic information systems, they also are not linked to the CTC system.

Feasibility and Readiness of Implementing Case-Based Surveillance

The CTC system currently performs several of the functions of CBS, collecting individual-level data from point of entry into care on approximately two-thirds of persons on ART in Tanzania. To move toward a comprehensive system for CBS, CTC data would need to be routinely and accurately linked across CTC and non-CTC facilities, HTC programs, and vital statistics.

The situational assessment found that CBS implementation would put pressure on resources and staff time and would potentially undermine clinical care and data quality if there were additional data collection requirements. Current data quality was a concern, as data quality assurance (DQA) through availability of, and adherence to, standard operational procedures, is not enforced, and there is limited use of data beyond mandated program reporting.

Republic of South Africa

Collecting Individual-Level Data

South Africa has implemented a national PMS that captures longitudinal information on persons on ART. The system, entitled TIER.Net, collects individual-level data at the facility level that are then reported nationally, including patient names and other personal identifiers. Although TIER.Net has modules for HIV testing and pre-ART care, neither was in operation in the places we assessed. Reportedly, these modules are used by some jurisdictions.

In South Africa, HIV testing is based on a point-of-care rapid-testing algorithm, with only discordant findings sent to a laboratory for confirmation. Health facilities do, however, use a robust and reliable transport system to routinely send specimens to regional laboratories for CD4 cell counts, viral loads, early infant diagnosis, full blood counts, and blood chemistry. As part of the NHLS, the national laboratory data warehouse has available all CD4 cell count and viral load tests from persons receiving HIV care in the public sector. The NHLS provides services to over 80% of the population (and a higher percentage of those living with HIV) through a national network of laboratories that use a LIMS to capture and centralize individual-level data for both adult and pediatric patients.

Other individual-level data sources are available nationally and regionally. In the Western Cape, individual-level data on hospital admissions, ambulatory visits, and medicine dispensing are accessible to government health services with varying completeness. Vital registration systems are well established in South Africa, with 96% of HIV deaths estimated to be recorded in a national population register [12]. These data, however, are no longer routinely available to health services as death certificates are now sealed and managed by other government departments after completion by health practitioners.

Uniquely Identifying and Linking Records

There are a number of distinct personal identifiers, HIV-specific and general, in use in South Africa. Health services issue medical record numbers that are unique to each facility. The national civil identifier is available to all citizens and is currently recorded as an identifier when patients register for health services. However, approximately 10% of the South African population are non-citizens and, therefore, are not assigned this identifier. Moreover, a substantial proportion of citizens have historically not presented their civil identification documents when availing themselves of services. A national health patient registration system is currently being developed, in which every patient will be eligible.

Recognizing the limitations of the national civil identifier and facility medical record numbers for resolving the issue of duplication of cases for surveillance purposes, the NHLS data warehouse considers name and date of birth alongside this identifier to distinguish unique individuals. The NHLS also includes barcodes that can be scanned for each test that uniquely identify the patient specimens and assist with resolving duplication issues and establishing the data quality of identifiers.

Patient master indexes are in use in some areas to identify and resolve duplication of records pertaining to a single patient. For example, in the Western Cape Province, a patient master index has enabled linkage of laboratory, pharmacy, and service data in a data center environment that meets the key requirements of CBS.

Capturing Key Events From Multiple Data Sources

The variables required by CBS to produce a number of the indicators along the care cascade are available. The PMS can be used to identify the number of patients on ART, ART retention, and viral suppression. Viral load and CD4 testing is standard for ART patients and is performed at centralized laboratories using the same national LIMS. Having been de-duplicated, the NHLS uses CD4 test data to estimate the number of persons in care and viral load test data to estimate the number of persons on ART and to measure viral suppression.

The number of persons newly diagnosed with HIV is only captured in registers at health facilities, as diagnosis is done by rapid testing.

Feasibility and Readiness of Implementing Case-Based Surveillance

Both the PMS and NHLS LIMS perform several of the functions of CBS, collecting individual-level data and routinely de-duplicating these data at the provincial and national level. To build a CBS system based on these systems, all point-of-care test results (not only discordant test results) will require to be digitalized for entry into the LIMS. To comprehensively describe the care pathway, data from vital statistics programs will also need to be routinely linked to these data. A CBS system built on laboratory and patient information systems would obviate the need for developing a formal notification process for surveillance purposes, an activity that has historically failed in South Africa.

The PMS has staff shortages and facility service pressures that could compromise adherence to standard operating procedures and, therefore, data completeness and quality. There is a backlog of laboratory results to be filed in medical charts in many facilities, resulting in incomplete laboratory data being reported through the PMS.

Republic of Kenya

Collecting Individual-Level Data

Multiple data systems exist in Kenya from which individual-level data for HIV CBS can be obtained. Information on new HIV diagnoses for both adult and pediatric cases is captured in paper registers at health facilities. Individual-level HIV care and treatment data are collected at facilities using standard Ministry of Health forms and registers, although the data are reported in aggregate at the national level. In the majority of the large HIV care facilities (>500 patients), EMRs have been implemented. Facilities with EMRs report quarterly to a data warehouse that was developed in 2015. At the time of the assessment, 347 (52%) of the EMR facilities were reporting data to the warehouse. There are also seven regional laboratories that conduct viral load and early infant diagnostic tests, all using a LIMS to capture patient-level data.

Existing infrastructure presents challenges to capturing and storing individual-level data electronically. All visited facilities reported having experienced periodic power outages, and only larger facilities reported having backup generators.

Uniquely Identifying and Linking Records

Adults (aged ≥18 years) are provided a unique national civil identification number. Although these numbers are currently not collected as part of routine health care, registers have recently been modified by the Ministry of Health to facilitate collection. Nationally, patient names (first, middle, and last names) and age are collected as identifiers in HTCs for all patients. All patients in care are assigned a unique number that is included in the PMS, regional LIMS, and EMR data warehouse. Although this number is unique within the country, it is often not transferred from one facility to the next, resulting in patients being assigned an additional number when obtaining care at a subsequent site. Names are not recorded at six of the seven regional laboratories, nor are they recorded at the EMR data warehouse. The lack of identifiers limits the accuracy of data matching and de-duplication processes.

Capturing Key Events From Multiple Data Sources

A high number of variables necessary for CBS are available in Kenya. The national PMS can be used to identify the number of patients in care, on ART, retained on ART, and achieving viral suppression, although many of the facilities use paper-based systems. The EMR data warehouse obtains the same variables as the PMS but is limited to facilities with an EMR. Interoperability between EMRs is currently not available as the systems have different software developers and are not designed to be networked.

Viral load testing is standard for ART patients and is performed at centralized laboratories using a LIMS, with results reported to care and treatment facilities. However, the time from obtaining the specimen to the availability of the result varies and can exceed the target of two weeks. In one laboratory, as a result of reagent stock outs, this time period exceeded six months.

A notable high-quality system is the Eastern Deanery AIDS Relief Program (EDARP), which operates fourteen health facilities. They have developed a fully integrated, networked, and paperless EMR system, which includes a LIMS and pharmacy system. Patients are entered into the EMR when they come to HTCs, allowing for tracking of patients from diagnosis into care. The system collects several identifiers, including the national identity number. It is a closed (self-contained) system that requires sustainable resources, and it highlights what can be achieved should resources be available.

Feasibility and Readiness of Implementing Case-Based Surveillance

The EMR data warehouse and LIMS systems are currently not sufficient for CBS, as names and national identifier are not included. Additionally, the data in the EMRs are not systematically compared against the paper medical records to assess accuracy of data entry. Limitations of the PMS for CBS are that for nearly all facilities, recording of data begins at entry to care, does not link to information on HIV diagnoses or vital registrations, and are often paper-based. Current demands on providers for patient management preclude the possibility of reporting patients for CBS, although HTC counselors could potentially report new diagnoses if variables are minimal.

Commonalities and Differences across the Three Countries

Stakeholders in the three countries indicated substantial interest in, and support for, CBS to effectively monitor HIV. In all three countries, routine HIV program monitoring is conducted, registers and paper medical records are standardized, and variables collected are sufficient for CBS. There are efforts in South Africa and Kenya to establish national data warehouses with individual-level data.

Stakeholders expressed concern over resources, indicating that CBS would only be feasible and sustainable if it could be

conducted without substantially increasing the workloads of health care providers and surveillance officers. Based on current reporting requirements, stakeholders felt that having sites report data through their existing electronic systems (EMRs and LIMS) would not require substantial additions to facility level staff but would require additional training and information technology support.

Implementing CBS based on current systems would result in gaps between care cascade indicators due to the absence of linkage between testing, care, and mortality data. Currently systems for testing and deaths are primarily paper-based with limited identifiers and are not routinely linked to health systems. Cascade of care data availability are presented in Table 2 [1].

Although EMRs are in place in each of the three countries, they vary in design, quality, and coverage of facilities. Unstable power sources and internet access was a problem often cited as it adversely impacted electronic and networked systems. Also often cited was the issue of poor data quality and difficulties in comprehensively collecting accurate personal identifying information. These and additional factors affecting the feasibility of CBS are presented in Table 3 [13].

Table 2. Data availability for care cascade indicators.

Cascade measure	Tanzania	South Africa	Kenya
People living with HIV diagnosed	Testing data are in paper-based registers but do not include names or other personal identifiers needed for de-duplication issues. The PMS[a] includes date of diagnosis.	Testing data are in paper-based registers and include names and other personal identifiers that may be used for de-duplication issues. The PMS includes date of diagnosis.	Testing data are in paper-based registers and include names and other personal identifiers, although data are not sufficient for de-duplication issues. The PMS includes date of diagnosis.
HIV care coverage	Unable to determine unduplicated number of people diagnosed; therefore, the proportion of people linked to care cannot be determined. The PMS starts at entry to care.	The PMS does not currently include care information prior to starting ART[b]. Care services are sometimes offered separately from ART services.	Insufficient identifiers obtained in testing to unduplicate and determine proportion linked to care. The PMS starts at entry to care.
ART coverage	Only the proportion of people in care on ART can be determined.	Only the proportion of people in care on ART can be determined.	Only the proportion of people in care on ART can be determined.
ART retention	Can be determined at the facility level; currently unable to resolve duplication issues at the national level.	Can be determined through viral load tests noted in the PMS and LIMS[c].	Can be determined at the facility level; currently unable to resolve duplication issues at the national level.
Viral suppression	Viral load testing for routine monitoring of patients on ART is being rolled out and is currently unavailable for most patients; tests conducted are noted in the PMS.	Viral load testing for routine monitoring of patients on ART is widely available. Test information is available in the PMS and LIMS, typically within 48 hours.	Viral load testing for routine monitoring of persons on ART is fairly recent; data are available in the LIMS and there is often a long lag time between tests and data entered into the PMS.
AIDS-related deaths[d]	Deaths are recorded in the PMS, although reporting is incomplete, especially cause of death. The death registry is a separate paper-based system and is not routinely linked to the PMS.	Deaths are recorded in the PMS. The death registry is a separate electronic system with limited access by health staff.	Deaths are recorded in the PMS, although reporting is incomplete, especially cause of death. The death registry is a separate paper-based system and is not routinely linked to the PMS.

[a]PMS: patient monitoring system.

[b]ART: antiretroviral therapy.

[c]LIMS: laboratory information management system.

[d]The ability to separately identify and report on AIDS-related deaths, as opposed to all-cause mortality amongst people living with HIV, was not assessed.

Table 3. Factors affecting the feasibility of case-based surveillance.

Factors	Tanzania	South Africa	Kenya
Data management	Currently de-duplication is performed only by clinical identifier. Although DQA[a] policies are in place, they are not fully implemented.	Roll out of a patient health registration system with a unique identifier is in progress. The NHLS[b] de-duplicates data utilizing an algorithm. DQA policies are in place and variably implemented for the PMS[c].	In a recent CBS[d] pilot, de-duplication was performed using an algorithm. The new EMR[e] data warehouse de-duplicates data based on clinical identifier. Limited DQA is being conducted at facilities.
Policies	There are no policies for HIV reporting, data security, and confidentiality. Policies in place for data quality are often not being followed.	There are no policies that mandate HIV reporting. Policies are in place for data quality, security, and routine program data management. There is a policy impasse around access by health department to vital registration data.	Policies are in place for infectious disease reporting, but not specific to HIV. There are gaps in policies for data security, confidentiality, and purpose and utilization of EMRs, LIMS[f], and the data warehouse.
Information technology	The majority of care facilities enter data into an electronic database; the database does not have connectivity and data are extracted on a quarterly basis and sent to the national level. The PMS database is national; therefore, interoperability is thought to be unnecessary. Although there is a pharmacy module in the CTC[g] system, it is rarely utilized. Various LIMS exist although are not connected to the CTC. Internet connectivity limited in rural areas.	TIER.Net[h] is a national system that limits interoperability issues. It is implemented off-line with quarterly dispatches sent centrally. The national LIMS captures the majority of laboratory tests, which are then checked for duplications. Regional laboratories all utilize the same LIMS to reduce interoperability issues. Internet connectivity is limited in rural areas. Staff shortages impact the quality of the implementation of the TIER.Net system.	Four main EMRs are operating at health facilities. The EMRs are not interoperable. Backup of the data varies between facilities. The quality of data in EMR systems has not been evaluated. A system is in the pilot phase to pull data from each type of EMR for CBS. Internet connectivity is limited in rural areas. Power outages are common; larger health facilities have a generator.

[a]DQA: data quality assurance.

[b]NHLS: National Health Laboratory System.

[c]PMS: patient monitoring system.

[d]CBS: case-based surveillance.

[e]EMR: electronic medical record.

[f]LIMS: laboratory information management system.

[g]CTC: care and treatment clinic.

[h]TIER.Net: Three Interlinked Electronic Registers.

Discussion

Principal Findings

The findings from the situational analyses support the development of CBS systems. However, none of the programs or PMS in their current forms can accurately monitor indicators along the care cascade to track progress toward the UNAIDS 90-90-90 targets.

The lack of a universal patient unique identification system in all three settings is the most important obstacle to the evolution of existing systems, whether electronic or paper-based, toward CBS because of its pivotal role in linking records across systems and resolving duplication in reports. A robust CBS system requires data collection systems that pertain to HIV infected persons to collect patient names (or an anonymized representation of their names) and a national identifier. A robust system must also maintain data confidentiality and security. Electronic medical records were present in all three settings, and they hold the potential for efficient and secure collection and transfer of data for CBS. However, investment in infrastructure and information technology is necessary to expand the use of EMRs to include information from HIV testing sites and laboratories.

To promote the collection and use of individual-level data from multiple sources through CBS, standard operating procedures and national policies need to be developed. These policies and procedures must address any legal requirements for disease reporting and endorse data security and confidentiality. It has been suggested that policies and procedures also engage civil society in the development of identifiers, promote performance standards for completeness, timeliness, and data quality, and take into consideration discriminative laws and policies on HIV, sex work, drug use, and same-sex relations [1,2,4,9].

Laboratory information management systems are increasingly common, and in many settings, viral load testing at regional laboratories is expanding, offering the potential for efficient reporting of these tests and results. Developing laboratory data are a key contributor to CBS goals. Countries should develop a harmonization strategy for laboratory data that includes comprehensive inclusion and sharing of available identifiers.

The ability to retrieve system-wide laboratory data would support the development of a CBS system; ideally, such a system could also promote continuity of care as patients increasingly move between health facilities.

In all settings, there was evidence of fragmentation of information systems. Multiple systems, limited interoperability, and inadequate capacity present barriers to managing the complex functions of stewarding the information system and the interoperability environment. To overcome these barriers, national and subnational health ministries should be actively capacitated to implement and sustain these functions for clinical care, service management, and surveillance purposes. This should include ensuring that available data, including vital registration, be accessible to the health ministries.

Limitations

Due to practical limitations, we conducted our assessments only in select regions within each of the three countries, and not all stakeholders, such as the private sector, were included in the assessment. As our aim was to assess whether existing data systems could facilitate the development of CBS in resource-limited countries, an evaluation of the data quality within each system, the potential to capture information on key populations, and the potential representativeness and timeliness of a future functioning CBS system was not performed. Despite these limitations, our findings indicate that with some important changes and additions to existing systems, CBS can be developed or strengthened in the three countries.

Conclusions

Evidence from several settings has demonstrated the ability of CBS to systematically capture routinely collected health data to describe and monitor HIV epidemics for program planning and evaluation and, ultimately, disease control [14-17]. It is likely that countries in sub-Saharan Africa, in addition to the three assessed, have existing systems that may be improved and expanded to accommodate CBS implementation. Considering the characteristics that define CBS, these countries should carefully examine and evaluate their existing infrastructure, human resource capacity, HIV PMS, EMRs, and infectious disease reporting systems and develop a CBS system that, to the greatest extent possible, leverages current systems and staff. In implementing HIV CBS, systems need to be developed so that they are context appropriate, feasible, scalable, secure, and importantly, given the resource environment, sustainable.

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Conflicts of Interest

None declared.

Authors' Contributions

All the authors provided extensive comments on the concept and the manuscript drafts. RH and BR oversaw the situational assessments in all three countries. SS participated in the assessments in Tanzania and Kenya, JT and SX in Tanzania and AB in South Africa. All the authors read the manuscript, provided feedback, and approved the final version.

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Abbreviations

ART: antiretroviral therapy
CBS: case-based surveillance
CTC: care and treatment clinic
EMR: electronic medical record
DHIS: District Health Information System
DQA: data quality assurance
HIV: human immunodeficiency virus
HTC: HIV testing center
LIMS: laboratory information management system
MeSH: Measurement and Surveillance of HIV Epidemics
MoH: Ministry of Health
NHLS: National Health Laboratory System
PMS: patient monitoring system
TIER.Net: Three Interlinked Electronic Registers
UNAIDS: United Nations Joint Program on AIDS
WHO: World Health Organization

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Short Paper

Sample Size Calculations for Population Size Estimation Studies Using Multiplier Methods With Respondent-Driven Sampling Surveys

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Abstract

Background: While guidance exists for obtaining population size estimates using multiplier methods with respondent-driven sampling surveys, we lack specific guidance for making sample size decisions.

Objective: To guide the design of multiplier method population size estimation studies using respondent-driven sampling surveys to reduce the random error around the estimate obtained.

Methods: The population size estimate is obtained by dividing the number of individuals receiving a service or the number of unique objects distributed (*M*) by the proportion of individuals in a representative survey who report receipt of the service or object (*P*). We have developed an approach to sample size calculation, interpreting methods to estimate the variance around estimates obtained using multiplier methods in conjunction with research into design effects and respondent-driven sampling. We describe an application to estimate the number of female sex workers in Harare, Zimbabwe.

Results: There is high variance in estimates. Random error around the size estimate reflects uncertainty from *M* and *P*, particularly when the estimate of *P* in the respondent-driven sampling survey is low. As expected, sample size requirements are higher when the design effect of the survey is assumed to be greater.

Conclusions: We suggest a method for investigating the effects of sample size on the precision of a population size estimate obtained using multipler methods and respondent-driven sampling. Uncertainty in the size estimate is high, particularly when *P* is small, so balancing against other potential sources of bias, we advise researchers to consider longer service attendance reference periods and to distribute more unique objects, which is likely to result in a higher estimate of *P* in the respondent-driven sampling survey.

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KEYWORDS

population surveillance; sample size; sampling studies; surveys and questionnaires; research design; data collection; sex workers; HIV

Introduction

Population size estimates (PSE) for those most at risk for human immunodeficiency virus infection are crucial to make epidemic projections, allocate funding, and monitor coverage of prevention and care programs [1,2]. However, these populations are frequently stigmatized and criminalized and it is often not feasible or practical to conduct a census. One approach to obtaining a PSE is to use multiplier methods, including the service multiplier method (SMM) and the unique object multiplier method (UOM). The former uses 2 sources of data: (1) a count of program attendance or receipt of a service targeted to the population in question, and (2) a representative survey of the population in which uptake of service can be determined. The latter is the same, except the count is of the number of recognizable objects distributed to a population in advance of a survey. Obtaining a random sample of a population lacking a sampling frame is challenging, but there has been guidance published on adapting one of the methods commonly in use, respondent-driven sampling (RDS) [3], for use with the service multiplier method [4].

While there has been research into sample size requirements for RDS surveys [5-7], we lack guidance applied to sample size requirements when used to obtain a PSE with a multiplier method. Here, we report our approach in the context of preparing a protocol to estimate the number of female sex workers (FSW) in Harare, Zimbabwe using the SMM implemented with an RDS survey.

Methods

Overview

We briefly outline multiplier method size estimation, the approach to estimating uncertainty in the resulting population size estimates, and integrate this with advice on design effects and sample size requirements for RDS surveys.

Multiplier Method Population Size Estimation

Multiplier methods use 2 sources of data to estimate population size as described above: (1) a count of unique individuals from the target population receiving a service or unique objects distributed among this population, *M*, and (2) a representative estimate of the proportion of the target population in receipt of the service or object, *P*. The count is divided by the proportion as in Equation 1 (Figure 1) to obtain the population size estimate.

Johnston et al. [4] suggest using the Delta method to estimate the variance of the PSE, which combines variance in *P* and variance in *M*. We assume that *M*, as a count of target population individuals on a roster or unique objects distributed to the target population, follows a Poisson distribution for which the mean and variance are equal to μM [8]. The variance of *P* depends on the sample size of the RDS survey.

Figure 1. Equations for estimating population size, study sample size, and variance of the population size estimate.

Equation 1

$$PSE = \frac{M}{P}$$

Equation 2

$$n = \text{DEFF} * \frac{\mu_P(1-\mu_P)}{se(P)^2}$$

Equation 3

$$n_{adj} = \frac{n}{1 + {(n-1)}/{N}}$$

Equation 4

$$se(P) = \sqrt{\left(\frac{\mu_P(1-\mu_P)DEFF}{n_{adj}}\right)\left(\frac{N-n_{adj}}{N-1}\right)}$$

Equation 5

$$Var\left(\frac{M}{P}\right) \approx \frac{se(P)^2\mu_m^2}{\mu_P^4} + \frac{\mu_M}{\mu_P^2}$$

Sample Size Calculations

RDS is a structured, peer-referral recruitment method assuming a model for estimating each participant's probability of inclusion; thus, allowing weighting of responses to be used to approximate a random sample [9]. Existing guidance for estimating proportions from a RDS survey suggests that the sample size required for a simple random sample must be multiplied by a design effect (DEFF) to account for the RDS design [10]. Empirical reviews of RDS surveys have found most DEFFs to lie between 2 and 4, though some studies have found higher DEFFs [5-7,11]. The sample size for the RDS survey used to estimate *P* can be calculated as Equation 2 (Figure 1) given that *n* is sample size, μ_p is the estimate for the proportion we wish to estimate, and *se(P)* is the standard error of *P*. Recognizing that PSE are often required for small sites, we additionally suggest using a sample size n_{adj} that has been corrected for an estimated finite population as Equation 3 (Figure 1), where *N* is the estimated population size.

Rearranging Equation 2, and using n_{adj} as obtained in Equation 3, *se(P)* as corrected for finite population size can be calculated as Equation 4 (Figure 1), and the effect on the variance of the PSE can be obtained by inserting *se(P)* into Equation 5 (Figure 1). The 95% confidence interval (CI) around the PSE can then be obtained by taking the square root of *var(M/P)*, multiplying by 1.96 (assuming an approximately normal distribution) and subtracting/adding to the PSE.

We examined the relationship between sample size, *P*, and the width of the 95% CI obtained for a population size estimate of 15,000, fixing this estimate so that *M* varied with *P*.

Application to Estimating the Number of Female Sex Workers in Harare

To estimate the number of FSW in Harare, we planned a RDS survey of FSW aged 18 and older who had resided in the city for at least the previous 6 months. For service data, we planned to use Sisters with a Voice clinic attendance records. FSW attending this clinic, which provides sexual and reproductive health services for self-identified FSW, are given unique identification numbers and their visits recorded and dated (described further elsewhere [12]). For *M*, we planned to record the number of unique women attending in the 6 months prior to the survey.

To identify a reasonable estimated FSW population size for sample size calculation, we used previous estimates from a systematic review of FSW prevalence among 15- to 49-year-old women in sites from sub-Saharan Africa (.07%–4.3%) and multiplied them by the number of women of this age in Harare [13]. The 2012 Zimbabwe census estimates that 30.2% of the population of Harare is female aged 15 to 49, and that the total population of Harare is 2,123,132 [14], giving a FSW population size in Harare of 4488 to 27,572, with a plausible midrange estimate of 15,000, or 2.3%, of the adult female population.

We examined the number of sex workers who visited the program for different reference periods up to April 23, 2015 to generate likely values for *M* and *P* given an assumed PSE of 15,000. We then examined the impact of reference period on sample size requirements assuming these values of *M* and *P*. Finally, we investigated the effect of DEFF on the width of the 95% CIs around the PSE for different sample sizes of the RDS survey. We developed a Web-based tool to implement the methods described here [15].

Results

Relationships Between RDS Survey Sample Size, P, M, and Width of the 95% Confidence Intervals

For all values of *P* and *M*, increasing the RDS survey sample size decreases the width of the CI around the PSE, Figure 2. The precision of the PSE also varies by the values of *P* and *M*, such that much larger sample sizes would be required to estimate the PSE with the same level of precision if *P* is small rather than large (and correspondingly, *M* is small rather than large).

In Figure 2, values of *M* are varied with *P* so that *M* / *P* is always equal to 15,000. For instance if *P*=.05, *M*=750, or if *P*=.4, *M*=6000.

Application to Planning a Population Size Estimation Study

For our Harare example, we were able to review earlier service attendance data to see how the value of *M* might depend on the reference period chosen. The value of *M* in turn affects the sample size required via the impact on *P*, as shown in Table 1 and Figure 3, which assume a population of 15,000 FSW in Harare. Depending on whether we chose a period of 1 or 24 months, we might be estimating a proportion of .006 or a proportion of .148. For a given sample size, the width of the 95% CI will increase if the reference period is shorter and *P* is smaller. Higher DEFFs increase the uncertainty around the PSE, Figure 4.

We used previous service attendance data to observe how *M* varied by reference period, and therefore to predict how our estimate of *P*, the proportion of women attending, might vary by the reference period we chose, see Table 1. Figure 3 shows the relationship between these values of *P* with the width of the 95% CI's around the PSE for different sample sizes.

Based on changes in the width of the estimated 95% CIs with increasing sample size (Figure 3) and on choosing a reference period that would both reduce the likelihood of recall bias while preventing *P* from being too low, we chose a sample size of 1500 FSW for the RDS survey and a reference period for Sisters service attendance of 6 months, for which we estimated *P* would be approximately .06.

Figure 2. Sample size and width of 95% confidence interval around a fixed population size estimate of 15,000 for different values of *P* and *M*, assuming a design effect of 3.

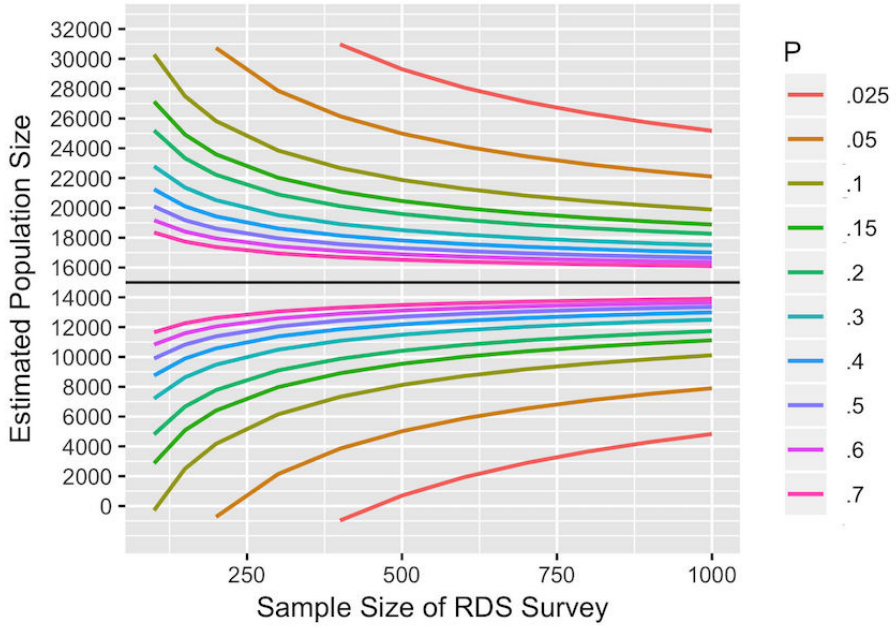


Table 1. Number of female sex workers attending the Sisters program and effect on *P* given the total female sex worker population = 15,000 in Harare.

Reference period to April 23, 2015	Number of unique female sex workers attending, M	Estimated *P*, assuming population = 15,000
1 month	85	.006
3 months	560	.037
6 months	952	.063
12 months	1542	.103
24 months	2227	.148

Figure 3. Effect of reference period (variations in *P*), width of the 95% confidence interval around the population size estimate and sample size required for estimating the number of female sex workers in Harare.

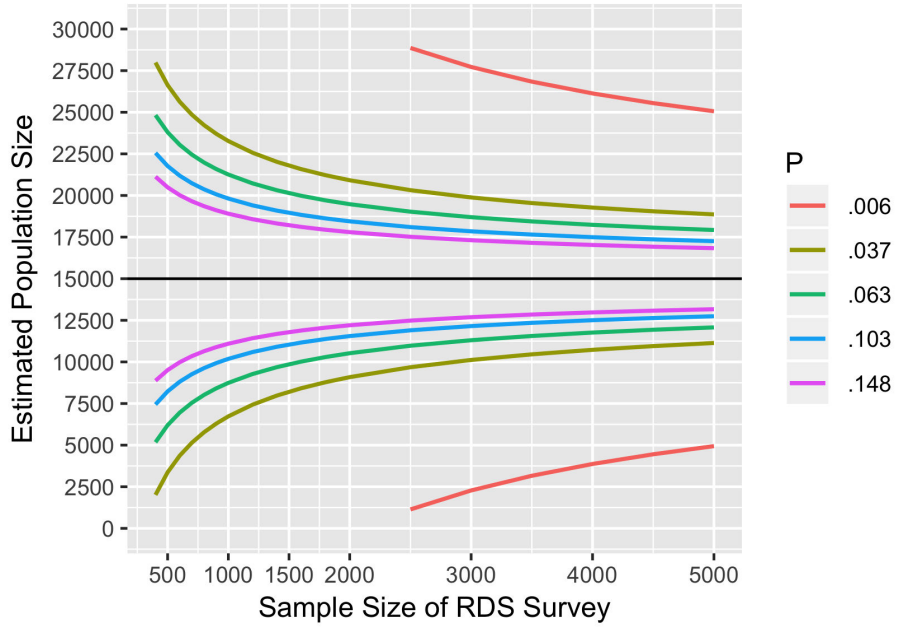
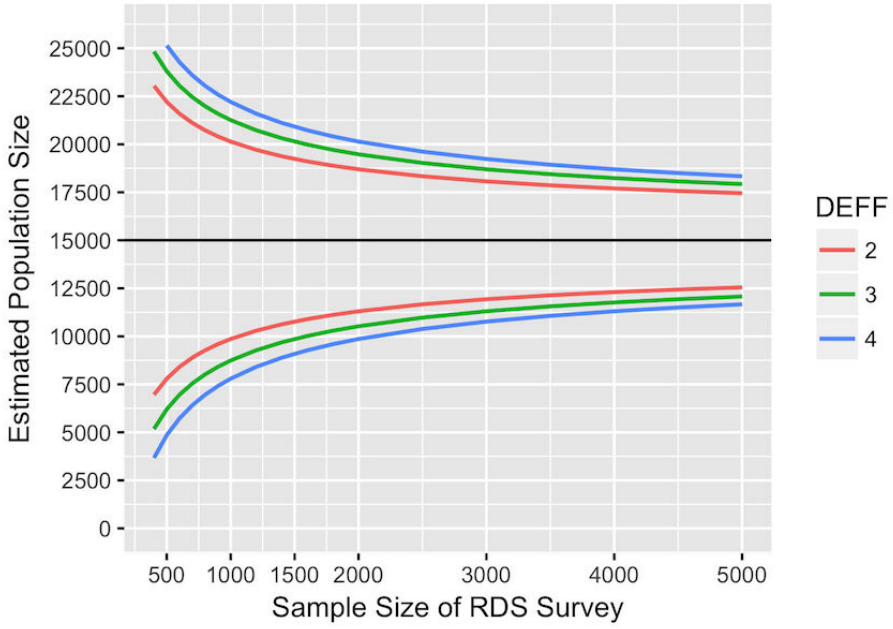


Figure 4. Sample size and width of 95% confidence intervals around a population size estimate of 15,000 female sex workers in Harare, for assumed reference period of 6 months and design effects (DEFF) of 2, 3, and 4.



Discussion

Summary and Discussion of Findings

We have applied current guidance on RDS and multiplier methods to propose an approach to planning population size estimation studies and determining sample size. We have given an example using the SMM, similar principles of which can be applied to the UOM.

Even for large sample sizes, 95% CIs around the PSE are wide. The uncertainty around the PSE is more sensitive to the uncertainty in *P* than in *M*, which is evident from the formula for *var(M/P)*. Researchers cannot choose a value of *P*, but they can encourage it to be higher by encouraging *M* to be higher. Concerned only with random error, it would improve the precision of the PSE to choose a longer reference period, and thus likely obtain a larger *P* in the case of the SMM, or to distribute a greater number of unique objects for the UOM. However, for the SMM this approach needs to be balanced against the potential for recall bias on estimation of *P*. It is also possible that the relationship between *M* and the reference period will differ across service types and according to whether individuals visit frequently or sporadically, and that bias in *M* might vary by reference period. If there are errors in unique identification of individuals in the service data, a longer reference period could lead to a higher likelihood of duplicate identification numbers, which would bias the PSE. For the UOM, care is needed to ensure that more objects distributed did not increase the likelihood of dependence between methods of distribution and RDS survey recruitment, a key source of potential bias.

We used DEFFs of 2 to 4 in our sample size calculations, but it is possible that a higher value would be more appropriate. Previous research has found that high levels of homophily (similarity) between recruiters and recruitees in RDS surveys is associated with higher DEFFs [7]. In SMM studies, the RDS survey is intended to measure program attendance, a characteristic that is likely to exhibit high homophily as it is a route by which participants might know and recruit each other. High homophily is also likely when the same social networks are used to distribute unique objects and to later recruit individuals to a RDS survey. Higher DEFFs might therefore be required, though in a previous population size estimation study of 9 communities in Zimbabwe, we found evidence of high homophily by program attendance for some sites but not all [8].

RDS surveys must have sufficient recruitment waves in order to reach stable estimates. There should also be sufficient numbers of seed participants to reflect diversity of the target population [16], concerns that need to be considered alongside the total sample size [17].

Recommendations

This short paper considers random error around size estimates and does not discuss a consideration of bias resulting from unmet assumptions of both the multiplier and RDS methods, which we consider elsewhere [8]. We agree with advice that researchers should use more than one multiplier and more than one method of estimating population size [18,19]. However, justification for sample size is often not given. Based on our findings, we strongly recommend conducting sample size calculations for estimating population size and considering the relationship between reference period or number of objects distributed and *P* for potential impact on uncertainty.

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Conflicts of Interest

None declared.

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Abbreviations

CI: confidence interval
DEFF: design effect
FSW: female sex workers
PSE: population size estimates
RDS: respondent-driven sampling
SMM: service multiplier method
UOM: unique object multiplier method

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Viewpoint

Insights From Flutracking: Thirteen Tips to Growing a Web-Based Participatory Surveillance System

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Abstract

Flutracking is a weekly Web-based survey of influenza-like illness (ILI) in Australia that has grown from 400 participants in 2006 to over 26,000 participants every week in 2016. Flutracking monitors both the transmission and severity of ILI across Australia by documenting symptoms (cough, fever, and sore throat), time off work or normal duties, influenza vaccination status, laboratory testing for influenza, and health seeking behavior. Recruitment of Flutrackers commenced via health department and other organizational email systems, and then gradually incorporated social media promotion and invitations from existing Flutrackers to friends to enhance participation. Invitations from existing participants typically contribute to over 1000 new participants each year. The Flutracking survey link was emailed every Monday morning in winter and took less than 10 seconds to complete. To reduce the burden on respondents, we collected only a minimal amount of demographic and weekly data. Additionally, to optimize users' experiences, we maintained a strong focus on "obvious design" and repeated usability testing of naïve and current participants of the survey. In this paper, we share these and other insights on recruitment methods and user experience principles that have enabled Flutracking to become one of the largest online participatory surveillance systems in the world. There is still much that could be enhanced in Flutracking; however, we believe these principles could benefit others developing similar online surveillance systems.

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KEYWORDS

epidemiology; surveillance; influenza; user centered design; World Wide Web

Introduction

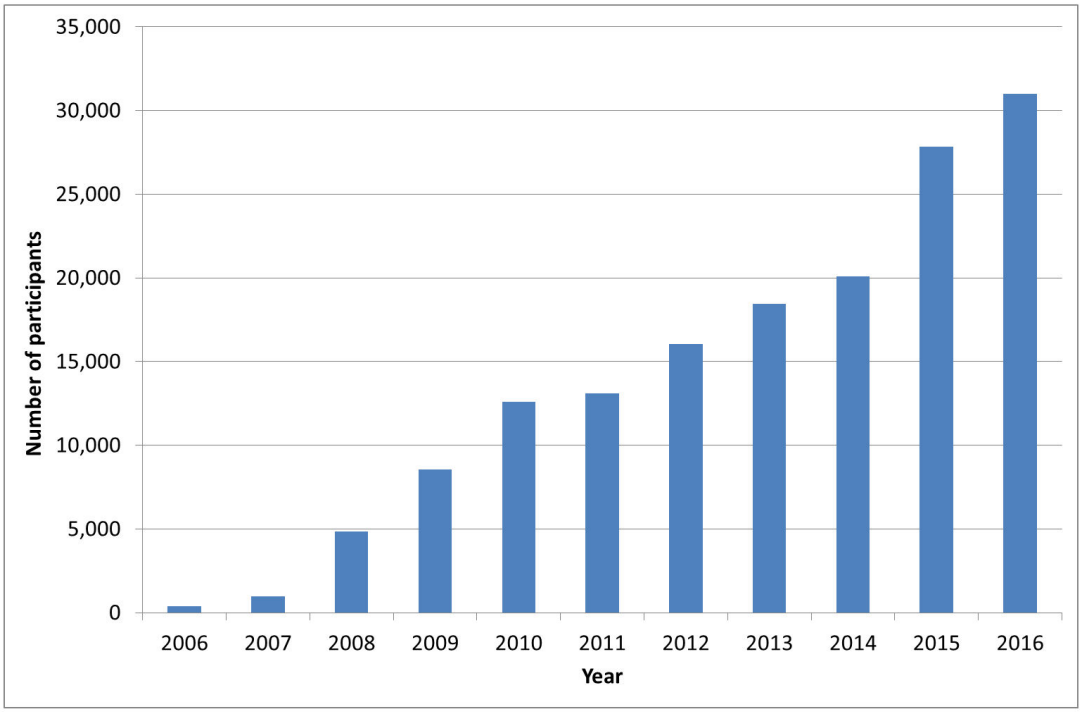
Flutracking (www.flutracking.net) is a weekly Web-based survey of influenza-like illness (ILI) in Australia that has grown from 400 participants in 2006 to over 26,000 participants every week in 2016, with 30,900 participants completing at least one survey (Figure 1). Flutracking monitors the transmission and severity of ILI across Australia [1,2]. The survey documents symptoms (cough, fever, and sore throat), time off work or normal duties, influenza vaccination status, laboratory testing for influenza, and health seeking behavior. The project was inspired by the publication of an article in 2005, "'Did you have the flu last week?' A telephone survey to estimate a point prevalence of influenza in the Swedish population" [3]. We believed that an online platform would allow a larger, less expensive, and continuous assessment of ILI incidence and morbidity.

Community based surveys of ILI, such as Flutracking, are integral to comprehensive influenza surveillance which also incorporates complementary primary care, emergency

department, hospital, intensive care unit (ICU), mortality, and laboratory surveillance. They can provide a unique insight into influenza epidemiology as they are not distorted by jurisdictional practices, health seeking, or practitioner behavior. Early in the 2009 H1N1 influenza pandemic, Flutracking was able to identify that the community level ILI attack rates were not appreciably different than they had been in the past seasonal influenza years. Rather, the high rates of ILI reported from emergency departments and influenza laboratory confirmations were due to increased health-seeking behavior and increased laboratory testing, respectively, due to the pandemic [4].

In this paper, we share our learnings on recruitment and retention of participants that have enabled Flutracking to become one of the largest online participatory surveillance systems in the world. In listing our recommendations, we divide the paper into two parts: (1) recruiting participants and (2) retaining participants.

Figure 1. Number of participants completing at least one survey by year, 2006 to 2016, Flutracking, Australia.



Recruiting Participants: Lessons Learned

We initially sent an invitation email to approximately 7000 employees of the Hunter New England Area Health Service in South-Eastern Australia. Additionally, an invitation to join was included in the Health Service newsletter. These two efforts jointly resulted in 400 participants completing at least one survey in 2006. We have identified seven lessons learned from our recruiting efforts so far.

Ask Participants to Invite Their Friends to Join

Since 2012, the current participants were emailed a week or two prior to the commencement of the survey each year and were asked to invite their friends or colleagues to join. This became one of our main recruitment methods, with typically over 1000 new participants in the week following the annual appeal to participants. We split tested emails and found that asking participants to invite a concrete number of people to join (eg, 2 or 3) is more successful than a generic "invite your friends" request. Comparing 1000 emails sent to participants who were asked to invite "friends" with 1000 emails sent asking to invite "3 friends," we found that the former resulted in 79 new participants versus 182 for the latter.

Leverage Organizational Email Invitations

After the 2006 pilot, we expanded Flutracking beyond the Hunter New England Area Health Service and accepted participants from across the state in 2007 and then nationally. From 2008 to 2013, we sought to identify organizations that would be willing to disseminate the invitation to join Flutracking via their corporate email networks. We reviewed lists of Australian companies and government organizations with high numbers of employees and then selected those with two features: (1) a high proportion of staff sitting in front of computers with Internet access and frequent email use and (2) an assumed high level of staff autonomy (eg, not a "call center").

We telephoned selected organizations and asked to speak to the "head of occupational health and safety" or, secondarily, "the director of human resources," assuming this position would be most amenable to discussing an intervention that could raise awareness about respiratory illness in the workplace. We telephoned about 500 organizations each year prior to the survey commencement, with approximately 30 organizations agreeing to circulate an invitation email to their workforce each year.

Health departments were asked to assist with recruitment; they were also offered jurisdictional specific data once a threshold of 1000 participants was reached. An email containing a clickable link to Tasmanian public health staff in 2008 recruited

556 participants in 2 days and by the end of the 2008 season, through continued promotion, Tasmania had recruited 1235 respondents. A newsletter with a clickable link promoting enrolment in Flutracking was sent to all South Australian Health employees on May 25, 2010. Flutracking participation in South Australia increased from 197 to 2189 participants for the week ending on May 30, 2010.

Seek Champions

The Director of Public Health in Tasmania, the southernmost state of Australia, was a strong advocate for Flutracking. The Director sent a personally signed memo encouraging participation in Flutracking via the Tasmanian Department of Health and Human Services email network and promoted enrolment through internal online newsletters. In 2015, Tasmania's peak year of participation, approximately one of every 250 Tasmanians (population of 517,000) were participants. Repeated annual promotions by the health department have maintained Tasmania as the highest participating jurisdiction in Australia.

Prioritize Electronic Mass Media With Clickable Hyperlinks

Media releases promoting Flutracking were issued each year in mid to late April before commencing the first survey in May. There has always been good coverage by both print and online newspapers, radio, and television at both the regional and national levels. It is very clear, however, that the driver of recruitment following media coverage is not necessarily the audience of a media outlet, but rather the immediacy and longevity of clickable hyperlinks to our flutracking.net website. An online Australian newspaper that featured an interactive map of our data led to over 4000 referrals to our website in 2016. Referrals from this site were associated with peaks in joining of up to 100 new participants in a single day early in the year. Following radio and television promotion of Flutracking, we monitored postcode regions within the estimated audience zone for impacts on recruitment. For example, a radio interview with a typical audience of approximately 10,000 resulted in only four people joining in the hour following a direct appeal for listeners to join during the broadcast. An unusually successful radio interview with a typical listener audience of 300,000 led to approximately 230 more participants enrolling in the 24 hours following the broadcast; however, this radio program also featured a link to Flutracking on their website. Radio and TV promotions require the listeners to recall and enter a website address in order to join. This contrasts with the immediate response to clickable links in online articles and in the email and online newsletter promotions in the South Australian and Tasmanian health departments described above. In the days following a media release, we conducted Google News searches for mention of "Flutracking" to identify online news coverage that lack hyperlinks to the flutracking.net website and request that the survey site be hyperlinked.

Use Social Media and Website Analytics

We have used Facebook to promote Flutracking since 2011. Most posts are "boosted" by paying a fee to increase its audience reach, as this is a relatively minor cost compared with the time involved in planning and formatting a post. Facebook is useful for surfacing frequently asked questions from participants (eg, whether participants should answer the survey when travelling), educating participants on the differences between ILI and influenza, sharing surveillance insights, and directing potential participants to the website to enroll.

We use Google Analytics to analyze the number of referrals to the Flutracking join page from Facebook as well as from other promotional sites. Approximately 300 participants join each year after referral from our Facebook page. We used a unique, short URL tracking link for each promotional strategy so that we can split test different subject headings and messages in invitation emails to determine which combinations generate the most new joins.

Invite Participants to Report on Their Household Members

In 2008, we invited current participants to begin answering for their immediate household members. This resulted in a 44.89% (1163/2591) increase in the number of participants on average per week in 2008. Household participants continued to be an important component of our survey base with 39% of participants being a household member of a primary respondent in 2016.

Do Not Use Barriers Such as Usernames and Passwords

Passwords and usernames are barriers to participation in any online system [5]. Instead of using passwords, we sent a unique link to each individual user for each specific week so that regardless of the order in which a user responds to the survey (eg, some participants answered surveys in reverse chronological order after missing some survey weeks), the data are captured for the appropriate participant-weeks. The link was cryptically encoded to prevent malicious interventions from generating valid links and entering false data into the database and to prevent users from accessing other users' data.

Retaining Participants: Lessons Learned

Although total recruitment is an important parameter for success, long term week to week participation is an equally important determinant of data quality. Continued year to year participation supports cohort analyses, with retention of cohorts over multiple years allowing for within-person comparisons (eg, comparisons between the ILI experiences of individuals in years that they were vaccinated against influenza versus when they were not and changes in vaccination uptake following incidents such as the adverse pediatric reactions to a pandemic vaccine in 2010) [6].

In 2015, 78% of participants who completed at least one survey in the first month of surveillance completed 90% or more of all 26 surveys that year (Figure 2). Although there has been a gradual loss of some participants each year, more than 60% of participants who joined in 2011 maintained participation over a 5-year period (Figure 3).

Figure 2. Percentage of participants who completed <20% to 90-100% of the 26 Flutracking surveys conducted in 2015.

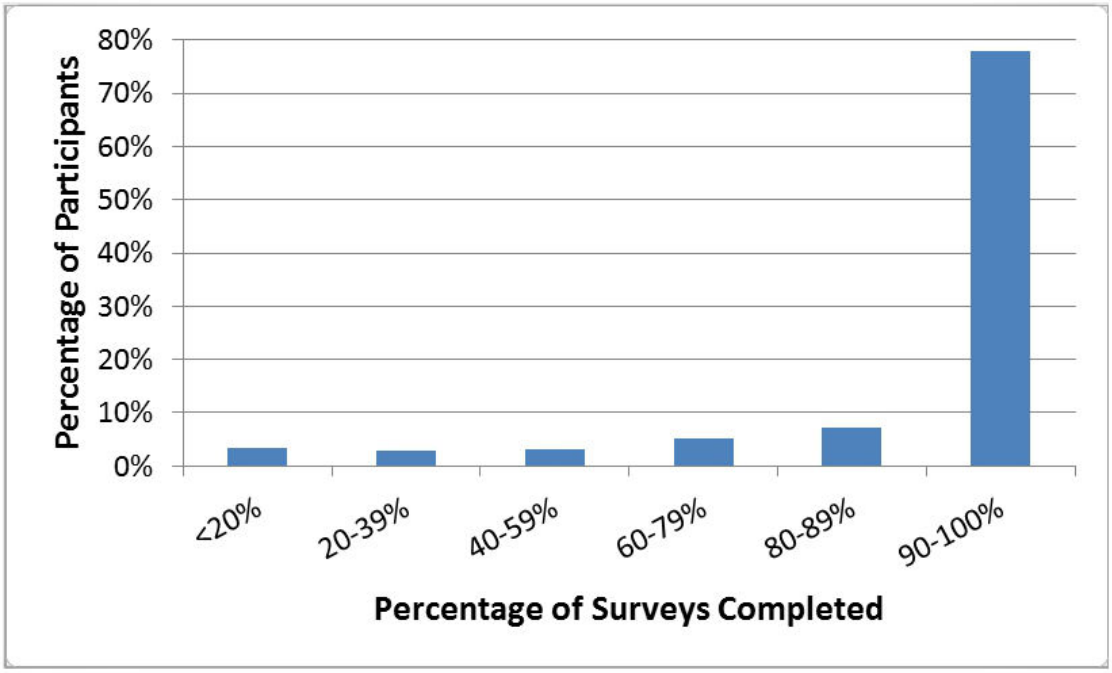
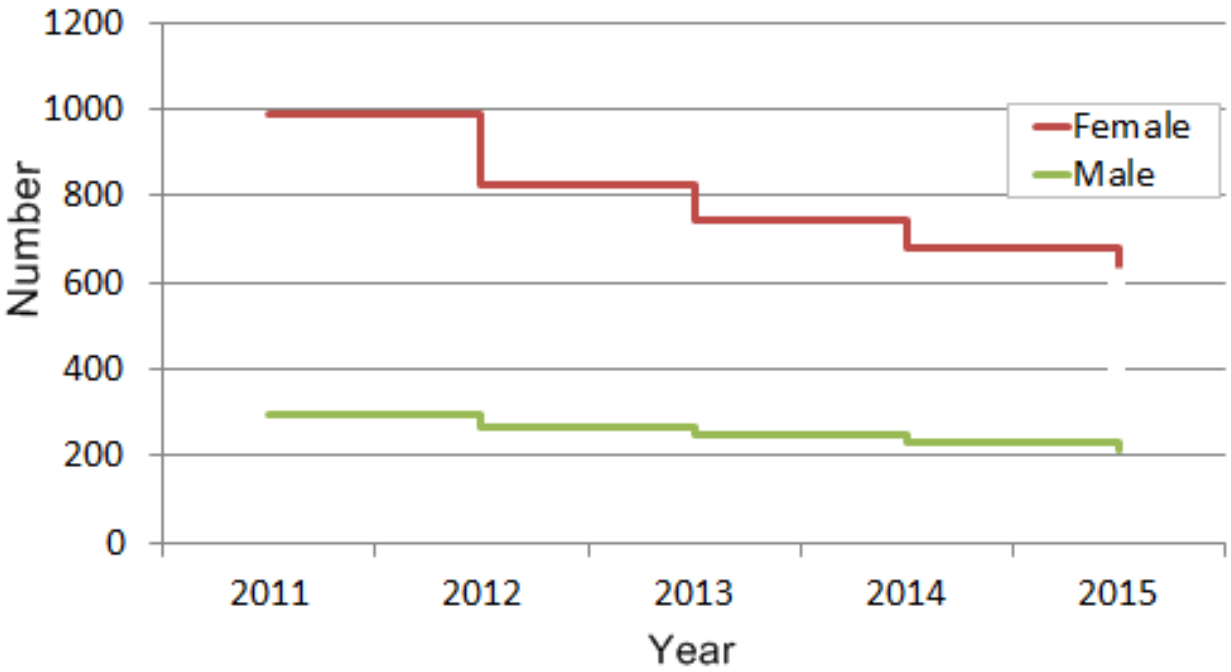


Figure 3. Five-year participation survival curve of 1400 survey respondents who joined in 2011 based on gender.



Consider the Short-Term Versus Long-Term Value of Inducements/Rewards for Participation

Flutracking has never offered rewards or inducements for participation. However, another online surveillance network, FluNearYou, has used significant recruitment inducements including iPads and rewards of US $10,000 for individuals and US $25,000 for groups reaching target recruitment goals [7]. Whereas inducements may increase initial recruitment, it is unclear whether they lead to more consistent participation. A trial of the impact of incentives on participation in online symptom surveys in Japan revealed that response rates were higher among the intervention arms with lower payments [8]. We conducted open-ended interviews with 30 participants who had participated in Flutracking for 6 years and asked, “Why have you participated in Flutracking for so many years?” Paraphrasing participant responses, they stated that the survey was quick and that they felt they were doing something useful for health research on a Monday morning. It is possible that short term inducements may only induce short term participation

and that the best inducement is the opportunity to contribute to health surveillance and research.

Most surveillance practitioners believe it is important to provide feedback to participants [9]. Flutracking participants receive a link to a map and weekly report on influenza activity after they submit their weekly survey. While it is believed that rapid reporting of results is important to maintain support for a surveillance system, in August 2015, 116,773 surveys were completed, but there were only 2670 unique page views of Flutracking maps (Flutracking participants and non-participants combined) and 454 unique views of our online weekly report by the 28,500 unique users of the site. This suggests that less than 10% of website users who visit flutracking.net engage with the reports in the month of peak influenza activity.

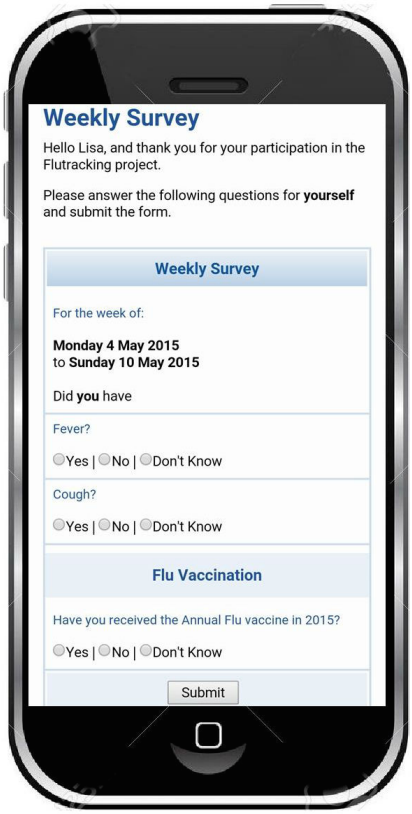
Collect the Absolute Minimum Dataset (to Make the Survey as Quick and Easy as Possible)

Reducing the number of questions on recruitment and in the weekly survey decreases the burden on participants. Thus, Flutracking focuses on collecting the minimum dataset required to fulfill present day surveillance objectives. We avoided collecting data on any variable for which we did not have an immediate plan for analysis. On recruitment we only collected month and year of birth, sex, identification as an Aboriginal or Torres Strait Islander, highest educational attainment, postcode of residence, whether each participant works face to face with patients, and receipt of the previous years' influenza vaccine. For example, having no initial analysis objective using the sex of participants we did not start collecting the sex of Flutracking participants until 2012. Initial analysis of our four years of collecting these data indicate a high female to male ratio of our participants and some divergence between males and females in participation patterns, with males exhibiting a greater retention rate year to year from 2011 to 2015 (Figure 3). Similarly, we did not collect any underlying medical condition. Granted such a condition might be a confounder or modifier of immunity, vaccination status, or health-seeking behavior, we will not add this variable until we are certain of its usefulness to inform an important surveillance objective.

We collected a minimal symptom profile comprising fever, cough, sore throat (if "yes" to both fever and cough), health care sought, days absent from normal duties, and collection and result of laboratory testing. We have been encouraged to adopt expanded symptom profiles that would allow comparison with established national and international case definitions for influenza, but resisted this move so far. The weekly survey displayed only three questions (Figure 4).

Specifically, participants were asked about any cough, fever, or vaccination in the last week (unless the participant had reported being immunized earlier in the year). If the respondent clicked no to either cough or fever, no more questions were presented and the survey was complete; this took less than 5 seconds for a survey on a single person. If the respondent clicked yes to both cough and fever, they were asked about sore throat and then time off work or normal duties and health-seeking behavior. Although asking about more symptoms (ie, more than three) and eliciting a measured temperature could enhance the predictive value of the collected data [10-12], we were not convinced that a minimal increase in predictive value justified extending the survey length.

Figure 4. Screenshot of first screen of the flutracking.net survey, 2016.



Asking more questions about symptoms makes for a longer survey, which can result in reduced participation; we and the other designers of online surveillance systems need to strike a balance between tracking multiple syndromes (eg, respiratory, gastrointestinal, and neurological) versus a single syndrome. A screening "yes or no" question about the presence of a collection of symptoms can keep a multiple syndrome survey shorter than it would otherwise be. We are currently split testing this method to determine whether it has any impact on participation or data quality.

Segment Participants Based on Their Preferences for Survey Duration and Length

There is a long history of audience segmentation in public health practice [13]. We segmented our participants one time based on the preference to continue surveys over the southern hemisphere summer of 2009-10. Flutracking did not routinely continue surveillance over the summer period, which means we were unable to detect out-of-season ILI activity. We made this decision because participation often decreased toward the end of winter. When the weather warmed up, we sometimes received emails from participants with "Are we done yet?" undertones. We made an exception following the 2009 H1N1 pandemic and continued surveillance through the summer by asking respondents to opt in to continued surveillance past the usual mid-October end date. In total, 80.89% (5541/6850) of participants chose to continue to participate. The 2009 pandemic was an exceptional event, and we did not expect that 80% of the cohort would opt-in to continued year round surveillance. However, we believe that given the broad range of motivations and preferences for survey content and length, any further expansion of question number or content should be explored by allowing respondents to opt-in. Although this may produce a self-selection bias, we believe that it is inevitable in this type of surveillance and has to be balanced against participant preferences and participation.

Conduct Usability Testing to Optimize User Experience

We learnt while designing the Flutracking survey interface that we inevitably built our own assumptions into the design and were unable to assess it as a naïve user would. Inviting a naïve user to test the interface was critical (eg, to test whether radio buttons should be placed before or after potential answers and whether vertical lines between answers assist users to click on the intended radio button). Usability testing ranges from creating simple paper based mock-ups of draft screens using a word processing or publishing package to testing an operational online module. There are extensive guidelines on how to conduct usability testing, but the basic approach that we use is outlined in Textbox 1 [14].

Textbox 1. Basic usability testing conducted routinely by Flutracking (with paper- or screen-based systems).

- Show the template to the user for two seconds and then conceal it. Ask: "What do you think this page is for, what can you do on it?" "What would you do on it?"
- Show the template again and ask: "Tell me again what you think this is for." "What is your eye drawn to?" "Is there anything that looks confusing or surprising?" "What do you think the designer of the website wants you to do on this page?" "What do you feel like clicking on?" "What do you think will happen if you click on that?" The test supervisor notes where the user's expectations differ from what actually happens.
- This testing can also be conducted using "concurrent talking aloud" in which the naïve tester is asked to provide a "stream of consciousness" commentary in which they articulate every thought about the web template including what their eye is drawn to, what they are thinking about clicking on, what they expect to happen, and whether they are surprised or confused about what happens.
- Provide the tester with a "sickness scenario" and ask them to complete the illness questions.
- Ask the test user "what sort of illness would someone have who answered 'yes' to this question?"

Try to Adopt "Obvious Design" Principles (Again, to Optimize User Experience)

We tried to adopt "obvious design," that is, there should be minimal need for explanations or textual guides to how the survey operates. Design should dictate flow without placing a cognitive load on the user. The Flutracking team is alert that any inclination to place a text explanation in our forms (eg, "click here to..." or "scroll down to...") indicates a design flaw where user action is not obvious. To assist with obvious design, we tried to incorporate design elements that will be familiar to Internet users, for example, by copying terms, user flow, colors, and button design elements from popular online platforms such as Google or Facebook.

Technology Platforms: Web Survey, App, SMS, or Email?

Technology platform options such as email versus SMS triggered notifications of Web-based versus mobile phone app-based surveys might well impact upon recruitment or retention. We have only used emails and online surveys whereas FluNearYou has additionally used a mobile phone app. We found that Vaxtracker, a vaccine adverse event surveillance system, achieved higher participation among parents who signed up to receive both email and SMS reminders for surveys. We noted the emerging trend against native and hybrid apps because of compatibility issues and the need to recode both Web and mobile app platforms for any system or survey upgrades. The Gov.UK Digital Services Manual strongly discourages use of apps recommending the use of responsive mobile websites and emerging progressive app technology which capture the benefits of both responsive Web and native apps [15]. We recommend the use of responsive web design with future consideration of progressive Web applications with notifications to alert participants to new surveys.

Discussion

The flutracking.net has grown rapidly over 10 years of its operation and maintained high participation rates. Invitations

from existing participants to friends and colleagues remain the most successful recruitment method. Minimizing the length of the survey and ensuring design simplicity has been an absolute commitment that we believe contributed to our high participation rates. In addition to the insights offered here, user feedback and error detection have revealed the importance of prompting completion of missed surveys, timing follow-up of influenza laboratory results, and developing an administrative platform that runs weekly error checks to detect system and email gateway errors. These will be explored further in future publications. While Flutracking shares some common features with other online influenza surveillance networks such as FluNearYou and Influenzanet, their unique features provide opportunities for comparison [16,17]. We welcome dialogue and collaboration with other groups exploring online surveillance systems.

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Authors' Contributions

CD drafted the initial article, revised the article and is founder of Flutracking.net. SC, MB, DC, SC, JF, and DD all contributed to writing and revision of the article. SC, MB, and DC conducted the analyses presented in the article. SC and JF provided application development for flutracking.net.

Conflicts of Interest

None declared.

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Abbreviations

ILI: Influenza-like illness

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Original Paper

Influenzanet: Citizens Among 10 Countries Collaborating to Monitor Influenza in Europe

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Abstract

Background: The wide availability of the Internet and the growth of digital communication technologies have become an important tool for epidemiological studies and health surveillance. Influenzanet is a participatory surveillance system monitoring the incidence of influenza-like illness (ILI) in Europe since 2003. It is based on data provided by volunteers who self-report their symptoms via the Internet throughout the influenza season and currently involves 10 countries.

Objective: In this paper, we describe the Influenzanet system and provide an overview of results from several analyses that have been performed with the collected data, which include participant representativeness analyses, data validation (comparing ILI incidence rates between Influenzanet and sentinel medical practice networks), identification of ILI risk factors, and influenza vaccine effectiveness (VE) studies previously published. Additionally, we present new VE analyses for the Netherlands, stratified by age and chronic illness and offer suggestions for further work and considerations on the continuity and sustainability of the participatory system.

Methods: Influenzanet comprises country-specific websites where residents can register to become volunteers to support influenza surveillance and have access to influenza-related information. Participants are recruited through different communication channels. Following registration, volunteers submit an intake questionnaire with their postal code and sociodemographic and medical characteristics, after which they are invited to report their symptoms via a weekly electronic newsletter reminder. Several thousands of participants have been engaged yearly in Influenzanet, with over 36,000 volunteers in the 2015-16 season alone.

Results: In summary, for some traits and in some countries (eg, influenza vaccination rates in the Netherlands), Influenzanet participants were representative of the general population. However, for other traits, they were not (eg, participants underrepresent the youngest and oldest age groups in 7 countries). The incidence of ILI in Influenzanet was found to be closely correlated although quantitatively higher than that obtained by the sentinel medical practice networks. Various risk factors for acquiring an ILI

infection were identified. The VE studies performed with Influenzanet data suggest that this surveillance system could develop into a complementary tool to measure the effectiveness of the influenza vaccine, eventually in real time.

Conclusions: Results from these analyses illustrate that Influenzanet has developed into a fast and flexible monitoring system that can complement the traditional influenza surveillance performed by sentinel medical practices. The uniformity of Influenzanet allows for direct comparison of ILI rates between countries. It also has the important advantage of yielding individual data, which can be used to identify risk factors. The way in which the Influenzanet system is constructed allows the collection of data that could be extended beyond those of ILI cases to monitor pandemic influenza and other common or emerging diseases.

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KEYWORDS

influenza; surveillance; Internet; vaccination; Europe

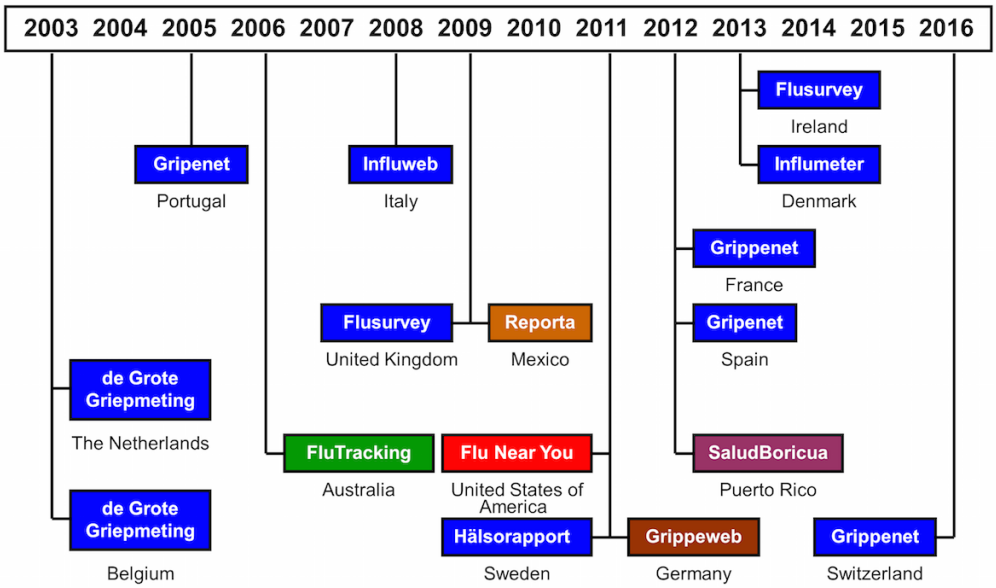
Introduction

Influenza is a global public health problem—whether seasonal, zoonotic, or pandemic—causing high general practice consultation rates, increased hospital admissions, excess deaths, and high absenteeism in schools and workplaces, including in health workers. Its high socioeconomic impact and burden is not just limited to the industrialized world but extends to low- and middle-income countries, encompassing multiple dimensions such as direct costs to the health service and households and indirect costs because of productivity losses, as well as broadly affecting the overall economy [1].

Influenzanet [2] is a participatory monitoring system for influenza-like illness (ILI) based on data reported by Internet users among the general population who volunteer as participants. It was initially conceived to make scientific information accessible to a broad public and to promote students' enthusiasm for science [3,4]. It was first launched in the Netherlands and Belgium as "The Great Influenza Survey" (De Grote Griepmeting [5]) in the 2003-04 influenza season. In 2005, Portugal joined (Gripenet [6]). Subsequently, the system was adopted by Italy (Influweb [7]) in 2008, the United Kingdom (Flusurvey [8]) in 2009, Sweden (Hälsorapport [9]) in 2011, France (Grippenet [10]) and Spain (Gripenet.es [11]) in 2012, and Ireland (Flusurvey.ie [12]) and Denmark (Influmeter [13]) in 2013. Switzerland joined in December 2016; however, at the moment of the writing of the paper, there were not enough data to be included in the analysis.

In 2009, the Influenzanet consortium was established to foster collaboration and pool resources toward using this uniform system of participatory ILI surveillance across Europe. Hereafter, we will refer to the system in each country as Influenzanet, instead of designating it by the actual name by which the system is known in each country. The Portuguese team also helped to introduce the system in Latin America, namely in Mexico (Reporta [14]) and supported the development of a similar system in Brazil but focused on dengue instead (Dengue na Web [15]). Similar systems were independently implemented in Australia (Flu Tracking [16]), the United States (Flu Near You [17]), and Germany (GrippeWeb [18]). Additionally, Salud Boricua [19] was launched in Puerto Rico, targeting 3 different acute febrile illnesses, which included influenza, dengue, and leptospirosis. Figure 1 (updated from [20]) shows a timeline of the launch date of the participatory surveillance systems for ILI in Europe and worldwide.

Figure 1. Timeline of Influenzanet (in blue) and other participatory surveillance systems for influenza-like illness.



Here, we describe the Influenzanet participatory surveillance system and provide an overview of the results obtained from different analyses performed with the data, including representativeness analyses, data validation (comparing ILI incidence rates between Influenzanet and sentinel medical practice networks), identification of ILI risk factors, and influenza vaccine effectiveness (VE) studies previously published. Additionally, we present new VE analyses for the Netherlands, stratified by age and chronic illness, and offer suggestions for further work and considerations on the continuity and sustainability of the participatory system.

Methods

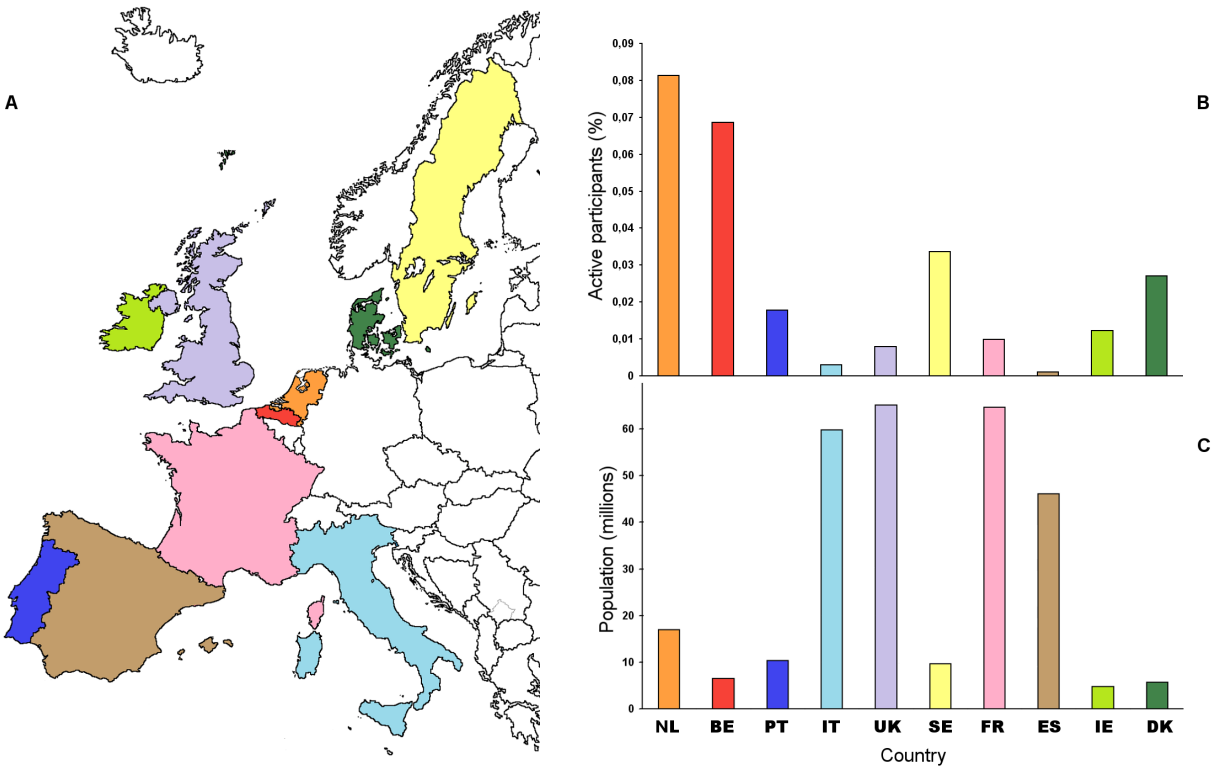
Influenzanet Data Collection

Any resident of a participating country can register on its national website by completing a simple Web-based intake questionnaire containing various sociodemographic, medical, and behavioral questions, in addition to the questions about postal code of residence and workplace (see Multimedia Appendix 1). Once registered, participants receive a weekly email newsletter with a reminder to complete a short symptoms questionnaire. In this questionnaire, participants are asked to report any symptoms that they have experienced since their previous visit to the Influenzanet website. If symptoms are reported, participants are asked to provide further information, including the date of onset, whether these led to a change of behavior (eg, missing school or work or taking medicines), and whether the participant visited a medical service, and if so, the outcome of the consultation. The system allows participants to also report for other members of their household to foster data collection for children and elderly people. On the basis of a unique user identifier, participants can be followed over multiple seasons and are urged to update changes in sociodemographic, medical, behavioral, residential, and workplace information every season.

Participation Rates

Several thousands of participants have been engaged yearly in Influenzanet, with over 36,000 volunteers in the last season of 2015-16. On the basis of the 2015-16 season, the Netherlands had the highest number of participants who completed at least 3 symptoms questionnaires (13,821 participants corresponding to 0.08% of the country's population), followed by France (6413; 0.01%), the United Kingdom (5134; 0.01%), Belgium (Dutch-speaking region: 4559; 0.07%), Sweden (3245; 0.03%), Portugal (1840; 0.02%), Italy (1822; 0.003%), Denmark (1541; 0.03%), Ireland (575; 0.01%), and Spain (487; 0.001%). Data for Sweden are for the 2013-14 season, as after that Sweden started using Influenzanet through invitation only to improve the representativeness of the monitored sample and compare it with the previous seasons. Figure 2 compares the participation rates across countries versus the country's population [21].

Figure 2. Participation rates across the 10 Influenzanet countries. Percentage of Influenzanet active participants (B) among each country's total population (C). Source: Influenzanet 2015-16 data for all countries, except for Sweden where data are for 2013-14; Country population per January 1, 2016 (Sweden per January 1, 2014)—the Netherlands (NL): 17 million (M), Belgium (BE): 7M, Portugal (PT): 10M; Italy (IT): 60M; The United Kingdom (UK): 65M; Sweden (SE): 10M; France (FR): 65M; Spain (ES): 46M; Ireland (IE): 5M; and Denmark (DK): 6M.



The number of participants has been relatively stable over the years for the countries that first started (after having increased during their first seasons) and is still increasing for the countries that joined after 2011. For example, of all participants who completed at least 3 symptoms questionnaires during a season (hereafter referred as active participants) analyzed from 2003-04 to 2012-13, on average in the Netherlands, 76% (Standard deviation [SD] 8; N=16,481) participated again in the following season, with 69% (SD 12; N=1894) in Portugal, whereas Belgium and Italy had values within that range [22]. During the influenza season from November 2013 until May 2014 (29 weeks of survey), 73% (9479/12,985) of the participants in the Netherlands completed the survey more than 20 times; 68% (7964/11,758) of the completed surveys were less than 9 days apart, reflecting a high level of engagement of the participants with the system [4].

Ethical Approval

In all the participating countries, Influenzanet studies were conducted in agreement with national regulations on privacy and data collection and treatment. Informed consent was obtained from individuals who participated in the studies enabling the collection, storage, treatment, and publication of data in anonymized, processed, and aggregated forms for scientific purposes. The Grote Griepmeting study is carried out according to the Dutch legislation on privacy, and the privacy regulation of the studies was approved by the Dutch Data Protection Authority. In Portugal, the Gripenet project was approved by the Ethics Committee of the Instituto Gulbenkian de Ciência, and the Portuguese Data Protection Commission approved the Gripenet study (Authorization Number 2868). In the United Kingdom, the Flusurvey was approved by the London School of Hygiene and Tropical Medicine Ethics Committee (Application Number 5530). In Sweden, the Influensaskoll study was approved by the Stockholm Regional Ethical Review Board (Dnr. 2011/387-31/4). In France, the Grippenet study was approved by the French Advisory Committee for research on information treatment in the field of health (ie, CCTIRS, authorization 11.565) and by the French National Commission on Informatics and Liberty (authorization DR-2012-024).

Results

Participant Representativeness

In Web-based surveys, the nonrepresentative nature of the Internet-using population can result in a selection bias [3]. In addition, people who do not experience any ILI symptoms may not consider themselves suitable for participation. Accordingly, representativeness analyses have been performed at various stages during the activity of Influenzanet to compare the demographic and health characteristics of the participants with those in the country's overall population.

In work from 2006, it was shown that the demographic and health characteristics of the participants in the Netherlands were remarkably similar with those observed by the National Information Network of General Practicioners (at that time Landelijk Informatie Netwerk Huisartsenzorg abbreviated as LINH; [3]). Namely, striking similarities were found between Dutch Influenzanet participants (N=13,000) and the population observed by the general practitioners (GPs) in LINH (N=255,000) with regard to the prevalence of asthma (6.9% in Influenzanet, n=918 vs 6.4% in LINH, n=6320) and influenza vaccination rates and, to a lesser degree, for diabetes (2.4% in Influenzanet, n=319 vs 3.5% in LINH, n=8925; $P<.005$). The vaccination rates in patients with asthma, diabetes, and persons older than 65 years were 68% (n=9044), 85% (n=11,305), and 85% (n=11,305), respectively, among Dutch Influenzanet participants, whereas the corresponding percentages in the LINH population were 73% (191,250), 85% (216,750), and 87% (221,850). Similar results were obtained for Belgium [23] and the United Kingdom [24] in terms of risk group status.

In 2011-12, Influenzanet launched a standardized common framework for data collection. A study of representativeness was then extended to all participating countries (7 at that time) to assess the representativeness of the sample in terms of a set of demographic, geographic, socioeconomic, and health indicators [25]. The Influenzanet population was not representative of the general population in terms of age distribution, underrepresenting the youngest and the oldest age groups. However, all age classes were represented. The gender imbalance differed between countries, although higher female participation occurred in most countries (the Netherlands, the United Kingdom, Sweden, and France). Differences between gender-specific information-seeking behavior (more prominent in women) and Internet usage (with higher rates in male populations) may have been at the origin of these gender imbalances. For instance, the countries with higher Internet usage by males were also the countries either having a larger prevalence of male Influenzanet participants (Belgium and Italy) or displaying similar participation of males and females (Portugal).

In the aforementioned 2011-12 representativeness study [25], smokers were underrepresented in the majority of countries, as were individuals with diabetes; the representativeness of asthma prevalence and influenza vaccination coverage for ≥65 years individuals in 2 successive seasons (2010-11 and 2011-12) varied between countries. Additionally, participants from most countries were found to be more frequently employed than the general population, except in the Netherlands where the contrary was observed, and in the United Kingdom where no significant difference was found. Participants also tended to have a higher education level than the general population, as shown by results from the 3 countries where such data were available to compare with Influenzanet data (France, Portugal, and Sweden; [25,26]).

Quantifying these biases allows them to be taken into account in future analyses of Influenzanet epidemiological studies.

Influenzanet Versus Traditional ILI Surveillance

Influenza surveillance in Europe is traditionally pooled by the European Influenza Surveillance Network (EISN), which combines epidemiological and virological surveillance of influenza. The EISN network includes a set of sentinel GPs in each country who collect information from patients reporting symptoms of ILI. The sentinel GPs report the aggregated number of ILI consultations, by age group, to the EISN via The European Surveillance System (TESSy) database, based on which the EISN calculates the ILI rates. A sample of these

patients is also tested for virological confirmation of influenza. The sentinel GPs usually represent 1% to 5% of the GPs working in the country or region [27].

The EISN is coordinated by the European Centre for Disease Control and Prevention (ECDC) since 2008 and participates in the wider World Health Organization (WHO) Regional Office for European Region influenza network and in the WHO Global Influenza Surveillance and Response System. Since 2014, the ECDC and WHO/Europe have a single joint Web-based bulletin called "Flu News Europe" [28].

The incidence of ILI among Influenzanet participants is determined in near real time using a syndromic case definition. From season 2011-12 onwards, all Influenzanet countries apply the case definition for ILI recommended by the ECDC when reporting feedback to participants on whether their reported symptoms might be due to ILI. Additionally, as the participants' individual symptoms data are available, this enables exploring different case definitions when analyzing the data (see Textbox 1). Graphic representation of the results is dynamically updated on the Influenzanet website.

Previous studies have established a positive correlation between the incidence of ILI determined by Influenzanet and that estimated through the clinical surveillance by sentinel GPs [3,22,23,29-33]. Although there is an approximately parallel rise, peak and decline of ILI activity between the Influenzanet and EISN epidemic curves, the incidence values obtained by Influenzanet are quantitatively higher than those collated by ECDC. For instance, Influenzanet ILI incidence rates in the Netherlands were found to be 5 to 10 times higher during the winters of 2010-11 to 2015-16 (when restricted to the period of virological influenza confirmation by the Dutch Sentinel Practice Network). Specifically, the percentage of ILI cases in the Dutch influenzanet volunteers ranged from 6% (616/10,803) to 14% (1532/11,034) during an observation period of 22 weeks, whereas the Dutch Sentinel Practice Network rates for the same period ranged from 0.8% to 2% (840 to 2220 per 100,000 patients) (unpublished data). Higher incidence rates in Influenzanet versus sentinel surveillance also occur in other participating countries, although the magnitude of the difference varies by country [22,30,32,33].

The greater magnitude of the incidence rates estimated by Influenzanet versus sentinel surveillance networks might possibly be partially explained by health care-seeking behavior, as this differs across countries. People may not seek medical care for a variety of reasons such as disease severity or sociodemographic differences and thus not be accounted as ILI cases by the traditional sentinel surveillance system [22].

Influenzanet allows estimating the fraction of the population with symptoms that seeks health care services, as this is a follow-up question asked to participants in the symptoms questionnaire. The data have shown that this fraction varies greatly by country [22], being also dependent on the severity of symptoms (and therefore, on the ILI case definition used [33,34]) and the season [22,34].

Textbox 1. Influenza-like illness case definitions.

The following case definition for influenza-like illness (ILI) is recommended by the European Centre for Disease Control and Prevention (ILI^{ecdc}). From season 2011-12 onwards, all countries participating in Influenzanet use the same questionnaires and apply this case definition when reporting feedback to participants on whether their reported symptoms might be due to ILI:

- Sudden onset of symptoms;
- AND at least 1 of the following systemic symptoms: Fever or feverishness (chills), Malaise, Headache, Muscle pain;
- AND at least 1 of these respiratory symptoms: Cough, Sore throat, Shortness of breath.

During the first seasons of Influenzanet, the questionnaire did not include some of the symptoms above; additionally, participants could only report fever if they measured their temperature. Therefore, the ILI^{ecdc} definition could not be applied. To overcome this and to allow comparing data across seasons, the following case definition was developed (ILI^{hist}, for historic reasons):

- Sudden onset of symptoms;
- AND Fever (≥38°C temperature);
- AND at least 1 of these systemic symptoms: Headache, Muscle pain;
- AND at least 1 of these respiratory symptoms: Cough, Sore throat

ILI^{ecdc} has a higher sensitivity, because more participants with influenza will fit the definition. Conversely, ILI^{hist} has a higher specificity, since fewer participants who do not have influenza will fit the definition.

The ILI^{hist} case definition was first used in the Netherlands and Belgium in 2003 to closely match the Dutch general practitioners' ILI case definition (sudden onset of symptoms with a prodromal phase of an already existing nonsickening respiratory infection of at the most 3 to 4 days; and fever (≥38°C temperature); and at least one of the following symptoms: cough, runny nose, sore throat, frontal headache, retrosternal pain, or muscle pain).

In addition to these, multiple case definitions can be used within the Influenzanet system to analyze the symptoms data provided by the participants.

The percentage of participants with ILI who sought medical care was shown to be lower in northern Europe (except Belgium) than in southern Europe [22]. For instance, in the 2013-14 season, Danish Influenzanet data have demonstrated that the fraction of Danish participants with ILI who visited a GP ranged between 16% (31/192), 22% (92/413), and 34% (33/97), when considering the ILI case definition used by Danish GPs, ECDC,

or the alternative ILI^{hist} definition, respectively ([33], complemented by Influenzanet unpublished data). In Belgium, a higher fraction of volunteers with ILI reported visiting a health care professional (71%, 112/158 ILI^{hist}), possibly because according to the Belgian law, an employer can require from its employee a medicaI statement within 24 hours to justify work absenteeism ([22], complemented by Influenzanet unpublished data).

Among the Influenzanet volunteers who did seek medical care, in southern Europe (France, Italy, Portugal, and Spain) and Belgium, the participants reported to generally visit a GP within 1 to 2 days after the onset of ILI symptoms, whereas in northern Europe (Sweden, the United Kingdom, the Netherlands, Denmark) with the exception of Belgium, participants generally sought medical care only 5 to 7 days after the onset of symptoms [22]. In countries where participants wait longer before seeking medical care, many ILI cases may no longer feel sufficiently ill to warrant a visit to a health care professional and therefore are not accounted as ILI cases by the traditional sentinel surveillance system [22,30].

This variation across countries in the rates of seeking medical care is one of the reasons why ILI incidence reported by ECDC cannot be compared directly between countries. Another reason is the disparities in ILI case definitions used by GPs in different countries. For example, many national surveillance systems do not apply the ILI definition recommended by ECDC, where fever is not mandatory but instead apply an ILI case definition that does require fever, especially to distinguish between an influenza infection and a common cold [22].

Estimates of disease burden can be informative for public health policy decisions regarding the prioritization of interventions and preventive measures. As the traditional health care-based surveillance tends to underestimate the true burden of disease in the population, Influenzanet can be used as a supplemental data source to obtain a more comprehensive estimate of the true disease burden [35]. It could also target the economic burden, including direct costs through health care as well as the indirect socioeconomic costs (school and work absenteeism); it could additionally contribute to estimate the cost-effectiveness of vaccination.

Identification of Risk Factors

The primary risk factor for acquiring an ILI infection is having direct or indirect contact with an infectious person. Analyses of individual-level data provided by the Influenzanet volunteers in the Netherlands, Belgium, Portugal, and Italy allowed identifying the following factors as additional independent predictors of increased risk of having at least one ILI episode during an influenza season [22]: having a chronic disease (asthma, diabetes, heart disease, and/or an immunocompromising condition), living with at least 1 child, belonging to a younger age group (<18 years of age), having one or more allergies (hay fever, dust mite allergy and allergy to cats and/or dogs), and being a smoker.

Seniors are generally considered a risk group for influenza, not because of a higher probability of infection but because of their greater risk for complications and increase in expected mortality [36,37]. In the Influenzanet study [22], the risk of ILI among participants over the age of 65 years was smaller than in the other age groups. This was not because of the higher uptake of influenza vaccine in seniors, as the risk factor analysis accounted for that factor by including vaccination status as a separate covariate in the multivariate model. The reduced risk among seniors may possibly be attributed to immunity from past exposures (ie, either from prior influenza infections and/or vaccinations). Immune responses of older adults are often markedly stronger than those of younger individuals for some influenza strains (eg, for A/H1N1 that circulated between 1918 and 1957 and that was reintroduced in 1976 and with a pandemic subtype in 2009) but are more similar for others (eg, A/H3N2 that has circulated since 1968; [38]). Alternatively, or additionally, the reduced risk among seniors may possibly also be because of a smaller contact rate with infectious individuals.

A small risk reduction was also observed in Influenzanet participants who practiced more than 1 hour of sports per week. Finally, public transportation did not appear to increase the risk of developing ILI relative to driving a car, riding a bicycle, or walking as a primary mode of transportation [22]. The results of these risk factor analyses have been shown to be consistent across all Influenzanet countries [39].

The identification of ILI risk factors is one of two main ways that ILI surveillance data have been used to gain a better understanding of ILI control and prevention; the evaluation of intervention effectiveness is another, as discussed in the next section.

Influenza Vaccine Effectiveness

Vaccination to prevent influenza is particularly important for people who are at a higher risk of developing serious complications if they get sick with influenza. According to WHO, the recommended risk groups for vaccination are as follows: all people ≥6 months of age with a chronic disease, children aged 6 to 59 months, pregnant women, residents of long-term care facilities, health care workers, and elderly (often defined as aged ≥65 years, but defined as aged ≥60 years in the Netherlands; [37]). The ability of an influenza vaccine to protect someone depends not only on the age and health status of the person getting the vaccine but also on the similarity or “match” between the virus strains in the vaccine and those in circulation. Effectiveness against ILI is therefore expected to be lower for influenza, as the influenza vaccine targets specifically the influenza virus and not other ILI. According to a large meta-analysis of 90 reports containing 116 datasets of randomized or quasi-randomized studies of VE in healthy adults, the overall effectiveness of inactivated parenteral influenza vaccines was estimated to be 16% (95% CI 5-25) against ILI and 60% (95% CI 53-66) against confirmed influenza [40].

Ideally, large-scale randomized controlled trials should be undertaken to assess vaccine efficiency, but it is impractical to conduct them every year. Also, because of global recommendations for influenza vaccination, placebo-controlled trials that could clarify the effects of influenza vaccines in individuals are no longer considered possible on ethical grounds [41]. For these reasons, most data on influenza VE come from observational studies.

The I-MOVE (Influenza-Monitoring Vaccine Effectiveness) network [42] aims at measuring influenza VE in Europe and has been operating since 2007, coordinated by ECDC. Eight study sites (Germany, Hungary, Ireland, Italy, Poland, Portugal, Romania, and Spain) participated in the test-negative 2014-15 multicenter case–control study [43]. The methods are based on the ECDC generic case–control study protocol [44]. Participating GPs interviewed (collecting clinical and epidemiological information) and collected nasopharyngeal specimens from patients consulting for ILI aged ≥60 years (Germany, Poland, and 3 regions in Spain), or ≥65 years (Hungary, Ireland, Italy, Portugal, Romania, and 3 regions in Spain), and from a systematic sample of ILI patients in the other age groups. Only patients who presented to the GPs more than 14 days after the start of the national vaccination campaigns and who met the ECDC ILI case definition, and who had not received antivirals before swabbing, were swabbed within 7 days of symptom onset. For the 2014-15 season, the overall VE against influenza A(H3N2) was 14.4% (95% CI −6.3 to 31.0), against A(H1N1)pdm09 was 54.2% (95% CI 31.2-69.6), and against B was 48.0% (95% CI 28.9-61.9).

Because Influenzanet also collects data on whether participants have been vaccinated for influenza, it allows measurement of ILI incidence in the self-reporting cohorts of vaccinated and unvaccinated participants, and therefore, the system could potentially be used as a complementary tool to measure the effectiveness of the influenza vaccine against ILI close to real time [45].

Several of the Influenzanet national project teams have carried out studies to assess VE among participants during specific years. For example, UK Influenzanet data were used to estimate the effectiveness of the influenza vaccine in the postpandemic influenza season of 2010-11 [46]. In that study, vaccination for seasonal influenza in combination with the vaccination against the pandemic influenza the previous year was associated with reduced ILI incidence, with an estimated VE of 52% (95% CI 27-68). It was also associated with reduced absenteeism, especially for those between 25 and 64 years of age, with 4.1% of the vaccinated participants reporting taking time off work because of symptoms, compared with 11.6% of the unvaccinated persons (P<.001). Furthermore, vaccinated absentees were away from work for a significantly shorter period of time compared with the unvaccinated persons.

In France, the effectiveness of the 2012-13 influenza vaccine against ILI (defined by cough and fever ≥38^{o}C in that study) was estimated as 49% (95% CI 20-67; P<.001) for the overall population and 32% (95% CI 0-58; P=.10) for the population at risk of developing influenza-related complications, based on data from Influenzanet participants in that season [47].

In the Netherlands, between 2003-04 and 2012-13, a reduction in ILI among vaccinated Influenzanet participants was estimated in 4 seasons (2007-08, 2008-09, 2010-11, and 2012-13), whereas in the other 6 seasons no statistically significant effect was observed [22]. The VE for all participants varied between 33% (95% CI 22-42) in 2010-11 and −10% (95% CI −28 to 6) in 2004-05. In addition to 2004-05, a negative although likewise nonstatistically significant VE was also estimated for 2003-04, both being seasons with a poor vaccine match with the circulating influenza virus strains [48].

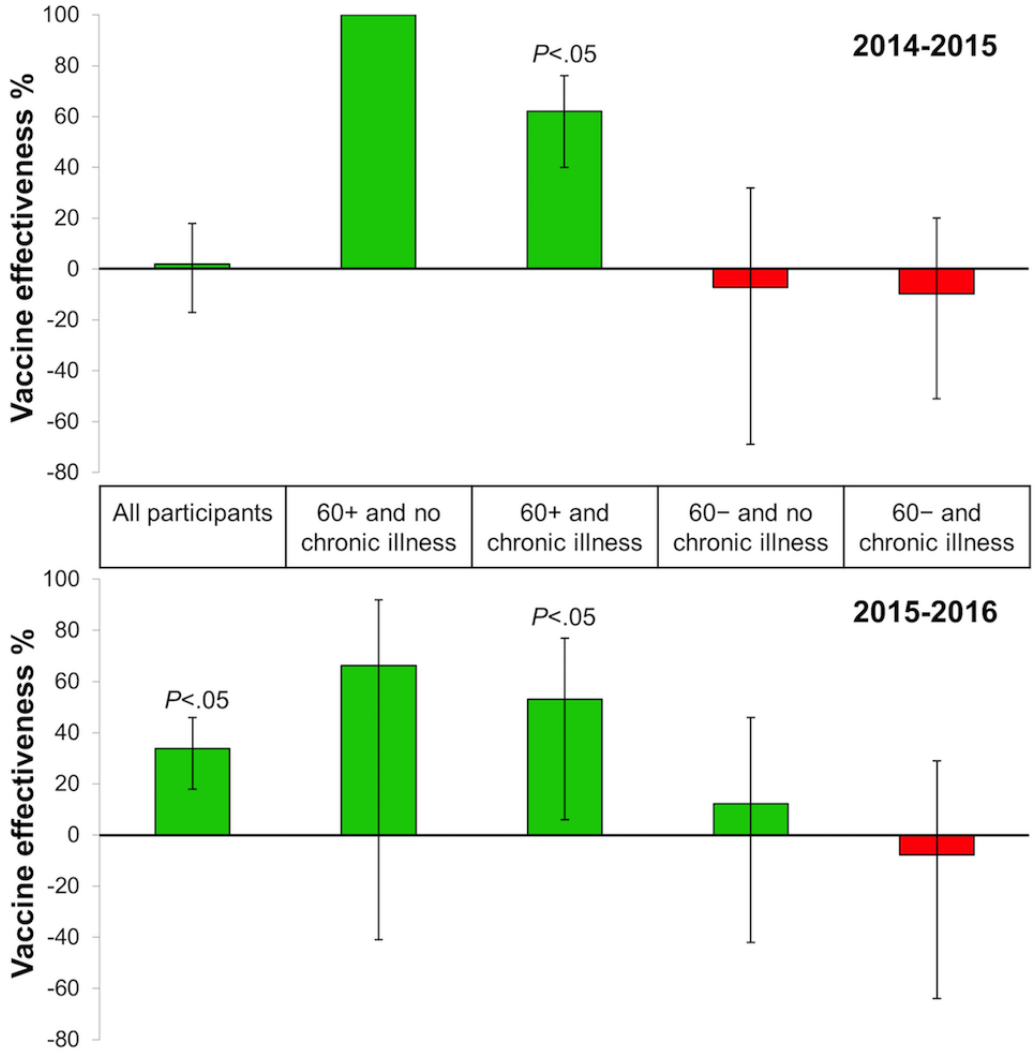
Additional VE Analyses

There are a few important considerations when using Influenzanet data as a complementary tool to estimate the effectiveness of the influenza vaccine. The influenza vaccine only protects against the influenza virus, but ILI may be caused by other infections. Additionally, vaccinated and unvaccinated participants cannot be compared directly, as participants who decide to take the vaccination may do so because they belong to a risk group, for instance, those with a chronic disease or those of older age; thus, differences in ILI rate between vaccinated and unvaccinated participants can be because of either the vaccine or an a priori difference between both groups [32]. Finally, influenza infections may develop asymptomatically.

At the request of the National Institute for Health and the Environment in the Netherlands, we estimated VE in the Dutch Influenzanet participants for the 2014-15 [49] and 2015-16 [50] seasons, stratified by age and underlying chronic disease, as the number of samples collected by the GPs sentinel networks was too low to allow for these stratified analyses. With 14,000 participants overall yearly, the Dutch Influenzanet database covers 0.08% of the 17 million population in the Netherlands. This large size warrants estimates of VE stratified for particular risk groups, namely, the presence of chronic conditions and older age. Here, we present these estimates, addressing the top two abovementioned considerations. Notably, we considered only the ILI cases in the weeks when there was virological confirmation of influenza by the Dutch Sentinel Practice Network, and of these cases, we used only the number of ILI cases above a seasonal baseline incidence for nonepidemic ILI. By excluding the weeks when there was no virological confirmation of influenza, we excluded the period when most ILI cases were likely because of noninfluenza infections; and by considering only the number of ILI cases above the typical number of ILI cases measured in the absence of circulating viruses, one can therefore obtain a more accurate proxy of VE against influenza. The VE calculated in this way is here designated as VE(influenza), also shown in Figure 3 (see Multimedia Appendix 2 for further details).

If considering the full period of 25 weeks during which Influenzanet collected data (mid-November to the end of April), then the estimated VE against ILI (ie, VE(ILI) in Multimedia Appendix 2) is considerably low. However, VE increases substantially when considering only ILI onsets during the weeks of virological confirmed influenza (17 weeks in 2014-15, 11 weeks in 2015-16) and subtracting the seasonal baseline (ie, VE(influenza) in Table A1 and Figure 3). Namely, the estimated VE in chronic patients almost doubled when considering only the influenza epidemic period with the baseline subtracted, that is, VE(Influenza)~41% in both seasons, compared with when considering the whole data collection period, that is, VE(ILI)~25% in both seasons; even greater VE increases were found for the participants with a chronic condition over 60 years of age (VE=62% [95% CI 40-76] in 2014-15 and 53% [95% CI 6-77] in 2015-16).

Figure 3. Influenza vaccine effectiveness (VE) in the Netherlands estimated with Influenzanet data during the period of virological confirmed influenza in the 2014-2015 and 2015-2016 seasons. VE(influenza) for all participants and stratified for age and chronic illness, based on self-reported influenza-like illness. The error bars denote the VE 95% CI. (In the "60+ and no chronic illness" stratification it was not possible to calculate the CI in 2014-2015 due to zero ILI cases in the vaccinated group).



The 2014-15 season had a circulating influenza A(H3N2) virus that mismatched with the strain in the vaccine [49]. The 2015-16 season had 2 circulating strains, A(H1N1) and A(H3N2), which appeared to be covered by the vaccine, although there was some mismatch between cocirculating influenza B Victoria compared with B Yamagata in the vaccine [50]. Hence, one would expect not very high VE against influenza in both seasons but higher in 2015-16, given that this season had a better match between the circulating and the vaccine strains. Our results do indeed reflect this pattern, with the estimated VE(influenza) for all participants being greater in 2015-16 (34%; 95% CI 18-46) than in 2014-15 (2%; 95% CI −17 to 18). Interestingly, however, the VE(influenza) in chronic patients was the same in both seasons (41% [95% CI 16-59] in 2015-16 and 41% [95% CI 24-65] in 2014-15). Although in both seasons among chronic patients, the VE(influenza) in participants ≥60 years seemed to be higher than in younger ones (which would seem to go against the current hypothesis that immunosenescense in the elderly results in lower VE [51]), we cannot make direct comparisons with participants aged under 60 years because of the nonstatistically significant estimated VE *P* values. A larger number of participants would be required to make stronger conclusions.

Care should be taken that results of this and the other abovementioned VE studies [22,40,45-47] should not be compared directly, as ILI definitions varied and different methods were used in computing VE.

Discussion

Further Studies

The Influenzanet system gathers a variety of valuable data on ILI activity. The analyses of Influenzanet data summarized in this paper reflect only a portion of what is possible. Influenzanet has the potential to monitor the geographical spread of ILI using the postal codes of the participants. Additionally, demographic data could be used to monitor ILI activity in different more or less vulnerable subgroups of the population. Moreover, extra questions can be included in the Web-based intake questionnaire

at any time and entire new questionnaires added in any particular season. For instance, a stress-related questionnaire was added in the Netherlands in the 2004-05 season, revealing significant trends between stress/personality and self-reported ILI [52]. Multivariable logistic regression analysis on ILI was performed to test the predictive power of stress and personality. Negative affectivity (Odds ratio [OR] 1.05, *P*=.009), social inhibition (OR 0.97, *P*=.01), and perceived stress (OR 1.03, *P*=.048) predicted ILI reporting. Older age was associated with less ILI reporting (OR 0.98, *P*=.01).

Also in the Netherlands, additional information was collected during the 2009-10 season, on the occurrence of adverse events after administration of the seasonal and pandemic influenza vaccines using either a traditional paper-based survey (for which participants were recruited via GPs) or a Web-based survey (for which participants were recruited via the Dutch Influenzanet; [53]). No significant differences were found in reporting local reactions (OR 0.98, 95% CI 0.88-1.10) or systemic adverse events (OR 1.12, 95% CI 0.99-1.27). There were, however, important differences in the age groups that responded. Namely, the elderly were more represented in the paper-based than in the Web-based survey. Additionally, in both surveys, females reported more local reactions and systemic adverse events than males, the risk of side effects decreased with age, and the presence of a comorbidity increased the risk of local reactions and systemic adverse events.

In other studies of the Influenzanet data in the United Kingdom [54] and the Netherlands [55,56], the analyses of questionnaires related to contact behavior have shown that the changes in contact patterns can explain alterations in disease incidence [54] and that Web-based respondent-driven detection could enhance identification of symptomatic patients by making use of individuals' local social networks [55,56]. Respondent-driven detection could enable a greater diversity in the age and social status of the participatory surveillance participants, thereby improving the representativeness of the study population and possibly also allow more accurate estimates of the effect of influenza vaccination. One would, however, also need to take into consideration that the proportion of ILI in the study sample could increase because of the participation of a select group of participatory surveillance volunteers with ILI symptoms, as has been observed in the study that tested this approach [56].

Finally, data validation is key to greater acceptance and credibility in the field of public health. In winter, the sentinel GPs that integrate the EISN are asked to take nose and/or throat swabs from a subset of patients with ILI for virological determination. These data inform the national and international decisions by health policy makers. The GP samples, however, do not cover the large part of the population that does not seek medical health care for ILI. A system of self-sampling (ie, swabbing nostrils and/or throat and then sending the swabs for virological testing) among Influenzanet participants could help to overcome this limitation.

This approach has been piloted outside the Influenzanet context by the national public health agencies in both the United Kingdom [57] and Sweden [58]. In the United Kingdom study, a group of 294 callers to the national telephone health helpline (National Health Service Direct) who mentioned colds or influenza were sent a self-sampling kit. They were asked to swab both nostrils and then send the swabs for influenza virus testing. About half the callers sent back the samples, and most did not experience problems in taking the test. The average time between the call and the results of the laboratory was 7 days. The overall influenza-positive rate (16%, 23/142) was lower than in the national virological surveillance system of the United Kingdom (26%), but peak positivity for both the schemes occurred during the same week. This study showed that people can self-sample in a reasonable time frame and that these samples were viable for antigenic characterization and molecular detection, which decreases the need for medical personnel to obtain samples. Self-sampling by the callers provided among the earliest reports of influenza circulating in the community and led to the detection of several strains of the virus [57]. These encouraging results have led to a self-sampling study with Influenzanet participants being planned in the United Kingdom to strengthen the validation of the participatory surveillance data.

We also plan to integrate the Influenzanet data with social networks, news streams, health forums, clinical records, and routine data to have a better understanding of the socioeconomic aspects of ILI epidemics in Europe and some behavioral insights on, for example, attitude toward influenza vaccination.

Early Warning

Detecting an earlier rise of ILI activity in certain subgroups could make Influenzanet a fast early-warning system. Indeed, it is often suggested that self-reporting surveillance systems might be able to detect changes in disease activity earlier than the traditional surveillance systems [32,33,59,60]. This is because of the self-reported data becoming instantaneously available for automated analyses, whereas in the traditional systems there is a delay from when data are collected in the medical facilities until they are available for centralized analyses. However, run-time detection of disease activity above baseline should not be confused with detection of a newly emerging disease. For a participatory surveillance system such as Influenzanet to become a viable system for early warning of the first cases of a new disease, a greater proportion of the population needs to be engaged [32]; so far the platform has been able to recruit at the most 0.08% of a country's population. For Influenzanet to become a European-level early warning system for serious cross-border health threats, all European countries would need to participate. Additional research is also needed to identify the best way to differentiate a signal caused by an influenza epidemic with one caused by a "new disease" of a respiratory nature, or producing respiratory symptoms, and how to set that threshold.

Continuity and Sustainability

Recruitment and Participation

The added value that the Influenzanet system brings to ILI surveillance depends on recruiting and retaining as many active participants as possible, covering a wide geographical area and from diverse age and risk groups.

Although specific Influenzanet recruitment strategies vary between countries, they tend to be based on mass communication [61,62]. Participants are recruited through press releases, direct mailings to schools, and interviews on national and local television and radio, in national and regional newspapers, and on social media. Schools are also provided with educational material on influenza to promote incorporation of disease surveillance concepts in science classes. At the beginning of each season, all participants from previous seasons are sent an email, inviting them to participate again by completing an intake questionnaire for the new season.

An important cornerstone for enhancing active participation is the information feedback offered to participants. The participants receive weekly emails containing a newsletter with country-specific data and influenza-related news articles written by professional science journalists, which helps keeping them involved and motivated.

From a science communication point of view, an interesting finding from the Dutch project is that Influenzanet has been able to attract and keep engaged many people without previous experience in scientific research, citizen science projects, or science activities in their daily lives. This contradicts previous findings that participants may be restricted to a self-selected group with previous experience and interest in science [63]. One way the Dutch Influenzanet reaches out to both current and potential participants is by having a well-known science communicator serve as the ambassador of the project. Other Influenzanet countries have also experienced the importance of having science communication experts working alongside scientists in the project to reach the general public. It is important to emphasize how participants have contributed to the findings and the success of the project and that their continued contributions are valued [4].

Sustainability

Influenzanet is low-cost to run in comparison with traditional systems. However, it is not free of costs and needs active support to continue, especially where self-swabbing, in addition to self-reporting, is concerned. Funding for Influenzanet is also vital for the project's maintenance, in particular to keep participants actively engaged via the weekly newsletter and social media interaction, to further improve the national platforms and to keep recruiting new participants by providing the media with the latest news and results. Also, acceptance must be sought among influenza health care professionals so that the results can be displayed and used along with other surveillance and response systems.

From 2009 to 2013, the European Union's FP7 project, EPIWORK, made it possible to extend the Influenzanet system, which at the time included only the Netherlands, Belgium, Portugal, and Italy, into 6 additional European countries. Influenza monitoring with self-reporting volunteers is now active in 10 European countries [39]. With the exception of the Netherlands and Belgium, where Influenzanet is run by a small private company, in all other countries it is coordinated by teams in national research and/or public health institutions.

Conclusions

Influenzanet can complement traditional health care–based systems by providing data that are not otherwise available. Influezanet is able to achieve this because it allows collecting data also from people who do not seek health care (and are therefore not accounted in traditional ILI surveillance), and it additionally gathers detailed information about the participants that is not routinely collected elsewhere. Due to its uniform nature across countries, it both allows for direct comparisons of ILI activity between countries and provides a platform to monitor the geographical spread of ILI throughout Europe. Moreover, Influenzanet provides an important channel for influenza awareness and health literacy in Europe. With its speed and flexibility, the system could be extended to detect diseases other than influenza, including those that emerge in low-income settings such as dengue, leptospirosis, severe acute respiratory syndrome, Ebola, Middle East respiratory syndrome, and Zika virus, and where community engagement is vital [35,64-66]. If so, this novel Internet monitoring system based on voluntary participants could develop into an important weapon to fight influenza as well as other contagious diseases globally. Influenzanet in Europe is an example of best practice here, not only by engaging citizens to report information that enables to complement the data obtained by traditional disease surveillance systems but also by providing a flexible and wide reach health literacy channel, delivering back reliable and updated information to the population about disease activity, transmission, and prevention strategies. During the second International Workshop on Participatory Surveillance (Amsterdam, the Netherlands, April 15-17, 2013) a letter of intent on cooperation and data exchange has been agreed between Influenzanet, Flu Tracking, and Flu Near You. The aim is to achieve a worldwide "disease radar," whereby everyone is invited to fill in their own health status.

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Authors' Contributions

Except for CEK and AOF, the authors are listed in alphabetical order of team leaders, followed by any additional team member involved in the work. All the authors were involved in the management, design, and editing of the Influenzanet national websites. CEK conceived the Dutch Great Influenza Survey, from which the other countries' systems were developed; performed the vaccination study presented here for the Netherlands 2014-15 and 2015-16 seasons; and, together with AOF, prepared the manuscript. All team leaders helped edit the manuscript, and all authors approved the final version.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Influenzanet intake and weekly symptoms' questionnaires used since 2012-13 (UK version 121101).

[PDF File (Adobe PDF File), 590KB - publichealth_v3i3e66_app1.pdf]

Multimedia Appendix 2

Influenza vaccine effectiveness analyses for the Netherlands 2014-15 and 2015-16.

[PDF File (Adobe PDF File), 682KB - publichealth_v3i3e66_app2.pdf]

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Abbreviations

ECDC: European Centre for Disease Control and Prevention
EISN: European Influenza Surveillance Network
GP: general practitioner
ILI: influenza-like illness
I-MOVE: Influenza-Monitoring Vaccine Effectiveness
LINH: Landelijk Informatie Netwerk Huisartsenzorg
OR: odds ratio
SD: standard deviation
TESSy: The European Surveillance System
VE: vaccine effectiveness
WHO: World Health Organization

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Original Paper

Online Reviews as Health Data: Examining the Association Between Availability of Health Care Services and Patient Star Ratings Exemplified by the Yelp Academic Dataset

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Abstract

Background: There have been public health interventions that aim to reduce barriers to health care access by extending opening hours of health care facilities. However, the impact of opening hours from the patient's perspective is not well understood.

Objective: This study aims to investigate the relationship between temporal accessibility of health care services and how patients rate the providers on Yelp, an online review website that is popular in the United States. Using crowdsourced open Internet data, such as Yelp, can help circumvent the traditional survey method.

Methods: From Yelp's limited academic dataset, this study examined the pattern of visits to health care providers and performed a secondary analysis to examine the association between patient rating (measured by Yelp's rating) and temporal accessibility of health care services (measured by opening hours) using ordinal logistic regression models. Other covariates included were whether an appointment was required, the type of health care service, the region of the health care service provider, the number of reviews the health care service provider received in the past, the number of nearby competitors, the mean rating of competitors, and the standard deviation of competitors' ratings.

Results: From the 2085 health care service providers identified, opening hours during certain periods, the type of health care service, and the variability of competitors' ratings showed an association with patient rating. Most of the visits to health care service providers took place between normal working hours (9 AM-5 PM) from Sunday to Thursday, and the least on Saturday. A model fitted to the entire sample showed that increasing hours during normal working hours on Monday (OR 0.926, 95% CI 0.880-0.973, P=0.03), Saturday (OR 0.897, 95% CI 0.860-0.935, P<0.001), Sunday (OR 0.904, 95% CI 0.841-0.970, P=0.005), and outside normal working hours on Friday (OR 0.872, 95% CI 0.760-0.998, P=0.048) was associated with receiving lower ratings. But increasing hours during outside normal working hours on Sunday was associated with receiving higher ratings (OR 1.400, 95% CI 1.036-1.924, P=0.03). There were also observed differences in patient ratings among the health care services types, but not geographically or by appointment requirement.

Conclusions: This study shows that public health interventions, especially those involving opening hours, could use crowdsourced open Internet data to enhance the evidence base for decision making and evaluation in the future. This study illustrates one example of how Yelp data could be used to understand patient experiences with health care services, making a case for future research for exploring online reviews as a health dataset.

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KEYWORDS

Yelp; health care access; health care availability; patient satisfaction; patient rating; patient experience; open hour; clinic hour; online reviews

Introduction

There have been attempts to reduce the physical barrier to health care access by offering extended opening hours, such as the incentive schemes introduced by the UK National Health Service (NHS) to extend hours of general practices [1-3]. Similar strategies are also found in countries like the Netherlands and New Zealand, but they are not as common in the United States [4-6]. Previous studies have found that increasing opening hours may lead to an increase in patient satisfaction or rating in surveys, and the distribution of opening hours may be more important than total opening hours per week [1,7]. A previous study examining extended hours of general practice in the United Kingdom suggested that there might be a possible association between the inability to take time away from work and lower patient experience [2]. Other emerging evidence suggested that increasing opening hours may have other potential benefits, such as reducing the demand of emergency department visits [3,8-10], avoiding delays in patients seeking care [11], and encouraging people to seek preventive health checks [12], all of which could potentially contribute to an increase in patient satisfaction or survey rating.

One of the challenges in conducting similar research about the temporal barriers to health care access is that questionnaires or interviews are the traditional methods of collecting data [1-3,7-9,12,13]. With the rise of online review websites, similar research questions may be answered using open Internet data such as those from Yelp, an online review website that is popular in the United States. This approach, if effective, may offer a novel strategy to assess patient-centered quality of care, while helping to reduce the burden and cost of surveying.

There are concerns that reviews on commercial websites, such as Yelp, are biased and may not reflect the quality of care delivered because the reviewers lack medical expertise [14,15]. However, it has been observed that consumer reviews on commercial websites may offer meaningful evaluations of quality of hospital care [14,16,17]. A previous study has found that hospitals' Yelp ratings show a high correlation with the Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS) survey, the industry standard for assessing hospital patients' experiences in the United States [14]. Similar to the HCAPHS, higher Yelp scores have shown correlations with lower mortality rates for myocardial infarction, pneumonia, and lower readmission rates for multiple other conditions [14]. In another study, Yelp data were shown to provide additional information to complement the HCAHPS survey because some topics with a strong correlation with Yelp ratings are not measured or reported by HCAHPS [17]. Another study examining Yelp reviews for emergency departments found that they contain similar themes to surveys of inpatient and specific to emergency care settings, thus may offer a new strategy to measure quality from patients' points of view [18]. Other examples of using online reviews as data about the patient experience include WebMD in studying the quality of physicians from the patient's perspective [19], Yelp and RateMDs in studying long-term relationships between patients and physicians [20], and HealthGrades, Vitals, and RateMDs in studying factors associated with high ratings of hand surgeons [21].

In this study, we aim to explore whether opening hours are associated with patient ratings of health care service providers. This study chose Yelp over other online review websites because Yelp offers a free limited dataset for research purposes and Yelp is known to have deployed an industrial-scale fake review filter since 2005 [22,23]. Examinations of Yelp's filter by previous studies suggest that Yelp's filter is not perfect, but is reasonably effective at detecting fake or fraudulent reviews [23,24].

Methods

Research ethics approval was not required for this study because the data were from the public domain and offered for free from Yelp.

Yelp Academic Dataset

Yelp users can submit reviews for businesses listed on Yelp by providing a numerical rating ranging from 1 to 5 stars, similar to a Likert scale in a survey, and a free-text comment. The primary outcome of interest for this study was the overall rating of health care service providers, reported by Yelp as the mean of all nonfiltered individual ratings. This study assumed that reviews submitted for health care service providers were made by patients who had visited the provider at least once and that fake reviews were removed by Yelp's filter.

Yelp also allows users to voluntarily check-in at a business using mobile devices in exchange for occasional discounts or some other loyalty rewards. In essence, check-in data provide a record of patient visits to health care service providers, which also makes Yelp data uniquely different than traditional survey data. Yelp provided the check-in data as a summary of the total number of check-ins at each business for each 1-hour window throughout the day. Because these data are the total count of check-ins during an undefined period of time, they are not suitable to be used to determine the busy or slow periods for a defined period of time, such as mean weekly or daily. However, the total number of check-ins can still give a rough overview of the busy and slow periods for health care service providers in the sample.

The limited dataset for this study was provided by Yelp for research purposes and a student competition organized by the company [22]. This study obtained version 8 of the dataset in September 2016 [22]. Yelp's raw data was processed and analyzed using the jsonlite package in R Studio version 1.0.136 [25]. This study analyzed health care service businesses from the dataset that contained 2,685,066 reviews submitted for 85,901 businesses, and 98 attributes for each listed business (eg, address, location, hours, amenities, parking availability) [22]. This limited dataset provided businesses from selected cities in the United Kingdom, Canada, Germany, and the United States. However, this study only considered those from the United States to reduce the effect of the differences in health care systems.

Sampling for Health Care Service Providers From the Yelp Limited Dataset

Yelp labels each business in a category (eg, restaurant, coffee and tea, family practice). A previous study identified 26

categories on Yelp that are health care services [26]. However, many of the labels overlap with one another (eg, "eyewear and opticians," "optometrists," and "laser eye surgery/Lasik"), and most businesses are labeled with more than one. Therefore, based on initial observations of the dataset, this study created a search strategy to identify, verify, and group similar health care service providers by category labels.

The types of health care services that this study examined are listed in Table 1 and accompanied by keyword terms used to identify them in Yelp's dataset (the results of the keyword searches are listed in Multimedia Appendix 1). This study focused on the types of health care services that were short term (ie, excluding those that required long-term physical residence such as rehabilitation facilities or nursing homes where accessibility and patient rating may interact differently), for human (ie, excluding those that care for animals such as veterinarians), for services that often require the provider to have minimum education or training equivalent to a Bachelor's degree (ie, excluding health care services such as massage therapy), and the core business is to provide health care services (ie, excluding drugstores that often also function as convenience stores) (Table 1).

The health service providers were from six metropolitan areas: Pittsburgh, PA; Charlotte, NC; Urbana-Champaign, IL; Phoenix, AZ; Las Vegas, NV; and Madison, WI. It is worth noting that Yelp groups multiple cities or towns into a metropolitan area. Therefore, the health care service providers in our sample were not exclusively located within the six cities listed, but also from the surrounding cities and towns of those cities to comprise greater metropolitan areas. This study adopted Yelp's metropolitan area grouping.

Analysis

First, this study explored the pattern of patient visits to health care services by plotting Yelp's check-in volume for each 1-hour window throughout the days of the week. Then, we examined if there were possible associations between patient rating and the variables extracted from Yelp, using ordinal logistic regression models with R package MASS [27]. This study considered significance level at P value ≤.05.

This study modeled the overall rating of the health care service provider as the dependent variable. The independent variables of primary interest were the number of opening hours during normal working hours and outside of normal working hours throughout the week. Although the rating may appear to be a continuous variable, this study assumed that it was an ordered categorical dependent variable because the numerical gap between consecutive categories may be inconsistent. For instance, the gap between 1 and 2 stars may be different than that between 3 and 4 stars. Therefore, we chose to use ordinal logistic regression as our main analytic method.

The following possible covariates found in the Yelp dataset were also modeled as independent variables: whether an appointment is required (true/false), the type of health care service (indicated by Yelp's category label in Table 1), the region of the health care service provider (metro area listed on Yelp), and the number of reviews for each provider (review count provided by Yelp).

Additionally, from the geographical coordinates listed on Yelp, we were able to derive the number of nearby competitors, the average rating of nearby competitors, and the variation in the ratings of nearby competitors, measured by standard deviation, as covariates. Competitors of each health care service provider were identified as providers of the same type as defined in Table 1 and within a 5-mile radius. The distance between a pair of providers is calculated using the geographical coordinates listed on Yelp in Figure 1 [28,29].

This study first evaluated a model of all the variables we were able to obtain from Yelp (model 1). Then we evaluated a limited model with only the continuous variables that showed a significant Pearson correlation to patient rating and categorical variables that showed a significant difference in mean rating among the groups using ANOVA, and without the mental health and speech therapy groups due to small sample size (model 2). Recognizing that different types of health care service may have different relationships between opening hours and rating, we evaluated stratified models for the types of health care service as well.

Table 1. Search keywords used to identify the health care service providers of interest by the category label in Yelp's dataset.

Health care service type	Included if contained the following keyword(s)	Excluded if contained the following keyword(s)
Chiropractic and physical therapy	Chiropractor OR physical therapy	
Dental	Dentist	
Dermatology	Dermatologist	Optometrist, veterinarians, pets
Family practice	Family practice	Psychiatrist, chiropractor, beauty, physical therapy, specialty, dermatologists, weight loss, acupuncture, cannabis clinics, naturopathic, optometrists
Hospitals and clinics	Hospital	Physical therapy, rehab, retirement homes, veterinarians, dentist
Optometry	Optometrist	Dermatologist
Mental health	Psychiatrist OR psychologist	
Speech therapy	Speech	

Figure 1. Equation for calculation the distance between a pair of providers using the geographical coordinates listed on Yelp, where (lat1, lon1) and (lat2, lon2) represent the latitude and longitude coordinates in radians of the two providers, and the radius of the Earth is 3961 miles.

$$a = sin^2\left(\frac{lat_2 - lat_1}{2}\right) + \cos(lat_1) \cdot \cos(lat_2) \cdot sin^2\left(\frac{lon_2 - lon_1}{2}\right)$$

$$distance = R \cdot 2 \cdot atan2(\sqrt{a}, \sqrt{(1-a)})$$

Opening Hours and Pattern of Visits

This study used the business hours (open and close times) listed on Yelp. The hours listed can be updated by either the owner of the business (if they are registered and verified by Yelp) or by any Yelp user who wishes to update the information.

Initially, this study examined the association between the total number of opening hours per week (Sunday to Saturday) and rating, but found that the linear regression model accounted for only 6.09% (P<.001) of the variation in the data. Additionally, the observation of the pattern of visits from the check-in data suggested that most of the visits to health care service providers took place between Sunday and Thursday and during regular working hours (9 am to 5 pm) on those days, and there was periodicity throughout the week. Therefore, the total number of opening hours per week may not be sufficiently granular, so this study considered the distribution of opening hours throughout the week to see if it was significantly correlated with patients' ratings. Specifically, the total hours of operation on each day of the week were separated into the number of opening hours during normal working hours between 9 am to 5 pm (range 0-8 hours) and outside of normal working hours (range 0-16 hours) to be used as independent variables in the ordinal logistic regression.

Results

Sample Characteristics

The keyword search identified 3098 providers. This study then excluded providers that were cross-listed in more than one type of health care service after the keyword search defined in Table 1 due to ambiguity (n=22 or 11 unique records), were from outside the United States (n=46), did not specify whether an appointment was needed (n=237), without any opening hours listed (n=642), and had total opening hours per week less than or equal to zero (n=66). This left a total of 2085 eligible health service providers for this study. Filtering the dataset identified 31,356 check-in events associated with the health care service providers in the sample.

From the 2085 health care service providers in the sample, the mean rating was 4.18 stars (SD 0.91; median 4.5, range 1-5). The mean opening hours was 42.94 hours per week (SD 11.51; median 43, range 7.5-105). In all, 93.09% (1941/2085) of the health care service providers in the sample operated outside of normal working hours on at least one day per week. The mean opening hours outside of normal working hours was 7.11 hours per week (SD 5.30; median 6, range 0-49). Further descriptive statistics for each type of health care service is presented in Table 2.

Table 2. Summary of the proportion of the sample, mean rating, and review count for each type of health care service and appointment attributes from the sample of 2085 health care service providers.

Variables	Sample size, n (%)	Rating,[a] mean (SD)	Review count, mean (SD)
Chiropractic/physical therapy	480 (23.02)	4.55 (0.69)	10.34 (10.89)
Dental	1014 (48.63)	4.31 (0.81)	11.68 (11.36)
Dermatology	88 (4.22)	3.43 (0.89)	17.54 (15.80)
Family practice	112 (5.37)	3.22 (0.92)	14.31 (15.01)
Hospitals/Clinics	20 (0.96)	3.33 (0.86)	10.75 (11.89)
Optometry	362 (17.36)	3.90 (0.98)	14.69 (14.17)
Mental health	7 (0.34)	3.00 (1.61)	6.43 (3.95)
Speech therapy	2 (0.10)	4.25 (1.06)	7.00 (4.24)
Appointment required	1580 (75.78)	4.17 (0.92)	11.68 (11.51)
Appointment not required	505 (24.22)	4.22 (0.87)	14.04 (14.48)

[a] Mean rating range: 1-5 stars.

Association Between Opening Hours and Patient Rating

The check-in data suggested that the volume of visits to health care service providers varied across the days of week (Figures 2 and 3). Contrary to other types of businesses on Yelp, most commonly restaurants, the majority of visits to health care service providers appeared to take place between Sunday and Thursday during normal working hours, and the volume decreased from Thursday to Saturday (Figure 2). Similar trends

were also observed for the top three most common health care services in the sample (Figure 3). One slight deviation was optometry, where the volume of visits was relatively constant from Sunday to Friday, but the lowest volume was still on Saturday (Figure 3).

Figure 2. Number of check-ins for each 1-hour interval in the week for all businesses, restaurants, and health care service providers from Yelp's limited dataset.

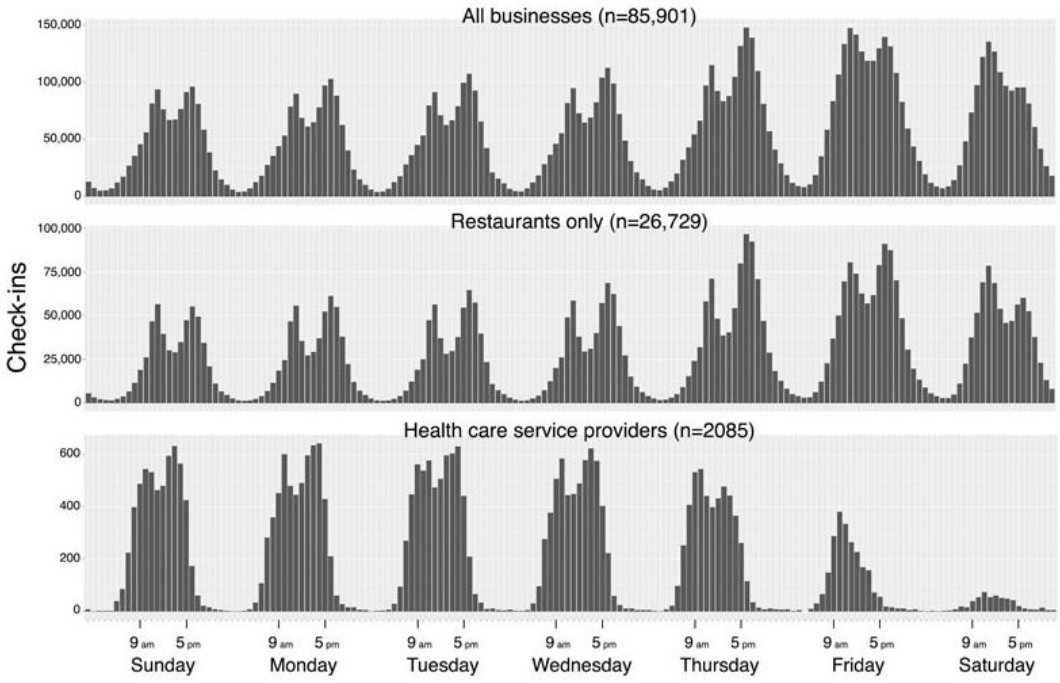

Figure 3. Number of check-ins for each 1-hour interval in the week for chiropractors/physical therapists, dentists, and optometrists from Yelp's limited dataset.

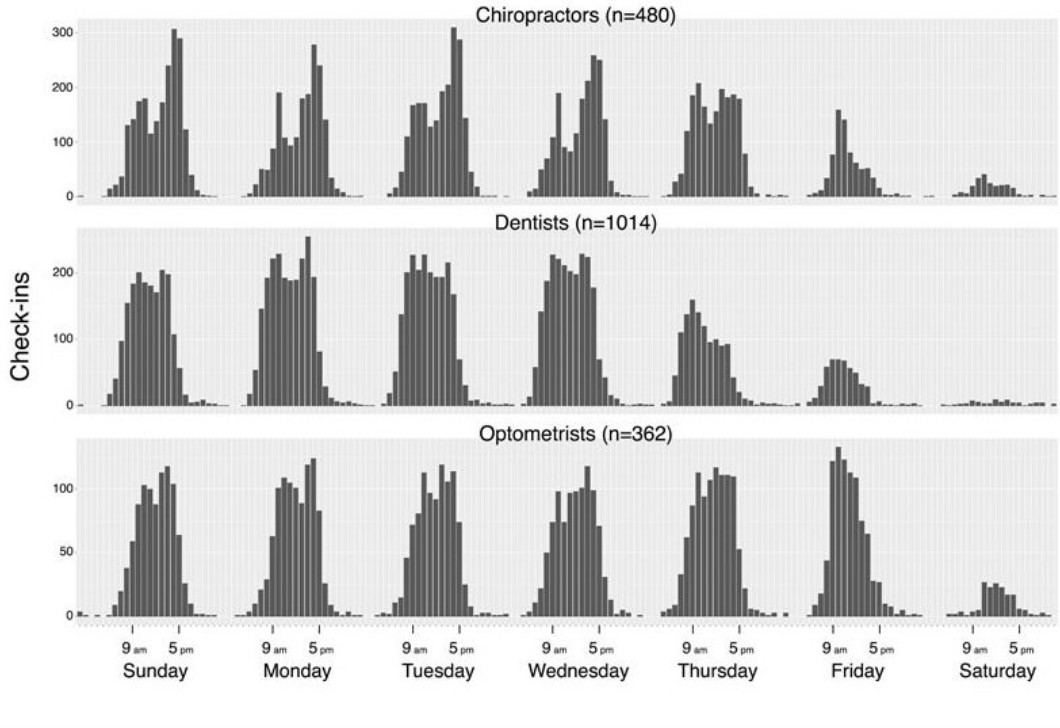

Table 3. Relative odds of achieving higher rating according to opening hours during different periods of the week and business characteristic variables available through Yelp's limited dataset. Bold indicates $P \leq .05$.

Independent variables	Model 1 (full), OR (95% CI)	Model 2 (limited),[a] OR (95% CI)	Model 3 (chiropractor/PT),[b] OR (95% CI)	Model 4 (dentists),[c] OR (95% CI)	Model 5 (optometrists),[d] OR (95% CI)
Number of opening hours during					
9am-5pm					
Monday	**0.926 (0.880-0.973)**	**0.924 (0.878-0.971)**	1.124 (0.966-1.312)	**0.895 (0.837-0.955)**	**0.825 (0.728-0.930)**
Tuesday	0.989 (0.927-1.056)	0.981 (0.919-1.046)	0.953 (0.849-1.068)	0.988 (0.898-1.085)	0.820 (0.639-1.034)
Wednesday	1.007 (0.954-1.061)	1.003 (0.951-1.057)	0.913 (0.792-1.047)	1.015 (0.945-1.089)	0.906 (0.778-1.048)
Thursday	0.997 (0.938-1.059)	0.997 (0.939-1.059)	0.985 (0.871-1.113)	0.975 (0.894-1.061)	1.068 (0.891-1.271)
Friday	0.972 (0.936-1.008)	0.974 (0.939-1.010)	0.967 (0.873-1.069)	0.996 (0.949-1.045)	**0.838 (0.713-0.977)**
Saturday	**0.897 (0.860-0.935)**	**0.907 (0.871-0.945)**	0.960 (0.868-1.063)	**0.866 (0.808-0.928)**	**0.876 (0.811-0.946)**
Sunday	**0.904 (0.841-0.970)**	**0.906 (0.844-0.972)**	0.913 (0.794-1.050)	1.069 (0.910-1.256)	0.891 (0.783-1.014)
Outside 9am-5pm					
Monday	0.999 (0.851-1.172)	0.994 (0.847-1.166)	0.872 (0.564-1.343)	1.079 (0.884-1.317)	0.722 (0.435-1.214)
Tuesday	1.047 (0.913-1.201)	1.062 (0.927-1.217)	1.249 (0.951-1.678)	0.967 (0.800-1.169)	**2.034 (1.321-3.167)**
Wednesday	0.936 (0.802-1.092)	0.938 (0.804-1.094)	1.123 (0.762-1.655)	0.938 (0.768-1.144)	1.026 (0.671-1.581)
Thursday	1.073 (0.922-1.250)	1.070 (0.919-1.246)	0.811 (0.559-1.164)	1.132 (0.931-1.378)	1.152 (0.750-1.779)
Friday	**0.872 (0.760-0.998)**	**0.868 (0.758-0.993)**	0.990 (0.747-1.311)	**0.734 (0.601-0.895)**	**0.607 (0.385-0.945)**
Saturday	0.882 (0.735-1.056)	0.876 (0.731-1.048)	0.989 (0.624-1.573)	1.001 (0.711-1.409)	0.818 (0.544-1.226)
Sunday	**1.400 (1.036-1.924)**	1.338 (0.994-1.819)	1.290 (0.748-2.288)	0.695 (0.339-1.373)	0.948 (0.339-2.702)
Other covariates					
Competitor count	1.001 (0.997-1.005)	1.003 (0.999-1.006)	1.004 (0.990-1.017)	1.002 (0.998-1.006)	1.016 (0.999-1.034)
Competitors' rating (mean)	1.052 (0.914-1.209)	1.102 (0.960-1.263)	1.113 (0.841-1.452)	1.038 (0.683-1.582)	0.808 (0.584-1.108)
Competitors' rating (SD)	**0.628 (0.458-0.862)**	**0.685 (0.501-0.935)**	**0.470 (0.220-0.998)**	0.748 (0.417-1.343)	0.622 (0.323-1.189)
Appointment required(false)	Referent				
Appointment required (true)	0.863 (0.706-1.055)				
Review count	1.005 (0.999-1.012)				
Health care service type					
Chiropractic/PT	Referent	Referent			
Dental	**0.452 (0.343-0.594)**	**0.428 (0.326-0.560)**			
Dermatology	**0.082 (0.050-0.132)**	**0.091 (0.057-0.146)**			
Family practice	**0.059 (0.037-0.094)**	**0.066 (0.042-0.104)**			
Hospitals/ clinics	**0.076 (0.032-0.182)**	**0.095 (0.040-0.226)**			
Optometry	**0.355 (0.252-0.493)**	**0.364 (0.262-0.506)**			
Mental health	**0.034 (0.007-0.189)**				
Speech therapy	0.673 (0.034-24.028)				
Metropolitan areas					
Phoenix, AZ	Referent				
Urbana-Champaign, IL	1.772 (0.451-7.655)				
Charlotte, NC	0.809 (0.563-1.168)				
Las Vegas, NV	1.041 (0.855-1.266)				
Pittsburgh, PA	1.325 (0.742-2.399)				

Independent variables	Model 1 (full), OR (95% CI)	Model 2 (limited),[a] OR (95% CI)	Model 3 (chiropractor/PT),[b] OR (95% CI)	Model 4 (dentists),[c] OR (95% CI)	Model 5 (optometrists),[d] OR (95% CI)
Madison, WI	0.621 (0.381-1.014)				

[a]Model 2 excluded appointment requirement, metro area due to no significant difference in rating among the groups were found in ANOVA; review count due to no significant Pearson correlation was found with rating; mental health and speech therapy groups due to small sample sizes.

[b]Model 3 contains only chiropractors or physical therapists (n=480).

[c]Model 4 contains only dentists (n=1014).

[d]Model 5 contains only optometrists (n=362).

Table 3 tabulates the results of the five different logistic regression models: model 1 that contained all variables available, model 2 with limited number of covariates and types of health care service types, model 3 that stratified for chiropractors/physical therapists, model 4 that stratified for dentists, and model 5 that stratified for optometrists. Because there were 17 to 20 independent variables in each model, a sample of roughly 200 or larger was required to avoid overfitting. Therefore, we only investigated the three stratified models for groups (chiropractors/physical therapists, dentists, and optometrists) that had sufficient sample size.

In our first ordinal logistic regression model (model 1), patient rating appeared to have an inverse association with opening hours during normal working hours on Monday, Saturday, Sunday, and outside normal working hours on Friday; and a positive association with opening hours outside of normal working hours on Sunday (Table 3). There was a statistically significant association between patient rating and the type of health care service (Table 3). The results suggest that ratings are more likely to be higher for chiropractic/physical therapy than other types of health care services (Tables 2 and 3).

In model 2, the review count variable was removed due to a lack of significant correlation with patient rating. In addition, appointment requirement and metropolitan area were excluded due to a lack of significant difference in rating means among the groups, and mental health and speech therapy were also removed due to small sample sizes. Despite removing these variables, models 1 and 2 had similar patterns of association between opening hours and patient rating, except for opening hours outside of normal working hours on Sunday, which was only statistically significant in model 1 (Table 3). Furthermore, both models 1 and 2 suggested that the variation in competitors' ratings measured in standard deviation was inversely associated with patient rating, whereas the number of nearby competitors and the mean rating of competitors were not (Table 3).

Separate models for the top three most common types of health care services in the sample in models 3 to 5 showed that the association between opening hours in different time periods and patient rating varied for different types of health care services (Table 3). In model 3, for chiropractic and physical therapy providers there appeared to be no association between opening hours in different time periods and patient rating, but the variation in competitors' ratings still showed an inverse association with patient rating, as in model 2 (Table 3). In model 4, dental providers also showed an inverse association between patient rating and opening hours during normal working hours on Monday, Saturday, and outside normal working hours on Friday (Table 3). In model 5, optometrists showed an inverse association between patient rating and opening hours during normal working hours on Monday, Friday, Saturday, and outside normal working hours on Friday; and positive association between patient rating and opening hours outside of business hours on Tuesday (Table 3).

Discussion

Association Between Opening Hours and Patient Rating

The check-in data and our ordinal logistic regression models consistently suggest that increasing the number of opening hours alone does not immediately lead to an impact on patient rating, and the impact may be specific to only certain time periods of the week (Figures 2 and 3,Table 3). The results from our study generally align with most previous findings. A previous study in the United Kingdom found that patient satisfaction rating in a survey was related to increasing opening hours, but was not linked to a specific time period [1]. Two other studies in the United Kingdom found that the ability to take time off from work to access health care may influence satisfaction ratings on a survey [2,30]. A survey conducted in Quebec, Canada, also found that increasing the total clinic opening hours per week may not immediately lead to an increase in patient rating, and the distribution of hours throughout the week may be more important [7]. Other factors such as the number of physicians, 24/7 telephone access, evening walk-in, and care are also important [7].

The difference in whether the association between patient rating and opening hours is linked to specific periods of the week could be due to the differences in the sample populations. It is possible that the results of our study are more aligned with the sample population in Quebec, Canada, than the United Kingdom sample because our sample population is also from North America.

It appears that there may be unmet demand for Sunday, when there is a positive association between patient rating and extended hours on Sunday (Figure 3 and Table 3, model 1). If health care providers only offer opening hours during normal working hours on Sunday, some patients may feel restricted in options in terms of the hours, which may cause ratings to be lower in that period and lead to inverse association for Sunday during normal working hours (Table 3, models 1 and 2). It is also plausible that those who seek to access health care on

Sunday but cannot find any open business may have to defer to working days, and the ability to take time off from work has been shown to be linked to patient rating [2,30].

On the other hand, models 1 and 2 suggest an inverse association between patient ratings and Saturday normal working hours and Friday outside normal working hours. No previous study has explored this topic in detail, but one plausible explanation may be that Friday night and Saturday are often perceived as time for family, leisure activities, or relaxation in most North American cultures. This was similarly observed from the check-in data that showed an increase in visits to restaurants and all businesses on Friday and Saturday (Figure 3).

Appointment

The need for an appointment did not show an association with patient rating in model 1, despite previous studies suggesting that it may be important to patient satisfaction rating, demand, and accessibility [1,7,30,31]. A possible explanation is that patients who require service immediately and are unable to make an appointment with a provider would not visit that provider. Consequently, they would not write a review for the provider whom they failed to visit; hence, the effect of the need of advanced appointment being a barrier to access may not have been captured. Given this speculation, Yelp data may be limited in its ability to explore this topic.

Type of Health Care Service

All our models suggest that the association between patient rating and opening hours varies across different types of health care services (Table 3). This was expected because there is a lot of variation in health care services. The relationship between patient rating and the type of health care service is an interesting area for future research that could help health care professionals improve their practices.

This study categorized different types of health care service into their subgroups to reduce possible confounding related to the types of health care services. The categorization was based on initial observation of the available dataset, and we tried to avoid overcategorization that could result in too few cases in each subgroup to produce any significant results (Table 1).

On the other hand, there may be challenges in categorizing health care services for future research based on Yelp-assigned labels. A nonspecific label such as “doctors” is ambiguous in identifying a specific specialist or to infer the type of health care service. Since Yelp allows any business to have multiple labels, there may be an incentive for overlabeling to ensure that a business appears more frequently in search results. As a consequence, future research should be aware of the ambiguity and uncertainty in categorizing health care services associated with using Yelp data. An additional verification step to ensure the accuracy of the category label is recommended.

Competition

The inverse association between patient rating and the variation in competitors’ ratings suggests that competition may play a role in patient rating. We chose a radius of 5 miles for nearby competitors in this study, but this may also depend on various factors such as type of service, population density, health insurance’s network of providers, etc. Therefore, the results may vary as the radius is changed.

Strengths and Limitations

The main contribution of this study is two-fold. First, surveying data was substituted by Yelp data and our results support previous findings that the distribution of opening hours may be more important to patient rating than simply total opening hours per week [1,7,30]. Second, this study provided an in-depth investigation of the distribution of opening hours and patient ratings, which to our knowledge had not been studied at this level of granularity.

However, this study had several limitations in sample size, geographical grouping, cross-sectional design, and the variables available through Yelp. Our sample population is likely to be younger people from only large metropolitan areas [22,32]. Therefore, they may have a very different pattern of health care service utilization than the general United States population. In addition, in the academic dataset, Yelp provides data only for businesses with three or more reviews older than 14 days at the time of data extraction. As a result, data quality may have been enhanced in terms of patient ratings, but this certainly is a limitation compared to the full dataset [22]. This study adopted Yelp’s regional grouping for the metro areas; we are not certain of their rationale, but suspect that it was based on proximity. Because this dataset was only a snapshot of the health care services, the results from this study can only infer cross-sectional associations, rather than causation, between patient rating and the independent variables.

This study was able to account for some possible confounding factors of patient satisfaction because the Yelp dataset is limited in the number of variables, which is often the case with many datasets and surveys. Compared to a traditional survey method, this study does not have access to the commonly collected demographic variables such as gender, age, and socioeconomic status. Therefore, Yelp data are limited in the ability to control for such covariates.

Furthermore, patient satisfaction and opinion rating remain complex, multifaceted concepts [13,33]. One commonly cited definition of a patient satisfaction rating by Ware and colleagues [34] states: satisfaction rating is “an attempt to capture a personal evaluation of care” reflecting “the personal preferences” of the patient, “the patient’s expectations,” and “the reality of care received.” Yelp’s guidelines asked users for their “firsthand consumer experience” [35]. Therefore, Yelp ratings appear to be a close proxy for patient satisfaction as defined in the literature. Our study detected some possible patient preferences for opening hours, but was limited in providing insights into patients’ expectations and reality of care.

Future Work

There are opportunities for future research and to overcome the limitations outlined. Future research should expand the sample size beyond the current available dataset. Other methods of regional grouping may yield additional insights and is worth exploring in future research. Since Yelp’s data contain rich geographical data, there is also an opportunity to link to other datasets, such as census data, that may inform future research

design. A longitudinal study could be conducted to shed more light on causality using multiple snapshots of the Yelp dataset over time. Although the variables used in this study may not be able to provide insights about differences among health services, the wealth of information in Yelp's free-text comments could be useful for future research. The free-text reviews submitted by Yelp users can be used to extract more information that could be associated with patient rating and help to explore more dimensions of patient satisfaction.

Conclusions

An association between opening hours of health care service providers and patient rating was observed from Yelp's limited dataset. In the context of our sample, the observed association appears to vary and is specific to only certain time periods of the week. Therefore, increasing opening hours alone as an attempt to influence patient rating or satisfaction, without considering patient demand or preference, may not be effective. Other factors, such as the type of health care service and ratings of nearby health care providers, may also be related to patient rating and further research is needed.

Yelp data demonstrate the use of crowdsourced open Internet data can complement and potentially replace traditional surveying methods to some extent. The knowledge generated from Yelp can complement and enhance the evidence base for decision making and evaluation of public health interventions. This study hopes to catalyze further exploration of publicly available online data for health research.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Resulting categories found from Yelp's dataset using the search terms in Table 1 and after applying the inclusion and exclusion criteria.

[PDF File (Adobe PDF File), 55KB - publichealth_v3i3e43_app1.pdf]

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Abbreviations

HCAHPS: Hospital Consumer Assessment of Healthcare Providers and Systems
NHS: National Health Service

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