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Guest Editorial

Shining a Light on America’s HIV Epidemic among Men who Have Sex with Men

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KEYWORDS

HIV surveillance; HIV diagnosis; HIV prevalence; HIV incidence; men who have sex with men; gay and bisexual men; demography

It’s accepted as axiomatic that surveillance is the “cornerstone” of public health action [1]. Truthfully, without an accurate and timely assessment of population-specific health indicators and disease outcomes, public health policy makers and practitioners are often obliged to operate blindly at the margins of bias, misconception and ignorance. Historically, an accurate accounting of cases of the acquired immune deficiency syndrome (AIDS) – and later, human immunodeficiency virus (HIV) infections– was deemed so critical to America’s public health response to AIDS that surveillance was memorably referred to as the “conscience of the epidemic” [2]. Extending that metaphor to recent work by Rosenberg and colleagues [3], published in this issue of *JMIR Public Health and Surveillance*, reveals a truly troubled conscience, indeed.

Building off of work by Grey and colleagues [4], also recently published in *JMIR Public Health and Surveillance*, who estimated the size of MSM (men-who-have-sex-with-men) populations within states, counties and US metropolitan areas, Rosenberg et al. were able to generate estimates of the prevalence of HIV diagnosis and infection and the rate of new diagnoses at national, state, MSA and county levels. Their analysis revealed that “HIV infection is hyperendemic among MSM in many areas of the United States, particularly in the South” [3]. Relying on the UNAIDS definition of hyperendemicity, this means that in many MSM communities in the United States the prevalence of HIV infection is sustained at levels of 15% or even higher [5].

Although these researchers are not the first to call out the enormous burden of HIV disease among gay and bisexual men in the United States–especially among MSM who are black [6] – nor to highlight geographic HIV disparities in southern states [7], their results superimpose a mantle of urgency over an already critical public health problem. These findings beg the question “Why are we seeing such horrific HIV disparities among MSM in the US, especially among black MSM?” Hyperbole aside, epidemiologists note “if black MSM in the United States formed a country…it would have the highest HIV prevalence on the globe” [8]. And, more to the point, what can we do to remediate the circumstances fueling these appalling outcomes?

The answer, of course, is *action*. Public health surveillance without responsive public health action is, at best, wasted effort and at worst, negligence. The action must be timely and commensurate with the scale and scope of the problem but, above all else, it must be informed. This last statement brings us to another well-accepted (if hard won) axiom gained from our decades of interaction with this virus: there is no “magic bullet” that will end the AIDS epidemic. In other words, there is no *single* action or intervention that, once undertaken, will wondrously wipe away these disparities. We have to accept the inescapable reality that successfully confronting HIV among gay and bisexual men in the United States, including attending to the special needs of MSM of color, will require us to mount a comprehensive array of interventions, including structural interventions and policy changes which address the social determinants underpinning the aforementioned health disparities. In the words of Teutsch and Fielding in their essay "Rediscovering the Core of Public Health," while the principles of public health "remain the same" the "solutions are different"; namely, to be successful, public health cannot rely solely on biomedical approaches but must also "create healthier communities" [9].

What specific actions must we undertake, as public health leaders, to reduce HIV disparities and create healthier communities for same gender-loving men? A sensible starting place is America's National HIV/AIDS Strategy, updated and released in 2015 [10]. Under Goal 3, "Reducing HIV-Related Disparities and Health Inequities," we find the following recommended actions: expand services, support engagement in care, scale-up programs that address social determinants of health (SDOH), and mobilize communities to reduce stigma. Each one of these recommendations represents a key component of the comprehensive response necessary to quell the HIV epidemic among MSM in the United States.

Acknowledging the reality that many MSM living in the United States face barriers to accessing HIV prevention and clinical services [11,12] should not be misconstrued to imply that we are powerless to confront the disparities described by Rosenberg and his colleagues. In truth, compared to the earliest days of the HIV epidemic, we possess a wealth of knowledge about the virus and a robust armamentarium of clinical and public health interventions to treat and prevent HIV infection. But, in the oft-quoted words of Goethe, "Knowing is not enough, we must apply; willing is not enough, we must do."

No intervention, regardless of efficacy, will demonstrate effectiveness if it's not implemented properly or to scale. In its most recent assessment of HIV prevention services provided by state and local health departments, the National Alliance of State and Territorial AIDS Directors (NASTAD) found that "a lack of adequate HIV prevention funding across all program areas examined presents a major challenge for health department programs" [13]. Consistent with NASTAD's findings is a model published by Holtgrave and colleagues estimating that unmet HIV service needs among black MSM in the United States approached nearly $2.5 billion in 2011 US dollars [14]. Clearly, as in any venture—health or otherwise—strategic investments pay dividends, in this case, reductions in preventable disease and death. Simply stated, if we want to end the HIV epidemic among MSM in the United States, we must increase our public health investment in needed prevention, care and social services.

Essential though it may be, investing additional resources into expanding HIV services for MSM is not the only necessary action we must undertake to resolve these disparities. Consider the findings of Oldenburg and her colleagues who documented a strong statistical association between state level structural stigma directed toward LGBT (lesbian, gay, bisexual and transgender) populations and "increased sexual risk behavior, decreased awareness and use of antiretroviral chemoprophylaxis and decreased comfort discussing sexual behavior with primary care providers" [11]. This is but one example of a burgeoning literature shining a harsh light on the insidious connection between stigma and suboptimal health outcomes. Indeed, if we seek to reduce HIV-related disparities among MSM populations (and other vulnerable groups) it is imperative that we support models of prevention and care that knowingly address the diversity of factors that interact to shape what we call "health" [15]. This brings us back, full-circle, to our shared mission as public health leaders: "fulfilling society's interest in assuring conditions in which people can be healthy" [16]. Assuring conditions in which MSM (whether gay identified or not) can be healthy–in this case free of HIV infection or continuously virally suppressed–requires that we move beyond strictly biomedical approaches. Even when those biomedical approaches are impressively effective, as in the case of PrEP (pre-exposure prophylaxis), provider attitudes can have a dampening effect on uptake, the daily realities of unemployment and unstable housing can minimize their relative importance among potential consumers and policies related to health care financing and reimbursement can inadvertently block access for those populations most likely to benefit from these amazing biomedical advances.

Analyses that continue to document the tremendous burden of HIV among MSM and call-out sub-populations and geographic areas that are particularly hard-hit may be disturbing to acknowledge. But every one of us–epidemiologist or not–understands that a troubled conscience will only grow worse if we continue to ignore the problem at hand rather than pursue those actions required to resolve the situation.

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Guest Editorial

The Importance of Population Denominators for High-Impact Public Health for Marginalized Populations

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HIV surveillance; HIV diagnosis; HIV prevalence; HIV incidence; men who have sex with men; gay and bisexual men; demography

The lack of consistent methods to enumerate population-level denominators for hidden populations has made it difficult for public health to articulate some of the most pressing disparities in America. For example, since the first cases of AIDS in the United States struck gay and bisexual men, injection drug users, and transgender persons, calculating rates of disease to compare impact across populations and geographic areas to highlight disparities and target resources has been challenging. While routine census data have allowed the Centers for Disease Control and Prevention (CDC) to calculate disease rates by sex, age, race/ethnicity, and geographic area [1], the census does not collect information on sexual orientation or same-sex sexual behavior, persons who inject drugs or injection behaviors, heterosexuals who are at higher risk of HIV infection, or transgender persons. This lack of information is nowhere more evident than among gay, bisexual, and other men who have sex with men (MSM), who comprise 67% of estimated number of persons with HIV diagnosed in 2014 (70% when MSM who also inject drugs are included) [1]. Among youth ages 13 to 24, 80% of diagnoses in 2014 were among MSM or MSM who also inject drugs [1]. The impact of HIV on MSM has made them a key focus of the National HIV/AIDS Strategy (NHAS) [2,3]; yet, proportions alone cannot accurately describe disparities, because the size of population denominators vary.

Over the past 5 years, CDC has tried to fill the gap in national, population-wide denominators by using various analytic techniques to estimate the US population size of MSM [4], persons who inject drugs [5], and high-risk heterosexuals [6], and to estimate the population size of MSM and persons who inject drugs by urbanicity and region [7]. Other groups have tried to estimate the size of the population of transgender adults [8] and youth [9]. These national estimates have allowed for the calculation of disease rates for these populations for HIV and other sexually transmitted diseases, which in turn has allowed for national disparities to be highlighted and for federal resources to be better targeted to maximize health impact and increase equity. MSM, who constitute 4% of men in the United States [4], have HIV prevalence and diagnosis rates at least 40 times as great, and syphilis rates at least 60 times as great as for women and other men [4]. However, national estimates may not be applicable to state or local areas because the proportion of the population that is MSM may differ greatly between and within states. Therefore, more refined information is necessary for accurate local information to help plan local programs and allocate resources.

Currently, the US Census and the American Community Survey (ACS), which provides annual supplemental data to the decennial census data, collect data on same-sex households, which can help enumerate the number of same-sex couples, but cannot, by themselves, lead to a population denominator for MSM nationally or locally. As described by Grey and colleagues [10] in this issue of *JMIR Public Health and Surveillance*, various algorithms have been developed for estimating MSM population size by various geography levels or urbanicity through use of data sources such as national behavioral surveys, census data on same-sex male households, and HIV prevalence among MSM from probability-based samples. Despite these existing methods, there has been an ongoing call from state and local health departments to provide more refined estimates of the size of the MSM population at multiple levels of geography that could be used easily for local purposes and regularly updated with latest data.

Two CDC divisions worked closely with Grey and colleagues to support development of the refined and updated methods for estimating the size of the MSM population at the state, county, and city levels [10]. This work, which is now available for use by programs, researchers, and other interested parties, took the best of previous methods, recent data, and urbanicity-specific parameters and combined them into an easy-to-use, updatable set of MSM population estimates. This work also introduced a novel imputation approach to estimate MSM in rural areas, where same-sex relationships may be underreported. This approach yielded estimates of MSM population sizes within states, counties, and metropolitan statistical areas (MSAs) in the United States, which provide denominators for calculation of any disease rates, including HIV and STI prevalence and incidence. While we believe that these are the strongest methods available for estimating MSM population size, it is important to acknowledge that these are estimates and are not based on an actual measurement of the population of interest. Methods may continue to improve if more direct data are collected and when stigma related to being part of this partially hidden population decreases so that self-reporting is not potentially hampered by fear.

In itself, this work on MSM denominators represents an important public health tool for public health action [10]. Rosenberg and colleagues [11], also reported in this issue of *JMIR Public Health and Surveillance*, have taken the additional step and applied these denominator estimates to CDC's HIV surveillance data to provide a snapshot of the devastating impact of HIV on MSM in the United States as a whole, in urban areas nationwide, and in southern states and cities. These data support, at a local level, CDC's findings using their national population size estimates – that the disproportionate impact of HIV on gay and bisexual men is one of the most extreme disparities amongst the many disparities seen with HIV [4]. The addition of state, city, and county data shows the burden of HIV among MSM in the south. Most of the cities with the highest rates of MSM living with HIV and new HIV diagnoses are clustered in the south. Six southern states had <15,000 cases and diagnosed prevalence rates of ≥15% [11]. Five highly populated states had ≥15,000 cases and rates between 10% and 15%. Georgia had ≥15,000 cases and ≥15% diagnosed prevalence rate. Of the 25 MSAs with the highest diagnosed prevalence rates in the United States, 21 were in the South and 6 had diagnosed prevalence rates ≥25%. County - level data showed high rates of diagnosed HIV in both urban and rural counties of the South. These results provide further evidence for the urgent call to action in the National HIV/AIDS Strategy, Updated to 2020, to focus our efforts on MSM, MSM of color, and the southern United States [3].

These important data can be used by local and state health departments to better understand the burden of HIV among MSM and act with the urgency needed to address the disparities between MSM and other population groups, between the south and other regions of the country, and between different regions or cities within states. Since 2010, CDC has pursued a high-impact prevention (HIP) approach to HIV prevention [12]. Through HIP, CDC supports combinations of scientifically proven, cost-effective, and scalable HIV prevention interventions, targeted to the most heavily affected populations and geographic areas. By definition, the South's disproportionate burden of HIV and disparities makes the region a core focus of prevention efforts. In addition, reducing the impact of HIV in the South is a core focus of NHAS: Updated to 2020 [3]. Since 2010, CDC has greatly increased HIV prevention funding to southern states, by reallocating prevention resources to reflect the burden of the epidemic [13].Closing these gaps is essential to ensuring the health of people in the region and to our nation's long-term success in ending the epidemic.

More than ever, we have a broad array of strategies to support high-impact prevention efforts, including condoms, routine and targeted HIV testing, accurate educational and behavioral interventions, antiretroviral therapy to improve the health of people living with HIV and dramatically decrease their likelihood of transmitting HIV, and the use of antiretroviral medicines for pre- or post-exposure prophylaxis [12]. Without a strong focus on MSM, who currently comprise approximately two-thirds of HIV diagnoses [1], we will not be able to meet the ambitious vision of the National HIV/AIDS Strategy to make HIV a rare event in the United States [3,4].

Conflicts of Interest

None declared.

The findings and conclusions in this manuscript are solely the responsibility of the authors and do not necessarily represent the official views of the Centers for Disease Control and Prevention or the Department of Health and Human Services.

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Abbreviations

ACS: American Community Survey
CDC: Centers for Disease Control and Prevention
HIP: high-impact prevention
HIV: human immunodeficiency virus
MSA: metropolitan statistical area
MSM: men who have sex with men
NHAS: United States National HIV/AIDS Strategy

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Original Paper

Why do Patients Forget to Take Immunosuppression Medications and Miss Appointments: Can a Mobile Phone App Help?

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Abstract

Background: Kidney transplant recipients must adhere to their immunosuppressive medication regimen. However, non-adherence remains a major problem.

Objective: The aim of this paper is to determine how kidney transplant recipients remember to take their medications, and assess their perception and beliefs about adherence to immunosuppressive medications and barriers to medication adherence. In addition, we aim to assess perception and beliefs about willingness to use a hypothetical, mobile phone app to improve adherence.

Methods: We conducted a qualitative study that included an average of three home or workplace visits of kidney transplant recipients (N=16) from a single urban transplant center.

Results: The qualitative study revealed that transplant recipients understood the importance of taking their immunosuppressive medications and this motivated them to take their medications. The visits showed that most participants have incorporated medication use into their daily lives and that any minor deviation from daily routines could result in non-adherence. Participants also reported other barriers to adherence. All participants were interested in using an app to remind them to take their medication; however, they reported potential barriers to using the app.

Conclusions: Although kidney transplant recipients understood the importance of medication adherence, there were significant barriers to maintaining adherence. Participants also reported interest in using a mobile phone app.

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KEYWORDS

adherence; immunosuppressive medications; appointments; mobile phone

Introduction

Despite advances in solid organ transplantation, allograft failure due to non-adherence to immunosuppressive medications and follow-up visits remains a major problem [1-12]. Several clinical studies in kidney transplantation have highlighted the negative impact of non-adherence on kidney function post-transplant [2-8]. Post-transplant care requires at least two or three oral immunosuppressive medications and intensive monitoring of kidney function during frequent follow-up visits [1]. Therefore, there is a dire need to understand how patients take their immunosuppressive medications.

A novel approach to improving adherence is the utilization of mobile phone medication adherence apps and the use of text messaging (short message service, SMS). A national study by the Pew Research Center reported that 90% of all American adults own a mobile phone, 58% own a mobile phone with app capabilities, and 42% own a tablet computer [13]. The use of mobile phones is increasing among kidney transplant recipients, especially among African Americans and those with lower household incomes [14]. This technology has shown promising results of improved medication adherence in the areas of HIV, tuberculosis, diabetes mellitus, asthma, and emergency department-prescribed antibiotics [15-20]. Adherence apps linked to an electronic medication tray and a wireless Bluetooth-enabled blood pressure monitor has been tested in kidney transplant recipients [14,21]. To the best of our knowledge, no other adherence apps tailored to kidney transplantation have been tested.

In order to understand kidney transplant recipients' perceptions and beliefs regarding barriers to medication adherence and potential use of a mobile device platform (presented as paper mock-ups) to improve adherence, we conducted one-on-one semi-structured interviews and home or workplace visits among kidney transplant recipients.

Methods

Participants

Transplant recipients were enrolled from August to December 2012 at Hennepin County Medical Center (HCMC). The purposeful sample of ethnically diverse transplant recipients was enrolled based on the perceptions of nurse coordinators that the subjects were either highly adherent or poorly adherent to immunosuppressive medications. Inclusion criteria included the ability to communicate in English, and residence in the Twin Cities area and surrounding suburbs in order to improve feasibility of conducting the interviews. At HCMC, among the 226 recipients transplanted from 2010-2012, 18.1% (41/226) were African American and 3.1% (7/226) were Hispanic. The transplant center actively follows approximately 800 recipients with a kidney transplant. The post-transplant care at the transplant center is routinely managed by a nephrologist. All transplant recipients are seen by a transplant pharmacist at a minimum interval of 2 weeks, 4 weeks, 3 months, 6 months, 12 months, 18 months, and 24 months post-transplant, and yearly thereafter.

All participants were invited for one-on-one semi-structured interviews and home or workplace visits. Initially, twenty participants were enrolled. Four participants dropped out for various reasons such as depression, living with boyfriend, construction at home or traveling. The data on these participants are not included. Each participant gave informed consent and the study was approved by the Human Subjects Research Committee at HCMC.

Procedures

Guides for the semi-structured interviews and home or workplace visits were developed with input from the study investigators. The questions used in the guide, which include closed and open-ended questions, are shown in Textbox 1.

The interviews and visits were conducted by the same individual (BK) who was coached on anthropologic approaches by CJW and/or AI before and weekly during the study. Key findings were discussed with other investigators (CJW, AI) in weekly to bi-weekly meetings for reflection. No clinic or medical personnel were present during these encounters to ensure solid rapport and full disclosure by study participants. The study design included individual interviews for several reasons such as (1) the interviews were conducted during several home or workplace visits; (2) they increased the interviewer's familiarity with study participants' perceptions and beliefs; and (3) they improved trust-building efforts to elicit sensitive data about adherence to medications and appointments during home or workplace visits.

The semi-structured interview methodology was informed by inductive reasoning. While quantitative studies use statistics to establish reliability and validity, qualitative research relies on trust and rapport-building. The semi-structured interviews require the skill of keeping participants on task, maintaining rapport with all to ensure equitable but not peer-pressured participation, and maintaining a high degree of comfort discussing sensitive topics [22]. All interviews were audio taped and reviewed by two authors (BK, AI). The later portion of the semi-structured interview consisted of an oral survey to collect demographic and transplant-related information. The participants' electronic medical records were reviewed for other medical information.

Textbox 1. Kidney transplant recipients' interview questions from the Moderator's Guide. Question number 16 and onwards were designed to assess perception, beliefs, and willingness to use a mobile phone app (presented as a paper mock-up) to improve medication adherence.

Question

1. Why do you choose to take your immunosuppression medications (eg, prednisone, Gengraf, Cellcept)
2. What gets in the way of taking your immunosuppression medications?
    1. Does anything ever prevent you from remembering to take your medications?
    2. What happened last time you did not take your immunosuppression medications?
3. Have you ever chosen to miss a dose when you were short on money?
4. Have you ever chosen to miss a dose when you went out of town?
5. Have you ever chosen to miss a dose when you felt depressed?
6. What pharmacy or pharmacies do you use to get your immunosuppression medications?
7. What don't you like about your pharmacy's service for immunosuppression medications?
    1. Why did you run out of your immunosuppression medications?
    2. How many days were you out?
    3. What can be done to try and prevent this in the future?
8. What do you like about your pharmacy's service for immunosuppression medications?
9. Do you have a keychain or travel pill holder?
    1. When do you usually use it?
10. Have you ever had any undesired side effects from your immunosuppression medications?
11. Have you ever chosen to miss a dose when you think your medications may have unwanted side effects?
12. In last three months, has any emotional or physical suffering prevented you from taking your medications?
13. Why do you choose to go to your doctor and lab appointments?
14. What gets in the way of making it to your doctor and lab appointments?
    1. What gets in the way of remembering?
    2. What happened last time you did not make it to your doctor or lab appointment?
15. What happened to make you forget your appointment?
16. Would you be interested in getting reminders for lab and doctor appointments?
    1. When would you like to get these reminders?
17. Are there certain situations where you do not want to get reminders for doctor and lab appointments?
18. Would you be interested in getting reminders for taking medications every day?
    1. Would you be interested in getting reminders for taking medications only if you forget?
19. Are there certain situations when you do not want to get reminders for medications?
    1. How often would this happen?
20. Would your social life ever get in the way of getting a reminder?
21. Would your work life get in the way of getting reminders?
    1. Would you be ok with a vibrating reminder going off during a meeting and/or quiet event?
    2. Would you be willing to take a mobile phone picture of your medications to prevent the reminder alert?
22. Would it be okay to have words like "kidney transplant" or "medications" show up on reminders on your phone?
    1. Are you comfortable with your friends, family members, and coworkers knowing that you have a kidney transplant?
    2. What about random people around you?

Data Analysis

Qualitative data was collected and analyzed according to the principles of grounded theory. Coding is an iterative process produced through several discussions by researchers to establish broad codes and then further refine the code.

The digital audio tapes of the interviews were transcribed verbatim and visit notes were transcribed to produce 124 pages of text. Coding was done manually without the use of specialized coding software. Two authors (BK, AI) reviewed the transcripts manually, line-by-line to generate a preliminary coding scheme through consensus: a list of codes and corresponding definitions. Therefore, no formal measure of agreement was generated for the codes generated by the two authors. The codes were ordered by thematic similarity or relationship into a project codebook. The resulting themes reflected ideas that emerged over a variety of areas of inquiry by the research team. Quotations that most closely represented the theme were then selected to support the analysis. The data from the transcripts was supplemented with notes taken during home or workplace visits.

Results

The characteristics of the study participants are shown in Table 1. All subjects were interviewed at their residence; however one subject was interviewed at his place of work and one at a coffee shop near her place of residence. The average of 3 visits per participant showed that most participants have incorporated medication use into their daily lives, such as one participant keeping morning medications by the car keys in order to remember to take the medications before leaving for work in the morning. However, any minor deviation from daily routines may result in non-adherence. With one exception, no participants had used electronic reminders on a phone (not a mobile phone) to alert them to take their medications. The one subject that did use reminders utilized the alarm feature on his mobile phone and would not turn off the alarm until he took his medications. None of the participants had mobile phones with app capabilities.

With one exception, all participants used pill boxes due to the large number of medications required. Some subjects also had a smaller pill holder, such as a plastic bag, to carry a single dose of medications. Having this smaller pill holder sometimes resulted in missed medications as some subjects forgot to put medications in this smaller pill holder or forgot to ingest the medications due to deviations from their daily routines.

Seven families of codes or themes were identified and yielded 133 non-discrete quotations. These seven main themes structure the rest of this paper.

Motivated to Take Immunosuppression Medication

Study participants demonstrated a clear understanding of the negative consequences of not taking their immunosuppressive medications (Theme 1, Table 2). They mentioned that non-adherence could increase their risk of rejection and increase risk of returning to dialysis. Taking the medications reassured them they would not experience rejection.

A participant described his motivation for taking his immunosuppression medications: "So I don’t have to go back on dialysis." Participants dreaded the return to dialysis. One participant remarked: "...I want this kidney to work. I don’t like the alternative (dialysis)."

Participants' Perceived Barriers to Taking Immunosuppression Medications

The participants reported barriers to adherence such as forgetting to take or renew medications, procrastination, being short on money, having depression, distractions, change in daily routine, forgetting medications while away from home, alcohol use, and falling asleep before taking evening dose (Theme 2, Table 3)

"I thought that I took it that morning, but then later on in the afternoon when I look at the medication package I found out it was not taken." Some patients found it difficult to maintain compliance while traveling:

> *If I’m in California I have to get up at 5:30 and take my (morning) medications at 6:00…I take them at 8:00 central time regardless of what time zone I’m on.*

Other participants admitted to simply overlooking their medications "…I just had forgotten to renew them…"

Reported Factors That Helped Participants to Take Their Immunosuppression Medications

Factors that help patients remember to take their immunosuppressive medications include creating a routine around taking their medications, monitoring their medication supplies regularly, using a travel-sized pill holder, having a support system, making medications a top priority, taking medications earlier in the day and trusting their physician (Theme 3, Table 4). Surprisingly, only one participant set an alarm.

> *I kinda like my alarm (that just) goes off. It only goes off twice a day. So once in the morning, I have it go off at 8:30 so that if I’m asleep then I can get up and be ready by 9:00 o’clock to take my meds. And then at night it goes off by 8:50 so I can take my meds at 9:00. It gives me a little 10 minute window*

Another participant noted the help he received from the pharmacy:

> *The pharmacy has been doing well. They remind me about my medication. Call me to check on my medications to know which one I should…refill…So they are a help to me.*

Motivated to Keep Appointments

The study participants were motivated to keep their appointments. They referenced their appointments as a way to stay alive and healthy and to monitor their kidney function (Theme 4, Table 5).

> *Well I choose to go to my appointments so we can monitor the kidney function. Make sure all my levels are where they need to be.*

Another participant cited similar curiosity to their health status as a reason to keep appointments:

> *It’s a necessary part of my treatment. I want to know. I’m curious to see how I’m doing. I like to talk to (the doctors), I have questions, I’m curious.*

Participants' Perceived Barriers and Motivation to Keeping Appointments

The study participants reported some barriers to keeping appointments such as transportation, busy schedule, forgetting, not feeling ill or due to personal sickness or sickness in the family (Theme 6, Table 6).

> *My schedule. I mean I have to do a lot of working around my schedule and then sometimes the clinic is not (open), I think the clinic needs to have extended hours because it just makes it hard*

Some patients found it difficult to maintain appointments when they were not feeling well:

> *I think I’m alright because I’m not that bad right now. So I didn’t go…*

Reported Factors That Helped Participants to Keep Appointments

The participants reported scheduling recurrent visits on the same day of the week, various types of reminders and support from others as strategies to keep appointments (Theme 6, Table 7). "When they first started it (the appointment) was Monday, Wednesday, Friday, Monday, Wednesday, Friday then it went down to just Wednesdays, and now I’m going to (every) two weeks so it’s every other Monday." Some participants utilized electronic medical record patient communication tools to maintain appointments:

> *I have MyChart and I get emails…‘You have so and so many appointments,’ and I’ll click them and then oh yeah that’s a reminder.*

Perceived Barriers to a Medication Adherence App

The participants voiced concern regarding their mobile phone being turned off or inaccessible, missing the alarm, and inflexibility of the app to adjust to irregular schedules (Theme 7, Table 8).

> *If I was in a job interview I would have my phone possibly off or on vibrate…in a meeting it is just common courtesy to do that (turn off phone)…Anywhere from one hour to all day. But there are frequent breaks and during that time everyone checks their phones.*

Other participants expressed concern about ignoring their phone during the day: "…when you are pretty busy or when you are enjoying sometimes you don’t look at the phone."

Table 1. Characteristics of study participants (N=16).

Characteristic		n (%)
Recipient male		10 (63)
Recipient race		
	Asian	2 (13)
	Caucasian	9 (56)
	Hispanic	1 (6)
Income		
	<$15,000	5 (31)
	$15,001-$30,000	3 (19)
	$30,001-$45,000	1 (6)
	$45,001-$60,000	1 (6)
	$60,001-$75,000	2 (13)
	>$75,000	4 (25)
Employment		
	Employed full-time	4 (25)
	Employed part-time	2 (13)
	Unemployed	7 (44)
	Retired	1 (6)
	Full-time homemaker	1 (6)
	Student	1 (6)
	Unable to work	0
Primary insurance		
	Private	10 (63)
	Medicare	5 (31)
	Medicaid	0
	Other	1 (6)
Had secondary insurance		9 (56)
Years of schooling, mean (SD)		13.6 (3.2)
Marital status		
	Married	9 (56)
	Separated	1 (6)
	Single/never married	2 (13)
	Divorced	3 (19)
	Living with someone	1 (6)
Transportation		
	Own a car/family owns a car	14 (88)
	Public transportation	1 (6)
	Other	1 (6)
Cause for end-stage renal disease (ESRD)		
	Diabetes	1 (6)
	Hypertension	5 (31)
	Polycystic disease	1 (6)
	Glomerular	2 (13)

Characteristic		n (%)
	Other	7 (44)
Duration since transplant in years, mean (SD)		4.2 (3.9)
Self-described health status		
	Excellent	0
	Very Good	6 (38)
	Good	7 (44)
	Fair	3 (19)
	Poor	0
Living donor		12 (75)

Table 2. Motivated to take immunosuppression medication (coded 15 times).

Authors' interpretation of interviews	Supportive quotations from patients	Study identification number
To avoid dialysis	"Because I want to keep my kidney working right. The alternative is dialysis, and that's not fun."	114
Because it was prescribed by the doctor	"For myself I never choose medications because I don't know anything medical so whatever they recommended I eat it. So it's not my choice at all."	116
To stay alive	"I take it (medication) because it helps me to continue to live to see another day, and also keeps me from going into the hospital…If I don't take it I'm only hurting myself."	108
To prevent rejection	"I don't want to have my kidney reject."	106
To be adherent because of a death in the family due to non-adherent behavior	"It's amazing what missing your medications can do to you, and my father is a good example of that. He (my father) might have been able to prevent that stroke had he taken his medications that morning. He felt good, he felt like he was not in a lot of danger."	108

Table 3. Perceived barriers to taking immunosuppression medications (coded 35 times).

Authors' interpretation of interviews	Supportive quotations from patients	Study identification number
Forgetting to bring meds to work and work schedule is inflexible	"Right now my main thing is my work schedule… I forgot to bring it along (to work) in a plastic bag in my pocket… I don't have enough time to go back and get them; otherwise it could be a termination from one of the jobs."	114
Procrastinating at taking meds	"Well so I take so many pills like in the morning I think there are fifteen or sixteen and at a point you get so tired of taking them and you say or you think 'I'll take them a little later'. Then you get to doing things and then something else comes up and then you don't."	113
Procrastinating at ordering meds	"I procrastinate about ordering my meds. Fairview (pharmacy) will call me and then I'm busy doing something else or in the car or something where they say can you look at your meds now and I say no I can't if I'm driving around."	115
Patients cannot feel the harm they are inflicting on their kidney	"If you are feeling very good and enjoying things then you forget you are sick. Easy to miss it…"	116
Due to being short on money	"I had run out (of money) in the middle of pay days. Even now I try to schedule it, like my wife gets payday Friday and then she and I both get our retirement on the first of the month…I have missed my immunosuppression meds for a day. There was another pill, it was really expensive."	113
Due to being depressed	"There was a time when I'm sure I was depressed…It was a duration (of non-adherence) probably of two days max I'm thinking…You just get that lethargic feeling, 'I'm sick of these pills,'…You take them late but you try not to miss them completely."	113
Pharmacy did not supply meds on time	"About one or two times it was delayed because of the…mail…I was called by the clinic, 'We are sorry we will be late because they were not picked up but by tomorrow it will be around,' and surely I receive it in that time. I ran out of it but I got it the day or two after.'"	101
Patient forgot to take it due to a distraction	"It was a night, I've never forgotten to take the morning pills, it's always been the night pills…I will sometimes get caught up in doing something else and my short term memory can sometimes be bad so sometimes. If I know I don't have to take this until 10:00 o'clock I get busy doing something and then before I know it it's the next morning."	106
Patient didn't want to take meds with alcohol	"I think maybe one time because I was enjoying myself too much. And I was like I don't think I should be taking my pills after just consuming alcohol. So I just didn't take it. Yeah I was out partying and enjoying myself too much.	110
Patient forgot to renew his/her prescription	"No, well not deliberately anyway. I just had forgotten to renew them…"	119
Patient changed pharmacies (due to insurance coverage)	"They (pharmacy) have just had issues with the exact company (insurance) that I need to use mainly because the companies (insurance) don't understand how to use Medicare as a secondary insurer… So there has just been an issue mainly with finding a place that will bill Medicare. That is the issue….I would be on the phone with the insurance company and I would beg, and I would say, 'I will get sick without them'…It was just kind of a mess. It was mainly on the administrative side."	106
Medications were stolen	"The one time I was living in the other place I was living in, they delivered them and left them at the door because it's a safe neighborhood and they weren't there when I got home from work…They said they delivered them, they traced it to the door and one of my roommates…so now I get them delivered to me at work and everyone leaves them alone when I'm not there."	119
Patient forgot to take their meds when they were out of their house	"I was late. It was just the first time I was off my schedule…I was at somebody else's house and we were talking at a dinner party or something…"	107
Patient fell asleep and missed PM meds	"Oh yeah, like I said before I had forgotten once or twice in the evening. Usually it's the evening dose. It's only a couple of pills and I fall asleep and then oops, ya know. And it's not like I deliberately don't take them."	119
Taking meds at different time than usual because the patient has their trough levels checked in the lab	"The morning of the Prograf (trough level) draws, you can't take your Prograf so after the appointment you have to remember to take Prograf because I didn't take it with my other pills. So one particular day I was…distracted so when I left the clinic I was not thinking and then four or five o'clock came and I took my pill box out of my purse and said, 'What are those two Prograf still doing there, oh shoot I didn't take it.'"	110

Table 4. Helps patients to take immunosuppression medications (coded 23 times).

Authors' interpretation of interviews	Supportive quotations from patients	Study identification number
Everyday bi-daily alarms	"Because you might be doing something, you might be driving and then if you turn it off once you stop driving you forget so I don't turn it off until I take the meds…It snoozes automatically for five minutes."	100
Taking pills around the same time and creating a routine	"I have a system and…my system it's (medications) the last thing I do before I walk out the door. And the way I know I have to take my medication is because it's by my keys. Keys to drive the car, keys to lock the door, keys to get into my office. So when I get up and do all these things that I need to do to get prepared to go out, the last thing I see is my medication by my keys…I have ten tubes of medications. I load all those up at the start of the week."	108
Patient monitors med supplies regularly	"Every weekend I check my medication. Because I do the packing in the separate (pill-boxes). So when I find out this is getting short…I call them and tell them those medications that I need and she told me in a day or two they will be here."	101
Patient uses a travel pill holder	"So if I'm going to go somewhere and I know I will be gone, I got a little pill box, so I pop them out and put them in a pill box. So say I'm at Bible study and we don't get out until 9:30 and I take my meds at 9:00. My alarm will go off, pop them pills."	100
	"Just a small sandwich size Zip Lock for the one dose that I'm taking. Like in the morning if I have to work AM. And everybody knows I just say, 'I'm going to take my meds, and they go, 'Okay.'"	105
Patient has a support system	"Right now I keep a very strict regimen of when I take my meds and like I said even my husband (helps)… (he) was like 'do you have your meds with?'…The support system I have (really helps). So he is my reminder too."	102
Patient makes taking medications a top priority	"…I make this a top priority…My meds come first."	102
Taking medications at times that are easy to remember	"I like to take my pills sometime between 7:30 8:00 o'clock in the morning and 7:30-8:00 o'clock at night. 7:30 is a time when I look at the clock at night because this is when my son has to come in... Boom pills go along with that."	112
Patient trusts their doctor	"I trust the doctors a little bit too much to be doing that (not taking medications)."	114

Table 5. Primary motivation to keep appointments (coded 16 times).

Authors' interpretation of interviews	Supportive quotations from patients	Study identification number
To stay healthy	"Because when my hemoglobin is very low then I feel very weak and quick tired. Sometimes when I go (to the clinic) the nurse is like, 'Only seven percent of blood is there.' It's very low."	116
The patient likes and believes in her doctors care	"…and I appreciate that about them because they are so vigilant. So I wouldn't not go to them."	105

Table 6. Perceived barriers to keeping appointments (coded 13 times).

Authors' interpretation of interviews	Supportive quotations from patients	Study identification number
Being distracted by kids	"…I don't really have anyone to watch my kids so I may have to bring them with me which I've never done and I don't really want to do that because it's very distracting and hard to do with two of them."	106
Not having transportation	"… Mostly I contact the transport company then sometime (they are) a little bit late. Sometime (they are) very early that I have to go and wait for almost one hour before I can see my doctor. Sometime they are late that when I reach there the doctor and nurses say we will consider seeing you but you are late."	101
Due to double booking doctors' appointments	"It's usually been a scheduling conflict…I would schedule a lab appointment down here and something at (hospital) at the same time."	114
Sickness	"Nothing (gets in the way of my appointments) unless I'm really sick with the flu or something."	119
Reminder too far in advance	"I guess if it's (the reminder) too far in advance then it's not really that meaningful for the same reason I sometime forget to take (my medications), if it's too far in advance it's not really that immediate. I'm really more in the moment."	106
Oversleeping	"Once I missed and it was just that I overslept."	113
Forgot the appointment	"…I did (forget), but I thought it was the following week. I think we got our dates switched…"	119

Table 7. Helps patients to keep appointments (coded 22 times).

Authors' interpretation of interviews	Supportive quotations from patients	Study identification number
Visits scheduled on the same day of the week or month	"Just mainly towards the end of the month so I remember that it's getting towards the end of the month so I should see when the next lab is."	115
Patient puts transplant clinic appointment card in his/her wallet	"The card...I put it in my wallet in the front."	117
Phone call reminder from the doctor's office	"Well it gives me a chance to get to know I'm on someone's mind as far as the clinic. I get a chance to hear a nurse's voice on the phone and kid around with them on the phone. So receiving that call does a lot. It shows that they're on their job making sure that patients don't forget their appointment. And you kind of build a little rapport with them on the phone. And I kind of look forward to those calls."	108
Work is accommodating and flexible	"…I have to go in (to a clinic appointment) on Friday and I've already emailed my boss saying that I will be working from home because I have a doctor's appointment."	102
Making appointments is a top priority	"…I make this a top priority. This is a very important priority that we keep in the back of our minds at all time. My meds come first. Doctors' appointments are first."	102
Patient has written personal reminders	"…I will write myself a note to remember. For example, 'I actually have to schedule one for December, but I know it is important enough that I actually have to write myself a note to remember because if I wait until December, chances are they just get really busy, so I need to call in advance."	106
Email doctor through MyChart	"Yup, and that way it's easier to remember because it's (email) in writing. Then I can always go back on MyChart and say, 'Hey that's what they said,' so I can always remember."	114
Mobile phone calendar reminders for appointments	"…my medical appointments I have set up for both a day and a half an hour before I'm supposed to go. So I get a one day alarm and I get a thirty-minute alarm. But once I get that one day alarm, it's already in my mind that I have to go tomorrow. Then I have thirty minutes, okay time to get ready to go."	108
Mobile phone calendar reminders for appointments	"Yeah, I usually have it set for forty-five minutes before hand so I have time to get there and stuff." (BL) "And is the same thing for lab appointments?" "Yeah, mmhmm."	119

Table 8. Future perceived barriers to the app (coded 9 times).

Authors' interpretation of interviews	Supportive quotations from patients	Study identification number
Phone turned off periodically	"I will turn it on silent at night, but I don't shut it off."	106
App alarms, though helpful, may become too annoying so the patient turns them off	"Well like for Prograf (trough levels)…they call you the day before and remind you to take your Prograf at a certain time. And just because I've been doing it for over a year it's like I know that I have to take it. Even though it is good sometimes because I have (forgotten)."	110
	"Straight reminder that's maybe after a while going to be a nuisance if you get the reminder….after you've already taken them and then you get something that says, 'Take your meds!'"	113
People not having their mobile phone on them all the time	"I have a little spot on the counter and so it's plugged in there right now and if I were to go out and do something in the garage it wouldn't be with me. My son comes home and we go out and play, it's not with me."	112
If the app is not flexible enough to work with irregular schedules	"So like I said send me a message before I go…If I work tomorrow at 6:00 then an automated (message) at 5:30 saying do you have your medications ready for work or something."	114
It may cumbersome to take a mobile phone picture to document medication ingestion to prevent the app alarm. (This option for the app was posed to the participants)	"That's…easy to forget to take the picture. And then they are going to think that I don't take my medication..."	117

Discussion

Principal Findings

The kidney transplant recipients that participated in these interviews demonstrated an understanding of the importance of immunosuppression medications. Commonly cited reasons to remain compliant included to avoid dialysis, stay alive, prevent rejection, and witnessed complications from noncompliance in family members (Table 2). Despite these appropriate concerns, participants shared numerous perceived barriers to maintain perfect adherence to immunosuppression medications. These barriers included simply forgetting to take or renew medications, procrastinating, being short on money, having depression, getting distracted, change in daily routine, forgetting medications while away from home, alcohol use, and falling asleep before taking evening dose (Table 2).

We found it reassuring that our participants identified understanding the importance of immunosuppression medication. In a previous publication using mailed surveys, Chisholm-Burns et al identified that kidney transplant recipients were more likely to miss doses of medications when they acknowledged a weaker belief on the necessity of maintenance immunosuppression medications [23]. Our results suggest that among the participants in our study, present efforts to educate kidney transplant recipients on the importance of immunosuppression are successful to a large extent and should be continued [24,25].

Similar to our findings, several previous investigations have reported patient-identified barriers to medication compliance. Consistent with our findings, these publications have cited limited financial resources, and forgetfulness, interruption of daily routine, travel or leaving home, change in dose, run out of medications, and no immediate access to a pharmacy as barriers to compliance [23,25-27]. Intentional non-adherence has been found previously to be significantly lower than unintentional non-adherence among kidney transplant recipients [26,28]. We found a similar trend among responses in our study. This suggests that larger improvements in adherence may be seen with strategies designed to remind patients to take medications and facilitate delivery and administration of medications in addition to education them on their importance. The behavioral change theories commonly used in mobile app applications, such as health belief model (perceived susceptibility, perceived severity, perceived benefits, perceived barriers, cues to action, and self efficacy), and social cognitive theory (self efficacy, expectations, behavioral capability, observational learning, reinforcements, and reciprocal determinism), combined with behavioral techniques such as nudges (eg, loss aversion, anchoring, and benchmarking), can facilitate medication adherence [29-31].

Interestingly, when we tested the idea of using a paper mock-up of a mobile phone app specifically designed for kidney transplant recipients we receive generally positive responses. While some participants reported interest in this utility, others raised concerns with this proposal such as what would happen when the phone was switched off or not in their immediate proximity, developing annoyance to a phone alarm, and the inflexibility of the app to adjust to chaotic and changing schedules were concerns raised by participants (Table 8). A recent review of mobile phone medication adherence apps identified 160 currently on the market. While their efficacy remains untested, medication adherence apps offer many potential benefits that include constant accessibility, ease of use, low cost, and ability to consolidate all medication-specific information for the patient and provider. Based on their respective capabilities and ease of use, the review distinguished ten medication apps as noteworthy. These apps are MyMedSchedule, MyMeds, MedSimple, Med Agenda, RxmindMe Prescription, Dosecast, TRxC (Beta) MediMemory, PillManager, and MedsIQ Individual/Multi-user. No free-standing app, however, was specifically tailored to kidney transplant recipients [32].

In response to the concerns identified by participants in this study, it is our belief that a mobile phone app designed for kidney transplant recipients would have the following features. First, it would be easy to input a multi-drug regimen into the app. Second, the app would offer a choice of options for notification of medication due time. These options would include a standard text message, an email generation or alarm feature when a medication would be due. Third, the app could generate a reminder of a due medication without cellular connectivity. Fourth, the app would feature a "snooze" button to allow for an additional reminder to take the medication if the user was unable to complete the task immediately. Fifth, instead of just a simple reminder, the app would have a feature that allow the user to voluntarily indicate if they did or did not take the medication and note the time when this occurred. This data could be collated and downloaded at the physician office as a way to prompt discussion between the caregivers and the patient of methods to improve adherence. Sixth, the app could communicate with the patient’s primary pharmacy and facilitate refills as they become necessary to prevent lapses in medication availability. Finally, any app created based on this input would have to be tested extensively among transplant patients to ensure the app engages the patients through social competition [33], and individual encouragement [34]. Previous focus groups have shown that peer-support relationships and talking to other patients on dialysis therapy have motivated transplant recipients [33].

To our knowledge, no studies utilizing mobile phone apps to improve outcomes in kidney transplant recipients have been published. One study of pediatric liver transplant recipients showed significant reduction in variation of tacrolimus levels using text messaging reminders and suggests that adopting this reminder system may lead to improved medication adherence and decreased episodes of rejection [35].

Limitations

There are several limitations in the current study. First, although we had a diverse group of participants based on their socio-economic information, this study was conducted with a small sample size of prevalent patients in a single center study. In addition, common themes were appearing in the qualitative data provided by the participants. Second, four patients with unstable living situations or depression dropped out of the study; thus, it is possible we may have missed some issues specific to vulnerable populations. We did not include patients that lost their allograft due to noncompliance. However, our findings are generally consistent with previous survey responses regarding the reported barriers to medication adherence from other transplant centers [23,25-27]. None of our subjects had mobile phones, despite no purposeful sampling in regards to access to mobile phone was used. The mobile phone use in 2012 at our county hospital was likely low. Lastly, we did not measure adherence in our study participants; thus, the barriers and facilitators to adherence may be participants’ perceptions.

From this qualitative study of medication adherence practices, it is clear that patients have incorporated medications into their daily lives and schedules, but that any variation to this schedule increases the risk of noncompliance. In addition, there are numerous barriers to medication adherence that participants in our studied identified, and participants utilized a variety of techniques to reduce the influence of these barriers. While no transplant-specific app exists presently, an app tailored to the needs of a busy transplant recipient may improve medication adherence.

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Authors' Contributions

All of the authors performed the data analysis and interpretation, drafting, revision, and approval of the final article. CJW and AI provided the concept and design of the article.

Conflicts of Interest

None declared.

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Abbreviations

HCMC: Hennepin County Medical Center

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Original Paper

Rates of Prevalent HIV Infection, Prevalent Diagnoses, and New Diagnoses Among Men Who Have Sex With Men in US States, Metropolitan Statistical Areas, and Counties, 2012-2013

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Abstract

Background: In the United States, men who have sex with men (MSM) increasingly represent the majority of people living with and acquiring human immunodeficiency virus (HIV) infection. Local and federal surveillance programs estimate the number of persons living with an HIV diagnosis, persons living with HIV infection, and new diagnoses. Given the absence of population-based estimates of the number of MSM for US states, metropolitan statistical areas (MSAs), or counties, it is not possible to accurately estimate rates using these indicators at these levels, inhibiting the ability to understand HIV burden and to direct prevention efforts.

Objective: To synthesize recently published estimates of MSM population size with publicly available HIV surveillance data, in order to estimate the prevalence of HIV diagnosis and infection and the rate of new diagnoses, at the national, state, MSA, and county levels.

Methods: The number of MSM living with HIV infection in 2012 (prevalence), living with an HIV diagnosis in 2012 (diagnosed prevalence), and newly diagnosed with HIV infection in 2013 (new diagnosis), at state, MSA, and county levels, were obtained from publicly available data from AIDSVu.org and the US Centers for Disease Control and Prevention. The estimated number of MSM living in every US county was calculated using recently published methodology that utilized data from the National Health and Nutrition Examination Survey and American Community Survey. Estimated county-level MSM counts were aggregated to form MSA- and state-level totals. From this, we estimated HIV prevalence, diagnosed prevalence, and new diagnosis rates.

Results: The estimated HIV prevalence among MSM in the United States in 2012 was 15.0% (666,900/4,452,772), the diagnosed HIV prevalence in 2012 was 11.1% (493,453/4,452,772), and the new diagnosis rate for 2013 was 0.7 per 100 MSM. For diagnosed prevalence at the state level, 6 states had both <15,000 cases and diagnosed prevalence rates of ≥15%, all in the South. Five highly populated states had ≥15,000 cases and rates between 10% and 15%. Georgia was the only state with ≥15,000 cases and ≥15% diagnosed prevalence rate. Of the 25 MSAs with the highest diagnosed prevalence rates in the United States, 21 were in the South and 6 had diagnosed prevalence of ≥25%. County-level data showed high diagnosed prevalence rates in both urban and rural counties of the South.

Conclusions: HIV infection is hyperendemic among MSM in many areas of the United States, particularly in the South. Our data emphasize the priorities for HIV prevention and care set forth in the United States National HIV/AIDS Strategy (NHAS) and provide updatable local estimates of NHAS indicators. Jurisdictions can use these results to direct resources, programs, and policies to optimally benefit the health of MSM.

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KEYWORDS

HIV surveillance; HIV diagnosis; HIV prevalence; HIV incidence; men who have sex with men; gay and bisexual men; demography

Introduction

The United States' human immunodeficiency virus (HIV) epidemic has long been characterized by a concentration of infection among men who have sex with men (MSM). MSM accounted for an estimated 53% of people living with a diagnosis of HIV in 2013 and 67% of new HIV diagnoses in 2014, despite representing a minority of men in the United States [1, 2]. Furthermore, individuals of color and those living in the Southern United States also comprise a disproportionate share of new infections, new diagnoses, those living with an HIV diagnosis, and deaths among persons living with an HIV diagnosis [1, 3, 4]. The intersection of these groups, black MSM in the South, represents the most affected subgroup in the United States, for whom extremely high levels of HIV prevalence and incidence have been recorded across a variety of surveillance and research designs [5-9]. The 2015 update to the United States National HIV/AIDS Strategy (NHAS) places priority on MSM, particularly black MSM, and individuals living in the South, and establishes indicators to monitor progress in reducing the extent of HIV disparities in these populations, to monitor the state of the US epidemic, and to guide the allocation of prevention efforts [10]. The implementation of the NHAS will require intensive local action, informed by local estimates of the extent of HIV infection [11].

To best understand the burden of existing and new HIV infections among MSM at subnational levels, high-quality data sources for both infection numerators and population-size denominators are needed, yet historically have been incomplete. In the United States, HIV infection is reportable; since 2004, name-based diagnoses of HIV infection have been reported by all 50 states to the Centers for Disease Control and Prevention (CDC). CDC routinely releases HIV surveillance data in reports and on HIV Atlas [1, 5, 12]. These data include estimated state-, county-, and metropolitan statistical area (MSA)-level counts of MSM newly diagnosed with HIV infection in each year and all MSM currently living with diagnosed HIV infection. AIDSVu.org is a website that uses these data to develop highly detailed maps and other visualizations of the HIV epidemic and allows downloads of county-specific CDC data on HIV prevalence [13]. There is no direct surveillance measurement of the total number of MSM living with HIV infection (ie, including those not yet diagnosed), but CDC has used existing surveillance data to model the number of MSM living with HIV infection at the state level [14]. Unlike for other groupings of persons (eg, by race, sex, or age) for which CDC publishes both counts and rates of HIV diagnoses and prevalence, surveillance-based estimates for MSM are available only as counts. This limits our understanding of not only the total burden of HIV infection among MSM but also the relative burden across geographic areas in which numbers of MSM may vary. CDC led an effort to create a national estimated rate of the MSM living with diagnosed HIV infection using surveillance data from 37 states and an MSM population-size denominator based on a synthesis of data sources, primarily the National Health and Nutrition Examination Survey (NHANES) [2]. CDC also funds an ongoing supplemental surveillance project in 20 of the largest US cities that directly measures the rate of prevalent HIV infection in a nonrepresentative sample of MSM [6-8, 15, 16]. These data are valuable for understanding the impact of HIV infection among MSM in those cities, but other areas need similar estimates to better understand their own community's HIV epidemic and to target resources appropriately. This is particularly critical as part of the nationwide call for organizations to incorporate the goals and indicators from the NHAS into their program plans [10, 11]. The rate of new HIV diagnoses is a central indicator for success in the NHAS goals of reducing new HIV infections (Goal 1, Indicator 2) and reducing HIV-related health disparities for MSM (Goal 4, Indicator 9) [10].

To generate these rates at the state, county, and MSA levels, we needed new data on the number of MSM in each of those areas. We have recently published a method that allocates the national proportion of MSM to all US states, counties, and MSAs, using additional NHANES results and American Community Survey (ACS) data [17, 18]. Here, we apply these new denominators to the publicly available HIV case surveillance data to obtain rates of HIV diagnoses and prevalence among MSM at national, state, county, and MSA levels.

Methods

We estimated and examined a variety of HIV infection indicators for MSM at multiple levels by combining publicly available disease numerator data with denominators for MSM, as follows.

Numerator Data Sources and Methods

Estimated MSM diagnosis and infection count data were extracted from public CDC and AIDSVu.org data sources to inform estimates at the national level and all 50 US states plus the District of Columbia (Table 1) [1, 12, 13]. County-level data on prevalence of persons living with diagnosed HIV infection (diagnosed prevalence) among MSM came from AIDSVu.org [13]. MSA-level data on diagnosed HIV prevalence and new HIV diagnoses among MSM came from a CDC surveillance report [5].

To protect the privacy of persons living with HIV infection in smaller communities, standard publication practices for HIV surveillance data suppress county data where there are fewer than 5 cases; this includes stratified counts, such as for MSM. In addition, CDC adheres to agreements with each individual state regarding additional restrictions on the public release of HIV surveillance data at the county level. Although for the 2012-2013 HIV case surveillance data most states (n=32) allowed CDC to release data about MSM from all counties that met the 5+ case rule, many either only allowed release of these data from large mostly urban counties (n=10) or did not allow the data to be released at all (n=8).

Table 1. HIV burden indicators and sources of numerator HIV data.

Level	Prevalence of living with an HIV[a] diagnosis, 2012	Rate of new HIV diagnoses, per MSM[b], 2013	Rate of new HIV diagnoses, per MSM without an HIV diagnosis, 2013	Prevalence of HIV infection, 2012	Prevalence of undiagnosed HIV infection, 2012
National	AIDSVu [13]	AIDSVu	AIDSVu	MMWR[c] [14]	MMWR
State	AIDSVu	AIDSVu	AIDSVu	MMWR	MMWR
MSA[d]	CDC[e]Surveillance Report [5]	CDC Surveillance Report	CDC Surveillance Report	—	—
County	AIDSVu	—	—	—	—

[a] HIV: human immunodeficiency virus.

[b] MSM: men who have sex with men.

[c] MMWR: Morbidity and Mortality Weekly Report.

[d] MSA: metropolitan statistical area.

[e] CDC: Centers for Disease Control and Prevention.

Denominator Data Sources and Methods

We used the method by Grey et al [17] to estimate the number of MSM in the United States in 2012 and 2013. In brief, we began with 2 published estimates. The first was the result of a meta-analysis-based estimate of the percentage of US men who have had sex with another man in the past 5 years [2]. The second, from an analysis of NHANES data, was the percentages of US men who had sex with another man in the past year, at each of 4 levels of urbanicity: large central metropolitan areas, large fringe metropolitan areas, medium or small metropolitan areas, and nonmetropolitan areas [18]. We next evaluated the percentage of same-sex male couple households among all households in each county, from the ACS [19]. We then calculated the ratio of these percentages to the percentage among all counties at the same level of urbanicity. By multiplying these ratios by the percentages reported by Oster et al [18], we assigned each county a new, locally tailored estimated percentage of men who had sex with a man in the past year among adult men, a method similar to that published by Lieb et al [20]. Finally, we multiplied each county’s estimate by the number of adult men in the county, according to the ACS. In order to estimate the number of men who had sex with a man in the past 5 years, generally considered more indicative of the sexually active MSM population, we scaled the single-year population sizes to equal the estimate given by Purcell et al [2] of 3.9% of the US adult male population. To obtain estimates at the state and MSA levels, we aggregated MSM population size estimates from their composite counties.

In addition to the numerator-based suppression previously mentioned, standard publication practices for HIV surveillance data also suppress the display of county-level rates where there are fewer than 100 persons in the population, including in any single group stratum, such as MSM. Ultimately, of the 1521 counties with available and unsuppressed data on MSM living with an HIV diagnosis, an additional 253 (16%) had fewer than 100 MSM according to our estimation method. The remaining 1268 counties, which contained 84% of the US adult male population and 89% of all MSM living with an HIV diagnosis in 2012, contributed to the county-level analysis.

HIV Burden Indicators

At the state level, we computed the rates of HIV prevalence in 2012 (diagnosed and undiagnosed), diagnosed prevalence in 2012, and new diagnoses in 2013. Prevalence rates were among all MSM; new diagnosis rates were among all MSM and among only MSM not previously diagnosed with HIV (total MSM in 2013 minus total MSM living with a diagnosis at year-end of 2012). State-level estimates were aggregated to yield national estimates. At the county level, we computed the rates of diagnosed HIV prevalence among all MSM in 2012. At the MSA level, we computed the rates of diagnosed HIV prevalence in 2012 and new diagnosis in 2013 among all MSM.

Sensitivity Analyses

To explore the potential effect of regional underreporting or within-urbanicity stratum underrepresentation of male-male cohabitation on the ACS-based Grey estimator, we also produced HIV prevalence and new diagnosis rates using MSM denominators according to more simplified models that assumed estimates from Oster et al and Purcell et al (see Supplement for details) [2].

Results

In the United States in 2012, an estimated 15.0% of MSM were living with HIV infection (diagnosed and undiagnosed) and 11.1% were living with an HIV diagnosis (Tables 2-3, Figure 1). Using the comparison method in Purcell et al [2], the diagnosed HIV prevalence rate among MSM was 57.5 times greater than among other US men. States in the South had the highest rates of diagnosed HIV prevalence among MSM, with all rates of ≥15% located in the South (Table 2, Figure 1). Among states, the rates of diagnosed HIV prevalence among MSM living in Louisiana, Mississippi, and South Carolina were all approximately twice the national rate. The rates of new HIV diagnoses among MSM for 2013 at the state level strongly followed the same pattern as HIV prevalence (Table 2, Figure 2). Only southern states had new diagnosis rates per MSM and per MSM without an HIV diagnosis of ≥1.00/100 MSM, with 2 (Louisiana and Mississippi) having rates per MSM without an HIV diagnosis of ≥2.00/100 MSM.

Plotting the diagnosed HIV prevalence case counts versus rates among MSM in 2012 (Figure 3), 4 groups are notable: populous states with ≥15,000 cases and diagnosed prevalence between 10% and 15% (California, Florida, Illinois, New York, Texas), southern states with diagnosed prevalence of ≥15% and <15,000 cases, and states with diagnosed prevalence of <15% and <15,000 cases. Georgia is uniquely high in both the rate and case count of MSM living with diagnosed HIV infection.

All but 4 high-prevalence MSAs are located in the South, and 6 southern MSAs have diagnosed HIV prevalence rates among MSM for 2013 of ≥25% (Table 4, complete MSA data provided in supplement). The map of county-level diagnosed HIV prevalence rates among MSM in 2012 shows a similar pattern of high-prevalence urban areas (Figure 4). This map also shows that several rural counties in the South have diagnosed HIV prevalence rates of ≥20% and ≥30% (Figure 4).

The new MSM population size estimation by Grey et al also appears to produce similar state-level HIV rates to previous approaches and, in the instances of certain MSAs, more plausible results (see Supplement for full sensitivity analysis results).

Table 2. Prevalence of HIV diagnoses and rates of new diagnoses among men who have sex with men, by US states and District of Columbia, 2012-2013.

State	MSM[a] living with an HIV[b] diagnosis, 2012		New MSM HIV diagnoses, 2013		
	n	Rate per 100 MSM	n	Rate per 100 MSM	Rate per 100 MSM without an HIV diagnosis
Alabama	6442	15.78	442	1.09	1.29
Alaska	335	6.49	12	0.24	0.25
Arizona	8748	8.14	513	0.46	0.50
Arkansas	2843	15.04	192	1.00	1.17
California	85,307	10.85	3860	0.49	0.55
Colorado	8028	11.42	241	0.33	0.37
Connecticut	3178	7.30	188	0.43	0.47
Delaware	1115	8.45	60	0.46	0.50
District of Columbia	7360	20.96	313	0.85	1.06
Florida	47,520	14.35	2711	0.80	0.93
Georgia	24,101	18.51	1708	1.30	1.59
Hawaii	1758	11.16	78	0.51	0.57
Idaho	477	4.92	15	0.15	0.16
Illinois	20,495	10.17	1273	0.64	0.71
Indiana	5876	8.37	332	0.47	0.52
Iowa	1133	5.45	77	0.37	0.39
Kansas	1723	7.59	109	0.48	0.51
Kentucky	3697	8.08	260	0.55	0.60
Louisiana	8954	21.72	730	1.76	2.24
Maine	771	5.13	21	0.14	0.15
Maryland	11,052	13.38	762	0.90	1.04
Massachusetts	8181	7.24	443	0.40	0.43
Michigan	9377	8.34	547	0.48	0.52
Minnesota	4416	5.54	202	0.24	0.26
Mississippi	4469	23.34	316	1.66	2.18
Missouri	7994	11.04	341	0.48	0.54
Montana	239	3.66	19	0.30	0.31
Nebraska	1015	8.01	51	0.39	0.42
Nevada	5070	9.86	329	0.64	0.71
New Hampshire	621	4.44	21	0.15	0.16
New Jersey	13,402	10.23	790	0.60	0.66
New Mexico	1729	10.18	102	0.57	0.63
New York	54,606	14.61	2264	0.61	0.72
North Carolina	13,202	13.06	859	0.83	0.96
North Dakota	132	3.33	13	0.29	0.30
Ohio	12,259	8.81	767	0.53	0.58
Oklahoma	3293	8.74	236	0.63	0.69
Oregon	3673	6.07	159	0.26	0.27
Pennsylvania	12,477	7.81	739	0.45	0.49
Rhode Island	949	4.09	54	0.23	0.24

State	MSM[a] living with an HIV[b] diagnosis, 2012		New MSM HIV diagnoses, 2013		
	n	Rate per 100 MSM	n	Rate per 100 MSM	Rate per 100 MSM without an HIV diagnosis
South Carolina	7332	21.63	452	1.24	1.56
South Dakota	196	3.62	9	0.17	0.18
Tennessee	9198	12.29	563	0.76	0.87
Texas	42,973	11.77	3129	0.84	0.95
Utah	1532	4.71	72	0.22	0.23
Vermont	275	3.96	12	0.17	0.18
Virginia	11,888	10.63	683	0.61	0.68
Washington	7681	6.82	325	0.29	0.31
West Virginia	930	7.41	46	0.35	0.38
Wisconsin	3388	5.82	190	0.32	0.34
Wyoming	133	4.04	11	0.34	0.36
50 US states & Washington, DC	*493,453*	*11.08*	*27,641*	*0.61*	*0.69*

[a] MSM: men who have sex with men.

[b] HIV: human immunodeficiency virus.

Table 3. Prevalence of HIV infection and undiagnosed HIV infection among men who have sex with men, by US states, 2012.

State	MSM[a] living with HIV[b] infection, 2012		MSM living with undiagnosed HIV infection, 2012	
	n[c]	Rate per 100 MSM	n[c]	Rate per 100 MSM
Alabama	7900	19.36	1600	3.92
Alaska[d]	410	7.94	20	0.39
Arizona	10,500	9.77	1200	1.12
Arkansas	3500	18.51	800	4.23
California	134,400	17.10	16,400	2.09
Colorado	8900	12.66	950	1.35
Connecticut	4600	10.57	710	1.63
Delaware	1600	12.13	240	1.82
District of Columbia	11,300	32.18	1400	3.99
Florida	60,500	18.27	8100	2.45
Georgia	33,100	25.42	6900	5.30
Hawaii	2500	15.87	220	1.40
Idaho[d]	630	6.50	80	0.83
Illinois	27,800	13.79	5300	2.63
Indiana	6900	9.83	1000	1.42
Iowa	1600	7.70	330	1.59
Kansas	2200	9.70	380	1.67
Kentucky	5300	11.59	890	1.95
Louisiana	10,700	25.96	2700	6.55
Maine[d]	1200	7.99	90	0.60
Maryland	16,200	19.61	3900	4.72
Massachusetts	12,200	10.80	2000	1.77
Michigan	10,900	9.69	1900	1.69
Minnesota	5200	6.53	770	0.97
Mississippi	5400	28.20	1200	6.27
Missouri	9100	12.57	1500	2.07
Montana[d]	420	6.43	30	0.46
Nebraska[d]	1300	10.25	190	1.50
Nevada	6500	12.64	1000	1.94
New Hampshire[d]	950	6.79	120	0.86
New Jersey	16,800	12.83	3700	2.83
New Mexico	2400	14.13	280	1.65
New York	75,900	20.30	7700	2.06
North Carolina	16,100	15.93	2600	2.57
North Dakota[d]	190	4.79	20	0.50
Ohio	14,800	10.63	3100	2.23
Oklahoma	4100	10.88	740	1.96
Oregon	5800	9.58	850	1.40
Pennsylvania	16,100	10.08	2700	1.69

State	MSM[a] living with HIV[b] infection, 2012		MSM living with undiagnosed HIV infection, 2012	
	n[c]	Rate per 100 MSM	n[c]	Rate per 100 MSM
Rhode Island	1100	4.75	200	0.86
South Carolina	9500	28.03	2000	5.90
South Dakota	200	3.70	30	0.55
Tennessee	11,000	14.70	1800	2.40
Texas	62,400	17.09	12,100	3.31
Utah	1700	5.23	250	0.77
Vermont[d]	520	7.49	0	0
Virginia	13,500	12.07	2000	1.79
Washington	10,400	9.23	1300	1.15
West Virginia[d]	1200	9.56	200	1.59
Wisconsin	4000	6.87	650	1.12
Wyoming[d]	180	5.47	40	1.22
50 US states & Washington, DC [e]	*666,900*	*14.98*	*98,700*	*2.22*

[a] MSM: men who have sex with men.

[b] HIV: human immunodeficiency virus.

[c] Counts are rounded model-based estimates, per the source Centers for Disease Control and Prevention (CDC) report [14].

[d] Counts indicated as numerically unstable, per the source CDC report [14].

[e] Total counts calculated by different methodology than used for jurisdictions and thus do not sum to column totals, per the source CDC report [14].

Table 4. Prevalence of HIV diagnoses and rates of new diagnoses among men who have sex with men, by top 25 HIV prevalence rates among US metropolitan statistical areas, 2012-2013.

Metropolitan statistical area[a]	MSM[b] living with an HIV[c] diagnosis (2012)		HIV diagnoses among MSM (2013)		
	n	Rate per 100 MSM	n	Rate per 100 MSM	Rate per 100 MSM without an HIV diagnosis
Atlanta–Sandy Springs–Roswell, GA	12,532	16.43	1393	1.36	1.62
Augusta–Richmond County, GA–SC	691	26.56	89	2.79	3.91
Baton Rouge, LA	1087	25.40	155	2.91	4.14
Birmingham–Hoover, AL	1809	13.35	130	0.79	0.92
Charleston–North Charleston, SC	931	20.08	84	1.46	1.81
Chattanooga, TN–GA	577	15.06	35	0.85	1.02
Columbia, SC	1619	29.65	99	1.43	1.96
Dayton, OH	807	13.84	61	0.89	1.02
Durham–Chapel Hill, NC	741	17.47	70	1.13	1.34
El Paso, TX	1131	28.53	96	2.22	3.11
Fresno, CA	998	13.79	88	1.16	1.35
Greensboro–High Point, NC	975	20.98	75	1.26	1.58
Greenville–Anderson–Mauldin, SC	806	16.07	80	1.42	1.69
Jackson, MS	1201	39.49	106	2.51	4.05
Little Rock–North Little Rock–Conway, AR	1081	23.33	124	2.24	2.87
Los Angeles–Long Beach–Anaheim, CA	34,919	12.92	1938	0.62	0.71
McAllen–Edinburg–Mission, TX	494	14.12	66	1.60	1.88
Memphis, TN–MS–AR	2954	17.61	257	1.18	1.43
Miami–Fort Lauderdale–West Palm Beach, FL	21,482	17.52	1592	1.13	1.35
New Orleans–Metairie, LA	3091	19.71	356	1.68	2.08
New York–Newark–Jersey City, NY–NJ–PA	46,869	14.61	3007	0.76	0.89
Tulsa, OK	944	14.08	111	1.47	1.70
Virginia Beach–Norfolk–Newport News, VA–NC	2930	14.40	242	0.97	1.13
Washington–Arlington–Alexandria, DC–VA–MD–WV	12,606	13.43	1105	0.90	1.03
Winston-Salem, NC	606	16.08	54	1.11	1.33

[a] Metropolitan statistical area (MSA) results are provided alphabetically for the top 25 MSAs (based on diagnosed prevalence rates). The results for the remaining MSAs are available in the supplement.

[b] MSM: men who have sex with men.

[c] HIV: human immunodeficiency virus.

Figure 1. Prevalence of human immunodeficiency virus diagnoses among men who have sex with men (MSM) per 100 MSM, by US states and District of Columbia, 2012.

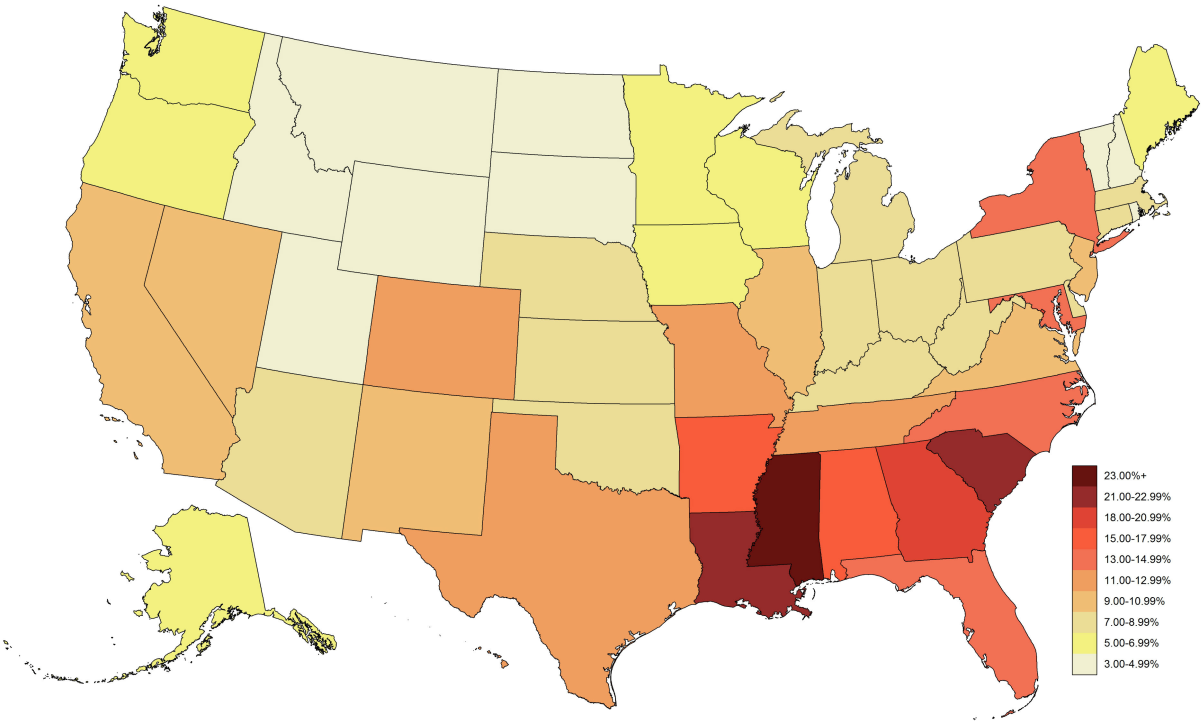


Figure 2. Rate of new human immunodeficiency virus diagnoses among men who have sex with men (MSM) per 100 MSM, by US states and District of Columbia, 2012-2013.

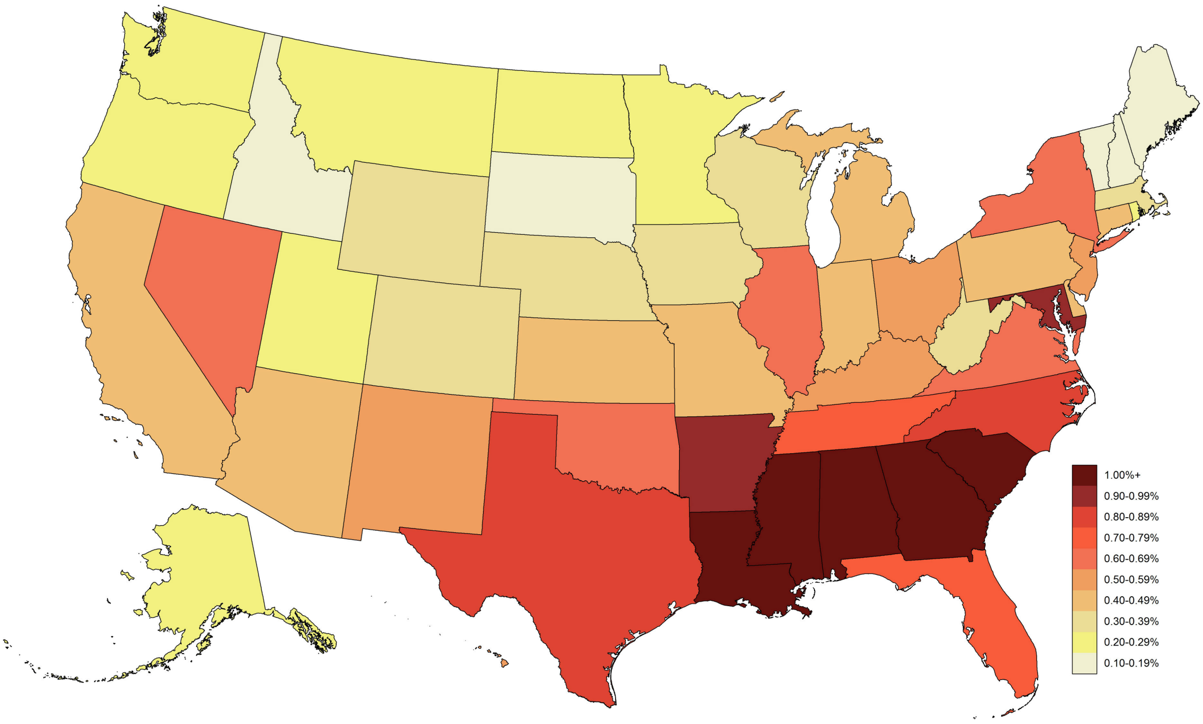


Figure 3. Prevalence versus number of men who have sex with men (MSM) living with a human immunodeficiency virus (HIV) diagnosis, by US states and District of Columbia, 2012.

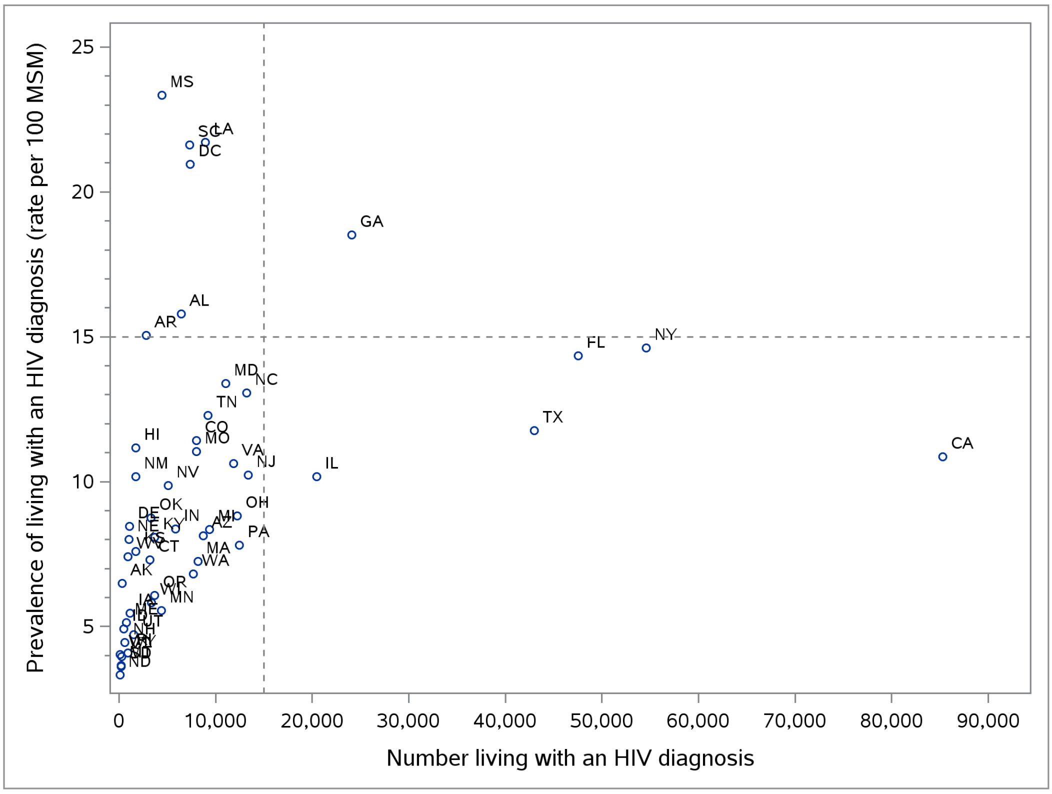
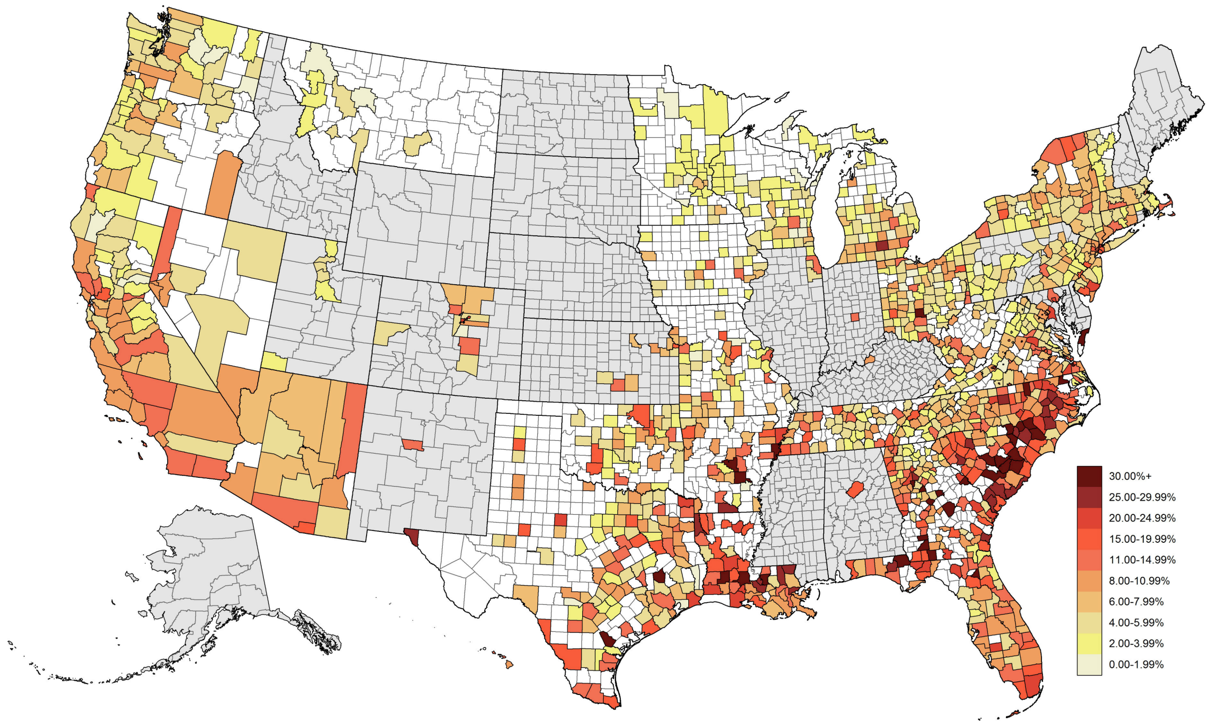


Figure 4. Prevalence of human immunodeficiency virus (HIV) diagnoses among men who have sex with men (MSM) per 100 MSM, by US counties, 2012. Counties in gray represent areas for which data were not permitted to be released by the state. Those in white represent areas for which data were available, but either the numerator or denominator was suppressed. The remaining counties with available and unsuppressed data represented 84% of US adult males and 89% of prevalent US MSM HIV diagnoses. A data file with the county-level HIV prevalence rate data is available on the Emory CAMP website [37]. Because all US counties are not included, it is inadvisable to rank counties based on HIV burden.



Discussion

Despite incredible achievements in prevention, HIV diagnosis, and antiretroviral therapies over the 35 years of the epidemic, the impact of HIV in US communities of MSM remains staggering. We examined prevalence of HIV at the state and county levels, and found that, although there are important local variations in HIV prevalence, the prevalence of HIV among MSM is consistently orders of magnitude higher than among other Americans. Whereas prevalence of HIV is routinely expressed in cases per 100,000 persons for other groups, for MSM, we report cases per 100 persons [5]. The levels of prevalence among MSM correspond to international benchmarks for epidemicity or hyperendemicity, with all 50 states at least tripling the prevalence criterion for generalized epidemics among MSM (>1% prevalence) and 6 states (all in the South) meeting the UNAIDS criterion for hyperendemicity (>15% prevalence) [21]. The county-level findings demonstrate that although most HIV infections among MSM are concentrated among urban-dwelling MSM, rural areas still represent important places of HIV burden that may be underserved by HIV prevention and care services [5, 22]. Furthermore, rates of new diagnoses among MSM provide insight into the ongoing trajectory of the epidemic, providing a national, regional, and local view of an epidemic force of infection that requires urgent response and prioritization [23].

Our analysis builds on previous reports of the importance of local variations in social and structural epidemic determinants [24], and underscores previous identification of the US South as the area of greatest concentration of HIV infection [10]. In terms of state-specific HIV prevalence rates among MSM, 9 of the top 10 are in the South. We also have new evidence that the HIV epidemic in the South is continuing to grow disproportionately to other regions. New HIV diagnoses rates among MSM for 2013 show that the top 13 states were all in the South, with 10 states having new diagnoses rates of >1% per year. These concentrations of new diagnoses in the South might represent relative increases in new transmissions or could represent previous successes in reducing HIV transmissions among MSM outside the South [25-27]. Our analysis furthers previous surveillance reports and analyses by recognizing that there are differences in the distribution of MSM by state and by county; having high-quality estimates of MSM denominators allows for more reliable comparisons in prevalence and diagnosis rates across geographic areas. Denominators also allow for a more direct quantification of the health disparity among MSM than do rates expressed against a denominator of all men.

Our estimates of HIV prevalence differ importantly from previous estimates of HIV prevalence in the United States. The study by Purcell et al, based on data from 37 states, reported a diagnosed HIV prevalence among MSM in 2007 of about 8% [2, 28]. Our estimate for 2012, including data from all states and the District of Columbia, is that diagnosed HIV prevalence was 11% and that, including estimated undiagnosed infections, 15% of US MSM live with HIV infection. Previous data from the National HIV Behavioral Surveillance System (NHBS) have shown higher HIV prevalence (18% in 2011) among MSM recruited in high-risk venues in the 20 largest cities in the United States [29, 30]; these differences likely reflect selection bias for men in high-risk venues, and the higher risk of HIV infection in urban areas. Our findings have relative advantages over NHBS-derived estimates because of population-based sources of numerator and denominator data and inclusion of areas outside the largest US cities, including rural areas.

Evaluating and monitoring data in smaller geographic areas is critical to making effective local responses and to measuring their impact. Indeed, the first step of the first goal of the NHAS is to assess the communities in which HIV is more *concentrated*[11]. Our data are also of relevance to the updated National Strategy [31]. In terms of Goal 3, reducing HIV-related disparities, our new data illustrate the extent of the health disparity among MSM—a staggering 57-fold disparity in diagnosed HIV prevalence rates among MSM compared with other US men. Because our method of calculating rates of new HIV diagnoses among MSM can be updated annually, it can also serve as a source of data to evaluate Indicator 9, measures of health disparities among MSM. The updated NHAS uses a denominator of all men to calculate the rate of new HIV diagnoses among MSM nationally, which was the best available data at the time. However, at the local level, similar metrics will have varying amounts of bias, depending on the relative concentration of MSM in a particular jurisdiction. Thus, for local planning and evaluation, rates based on local MSM denominators should be used. To most comprehensively address this purpose, it will require developing similar race-specific estimates of MSM at the state and county levels. Such data are not yet available but would be important for the ongoing evaluation of an epidemic with profound disparities by race and ethnicity.

Limitations

These results have important limitations. Because all residential locations informing HIV case numerators were determined at the time of diagnosis, and the denominators were based on recent ACS data, postdiagnosis migration and undercounting of nonresidents may contribute to mismeasurement. Furthermore, there are differences in the time frames for assessment of male-male sex for numerators and denominators. HIV surveillance classifies males as MSM if the individual reports any sex with a man since 1977, whereas MSM denominators were defined as having male-male sex in the previous 5 years [1, 17]. This shorter time frame is more informative for assessing public-health-actionable HIV burden, compared with a lifetime definition of male-male sex. However, to the extent that some men living with HIV were classified as MSM at the time of diagnoses but may not have engaged in sexual activity in the previous 5 years, some inflation of prevalence may be observed. There is also a potential age mismatch between the HIV case surveillance-based numerator data and the MSM population size denominators. Publicly available HIV surveillance data reports MSM cases for all persons 13 years of age and older, whereas MSM population size methodologies are for MSM 18 years of age and older. This potentially inflates MSM prevalence. However, persons aged 13-19 years compose only 0.96% of all US HIV diagnoses and diagnosed HIV prevalence is low among MSM aged 13-17 years, so the extent of this bias is likely minimal [1, 32].

Conclusions

Surveillance data have been described as the conscience of the HIV epidemic [33], and the new insights provided here on the rates of HIV prevalence and new diagnoses for US MSM constitute a call of conscience for heightened responses and improved monitoring of HIV epidemics among MSM, especially in the South. Across the United States, MSM are affected by HIV at rates that are orders of magnitude higher than for other Americans. This health disparity is even more pronounced in the South. There is a need for increased resources for HIV prevention, treatment, and care for MSM. In the South, this must include expansion of access to health care through Medicaid expansion under the Affordable Care Act; increased access to comprehensive HIV prevention services, including for preexposure prophylaxis (PrEP); and increased resources for programs to support immediate referrals for antiretroviral therapy for those who are newly diagnosed with HIV. Despite the disproportionate impact of HIV in the South, PrEP uptake among MSM is lower in the South than in other geographic areas [34, 35]. In terms of monitoring, we believe that our analysis illustrates the power of having denominators available to characterize health outcomes of sexual minority groups, and we join the Institute of Medicine’s call [36] to collect data on sexual orientation and gender identity in federal data collections and electronic health records, as well as to consider collecting such data in the United States Census. The health disparities in HIV for US MSM illustrated in this report are intolerable, and we call for urgent action to meet the treatment and care needs of those MSM living with HIV and to support all available evidence-based approaches to prevent new infections.

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Conflicts of Interest

THS and PSS are editors at JMIR Public Health and Surveillance. Because of this, the paper was handled by another academic editor and THS and PSS played no role in assigning reviewers or making editorial decisions.

Multimedia Appendix 1

Supplement with additional data and sensitivity analyses.

[PDF File (Adobe PDF File), 250KB - publichealth_v2i1e22_app1.pdf]

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Abbreviations

ACS: American Community Survey
CDC: Centers for Disease Control and Prevention
HIV: human immunodeficiency virus
MSA: metropolitan statistical area
MSM: men who have sex with men
NHANES: National Health and Nutrition Examination Survey
NHAS: United States National HIV/AIDS Strategy
NHBS: National HIV Behavioral Surveillance System
PrEP: preexposure prophylaxis

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Original Paper

Estimating the Population Sizes of Men Who Have Sex With Men in US States and Counties Using Data From the American Community Survey

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Abstract

Background: In the United States, male-to-male sexual transmission accounts for the greatest number of new human immunodeficiency virus (HIV) diagnoses and a substantial number of sexually transmitted infections (STI) annually. However, the prevalence and annual incidence of HIV and other STIs among men who have sex with men (MSM) cannot be estimated in local contexts because demographic data on sexual behavior, particularly same-sex behavior, are not routinely collected by large-scale surveys that allow analysis at state, county, or finer levels, such as the US decennial census or the American Community Survey (ACS). Therefore, techniques for indirectly estimating population sizes of MSM are necessary to supply denominators for rates at various geographic levels.

Objective: Our objectives were to indirectly estimate MSM population sizes at the county level to incorporate recent data estimates and to aggregate county-level estimates to states and core-based statistical areas (CBSAs).

Methods: We used data from the ACS to calculate a weight for each county in the United States based on its relative proportion of households that were headed by a male who lived with a male partner, compared with the overall proportion among counties at the same level of urbanicity (ie, large central metropolitan county, large fringe metropolitan county, medium/small metropolitan county, or nonmetropolitan county). We then used this weight to adjust the urbanicity-stratified percentage of adult men who had sex with a man in the past year, according to estimates derived from the National Health and Nutrition Examination Survey (NHANES), for each county. We multiplied the weighted percentages by the number of adult men in each county to estimate its number of MSM, summing county-level estimates to create state- and CBSA-level estimates. Finally, we scaled our estimated MSM population sizes to a meta-analytic estimate of the percentage of US MSM in the past 5 years (3.9%).

Results: We found that the percentage of MSM among adult men ranged from 1.5% (Wyoming) to 6.0% (Rhode Island) among states. Over one-quarter of MSM in the United States resided in 1 of 13 counties. Among counties with over 300,000 residents, the five highest county-level percentages of MSM were San Francisco County, California at 18.5% (66,586/359,566); New York County, New York at 13.8% (87,556/635,847); Denver County, Colorado at 10.5% (25,465/243,002); Multnomah County, Oregon at 9.9% (28,949/292,450); and Suffolk County, Massachusetts at 9.1% (26,338/289,634). Although California (n=792,750) and Los Angeles County (n=251,521) had the largest MSM populations of states and counties, respectively, the New York City-Newark-Jersey City CBSA had the most MSM of all CBSAs (n=397,399).

Conclusions: We used a new method to generate small-area estimates of MSM populations, incorporating prior work, recent data, and urbanicity-specific parameters. We also used an imputation approach to estimate MSM in rural areas, where same-sex sexual behavior may be underreported. Our approach yielded estimates of MSM population sizes within states, counties, and metropolitan areas in the United States, which provide denominators for calculation of HIV and STI prevalence and incidence at those geographic levels.

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KEYWORDS

sexual behavior; population; men who have sex with men; demography

Introduction

In the United States, male-to-male sexual transmission accounted for 58-65% of human immunodeficiency virus (HIV) diagnoses from 2009 to 2013 [1], despite the fact that a relatively small proportion of men in the United States are men who have sex with men (MSM) [2]. Prior work on estimating the population size of MSM in the United States [2-5] and at the city [6] and state [3,7-10] levels show that prevalence and incidence rates of HIV and some sexually transmitted infections (STIs) are higher among MSM than other groups. In order to estimate the prevalence or incidence rates of HIV or other STIs among MSM in additional areas, we need to estimate the denominator of population size [2].

Having male sex partners is not necessarily the same as self-identification as gay, bisexual, or queer . MSM defines a group of men behaviorally and temporally, and is preferred by public health researchers over identities such as gay or bisexual men because behavior, not identity, leads to sexual transmission of HIV and STIs. Many MSM self-identify as gay or bisexual, but not all. Thus, reports such as a recent Gallup publication [11] that estimate population sizes of lesbian, gay, bisexual, or transgender (LGBT) individuals have limited use for public health. The choice of timeframe influences the estimated percentage of MSM among adult men, and consequently, the estimated size of the MSM population. Most studies use “sex with a man in the past 12 months,” “sex with a man in the past 5 years,” or “any sex with a man ever,” with longer recall periods leading to higher population size estimates [2].

Data regarding cohabitating same-sex partners are collected by the US Census Bureau, but behavioral data on same-sex behavior among men are not. Therefore, researchers studying MSM populations often use estimates from national probability surveys such as the General Social Survey (GSS) [12], National Health and Social Life Survey (NHSLS) [13], National Health and Nutrition Examination Survey (NHANES) [14], and National Survey of Family Growth (NSFG) [4,5,15]. The most recent effort to synthesize data from multiple studies in order to estimate the percentage of MSM among adult men in the United States comes from a meta-analysis of these and other data sources by Purcell and colleagues [2]. However, given uneven geographic dispersion of MSM in the United States, national estimates are inadequate for state and local prevention planning. Examining HIV prevalence and incidence at smaller geographic levels, and comparing HIV burden among MSM in different areas, requires estimation approaches at finer levels.

Several methods have been proposed to estimate state and local population sizes of MSM. Some researchers begin with HIV prevalence assumptions and work backward to determine the population size of MSM in a given area. For example, Lieb and colleagues [16] used data on HIV prevalence among a probability sample of MSM to estimate the number of MSM in six large metropolitan statistical areas (MSAs) in Florida. Other researchers have used data from the US Census Bureau and from large, national health surveys to generate state [3,7,10] and county [9,17-19] MSM population estimates. Gates and Black [20] reported findings separately from the GSS and NHSLS as well as from the 1990 US Census.

One recent approach used both data from the American Community Survey (ACS) and NHSLS estimates [7]. Lieb and colleagues [10] proposed two models to estimate state population sizes for MSM. The first, Model A, assumes different percentages of MSM among men in urban, suburban, and rural areas. For those percentages, Lieb et al. [10] refer to estimates reported by Laumann and colleagues [13] from the 1992 NHSLS. They multiply these percentages by each state’s proportion of total population in rural, suburban, and urban areas, then multiply the result by the 2007 midyear population estimates from the US Census Bureau [3,10]. For Model B, they weight the overall percentage of MSM among US adult men, estimated to be 6% from the 2002 NSFG [3,5,10], according to the representation of same-sex male (SSM) households in a state, relative to the overall proportion of SSM households in the United States as reported in the 2000 Census. They then multiply these weighted percentages by the population in each state, again taken from the 2007 midyear population estimates. The final state estimates are the mean of Models A and B.

Here, we create a new method to estimate the population sizes of MSM in US states, counties, and core-based statistical areas

(CBSAs). Our approach uses elements of Lieb et al.'s [10] Models A and B, data on total and SSM households from ACS 2009 to 2013 [21], urbanicity-stratified estimates of the percentage of adult men who had sex with a man in the past year from NHANES [22], and the meta-analytic estimate of the national percentage of adult men who had sex with a man in the past 5 years [2]. By estimating population sizes at smaller geographic levels and within urbanicity strata, we hope to provide public health practitioners and policy makers with a useful tool for determining disease burden and allocating resources at state and county levels, including among nonurban areas.

Methods

Data

We used data from the ACS 5-year summary file, 2009 to 2013, to obtain the total number of households, total number of SSM households (male householder and male partner), and total number of men aged 18 years and older for each county in the United States (Multimedia Appendix 1) [21]. The ACS is a supplement to the decennial census that provides annual updates to housing and demographic statistics for the United States [23]. Approximately 1 in 38 US households are randomly sampled each year, and the selected individuals respond using either Web-based or paper questionnaires. Staff from the US Census Bureau follow up with individuals who do not respond, in order to improve response rates.

ACS data are publicly available as 1-, 3-, or 5-year summary files or as a Public Use Microdata Sample (PUMS), which contains a de-identified and unaggregated sample of ACS data. The 1- and 3-year summary files are limited to areas with populations of 65,000 or 20,000 or more, respectively. However, the 5-year ACS summary files contain data at all available geographic areas. We did not include data from US territories.

To more accurately describe where MSM reside, we supplemented data from the ACS using the urbanicity categories produced by the National Center for Health Statistics (NCHS) [24]. According to the NCHS classification scheme, counties fall into six categories: central (ie, inner city) or fringe (ie, suburban) portions of large MSAs (population size ≥ 1,000,000 population), medium-sized MSAs (population size of 250,000-999,999), small MSAs (population of < 250,000), micropolitan area (counties that contain all or part of a city of 10,000 or more), and noncore (counties that do not contain any part of a city of 10,000 or more) [24]. In order to incorporate urbanicity-specific percentages of MSM among adult men, we then collapsed the categories according to the four-level urbanicity classification used by Oster et al. [22]: large central metropolitan county, large fringe metropolitan county, medium/small metropolitan county, and nonmetropolitan county.

Analysis

We developed a method to estimate small-area MSM populations by combining two models reported by Lieb et al. [10]. The first, Model A, applied estimates of the percentage of MSM among adult men, stratified by urbanicity, to the adult male population. The second, Model B, weighted the national MSM percentage according to the relative representation of SSM households among all households in an area, referred to as the MSM Index. We combined these two models into a single model by stratifying the MSM Index formula to determine the urbanicity-specific relative representation of SSM households (Figure 1, Equation 1). We then multiplied this within-stratum MSM Index to the urbanicity-specific estimated percentage of MSM among adult men from NHANES, as reported by Oster et al. [22] (Figure 1, Equation 2), to arrive at the percentage of males who are MSM in each county. Next, for each county, the number of MSM was estimated by multiplying the MSM percentage by the total adult males (Figure 1, Equation 3).

Figure 1. Equations 1–3

Equation 1. Calculation of the MSM Index for each county.

$$\text{MSM Index}_{\text{county i, urbanicity j}} = \left(\frac{\text{SSM households}_{\text{county i, urbanicity j}}}{\text{Total households}_{\text{county i, urbanicity j}}}\right) \div \left(\frac{\text{SSM households}_{\text{urbanicity j}}}{\text{Total households}_{\text{urbanicity j}}}\right)$$

Equation 2. Calculation of the estimated percentage of MSM among adult men in each county.

$$\%\ \text{MSM}_{\text{county i, urbanicity j}} = \text{MSM Index}_{\text{county i, urbanicity j}} \times \%\ \text{MSM}_{\text{urbanicity j}}$$

Equation 3. Calculation of the estimated number of MSM in each county.

$$\text{MSM}_{\text{county i, urbanicity j}} = \%\ \text{MSM}_{\text{county i, urbanicity j}} \times \text{Adult males}_{\text{county i, urbanicity j}}$$

By calculating the MSM Index within strata of urbanicity, we expected to reduce inter-urbanicity differences in same-sex cohabitation and reporting among MSM due to stigma. However, 35.4% (1112/3143) counties had no reported SSM households, and consequently had MSM Index values and estimated MSM population sizes of zero, which likely reflected these biases in detection of MSM. To impute MSM in these areas for our final estimates, while preserving the relative population sizes based on SSM households, we added households to both the numerator and denominator of the above equations. For each county, we increased the number of SSM households and the number of total households by adding the urbanicity-specific percentage of SSM households (Figure 2, Equation 4).

Figure 2. Equation 4.

Equation 4. Addition of households to counties in order to impute MSM in areas with no reported SSM households.

$$\widehat{\text{SSM households}}_{\text{county } i,\ \text{urbanicity } j} = \text{SSM households}_{\text{county } i,\ \text{urbanicity } j} + \left(\text{Total households}_{\text{county } i,\ \text{urbanicity } j} \times \%\text{SSM households}_{\text{urbanicity } j}\right)$$

As an example of our imputation method, we will use two hypothetical nonmetropolitan counties. The total percentage of SSM households among all households in nonmetropolitan counties in our data was approximately 0.1%. For a county with 1000 households, of which zero were SSM households, we added one SSM household, or 0.1% of 1000. This meant that, for the part of our model that calculated urbanicity-specific indices, the new totals for that county were 1001 households, of which one was a SSM household. For another nonmetropolitan county with 20,000 households, of which 15 were SSM households, we added 20 SSM households, for a new total of 20,020 households and 35 SSM households. By adding a proportionate number of SSM households to all counties, we effectively maintained the relative representation of SSM households within urbanicity strata while estimating at least some MSM in counties with no SSM households. Because the index was used as a way of weighting the percentage of MSM among adult men in each county and not as a direct method of estimation, adding SSM households did not add MSM to our final population estimates.

For our analysis, we chose to estimate the number of men who had sex with men within the past 5 years, rather than the past 12 months or over the lifetime, as others have reported [2]. Using past-year estimates might underestimate the total sexually active population, particularly because we are using 5-year population estimates, while lifetime estimates would do the opposite: under that scenario, all men who had sex with another man would be counted, regardless of how recent or frequent the behavior. Because NHANES only has data regarding same-sex sex in the past 12 months and over a lifetime, we scaled our results to sum to 3.9% of the US adult male population, the estimated national percentage of adult men who had sex with a man within the past 5 years from the Purcell et al. meta-analysis [2].

All analyses were conducted using R Studio, version 0.98.953 [25]. Data were analyzed at the county level and aggregated to state and the Office of Management and Budget's core based statistical areas (CBSAs). CBSAs refer to both metropolitan and micropolitan statistical areas. MSAs are CBSAs with at least 50,000 people. Micropolitan statistical areas have fewer than 50,000 people.

Results

State Population

Using Purcell et al.'s [2] estimate of 3.9% MSM (past 5 years) among US adult men and summary data from the 2009 to 2013 ACS, we estimated that there are approximately 4,503,080 MSM in the United States. Table 1 presents the state-level population sizes of MSM, ranked from largest MSM population to least. California, which has 12.1% (13,997,953/115,463,694) of the US adult male population according to ACS estimates from 2009 to 2013, had the largest percentage of the US MSM population at 17.6% (792,750/4,503,080). Furthermore, over one-half of US MSM resided in that and the next six states: Texas at 8.3% of US MSM (371,781/4,503,080; New York at 8.2% of US MSM (371,087/4,503,080); Florida at 7.6% of US MSM (340,163/4,503,080); Illinois at 4.4% of US MSM (199,486/4,503,080); Pennsylvania at 3.6% of US MSM (162,745/4,503,080); and Ohio at 3.2% of US MSM (144,367/4,503,080). Despite 52.9% (2,382,379/4,503,080) of the US MSM population residing in those seven states, they represent only 44.6% (51,508,277/115,463,694) of the US adult male population.

County Population

Of the 3143 counties or county-equivalent areas in the United States, we estimated that over one-half of the total US MSM population resided in only 51 (Table 2). The largest number of MSM lived in Los Angeles County, California at 5.6% of US MSM (251,521/4,503,080), followed by cook County, Illinois at 2.8% of US MSM (125,923/4,503,080); Maricopa County, Arizona at 2.0% of US MSM (87,894/4,503,080); New York County, New York at 1.9% of US MSM (87,556/4,503,080); and Harris County, TX at 1.9% of US MSM (83,401/4,503,080). A total of 9.9% (310/3143) US counties had fewer than 20 MSM, and 39.5% (1242/3143) had fewer than 100 (Figure 3).

Table 1. Estimated MSM populations in 50 states and the District of Columbia, ranked by size of MSM population, using housing and population estimates from the American Community Survey, 2009-2013.

		Adult males	MSM	US MSM	
Rank	State	N	n (%)	% of total	Cumulative % of MSM
1	California	13,997,953	792,750 (5.7%)	17.6%	17.6%
2	Texas	9,189,027	371,781 (4.0%)	8.3%	25.9%
3	New York	7,247,605	371,087 (5.1%)	8.2%	34.1%
4	Florida	7,283,572	340,163 (4.7%)	7.6%	41.7%
5	Illinois	4,728,089	199,486 (4.2%)	4.4%	46.1%
6	Pennsylvania	4,798,340	162,745 (3.4%)	3.6%	49.7%
7	Ohio	4,263,691	144,367 (3.4%)	3.2%	52.9%
8	New Jersey	3,257,962	132,520 (4.1%)	2.9%	55.8%
9	Georgia	3,522,525	131,374 (3.7%)	2.9%	58.8%
10	Michigan	3,671,762	113,860 (3.1%)	2.5%	61.3%
11	Virginia	3,030,663	112,785 (3.7%)	2.5%	63.8%
12	Washington	2,590,196	111,960 (4.3%)	2.5%	66.3%
13	Massachusetts	2,477,594	111,625 (4.5%)	2.5%	68.8%
14	Arizona	2,393,283	110,344 (4.6%)	2.5%	71.2%
15	North Carolina	3,536,017	103,010 (2.9%)	2.3%	73.5%
16	Maryland	2,136,890	84,465 (4.0%)	1.9%	75.4%
17	Minnesota	2,000,472	83,027 (4.2%)	1.8%	77.2%
18	Tennessee	2,357,860	73,639 (3.1%)	1.6%	78.9%
19	Colorado	1,939,236	73,357 (3.8%)	1.6%	80.5%
20	Missouri	2,219,565	70,783 (3.2%)	1.6%	82.1%
21	Indiana	2,389,263	70,103 (2.9%)	1.6%	83.6%
22	Oregon	1,472,740	61,607 (4.2%)	1.4%	85.0%
23	Wisconsin	2,154,753	59,078 (2.7%)	1.3%	86.3%
24	Nevada	1,038,437	51,726 (5.0%)	1.1%	87.4%
25	Kentucky	1,621,844	47,034 (2.9%)	1.0%	88.5%
26	Connecticut	1,334,105	43,313 (3.2%)	1.0%	89.4%
27	Louisiana	1,665,801	41,492 (2.5%)	0.9%	90.4%
28	Alabama	1,754,583	40,600 (2.3%)	0.9%	91.3%
29	Oklahoma	1,394,881	37,739 (2.7%)	0.8%	92.1%
30	District of Columbia	239,916	36,775 (15.3%)	0.8%	92.9%
31	South Carolina	1,726,807	36,316 (2.1%)	0.8%	93.7%
32	Utah	962,285	33,294 (3.5%)	0.7%	94.5%
33	Rhode Island	395,905	23,815 (6.0%)	0.5%	95.0%
34	Kansas	1,054,271	22,900 (2.2%)	0.5%	95.5%
35	Iowa	1,145,708	20,753 (1.8%)	0.5%	96.0%
36	Arkansas	1,076,736	19,264 (1.8%)	0.4%	96.4%
37	Mississippi	1,063,557	18,992 (1.8%)	0.4%	96.8%
38	New Mexico	762,051	17,969 (2.4%)	0.4%	97.2%
39	Hawaii	534,961	15,411 (2.9%)	0.3%	97.6%
40	Maine	511,631	15,071 (2.9%)	0.3%	97.9%

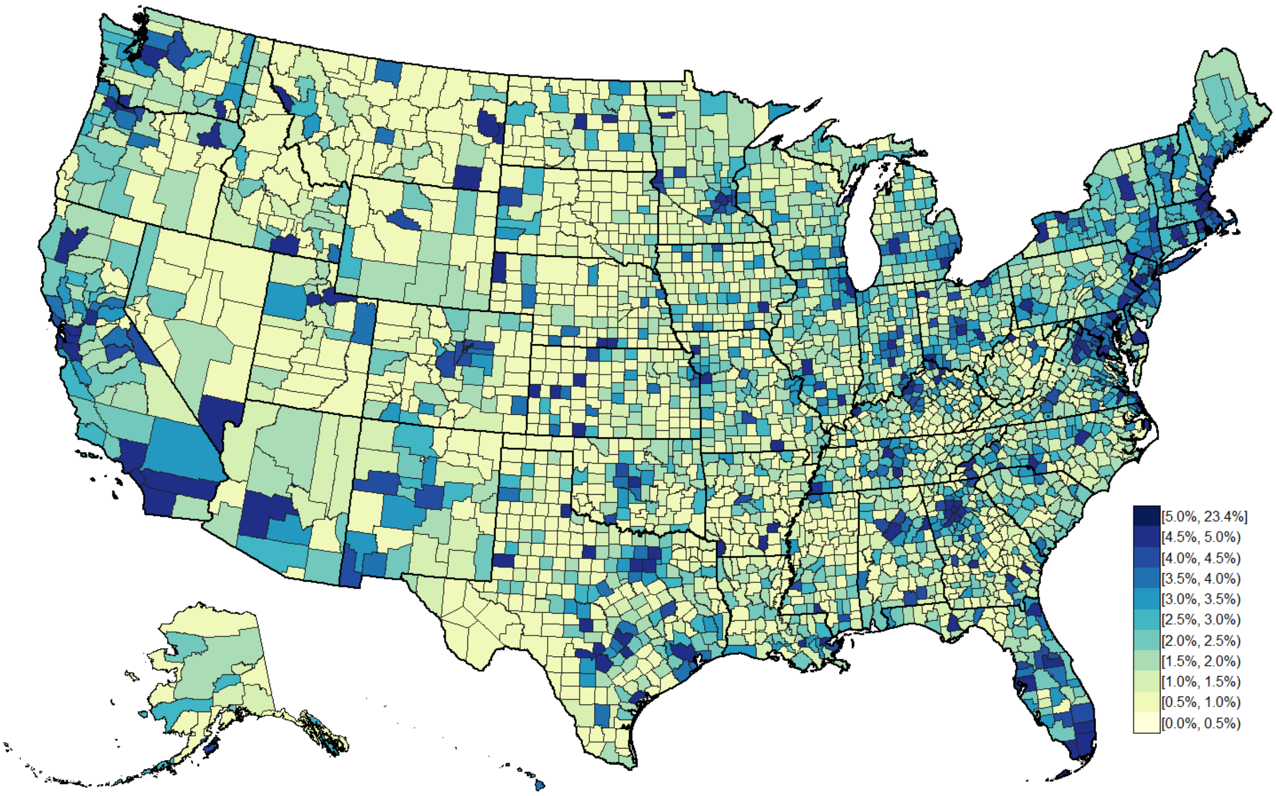
		Adult males	MSM	US MSM	
Rank	State	N	n (%)	% of total	Cumulative % of MSM
41	New Hampshire	507,277	14,122 (2.8%)	0.3%	98.2%
42	Nebraska	678,518	13,199 (1.9%)	0.3%	98.5%
43	West Virginia	716,528	13,063 (1.8%)	0.3%	98.8%
44	Delaware	335,554	13,049 (3.9%)	0.3%	99.1%
45	Idaho	574,213	9,907 (1.7%)	0.2%	99.3%
46	Vermont	243,332	7,069 (2.9%)	0.2%	99.5%
47	Montana	386,653	6,374 (1.6%)	0.1%	99.6%
48	South Dakota	309,108	5,171 (1.7%)	0.1%	99.7%
49	Alaska	278,464	5,074 (1.8%)	0.1%	99.8%
50	North Dakota	270,992	4,447 (1.6%)	0.1%	99.9%
51	Wyoming	220,518	3,225 (1.5%)	0.1%	100.0%
	Total	115,463,694	4,503,080 (3.9%)		

Table 2. The 51 US counties with the largest estimated MSM populations, representing approximately one-half of the estimated US MSM population and ranked according to size of MSM population, using housing and population estimates from the American Community Survey, 2009-2013.

		Adult males	MSM	US MSM		
Rank	County	State	N	n (%)	% of total	Cumulative % of MSM
1	Los Angeles County	CA	3,666,190	251,521 (6.9%)	5.6%	5.6%
2	Cook County	IL	1,905,622	125,923 (6.6%)	2.8%	8.4%
3	Maricopa County	AZ	1,408,797	87,894 (6.2%)	2.0%	10.3%
4	New York County	NY	635,847	87,556 (13.8%)	1.9%	12.3%
5	Harris County	TX	1,490,581	83,401 (5.6%)	1.9%	14.1%
6	San Diego County	CA	1,204,728	80,968 (6.7%)	1.8%	15.9%
7	Riverside County	CA	794,695	70,803 (8.9%)	1.6%	17.5%
8	San Francisco County	CA	359,566	66,586 (18.5%)	1.5%	19.0%
9	Dallas County	TX	855,958	64,385 (7.5%)	1.4%	20.4%
10	Orange County	CA	1,134,443	62,190 (5.5%)	1.4%	21.8%
11	King County	WA	769,969	61,752 (8.0%)	1.4%	23.2%
12	Kings County	NY	895,148	59,767 (6.7%)	1.3%	24.5%
13	Miami-Dade County	FL	956,927	59,733 (6.2%)	1.3%	25.8%
14	Broward County	FL	664,314	58,629 (8.8%)	1.3%	27.1%
15	Clark County	NV	744,929	46,529 (6.2%)	1.0%	28.2%
16	Queens County	NY	855,853	45,656 (5.3%)	1.0%	29.2%
17	Alameda County	CA	578,149	40,924 (7.1%)	0.9%	30.1%
18	Hennepin County	MN	441,369	37,611 (8.5%)	0.8%	30.9%
19	Santa Clara County	CA	689,137	37,041 (5.4%)	0.8%	31.7%
20	District of Columbia	DC	239,916	36,775 (15.3%)	0.8%	32.5%
21	Sacramento County	CA	517,617	34,556 (6.7%)	0.8%	33.3%
22	Tarrant County	TX	645,094	34,529 (5.4%)	0.8%	34.1%
23	Philadelphia County	PA	550,353	33,549 (6.1%)	0.7%	34.8%
24	Bexar County	TX	621,564	32,401 (5.2%)	0.7%	35.5%
25	Franklin County	OH	431,661	31,220 (7.2%)	0.7%	36.2%
26	Travis County	TX	407,740	30,741 (7.5%)	0.7%	36.9%
27	Orange County	FL	438,963	30,732 (7.0%)	0.7%	37.6%
28	Fulton County	GA	348,541	30,169 (8.7%)	0.7%	38.3%
29	Wayne County	MI	638,235	30,161 (4.7%)	0.7%	38.9%
30	Multnomah County	OR	292,450	28,949 (9.9%)	0.6%	39.6%
31	Hillsborough County	FL	461,567	28,246 (6.1%)	0.6%	40.2%
32	Middlesex County	MA	577,698	28,122 (4.9%	0.6%	40.8%
33	Allegheny County	PA	466,388	26,666 (5.7%)	0.6%	41.4%
34	Suffolk County	MA	289,634	26,338 (9.1%)	0.6%	42.0%
35	Cuyahoga County	OH	460,353	25,837 (5.6%)	0.6%	42.6%
36	Denver County	CO	243,002	25,465 (10.5%)	0.6%	43.2%
37	Pinellas County	FL	358,997	25,204 (7.0%)	0.6%	43.7%
38	Suffolk County	NY	556,340	24,597 (4.4%)	0.5%	44.3%
39	San Bernardino County	CA	722,111	24,060 (3.3%)	0.5%	44.8%
40	Salt Lake County	UT	372,182	23,244 (6.2%)	0.5%	45.3%

Rank	County	Adult males State	MSM N	US MSM n (%)	% of total	Cumulative % of MSM
41	Palm Beach County	FL	510,352	22,727 (4.5%)	0.5%	45.8%
42	Bronx County	NY	469,573	22,370 (4.8%)	0.5%	46.3%
43	Mecklenburg County	NC	336,345	20,920 (6.2%)	0.5%	46.8%
44	DeKalb County	GA	249,589	20,302 (8.1%)	0.5%	47.2%
45	Marion County	IN	323,768	19,553 (6.0%)	0.4%	47.7%
46	Wake County	NC	331,066	19,021 (5.7%)	0.4%	48.1%
47	Contra Costa County	CA	387,213	18,974 (4.9%)	0.4%	48.5%
48	Erie County	NY	344,098	18,706 (5.4%)	0.4%	48.9%
49	Hudson County	NJ	251,902	18,523 (7.4%)	0.4%	49.3%
50	Milwaukee County	WI	339,381	18,428 (5.4%)	0.4%	49.7%
51	Shelby County	TN	321,669	17,466 (5.4%)	0.4%	50.1%

Figure 3. Estimated percentage of adult men who had sex with a man in the past 5 years, using housing and population estimates from the 2009-2013 American Community Survey.



Core-Based Statistical Areas

By aggregating our county-level findings to CBSAs, we found that 97.4% (4,384,172/4,503,080) of the MSM in our model resided in the 917 CBSAs in the United States. One-half (2,251,068/4,503,080) lived in one of 16 CBSAs (Table 3), all of which were MSAs. Of those residing in a CBSA, the largest population of MSM was in the New York-Newark-Jersey City CBSA at 8.8% of US MSM (397,399/4,503,080); followed by Los Angeles-Long Beach-Anaheim at 7.0% of US MSM (313,711/4,503,080); Chicago-Naperville-Elgin at 3.9% of US MSM (175,118/4,503,080); San Francisco-Oakland-Hayward at 3.2% of US MSM (145,972/4,503,080); and Miami-Fort Lauderdale-West Palm Beach at 3.1% of US MSM (141,088/4,503,080). Thus, 26.1% (1,173,288/4,503,080) of the MSM in the United States live in these five areas.

Table 3. The 16 CBSAs with the largest estimated MSM populations, representing one-half of the US MSM population and ranked according to size of MSM population, using housing and population estimates from the American Community Survey, 2009-2013.

		Adult males	MSM	US MSM	
Rank	State	N	n (%)	% of total	Cumulative % of MSM
1	New York-Newark-Jersey City	7,239,158	397,399 (5.5%)	8.8%	8.8%
2	Los Angeles-Long Beach-Anaheim	4,800,633	313,711 (6.5%)	7.0%	15.8%
3	Chicago-Naperville-Elgin	3,443,489	175,118 (5.1%)	3.9%	19.7%
4	San Francisco-Oakland-Hayward	1,700,219	145,972 (8.6%)	3.2%	22.9%
5	Miami-Fort Lauderdale-West Palm Beach	2,131,593	141,088 (6.6%)	3.1%	26.1%
6	Dallas-Fort Worth-Arlington	2,320,338	133,944 (5.8%)	3.0%	29.0%
7	Washington-Arlington-Alexandria	2,113,258	122,895 (5.8%)	2.7%	31.8%
8	Houston-The Woodlands-Sugar Land	2,159,519	103,722 (4.8%)	2.3%	34.1%
9	Atlanta-Sandy Springs-Roswell	1,899,899	102,642 (5.4%)	2.3%	36.3%
10	Philadelphia-Camden-Wilmington	2,189,761	100,293 (4.6%)	2.2%	38.6%
11	Riverside-San Bernardino-Ontario	1,516,806	94,863 (6.3%)	2.1%	40.7%
12	Phoenix-Mesa-Scottsdale	1,557,094	92,825 (6.0%)	2.1%	42.7%
13	Boston-Cambridge-Newton	1,729,903	92,527 (5.3%)	2.1%	44.8%
14	Seattle-Tacoma-Bellevue	1,342,052	82,002 (6.1%)	1.8%	46.6%
15	San Diego-Carlsbad	1,204,728	80,968 (6.7%)	1.8%	48.4%
16	Minneapolis-St. Paul-Bloomington	1,247,688	71,099 (5.7%)	1.6%	50.0%

Discussion

Principal Results

We used recent estimates of the population size of US MSM [2], data from ACS 2009 to 2015 [21], and recent estimated percentages of MSM among adult men by urbanicity [22] with an existing estimation method [10] to estimate state-, county-, and CBSA-level populations of MSM. Based on the relative representation of SSM households and prior estimates of MSM percentages in large central metropolitan areas, large fringe metropolitan areas, medium and small metropolitan areas, and nonmetropolitan areas [22], we found that a majority of MSM live within relatively few counties and CBSAs. Our method is a relatively simple, robust approach to estimating small-area population sizes for MSM that can easily be updated as new data become available.

Our findings are consistent with other studies, although ours is the first to use this method at this fine of a geographic level for the entire country. For example, Gallup's March, 2015 [11] report on the LGBT population sizes found that the San Francisco-Oakland-Hayward, California, metropolitan area had the highest percentage of LGBT individuals among the general population. This same metropolitan area had the highest percentage of MSM among adult men, according to our method. Furthermore, our estimated number of MSM in San Francisco County, 66,586, was very close to a method that incorporated HIV prevalence estimates and HIV diagnoses: Raymond and colleagues [6] estimated 66,487 MSM in the same area in 2010, which is within the timeframe of our ACS data.

Despite similarities with other studies, our results were different from other recent publications, notably the ones from which we derived part of our method. We estimated fewer MSM at the state level than Lieb and colleagues [3] did in their 2011 article. We also estimated fewer MSM at the state and county level in Texas than Campagna et al. [17,18]. However, Lieb et al. [3] and Campagna et al. [17,18] used a higher estimated proportion of MSM in urban areas for their studies [13]. There are also several additional assumptions about geography in their models that likely contribute to differences: Lieb and colleagues [10] use “urbanized,” “within urban cluster,” and “rural” designations from the US Census Bureau to approximate urban, suburban, and rural, as reported by Laumann et al. [13]. However, “urbanized” and “within urban cluster” refer to metropolitan and micropolitan areas, respectively, or areas with more than 50,000 individuals and areas with greater than 2500 individuals but less than 50,000 individuals. Under these definitions, many suburban areas would be considered “urbanized,” while rural communities might be considered “within urban cluster.”

In addition to the different definitions of urbanicity, the percentages cited by Lieb et al. [10], 1% for rural areas, 4% for suburban areas, and 9% for urban areas, represent Laumann and colleagues' [13] estimates for gay identity, rather than same-sex behavior. Within the identity category, those percentages were derived from individuals in the urban cores and suburbs of the “top 12 urban areas.” Thus, Model A appears to apply an identity-based measure from major metropolitan areas to different classifications from the US Census Bureau.

Our findings substituted the Laumann et al. [13] estimates with those from Oster and colleagues [22]. We also allowed MSM to exist in areas with no reported SSM households, and we scaled our findings to Purcell and colleagues' [2] national estimate for the percentage of adult men who had sex with a man in the past 5 years. Consequently, our methods and its results represent a new, improved approach to the important work by Lieb and colleagues [3,7-10,19].

Limitations

We made several assumptions and adjustments to prior methods that may limit the interpretation and use of our results. First, we decided that computing the MSM Index according to stratum would more accurately compare geographic areas, given possible within-urbanicity tendencies for MSM either not to cohabitate or to underreport SSM households. However, it may be that it is more accurate to compare all geographic areas, rather than to generate urbanicity-specific MSM Index values. Second, we used urbanicity-specific MSM percentages from Oster and colleagues [22], rather than the original estimates from Laumann et al. [13]. However, the urbanicity estimates from Laumann et al. [13] are identity-based, and the Oster et al. [22] estimates provided the most congruent urbanicity classifications for Model A. Finally, in order to avoid underestimating the number MSM outside of large urban areas, we imputed a proportional number of MSM to areas with no reported SSM households. It may be that some areas with no SSM households truly also have no MSM. However, the relative percentages of MSM (and resulting MSM population sizes) in all areas was mostly preserved because we altered the number of households and not the number of individuals, which was used only for weighting.

In addition to our method, our findings may be limited by our use of ACS data. The ACS is a sample of the population that is weighted, unlike the decennial census, which contains more data. As a result, inferences based on the ACS may be less accurate than data from the decennial census. ACS might also miss some of the same-sex households that are not in urban areas, particularly if they are less likely to respond to a survey other than the decennial census. It could also be due to more cohabitation, including marriage, among same-sex couples due to differences in legislation permitting marriage. However, because our data span several years, we cannot determine the extent to which policies and laws regarding marriage influence geographic differences.

Conclusions

Small-area estimates of MSM populations that incorporate the most recent data and estimates available may provide a useful tool to public health practitioners and policy makers for determining the burden of HIV and STIs among MSM in local contexts and planning prevention and treatment responses. Our method produced similar results to a recent effort to estimate MSM population sizes in San Francisco County but different from other studies that used a similar method, largely due to differences in the assumptions underlying the models. The method we presented can be updated annually as new ACS data are released, which would provide counties and larger geographic areas with up-to-date population sizes and, potentially, incidence and prevalence rates. These local statistics would allow for better resource allocation, intervention development, and service delivery. For data from the current analysis and for future updates, visit the study website [26].

The findings and conclusions in this manuscript are solely the responsibility of the authors and do not necessarily represent the official views of the Centers for Disease Control and Prevention or the Department of Health and Human Services.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Variable names and locations of key data from the American Community Survey, 2009-2013.

[PDF File (Adobe PDF File), 103KB - publichealth_v2i1e14_app1.pdf]

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Abbreviations

ACS: American Community Survey
CBSA: core-based statistical area
GSS: General Social Survey
HIV: human immunodeficiency virus
MSA: metropolitan statistical area
MSM: men who have sex with men
NHANES: National Health and Nutrition Examination Survey
NHSLS: National Health and Social Life Survey
NSFG: National Survey of Family Growth
SD: standard deviation
SSM: same-sex male
STI: sexually transmitted infection

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Original Paper

Improving HIV Surveillance Data for Public Health Action in Washington, DC: A Novel Multiorganizational Data-Sharing Method

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Abstract

Background: The National HIV/AIDS Strategy calls for active surveillance programs for human immunodeficiency virus (HIV) to more accurately measure access to and retention in care across the HIV care continuum for persons living with HIV within their jurisdictions and to identify persons who may need public health services. However, traditional public health surveillance methods face substantial technological and privacy-related barriers to data sharing.

Objective: This study developed a novel data-sharing approach to improve the timeliness and quality of HIV surveillance data in three jurisdictions where persons may often travel across the borders of the District of Columbia, Maryland, and Virginia.

Methods: A deterministic algorithm of approximately 1000 lines was developed, including a person-matching system with Enhanced HIV/AIDS Reporting System (eHARS) variables. Person matching was defined in categories (from strongest to weakest): exact, very high, high, medium high, medium, medium low, low, and very low. The algorithm was verified using conventional component testing methods, manual code inspection, and comprehensive output file examination. Results were validated by jurisdictions using internal review processes.

Results: Of 161,343 uploaded eHARS records from District of Columbia (N=49,326), Maryland (N=66,200), and Virginia (N=45,817), a total of 21,472 persons were matched across jurisdictions over various strengths in a matching process totaling 21 minutes and 58 seconds in the privacy device, leaving 139,871 uniquely identified with only one jurisdiction. No records matched as medium low or low. Over 80% of the matches were identified as either exact or very high matches. Three separate validation methods were conducted for this study, and they all found ≥90% accuracy between records matched by this novel method and traditional matching methods.

Conclusions: This study illustrated a novel data-sharing approach that may facilitate timelier and better quality HIV surveillance data for public health action by reducing the effort needed for traditional person-matching reviews without compromising matching accuracy. Future analyses will examine the generalizability of these findings to other applications.

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KEYWORDS

HIV; surveillance; data sharing; public health; technology

Introduction

The US National HIV/AIDS Strategy has an increased focus on retention and re-engagement in medical care and therefore includes an action step to “strengthen the timely availability and use of data” [1]. It calls upon human immunodeficiency virus (HIV) surveillance programs to better measure the continuum of care for persons living with HIV (PLWH) in their jurisdictions and also to identify individuals who are in need of public health services aimed at improving linkage, retention, and viral suppression for PLWH. These activities are often described as data to care (D2C), as they utilize HIV surveillance data for public health action [2]. To effectively perform these D2C activities, HIV surveillance programs need more complete, accurate, and timely measures of PLWH currently in their jurisdictions, and information on whether and where they are receiving care, and their health status (eg, antiretroviral therapy use, CD4, and viral load measurements). However, several challenges that affect HIV surveillance programs’ D2C activities still remain, including technical (eg, data format, missing data caused by case migration across jurisdictions, out-of-jurisdiction care utilization by HIV cases, and incomplete reporting by out-of-jurisdiction laboratories used by in-jurisdiction HIV care providers), motivational (opportunity cost), economic (ownership/copyright), privacy, and ethical barriers [3,4].

Cross-jurisdictional notification of HIV cases, as directed by the Centers for Disease Control and Prevention (CDC) and the Council of State and Territorial Epidemiologists, was designed to ensure that all HIV cases are reported, but it does not function well at tracking PLWH and their residence data over time or reporting all instances of HIV care. The existing national de-duplication process, the Routine Interstate Duplicate Review (RIDR), is time- and resource-intensive, operates with a significant delay between case report and duplicate resolution, and most importantly, focuses mainly on residence at initial diagnosis [5]. RIDR therefore does not adequately serve as an effective tool to notify jurisdictions of updates to vital status or address information, or to provide updated information on migration or participation in out-of-jurisdiction care.

Effective utilization of big data can now facilitate timelier HIV surveillance. Previous studies have demonstrated the potential of effective data sharing technologies. In 2008, Pacheco et al developed a hierarchical deterministic linkage technique and fully automated matching algorithm for recovering the vital status of people from different cohort data in Brazil [6]. They did so to facilitate investigators’ efforts at finding people lost to follow-up in mortality databases. Effective technological advances can help public health officials develop more up-to-date models of HIV diagnosis, linkage to, and retention in care in the United States and elsewhere.

The US mid-Atlantic region experiences some of the highest HIV prevalence rates among key population groups in the country and is therefore critical to the national response to HIV [7]. Health officials in this region have long hypothesized movement of PLWH across the jurisdictions of the District of Columbia (DC), the State of Maryland (MD), and the Commonwealth of Virginia (VA), but traditional barriers to data sharing have prevented comprehensive examinations of this phenomena. In addition, there has been a longstanding dialogue about HIV in the Washington, DC, metropolitan region between Georgetown University and the DC Department of Health on elements of clinical care, longitudinal research, student internships, project planning, and many shared speaking engagements, and also collaboration through the District of Columbia Center for AIDS Research (DC-CFAR). Therefore, in January 2013, health officials from DC, MD, and VA and others met at Georgetown University to discuss regional sharing of HIV/AIDS data in the Washington DC metropolitan region (including areas in DC, MD, and VA). During the meeting, they identified the pressing need for a novel and more timely approach to sharing HIV surveillance data for D2C activities in this region. They emphasized that any such approach must account for the highly private and sensitive nature of public health data. Following these aims, this study used a novel data-sharing approach to examine cross-jurisdictional person-matches of PLWH among the public health departments of DC, MD, and VA.

Methods

Study Population

The study population included all persons with valid Enhanced HIV/AIDS Reporting System (eHARS) records in DC, MD, and VA databases from 1981 to 2015. eHARS is a Web-based data system with an SQL-server back-end that is provided by the CDC to all jurisdictions that collect HIV surveillance data. Most jurisdictions maintain their HIV surveillance data in eHARS, and all jurisdictions submit monthly data to the CDC through eHARS. SAS versions 9.3 and 9.4 were used to preprocess data from eHARS into a standardized format across jurisdictions. These criteria excluded noncases, perinatal HIV exposure records, records still under investigation, and not yet designated as cases, and cases with errors, required fields missing, or marked for deletion/purging.

Institutional Review Board and Privacy

The study was reviewed by the Georgetown University Institutional Review Board and was deemed exempt because of the experimental design and computer technology that specifically prevents persons from seeing person-identifiable information, including the Health Insurance Portability and Accountability Act (HIPAA)-protected information (see Multimedia Appendix 1). For pre- and post-experiment disaggregated data processing and analysis of HIPAA-protected information, each public health department followed internal procedures specific to their jurisdiction. A collaboratively developed project-specific data security and confidentiality procedures manual was applied in this study and was signed by all jurisdictions and Georgetown University representatives.

Algorithm, Hardware, and System Configuration

Ada is a structured programming language defined by ISO/IEC 8652:2012. Originally funded by the United States Department of Defense in 1973 to supersede hundreds of programming languages then in use, Ada was specifically designed for high integrity applications where code safety and reliability is paramount. The Ada programming language was selected for algorithm implementation here because of its unambiguous semantics, extremely strong type and constraint checking, exception protections, and overall reliability philosophy. A deterministic treatment sustainment algorithm of approximately 1000 lines and a technologically robust computer (ie, the privacy device) and physically secure environment were used in this study (see Multimedia Appendix 1; [8]) following a privacy technology approach previously described [9]. For identifying false positives (ie, people who matched across jurisdictions but should not have been matched) or locating false negatives (ie, people who were not matched across jurisdictions but should have been matched), manual case investigations of suspected cases were conducted by each jurisdiction. No direct access existed between jurisdictions’ eHARS servers and the privacy device. Instead, jurisdictions posted information onto a secure file transfer protocol site that then sent information (synthetic test and real eHARS data) to the privacy device.

Algorithm Testing and Verification Using Synthetic Data

Verification of the privacy device system was undertaken using conventional component testing methods, manual code inspection, and comprehensive output file examination. A separate, but similar computer from the production company was used for testing and verification of the program described above. Facilitated by the participating jurisdictions and the CDC, a large corpus of synthetic test data were made available to test the algorithm. The majority of programming errors were identified in the conversion process of external data files. Once ingested and represented within Ada's strongly typed framework, no errors that would result in program failure were identified. Thorough testing of the algorithm uncovered an incorrect assumption about the initial value of the variable at the beginning of a programming loop under wildcard matching conditions. This error was detected and corrected with the aid of Ada 2012 preconditions and inline assertions. The matching algorithm categories included (from strongest to weakest): exact, very high, high, medium high, medium, medium low, low, and very low (see Table 1).

Table 1. Overview of categories and definitions used in the study’s person-matching algorithm.

Matching categories	Variable definitions[a]
Exact	if m.last_name and m.first_name and m.dob and m.ssn and m.sex and m.race then m.score := exact;
Very high	elsif (m.last_name and m.first_name and m.dob and m.sex) or m.ssn then m.score := very_high;
High	elsif m.last_name and m.first_name and m.dob and (m.sex or m.race) then m.score := high;
Medium high	elsif m.last_name and m.first_soundex and m.dob and m.sex then m.score := medium_high;
Medium (1st definition)	elsif m.last_name and m.dob and m.sex and m.race then m.score:= medium;
Medium (2nd definition)	elsif m.last_soundex and m.first_soundex and m.dob and (m.sex or m.race) then m.score := medium;
Medium low	elsif m.last_soundex and m.first_soundex and m.partial_dob and m.partial_ssn and (m.sex or m.race) then m.score := medium_low;
Low	elsif m.last_soundex and (m.partial_dob and m.partial_ssn) and (m.sex or m.race) then m.score := low;
Very low	elsif m.last_soundex and (m.partial_dob or m.partial_ssn) then m.score := very_low;

[a] Last name=Last name of PLWH in eHARS person file; First name=First name of PLWH in eHARS person file; DOB=Date of birth of PLWH in eHARS person file; SSN=Social Security Number of PLWH in eHARS person; Race=hierarchical race/ethnicity assignment for PLWH in eHARS person-view; Soundex=Soundex is a phonetic, alphanumeric code created by converting a name into an index letter and a 3-digit code. The index letter is the first letter of the name. The 3-digit code is calculated from the remaining letters of the name, based on rules found in the eHARS Technical Guidance. There is a Soundex variable for first name and a Soundex for last Name.

Output Validation

Three separate validation methods were used to verify the findings of the privacy device to ensure validity across all jurisdictions.

DC utilized Link Plus software to validate the matching algorithm returns using the following parameters selected on the basis of being frequently used for other internal matching purposes: first name, last name, date of birth, and social security number. The Link Plus–selected matching method for first name and last name was "exact" and the matching method for date of birth and social security number was "generic string." Generic string was selected for date of birth and social security number to allow for matches of partial dates of birth and social security number. A minimum selection score of zero was selected in order to maximize the number of potential matches that would be manually reviewed. Link Plus selected potential matches at 95% confidence interval based on the parameters specified, and cases that were not within the confidence interval for the four selected parameters were deemed nonmatches by the program and were exported and not reviewed. For cases that were reviewed, a hierarchy was used to determine where a case was a match: (1) all cases with exact matches with all four parameters were deemed matches; (2) all cases with matching social security numbers (even in cases where there were discrepancies in the other three parameters) were deemed matches; (3) for all four parameters, a fuzzy match approach was taken to determine if cases were matches, but typographical errors were made in data entry or in the data received by the health department; and (4) cases that were selected as nonmatches during manual review, but that had the previously described RIDR table or ID table (created when eHARS is exported out as a dataset, where unique identifiers are stored) information with matching STATENO (state number) were considered a match.

For accepted matches, MD used matches where the STATENO from other jurisdictions matched the previously collected STATENO from that jurisdiction already in the MD eHARS database, both from RIDR and ID tables. In cases where there was a conflict between the RIDR and the ID tables, manual review of the matching variables (name, DOB, SSN, race, sex) was conducted before the match was accepted or rejected. Any matches that had nonmatching STATENOs were checked to see if there was an apparent error in the MD version of the STATENOs. If there was, manual review of the matching variables was done to determine an acceptable match using the STATENO provided by the other jurisdiction as the correct STATENO (meaning the STATENO that MD had in their eHARS database was an error). For matches with missing STATENO in the MD database, manual review of the matching variables was done to establish if they were acceptable matches or not. Manual review was done for all exact and very high matching categories and on a 5% sample (no less than 10) from each of high, medium high, medium, and very low categories.

For the last validation method, VA split the DC/MD-VA matched dataset into VA, MD, and DC datasets by STATENO and matched with their respective states' patient identifying data. The match was based on VA and the respective state's STATENO. The datasets were then run through the Link King software that identified potential matches between the DC/MD and VA data. Potential matches were identified based on first name, last name, date of birth, race, and social security number. Potential matches were assigned a certainty level from 1 to 4 (strongest to weakest). Observations with no potential matches identified were left unmatched for manual review. The Link King results were matched again by STATENOs to the privacy device match level. A simple random sample from each privacy device match level was taken. A 25% sample was taken from the exact and very high match levels, a 30% sample from the high match level, a 40% sample from the medium high match level, and a 50% sample from the medium and very low match levels. The Link King software did identify a few DC/MD cases that were duplicates within the same DC/MD datasets. While noted, only one of the cases was included in the analysis dataset. There were several cases in the DC and MD datasets that were matched to more than one STATENO; however, only the matches that were accounted for by Link King and were the highest match level were incorporated in the analyses. The review indicated that over 90% of matches in the exact, very high, and high categories were affirmed by Link King to be strong matches.

Results

This study found that from 1981 to 2015, a total of 21,472 persons were matched in eHARS databases across DC, MD, and VA over various strengths in a matching process totaling 21 minutes and 58 seconds in the privacy device, leaving 139,871 uniquely identified with only one jurisdiction (see Table 2). More than 80% were high-level matches, including 5933 exact matches, and 11,590 very high matches. Overall, more than 90% of matched records across all three jurisdictions were considered accurate matches after the three separate validation methods were applied in each jurisdiction (see Tables 3-5).

Table 2. Overview of person matches in eHARS databases across DC, MD, and VA from 1981 to 2015.

Person matches across jurisdictions	Exact	Very high	High	Medium high	Medium	Very low	Total
DC-MD[a]	4013	5907	53	268	645	482	11,368
MD-VA[b]	856	2343	11	117	377	865	4569
VA-DC[c]	1064	3340	15	149	438	529	5535
Total	5933	11,590	79	534	1460	1876	21,472

[a] DC-reported MD matches were equal to MD-reported DC matches.

[b] MD-reported VA matches were equal to VA-reported MD matches.

[c] VA-reported DC matches were equal to DC-reported VA matches.

Table 3. DC validation results.

	Nonmatch		Match		Total	
	N	%	N	%	N	%
District of Columbia/Maryland						
Exact	0	0.0	4009	100.0	4009	100.0
Very High	264	4.5	5560	95.5	5824	100.0
High	0	0.0	52	100.0	52	100.0
Medium High	3	1.1	264	98.9	267	100.0
Medium	178	28.0	457	72.0	635	100.0
Very Low	329	69.9	142	30.2	471	100.0
Total	774	6.9	10484	93.1	11,258	100.0
District of Columbia/Virginia						
Exact	0	0.0	1067	100.0	1067	100.0
Very High	33	1.0	3286	99.0	3319	100.0
High	0	0.0	13	100.0	13	100.0
Medium High	5	3.4	144	96.6	149	100.0
Medium	91	20.9	344	79.1	435	100.0
Very Low	401	79.1	106	20.9	507	100.0
Total	530	9.7	4960	90.4	5490	100.0

Table 4. MD validation results[d].

	Nonmatch		Match		Total	
	N	%	N	%	N	%
Maryland/District of Columbia						
Exact	0	0.0	4030	100.0	4030	100.0
Very High	24	0.4	5846	99.2	5870	100.0
High	0	0.0	52	100.0	52	100.0
Medium High	0	0.0	272	100.0	272	100.0
Medium	431	67.5	N/A	73.9	638	100.0
Very Low	441	94.4	N/A	28.6	467	100.0
Total				98.6	11,329	100.0
Maryland/Virginia						
Exact	0	0.0	855	100.0	855	100.0
Very High	10	0.4	2336	99.7	2344	100.0
High	0	0.0	11	100.0	11	100.0
Medium High	0	0.0	118	100.0	118	100.0
Medium	292	77.5	N/A	90.3	377	100.0
Very Low	827	96.3	N/A	15.3	858	100.0
Total				97.7	4563	100.0

[d] Since a 5% random sample was used to manually review Medium & Very Low categories, exact numbers (N) of matches could not be shown in this table.

Table 5. VA validation results.

	Nonmatch		Match		Total	
	N	%	N	%	N	%
Virginia/Maryland						
Exact	0	0.0	214	100.0	214	100.0
Very High	21	3.6	562	96.4	583	100.0
High	0	0.0	4	100.0	4	100.0
Medium High	3	6.4	44	93.6	47	100.0
Medium	98	53.3	86	46.7	184	100.0
Very Low	400	98.0	8	2.0	408	100.0
Total	522	36.3	918	63.8	1440	100.0
Virginia/District of Columbia						
Exact	0	0.0	264	100.0	264	100.0
Very High	14	1.7	802	98.3	816	100.0
High	0	0.0	4	100.0	4	100.0
Medium High	4	6.9	54	93.1	58	100.0
Medium	69	33.3	138	66.7	207	100.0
Very Low	199	87.7	28	12.3	227	100.0
Total	286	18.1	1290	81.9	1576	100.0

Discussion

Application to HIV Surveillance Data and Public Health Action

Public health resources are limited and enhancements in surveillance data can assist with improved utilization of such resources. More specifically, improvements in the accuracy and timeliness of surveillance data is critical for D2C activities because it reduces the time and effort expended by staff in tracking down persons moving across jurisdictions who do not require assistance re-engaging in care. Using the novel data-sharing approach developed in this study, DC, MD, and VA were able to identify the number of person matches of people with known HIV status from 1981 to 2015 across their eHARS databases in a relatively short amount of time. This allowed more detailed follow-up data exchanges among the public health jurisdictions that will facilitate future outreach efforts to people living with HIV, and it provided a direct opportunity to clean up outdated HIV surveillance records, including updating vital status and current address.

As expected, this study saw that higher matching strength categories (eg, exact, very high, and medium high) observed higher rates of accuracy (>90%) with matches across jurisdictions, while lower matching strength categories (eg, low and very low) saw lower rates (15-30%) of accuracy with matches across jurisdictions (see Tables 3-5). It is worthy to note that lower matching categories still provided important data on potential matches for jurisdictions. Additionally, after manual review of the lower strength matches, this study found that lower strength matches remain valid for finding person matches. Higher-level matches may therefore be more readily accepted, while lower-level matches should still require manual verification. These higher matching categories are good for keeping updated surveillance records or for doing matching across different public health jurisdictions. The higher level matching strength categories (ie, exact, very high, and high) had very high levels of match validation with almost no false matches. This would support accepting an automated matching process that could be used either for more timely surveillance activities, allowing jurisdictions to identify individuals for interventions or to produce reliable statistical analyses of care patterns across jurisdictions without direct sharing of confidential identifying data and protected health information.

Additionally, lower matching categories are useful for improving matches. The lower matching strength categories (ie, low, very low) had low levels of match validation (15-30%), which would not be appropriate for routine matching and specifically not appropriate for automated real-time matching. However, they did produce initially large numbers of valid matches and could be utilized by jurisdictions to improve the completeness of their datasets, which would then improve later automated matches.

The importance of this effort for improving the effectiveness of surveillance data can already be seen in recent pilot efforts by jurisdictions to utilize surveillance data for public health action. For example, in VA, a pilot study of intervening with persons considered lost to care (n=43) found that 39% of these persons were actually in care, 21% were living out of state, and 7% were deceased. It appears that the majority of the in-care cases were categorized as lost to care due to incomplete lab reporting, although ongoing investigation continues of each case. These results translated into two-thirds of persons not requiring follow-up by VA D2C personnel, but because this information was not known to the surveillance team, time and effort was expended to locate and re-engage these persons. The matching method applied here can dramatically improve the timeliness and efficiency of public health action in the DC metropolitan region.

Comparison to Traditional Surveillance Methods and Timeliness of Public Health Action

RIDR is an activity that relies on CDC to run its algorithm to identify potential matches across jurisdictions using the Soundex and other variables. Semi-annually, the CDC produces a list of potential matches for each jurisdiction to review with the other identified jurisdictions to ascertain who diagnosed the case. Then each jurisdiction exchanges information over the phone, updates the eHARS records, and gives the record a designation of either “same as” or “different than.” In contrast, our method identified persons already included in prior RIDR lists and also added to such lists new matches that were not previously included at a much faster rate than RIDR. Additionally, this method allowed for inclusion of recently updated data, unlike RIDR, which may include outdated information on vital status and residence.

Addressing Barriers to Public Health Data Sharing

This novel data-sharing method also provided means for improved surveillance data and public health action, while it simultaneously addressed the six major barriers to public health data sharing as previously outlined by van Panhuis et al [3]:

1. *Technical:* According to van Panhuis et al, incompatible electronic record systems in multiple languages tend to prevent sharing public health data. This project employed the system that all public health jurisdictions use to report HIV information to CDC known as eHARS. The mode of connecting each local eHARS to the privacy device fell within the technical competence of each jurisdiction in consultation with the Georgetown University Information Services staff.
2. *Motivational:* The literature review found that different missions and local orientation undermined motivation for sharing information among public health jurisdictions. From the perspective of the public health jurisdictions in this project, the matching algorithm enabled finding persons otherwise lost to care, enhanced the value of available data, and established jurisdictions as pioneers—all strong motivating factors in their participation.
3. *Economic:* The literature review identified cost of partnering as a barrier to data sharing. Although staff from the jurisdictions invested many more hours in this project than the grant covered, they realized that, if successful, the matching algorithm could reduce time and labor to find persons in other jurisdictions from months to minutes, impractical to feasible, and unaffordable to affordable.
4. *Political:* According to van Panhuis et al, barriers of mistrust often prevent data sharing among public health

agencies. Participating in this project encouraged the jurisdictions to exchange formal data use agreements. Beyond these formal agreements, however, the project work built a solid collaboration through a continuous series of project meetings, milestones, and major achievements over 2 years, including conferences hosted by Georgetown University in Washington, DC, on regional sharing of infectious disease data (January 2013) and the privacy device (November 2014), and presentations at the National Institutes of Health (NIH) "Harnessing Big Data to Halt HIV" conference (July 2015) and the National HIV Prevention Conference in Atlanta, Georgia (December 2015).

5. *Legal:* The literature review notes that, in many cases, incompatible laws, rules, and policies block data sharing. The jurisdictions in this project always had the legal right to share data for cases that involved other jurisdictions through separate data-sharing agreements. Nonetheless, the precise design of the technology enabled the algorithm to compare cases across jurisdictions without exposing data that should not be shared (ie, cases that did not involve other jurisdictions) either to other jurisdictions or to the third party facilitating the matching (Georgetown University).
6. *Ethical:* From a purely ethical perspective, we see our responsibilities with respect to this novel architecture and data flow in terms of data stewardship—the total process of investigating and safeguarding the ethical and privacy implications of recombining, reusing, repurposing, and reanalyzing multiple types of data from multiple sources with the explicit purpose of identifying and providing care to PLWH, especially those who, for various reasons, have dropped out of care [10]. However, the authors of the literature review focus on fairness of organizational work distribution in partnering for data sharing. Partnerships in data sharing often fail because some partners do more work than others and feel abused. From the perspective of the literature review, therefore, this project functioned as a true collaboration where the public health jurisdictions served as co-investigators, co-designers, data providers, and project beneficiaries. The actual data exchange fell within their purview and authority as public health jurisdictions with the right and responsibility to manage information about persons with HIV in their jurisdictions. Georgetown University did not view protected health information within the course of this study.

Limitations and Future Directions of Study

While this method of matching people across eHARS databases in different jurisdictions saved time in comparison with more traditional methods, the manual validation process of this study was relatively time consuming. Therefore, future efforts should consider how to more effectively streamline this manual validation process. Also, although it was clear to the authors that the privacy device computed person matches across eHARS databases in a relatively short amount of time, while outside the scope of this initial study, future studies could perform a comprehensive assessment of the economic impact of implementing this technology in comparison with more traditional methods. Additionally, although the privacy platform provided high privacy assurance, one should note that with fewer resource constraints, more computational and mathematical power could be added to develop an even higher level of privacy assurance. Furthermore, no records were matched as medium low or low. This might indicate that parameters that defined such matching categories were insufficient for these purposes and should be revised for future projects. Moreover, it is important to underline that since this study considered all valid eHARS case records, its outcome is reflective of both historical and current patient migration in this metropolitan region from 1981 to 2015. This may or may not be aligned with current patient migration rates; therefore, future efforts should further examine the levels of migration over the last 3-5 years in the cross-jurisdictional DC metropolitan region. Although this study used RIDR information as part of the validation processes to check if the privacy device matches were indeed reported in pre-existing RIDR lists, future study directions could include a comprehensive evaluation to check if the opposite is also true—that all known RIDR matches can be detected using the privacy device. Similarly, while beyond the scope of this methods-focused study, future research efforts could also assess the overall impact of this data-sharing technology on public health reporting to CDC.

The person matching in this study was performed on all valid cases, ignoring any previously known information on migration and data sharing between jurisdictions. Future iterations should incorporate existing knowledge on interjurisdictional cases and also explore characteristics of individuals who migrate across state borders for HIV care to find patterns that can be helpful in identifying intervention points along the HIV care continuum. Exploring longitudinal cohort data from this geographic region may help supplement essential data on why people experience patient in- and out-migration in this region. In this regard, it may be useful to examine data from observational cohorts like the District of Columbia Metropolitan Women's Interagency HIV Study—an ongoing prospective cohort study of HIV infection in women across Washington DC, Montgomery County, Maryland, and Northern Virginia [11]. It is also worthy to note that this study considered those who were already confirmed as HIV infected (as indicated by eHARS case record) and was not designed to address individuals who are unaware of their HIV status (ie, no eHARS record) or address those who were not matched.

This method can be used to help public health officials and their partners develop HIV care continuum models that better contextualize HIV in the United States for resource allocation purposes [12,13]. It can, for example, be used in future efforts comparing more traditional surveillance methods (eg, eHARS) with newer social media techniques (eg, Twitter, Google Flu Trends, HealthTweets) or in exploring patient in- and out-migration, which remains a large knowledge gap in HIV epidemiology [14-16]. Moreover, since large metropolitan regions experience high levels of person movements, such areas may provide fruitful grounds for further examination of mobility in HIV care using this novel approach [17]. Lastly, this technology is applicable to public health data sharing outside of HIV disease surveillance, and the authors have already began to explore applications to other infectious disease data.

Conclusion

Using a novel technology and interdisciplinary and public-private partnership, this study effectively addressed how to improve HIV surveillance data for public health action. This approach can provide a more effective bridge between data and care in public health and may be applied to other purposes.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Algorithm development.

[PDF File (Adobe PDF File), 37KB - publichealth_v2i1e3_app1.pdf]

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Abbreviations

AIDS: acquired immune deficiency syndrome
CDC: Centers for Disease Control and Prevention
D2C: data to care
DC: District of Columbia
DC-CFAR: District of Columbia Center for AIDS Research
DOB: date of birth
eHARS: Enhanced HIV/AIDS Reporting System
HIPAA: Health Insurance Portability and Accountability Act
HIV: human immunodeficiency virus
MD: State of Maryland
PLWH: people living with HIV
RIDR: Routine Interstate Duplicate Review
SSN: social security number
STATENO: state number
VA: Commonwealth of Virginia
WIHS: Women’s Interagency HIV Study

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Original Paper

Effectiveness of Implementation of Electronic Malaria Information System as the National Malaria Surveillance System in Thailand

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Abstract

Background: In moving toward malaria elimination, one strategy is to implement an active surveillance system for effective case management. Thailand has developed and implemented the electronic Malaria Information System (eMIS) capturing individualized electronic records of suspected or confirmed malaria cases.

Objective: The main purpose of this study was to determine how well the eMIS improves the quality of Thailand’s malaria surveillance system. In particular, the focus of the study was to evaluate the effectiveness of the eMIS in terms of the system users’ perception and the system outcomes (ie, quality of data) regarding the management of malaria patients.

Methods: A mixed-methods technique was used with the framework based on system effectiveness attributes: data quality, timeliness, simplicity, acceptability, flexibility, stability, and usefulness. Three methods were utilized: data records review, survey of system users, and in-depth interviews with key stakeholders. From the two highest endemic provinces, paper forms matching electronic records of 4455 noninfected and 784 malaria-infected cases were reviewed. Web-based anonymous questionnaires were distributed to all 129 eMIS data entry staff throughout Thailand, and semistructured interviews were conducted with 12 management-level officers.

Results: The eMIS is well accepted by system users at both management and operational levels. The data quality has enabled malaria personnel to perform more effective prevention and control activities. There is evidence of practices resulting in inconsistencies and logical errors in data reporting. Critical data elements were mostly completed, except for a few related to certain dates and area classifications. Timeliness in reporting a case to the system was acceptable with a delay of 3-4 days. The evaluation of quantitative and qualitative data confirmed that the eMIS has high levels of simplicity, acceptability, stability, and flexibility.

Conclusions: Overall, the system implemented has achieved its objective. The results of the study suggested that the eMIS helps improve the quality of Thailand’s malaria surveillance system. As the national malaria surveillance system, the eMIS’s functionalities have provided the malaria staff working at the point of care with close-to-real-time case management data quality, covering case detection, case investigation, drug compliance, and follow-up visits. Such features has led to an improvement in the quality of the malaria control program; the government officials now have quicker access to both individual and aggregated data to promptly react to possible outbreak. The eMIS thus plays one of the key roles in moving toward the national goal of malaria elimination by the next decade.

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KEYWORDS

surveillance system; epidemiology; mixed-methods; evaluation; malaria; eMIS; data quality; public health informatics; Thailand

Introduction

Malaria transmission occurs in all six World Health Organization regions. An estimated 3.3 billion people are at risk of malaria infection worldwide, and 1.2 billion are at high risk (>1 in 1000 chance of contracting malaria in a year). In 2013, there were 33,302 confirmed cases in Thailand, with 37 confirmed deaths [1]. Although Thailand is on track to achieving a 50%-75% decrease in case incidence by 2016, the country still faces the challenge of drug resistance, particularly regarding malaria from *Plasmodium falciparum*, to artemisinin treatments [1]. The Thai Ministry of Public Health has introduced several intensive malaria prevention and control strategies and is moving toward malaria elimination [2]. One proposed strategy concerned the introduction of an active surveillance system for effective case management, and thus the electronic malaria information system (eMIS) was developed and implemented in 2009 [3]. Initially, the eMIS was implemented in 7 provinces alongside the Thai-Cambodia border. However, the system now covers 38 malaria-endemic provinces along the Thai-Cambodia and Thai-Myanmar borders and encompasses 147 data entry units. The system has been transmitting epidemiology data from remote areas since October 2011 [2].

The eMIS was originally developed by the Center of Excellence for Biomedical and Public Health Informatics (BIOPHICS) and Mahidol University via support from the World Health Organization and the Bill and Melinda Gates Foundation. The specific aim was to replace the traditional paper-based malaria reporting system with an active and close-to-real-time electronic reporting system [4]. That is, the main goal of the eMIS is to use electronic records that capture daily information about the malaria case management of each individual patient at the point of care. These records can then be retrieved by higher-level health authorities for use in situation analysis. The data flow via eMIS solves the problem inherent in the original paper record reporting mechanism, where authorities would only obtain aggregated data on a monthly basis. Thus, the time delay meant that it was often too late for making any decision about malaria control. With Global Fund support since 2011, the system has been imbedded into the routine work of malaria control authorities in Thailand. Both Web-based applications and mobile technologies have been integrated into the eMIS to enhance and manage case detection, investigation, and follow-up at point-of-care units [2].

The eMIS is operated and overseen by the Bureau of Vector Borne Disease (BVBD), which falls under the Department of Disease Control within the Thai Ministry of Public Health. This occurs through a network of malaria clinics and malaria posts located in villages in malaria-endemic areas. Between the highest decision-making level at the ministry and the local operating sites, there are regional offices of disease prevention and control, vector-borne disease control center (VBDC), and vector-borne disease control unit (VBDU). Currently, eMIS data are hosted at a secure server located at BIOPHICS, only accessible by authorized system users at the Ministry of Public Health. As the eMIS operates under local BVBD staff, BIOPHICS acts as a system developer and active technical system support for the ministry.

The eMIS platform uses offline and online replication technology to enable malaria staff to continue entering data offline when facing an unstable Internet connection. Whenever Internet is available, data can be later synchronized between data entry sites and the central database. Thus, there are some limitations regarding available computer hardware and Internet signal in certain remote areas and/or difficulties in performing simultaneously case management and online data entry. Therefore, each malaria record is captured through a hybrid process in which data are initially collected on paper and subsequently entered into the eMIS via a desktop offline/online client software platform (Figure 1). At point-of-care units (malaria clinics and malaria posts), diagnosis is carried out using a malaria rapid diagnostic test, and standard medical treatment according to national guidelines is immediately administered. A blood film is also collected and sent to the VBDC for archiving and subsequent microscopic confirmation. Both noninfected (negative) and infected (positive) cases are recorded on a “case detection form” (CDF). If a patient’s test result is positive, more information will be collected to record risk factors, signs and symptoms, and the radical malaria treatment provided. Such details are recorded on a “case investigation form” (CIF). Both paper-based CDF and CIF, so-called pCDF and pCIF, are then sent from the malaria point-of-care units in villages in remote areas to VBDC/VBDU where the data are entered either online or offline, and later synchronized with the eMIS. The electronic records of CDF and CIF, so-called eCDF and eCIF, are kept in the eMIS as the national malaria central database, currently located at BIOPHICS’s secure server (Figure 2).

Since its implementation, the eMIS has been evolving; the system has demonstrated its ability to capture essential data from individual malaria cases at local operational units and the data are being used for effective analysis and decision support at upper management levels [4]. Different types of epidemiological reports can be generated and distributed among administrative levels, from the top down to operational levels. Data can be displayed and toggled from tables into graphs via selected variables using business intelligence and geographic information systems for the purpose of creating an effective informatics tool for malaria control and elimination (Figure 2). Informal observations via the periodic training sessions and routine monitoring of the system's usage show that the eMIS is well accepted by users. However, no formal evaluation of the eMIS has been conducted. Thus, the main research question of this study was to determine how well the eMIS improves the quality of Thailand's malaria surveillance system. By examining the effectiveness of implementation efforts as evidence-based public health practice [5,6], this study specifically focused on the system users' perception about the eMIS and the system outcomes in terms of quality of data captured in the eMIS, which were used for management of malaria patients.

Figure 1. Paper-based forms and electronic data entry screens.

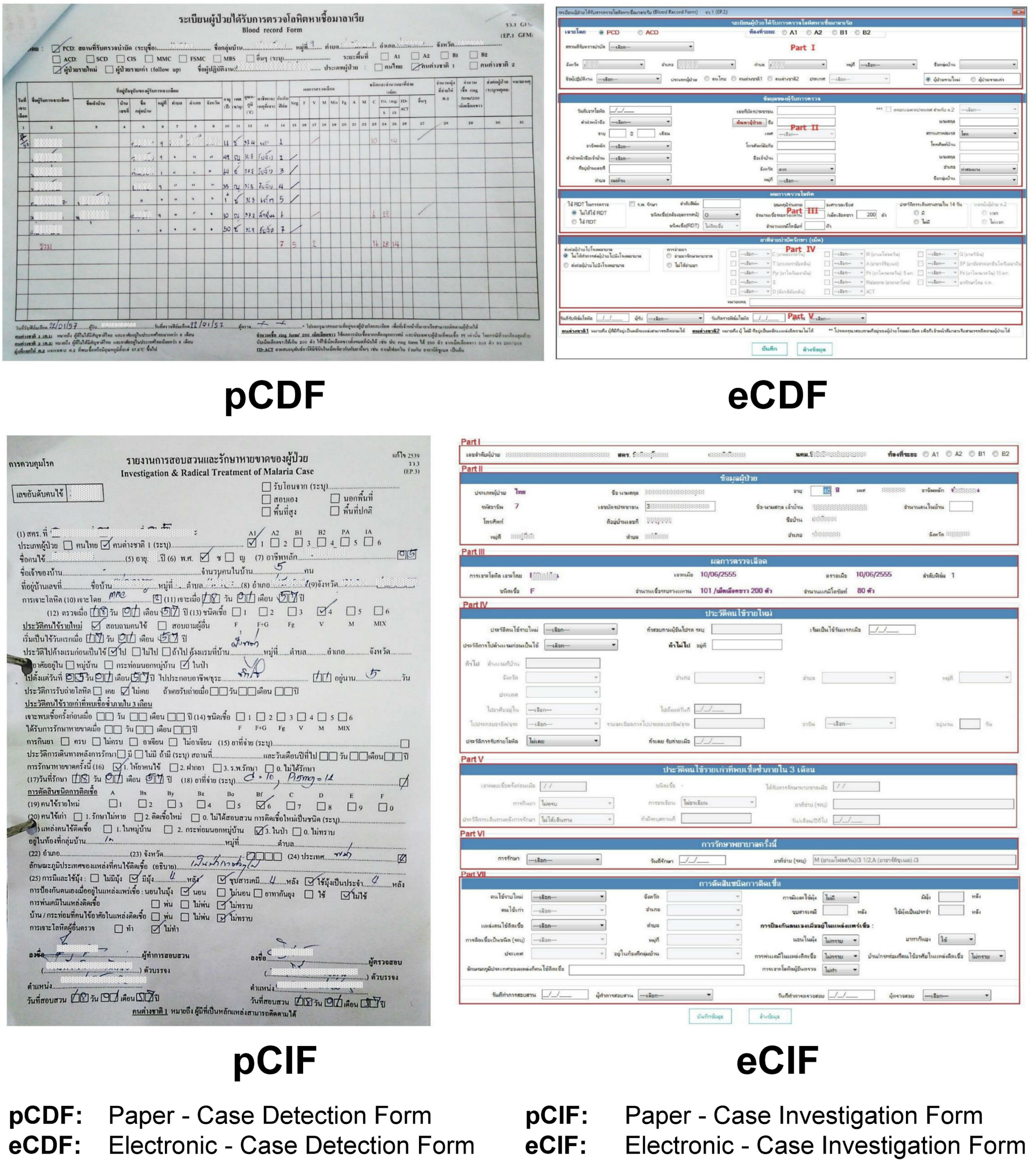
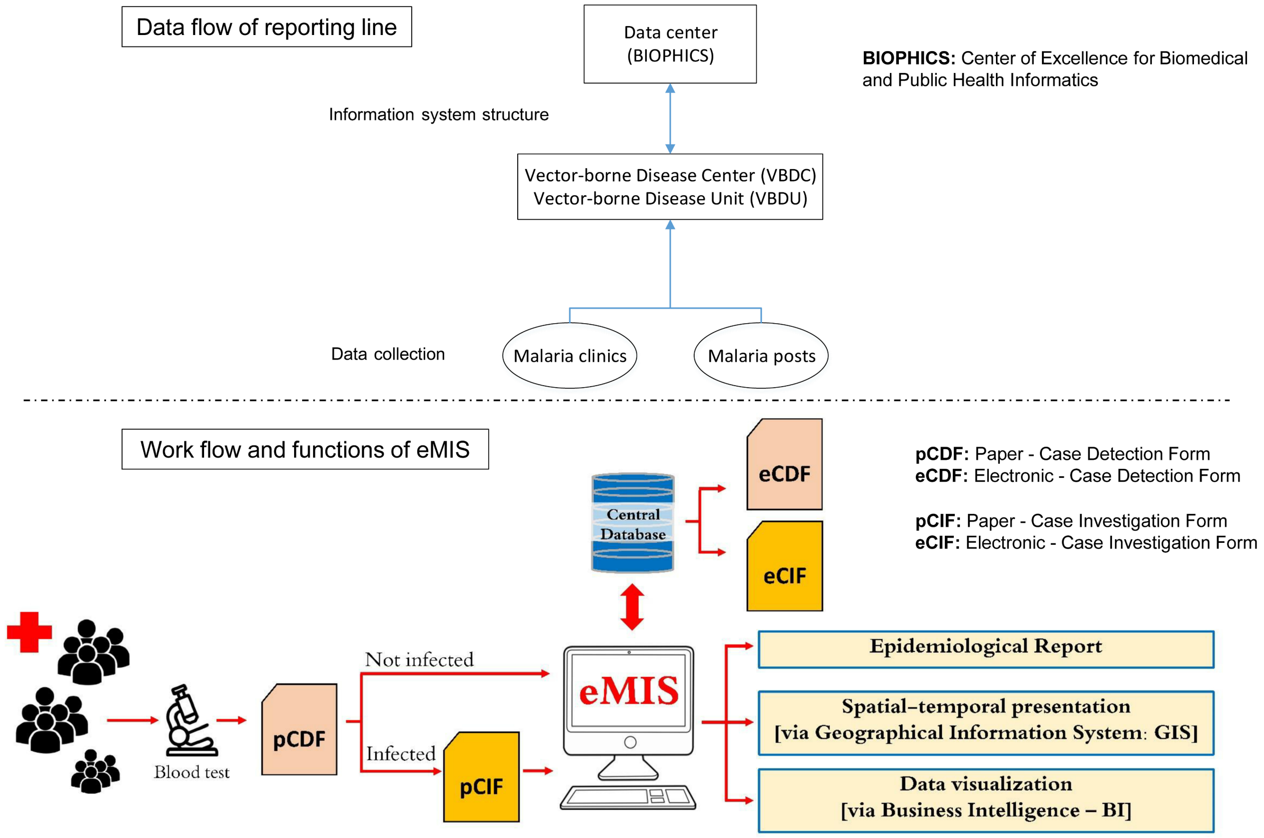


Figure 2. Data flow of the electronic Malaria Information System (eMIS).



Methods

Study Design

This is a descriptive study using a mixed-methods evaluation, combining quantitative and qualitative approaches. A number of previous studies have evaluated system innovations using mixed methods and confirmed that multiple evaluation methods can comprehensively identify system and/or electronic record usability, challenges, and specific problems [5,7-9]. In this study, three methods were utilized: data records review, survey of system users (system operating staff), and in-depth interviews with key stakeholders ("advanced" system users and a system developer).

Study Site and Study Participants/Data Records

Tak and Trat, the two border provinces closest to Myanmar and Cambodia, respectively, were purposively selected as provinces with the highest number of malaria cases along Thailand's malaria-endemic borders. Source data in the paper-based forms (pCDF and pCIF) versus the electronic data records in the eMIS (eCDF and eCIF) were reviewed and compared. Overall, 4455 pCDFs and 784 pCIFs from the period December 2013 to January 2014 were collected from record books for the two provinces. Similarly, eCDF and eCIF for the same period were extracted from eMIS databases. A Web-based anonymous electronic questionnaire was distributed to all eMIS data entry staff at VBDC/VBDU; of all 129 data entry staff, 128 (99.22%) completed the questionnaire. Semistructured interviews were conducted with management-level users: 1 malaria surveillance officer at the ministry, 12 monitoring and evaluation officers (M&Es) at VBDC/VBDU in Tak and Trat provinces, and 1 information technology (IT) officer at BIOPHICS.

Data Collection and Data Analysis

There are several methods available for the evaluation of the effectiveness of health care systems, innovation, or tools used for capturing electronic data records [5-8,10,11]. The evidence-based public health practice approach looks at how routinely practices are performed in usual care procedures by analyzing retrospective data from previous site implementation efforts and prospective data from newly adopting sites in terms of implementation and sustainability outcomes [5,6]. Regarding the evaluation of the implementation of a system innovation in terms of its impact and contingency factors, it is necessary to explore changes in workflow and work disruption, data quality, adoption, and user satisfaction [7]. An earlier study on the organizational adoption of systems among family physician practices identified several beneficial aspects and barriers including logistical organization problems, quality of professionals' clinical decisions, reduction in the cost of managing clinical information, and the barriers faced by system users [8]. A systematic review of the evaluation of surveillance systems highlighted that the approach must be complete; that is, the list of attributes to be assessed should cover not only epidemiological aspects of the evaluation but also social and economic factors. Furthermore, regarding operational factors, a structured process to conduct the evaluation should cover the selection of appropriate attributes and practical methods and tools for their assessment [10]. Thus, in the evaluation of the effectiveness of eMIS, several contextual factors and important attributes and their assessment methods were identified. As an electronic surveillance system for malaria disease, the US Centers for Disease Control and Prevention guidelines for evaluating public health surveillance systems [11] were selected as the evaluation framework for the eMIS. According to the guidelines, the most important attributes for a particular surveillance system and its objectives should be selected. The following attributes are considered key to assess the effectiveness of eMIS: simplicity, flexibility, data quality, acceptability, timeliness, stability, and usefulness. A description of each attribute and its appropriate data collection methods are provided in Table 1.

Table 1. Attribute definitions and corresponding data collection approaches.

Attributes	Description[a]	Data collection approaches
Data quality	Completeness (absence of missing values) and validity (absence of errors)	Data record review and semistructured interview
Timeliness	Delay in reporting	Data review
Simplicity	Method of collecting data and time needed to collect data; structure of the system	Structured questionnaire
Acceptability	Willingness of users to use the eMIS[b]	Structured questionnaire
Flexibility	Capacity to cope with new requirements and standards the system follows	Structured questionnaire and semistructured interview
Stability	Downtime of server and response of technical support	Structured questionnaire and semistructured interview
Usefulness	Dissemination of knowledge	Structured questionnaire and semistructured interview

[a] Based on Centers for Disease Control and Prevention *Updated Guidelines for Evaluating Public Health Surveillance Systems* [11], and tailored for the purpose of eMIS [3].

[b] eMIS: electronic Malaria Information System.

Data quality was assessed in terms of the number of records captured using both paper and electronic data collection methods, data completeness or missing data, data validity or consistency between the data in paper and electronic formats, and logical errors or conflicting values among data elements. Timeliness was assessed in terms of delays in data entry from paper data collection forms into electronic records in the eMIS. Both data quality and timeliness were evaluated by comparing the electronic data records in the eMIS (eCDF and eCIF) against the paper data collection forms (pCDF and pCIF). The data from paper-based forms were entered using Microsoft Excel 2013 and double-checked for comparisons with electronic records in the eMIS.

Other surveillance attributes were assessed via a structured questionnaire and semistructured interviews. To fit within the eMIS context, the questionnaire was adapted from a previous study that measured similar attributes concerning data quality in a surveillance system [12]. The questionnaire consisted of choices, dichotomous questions, a 5-point Likert scale, and 1 open-ended question. There were 6 questions asking about the staff practices and perception in using eMIS in terms of time spent, making use of data, and technical problems encountered; 8 items on general impression about the eMIS; 3 questions on eMIS administrative or support team; 4 items on overall thoughts about eMIS; 1 item on eMIS functions that should be improved; and an open question. The anonymous Web-based questionnaire was distributed via Google Form to all data entry sites throughout Thailand; the questionnaire was then responded to by the only one data entry personnel hired by the Ministry of Public Health (one per site). With unknown and unidentifiable responding status, all respondents received a phone call reminder 1 week after the questionnaire was distributed, asking them to complete the questionnaire; this is deemed to be an effective method to achieve a good response rate [13]. Semistructured interviews were conducted with individuals involved with the management and administration of the eMIS. The main purpose of qualitative data collection via in-depth interviews was to gain insightful information or reasons for each attribute measured in the quantitative data analysis. The key interview questions for eMIS officers at the BVBD included issues related to resources used to operate the eMIS, performance of the system and level of usefulness, and opinions on the limitations of the eMIS. The questions for M&E at VBDC included their practices in checking the data quality, the difficulty in managing the system, the use of the data collected by the system, the reports and analysis of the data, and the limitation and suggestion for improvement of the eMIS. The key interview questions for the eMIS technical supporter included their opinions on applying health information standard code sets (ie, Systematized Nomenclature of Medicine -- Clinical Terms [SNOMED CT], *International Classification of Diseases, Tenth Revision* [ICD-10], Health Level Seven [HL7]), the changed or upgraded versions of the eMIS, the evidence of server downtime and time to recover, and the database back up process. The answers from the structured questions were downloaded from Google Forms to be analyzed in Microsoft Excel. The answers to the open-ended question, comments, and interview results were reported verbatim and subsequently reviewed and organized into specific themes related to each attribute shown in the quantitative data analysis section.

Ethical Considerations

This study was approved by the Ethics Committee of the Faculty of Tropical Medicine, Mahidol University. This study did not involve vulnerable participants. The participants were informed and provided their consent after reading documents explaining the purpose of the study, the participant's risks and benefits, and the confidentiality and protection of their data. The participants were informed that their answers to the questionnaire were anonymous and would not affect their employment.

Results

Data Quality

In general, based on qualitative data collection methods, the data quality of the eMIS was perceived as "good" among management-level users. Officers at the BVBD stated that the data quality of the eMIS was acceptable and better than paper reports, despite no previous evaluation. All M&Es stated that they check the data entered in the eMIS against the paper forms; however, they only check the aggregated case number. One M&E mentioned that the eMIS data were complete while others claimed the data were more accurate than the paper forms.

> *I think the data quality is acceptable but needs to be improved. But it's better than paper reports.* [Officer at BVBD]
>
> *The eMIS helps me a lot. The data are more accurate than paper.* [M&E]

Numbers of Initial Paper-Based Forms Versus Electronic Records

In evaluating data quality based on the number of data records being reviewed, the total number of pCDFs did not match eCDF numbers: 38,860 noninfected cases were reported using 4455 pCDFs (several cases were listed on a single paper page) but 41,451 records (one case is one record) were found as eCDFs in the eMIS database. Similarly, fewer infected cases were found in the paper records (one case per single paper page) than those recorded electronically (one case is one record): 781 pCDFs versus 964 eCDFs and 784 pCIFs versus 969 eCIFs.

Completeness of Data

Completeness of core data elements (data fields) in the CDFs and CIFs was only checked among infected cases as shown in Table 2. Whereas all elements in the 964 eCDFs showed 100% completeness, among the 781 pCDFs, only the data elements patient name, age, and blood test result were 100% complete. Data were found to be missing for the following elements: date of receiving blood film (186/781, 23.82%; 95% CI 20.83%-26.80%), date of blood test (173/781, 22.15%; 95% CI 19.24%-25.06%), and area classification (266/781, 34.06%; 95% CI 30.74%-37.38%; Table 2). Again, data for the 969 eCIF records were complete, but among the 784 pCIFs the number of missing values for certain elements was high, including area classification (142/784, 18.11%; 95% CI 15.42%-20.81%), followed by infection location (65/784, 8.29%; 95% CI 6.36%-10.22%) and case classification (53/784, 6.76%; 95% CI 5.00%-8.52%).

Data Consistency

To evaluate data validity regarding the consistency of the core data elements in the paper and electronic forms, a linkage between the two data entry forms was made. Adapting the data matching method suggested in the literature concerning the assessment of data quality in a cancer registry [14], the linkage of malaria-infected cases between paper and electronic forms was accomplished using patient demographics, blood drawn date, and health care facility location. Such data elements were matched to confirm that each analyzed pair belonged to the same person who was infected at the same time point and was residing in the same location. From the paper and electronic records, 711 pairs of pCDF-eCDF and 719 pairs of pCIF-eCIF were identified and analyzed. The validity of the eMIS data was generally observed as consistent pairs; only a few elements showed significant differences. Among the 711 pCDF-eCDF pairs, discordant pairs were found in the following data elements: area classification (51.88%; 95% CI 47.41%-56.34%), date of receiving blood film (183/711, 25.74%; 95% CI 22.52%-28.95%), and date of blood test (180/711, 25.32%; 95% CI 22.12%-28.51%). Among the 719 pCIF-eCIF pairs, most discordant pairs were found in similar data elements: area classification (260/719, 36.16%; 95% CI 32.65%-39.67%) and infection location (118/719, 16.41%; 95% CI 13.70%-19.12%); for other elements, the discord was less than 10% (Table 3).

Table 2. Completeness of core elements.

Core data elements	Total missing	% missing	95% CI	Total missing	% missing	95% CI
Case detection form	pCDF[a](n=781 records)			eCDF[a](n=964 records)		
Date of form entry	-	-	-	0	0	-
Date of drawing blood	8	1.02	0.32-1.73	0	0	-
Date of receiving blood film	186	23.82	20.83-26.80	0	0	-
Date of blood test	173	22.15	19.24-25.06	0	0	-
Type of blood test	6	0.77	0.16-1.38	0	0	-
Type of patient	4	0.51	0.01-1.01	0	0	-
Area classification	266	34.06	30.74-37.38	0	0	-
Nationality	17	2.18	1.15-3.20	0	0	-
Patient name	0	0	-	0	0	-
Age	0	0	-	0	0	-
Sex	5	0.64	0.08-1.20	0	0	-
Blood test result	0	0	-	0	0	-
Medicine	6	0.77	0.16-1.38	0	0	-
Case investigation form	pCIF[a](n=784 records)			eCIF[a](n=969 records)		
Date of form entry	-	-	-	0	0	-
Date of drawing blood	1	0.13	0-0.38	0	0	-
Date of blood test	1	0.13	0-0.38	0	0	-
Date of investigation	1	0.13	0-0.38	0	0	-
Area classification	142	18.11	15.42-20.81	0	0	-
Nationality	22	2.81	1.65-3.96	0	0	-
Patient name	0	0	-	0	0	-
Age	3	0.38	0-0.81	0	0	-
Sex	7	0.89	0.23-1.55	0	0	-
Blood test result	1	0.13	0-0.38	0	0	-
Case classification	53	6.76	5.00-8.52	0	0	-
Infection location	65	8.29	6.36-10.22	0	0	-

[a] pCDF: paper case detection form; eCDF: electronic case detection form; pCIF: paper case investigation form; eCIF: electronic case investigation form.

Table 3. Agreement between paper-based and electronic data.

Core data elements	No. of discordant pairs	Percentage of disagreement	95% CI
pCDF[a]-eCDF[a](n=711 pairs)			
Date of drawing blood	12	1.69	0.74-2.63
Date of receiving blood film	183	25.74	22.52-28.95
Date of blood test	180	25.32	22.12-28.51
Type of blood test (ACD/PCD)	8	1.13	0.35-1.90
Type of patient (new case/follow-up)	3	0.42	0-0.9
Area classification (A1, A2, B1, B2)	249[b]	51.88	47.41-56.34
Nationality (Thai, M1, M2)	21	2.95	1.71-4.20
Age	7	0.98	0.26-1.71
Sex	7	0.98	0.26-1.71
Blood test result (type of malaria)	2	0.28	0-0.67
Medicine	7	0.98	0.26-1.71
pCIF[a]-eCIF[a](n=719 pairs)			
Area classification (A1, A2, B1, B2)	260	36.16	32.65-39.67
Nationality (Thai, M1, M2)	28	3.89	2.48-5.31
Age	26	3.62	2.25-4.98
Sex	16	2.23	1.15-3.30
Date of drawing blood	10	1.39	0.53-2.25
Date of blood test	9	1.25	0.44-2.06
Blood test result (type of malaria)	13	1.81	0.83-2.78
Date of investigation	60	8.34	6.32-10.37
Case classification	66	9.18	7.07-11.29
Infection location (within village/cottage/forest)	118	16.41	13.7-19.12

[a] ACD: active case detection; pCDF: paper case detection form; eCDF: electronic case detection form; pCIF: paper case investigation form; eCIF: electronic case investigation form; PCD: passive case detection; M1: migrant group 1; M2: migrant group 2.

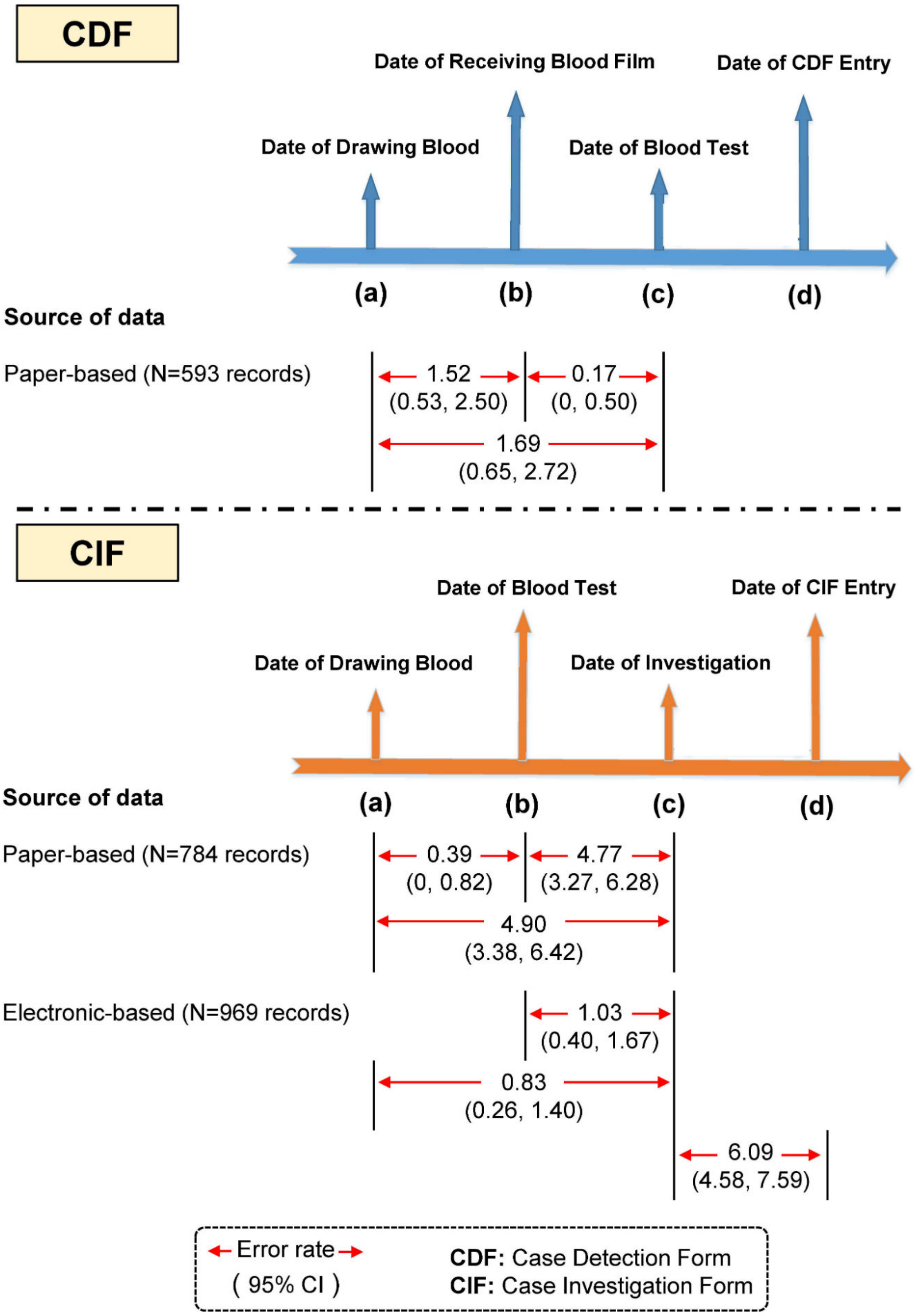
[b] Denominator varied because some paper-based blood record forms did not include this item.

Logical Errors in Data

A further factor to measure data quality was evaluated: logical errors in the data elements. Logical errors were assessed in two ways: (1) illogical chronological sequence of data capture and reporting dates and (2) discrepancies in reporting malaria prescriptions against national standard guidelines for each type of malaria infection. It should be noted, however, that there were a number of incomplete dates on pCDFs because some infected cases were detected at district or provincial hospitals rather than at the malaria clinics or posts, and hospital health care personnel may not have provided detailed data concerning detection dates (eg, date of receiving blood film, date of blood test) for those infected cases. Thus, complete information regarding the dates of those cases on pCDFs was based on just 593 cases. However, the CIFs were completed and all 784 pCIFs and 969 eCIFs for infected cases were used in the analysis. First, discrepancies in chronological order were checked for different time points (Figure 3). For a CDF, the sequence of dates should be in the following order: (a) date of blood drawn, (b) date of receiving blood film, (c) date of blood test, and (d) date of data entry on the form. A total number of 20 chronological order errors were found in the 593 pCDFs. Illogical date sequences were found among all pCDFs as follows: date (a) > date (b) for 9/593, 1.52% (95% CI 0.53%-2.50%), date (b) > date (c) for 1/593, 0.17% (95% CI 0%-0.50%), and date (a) > date (c) for 10/593, 1.69% (95% CI 0.65%-2.72%). None of the eCDFs showed any discrepancies regarding chronological sequence errors. Similarly, fewer chronological errors were found in the electronic records than on paper forms for case investigation, in which the sequence of dates should follow the following order: (a) date of blood drawn, (b) date of receiving blood film, (c) date of investigation, and (d) date of data entry on the form. Illogical date sequences were found among all 784 pCIFs as follows: date (a) > date (b) for 3/784, 0.39% (95% CI 0%-0.82%), date (b) > date (c) for 37/784, 4.77% (95% CI 3.27%-6.28%), and date (a) > date (c) for 38/784, 4.90% (95% CI 3.38%-6.42%). In the 969 eCIFs, similar discrepancies among dates were also found, with a relatively high number of errors (59 records) found between one type of date order error: date (c) > date (d), at 6.09% (95% CI 4.58%-7.58%; Figure 3).

Another illogical error examined in this study concerned discrepancies in medication prescriptions (type of medicine provided). In Thailand, malaria treatment is regulated and only available at governmental health care facilities for both Thai and non-Thai patients across malaria-endemic areas. Specific standard regimens for each type of malaria infection, mainly *Plasmodium falciparum* and *Plasmodium vivax*, are set as policy according to national guidelines. In this study, prescriptions that differ from the national malaria treatment guidelines were counted as data inconsistencies. Among pCDFs, data inconsistencies in medication prescription were observed at 0.37% (95% CI 0%-1.09%) for *P falciparum* infection and at 0.4% (95% CI 0%-0.94%) for *P vivax* infection. In contrast, among eCDFs, data inconsistencies were recorded at 2.94% (95% CI 1.23%-4.65%) and 1.2% (95% CI 0.32%-2.09%) for prescriptions for *P falciparum* infection and *P vivax* infection, respectively (results not shown).

Figure 3. Error rate of date sequence inconsistencies in case detection forms (CDFs) and case investigation forms (CIFs).



Timeliness

In exploring timeliness, the descriptive statistics shown in Table 4 reveal delays in data reporting to the eMIS (ie, data entry date on eCDF) after case detection (ie, blood drawn date on pCDF) and delays in data reporting to the eMIS (ie, data entry date of eCIF) after case investigation (ie, investigation date of pCIF). Note that, in the calculation of delays, records with more than a 200-day delay and negative delays were considered as outliers and/or data entry errors. After excluding such outliers, the mean delay times for case detection and case investigation were 9.34 days (SD 10.63) and 9.14 days (SD 16.27) and median delay times were 4 and 3 days, respectively. From the qualitative information analysis, some M&Es mentioned that paper forms were sent late and therefore they could not enter data in a timely manner.

> *Some papers arrive late, so we report late.* [M&E]

Table 4. Timeliness analysis.

Reporting delay (days)	Mean (SD)	Median (minimum-maximum)
Delays between date of blood drawn and date of form entry for eCDF[a](n=963 records[b])	9.34 (10.64)	4 (0-69)
Delays between date of investigation and date of form entry for eCIF[a](n=906 records[c])	9.14 (16.27)	3 (0-134)

[a] eCDF: electronic case detection form; eCIF: electronic case investigation form.

[b] One record with more than a 200-day delay (242 days) was considered an outlier and excluded.

[c] Five records with more than 200 days (369, 372, 372, 366, and 242 days) were considered as outliers and excluded; 58 records with negative delays were excluded, ranging from −1 to −15 days.

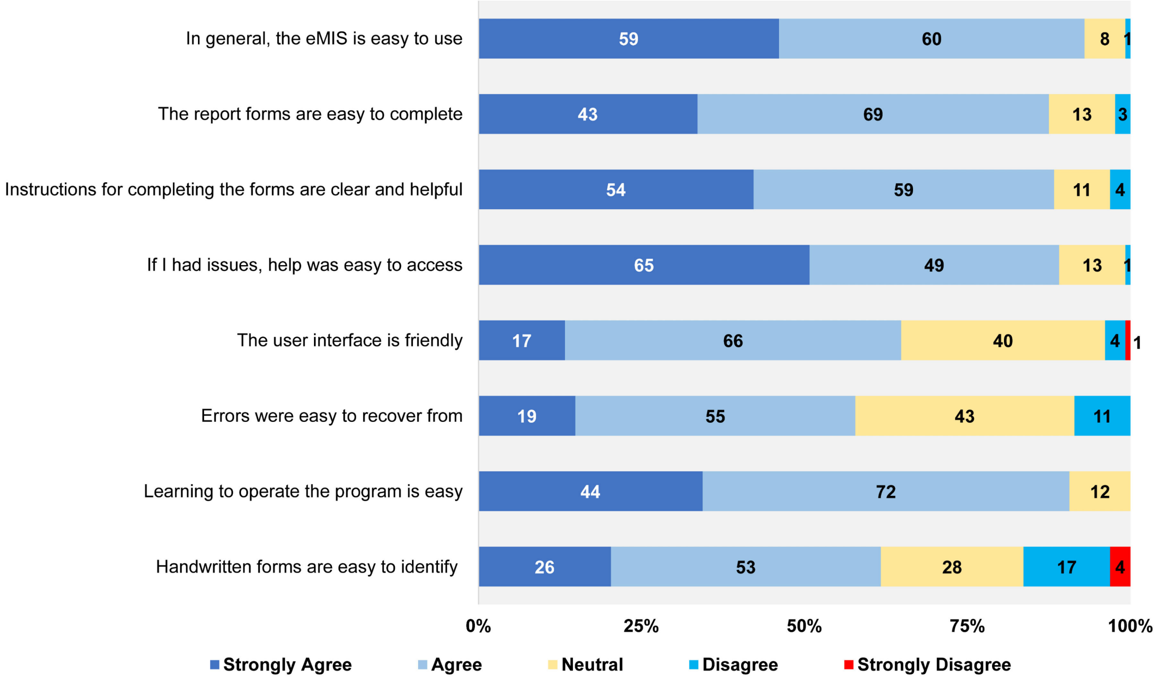
Simplicity

The simplicity of the eMIS refers to both its structure and ease of operation. The eMIS represents a single, vertical, streamlined data entry process. It has a simple and vertical information structure with one central data center at BIOPHICS. All data entry staff report that the time required to enter eMIS data was easy to incorporate into their daily work duties. A total of 85/128, 66.40% of respondents reported spending less than 5 minutes entering into the eCIF the details of 1 infected case (with approximately 80 data elements), and much less time completing 1 CDF via eCDF (42 data elements for a noninfected case and 52 for an infected case). Respondents reported that the time burden for data entry was manageable.

The majority agreed or strongly agreed that the eMIS is easy to use (119/128, 92.97%), the report forms in the eMIS are easy to complete (112/128, 87.5%), instructions for completing the forms are clear and helpful (113/128, 88.28%), help is easy to access (114/128, 89.06%), and that learning to operate the program is easy (116/128, 90.63%). A slightly lower percentage of respondents agreed or strongly agreed that the eMIS has a user-friendly interface (83/128, 64.84%), with 31.25% (40/128) feeling neutral about this statement (Figure 4). Some respondents also commented that a color-labeled data entry screen would improve the system.

> *The data entry part of the system should be labeled with colors, especially in fields which have been entered.* [Data entry staff]
>
> *The screen for CIF data entry should be separated according to each part of the CIF form. It could use lines or colors to separate each screen for more convenient data entry.* [Data entry staff]

Figure 4. Simplicity of the electronic Malaria Information System (eMIS).

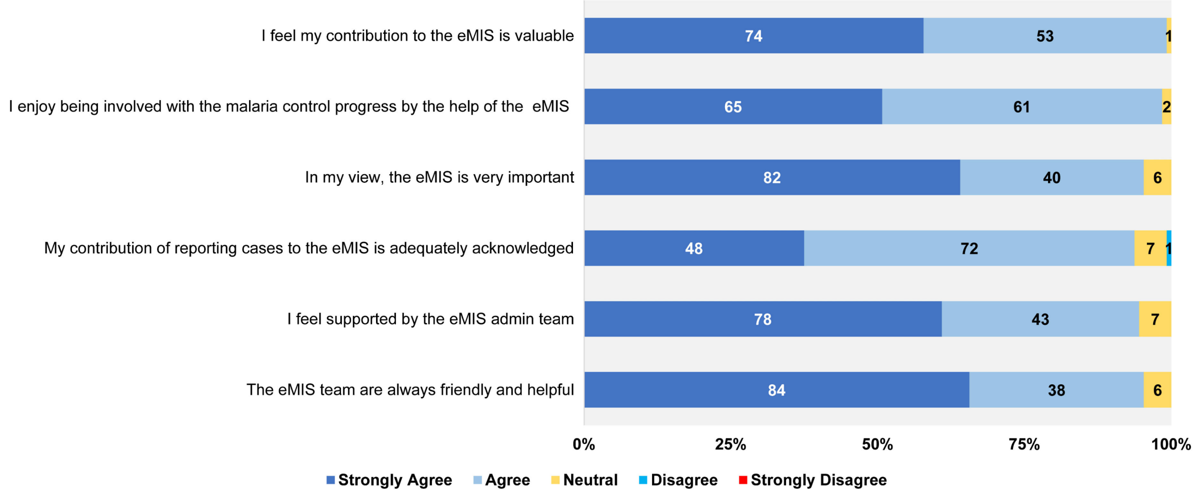


Acceptability

Acceptability refers to the willingness of users and organizations to use the system on a daily basis. Initially, the eMIS was implemented in 7 provinces along the Thai-Cambodia border but now includes 38 provinces in Thailand. As of mid-2015, access to the eMIS is expanding to include a number of subdistrict health centers in malaria-endemic provinces.

A significant majority of eMIS data entry staff agreed or strongly agreed that their contribution to the eMIS is valuable (127/128, 99.22%), they enjoy being involved with the malaria control progress via the eMIS (126/128, 98.44%), and that their contribution to the reporting of malaria cases to eMIS was adequately acknowledged (120/128, 93.75%). Most (122/128, 95.31%) agreed that the eMIS is very important. Most data entry staff (121/128, 94.53%) felt that they received support from the eMIS support team (Figure 5).

Figure 5. Acceptability of the electronic Malaria Information System (eMIS).



Flexibility

Flexibility reflects how the system copes with changes. Initially, the eMIS was implemented in 7 provinces as an online system; users were only able to enter data when connected to the Internet. However, because of an unstable Internet connection, the eMIS was changed to include an offline mode. After this big change, eMIS underwent three other main revisions.

> *We always maintain the core structure and do minor changes according to users' requirements. Technically, eMIS adapts to change very well.* [IT manager of the eMIS]

However, the eMIS is not based on any health information standard, such as SNOMED CT, ICD-10, or Health Level Seven. An IT manager mentioned that it would not be difficult to apply some standard code to ensure better data integration in the future.

> *eMIS only focuses on one disease, malaria, so we didn't apply any health information standard. But we think it would be good if we applies a standard code in order to integrate our data with the national disease report system in the future.* [IT manager of the eMIS]

Stability

Stability reflects the reliability and availability of the eMIS. In all, 100/128, 78.13% of data entry staff reported experiencing some technical problems with the eMIS. The most frequently reported technical problem was data synchronizing, with 87/128, 67.97% of respondents stating they had difficulty synchronizing offline data with the eMIS. This is consistent with interviewed respondents, with 6 M&Es (50%) mentioning the issue of data synchronizing. One M&E specified that data synchronizing was slow, especially at the end of month when many users attempt to upload data at the same time. When asked about technical support for the eMIS, 116/128, 90.63% agreed or strongly agreed the technical issues were dealt with quickly and efficiently.

In terms of reliable resources, the eMIS currently receives funding from the Global Fund and is seeking long-term governmental funding.

> *At the beginning, eMIS was supported by the Global Fund. Now we plan to use domestic funds. We have both the Global Fund and government funds for staff salaries. In the future, all salaries will be covered by domestic funds.* [Officer at BVBD]

> *We have a limited budget for IT after the Global Fund stopped its support. We need a budget for new computers.* [M&E]

> *Now the eMIS is very good. But we hope the eMIS will be a long-term program. We need funding to support our IT staff after the Global Fund stops its support.* [M&E]

The eMIS platform appears stable and performs well with no records of system failure. Data stored in the eMIS is backed up daily to tape media.

> *The eMIS has never been down since implementation. We have installed and configured virtual machine technology that can perform live migration for the eMIS. Live migration can move a running virtual machine (web and database server) from one physical server to another without any effect to the users.* [IT manager at BIOPHICS]

By the end of 2016, it is hoped that the management of the eMIS functional hardware and software architecture will be transferred from BIOPHICS to the BVBD at the Ministry of Public Health. One M&E expressed some concern over this change.

> *In the future, the management of the eMIS will be led by BVBD. My concern is who will take care of the IT problems. Now BIOPHICS do a great job of IT support. And I worry about the salary of IT staff that we will hire for the eMIS in the future.* [M&E]

Usefulness

The eMIS is considered a powerful tool and is used by the BVBD in its aim toward eliminating malaria in Thailand. With data from the eMIS, the BVBD is able to change policies, allocate funds, and prioritize malaria elimination activities. The BVBD provides weekly reports and presentations based on eMIS data. An officer at the BVBD reported that the eMIS can influence and guide future research.

> *We use the results from eMIS to plan elimination. It has helped us to change policy. Before we didn't have data to indicate how to implement malaria elimination. Now we are involved in subregional elimination. The data from the eMIS help us to target where we are going to eliminate malaria and apply a budget, and also to verify where malaria has been eliminated. eMIS is a powerful tool, without it, I don't think we can ensure malaria elimination. It's a key tool for malaria elimination in Thailand to change policy.* [Officer at BVBD]

At a lower level, all M&Es described the eMIS as being very useful, and considered the eMIS as integral to their routine work. It also provides useful information on malaria patients and tracks malaria patients to ensure effective action. The most commonly reported functions were data analysis, data presentation, and trend analysis. With the eMIS, M&Es are able to track patients, efficiently manage and control any outbreaks, perform campaign and training tasks, and make future plans.

> *For new cases, we take action quickly and we can predict the management for the next month. With the eMIS, we can see the malaria cases easily and make plans for the future.* [M&E]

> *eMIS helps to track patients. We can see the nearby situation and we can get prepared. We can see the real-time situation. We are able to plan how to control before an outbreak and understand the endemic. We can do an analysis for control and prevention. eMIS can quickly transfer data to the VBDU according to the patient's address. eMIS provides information on the outbreak of disease and accurate patient addresses.* [M&E]

> *We compare the malaria cases between different years to see trends in malaria outbreaks. We can track cases and control these cases with well-timed action.* [M&E]

Discussion

eMIS as Thailand's Malaria Surveillance System

After its development and implementation throughout malaria-endemic areas in Thailand, the eMIS has fully become the national malaria surveillance system. The eMIS appears to be well accepted by system users at both management and operational levels. The reason for its success could be that the design of the eMIS is not overly complex; it still combines original paper-based data collection forms with electronic records. The system flow is practical and can be used as a standard for health care activities in limited-resource settings. Some studies have shown that although paper forms can serve as an important tool for health care personnel in their work, their use can circumvent the intended system design. The following categories describe the benefits of using a paper-based system despite an electronic information system designed for capturing as electronic records: (1) efficiency; (2) knowledge, skill, ease of use; (3) memory; (4) sensorimotor preferences; (5) awareness; (6) task specificity; (7) task complexity; (8) data organization; (9) longitudinal data processes; (10) trust; and (11) security [15]. However, in the eMIS workflow, the paper-based forms are only used as initial data capture at point-of-care units in remote areas. The data are then transferred to the system as individualized electronic data records that can be accessed and utilized throughout the health care system—from point-of-care units to health care management departments. This is in contrast with the original paper-based system in which management could only view aggregated data after some delay, and largely after an outbreak had occurred. In designing any system, it is important to understand the setting so that the technology designers can ensure effective model processes to mitigate any barriers to using eHealth data [16]. Taking into consideration the difficulties of entering an electronic data record directly while caring for malaria patients in remote areas via the eMIS, the system designers decided to use a hybrid of paper-based forms before the introduction of a purely electronic surveillance system. With limited resources and choices in health care settings and a focus on patient-centered services, the system development should aim for a workable system rather than a high-end, perfect solution [17]. The geographically isolated nature of malaria-endemic areas had led to a mixed-design system (combining paper and electronic records) for the eMIS project, representing the most practical and workable solution at the time of system development.

Practices That Affect Data Quality

In general, data quality was acceptable. The quality of data has provided useful information for malaria personnel to ensure a high level of prevention and control activities. As mentioned above, there were some discrepancies regarding the number of source data forms (pCDF, pCIF) and electronic data records in the eMIS (eCDF, eCIF) for both noninfected and infected cases. There are a number of possible reasons for this result. First, the filing system for the source documents (pCDF, pCIF) was not well organized; some forms may have been misplaced or lost at the time of data collection. Second, as mentioned before, many noninfected cases were captured from the other sources (ie, district or provincial hospitals beyond BVBD primary care units); these were entered directly into the eMIS and thus there were no source documents (pCDF) for such cases. However, almost all infected cases have a source document (pCIF), no matter from which health care facility the data were obtained.

A small number of chronological errors were observed with the pCDF but not for eCDF; however, date errors were found for both pCIF and eCIF. In general, fewer chronological errors were seen in electronic records than on paper-based forms. This type of error might occur because of human error during the filling out of the paper source document and/or data entry into the system. Where the date of the eCIF entry was earlier than the date of investigation, this could be explained as a transcription error in the data entry process. This finding concurs with that suggested in the literature—should be the use of personal digital assistant based data collection or entry system could increase efficiency and reduce data transcription errors for public surveillance data collection in developing countries [18]. However, chronological errors might raise an important data management question: if there were conflicting dates on the paper forms, then why did these not appear in the electronic records when data were entered from the paper source document? In other words, did the data entry staff at VBDC/VBDU enter the same dates as shown on the paper forms? An investigation into this issue revealed that data entry staff usually corrected the dates when entering them into the eMIS because health care staff at point-of-care units can sometimes omit dates on the paper forms. This is particularly true for the date of receiving a blood film and the date of blood test, which match the date of blood drawn. For one electronic health record system [19], it was suggested that data transposition should be as faithful to the original records as possible, given some limitations to the clarity of the originals. However, it has been recommended that logic check programs should be written and integrated into electronic health record systems to reduce the possibility of illogical entry [20].

Another logical check conducted in this study revealed that there were incorrect prescriptions of malaria treatment in both paper-based and electronic data. However, this result should be interpreted with care. This does not mean that the patients received the inappropriate medication; it simply reflects that some patients received treatment that differed from the national standard guidelines. In the eMIS, data elements regarding medication prescriptions are more extensive than the treatment list provided on paper forms. Thus, the conflicting statistics found in this study could occur because some hospital reports did not apply the same malaria treatment as that in the national guidelines.

In this study, a high level of completeness was identified for electronic data records and is consistent with other studies [20-25]. This may due to the fact that there are required fields as well as logic checks across certain fields in the online eMIS. Regarding missing values, high percentages were found for the date of receiving blood film and the date of blood test. As stated before, in real practice, if the date of receiving a blood film and the date of the blood test share the same date as that of drawing blood, then only one date is entered on the paper form for convenience. Interestingly, a high volume of missing values was also observed for “Area classification” for both pCDF and pCIF. Area classification is the term used at the management level to classify the intensity of the malaria burden (eg, A1, A2, B1, and B2 areas) and such definitions change over time. Therefore, data collectors at point-of-care units tend to skip this field when they fill in the paper forms because such information is of no relevance to them. In the electronic records in the eMIS, that data element was completed 100% of the time, probably because of data editing during the data entry process. Data validity check results reveal discordant pairs when comparing data between paper and electronic forms. Such discord was also found in a previous study of the eMIS [26]. In our study, high levels of discord were found for chronological dates, area classification, and infection location. As explained before, the experienced data entry staff at VBDC/VBDU might enter missing values into electronic records based on their own judgment. Thus, the high level of data disagreement might not reflect poor data quality. It is well recognized that data must be complete, consistent, and accurate in any electronic health record system to deliver good health care services. Capturing important data elements is thus critical, but forms are only one part of the procedure to deliver quality health care during a clinician-patient encounter [22]. These results for data quality thus provide evidence-based practices for system improvement, such that (1) paper forms may need to be redesigned, (2) data collectors at the point of care and data entry staff at higher levels should be trained on data quality issues, (3) the need for certain data elements on paper forms (eg, certain dates or classification of areas) should be reconsidered for use at the point of care, (4) to avoid date transcription errors from paper to electronic records, a date-picker function might be the solution to avoid typing errors, and (5) logic validation programming may help reduce human errors.

System Usability and Suggestions for Improvement

The timeliness analysis indicated that the median time from data captured in paper forms at point-of-care units to data entry as electronic records at VBDC/VBDU was approximately 3-4 days. A previous study on the timeliness of a public health surveillance system [27] indicated that a reporting delay may be the result of several factors as follows: the volume of cases detected at the sites; case follow-up investigations to collect additional case information; system activity due to variable staffing levels; computer system downtime for maintenance, upgrades, or new application development; and data processing routines, such as data validation or error checking. Although timeliness is a key performance measure of public health surveillance systems, it can vary by disease and intended use of data [27]. The timeliness of eMIS is thus considered to be at an acceptable level, as a delay of 3-4 days could still support timely notifications and responses to outbreaks by management personnel. As noted in the Results section, a few cases had outlier values of more than a 200-day delay; this was possibly human errors during the data entry process. A few records showed negative-day gaps; again, this was probably due to a typing error as those records were entered around a change of year, between 2013 and 2014. A logic validation for eMIS might be a solution to reduce human error in the data entry process. Another possible solution is to reduce the time it takes to send paper forms from remote areas to the data entry centers at VBDC or VBDO or to have data entry directly at point-of-care units, which would require a further investment in infrastructure and equipment.

Respondent eMIS users indicated that the system is simple, with the eMIS based on the routine workflow of a vertically structured health care system in Thailand. Most users (both management and operational) accepted the eMIS and were satisfied with its performance; they considered the system easy to incorporate into other work duties. Furthermore, their commitment to be part of the eMIS was high. The M&Es reported being satisfied with the data analysis function and BVBD valued the eMIS as having a key role in the malaria elimination process. Factors influencing the effectiveness of the system have been frequently mentioned in the literature and include trust in quality of the data, motivation of the system users, and outcome expectancy [28-30]. Evaluation via measures that are sensitive to behavior change and feedback strategies is important. The user's perception is crucial to assure the success of public health systems [28]. Furthermore, differences between "basic" and "advanced" system users can be observed in terms of the expectations of the system's characteristics and perceived performance outcomes [29]. Similar findings can be seen in other studies about surveillance systems [26,31-34]. The eMIS has different functionalities: it has those that serve operational staff for simple data entry and those that link data for management staff in their data analysis and presentations with mapping and business intelligence tools for decision making. The system's high participation rates and acceptability among stakeholders show the value of the eMIS.

In assessing the usability of the system, one approach is to define usability as how useful, usable, and satisfying a system is for intended users [35]. A system is useful if it supports the work domain of the users and is independent from the system implementation; a system is usable if it is easy to learn and use and error tolerant; and a system is satisfying if the users have a good subjective impression that the system is useful, usable, and likable. The key characteristics of system usability [35] can be summarized as follows: (1) consistency and standards in design, (2) visibility of system state, (3) matching between the system and the world, (4) minimalist design, (5) minimize memory load, (6) informative feedback, (7) flexibility and customizability, (8) good error messages, (9) prevent use errors, (10) clear closure, (11) undo or reversible actions, (12) use users' language, (13) users are in control, and (14) help and documentation. Moreover, the usability of a system should be considered whether the system is well adapted to reflect with local priorities in favorable contexts and the use of the collected data [6]. In terms of system flexibility, after its initial implementation there were three major changes; the main system structure was maintained while minor changes were made based on user feedback. As suggested in the literature, the exchange of electronic data records in standard data format can make it easier for data access across institutes, reduce resource waste, and improve the quality of care [36]. However, one drawback concerning the flexibility of the eMIS is that it still does not apply a standard code. The reason for this is that it was designed and used only in a vertically structured malaria control program; however, it could be converted to a standard code should there be such a requirement. Regarding the usefulness of the eMIS, the system has improved the data flow from lower levels to decision-making levels; all interviewed M&Es stated that they frequently used eMIS data to make decisions regarding malaria control (eg, resource allocation and control plan making). Some M&Es sought more information for their data analysis, such as more details for occupation analysis and village-level data analysis. The linkage of data from eMIS to a customizable business intelligence platform has enabled the system users to visualize their own data in the way they want.

Infrastructure is the backbone of every system, and the successful adoption of any eHealth system depends on the infrastructural arrangements [37]. The willingness and interest of system users can be developed and maintained if the system is stable and the users are equipped with appropriate tools and receive regular training. The eMIS has demonstrated great stability: the server has never been down thanks to advanced technical strategies and careful maintenance. Although data synchronization is a common technical problem for data entry staff, it has been resolved by asking users to access the Internet at different times during the end-of-the-month periods when all sites are trying to synchronize data. One system drawback is that eMIS is primarily supported by the Global Fund and requires long-term ongoing funding. Insufficient investment has been proven to be a barrier to health technology in public health systems [32,38]; thus, long-term financial support from the government is essential for eMIS stability.

Conclusions

Overall, this evaluation, based on data from two malaria-endemic provinces for the period December 2013 to January 2014, has confirmed that eMIS is achieving its objective as an effective platform. The data quality assessment via an intensive look at the data records in the system flow, and the conduct of a Web-based questionnaire survey with all data entry staff throughout Thailand and the in-depth interview with data users from lower level to management level, have suggested that the eMIS helps improve the quality of Thailand's malaria surveillance system. As the national malaria surveillance system, the eMIS's functionalities have provided the malaria staff working at the point of care with close-to-real-time case management data quality, covering case detection, case investigation, drug compliance, and follow-up visits. Having access to such information in forms of individual case report, aggregated data in the geographical mapping, and data visualization platform could lead them to respond in a timely manner to the situation in their areas of responsibility. The benefits of eMIS, particularly in assessing the malaria situation, are recognized as exceeding those of the original paper-based reporting system alone. In other words, the eMIS is an information system that supports Thailand's malaria surveillance. One of the system features that makes the system users satisfied was that it can bring more evidence in the individual practice, for instance by providing electronic reminders about actions to take or treatments to prescribe at point of care (both triggered by previously keyed information). It has also led to an improvement in the quality of the malaria control program because case management is now somewhat standardized and government officials can have quicker access to both individual and aggregated data to promptly react to a possible outbreak. With such features of the system, the eMIS plays one of the key roles in moving toward the national goal of malaria elimination by the next decade.

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Authors' Contributions

SM and JK designed and planned the study, drafted the first version of the paper, submitted the paper, and approved the final version. SL, NS, and BK assisted in designing and planning the study, wrote the submitted paper, and approved the final version. SM, JK, KJ, and AK managed the literature search as well as performed the statistical analysis. RP, SJ, KT, AK, and KJ supervised data collection at the study sites. All authors read and approved the final manuscript.

Conflicts of Interest

None declared.

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Abbreviations

BIOPHICS: Center of Excellence for Biomedical and Public Health Informatics
BVBD: Bureau of Vector Borne Disease
eCDF: electronic case detection form
eCIF: electronic case investigation form
eMIS: electronic Malaria Information System
IT: information technology
M&E: monitoring and evaluation officer
pCDF: paper case detection form
pCIF: paper case investigation form
VBDC: vector-borne disease control center
VBDU: vector-borne disease control unit
VBDO: vector-borne disease control office

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Original Paper

Construct Validity of the eHealth Literacy Scale (eHEALS) Among Two Adult Populations: A Rasch Analysis

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Abstract

Background: The Internet has become a ubiquitous venue for information seeking, especially for health information. Public health practitioners have noticed the promise and potential of the Internet, however, little is known about individuals' skills of their eHealth literacy. The eHealth Literacy Scale, eHEALS, was designed to measure perceptions of individuals' eHealth literacy skills.

Objective: The objective of the study was to examine the psychometric validity and reliability of the eHEALS with two adult populations using the Rasch Model.

Methods: A college-aged sample and an Internet-based sample (Amazon's MTurk) were recruited to complete the eHEALS, demographic questions, and a health literacy scale. Using WINSTEPS and SPSS, unidimensionality, item fit, rating scale, item hierarchy, person ability-item match, and reliability were analyzed, compared, and contrasted against each sample and to other samples found in the literature.

Results: An exploratory factor analysis supported unidimensionality in both samples. More than 90% of respondents from both samples fit the model. No items were outright misfitting. Both samples separated into three distinct groups.

Conclusions: Based on the results, the eHEALS is a reliable and consistent measurement tool for a college sample and an Internet-based sample. As these individuals are most likely to use the Internet as a health resource, it is necessary to learn and know their skills versus perceiving that they can critically and successfully navigate the Internet. Further analyses are necessary to ensure that the eHEALS can serve as a standard eHealth literacy measure for public health.

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KEYWORDS

eHealth; eHEALS; internet; measurement; rasch; public health

Background

Using the Internet is now a standard practice for people seeking information about health care and health conditions. The PewResearch Internet Project estimates that more than 85% of adults in the United States use the Internet, with nearly three-quarters using the Internet for health information research [1]. Consequently, public health researchers are studying critical issues such as the quality of the Web-based health content and individuals’ ability to navigate the Web and find information [2-6].

Norman and Skinner [7] coined the term “eHealth literacy” to describe the ability to navigate the Internet for health information. Unlike general health literacy, eHealth literacy also considers individual computer and Web navigation skills. Thus, eHealth literacy encompasses a constellation of literacies, including computer literacy, scientific literacy, health literacy, traditional literacy, media literacy, and information literacy. Using this model, Norman and Skinner [8] created the eHealth Literacy Scale (eHEALS) to measure individuals’ perceptions of their own digital health literacy skills [9].

Accurately measuring eHealth literacy is imperative to addressing public health disparities. Many studies have used the eHEALS to measure eHealth literacy despite a lack of psychometric evidence [3-7,10]. When first created, the instrument was tested on a sample of middle school children [9]. Since then, Dutch and Japanese researchers have explored the psychometric properties of the eHEALS; however, both Dutch and Japanese researchers translated the instrument into their own native languages [4,11]. There are no known follow-up attempts to analyze the eHEALS using an English-speaking adult sample.

A 1-parameter logistic item response theory model, the Rasch model, is a mathematical framework created to empirically analyze categorical data [12]. The Rasch model is commonly used within the health professions, social sciences, education field, and market research [9,13-16]. The Rasch perspective examines each item contained in the measure versus examining the items as a conglomerate. Essentially, the Rasch model accounts for the “difficulty” of the item and expects that if a person of average ability were to accomplish a task of average difficulty, the person should have a high probability of accomplishing the “easier” tasks as well. The simplest Rasch formula is: $\log [P_{\mathrm{n}}/1- P_{\mathrm{n-1}}]=\mathrm{B}_{\mathrm{n}}-\mathrm{D}_1$, where P_{n}=probability of person n responding to item *i* correctly, P_{n}=probability of person n responding to item *i* incorrectly, B_{n}=trait/ability level of person n, and D_1=difficulty of item *i* [17].

In this study, the construct validity of the eHEALS was analyzed among 2 adult samples—university students and adults who use the Internet. The following constructs were investigated: (1) unidimensionality, (2) fit of items and participants, (3) item rating structure, (4) item difficulty hierarchy, and (5) person ability-item difficulty match.

Methods

Instrument: eHEALS

Created to measure a combination of comfort, knowledge, searching, evaluation, and application skills, eHEALS was developed as a self-reporting tool that can be administered by any health professional with little to no training [9]. Items reflect conceptualizations of the 6 key eHealth literacy constructs, and specialists were contacted for their expert feedback, whereas youth in TeenNet Research provided their views on readability and relevance [9]. After pilot testing with 89 teenagers and young adults, the instrument was finalized into its 8-item form (see Multimedia Appendix 1).

Validated with a middle school sample (n=664, mean age 14.95 years) in Canada, the analysis revealed an α =0.88 with item-scale correlations ranging from *r* =0.51 to 0.76. A principal component analysis found a single-factor solution, with factor loadings from 0.60 to 0.84 among the 8 items [9]. All questions use a 5-point Likert scale ranging from strongly disagree to strongly agree. An exploratory factor analysis conducted on a modified 6-item version of the eHEALS on an adult, Israeli sample (n=1289) produced similar factor loadings (.62 to .84) among the items. The item-scale correlation ranges from r=0.51 to 0.76. The coefficient alpha was lower (α =0.86) but similar to that in reported results [9]. The principal components analysis also revealed a single-factor solution [6]. Neter et al. conducted a confirmatory factor analysis on their modified eHEALS, alongside a few other measures that they used in their study, including outcomes perception, Internet access, and digital literacy [6]. They found that the scales were independent of each other via a 2-model fit analysis. Other psychometric evaluations have been conducted; however, they have been on translated versions of the eHEALS [11,16,18,19].

Recruitment and Participants

The first adult sample was obtained through a convenience sampling of college students. Undergraduate students enrolled in a health science research methods course in a large, southern university completed a questionnaire comprising the eHEALS in addition to questions pertaining to knowledge, attitudes, and beliefs. The questionnaire was used to demonstrate the process of informed consent, the various types of questions in psychosocial research, and how researchers analyze data. Inclusion criteria for eligible participants consisted of being 18 years of age or older, registered for the course, being present on the day of data collection, and agreeing to participate in the data collection. Results from this sample are in Table 1.

The second adult sample was acquired through Amazon’s Mechanical Turk (MTurk), a crowdsourced Internet marketplace, wherein individuals and/or businesses can ask people to perform tasks that computers cannot complete. Requesters post various tasks, known as human intelligence tasks (HITs), for individuals to choose and complete. Some HITs often involve transcription requests, translation requests, market survey research, opinion essays, and social science research. Individuals who complete these tasks are known as workers or providers or turkers and are compensated for their time [20].

Despite being a relatively new presence within social science research, MTurk appears to deliver reliable and usable user data. Several studies demonstrate that there are almost no differences in effect sizes when compared to other convenience samples. In addtion, samples from turkers are as reliable as other samples collected from the Internet. There are no statistical differences between in-laboratory or field samples, and samples from turkers tend to be more diverse than other Internet samples [21-23].

To access the HIT for this study, turkers get qualified if their HIT approval rate percentage was ≥98 with at least 500 completed and approved HITs. These scores are based on past performance ratings given by requesters. Those turkers who fail to follow instructions have their approval rating lowered. This stipulation was desgined to ensure that only individuals with MTurk familiarity and a good work history could participate in the data collection. Turkers had to first accept the task and then consent to being a part of the study. Results from this sample are presented under Study 2.

Data Analysis

Unidimensionality

A critical assumption in item response theory models, including Rasch, predicates on unidimensionality, which refers to the focus of the measure and its ability to focus on one variable at a time [12]. An exploratory components analysis using SPSS [24] was conducted. Eigenvalues and a visual inspection of the scree plot determined the number of extracted factors.

Item Fit

Using infit and outfit statistics, the fit to the model was analyzed. infit statistics are sensitive to data that are related to the items, whereas outfit statistics represent the relationships between data that are not related to the item (or person). The ideal fit statistic is 1.0, as fit is determined by calculating observed variance over expected variance [15]. Because the eHEALS is a survey of lower stakes (ie, the results of the survey do not have direct or definite consequences for the test-taker), the acceptable range of fit statistics is 0.6-1.4 [25]. An infit value of 0.6 indicates that 40% less variation was observed than modeled and a value of 1.4 indicates that 40% more variation was observed than modeled [12]. Mean-squares below the threshold overfit the model and thus suggest the data are more predictable than expected. Conversely, mean-squares above the threshold underfit the model, suggesting that the data are less predictable than expected. The second criterion of fit is the standardized *t* score, represented as the ZSTD by Winsteps. ZSTD scores examine the probability of significance that the data fit the Rasch model, determining the actual fit versus the theorized fit based on the model (observed vs expected). The acceptable range for ZSTD scores is ±2.0 [15]. Consequently, for an item or a person to misfit, the mean-square must be outside of the range of 0.6-1.4 as well as exceed the acceptable range for ZSTD.

Rating Scale

Although Linacre outlines 10 guidelines for rating scale optimization, he stresses the following 3 as essential critieria[17]: first, each rating category must have at least 10 observations. Linacre determined that without 10 observations for each rating category, a stable estimation of threshold value cannot be calculated, suggesting that the category may be unnecessary to measure . Second, average calibrations advance monotonically, meaning that on average, individuals with stronger ability should respond to higher categories, whereas individuals with lower ability should respond to lower categories. Lack of monotonicity strengthens the call for collasping categories. The third essential criterion stipulates that the outfit mean-squares be less than 2.0 for each rating category. Values greater than 2.0 indicate that there is unnecessary noise and misinformation in that particular category [17].

Item Hierarchy, Person Ability-Item Match, and Reliability

The Rasch model allows inferences to be made about a individual ability with regard to the difficulty of the items. For instance, a person with a high math ability level should have a higher probability of answering more difficult questions correctly than a person with lower math ability. Similarly, more difficult items are less likely to be answered correctly than easier items [19]. The analysis revealed the order of item difficulty, ranked from easiest to hardest items. In addition, Rasch analysis allows the researcher to examine how well the ability of the sample matches the difficulty of the items. Person reliability (similar to Cronbach’s alpha) estimates how well a measure can separate individuals on the construct. Conversely, person separation determines the strata or distinct levels that individuals are “spread” out on the measured construct.

Results

Study 1

Sample

In total, 164 students took the survey. Of the respondents, 20% (n=33) were male, and 80% (n=131) were aged between 18-34 years, with 83.6% of the students being aged 20 or 21 years. Almost 72% (n=118) of students reported that they spent more than 3 hours each day on the Internet, 25.6% (n=42) of students reported only 1-3 hours on the Internet, and less than 3% (n=4) reported spending less than an hour daily online [18]. Table 1 displays the demographic summary.

Unidimensionality

An ECA revealed that only one factor had an eigenvalue greater than 1. The scree plot showed one “bend,” and the factor score matrix only extracted one factor, which supported the assumption of unidimensionality.

Rating Scale Analysis

The most common criteria violation was failing to have at least 10 observations for each rating category. Few respondents chose “strongly disagree” and “disagree.” There were 2 instances in which the outfit mean-squares were outside the range of +2.0; the outlier could be due to the low observations in those rating categories. Table 2 presents the categories for each item that violated the essential criteria.

Model Fit

Fit order is presented in Table 3. All the items met the criteria for both infit and outfit. Ninety-five percent of participants (155 of 163) fit the model. Eight (n=8) participants violated both infit and outfit criteria.

Precision

The Rasch model’s equivalency of Cronbach’s alpha is person reliability, which was 0.80. Person separation was 2.02, indicating that the eHEALS separated the sample into 3.03 strata or 3 distinct groups.

Person Ability Item-Difficulty Match

Figure 1 is the map of item difficulty contrasted with person ability. Person ability (on the left side of the line) is presented from the highest ability (top) to the lowest ability (bottom). Items, on the right side of the line, are ranked from easiest (bottom) to hardest (top). Although there were no floor effects, there was a ceiling effect, with 6 individuals. Thus, the eHEALS was incapable of measuring individuals of extremely high ability.

Study 2

Sample

A total of 366 individuals took the survey. More than half of the participants were males (n=203), leaving a total of 159 female respondents. Almost 59% (n=210) of the individuals were aged 18-32 years. The age range of participants captured a wider group; some participants indicated being agedolder than 65 years.Eleven percent (n=40) of participants reported being online only 1-3 hours a day; 33% (n=120) of participants reported spending 4-6 hours online daily; and approximately 26% (n=94) of respondents spend a reported 7-10 hours online daily. Table 4 displays the demographic summary.

Unidimensionality

Similar to the results from Study 1, an EFA showed that only one factor was extracted, suggesting one latent variable or factor.

Rating Scale Analysis

Paralelling Study 1 outcomes, the most common essential guideline violation was not having 10 observations in each rating category. In addition, items 3 and 5 violated all essential criteria. Table 5 shows where all violations occurred.

Table 1. Demographics of respondents: study 1 (n=164).

Demographic		N	%
Sex			
	Male	33	20.1
	Female	131	79.9
Age			
	18-24	158	96.3
	25-32	5	3.0
	33-39	1	0.7
Time online/day			
	<1 hour	4	2.4
	1-3 hours	42	25.6
	>3 hours	118	72.0

Table 2. Ratings that violate essential criterion: study 1.

Item	Observed count[a]	Monotonicity[b]	Outfit[d]
I know what health resources are available on the Internet.	1-(SD)[d], 8-(D)		
I know where to find helpful health resoures on the Internet.	0-(SD)		
I know how to find helpful health resources on the Internet.	0-(SD), 6-(D)		
I know how to use the Internet to answer my questions about health.	0-(SD), 5-(D)		
I know how to use the health information I find on the Internet to help me.	1-(SD), 7-(D)		4.12-(SD)
I have the skills I need to evaluate the health resources I find on the Internet.	2-(SD), 7-(D)		
I can tell high-quality health resources from low-quality health resources on the Internet.	3-(SD)		
I feel confident in using information from the Internet to make health decisions.	1-(SD)		

[a] The numbers in the "Observed count" column are the counts of each answer choice in violation of the essential criterion.

[b] Because none of the items violated montoncity, no data are reported in that column.

[c] The numbers in the "Outfit" column are the values of the misfitting outfit means-square.

[d] SD: strongly disagree, D: disagree.

Table 3. Item fit: study 1 (college sample)[a].

			Infit		Outfit	
Item	Measure	Model SE	MNSQ	ZSTD	MNSQ	ZSTD
I know what health resources are available on the Internet.	−0.34	0.14	0.89	−0.80	0.8	−1.4
I know where to find helpful health resoures on the Internet.	0.74	0.15	0.84	−1.20	0.79	−1.2
I know how to find helpful health resources on the Internet.	0.06	0.16	1.16	1.20	1.12	0.9
I know how to use the Internet to answer my questions about health.	−0.16	0.15	0.99	0.0	0.91	−0.5
I know how to use the health information I find on the Internet to help me.	−0.54	0.14	0.90	−0.60	0.88	−0.7
I have the skills I need to evaluate the health resources I find on the Internet.	−0.15	0.14	1.06	0.50	1.05	0.4
I can tell high-quality health resources from low-quality health resources on the Internet.	0.07	0.12	1.16	1.20	1.12	0.9
I feel confident in using information from the Internet to make health decisions.	0.31	0.13	1.15	1.40	1.2	1.8

[a]This is a table showing item statistics and the fit of each of the items. There were no infit or outfit violations. The infit statistics are weighted to the performance of persons close to the item value. These individuals give a sensitive insight into the item’s performance. The outfit statistics are not weighted and are not sensitive to the influence of outlying scores.

Figure 1. Person ability item-difficulty match of the college sample. Persons are on the left of the line, whereas the item difficulty map is to the right of the line. Each “O” represents 1-2 individuals, whereas each “X” represents 3 persons.

Table 4. Demographics of respondents: study 2 (n=366).

Demographics		N	%
Sex			
	Male	203	55.5
	Female	159	43.4
Age			
	18-24	47	12.9
	25-32	163	45.0
	33-39	71	19.5
	40-46	31	8.6
	46-52	23	5.2
	53-59	17	4.7
	60-64	10	2.8
	>65	4	1.1
Time online/day			
	1-3 hours	40	11.0
	4-6 hours	120	33.1
	7-10 hours	94	25.9
	11-13 hours	36	9.9
	14-16 hours	20	5.5
	>17 hours	6	1.7
Education			
	8th grade	1	0.3
	Some high school, no diploma	4	1.1
	HS diploma or equivalent	44	12.2
	Some college, no degree	75	20.7
	Trade/technical/vocational training	13	3.6
	Associate’s degree	42	11.6
	Bachelor’s degree	148	40.9
	Master’s degree	28	7.7
	Professional degree	5	1.4
	Doctorate degree	2	0.6

Table 5. Ratings that violate essential criterion: study 2.

Item	Observed count[a]	Monotonicity[b]	Outfit[c]
I know what health resources are available on the Internet.[d]	2-(SD)[e]	(D)[f]	(SD)-9.90
I know where to find helpful health resoures on the Internet.	1-(SD)		
I know how to find helpful health resources on the Internet.	0-(SD)		
I know how to use the Internet to answer my questions about health.	0-(SD), 2-(D)		
I know how to use the health information I find on the Internet to help me.[d]	1-(SD), 6-(D)	(D)	(SD)-6.83
I have the skills I need to evaluate the health resources I find on the Internet.	1-(SD)		
I can tell high-quality health resources from low-quality health resources on the Internet.			
I feel confident in using information from the Internet to make health decisions.	3-(SD)		

[a] The numbers in the “Observed count” column are the counts of each answer choice in violation of the essetia criterion.

[b] There were 2 instances where “disagree” did not advance motonically.

[c] The numbers in the “Outfit” column are the values of the misfitting Outfit means-squares, including where the violation occur.

[d] This indicates violations of all essential criteria.

[e] SD: strongly disagree.

[f] D: disagree.

Table 6. Item fit: study 2

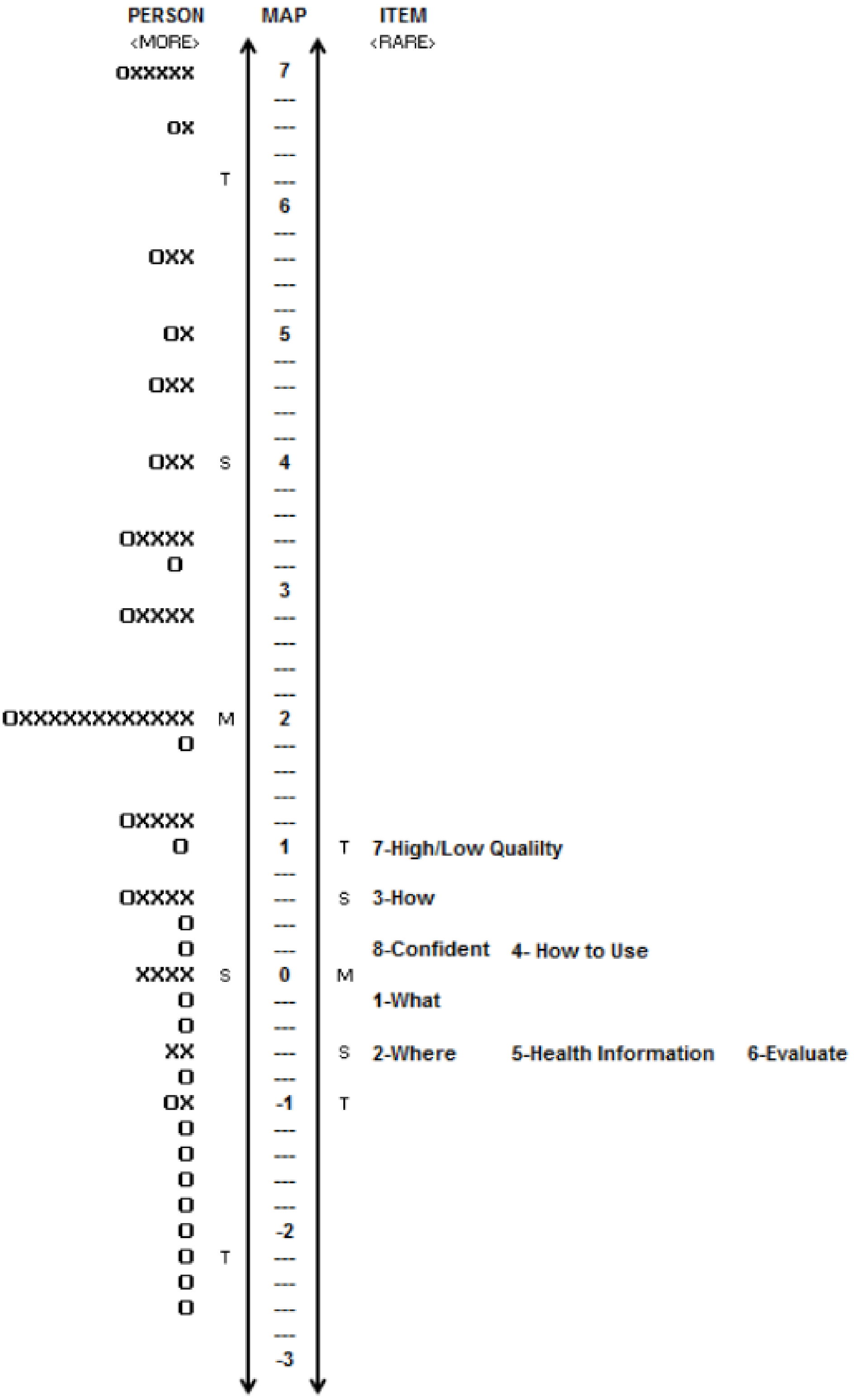
Item	Measure	Model SE	Infit[b]		Outfit[c]	
MNSQ	ZSTD	MNSQ	ZSTD			
I know what health resources are available on the Internet.	−0.18	0.11	1.27	2.5[a]	1.42[a]	3.0[a]
I know where to find helpful health resoures on the Internet.	−0.56	0.11	0.91	−0.9	0.71	−2.4[a]
I know how to find helpful health resources on the Internet.	0.51	0.12	0.83	−1.8	0.70	−2.5[a]
I know how to use the Internet to answer my questions about health.	0.16	0.12	0.78	−2.5[a]	0.64	−3.5[a]
I know how to use the health information I find on the Internet to help me.	−0.58	0.12	0.79	−2.1[a]	0.77	−2.0
I have the skills I need to evaluate the health resources I find on the Internet.	−0.57	0.11	0.98	−0.1	0.9	−1.0
I can tell high-quality health resources from low-quality health resources on the Internet.	0.99	0.10	1.21	2.5[a]	1.25	2.6[a]
I feel confident in using information from the Internet to make health decisions.	0.25	0.10	1.04	0.5	1.00	0.00

[a] It denotes violation of model fit; no items violated all criteria.

[b] Infit statistics are weighted to the performance of persons close to the item value. These individuals give a sensitive insight into the item’s performance.

[c] Outfit statistics are not weighted and are not sensitive to the influence of outlying scores.

Figure 2. Person ability of the MTurk sample is on the left side, whereas item difficulty is on the right side. Each “O” represents 1-2 individuals, whereas each “X” represents 3 persons.



Model Fit

Table 6 displays the corresponding values for model fit. Although there are violations of outfit criteria (eg, item 1), no items violated both infit and outfit. Almost 93% of respondents fit the model, with 27 individuals violating both infit and outfit criteria.

Precision

The person reliability was 0.81, whereas person separation was 2.07. The eHEALS separated the sample into 3.07 separate strata.

Person Ability Item-Difficulty Match

The map of item difficulty and person ability is presented in Figure 2. Like Study 1, person ability is on the left side of line, with individuals with higher levels of ability on top. Item difficulty is on the right side of the line, with more difficult items on top. Approximately 8.3%-9.7% of the sample had ability levels that eHEALS could not capture (n=30-35).

Discussion

Principal Findings

Overall, eHEALS is a reliable and consistent measurement tool for perceived measurement of eHealth literacy. An exploratory factor analysis showed that items loaded on a single factor solution, thereby supporting the criterion of unidimensionality. More than 90% of respondents from both samples fit the model. Although some items violated either infit or outfit guidelines, there were no outright misfitting items. Furthermore, the discordance between the mean of person ability and the mean of item difficulty was assumed as we sampled from a college population and a younger generation. The analysis separated both samples into 3 distinct groups, but further analyses are needed to describe the groups.

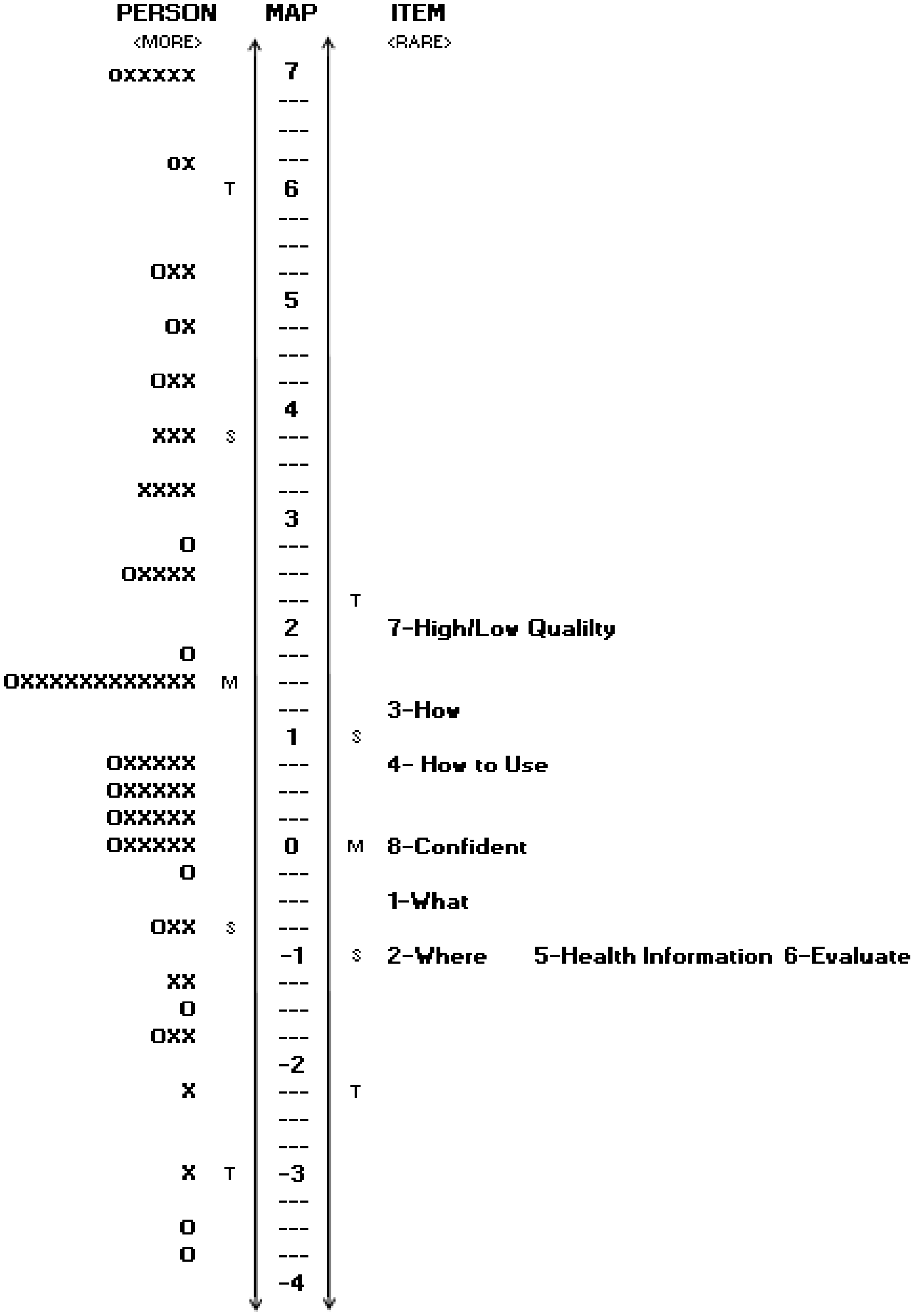
As eHEALS measures individuals' level of eHealth literacy, a small ceiling effect and no floor effect both occurred, as expected. The eHEALS did not adequately measure every participant's ability level. The item map only showed a spread of 2 logits, whereas person ability level spread over multiple logits. Furthermore, there are limitations in the eHEALS' rating scale, as evident in the ratings that violated the essential criteria as outlined in Linacre [18]. The violations were due to the low number of observations (less than 10) in the lower parts of the rating scale (ie, the strongly disagree and disagree choices).

It was hypothesized that it may be beneficial to collapse "strongly disagree" and "disagree" together, to avoid violating essential guidelines. For the MTurk sample, collapsing the 2 categories did not change person reliability (0.81) and remained to separate the sample into 3.09 distinct strata. As demonstrated in Figure 3 , a ceiling effect is still present; however, item difficulty is more spread out, approximately over an additional half logit. Moreover, the means between person ability and item difficulty are approximately one and a half logits away from each other. In contrast, before combining "strongly disagree" and "disagree," the two means were approximately two logits away from each other. Although further analysis should be conducted to ensure that there is no loss of validity and reliability, the reduction of the rating scale may relieve some test-taking burden and separate persons and items more distinctly.

Although the item difficulty map was similar between the 2 samples, some subtle differences exist. For instance, the college sample rated "I know where to find helpful health resources on the Internet" to be the easiest item and "I know how to use the health information I find on the Internet to help me" to be the hardest item. For the turkers, the easiest item was "I can tell high quality health resources from low quality health resources on the Internet," whereas the hardest item was "I have the skills I need to evaluate the health resources I find on the Internet." These differences could be attributed to the demographic make-up of each sample group. The college students are health science students and may therefore be more familiar with the location of health resources on the Internet. With higher education level in the turkers' sample, it may be plausible that they possess higher perceptions of their own ability to distinguish high-quality health information versus low-quality health information.

Knowledge of person ability and item difficulty is strongly relevant, as many public health organizations and doctors communicate with clients and patients online. With constant and easy access to the Internet, health care entities can use the information to tailor their materials and provide effective public health interventions to their targeted audience. For instance, community health workers can use outreach measures to those individuals with lower eHealth literacy by illustrating the differences between a verified Web resource and a blog with questionable health advice, thereby refining individuals' skills in identifying reliable and accurate online sites.

Figure 3. The person and item map after the rating scale was collapsed. Person ability is on the left side, whereas item difficulty is on the right side. Each “O” represents 1-2 individuals and each “X” is equal to 3 persons.



Limitations

This analysis bears some limitations. The college sample answered the eHEALS via paper and pencil method. Although Norman and Skinner also administered the eHEALS using paper and pencil, it may be more appropriate to have individuals take the instrument using a mobile or an Internet-connected device [9]. In addition, the college sample covered a somewhat homogeneous group. These students were in a core research methods class that required the usage of the Internet to find health information. Accordingly, their online searching abilities were crucial to their success in the course. Moreover, although involving turkers is novel, the sample cautions the generalizability of the study. Millennials are becoming the largest living generation, yet the higher rates in numbers are attributed to immigrants [26]. Turkers are a special subset of individuals; knowledge of the site, signing up on the site, and completion of a number of tasks were necessary conditions for verification of survey participation.

It is important to note that the combination of the 2 samples represents a large number of millenials in the United States. As young adults and minorities are liklier than any other group to have mobile Internet access, the Internet can serve as a valuable public health tool to improve the health of young adults and minorities in this country [1]. Using the Internet to improve behavioral change outcomes has been shown to be fruitful, especially among such vulnerable populations [27,28]. The productive potential of using the Internet is evident. Now, it is a public health imperative to study eHealth literacy measurement to maximize both the potential impact and reach that the Internet can have on our populaces.

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Multimedia Appendix 1

eHEALS: eHealth Literacy Scale.

[PDF File (Adobe PDF File), 26KB - publichealth_v2i1e24_app1.pdf]

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Original Paper

The Measles Vaccination Narrative in Twitter: A Quantitative Analysis

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Abstract

Background: The emergence of social media is providing an alternative avenue for information exchange and opinion formation on health-related issues. Collective discourse in such media leads to the formation of a complex narrative, conveying public views and perceptions.

Objective: This paper presents a study of Twitter narrative regarding vaccination in the aftermath of the 2015 measles outbreak, both in terms of its cyber and physical characteristics. We aimed to contribute to the analysis of the data, as well as presenting a quantitative interdisciplinary approach to analyze such open-source data in the context of health narratives.

Methods: We collected 669,136 tweets referring to vaccination from February 1 to March 9, 2015. These tweets were analyzed to identify key terms, connections among such terms, retweet patterns, the structure of the narrative, and connections to the geographical space.

Results: The data analysis captures the anatomy of the themes and relations that make up the discussion about vaccination in Twitter. The results highlight the higher impact of stories contributed by news organizations compared to direct tweets by health organizations in communicating health-related information. They also capture the structure of the antivaccination narrative and its terms of reference. Analysis also revealed the relationship between community engagement in Twitter and state policies regarding child vaccination. Residents of Vermont and Oregon, the two states with the highest rates of non-medical exemption from school-entry vaccines nationwide, are leading the social media discussion in terms of participation.

Conclusions: The interdisciplinary study of health-related debates in social media across the cyber-physical debate nexus leads to a greater understanding of public concerns, views, and responses to health-related issues. Further coalescing such capabilities shows promise towards advancing health communication, thus supporting the design of more effective strategies that take into account the complex and evolving public views of health issues.

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KEYWORDS

social media; health narrative; geographic characteristics; data analysis; health informatics; GIS (geographic information systems)

Introduction

The Internet has provided health informatics with a new lens to study health-related issues. For example, Internet-based biosurveillance and digital disease detection approaches have been used to gain insight into emerging disease threats [1,2]. A main focus of earlier efforts was placed on identifying the likelihood of new outbreaks based on observations of increased mentions of disease-related terms. For example, Google Flu Trends maps the number of search engine queries about the word influenza and related terms and predicts emerging outbreaks as changes in the frequency of such queries [3]. While those types of approaches have been successfully applied to tracking and monitoring disease outbreaks, the emergence of social media enables researchers to move beyond this by incorporating valuable insights about people's opinions and perspectives on health issues.

In this paper, we present a case study that showcases the emergence of a health narrative from social media content, focusing on the reaction on Twitter to the recent outbreak of measles. In the context of this study, we use the term "health narrative" to refer to the structure of the discussion as it is observed on Twitter. This structure is characterized by associations. Associations between words reveal the semantic composition of the discussion, exposing themes and clusters of topics, and even term connotations. Associations between cyber contributions and their corresponding geographical space help reveal the connection between observations in the Twittersphere and current health issues that affect the general public. It has to be noted here that the structure of this narrative is implicit and emerges from the individual contributions, rather than being explicit and imposed by a certain authority.

The research objective of this paper is to explore how such health narrative structure may be discerned from individual contributions and its value. In order to pursue this goal, we use the 2015 measles outbreak as a case study and demonstrate how narrative elements are extracted from it and how they relate to the ongoing public debate regarding this issue. We show the relative impact on this process of different sources of information (namely media and authoritative health organizations) and highlight the cyber and spatial footprints of an ongoing debate regarding vaccination.

Social media provide the general public with newfound mechanisms to receive and contribute information, often in real-time. While these communities started off as cyber curiosities, participation has now reached massive levels. As of spring 2015, Twitter has nearly 300 million active users globally, and Facebook has a remarkable 1.4 billion active users [4]. According to a survey conducted by the Pew Research center in late 2014, 58% of all American adults use Facebook, 21% use Instagram, and 19% use Twitter [5]. Accordingly, these social media platforms are no longer limited to supporting the simple exchange of messages among friends. They have evolved to play a formative role in shaping global public opinion on a broad array of topics, ranging from politics [6] and entertainment [7] to science [8] and business [9].

Researchers from the health community realized early the potential offered by social media to change health-related communication patterns across the United States and the rest of the globe [10]. By their nature, social media represent a transition from one-to-one health communications between clinicians and their patients to many-to-many communications between health care providers, patients, and broader communities. They also broaden the scope of health discussions, no longer focusing exclusively on reporting disease outbreaks but also addressing health care service, with patients sharing their experiences with various health providers [11].

This transition toward interactive communication presents opportunities and challenges [12] that exceed those introduced by the traditional role of the Internet merely as a publicly accessible repository of information [13-16]. Collective discourse in social media leads to the formation of a complex narrative, conveying public views and perceptions.

With major health organizations embracing social media as a new avenue to communicate (and also harvest) health-related information to (from) the general public, advancing our understanding of the patterns of health narrative in social media is becoming essential. Terry [17] discussed how the Centers for Disease Control and Prevention (CDC) utilized Twitter in the context of the 2009 H1N1 influenza outbreak. On the same issue, Chew and Eysenbach [18] studied the use of Twitter traffic related to H1N1 for real-time content analysis and knowledge extraction in the context of infodemiology. More recent studies suggest that such analysis can even be applied not only to monitor broad epidemics [19], but also to harvest more personal content, such as reports of adverse reactions to medication [20,21].

Reflecting the strong potential of social media for health communication, in 2014 the World Health Organization (WHO) used Twitter to communicate information regarding the Ebola outbreak in West Africa. However, public opinion is formed not only as a top-down process (ie, authoritative sources such as WHO communicating their views to the general public) but also as a bottom-up process (whereby individual users establish circles of influence) [22,23]. These patterns of health narrative are complex and need to be studied in order to be better understood.

This paper contributes to this goal by presenting a study of the narrative in Twitter regarding measles vaccination in early 2015, focusing specifically on the intersection between this narrative and a grass-roots antivaccination movement. The contributions of this work are the analysis of the data for this particular case study, as well as the presentation of a broader approach to analyze such open-source data. As such, this line of inquiry has the potential to further advance health communications by improving our understanding of the mechanisms through which information is disseminated in social media.

Methods

Design

The objective of this analysis was to study the Twitter narrative about vaccination in the aftermath of the 2015 measles outbreak, both in terms of its cyber and physical characteristics. Toward this goal, the Twitter application program interface (API) was accessed in order to collect tweets between February 1 and March 9, 2015, using the keyword “vaccination” or its derivatives that are often encountered in social media (ie, “vaccine,” “vaccines,” “vax,” “vaxine,” and “vaxx”). These 6 variants of the term vaccination were selected following a brief study of Twitter traffic related to vaccination for a 48-hour period directly preceding our formal study. In that pre-study, these five variants were the predominant alternate versions of the word vaccination, and as such were used together with it for our subsequent formal study.

Data Collection

The GeoSocial Gauge system prototype was used to collect data from Twitter using a user-specified set of parameters such as keywords, locations, and time [24]. This system allows researchers to retrieve the actual tweet content as well as its metadata, including information such as user name, timestamp, and location. The system also performs basic quantitative analysis of extracted data. A geosocial analytic approach was used to explore the geographical distribution of tweets as well as social network properties.

Data Characteristics

Using these keywords, a total of 669,136 tweets were collected from across the globe. Among these tweets, 356,248 tweets (53.24% of the total) had some type of geolocation associated with them, to indicate the location of the user that posted them. A total of 6266 tweets had geolocation in the form of precise coordinates, which tends to be as accurate as few meters and is typically associated with tweets posted from users through their mobile phones. An additional 351,973 were geolocated at the level of a toponym reference (ie, at the level of a city or neighborhood). These patterns of geolocation are consistent with figures reported from other analyses. More specifically, the precisely geolocated tweets represented 0.94% (toponym reference: 52.60%) of the total number of tweets, and broader studies have reported such precisely geolocated tweets to amount to between 0.5% and 3% of the overall traffic with toponym references typically ranging from 40-70% [25].

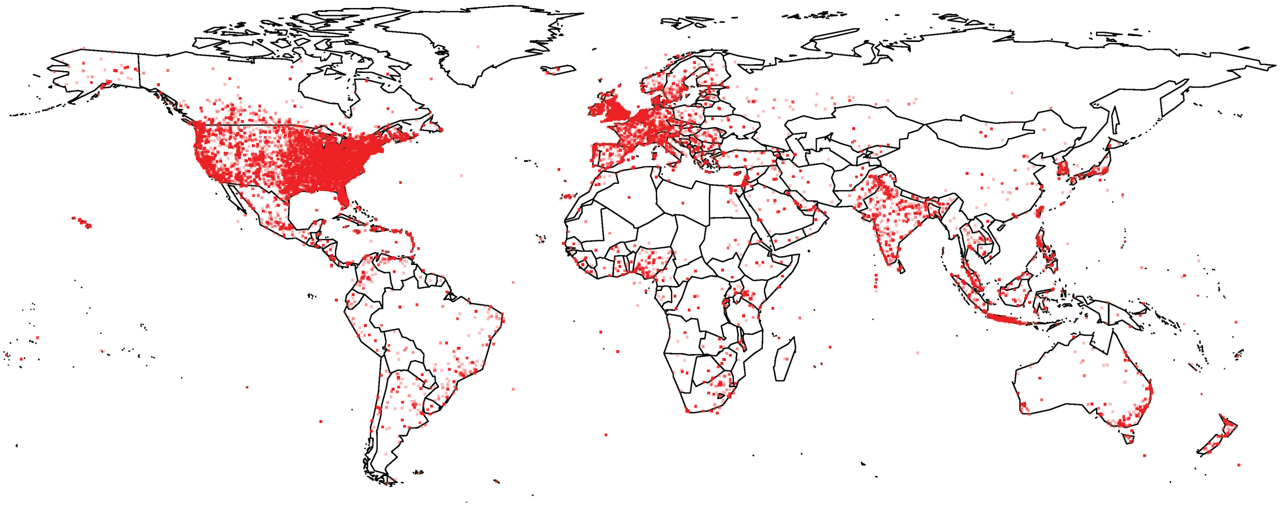
Figure 1 shows the global distribution of the geolocated tweets in our data corpus, with 60.18% of them (214,396/356,248) originating from within the United States. Similarly, over half (54.69%, 3432/6266) of the precisely geolocated tweets originated from the United States. Table 1 summarizes the 10 countries contributing the most tweets during that period. Tweets originating from the United States dominate the data, with a volume of contribution that is one order of magnitude larger than that of the second country (Canada), and two orders of magnitude larger than the rates of the countries that round off that list. This pattern of distribution of contributions is not uncommon for Twitter, especially when it is affected by high profile events (as was the 2015 measles outbreak for our study), which tend to amplify Twitter traffic [26].

Table 1. The 10 countries contributing the highest number of tweets in our data corpus.

Country	Tweets (% of geolocated total), n (%)
United States	214,396 (60.18)
Canada	20,039 (5.63)
United Kingdom	15,018 (4.22)
India	9249 (2.60)
Australia	8207 (2.30)
Indonesia	2864 (0.80)
France	2492 (0.70)
Pakistan	2448 (0.69)
Germany	2370 (0.67)
Nigeria	2263 (0.63)

Regarding frequency of contributions, our data reflect a global average of just over 18,000 tweets daily, or more than 750 tweets hourly (5794 geolocated tweets originating daily from the United States); 272,795 distinct users contributed the tweet corpus. While this would indicate an average of 2.45 tweets on the subject per user, participation in social media deviates from a normal distribution and instead tends to follow power law patterns [27]: a large number of users tweet infrequently, while a small number of them are very prolific. This behavior is consistent with observed blogosphere characteristics [28] and is comparable to behavioral patterns observed in online forums [29]. In the data corpus, the median number of vaccine-related tweets per user was 5, while the three most active users contributed more than 1000 tweets each. Six of the 10 most prolific authors are notable antivaccination advocates (account handles are not reported here for privacy considerations).

Figure 1. Global distribution of tweets in our data corpus.



Analysis Objectives

Our primary objective was to assess the characteristics of the vaccination narrative in cyber and physical spaces. Toward this goal, our study assesses the characteristics of discussion terms that comprise the narrative in Twitter and of the communities that were involved in this discussion. Figure 2 summarizes our approach. We start with a selection of search parameters, which are typically a set of keywords and potential geographical areas of interest. Using these parameters, we access the Twitter API for data collection, harvesting tweets that include these keywords and originate from the area of interest. These tweets are then analyzed to extract terms and patterns that reveal the narrative structure. This structure comprises three dimensions: text, retweeting patterns, and spatial patterns.

Regarding text analysis, we identify dominant terms and popular hashtags, as well as their associations in the form of co-occurrences. Terms and hashtags serve as the equivalent of keywords for the overall narrative: they reflect the topics that are considered relevant and important by the general public. Their associations reveal the thematic components of the narrative structure, in the form of subthemes and contextual connotations, as they emerge from the crowd. Regarding communication patterns as they are revealed through retweeting, our primary objective is to assess the impact of various sources of information, contrasting diverse types of authoritative content (eg, health organizations and official news organizations) and grass-roots campaign arguments (with the antivaccination community views serving as a prototypical example). We are also interested in assessing the spatial patterns of communications by studying the locations from which these contributions are being made to social media. This allows us to gain insights on the debate in cyberspace as well as the connection between cyber and physical communities, and consequently between the ongoing community debates across the continental United States regarding vaccination.

Results

Dominant Terms

Given the design of the data collection process, all of the tweets in the data corpus for this analysis included the word vaccination or one of its derivatives. Figure 3 shows a word cloud visualization of the 75 most frequently encountered terms in the data corpus, in order to provide a general overview of the dominant narrative terms. The word cloud excludes the search words vaccine and vaccination because their very high frequency (appearing in 279,684 and 123,342 tweets respectively) would make all other data dwarf. The word cloud also excludes stop words (ie, articles, prepositions, and common verbs), as such words are common to all discussions and therefore lack semantic significance. In the word cloud, the relative size of each word is proportional to its frequency, where words in larger font are the ones more often encountered in the data corpus. In the word cloud, hashtags are treated as distinct words. For example, measles and #measles are considered as two separate terms. A hashtag reference indicates a stronger emphasis on the word, rather than the simple reference to it within the tweet text [30], so these terms have distinct uses within the Twitter discussion.

Table 2 lists the 10 most frequently encountered health-related terms in the data corpus. The list excludes vaccination and its various derivative forms, stop words as defined above, and common words such as new, now, people and against. The overall number of mentions is listed, along with the percentage of tweets in which each term was present.

Figure 2. A summary of our approach.

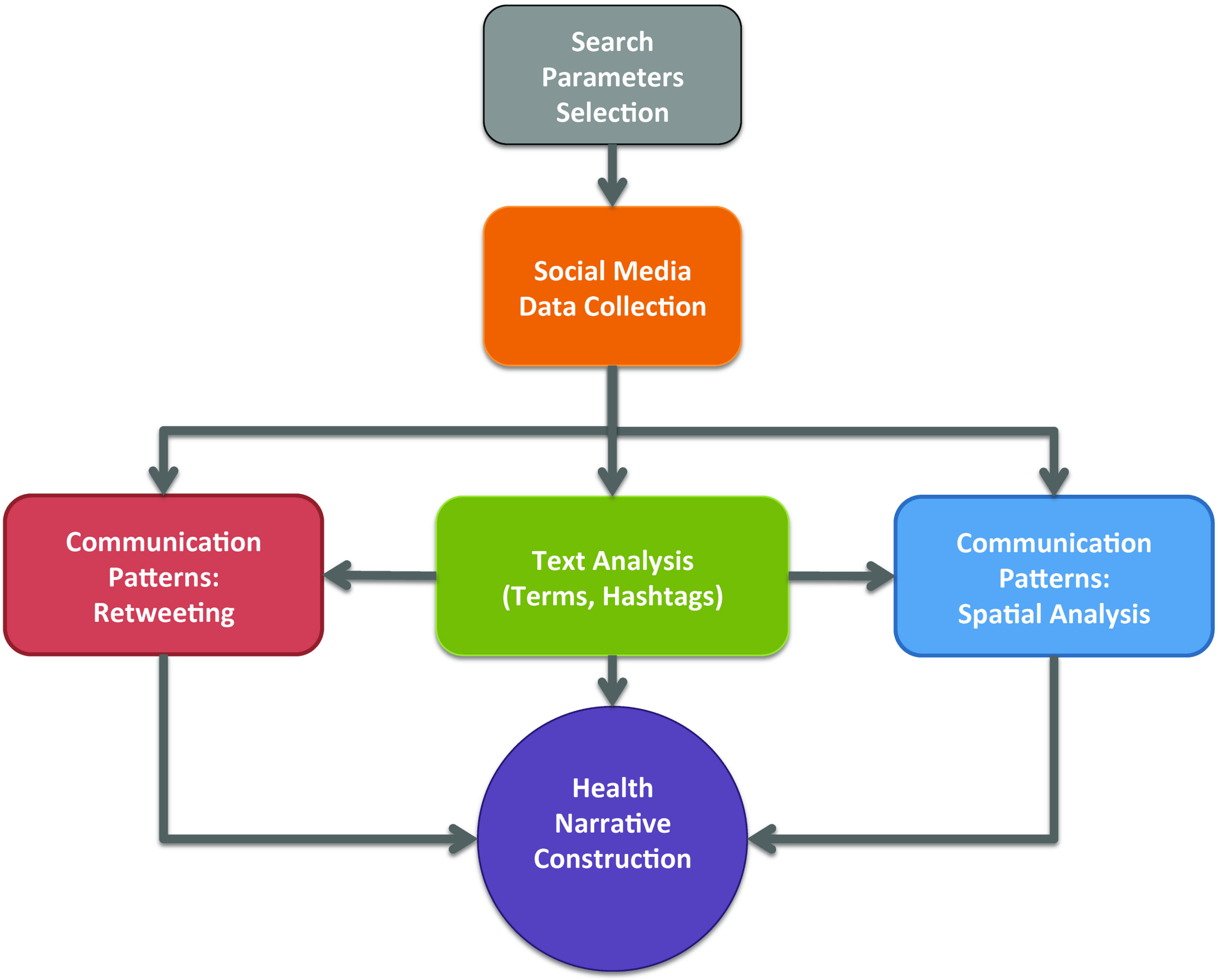


Table 2. Ten most frequently encountered health-related terms in the data corpus.

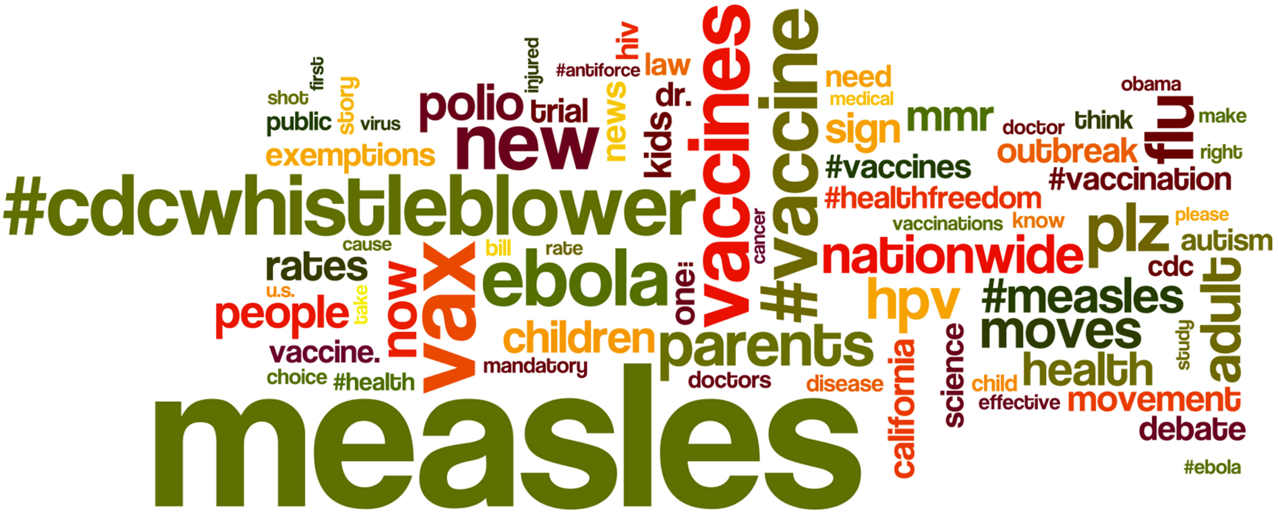
Term	Mentions (frequency)
measles (and #measles)	82,179 (12.28%)
#cdcwhistleblower	27,876 (4.17%)
Ebola	26,273 (3.93%)
flu	22,429 (3.35%)
HPV	19,253 (2.92%)
polio	16,749 (2.50%)
health	15,546 (2.32%)
MMR	14,777 (2.21%)
#healthfreedom	10,356 (1.55%)
autism	10,101 (1.51%)

Measles was the most common term encountered in these tweets about vaccination, which is expected given that these data were collected during the US measles outbreak in early 2015. Furthermore, Ebola and HPV (human papilloma virus) are also encountered among the top terms associated with the discussion, reflecting the general interest in the media regarding vaccinations for them during that period.

It is interesting to observe that the second most popular term was #cdcwhistleblower, which emerged in August 2014 as a quick identifier to the antivaccination community of messages aligned with antivaccination views. This term did not originate from a formal organization, but instead it is one that has emerged from an online advocacy community as a means to consolidate its views and promote its perspectives. In contrast, references to official health organizations were uncommon. For example, CDC had only 9611 mentions in the data corpus, making it the

47th most popular term, while WHO and NIH (National Institutes of Health) had only 351 and 330 mentions respectively and were not within the top 2000 terms in the data corpus. Accordingly, the data indicated that a bottom-up campaign (represented by #cdcwhistleblower) far outweighed the presence of official sources such as the top-down efforts of CDC and WHO. This pattern is indicative of the complex notion of authority in the information dissemination landscape of social media.

Figure 3. Word cloud of the 75 terms most frequently encountered in Twitter in the context of the vaccination study.



Communication Patterns: Retweeting

Among the 669,136 tweets, 296,223 were retweets (and conversely, 372,913 were original tweets). These retweets account for 44.27% of the overall data corpus (42.20% within the United States and 45.25% overseas). This is substantially higher than reported figures regarding retweet activity in Twitter overall, whereby retweets typically account for only 30% of overall Twitter traffic [31]. Such increased retweeting patterns are comparable to ones observed in studies of Twitter traffic during elections [32], which showed that highly opinionated users tend to retweet more than their less opinionated counterparts. Vaccination appears to be a "political" or partisan topic among Twitter uses, and high levels of retweeting activity may reflect high levels of activism among the participants.

Retweeting is part of the process of community formation and information dissemination in Twitter [33]. Similar to the patterns of participation, the pattern of retweeting has been shown to be highly skewed [34], with the large majority of tweets receiving one to two retweets each and very few receiving high numbers. The data corpus was consistent with this pattern, with a median number of 1 retweet per tweet, and a maximum value of 3399 retweets of a single tweet (see Textbox 1).

Textbox 1. The five most retweeted messages.

1: "The Disneyland Measles Outbreak Is A Turning Point In The Vaccine Wars http://t.co/qHVBxyvDMF via @username1" (3399 retweets in the data corpus)

2: "@username2 @username3 Parents can delay timing of vaxx if they want more time between shots. Should be done by time they enter school." (2899 retweets)

3. RT @username4: Anti-vax dad is cool with his kid fatally infecting others, also blames leukemia on vaccines. http://t.co/XuSkaK9SdQ http:/..." (2002 retweets)

4. RT @username5: Vaccination isn't a private choice but a civic obligation." F****' A right. http://t.co/pNj5w7fp9t" (1630 retweets)

5. RT @username6: Vaccination rate at Google's and Pixar's daycare is less than 50% http://t.co/6GFxs6VDI2 http:/..." (1604 retweets)

Four of these five tweets were about news stories: the first was a reference to a *Forbes* magazine article published on February 4, 2015; the third referred to a CNN story published on February 2; the fourth to a *New York Times* op-ed feature published on February 7; and the fifth to a *Wired* article published on February 11. (Note that some user names and references to some Web links were anonymized in order to protect privacy.) In contrast, the most-retweeted tweet originating from @CDCGov (the Twitter handle of CDC) during that period was "How effective is vaccine against measles? 1 MMR vax dose is ~93% effective at preventing #measles if exposed; 2 doses are ~97% effective." This was posted on February 9 and was retweeted 182 times during our study period. The average and median retweets per vaccination-related CDC tweet during our study period were 27.9 and 1 respectively.

These statistics suggest that news stories from mainstream media have a substantial impact on health-related social media narratives as well. This is in contrast to official health agencies, which do not appear to have the ability to directly drive these conversations. The importance for the general public of news stories about health issues has been shown before [35], and our data indicate that this holds for social media as well. This finding is in line with other reports [36] that also observed similar patterns in the Netherlands in 2013. Accordingly, an argument is emerging that using such stories to reach the general public offers the potential of higher impact in comparison to direct communications by authoritative official health organizations.

Communication Patterns: Narrative Structure

The association between words in the data corpus provides additional insights that go beyond mere frequencies. Figure 4 is a visualization of hashtag co-occurrences in tweets. The most frequently encountered hashtags in the data are shown as nodes, with the size of the nodes proportional to their frequencies. The connections between these nodes reflect the frequency of hashtag co-occurrence within single tweets. Every time two hashtags appear together in a single tweet, a connection is established between them. Thicker connecting lines correspond to more frequent co-appearances.

Figure 4 shows how the patterns of co-occurrence of the most popular hashtags can be grouped into four different narrative sets through the application of the Louvain method [37]. We used the Louvain method because it is a data-driven, unsupervised community detection algorithm. As such, this approach does not require an a priori selection of the number of communities (clusters), instead this number emerges through an optimization process. Therefore, it eliminates potential perceptual biases, to maintain a data-driven approach to analyzing these public contributions.

As hashtags have an elevated semantic meaning compared to other words in a tweet, their co-occurrence has been shown to be an important indicator of the sentiment of the crowd [38]. This finding can be extended by arguing that these co-occurrences reflect the contextual association of the corresponding topics/issues by the authors. Accordingly, hashtag co-occurrences reveal the structure of the narrative by showing the distinct themes (as clustered associations of hashtags) that are present in the data corpus. More specifically, the Louvain clustering revealed four communities of words that can be considered distinguishable among our data (see Figure 4). In this figure, the color of a node corresponds to its cluster.

Through this clustering shown in Figure 4, we are able to identify the four key thematic dimensions that characterize the public views of the issue. The blue nodes focus on the political aspects of the vaccination, grouping hashtags such as #vaccines, #gmo, #bigpharma, #news, #obama, #gop, and #tcot (standing for "top conservatives on twitter"). The green nodes connect #vaccine to less overtly political, and more health-oriented issues like #cdcwhistleblower, #mmr, and #autism. The light brown nodes show the narrative cluster reflecting the anti-antivaccination activism, which uses polio (#polio) as an argument in support of vaccination practice (#vaccineswork). The red nodes for HPV and cancer represent a conversation occurring outside the measles epidemic that also touches on vaccine themes.

Links among nodes in Figure 4 indicate how frequently terms co-occur in the data corpus. The strongest link in Figure 4 is for the co-occurrence between #vaccine and #measles, which is expected given that the target dates were selected to capture reactions to a measles outbreak linked to under-vaccination. Taking this co-occurrence as having a strength of 1.00, the second strongest co-occurrence is between #vaccine and #cdcwhistleblower (with a strength of 0.64), followed by #vaccine and #autism (0.62), #vaccination and #measles (0.53), and #vaccines and #gmo (0.43).

The information that is gained from such an analysis is primarily an explicit view of how the public associates different topics in its communications, and as such exposes the meta-meaning of these terms. Some of that information may be expected: it is not surprising that measles and vaccine are indeed highly connected in our data. Nevertheless, it is the ensemble of connections that carries high observational value. For example, observing that the antivaccination views (reflected here through the term #cdcwhistleblower) are clustered within the main health-oriented discussion (green nodes) rather than as a peripheral activist debate topic (brown nodes) shows the success of a grass-roots campaign that has brought this issue to broader view in the context of vaccination. Similarly, the fact that Ebola was clustered within the same green group as measles, and not together with HPV and cancer also signifies the semantic affinity that the general public assigns to two infectious diseases that were recently subjects to outbreaks. The data-driven Louvain approach for clustering is highly suitable for that purpose, as it allows us to derive these associations directly and agnostically, unlike for example a top-down thematic approach (eg, k-means clustering) where such information would have been kept separate under the general term of "other diseases."

While Figure 4 shows a high-level representation of the themes of the Twitter narrative and some connections among them, the inherently hierarchical structure of this narrative enables further analysis. Figure 5 shows a finer resolution view of the #cdcwhistleblower cluster that was represented as a single node in the hashtag network of Figure 4. Figure 5 uses the same visualization principles as Figure 4: node sizes reflect the frequency of the corresponding hashtag, connections reflect co-occurrence, and the widths of connecting lines represents the frequency of co-occurrences.

The top 10 hashtags associated with #cdcdwhistleblower are shown in Table 3. The first column lists the hashtag itself, while the second column lists the number of times that each hashtag co-occurred with #cdcwhistleblower in the data corpus. The widths of the links among terms in Figure 5 are directly proportional to these numbers. In order to better communicate the level of association among these terms, column 3 of Table 3 lists the percentage of these co-occurrences relative to the overall presence of a particular hashtag. It expresses the ratio of column two over the total number of occurrences of this hashtag in the entire data corpus. This percentage is referred to as the "level of affiliation with #cdcwhistleblower." For example, #b1less is encountered 2371 times in the same tweets as #cdcwhistleblower, corresponding to 51.48% of all of the tweets in the vaccination data corpus that use the term #b1less. As such, it can be considered as a term with a very high affiliation to the #cdcwhistleblower movement. The same argument can be made for hashtags like #nomandates or #cdcfraud (34.08% and 31.72% respectively). In contrast, #autism, while having a strong presence within the #cdcwhistleblower community (it was encountered 1215 times in conjunction with #cdcwhistleblower) is not exclusive to that discussion, as only 8.97% of its encounters are affiliated with it. These pairwise association strengths communicate the level to which certain arguments are aligned in the context of this health-related argument. Such data analysis processes progressively reveal the complex structure of the health-related narrative in social media, which is essential knowledge in the quest for more effective health communication campaigns.

From Cyber to Geographical Space

While these social media interactions take place in cyberspace, the communities that participate in them have definitive footprints in the physical space. Accordingly, assessing the geographical patterns of involvement in this discussion provides greater understanding of the motivating factors behind this process. In order to study this, the geolocated tweets from the data corpus were mapped to explore spatial patterns.

Figure 6 shows maps of the frequency of tweets mentioning several key terms in the data corpus, aggregated by state. In order to make the data comparable across states, they were normalized by population. The number of tweets originated from within each state were divided by the state population in order to capture the rate of tweets per 10,000 residents for each state. The top left figure communicates the degree of participation in the vaccination debate, expressed as levels of normalized tweets per state. The top right map shows the corresponding metric for references to autism, the bottom left map shows frequency of references to measles, and the bottom right map shows references to #cdcwhistleblower. In these maps, the level of participation is visualized by a color scale, ranging from dark red (highest participation) to light yellow (lowest). The lowest number of tweets per capita (light yellow in top left map) was 1 tweet per 4527 persons in Michigan, the highest rate was 1 tweet per 817 persons in Vermont, and the median was 1 tweet per 1766 residents. Table 4 presents the top five participating states per topic. Participation is expressed in terms of "1 tweet per X persons," so lower denominators reflect higher levels participation.

Figure 4. Hashtag associations: clustering based on co-occurrences of hashtags in individual tweets.

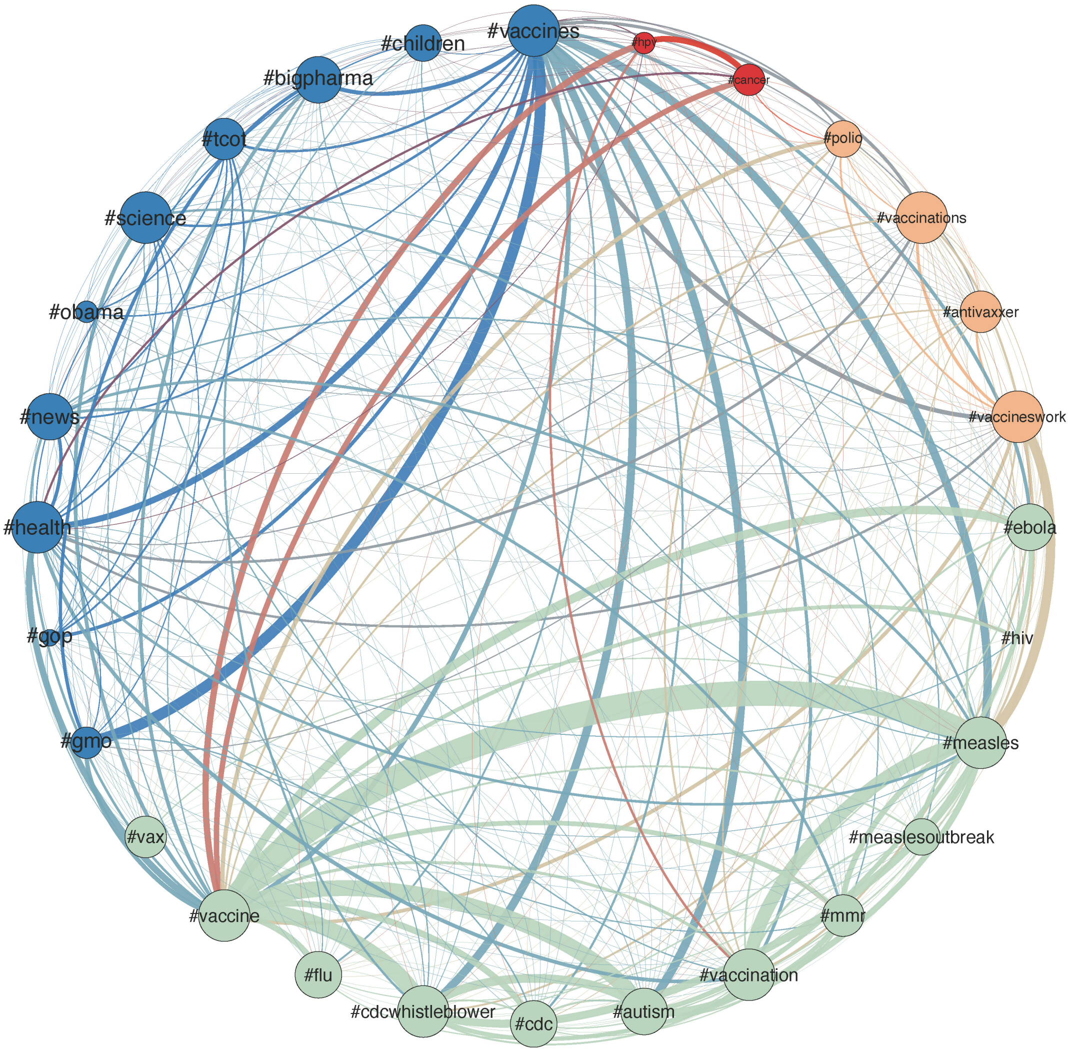


Table 3. Levels of association of the hashtags most frequently encountered in conjunction with #cdcwhistleblower.

Hashtag	Co-occurrences with #cdcwhistleblower, n	Level of affiliation with #cdcwhistleblower, %
#b1less	2371	51.48
#vaccine	2306	4.41
#hearthiswell	1686	37.65
#autism	1215	8.97
#vaccines	1123	4.01
#measles	1085	4.21
#blacklivesmatter	960	46.13
#nomandates	779	34.08
#vaccineinjury	699	33.10
#cdcfraud	623	31.72
#breakabillion	421	49.36

Figure 5. A finer resolution view of the #cdcwhistleblower cluster of Figure 4.

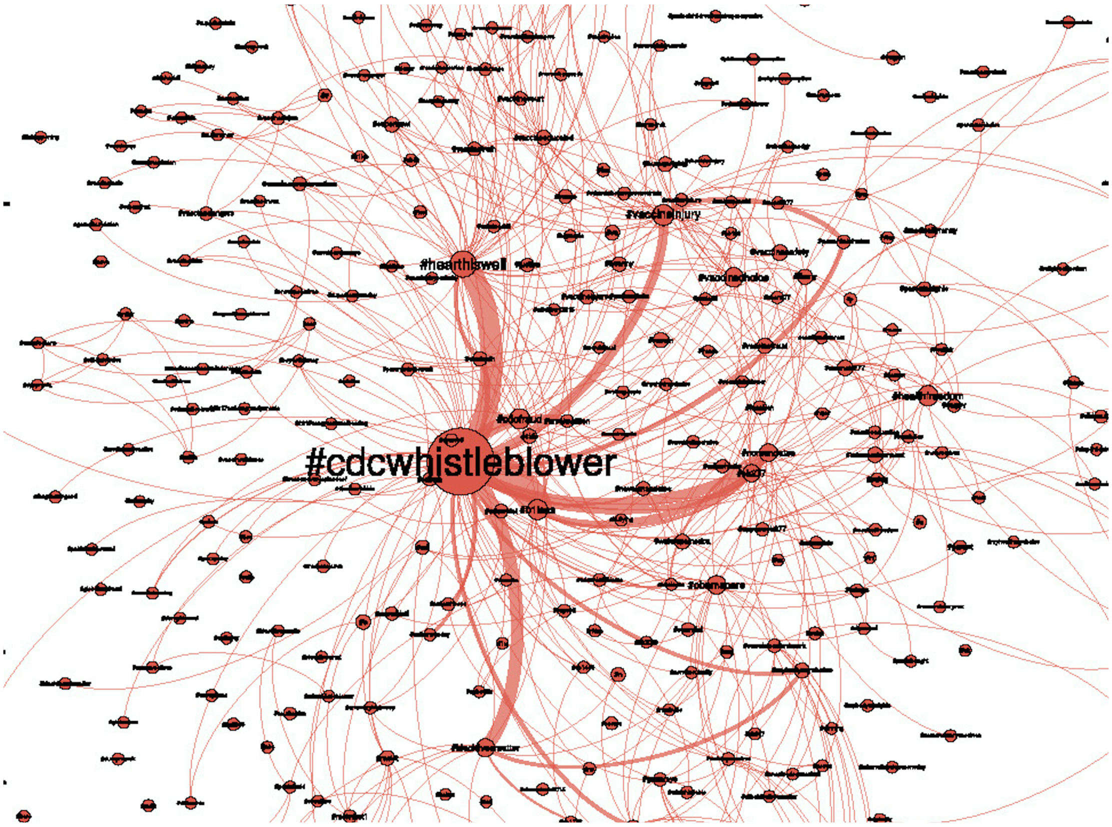


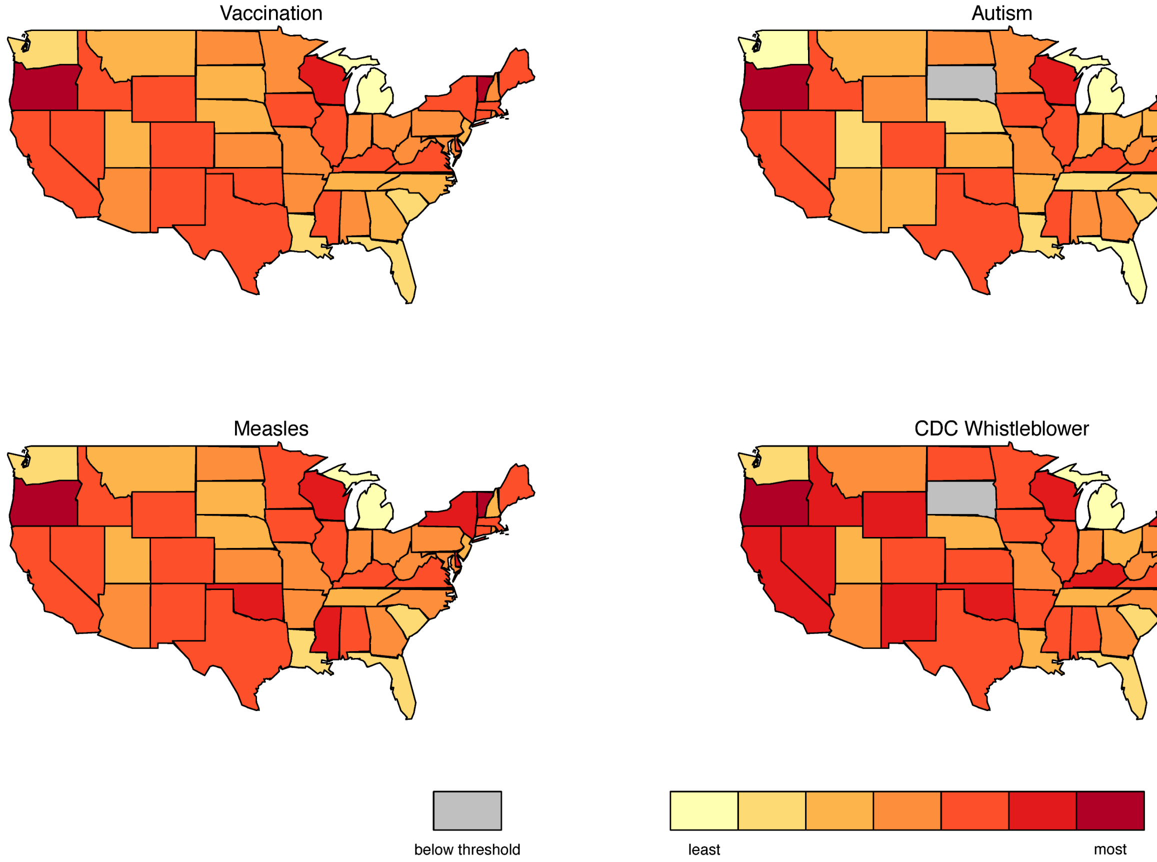
Table 4. Highest levels of participation per state per topic.

Vaccination		Autism		Measles		CDC whistleblower	
State	Participation	State	Participation	State	Participation	State	Participation
VT	1 in 817	OR	1 in 22,410	OR	1 in 6330	VT	1 in 20,194
OR	1 in 849	VT	1 in 24,077	VT	1 in 6660	OR	1 in 20,204
WI	1 in 1100	WI	1 in 33,100	MS	1 in 8268	WI	1 in 24,162
NY	1 in 1270	MS	1 in 34,309	NY	1 in 8892	WY	1 in 26,201
OK	1 in 1329	OK	1 in 36,332	OK	1 in 8955	KY	1 in 27,378

Two states stand out for high levels of involvement: Oregon and Vermont, which are the two states with the highest rates of religious and philosophical exemption from school-entry vaccines nationwide (6.5% and 5.7%, respectively) [39]. Residents of these states are clearly engaging in strong ongoing debates about vaccination that are visible in the partisanship of their social media posts.

We further studied retweeting patterns in order to differentiate between influencers and amplifiers in social media. Influencers are users whose tweets are the most retweeted and as such have a higher impact on the social media community. Vermont and Oregon lead in influence for the terms vaccination and measles (they are the origins of the most retweeted content), which is consistent with the overall traffic data that we have presented in Figure 6 and Table 3. When it comes to autism and #cdcwhistleblower though, while Oregon remains strong, Ohio and Illinois are the two states that follow. Wisconsin, which also features prominently in the levels of participation (Table 4) is emerging as the leading message amplification hotspot, the state that contributes to the dialogue primarily by retweeting other messages. Mississippi and Iowa serve the same role for measles (MS), and autism and #cdcwhistleblower (IA). This allows us to differentiate the role of different communities, separating ones where the message is formed (influencers) from those where the message is amplified.

Figure 6. Geographical patterns of participation in the vaccination debate in social media across the contiguous United States.



Discussion

Principal Results

This quantitative study of Twitter discourse showed how social media can be used to study public perceptions of health-related issues. The anatomy of the themes and relations that make up this discussion accurately reflected the major public health news items of the day. The data suggest that the social media discourse regarding vaccination reflects a high level of partisanship and ardor (which are typically associated with polarization) among the involved community.

During the observation period in early 2015, references to measles dominated vaccination-related traffic. Preliminary tests of Ebola candidate vaccines and the release of a high-profile research report regarding HPV vaccination were matched by the strong presence of such terms in the data corpus and the corresponding vaccination narrative (Figure 3 and Table 2). Accordingly, our data indicate that the perceived importance for the general public of news stories about health issues also holds for social media as well: news stories drive public participation. This is an important finding for health information communication in the emerging age of social media, which is becoming only more important if we also consider the weak standing of official health organizations in this emerging landscape. The most popular retweets made references to articles published online by major media outlets. However, official public health agencies, such as the CDC, were not as strongly featured in the narrative.

These observations are indicative of the complex notion of authority in the information dissemination landscape of social media. In this particular case, a bottom-up campaign (represented by #cdcwhistleblower) appears to far outweigh the impact of authoritative sources such as the top-down efforts of CDC and WHO. These findings highlight the inherent bottom-up nature of social media communications and the strong potential of such campaigns to support grass-roots activism (eg, [40]). At the same time, the findings highlight the fact that governmental agencies might find that mainstream media coverage of key health issues is more effective at reaching diverse online communities than direct outreach from authorities. This appears to be counter-intuitive at first, with an indirect approach being more effective than a direct one. But it is substantiated once we consider the fact that social capital is a great commodity in social media, and news organizations clearly outweigh the presence of government organizations in that aspect. Until this difference is addressed, our study suggests that it would be advisable to combine such news features with official Twitter posts by government agencies in order to improve health communications.

These same agencies may find social media analysis to be invaluable for providing insights about how popular health narratives are being shaped, as a better understanding of public perception of health issues can lead to more effective communication strategies. The data analysis showed how the narrative can be broken down into subtopics, ranging from politics and policy to specific health issues (Figure 4), exposing the substructure of this narrative. It also captured the associations among terms (Figure 5 and Table 3) to reveal how individual terms form higher level subnarratives. Detailed analysis of the narrative around #cdcwhistleblower showed how certain terms are highly affiliated with it, to form a specific code language for a grass-roots antivaccination dialogue.

A projection of this cyberspace dialogue onto the geographical space (Figure 6) shows that the two states with the highest rates of exemption from mandatory child school-entry vaccines had notably higher rates of engagement in the vaccination discourse on Twitter. This illustrated the spatial nature of online communities, even though they exist in cyberspace. Projecting social media traffic patterns to the corresponding geographical space provides new insights on where particular health issues are hot topics. Such information can therefore be used to devise more targeted awareness campaigns.

While this study has addressed the issue of vaccination in the context of the 2015 measles outbreak, the methodology presented herein is generalizable and could be applied to the study of any health issue that elicits participation in social media. While doing so, we need to remain aware of the fact that public views and opinions are shaped and re-shaped over time, in response to seminal events, or as a result of an ongoing public debate. Accordingly, while the results of our analysis address the discussion at a specific time period, a longitudinal study of the narrative over time would enhance our understanding of the subject and its multiple societal dimensions.

Limitations

Arguably the two key limitation considerations associated with the analysis of social media relate to the degree to which social media demographics are reflective of the overall community and to the privacy issues behind such analysis.

The demographic profiles of social media users have been evolving, as participation in such platforms has moved well past the point of being a niche practice to become globally adopted. A recent Pew study [41] indicates that while overall approximately three out of four Internet users in the United States are active in social media, there is a certain age bias. More specifically, there is stronger participation in the 18-49 age group (on average 85%) compared to the 50-64 (65%) and 65+ (49%) age groups. Accordingly, in the context of health informatics, when analyzing such data of certain diseases that have a strong demographic profile associated with them, a certain bias may be introduced [19]. Similarly, when studying participation on a global scale, one needs to account for participation variations across different countries and continents. In our study, considering that our regional analysis focused on the United States and that there are no particular demographic profile data associated with the discussion regarding vaccination, an adjustment for age groups would be of little value. If we are to assume that the participants in this discussion are most likely parents of vaccination-age kids and parents of kids who are at risk of infection in a measles outbreak, their majority would most likely fall in the 18-49 age group, corresponding to the highest levels of participation in social media. Subsequent studies of the demographic profiles of individuals who participate in this ongoing debate in the real world would be beneficial for future analyses. Similarly, adjustments for different age groups would also be very appropriate for studies of other health issues, especially ones where the affected communities are highly skewed age-wise.

While social media demographics are expected to become less of an issue in the future, as the adoption of such technologies becomes even more prevalent, the issue of privacy is a topic that will affect such studies. While we are pursuing these newfound opportunities, we have to remain cognizant of the associated privacy issues, in order to ensure the proper use of this public domain information. This challenge exceeds the simple anonymization of such data. A variety of private attributes can easily be revealed through the integrative analysis of multiple datasets, and revealing the identity of social network contributors who may have opted to keep it secret is feasible [42]. The availability of geolocation information further enhances these concerns, as studies have shown that the analysis of human mobility data (eg, cell phone tracks) allows the unique identification of individuals by using as few as four spatiotemporal points in these trajectories, even when coarse geolocation information is made available [43]. Accordingly, the broad range of information that is communicated through social media, an aggregate of location, social connections, and personal views, is accentuating the need for better multi-source anonymization solutions.

Comparison With Prior Work

Quantitative studies of the patterns and mechanisms of health-related communication in social media have the potential to yield valuable and actionable information about how health knowledge, attitudes, and beliefs are shaped. Our paper is making a contribution toward this goal by presenting a case study and components of a broader emerging analysis framework, pursuing discernible patterns of this narrative across the cyber-physical nexus.

This emerging research direction is still in its early stages, and only recently some studies have examined attitudes about vaccination in social media. Salathé and Khandelwai [44] studied Twitter content to assess the level of polarization between supporters and opponents of swine flu (H1N1) vaccination, in the broader context of digital epidemiology [45]. Their study focused on sentiment analysis and assessed information flow in social networks by studying follower patterns (rather than retweets, which was the case in our study). This showed the high level of polarization in such exchanges, with Twitter users tending to follow other users who share the same sentiments on the topic. Kaptein et al [46] analyzed a data corpus of 12,500 tweets related to the discussion about HPV vaccination in the Netherlands and showed that health-related discussions on Twitter do not drift to other topics. Comparable polarization patterns were observed in a study of Twitter traffic related to a scheduled vote in Chicago on the regulation of electronic cigarettes by Harris et al [47]. This was a small scale study of 683 tweets of a highly localized event.

Odlum and Yoon [48] studied the use of social media during the 2014 Ebola outbreak, using a set of 42,236 tweets to assess the potential benefits of using social media as a real-time outbreak tracking tool. Toward the same goal, Gurman and Ellenberger [49] studied 2616 tweets in the aftermath of the 2010 Haiti earthquake. These preliminary studies further highlight the potential utility of quantitative studies of social media content and health communication.

Our work advances this state-of-the-art by contributing an additional case study that addresses the attitude toward vaccination in the context of a disease outbreak and by pursuing this study as a complex cyber-physical narrative. The term “narrative” is broad in its nature and has been used in the past in the context of health information (eg, a linguistic analysis of YouTube contributions regarding cancer stories [50]). In the context of this study, we position narrative at the intersection of linguistic, social, and geographical networks. Toward that goal, we analyzed text content, spatial patterns of contributions, and retweet patterns. We focused on retweet activities rather than follow patterns, as retweets tend to be more dynamic. As such, retweet patterns can reveal actual impact rather than potential impact (which is the case with follow patterns in social media). For example, @CDCgov has almost half a million followers, but we observed that the actual impact of its tweets is rather limited. Earlier studies [51] had indicated the need for a more strategic approach by health organizations to manage information dissemination. Our work builds on this observation to show the great value of employing news stories to disseminate such information, rather than relying on the direct connection between health organizations and the public. Accordingly, an indirect dissemination avenue (from health organizations to the public through news stories) appears to be more effective than a direct alternative (from health organizations to the public directly).

Furthermore, our paper shows the value of studying this discourse on Twitter as a complex narrative, whereby word associations and the connections between cyber and physical communities reveal the public’s connotations of key issues and actors and the driving forces behind this participation. The fact that we observe strong levels of participation in the social media discourse from states where there is an ongoing debate on vaccination shows the strength of the connections that link the cyber to the physical domains. Examining such connections enables a more comprehensive study of the mechanisms that drive information dissemination and opinion formation in social media. Such findings can be used to design better awareness campaigns and to improve our ability to harvest actionable knowledge from social media data.

Conclusions

The cyber-physical debate nexus, which connects the cyber narrative in social media to the corresponding geographical space, allows the study of the public’s concerns, views, and responses to health-related issues and thus offers a new avenue for exploring health narratives. As these new mechanisms of discourse are emerging, health communications and health informatics have to adapt to these newfound capabilities and challenges. Advancing our understanding of the mechanisms and patterns of communication in these media is therefore becoming increasingly important. Toward this goal, this study showcased emerging data analysis approaches. These approaches are inherently interdisciplinary, bringing together principles and practices from health informatics, data analytics, and geographical analysis. Further coalescing such capabilities will advance health communication, supporting the design of more effective strategies that take into account public perceptions and concerns. At the same time, we need to remain cognizant of privacy issues associated with the nature of social media communications. Studying the narrative rather than the individuals and aggregating data in geographical spaces can maintain the relevance of the analysis while also preserving user anonymity.

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Authors' Contributions

JR led the acquisition and preliminary analysis of the data. All the authors contributed substantially to the design of the study and the analysis and interpretation of the data. All authors contributed to the preparation of the manuscript and approved the final version.

Conflicts of Interest

None declared.

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Abbreviations

API: application program interface
CDC: Centers for Disease Control and Prevention
HPV: human papilloma virus
NIH: National Institutes of Health
WHO: World Health Organization

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Original Paper

Gordie Howe's "Miraculous Treatment": Case Study of Twitter Users' Reactions to a Sport Celebrity's Stem Cell Treatment

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Abstract

Background: Former Detroit Red Wing Gordie Howe received stem cell (SC) treatment in Mexico in December 2014 for a stroke he suffered in October 2014. The news about his positive response to the SC treatment prompted discussion on social networks like Twitter.

Objective: This study aims to provide information about discussions that took place on Twitter regarding Howe's SC treatment and SC treatment in general. In particular, this study examines whether tweets portrayed a positive or negative attitude towards Howe's SC treatment, whether or not tweets mention that the treatment is unproven, and whether the tweets mention risks associated with the SC treatment.

Methods: This is an infodemiology study, harnessing big data published on the Internet for public health research and analysis of public engagement. A corpus of 2783 tweets about Howe's SC treatment was compiled using a program that collected English-language tweets from December 19, 2014 at 00:00 to February 7, 2015 at 00:00. A content analysis of the corpus was conducted using a coding framework developed through a two-stage process.

Results: 78.87% (2195/2783) of tweets mentioned improvements to Howe's health. Only one tweet explicitly mentioned that Howe's SC treatment was unproven, and 3 tweets warned that direct-to-consumer SC treatments lacked scientific evidence. In addition, 10.31% (287/2783) of tweets mentioned challenges with SC treatment that have been raised by scientists and researchers, and 3.70% (103/2783) of tweets either defined Howe as a "stem cell tourist" or claimed that his treatment was part of "stem cell tourism". In general, 71.79% (1998/2783) of tweets portrayed a positive attitude towards Howe's SC treatment.

Conclusions: Our study found the responses to Howe's treatment on Twitter to be overwhelmingly positive. There was far less attention paid to the lack of scientific evidence regarding the efficacy of the treatment. Unbalanced and uncritical discussion on Twitter regarding SC treatments is another example of inaccurate representations of SC treatments that may create unrealistic expectations that will facilitate the market for unproven stem cell therapies.

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KEYWORDS

Gordie Howe; stem cell treatment; stem cell tourism; social network; Twitter; infodemiology; infoveillance

Introduction

Over the past few decades, stem cell (SC) research has gained considerable attention from the international bioscience community. With continued developments in basic SC research, the potential for clinical application of SCs has generated a great deal of hope for therapies and treatments for a wide range of diseases, including neurodegenerative diseases and fatal illnesses that cannot be treated with existing medical treatments [1,2]. To date, very few SC therapies have received approval from governmental regulatory authorities in countries like the United States and Canada [3]. Despite this, many direct-to-consumer clinics exist in countries throughout the world that offer unproven SC therapies (eg, United States, China, and Ukraine) [4-8]. Research has suggested that many patients, often with serious and/or terminal conditions, travel to these clinics to receive SC therapies, a phenomenon that is often referred to, controversially, as “stem cell tourism” [9-12].

Stories about well-known individuals, such as athletes, seeking unproven SC treatments to heal injuries or accelerate the speed of recovery, have proliferated in recent years [13,14]. One study, for instance revealed that between 2012 and 2013 numerous National Football League (NFL) players claimed to have received SC therapies in the United States or abroad (eg, Germany and South Korea) [14]. A more recent high-profile example is that of Gordie Howe, a former Detroit Red Wing hockey player nicknamed “Mr. Hockey”. In December 2014, Howe traveled outside the United States to receive SC treatment in Mexico for a stroke he suffered on October 26, 2014 [15]. The news release about Howe’s positive response to the SC treatment attracted a great amount of attention in the news and sports media, and on social networks. A study of news stories and readers’ comments about Howe’s SC treatment revealed that the efficacy of Howe’s treatment is often assumed and that public debates tend to focus on the lack of access to SC treatments more than the lack of scientific evidence and possible risks associated with the unproven therapies [16].

Popular media are an important source of health information for the public and can both shape and reflect public opinion of major health stories [17-21]. Media coverage has also been shown to play a role in creating public interest in new biomedical technologies [6,22,23], and influencing health policy debates [24]. More recently, social networking websites that facilitate online interaction and communication, like Twitter, have allowed for rapid and widespread dissemination of important health information [25-27]. Twitter users can post, share or re-tweet messages with a 140-word limit to express their opinions and join the public debate. With more than 300 million users, Twitter offers a rich source of online discussion and debate between users that include individual members of the public and organizations from news media to academic institutions. As such, it provides a rich source naturalistic data to gauge health trends and public responses to major health issues [28,29]. This approach is also known as infodemiology or infoveillance [29]. In addition, celebrities’ engagement with the public through the popular media, as well as the information shared on social networking sites, can influence individual health-related attitudes and behaviors [30,31]. Research using Twitter may be limited because users include both organizations, who may have vested interests, and individuals, commonly college-educated adults under the age of 50 [25], but it can still provide valuable insights into what kind of information the public are exposed to and interact with.

Although popular media, including Twitter, have been shown to contribute to the hype surrounding stem cell research [16,32-33], less is known about whether discussions on Twitter about a specific individual’s SC treatment also contributes to this hype. Howe’s SC treatment and its concomitant Twitter discussions provide the opportunity for exploring this topic, specifically discussions about an individual’s SC treatment on Twitter when such treatments are associated with a sports celebrity. This study consists of a content analysis of tweets about Howe’s SC treatment that were posted within five weeks after news of his treatment was announced, and examines the information provided in and the tone of tweets about Howe’s SC treatment in Mexico.

Methods

A corpus of tweets was compiled by developing a program using Python programming language through Topsy API that allowed for the collection of tweets that contain specific terms within a specified time frame [34]. We used the Topsy API program because it is Twitter’s only certified partner and it provides unlimited access to and full coverage of tweets since Twitter was launched in 2006. Our program was developed to automatically crawl English-language tweets containing the search terms “Gordie Howe” and “stem cell” that were posted on Twitter from December 19, 2014 at 00:00, the date that the story first appeared in the media, to February 7, 2015 at 00:00, the time when we started data collection. We limited our search terms to compile a manageable sample of tweets. As such, our corpus may not contain related tweets with variations on the terms, but still represents a large sample that provides insight into the nature of the discussions about Gordie Howe’s stem cell treatment in Mexico. The program collected 2788 tweets that included the date and time, tweet content, tweet URL, its author, and author URL. We excluded 5 tweets that were not directly and specifically related to Howe’s SC treatment story, resulting in a final data set of 2783 tweets.

A content analysis of the tweets was conducted in two stages. First, we conducted an exploratory thematic analysis of a random sample of 10% of tweets from the data set by which we established a set of common themes (eg, improvements of Howe’s condition, risks associated with Howe’s treatment) that appeared in the representations of Howe’s SC treatment story on Twitter. Second, we developed a coding framework that was based on the common themes that emerged during the exploratory thematic analysis. The coding framework was also informed by previous coding frameworks developed by our team [35-37]. The coding framework included 7 items about whether tweets (1) included a claim that Howe’s health condition improved; (2) mentioned that Howe’s SC treatment is unproven; (3) defined the treatment as a miracle or miraculous; (4) mentioned or defined Howe’s treatment as part of SC tourism; (5) mentioned challenges raised by scientists, researchers, and/or ethicists; and (6) mentioned risks associated with Howe’s SC intervention. Finally, the coding framework included an item that considered the overall tone, which assessed whether the attitude conveyed in a tweet towards Howe’s SC treatment was positive, negative or neutral.

Due to the large data set, a single coder with expertise in stem cell tourism applied the coding framework to the entire data set. In order to minimize coder bias for subjective items in the coding framework, an independent coder without expertise applied the same coding framework to 10% of the data set to assess inter-coder reliability. Inter-coder reliability was calculated using Cohen's kappa (K), which generated K scores on different coding categories in the range of 0.750-1.000, thereby indicating substantial or almost perfect agreement as based on the Landis & Koch's benchmark for interpreting kappa [38].

Results

In the first five weeks following the announcement about Howe's SC treatment, much of the discussion on Twitter appears to have been prompted by the publication of news media reports. A press release announcing Howe's SC treatment and recovery was published on December 19, 2014, and was picked up by several news media outlets that same day [16,39-42]. Over 710 tweets from our corpus were posted on that day. Following the initial interest, another spike in published tweets in our corpus (419 tweets) appeared on January 27, 2015 in response to the CBC Sports report that Howe showed dramatic improvement after his SC treatment. Tweets that generated re-tweets or were shared were often article titles published in media sources like newspapers and sports websites, with fewer original tweets coming from individuals (Tables 1 and 2).

Table 1. Examples of the most frequently re-tweeted messages that show positive attitude towards Howe's SC treatment.

Tweets	Original sender	Number of times re-tweeted or shared[a]
Gordie Howe makes "amazing" recovery following stem cell treatment in Mexico	NBC Sports	188
Gordie Howe shows improvement after stem cell treatment	CBC Sports	157
VIDEO: Stroke victim Gordie Howe, now (back) playing hockey! Stem Cell Co. CEO joins me (ClinicalTrials website)	Keith Olbermann	68
Gordie Howe continues progress following stem cell treatment	Michigan Live	58
Experimental stem cell treatment key in Gordie Howe's dramatic improvement	The Globe and Mail	55
Gordie Howe shows dramatic improvement after stem cell treatment	CBC Sports	54
Gordie Howe back stick-handling after stem cell treatment	The Detroit News	51
Gordie Howe's "miraculous" recovery after stroke credited to stem cell treatments in Mexico, says family.	SportsNET Canada (online)	46

[a] Re-tweets are defined as tweets started with the "RT"; shared tweets are those tweets posted without the "RT" but having exactly the same tweet content.

Table 2. Examples of tweets that mentioned challenges raised by scientists and/or researchers regarding Gordie Howe's stem cell treatment.

Tweets	Original senders	Number of times re-tweeted or shared[a]
Gordie Howe, stem-cell tourist: experts warn of a worrisome trend	Ottawa Citizen	79
Gordie Howe's stem cell therapy raises concerns among regenerative medicine	National Post	76
Gordie Howe's stem cell therapy raises concerns among medical experts	CTV News	40
Gordie Howe's "miracle" in Mexico stirs experts' doubts about stem-cell therapy	The Global and Mail	30

[a] Re-tweets are defined as tweets started with the "RT"; shared tweets are whose tweets posted without the "RT" but having exactly the same tweet content.

The majority of tweets in our corpus cited that Howe's health improved following his SC treatment in Mexico (78.87%, 2195/2783). Many of these tweets used descriptive words, such as "miraculous", "dramatic", "amazing", and "remarkable", to describe the degree to which Howe's condition had improved (Table 1). In addition, detailed descriptions of the hockey player's progress were frequently re-tweeted, such as "Gordie Howe goes from not being able to walk to pushing a cart around following stem cell treatment" and "Gordie Howe back stick-handling after stem-cell treatment" (Table 1). Other common topics in the tweets included excerpts from interviews with Howe's family members that confirmed and provided evidence for the improvements in Howe's health, for example, "Gordie Howe's family said Gordie has made a miraculous recovery with stem cell injections" and "Mark Howe says Gordie's health has improved dramatically since stem cell treatment" (Tables 1 and 2).

Tweets with criticisms or that raised concerns were less frequent. Of the 2783 tweets in the corpus, only one tweet mentioned that Howe's SC treatment was unproven (which was posted by one of this paper's authors); and 3 tweets warned that SC treatments lacked scientific evidence and that further research was needed to determine the efficacy and safety of SC treatments. While 10.31% of tweets (287/2783) mentioned scientists and researchers have cited challenges associated with Howe's SC treatment, only 5 tweets directly considered its potential health risks (Table 2). References to stem cell tourism also appeared in tweets, with 3.70% of tweets (103/2783) either defining Howe as a “stem cell tourist” or describing his treatment in Mexico as “stem cell tourism”. Among this 3.70% (103/2783), the most frequently re-tweeted message was: “Gordie Howe, stem-cell tourist: experts warn of worrisome trend”, which was re-tweeted 79 times (Table 2).

Overall, Howe’s SC treatment was represented as a success story. The majority of tweets were positive (71.79%, 1998/2783). These tweets either used positive words to describe the treatment or provided details to remark on the great improvement in Howe’s health. In contrast, only 14.73% (410/2783) of tweets were negative in tone, and usually focused on criticisms of Howe’s decision to travel outside of the United States for treatment and concerns that medical experts have with the treatment. Some of the tweets (13.47%, 375/2783) were considered neutral since they simply relayed news of Howe’s treatment (eg, “Gordie Howe underwent stem cell clinical trial in Mexico” and “Marty Howe recounts the trip to Mexico for Gordie Howe's stem cell treatment”).

Discussion

Principal Findings

Our data show an overwhelmingly positive attitude towards Howe’s SC treatment, about 71.79% (1998/2783) of our corpus. In comparison, safety concerns and potential harms associated with unproven SC treatments (eg, physical harm, financial exploitation, and creation of unrealistic expectations) were rarely mentioned. These results may suggest misunderstandings of the current state of SC research. Previous studies have found news media representations of SC research is often inappropriately “hyped”. For example, studies have found that the coverage of SC research often provides overly optimistic estimates of the length of time it takes for research to reach the clinics [33,43]. Given that many of the original tweets come from news media sources like newspapers and sports websites, our results illustrate how social networks, such as Twitter, bias exposure to information and contribute to the dissemination of these overly optimistic portrayals [16,26,32,33,44].

Previous studies have explored the nature and role of social media in the context of stem cells and found representations to be, in general, predominantly positive in tone [32,33]. Our results fit with this trend. We found that a large number of tweets were published immediately following the initial press release and media reports detailing Howe’s treatment and recovery. The immediacy of reactions on Twitter highlights the power of celebrity to generate public interest. This finding is consistent with other research on celebrities’ impact on the public regarding health-related issues [31,45,46]. For example, Angelina Jolie’s announcement of her genetic predisposition to cancer and her decision to have prophylactic surgeries [47,48], resulted in an increase in interest in breast cancer genetic testing and prophylactic surgery [49].

Since Howe received his SC treatment outside the United States, issues surrounding stem cell tourism were raised on Twitter. However, compared to tweets focused on the improvements in Howe’s health, the number of tweets that critiqued the phenomenon of stem cell tourism accounted for a very small portion (3.70%, 103/2783). We also observed that news media (eg, National Post and The Globe and Mail), and academic groups (eg, medical experts, scientists, and ethics scholars) did provide more critical views on, and warnings about, the implications of Howe’s SC treatment. For example, the National Post stated: “Gordie Howe's stem cell therapy raises concerns among regenerative medicine”, while The Globe and Mail stated: “Gordie Howe’s ‘miracle’ in Mexico stirs experts’ doubts about stem-cell therapy” [50,51]. Unfortunately, these more circumspect voices were eclipsed by the positive reactions in the majority of tweets and, as such, the social media coverage was unbalanced.

Limitations

Our study had several limitations. The search terms we used to collect tweets were limited and related tweets with other variations on the search terms may have been excluded. The corpus was analyzed by only a single coder with expertise in stem cell tourism, whose perspective may have influenced results, but we have taken steps to assess the reliability of the coding. Our data analysis did not include Web links included in tweets, so we are unable to evaluate the spectrum of information sources reached through social media, or make claims regarding which types of news media are most frequently shared and may have more social impact. We also did not collect background information on Twitter users. Therefore, we cannot evaluate other contextual factors, such as whether tweets about Gordie Howe’s SC treatment originated from a specific country. Further research is needed to examine to what extent Twitter has helped to increase the public’s scientific understandings of SC research and treatment.

Conclusions

Much of the Twitter discussion about Howe’s SC treatment was prompted by news media reports. Our research highlights how tweets expressed a largely positive attitude toward Howe’s SC treatment. There was little discussion about the lack of scientific evidence on the efficacy of SC treatments. Less attention was also paid to the potential risks and safety concerns associated with unproven SC treatments. Given these findings, it seems reasonable to conclude that discussions on Twitter regarding celebrities’ SC treatments may contribute to the hype around SC research and to the dissemination of inaccurate representations of the benefits and risks associated with unproven treatments. This may, in turn, mislead patients and the public and prompt their engagement with clinics that market unproven stem cell products and procedures [52].

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Authors' Contributions

LD and TC designed the study. LD developed the methodology, performed the analysis and drafted the manuscript. CR and TC contributed extensively in editing and revising the manuscript. ZCG collected data and provided suggestions for the data analysis.

Conflicts of Interest

None declared.

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Abbreviations

SC: stem cell

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Original Paper

Leveraging Big Data to Improve Health Awareness Campaigns: A Novel Evaluation of the Great American Smokeout

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Abstract

Background: Awareness campaigns are ubiquitous, but little is known about their potential effectiveness because traditional evaluations are often unfeasible. For 40 years, the “Great American Smokeout” (GASO) has encouraged media coverage and popular engagement with smoking cessation on the third Thursday of November as the nation’s longest running awareness campaign.

Objective: We proposed a novel evaluation framework for assessing awareness campaigns using the GASO as a case study by observing cessation-related news reports and Twitter postings, and cessation-related help seeking via Google, Wikipedia, and government-sponsored quitlines.

Methods: Time trends (2009-2014) were analyzed using a quasi-experimental design to isolate spikes during the GASO by comparing observed outcomes on the GASO day with the simulated counterfactual had the GASO not occurred.

Results: Cessation-related news typically increased by 61% (95% CI 35-87) and tweets by 13% (95% CI −21 to 48) during the GASO compared with what was expected had the GASO not occurred. Cessation-related Google searches increased by 25% (95% CI 10-40), Wikipedia page visits by 22% (95% CI −26 to 67), and quitline calls by 42% (95% CI 19-64). Cessation-related news media positively coincided with cessation tweets, Internet searches, and Wikipedia visits; for example, a 50% increase in news for any year predicted a 28% (95% CI −2 to 59) increase in tweets for the same year. Increases on the day of the GASO rivaled about two-thirds of a typical New Year’s Day—the day that is assumed to see the greatest increases in cessation-related activity. In practical terms, there were about 61,000 more instances of help seeking on Google, Wikipedia, or quitlines on GASO each year than would normally be expected.

Conclusions: These findings provide actionable intelligence to improve the GASO and model how to rapidly, cost-effectively, and efficiently evaluate hundreds of awareness campaigns, nearly all for the first time.

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KEYWORDS

big data; evaluation; health communication; mass media; social media; tobacco control; infodemiology; infoveillence; twitter; smoking cessation

Introduction

Public health awareness campaigns are annual events designed to foster knowledge of health risks and engagement during specific days, weeks, or months. The number of public awareness campaigns has substantially risen, with one catalogue listing more than 200 ongoing domestic campaigns [1].

The ubiquity of awareness campaigns likely stems from the ease of their implementation. While most mass media campaigns require substantial advertising budgets [2], awareness campaigns require minimal assets. For example, many awareness campaigns are accomplished by issuing a press release that is freely carried across news media outlets and potentially on social media.

The ease of implementing awareness campaigns, however, sharply contrasts with the pragmatic and methodological barriers that have made assessing their potential effectiveness unfeasible. As an example, a recent systematic review found that only 5 of 79 published reports on awareness campaigns were evaluation studies [3]. One reason for the absence of evaluations is that the driving incentive for awareness campaigns is to minimize operational expenses, which can make traditional evaluations too costly [4]. In addition, because most awareness campaigns occur on a single day, traditional evaluations may not be possible, such as collecting survey responses for a pre-post analysis. Regardless, traditional modalities alone cannot altogether inform how awareness campaigns are expected to work, as they often cannot assess how campaign messages are diffused via news media, are shared on social media, or how the population engages with these messages (such as seeking out information online). Alternative evaluation approaches that rely on metrics assessing both media and popular reactions to media are needed to ensure that awareness campaigns' important public health messages are scientifically supported.

Big data may fill the knowledge gap for evaluating health awareness campaigns. It has to be noted that other public health surveillance gaps are already being filled by big data's inexpensive, fine-grained, and real-time capabilities, especially in cases where little or no traditional data exist [5-7]. However, to date, big data have rarely been applied to studying health communication campaigns [8-14], or even health communication research more broadly [15-18]. The few studies harnessing big data have often relied on a single outcome, such as Internet search queries, and loosely interpreted these outcomes in the absence of any framework for campaign evaluations. We take a step forward by proposing a simple and actionable approach to monitoring trends in the most frequently mentioned kinds of big data (news media, social media, and help seeking on Google, Wikipedia, and telephone counseling services). Our analyses are presented in the context of a novel evaluation framework that takes into account how awareness campaigns are expected to diffuse [3], and thus provide actionable intelligence for program managers at each stage of campaign diffusion from news media at the population level to individual help seeking regarding campaign outcomes.

In this report, we specifically developed a framework to evaluate the *American Cancer Society's* "Great American Smokeout" (GASO). This past year (2015) marked the 40th commemoration of the GASO, held annually on the third Thursday of November, making it the world's longest running health awareness campaign. The GASO aims to generate and diffuse media encouraging individuals to go smoke-free for a day, and to consider quitting for good. Although activities promoting the GASO have varied over time, GASO is currently promoted by scheduling interviews with selected news outlets; producing media fact sheets with information about tobacco harms and quitting tips; disseminating toolkits with infographics, email templates, and event ideas such as quitting competitions for partnering organizations or businesses to celebrate the GASO; and more recently, by posting similar messages on social media.

Our aim was to develop a method for studying how a message diffuses through news and social media and ultimately leads to engagement via information seeking with the core message. Our novel evaluation framework was based on the key intended aims of the GASO and available big data sources. First, we examined the extent to which the GASO's cessation-related messages for 2009-2014 were carried in news media; second, how similar messages were shared on Twitter; and third, the extent to which these messages were associated with help seeking via Internet searches for quitting smoking, information retrieval on Wikipedia's cessation page, and calling state-sponsored quitlines, all informed by an analysis of 2191 days of data. We hypothesized that trends would spike on the day of the GASO. Moreover, the interrelationships between these data (eg, news media's relationship with social media) were explored, under the assumption that news media begets social media, progressing through individual help-seeking actions for cessation.

Methods

Data were compiled into a daily time series for the period between January 1, 2009, and December 31, 2014. Each data source was purposively selected to provide insights on a different level of analysis or specificity. For example, news media trends indicate how well GASO's message of quitting smoking is disseminated, whereas search query trends indicate that the searcher is thinking about cessation or that the searcher is taking some action toward investigating behavior change. Table 1 presents the diverse data sources, as briefly described in the following section.

Cessation-related news media coverage that mentioned "quit" or "stop" and "smoking" was retrieved from News Library, a comprehensive repository of US newspaper articles, including online and print content. This included stories with titles such as "The last cigarette: Nine ex-smokers who quit the habit for good," "Quit smoking, one of the most important ways to improve health," and "Quitting smoking reduces heart risk faster than previously thought." Stories mentioning cessation were normalized relative to all news stories to adjust for potential biases arising from changes in media volume over time.

Social media shares about cessation were obtained from the public Twitter application programming interface. This did not include any data that had been marked as "private" by the author or any direct messages. Initially, the data were derived from 2 feeds, each a random sample of 10% of all tweets. We retained

600,000 tweets mentioning "quit" or "stop" and "smoking" (including variations on "quit" like "quitting") while not mentioning "fire," "marijuana," "mj," "pot," "pott," or "weed." Subsequently, we randomly selected 10,000 of these tweets and a single reader labeled them as to whether the tweeter was indeed tweeting about smoking cessation. We then trained an automated classifier on that data to mimic human coding, obtaining about 90% precision and 70% recall. The resulting classifier was ran on all 600,000 tweets to obtain the analyzed trend. This included tweets such as "tryn quit smoking waiste to much money" (sic) or "quit smoking and start exercising because healthy body healthy mind" (sic). Tweets were measured in raw volume, but trending (increases in tweets over time) was corrected for in the analysis as detailed in the following section.

Internet searches for cessation information were obtained from *Google Trends*, a public archive of Google search queries. Queries that included "quit" or "stop" and "smoking" (such as "quit smoking methods," "help stop smoking," or "quit smoking") after excluding searches that also included "fire," "marijuana," "mj," "pot," "pott," or "weed," were monitored relative to all queries each day, reported as a relative search volume (RSV), where RSV=100 is the day with the highest search proportion, and RSV=50 is a day with 50% of that highest proportion.

Table 1. Big data codebook.

Type	Source	Description	Privacy	Aim
News coverage	News Library [19]: Available with a paid subscription, including papers since 1903.	Includes news articles from 5689 US newspapers. Described as "virtually all" US newspapers.	All publicly available data. Complete text not available for some papers behind pay walls.	To evaluate how frequently the primary GASO message was carried by news media.
Social media	Twitter [20]: Available prospectively with a paid subscription.	Includes either samples of all tweets or all tweets for specific keywords/phrases on the global Twitter platform.	Derived from public tweets (excluding direct messages or tweets marked "private"). Includes username and location for users sharing their location.	To evaluate how frequently cessation-related tweets were shared on social media (a secondary aim of the GASO).
Internet searches	Google [21]: Available to any user with a Google account.	Includes global search trends for investigator-selected keywords or phrases.	Derived from private search activity on Google. Disaggregated to city, national, or global units without any identifying information to protect privacy.	To evaluate how the GASO motivated some to engage in behavior change by seeking out additional information on cessation.
Information retrieval	Wikipedia [22]: Raw access logs are available here; those used in the study were aggregated by a third party.	Includes counts of all Wikipedia page visits. Aggregated by language, but unable to aggregate by location.	Derived from private online activity. Disaggregated to preserve privacy.	To evaluate how the GASO motivated specific information retrieval on the most popular cessation resource.
Quitline calls	Sourced privately, covering 29 US states. Additional states are only available from other providers or state representatives.	Includes call language, frequency, and duration to US state-sponsored quitlines.	Derived from privately obtained calls. Data were aggregated nationally to protect privacy.	To evaluate how the GASO motivated some smokers to engage in quit counseling.

Wikipedia visits to the primary English language "smoking cessation" entry were also counted. Wikipedia was selected because it is typically the first or second result on Internet search engines. Web page views for this Wikipedia page were normalized by dividing by all Wikipedia English language page views reported per 1,000,000 each day.

Quitline call records were obtained from aggregating daily call logs for 28 states whose quitline service is provided by Alere Wellbeing, Inc. Demographic details for each call are recorded (eg, language of the call), but here we focused on all English-language calls. The raw call counts were used because there was no suitable denominator for normalization; however, trending (and other problems normalization typically resolves) was corrected for in the analysis as detailed in the following section.

Our statistical approach was quasi-experimental, focusing on deriving a single treatment effect for any potential spike proximal to the GASO in the time series for each of the 5 data sources [18,23]. The treatment period was the day of the GASO and the reference was based on the empirically derived counterfactual had the GASO not occurred. For the overall estimate we used autoregressive integrated moving average (ARIMA) models that included all the days in each time series with a regression coefficient for the days of GASO fit to maximize Akaike information criterion using the algorithm outlined by Hyndman and Khandakar [24]. For the individual years, we fit the same ARIMA models to the year prior to each GASO event. The counterfactual value for the GASO was imputed based on this model for each of the 5 analyzed time series. The ratio of the observed values (treatment) and derived values from the ARIMAs (counterfactual) was computed, thereby making the effect estimates comparable across each time series [eg, (Treatment − Counterfactual)/Counterfactual]. These models are robust to the most well-known biases. For instance, the models are adjusted for seasonal [25] and circaseptan (day of the week) [26,27] periodicities, and trending in the data, such as declines in smoking-cessation Internet search queries as a proportion of all queries due to shrinking smoking populations or how cessation tweets may be growing as

Twitter's user base grows. Confidence bounds (alpha=.05) around these estimates were estimated using 10,000 random draws from the multivariate normal sampling distribution with mean equal to the maximum-likelihood point estimates, and variance equal to the variance-covariance matrix [28].

To examine how increases in each time series were related to increases in media, we fit a linear model with the percent increases on GASO for media as the predictor and the percent increases for tweets, search, Wikipedia, and quitline calls as the outcome. Coefficients of these models were used to estimate the percent increase in outcome for a given increase in media. Confidence intervals were calculated analogously to those above.

Last, we replicated the aforementioned models focusing on estimating treatment effects for New Year's Day, which typically sees the greatest spike in cessation-related activity. These estimates were used as a baseline to judge the practical impacts of the GASO relative to New Year's Day (eg, ΔNYD divided by ΔGASO).

Results

Three patterns were observed from visual inspection of the time series across outcomes (Figure 1). There was substantial variability across outcomes in the size of the spikes (if any) around the GASO. For example, the GASO concurred with large spikes in cessation-related news media in 2009 but it was not replicated in tweets. There was substantial year-to-year variability within outcomes in the size of the spikes around the GASO. For example, news media coverage of cessation appeared to be following a downward trend with potential spikes appearing smaller later in the study period. Last, it appeared that the timing of the GASO closely preceded or occurred during lows in many of the outcomes. For example, Google searches were at their annual low around the holiday season, just days after the GASO.

Statistical analysis indicated that across all years, smoking cessation news stories were 61% (95% CI 35-87) higher than would be expected if the GASO did not occur. The largest increases occurred earlier in the analyzed period and the smallest in 2013 (Figure 2). Tweets were 13% (95% CI −21 to 48) higher than would be expected, although these differences were also decreasing over the study period, ranging from an increase of 48% (95% CI 9-131) in 2011 to a nonsignificant 3% decrease (95% CI −478 to 47) in 2013. Analyses of the year-by-year relationship between news and social media coverage indicated that a 50% increase in news media was associated with an increase in tweets (28%; 95% CI −2 to 59; *P*<.06).

Google searches for cessation information were 25% higher (95% CI 10-40) across all years, with a peak increase of 52% (95% CI 26-92) in 2011, when news media and Twitter interest also peaked. Wikipedia views increased by 22% (95% CI −26 to 67) across all years but the increase was not statistically significant overall or for any one year. Call volume to quitlines increased by 42% (95% CI 19-64) across all years, with the largest increases in 2011 (76%; 95% CI 12-308), 2013 (110%; 95% CI 32-412), and 2014 (92; 95% CI 24-322). In absolute terms over the entire 5 years, this amounts to about 42,600 more Google queries, 4600 more Wikipedia visits, and 13,400 more quitline calls than would be expected had the GASO not occurred.

Increased cessation-related news coverage was positively associated with tweets and cessation-related help seeking on Wikipedia and Google (Figure 3). Specifically, a 50% increase in cessation-related news media predicted a 12% (95% CI −22 to 46) increase in Internet cessation queries and 26% (95% CI −22 to 73) increase for Wikipedia cessation page visits, albeit neither trend was statistically significant based on a small sample of 6 years. Quitline calls were inversely related to news media, a relationship largely driven mute by the 2 most recent years when quitline call increases were greatest and news volume was lowest.

To provide a comparison for the GASO, we fitted similar models for increases around New Year's Day, the only other period with visually significant spikes. Over all New Years (2009-2014), for example, news media coverage of cessation increased by 121% (95% CI 101-139) and Internet searches were 37% (95% CI 26-47) higher around New Year's Day. Thus, the GASO approximates 70% of the expected increase in news media and 68% of the expected increase in cessation searches for New Year's Day (ΔGASO divided by ΔNYD).

Figure 1. Trends in all outcome measures (news volume, Tweets, Google searches, Wikipedia article views, and quitline call volume, top to bottom panels) across the entire study period (2009-2014). Gray lines indicate GASO (dashed lines) and New Years Day (NYD, dotted lines). The right panels display the same data focused around the days before and after the GASO for each year of the study period.

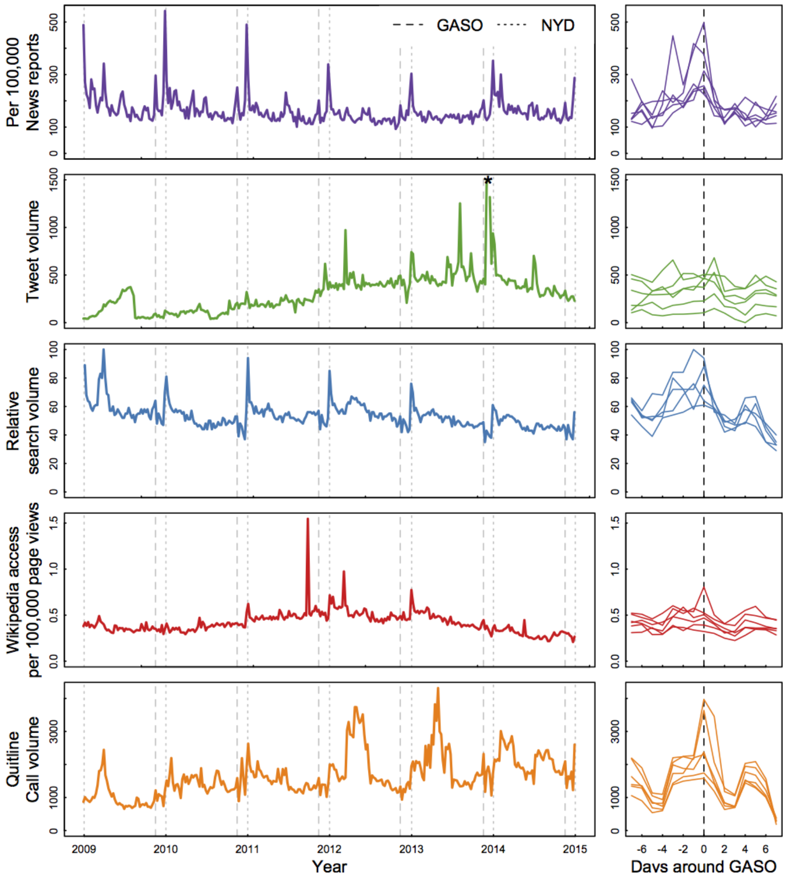


Figure 2. Percent increases in outcomes on the GASO compared to the counterfactual had the GASO not occurred, as detailed in the text. Asterisks indicate statistical significance (P<.05).

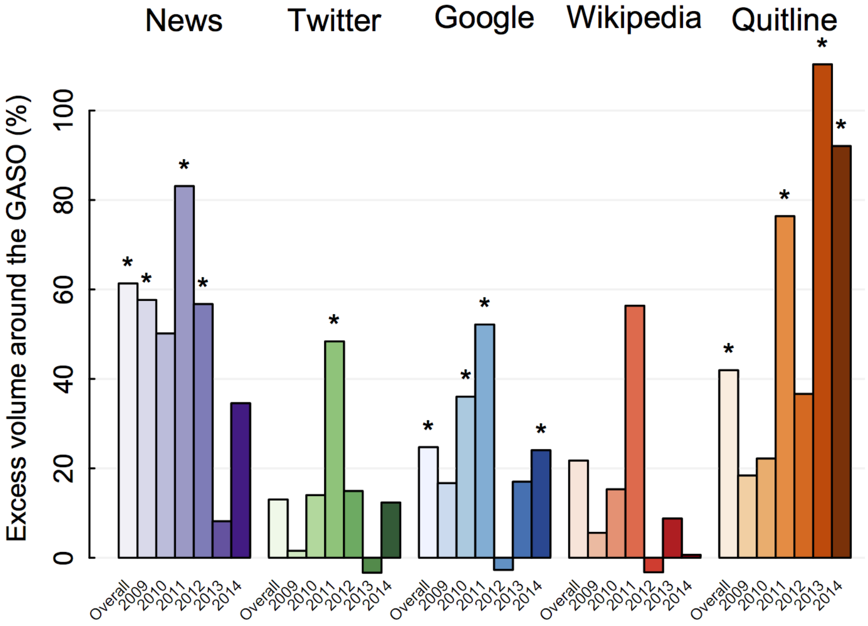
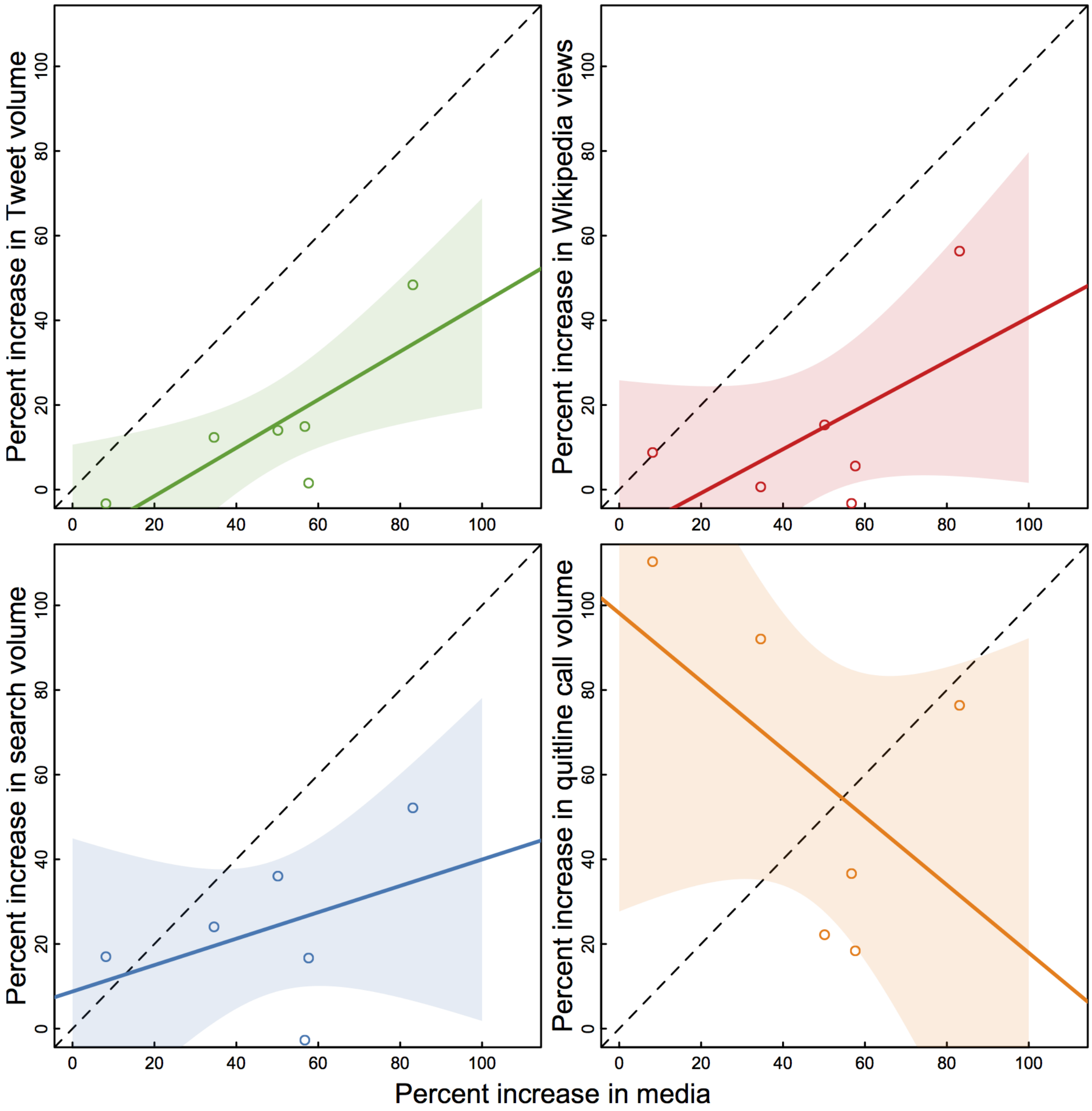


Figure 3. Relationships between increases in cessation-related news media and help-seeking online (Google and Wikipedia) and on quitlines. Each circle captures the co-occurring annual mean effect estimate for the outcomes as displayed on the (y) and (x) axis, with a plotted line and confidence interval as derived from a linear regression. The slope of the dashed reference line indicates a perfect one-to-one relationship between the outcomes.



Discussion

This study demonstrated a novel big data approach to rapidly, cost-effectively, and efficiently evaluate hundreds of awareness campaigns, nearly all for the first time. In doing so we found that the GASO often corresponded with increased cessation-related news coverage and cessation-related help seeking on Google, Wikipedia, and quitlines.

Our case study provided insights into how the GASO may have filtered through to the public and influenced cessation-related behavior in a way that has not been possible with traditional data. For example, we found that the GASO corresponded with increased cessation-related news coverage. Although this increase was not associated with more cessation-related tweets, it did correspond with about 61,000 more instances of cessation-related help seeking on Google, Wikipedia, and quitlines each year. These increases also compared favorably with New Year’s Day, representing about two-thirds of the effectiveness of New Year’s Day for news media and Google searches. Most critically, these novel effectiveness estimates offer suggestions for how GASO can be expanded or modified to further enhance its impact.

Because media messages need to be timed to reach receptive audiences [29], one suggestion to better ensure GASO’s cessation messages reach a more receptive audience would be to relocate these on the calendar. GASO is currently celebrated close to the holiday season when the lowest cessation-related help-seeking outcomes were observed. Add to this the recent discoveries about repeating seasonal [25] and circaseptan (day of the week) [26,27] patterns in cessation contemplations with the greatest interest during late winter and particularly on Monday, an empirically justified date of observing GASO, for example, would be the last Monday in February. With more smokers primed to consider cessation already, the GASO may very well realize larger increases apart from any specific change to its implementation.

Another potential strategy to improve effectiveness would be to attempt to increase news coverage, which, although positively related to changes in Google and Wikipedia help seeking for cessation, has been down most recently. Based on a review of prior press releases, it appears that GASO uses a repeating theme focused on smoking cessation alone. Changing themes each year to highlight novel content, such as rare health risks as with the Tips from Former Smokers Campaign [30], may engender more widespread media attention. For example, World No Tobacco Day changes themes every year and a recent analysis of that campaign showed more consistent year-to-year spikes in news coverage and correspondingly more consistent help seeking for smoking cessation on Google [12].

An enhanced strategic focus for using Twitter could also potentially increase GASO's effect on discussions about quitting. A reliance on news media to propagate tweets is not likely to be effective given the weak relationship between news coverage and tweets. Only recently has the *American Cancer Society* addressed the GASO's social media presence, which has included a handful of tweets announcing the GASO, and/or a few tweets with quitting tips leading up to and including the day of the GASO. Most tobacco control programs have been slow to adopt online social marketing strategies [31] and some that have engaged in these activities were quickly met with opposition or "Twitter Bombing" [32]. How best to engage awareness campaigns on social media websites, such as Twitter, continues to remain an important open question. With cessation-related tweets highest in 2011, GASO implementers might further investigate the context of that year and why tweets spiked.

The increase in online help seeking was promising, but these increases need to be concomitant with strategies to better ensure that those seeking help have an online pathway to evidence-based cessation assistance. Given the frequency with which smokers seek and find dubious cessation treatments online, such as laser therapies [33,34], a strategy to direct smokers to evidence-based cessation aids (such as information available at smokefree.gov, becomeanex.org, or cancer.org) may be beneficial for smokers attempting to quit [35]. This can be achieved in several ways such as purchasing advertisements on search engines for reliable cessation support or curating Wikipedia entries to provide reliable cessation support. For the latter, at the time we studied the general cessation Wikipedia entry, it did not include any reference to or links to proven cessation techniques, but an effort by the *Society for Nicotine and Tobacco Research* is underway to revise and update relevant Wikipedia entries. Similarly, tailoring of quitline call scripts to target GASO-motivated callers may encourage cessation by highlighting how more smokers are choosing to quit on the GASO. This could potentially increase conversions from callers contemplating to making a quit attempt via social norm mechanisms [36].

A limitation of our analyses is that (even with multiple data sources) we could not observe all the pathways by which the GASO could motivate help seeking. For example, radio discussions about cessation might motivate purchases of nicotine replacement therapies at brick-and-mortar stores, both of which we did not observe. However, given that television and radio news strongly correlate with print news in other settings [37] and the Internet is by far the most popular vehicle for health seeking, we would not expect the overall interpretation of the campaign's effectiveness to change substantially. Still, we are actively working on identifying and adding additional data sources to our novel evaluation framework, such as Facebook [38,39]. In the same vein, our analysis focused on a single trend from each data source and did not describe subtle variations in the content of news, tweets, Google searches, etc. In subsequent evaluations, we plan to enhance our framework by diving deeper into these data, as we have done with searches for syndromic surveillance [40]. Last, the validity of our metrics is unknown because we were not able to make comparisons with surveys or other traditional data. Nonetheless, where overlap exists, our novel data sources often compare favorably with more traditional data. For example, Google searches mirror both disease outbreaks [41,42] and behavioral outcomes [43], including tobacco-related behaviors [44,45].

This study serves as an example framework for how to leverage big data for novel evaluations of awareness campaigns. As a result, the goals of awareness campaigns, like GASO's vital aim to encourage quitting, can be better realized based on scientific data. Moreover, if GASO and related awareness campaigns are modified or enhanced based on the interpretation of our results, they can be swiftly reassessed using the same low-cost, fine-grained, and real-time big data framework.

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Conflicts of Interest

Drs Ayers and Althouse share an equity stake in a consultancy, Directing Medicine LLC, that advises clinician-scientists on how to implement some of the methods embodied in this work. Dr Dredze has been paid by Directing Medicine LLC in the past 5 years. Dr Ayers owns an equity position in HealthWatcher Inc. a data analytics firm specializing in media monitoring. Neither the data nor the methods described in this article are proprietary. There are no other potentially relevant conflicts. The other authors have no conflicts of interest to declare.

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Abbreviations

ARIMA: autoregressive integrated moving average
GASO: Great American Smokeout
RSV: relative search volume

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Original Paper

Leveraging Social Media to Promote Public Health Knowledge: Example of Cancer Awareness via Twitter

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Abstract

Background: As social media becomes increasingly popular online venues for engaging in communication about public health issues, it is important to understand how users promote knowledge and awareness about specific topics.

Objective: The aim of this study is to examine the frequency of discussion and differences by race and ethnicity of cancer-related topics among unique users via Twitter.

Methods: Tweets were collected from April 1, 2014 through January 21, 2015 using the Twitter public streaming Application Programming Interface (API) to collect 1% of public tweets. Twitter users were classified into racial and ethnic groups using a new text mining approach applied to English-only tweets. Each ethnic group was then analyzed for frequency in cancer-related terms within user timelines, investigated for changes over time and across groups, and measured for statistical significance.

Results: Observable usage patterns of the terms "cancer", "breast cancer", "prostate cancer", and "lung cancer" between Caucasian and African American groups were evident across the study period. We observed some variation in the frequency of term usage during months known to be labeled as cancer awareness months, particularly September, October, and November. Interestingly, we found that of the terms studied, "colorectal cancer" received the least Twitter attention.

Conclusions: The findings of the study provide evidence that social media can serve as a very powerful and important tool in implementing and disseminating critical prevention, screening, and treatment messages to the community in real-time. The study also introduced and tested a new methodology of identifying race and ethnicity among users of the social media. Study findings highlight the potential benefits of social media as a tool in reducing racial and ethnic disparities.

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KEYWORDS

awareness; breast cancer; colorectal cancer; disparities; lung cancer; prostate cancer; social media; Twitter

Introduction

Cancer is a major public health problem, impacting more than 14 million men and women in the United States. As of January 2014, an estimated 1.6 million additional new cancer cases will be diagnosed among Americans in 2015 [1]. African Americans have experienced higher age-adjusted mortality rates when compared with Caucasians [1,2]. Many factors contribute to these disparities. Socioeconomic status (SES) as a whole, along with its primary components, including education, income, employment status, and neighborhood appear to be obvious correlates of cancer mortality disparities [3-5]; however, other factors that are not clearly understood may also play a role [2,6,7]. One important factor that could particularly contribute to improved cancer prevention and thereby possibly reduce cancer disparities is knowledge and awareness about cancer.

Knowledge and awareness about the four cancers with the highest incidence and mortality among adults in the United States, namely lung, breast, prostate, and colorectal cancer, has been shown to differ by race and ethnicity [8-17]. Lung cancer is a good example of these differences. It is widely known that cancer of the lung is the leading cause of cancer death in the United States among both men and women and that tobacco smoking is the most significant and preventable cause of the disease. However, findings from one study [11] suggested that two-thirds of US women could not correctly identify lung cancer as the leading cause of cancer death, and this lack of knowledge was greatest among African American women [11]. In terms of breast cancer, evidence has shown that breast cancer knowledge also greatly varies by racial and ethnic group. One study [13] showed that African American women were generally unaware of disparities in breast cancer mortality. Furthermore, one study found that South Asian women tend to have better knowledge of age-related breast cancer risks when compared with black and white women [14]. Knowledge and awareness about both prostate and colorectal cancers have been shown to be low among US adults overall and particularly among low SES groups [12,15-17]. These examples highlight the importance of promoting knowledge about cancer among some segments of the US population, particularly among groups with the highest cancer burden.

Today, social media outlets including Twitter, Facebook, and Instagram, are popular online platforms to engage in communication about any and everything, and many studies [18-32] have begun examining the importance of social media in reaching larger audiences for promotion of public health knowledge and patient advocacy. Twitter has become a very popular site and application for the exchange of health-related information. Twitter allows users (individual users and organizations) to exchange information with other users around the world in real-time, through short messages called "tweets" (less than or equal to 140 characters) posted on a given users' timeline (ie, the chronologically ordered collection of tweets posted by a given user). Twitter also allows users to re-tweet (repost) other users' tweets, which promote the exchange of messages to a very large number of individuals. Many health care agencies and public health organizations (ie, local and national organizations and private companies) [21,23,27,33,34] use Twitter as a major online platform for health education and promotion because the majority of Twitter content is publicly available and may provide a novel source of health-related information. In fact, recent studies [35,36] have touted the numerous epidemiological advantages of coupling machine learning techniques with social media mining. Marathe et al [36] discuss the real-time possibilities of understanding disease outbreaks using social media data. Dredze et al [35] state that geo-specific data coupled with the public forum nature of social media (which encourages the sharing of detailed information) creates new public health capabilities not previously seen. Simultaneously, advances in demographic extraction techniques and computational linguistics have allowed for a deeper understanding of user demographics [37,38]. In these studies, Beretta and Burger connected age and gender to linguistic patterns (often word usage). In the case of Beretta [37], user profile images manually labeled by human experts helped to verify the experimental results. Much of the demographic extraction studies have built upon studies originating in the field of psychology, connecting linguistic patterns to demographic elements of participants [39,40]. In Colley's work [39], participants' inboxes were examined for linguistic differences differentiating the genders.

In this study, we aim to explore differences in cancer-related tweeting by race and ethnicity, basing our work on Rickford's assertion of unique vernacular patterns amongst African-Americans [40]. Findings from this study will ultimately contribute to the development and implementation of cost-effective, prevention, and dissemination strategies, delivered through social media messaging, targeting specific subgroups that would benefit from increased cancer knowledge and awareness.

Methods

Preprocessing

Tweets were collected from April 1, 2014 through January 21, 2015 using the Twitter public streaming Application Programming Interface (API) to collect 1% of public tweets, yielding 281,276,343 tweets. For this study, we restricted our collection to English-only tweets. We provided no restriction on Global Positioning System (GPS) values for each Tweet due to the sparsely available GPS data and instead focus our Tweet location to US-only accounts using an approach introduced later in this paper. Due to a technical issue with our collection system, tweets from May 13, 2014 through July 24, 2014 were not retained. During the data collection period, the Twitter-provided unique user identification (ID) number, tweet, data/time, profile-identified location, and GPS latitude and longitude values were collected (when available). Following the collection of tweets, user timelines were re-constructed by grouping tweets using the unique user ID number. The distribution of character lengths for tweets in the collection are shown in Figures 1 and 2.

Figure 1. Histogram showing the distribution of Tweet character lengths.

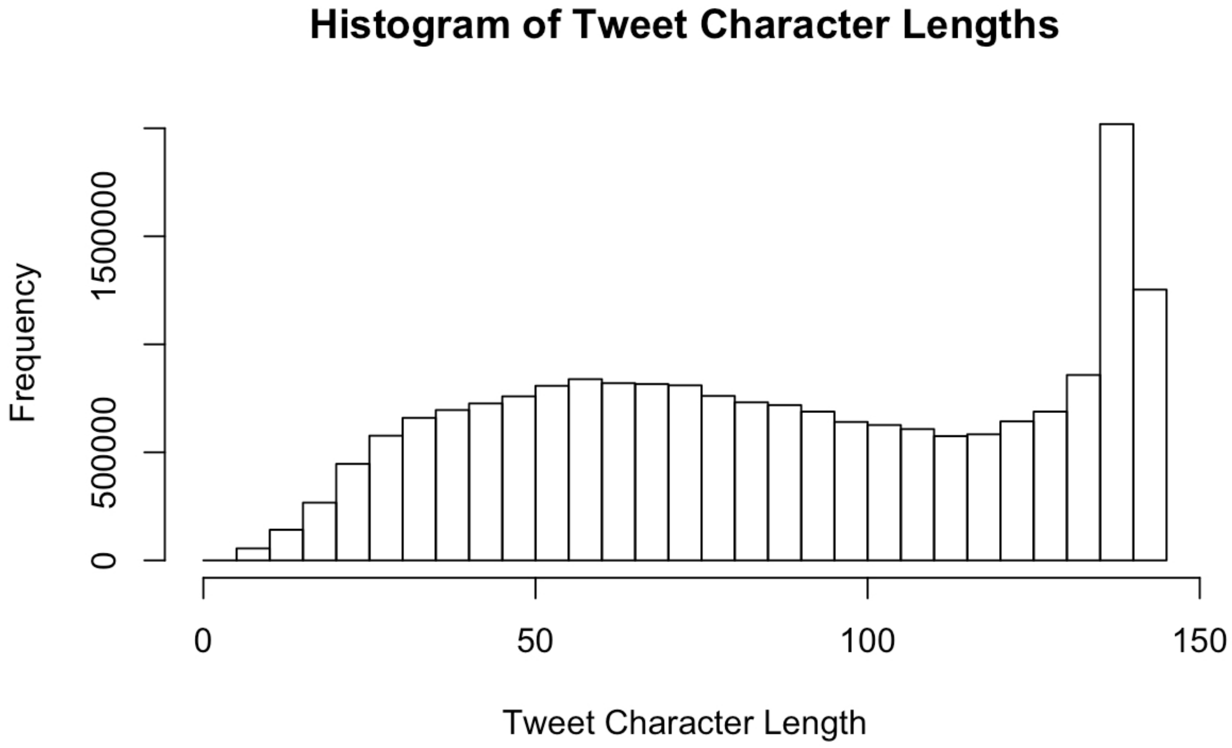
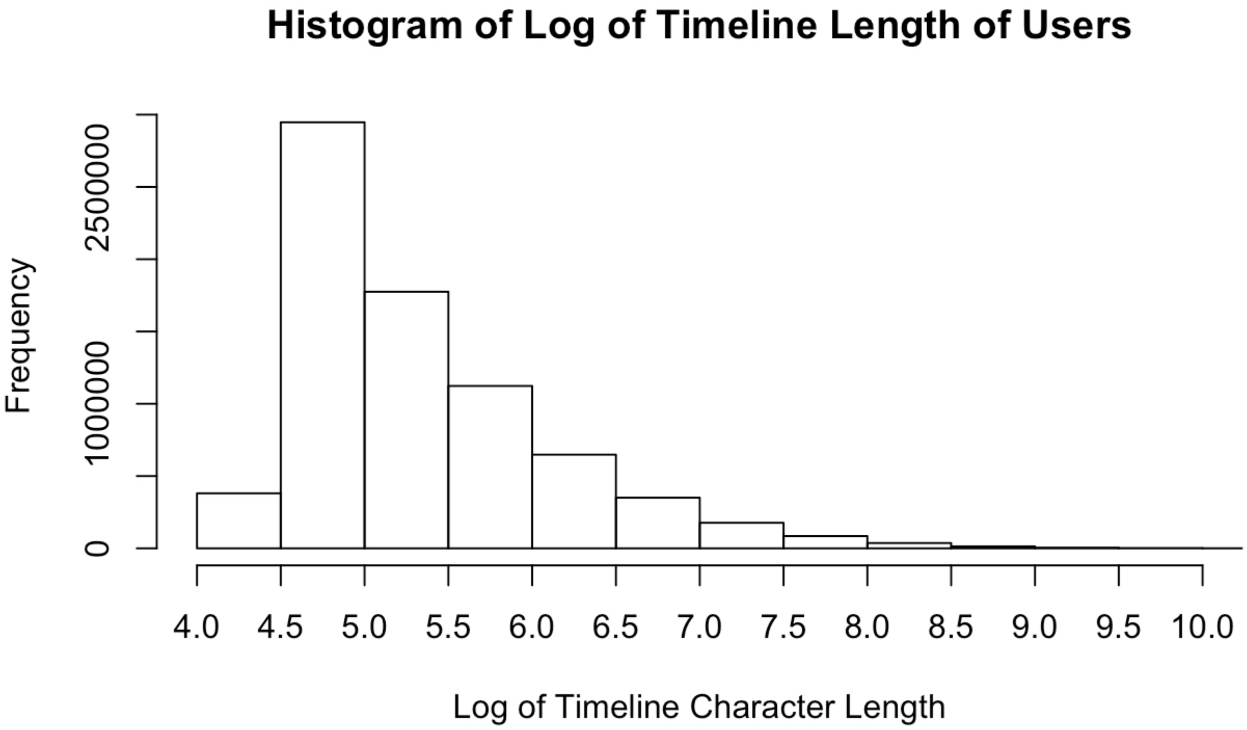


Figure 2. Histogram of the log of the character length of user timelines. We present this graph in log-form due to the wider distribution of character lengths in timelines.



The preprocessing procedure for cleaning tweets followed a consistent approach across all collected timelines. Given that the focus was on the predictive power of text, tweets containing linking information outside of the self-contained tweet, predominately non-language elements (ie, URLs, usernames, and re-tweet information) were systematically removed. For example a tweet containing elements such as, "www.t.co", "cnn.com", "@username", and "RT @username" would be removed from the collection. While re-tweeted text may provide information about individuals and/or organizations a user interacts with via Twitter at this scale, we were unable to include all re-tweets using the provided Twitter API due to rate limitations (ie restrictions imposed by Twitter limiting the number of searches we could conduct in a 15-minute period). User timelines (tweets aggregated by user) that contained little information were removed by systematically eliminating those that were shorter than 85 characters from the study. To select this character threshold, we randomly selected timelines of varying length and observed that timelines shorter than 85 characters generally contained fewer than fifteen words, which provided little information to make accurate classifications. These preprocessing methods left us with a final Tweet count of 19,818,236 belonging to 779,653 unique users' timelines for analysis.

Identification of Race and Ethnicity

The approach to classifying users' ethnicities presented in this paper relies on a supervised learning classification approach [41], which requires accurate training data to inform the classification model and also a reliable set of testing data for assessing the accuracy of classifications. To acquire training data indicating the ethnicity of Twitter users, we looked for specific declarative statements within each user's timeline (ie, statements where users explicitly defined an element of their personal identity). Timelines that contained such declarative statements were labeled accordingly, receiving one of four enumerated keys. These keys indicated the types of ethnicity explored by this study, taking the values of: *Caucasian, African-American, Asian,* and *Hispanic.* Examples of declarative statements include: "I am African-American", "I'm Asian", or "I'm a black man." These statements were chosen by manually observing statements around ethnic terms (eg, white, black, Caucasian, African-American, Asian, etc), which determined that many self-identifying statements took on similar forms compared to the declarative statement examples provided above. Although we are aware of the differences in race and ethnicity, this study does not make distinctions between the two types of declarative statements since the end Twitter users who contributed to such statements are not always sound or consistent.

Classification of Race and Ethnicity

Individual tweets are short, often uninformative messages providing little classification potential for identification of user profile information. This led us to examine users' timelines, rather than individual tweets, to enhance the accuracy of our classification approach by extracting features consisting of deeper information around users' activities. Users' tweets were collapsed into timelines containing the chronological order of their submitted tweets for the 10-month data collection period. This provided a larger text source for identifying descriptive elements indicative of a given user's ethnicity.

Baseline classification models described in previous work [38] adopt document-term matrices for representing the frequency with which terms appear in a given timeline. Classification algorithms are used to detect vocabulary usage patterns among a common set of users. In this study, a common set consisted of users with the same *self-identified* ethnic background (eg, "I'm African-American" appearing within their timeline). The vocabulary usage patterns detected among the self-identified users were then applied to users who chose not to explicitly define their ethnicity. Two opposing scenarios were examined in this study (1) how timeline synonym expansion can enhance predictive ability; and (2) how dimensionality reduction can enhance predictive ability of users' ethnicities. These scenarios were born from two ideas. The first is that users often express similar thoughts on social media with varying lexical choices, and secondly, sparsely populated timelines potentially compromising the accuracy of our classifications.

When building the baseline classifier [42-44], based exclusively on users' choices of vocabulary, we discovered that there was often difficulty connecting some classifiers to specific ethnicities. For example, one ethnic group may often use terms such as *wife, spouse,* and *marriage,* consistently appearing as some of the most identifying terms for that group. Having identified that Twitter users often used varying terms to describe the same concept, we expanded tweets with additional vocabulary in an attempt to increase lexical overlapping of group member term usage to easily segment profile types. Using part-of-speech tagging, we identified nouns and verbs within tweets. Then for each tweet, using Wordnet (a lexical database where nouns, verbs and adjectives are collected into sets of cognitive synonyms) [45,46], the top five synonyms, when available, for each noun and verb were appended to the tweets, resulting in expanded tweets while retaining their original meanings. This allowed for more frequent overlap between tweet term usage among racial and ethnic groups and a more accurate classification algorithm. To the best of our knowledge, using synonym expansion of tweets to enhance the bag-of-words feature set has not been explored in detecting the ethnicity of Twitter users.

Latent Dirichlet allocation (LDA) [47] is a statistical method for computing abstract topics of a given document using the co-occurrences of terms within the documents of a corpus. Our second ethnic classification approach used LDA to detect patterns among topics rather than vocabulary usage by first converting tweets into topics. We acknowledge that LDA is typically used for topic detection in long documents and its limitation when applied to topic detection from short text. Nevertheless, by our study design, all tweet text contributed by a Twitter user were first aggregated to generate the user's total writing record on Twitter, after which LDA was applied onto the aggregated writing record of a user (averaging 324 characters). In Figures 1 and 2, we summarize tweet and total tweet writing record (user timeline) length of the collection of tweets examined herein. This author-based aggregation step greatly mitigates the sparsity issue of short input text to the LDA model. It is noted that the above preprocessing step is also popularly adopted when topic modeling is applied to Twitter data [48-50]. Using LDA topic distributions to represent timelines resulted in a reduction of features (variables used for classifying the ethnicity of a user-for example, these variables consisted of frequency counts of stemmed-words such as "togeth", "damnnn", and "sharp", which generally indicated an African American user, and "newyork", "lifetime", and "whatchya", which were strongly associated with Caucasian users) by 99.7% while improving classification accuracy for some ethnic groups. The number of abstract topics, and thus the number of features representing Twitter timelines, was decided on systematically by iteratively building classification algorithms with increasing larger topic sizes. Accuracy of the model within this corpus of timelines peaked at approximately 45 abstract topics, which was then adopted for each testing set. In this approach, we aimed to reduce the number of features representing the activities of each Twitter user. Having reduced users' timelines to representation comprised of LDA topic distributions, we then adopted a Support Vector Machine classification approach with a radial basis function kernel for our classification algorithm. This method was chosen for its demonstrated ability to perform well with text data and is consistently considered the best approach in text classification studies [51].

We used ten-fold cross validation to test the accuracy of the models. The labeled dataset was divided into ten, equally sized bins. Nine of the ten bins were used to train the model, while the remaining bin was used for testing. We iterated over the bins ten times, reserving a new bin for testing with each additional iteration. Due to the unbalanced nature of our dataset, we chose two evaluations metrics. First, for each ethnicity, we computed the balanced accuracy (Equation a, Figure 3), a performance metric intended for unbalanced classes [52]. Second, we provided the overall accuracy for all ethnicities (Equation b, Figure 3), as well as the accuracy for Caucasians and African Americans (the two groups focused on in the second part of this study). In addition, we provided a confusion matrix of the classification results (results for text classification with synonym expansion and results for the topic-based method) to give further details of the classification performance.

Figure 3. Balance and overall accuracy equestions.

$$\text{Balanced Accuracy} = \frac{1}{2}\left(\frac{TP}{P} + \frac{TN}{N}\right) \qquad \text{(a)}$$

$$\text{Overall Accuracy} = \frac{(TP + TN)}{(P + N)} \qquad \text{(b)}$$

Statistical Analysis

All statistical analysis for this study was carried out using R Statistical Software Package. To measure the statistical significance of the observed differences between groups, *t* tests were conducted with pairwise comparisons of ethnic groups (ie, Caucasian vs African American, Caucasian vs Hispanic, etc). We tested the hypothesis that there were no statistically significant pairwise racial and/or ethnic group differences in cancer term usage during each month of the study period. Because pairs of ethnic groups were tested independently of one another, no adjustments for multiple comparisons were made. *P* values <0.05 were considered statistically significant.

Results

To evaluate the success in the classification of race and ethnicity, we compared the accuracy of text classification with synonym expansion against the topic-based method (Tables 1 and 2). We found that the accuracy of text classification with synonym expansion outperformed the topic-based approach in most cases. Using the synonym expansion approach, we achieved the following accuracies for correctly identifying user ethnicities: 88.87% among Caucasian users, 81.26% among African-American users, 72.32% among Asian users, and 69.07% among Hispanic users. The overall accuracy for all groups using this approach was 76.07%. Using topic detection, we observed no improvement in overall accuracy at 55.59%. Among the groups we also observed a lower accuracy score (Caucasian, African-American, Asian, and Hispanics resulting in 71.89%, 68.32%, 53.43%, and 54.50% respectively). We suspect topic detection classification produced lower accuracy scores due to the loss of nuanced lexical differences between ethnic groups lost during the feature reduction process.

Table 1. Text classification with synonym expansion model classification and accuracy results.

Race and ethnicity		%
Balanced accuracy		
	Caucasian	88.87
	African American	81.26
	Asian	72.32
	Hispanic	69.07
Overall accuracy		
	All groups	76.07
	Caucasian and African Americans	88.30

Table 2. Confusion matrix.

Classification	Reference, n			
	Caucasian	African American	Asian	Hispanic
Caucasian	1067	117	49	71
African American	890	1286	337	380
Asian	26	10	39	35
Hispanic	7	7	25	54

Given the higher overall accuracy, as well as the high accuracies among Caucasian and African-American users, we selected the synonym expansion approach for classifying the remaining unlabeled users within the collection. Additionally, we elected to exclude users classified as Asian and Hispanic from this study for multiple reasons. First, the population sizes where users declared ethnicities of these types were markedly smaller than populations of Caucasians and African-Americans. In addition, we believe we may have excluded some Asian and Hispanic users by limiting the Tweet collection to English-only tweets. The combination of these complications (small population sizes and the restriction of English-only tweets) is likely reasons for the reduction in accuracy among these groups and their subsequent exclusion from the study.

In this study, we have established and tested a systematic method for detecting ethnicities among Twitter users. Using the more accurate approach, text classification with synonym expansion, we detected and assigned ethnicities to all users within the collection consisting of 19,818,236 tweets posted by 779,653 unique users. Tweets were divided by posting date into nine months, accounting for the ten-month study period with portions of May and July and the entirety of June lost due to system failure. Various descriptive statistics were calculated to describe the health effects extracted from the dataset.

As shown in Table 3, the number of unique users varied widely by race and ethnicity. To detect significant differences in term usage between ethnic groups, each term contribution was normalized by the percentage distribution of population. Additionally, the term frequency for each ethnic group is provided without normalization. The number of unique users from each ethnic group was examined for each month. Caucasian users dominated the dataset (92.32%, 719,798/779,653), while African-American users often represented 7.12% (55,549/779,653) of the population, and both Asian and Hispanic users made up a small percentage of the overall population (0.55%, 4306/779,653). We were less confident in predications of Asian and Hispanic ethnicity among users based on the smaller training set as well as the lower accuracy values among these ethnic groups.

Table 3. Distribution of unique active Twitter users during each month of the study period by race and ethnicity.

Month	Race and ethnicity, n (%)				Total
	African American	Caucasian	Asian	Hispanic	
April	49,104 (9.72)	452,924 (89.64)	1289 (0.25)	1935 (0.38)	505,252
May[a]	40,956 (12.76)	277,169 (86.36)	1177 (0.37)	1646 (0.51)	320,948
July[a]	43,349 (9.58)	405,185 (89.57)	1661 (0.37)	2191 (0.48)	452,386
August	54740 (7.91)	632,687 (91.47)	1820 (0.26)	2466 (0.36)	691713
September	52,224 (10.16)	457,300 (89.02)	1789 (0.35)	2417 (0.47)	513,730
October	50,120 (11.07)	398,440 (88.02)	1763 (0.39)	2371 (0.52)	452,694
November	50,060 (10.80)	409,125 (88.30)	1762 (0.38)	2370 (0.51)	463,317
December	48,247 (11.20)	378,412 (87.86)	1727 (0.40)	2292 (0.53)	430,678
January	30,707 (15.62)	162,682 (82.75)	1435 (0.73)	1780 (0.91)	196,604

[a] Tweets from May 13, 2014 through July 24, 2014 were not retained due to a system outage.

This study focused on the social media attention given to site-specific cancers and differences by race and ethnicity. Specifically, Twitter timelines were examined for the frequency of occurrence of the following terms: "cancer", "breast cancer", "prostate cancer", "colorectal cancer", and "lung cancer." These terms were detected using methods adopted in previous studies examining discussions about specific health topics on Twitter [53]. We are aware of other work [54] that distinguishes between medically-related use of the term "cancer" and non-medically related uses. However, when examining our own dataset, by sampling 200 randomly chosen tweets, we observed only 8.5% (17/200) of tweets were used in the context of Zodiac signs and 2.0% (4/200) referred to destructive practices (eg, "he was a cancer to the community"). We suspect the low percentage of non-medically related usage may be a result of the cleaning process performed, where tweets containing URLs were stripped from the collection (ie, horoscope tweets often contain links to an extended version of the horoscope). Furthermore, we examined samples of each of the bi-gram terms of interest (eg, "breast cancer", "prostate cancer", "colorectal cancer" and "lung cancer"). We observed no uses of the term "cancer" in a context other than the medical terminology when examining these samples, presumably because of their specificity. We retained the uni-gram term in our study for comparison; however, we focus the discussion on the results related to the bi-gram terms.

First, we examined user activity by ethnicity during each month of the study period to understand seasonal peaks in term usage on Twitter (Table 3). We then counted the frequency of cancer terms for each month and by ethnicity. The types of cancer examined in this study include: breast cancer, prostate cancer, colorectal cancer, and lung cancer. For "cancer"-related tweets, we counted the detection of the following keywords: *benign, cancer(s), cancerous, carcinogen, carcinogenic, chemo, chemotherapy, chemotherapeutic, cyst(s), growths, leukemia, lymphoma, malignant, metastases, metastasis, metastatic, neoplasm, neoplasm, oncologist, oncology, radiation, radiotherapy, recurrence, and tumor(s)*. These set of terms were adopted from a previous study [55]. For specific cancer types, we used the National Institute of Health’s website for other disease synonyms. For breast cancer, we searched for: *breast cancer, breast carcinoma, cancer of the breast, malignant neoplasm of (the) breast, malignant tumor of (the) breast, and mammary cancer.* For colorectal cancer, we searched for: *colorectal cancer and colon cancer.* For lung cancer, we searched for: *lung cancer, cancer of bronchus, cancer of the lung, lung malignancies, lung malignant tumors, lung neoplasms, malignant lung tumor, malignant neoplasm of lung, malignant tumor of lung, pulmonary cancer, pulmonary carcinoma, pulmonary neoplasms, and respiratory carcinoma.* Finally, for prostate cancer, we searched for: *prostate cancer, cancer of the prostate, malignant neoplasm of the prostate, prostate carcinoma, prostate neoplasm, prostatic cancer, prostatic carcinoma, and prostatic neoplasm*. All searches were conducted within our tweet collection. Observable differences between Caucasian and African American groups were present in almost all of the chosen cancer terms across each month of the study period (Figure 4). However, observations of certain terms, namely "colorectal cancer", showed prominently lower frequency counts when compared with other terms and thus were not shown graphically.

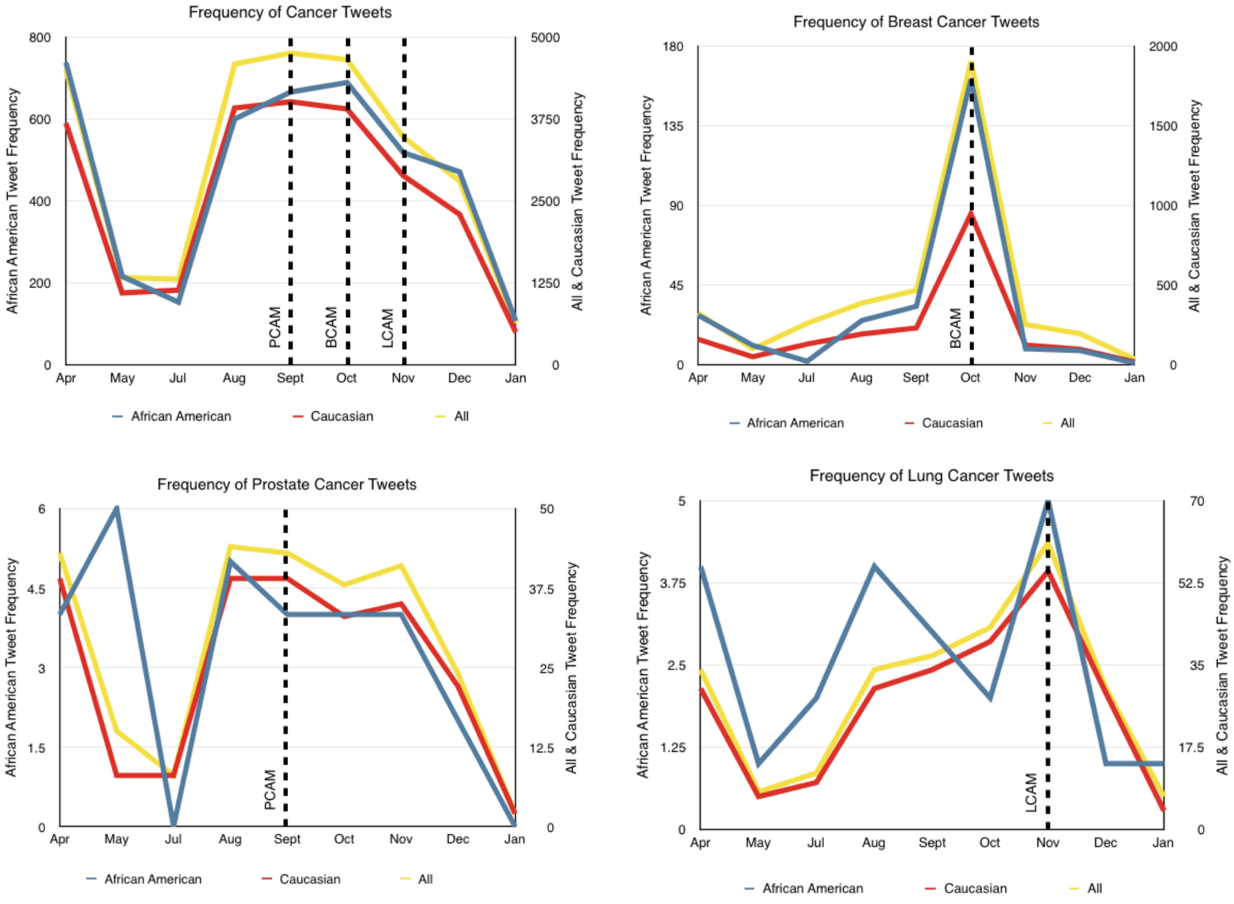
Finally, we examined the differences in term usage by race and ethnicity within each month of the study period using *t* tests of pairwise differences (Table 4). During most months, the Caucasian and African American groups showed statistically significant differences in terms of Twitter activity. However, in terms of colorectal cancer, we observed few months where there was a statistically significant difference between these two groups. Again, we suspect this is a result of the limited number of users discussing this particular type of cancer via Twitter. Lastly, lung cancer showed a statistically significant difference between Caucasians and African Americans during the months of September through December, excluding other months.

Table 4. Statistical significance of pairwise differences in cancer term usage between African Americans and Caucasians during each month of the study period[a].

Month	Cancer term, *t* test				
	"Cancer"	"Breast cancer"	"Prostate cancer"	"Colorectal cancer"	"Lung cancer"
April	0.00003	0.053025	0.014894	0.025347	0.080356
May	0.008194	0.584394	0.122251	0.095581	0.510364
July	0.013599	<0.0001	0.006656	0.157299	0.890133
August	<0.0001	0.001168	0.157209	0.312076	0.165111
September	<0.0001	0.00007	0.017132	0.157299	0.013196
October	<0.0001	<0.0001	0.242175	0.974206	0.000162
November	<0.0001	<0.0001	0.027708	0.014306	0.000631
December	0.000266	0.000001	0.027575	0.317311	0.000067
January	0.241671	0.00945	0.1573	0.083265	0.91944

[a] Each user’s total term usage was calculated by summing the frequency with which cancer terms appeared in their timeline.

Figure 4. Monthly frequency of cancer terms by race/ethnicity (African American, left axis; Caucasian, right axis), and all Twitter users (right axis). Cancer terms are "Cancer" (top left), "Breat Cancer" (top right), "Prostate Cancer" (bottom left), and "Lung Cancer" (bottom right). It is important to note the sharp decreases seen following cancer awareness months (Prostate Cancer Awareness Month [PCAM, September], Breast Cancer Awareness Month [BCAM, October], and Lung Cancer Awareness Month [LCAM, November]), particularly among African Americans. Both groups are seen returning to lower frequencies following awareness months; however, this observation is more prevalent among African Americans, specifically following BCAM.



Discussion

Principal Findings

In this study, we observed interesting patterns of media attention given to specific cancer terms among unique Twitter users during a 9-month period in 2014. With a focus on cancer in general, and breast, prostate, and lung cancers specifically, which are the leading cancers among men and women in the United States, we observed some variation in the frequency of term usage during and after specific months known to be cancer awareness months, specifically September (Prostate Cancer Awareness Month [PCAM]), October (Breast Cancer Awareness Month [BCAM], and November (Lung Cancer Awareness Month [LCAM]). Interestingly, colorectal cancer, the third most common cancer in both men and women [1], received the least attention on Twitter among users sampled in this study across the board. We observed differences in frequency of use of each of the cancer terms of interest throughout the duration of the study period by race and ethnicity which we hypothesize are related to observable cancer disparities in the United States. These findings highlight the necessity for increased cancer awareness in the population and the importance of studying how individuals use social media to spread information about cancer, which could ultimately be utilized in the future for real-time cancer awareness intervention implemented through Twitter (and other social media channels).

Overall, we found that the frequencies of mentions of "cancer" among Caucasian and African American users were similar in terms of seasonal increases or decreases, although it appeared that African Americans maintained a higher percentage of normalized Tweet frequency of this broad term compared to the Caucasian group. In terms of the frequencies of mentions of "breast cancer", Caucasian users consistently had a higher percentage of use during all months of the study period. As expected, the frequency of use of this term was highest during BCAM, with a dramatic decrease in the months following, ultimately returning to levels lower than observed leading up to BCAM. This was true among both Caucasians and African Americans; however, there was a steeper decline in the mentions of "breast cancer" on Twitter among African Americans following BCAM.

This may be an area that can be the focus of future interventions aimed at increasing breast cancer awareness throughout the year, which could contribute to increased knowledge, improved within-guidelines screening rates, and increased preventive activities among groups with a disproportionate disease burden. For example, weekly Twitter chats hosted by the #bcsm ("breast cancer social media") community have been shown to raise awareness and decrease medical anxiety in patients [31]. Identifying individuals who were active during BCAM and inviting them to participate in Twitter chats could be a way to build an engaged, on-going community of active participants in discussions about cancer in groups with a disproportionate disease burden. Chats can be facilitated with the use of a consistent hashtag, which is a convention on Twitter designed for marking tweets about specific topics. Enlisting experts and celebrities to guest host chat sessions may be a way to promote sustained engagement, particularly because people tend to prefer health-related messages on social media that come from sources with high status and credibility [25]. These interventions would leverage Twitter's capabilities to deliver just-in-time information and social support, involving individuals proactively in evidence-based discussions about cancer throughout the year [56]. This intervention method may be appropriate for other types of cancer as well.

During PCAM, there was a substantially higher frequency of discussion of prostate cancer among Caucasians compared to African Americans. In July and January, among Caucasian users, we observed the lowest levels of prostate cancer discussion. Conversely, among African Americans, we observed a steady decrease in prostate cancer discussion from August through January. Following PCAM, we observed a decline in the frequency of use of the term "prostate cancer" among both groups; however, these declines were slower than that observed with other cancer awareness campaigns. For example, when examining the frequency of use of the term "lung cancer", we observed a peak in November (LCAM) and then a dramatic decrease to levels lower than observed in the months prior to LCAM.

The months following cancer awareness month campaigns also presented interesting findings. While awareness month campaigns (eg, PCAM, BCAM, LCAM) could be considered successful in promoting discussion around various cancer topics, our findings suggest that these campaigns as evidenced by mentions of cancer terms via Twitter during specific cancer awareness months, did not appear to sustain long-term interest and discussion. This phenomenon was particularly evident when examining breast cancer discussion frequency, but was also present in both lung cancer and prostate cancer social media activity. In fact, our findings showed that racial and ethnic groups often returned to a state of lower participation following awareness campaigns when compared with preceding months. Notably, this reduction in discussion frequency appeared to be more prevalent among minority groups. For example, African Americans reduced their participation by 73% in the month following BCAM when compared with months preceding the program. Among Caucasians, we also saw a drop in participation where we observed only a 47% reduction. Similarly for LCAM, we observed a 50% drop among African Americans compared with a 25% drop in the Caucasian cohort. Finally, in terms of discussion of colorectal cancer, we saw poor participation throughout the months of the study. This could be an indication of poor marketing or the taboo nature of the topic among some populations as well as lack of collection of tweets during Colorectal Cancer Awareness Month (CRCAM) due to a technical issue with our data collection system.

These drops in participation are likely related to media exposure and framing, two media effects that are mediated by structural determinants of health (eg, SES, race, ethnicity) [57]. Media exposure is the extent to which individuals encounter information about cancer in the mass media rather than specifically seeking it out; framing describes how topics like cancer are discussed in the mass media. This finding points to the need for interventions that use appropriate framing for minority populations. For example, using Twitter to share narratives about cancer could be particularly fruitful. Digital narratives have been successfully implemented in interventions aimed at raising awareness and improving screening rates in breast cancer, colorectal cancer, and prostate cancer [57-59]. Although tweets are short, they could be used to share short-form narratives or could be employed in conjunction with other storytelling techniques to provide engaging narratives about cancer with the aim of raising awareness and disseminating credible information about cancer to populations with a disproportionate disease burden [60].

With the growing popularity of social media and the previously unavailable personal insights it offers, social media mining presents new opportunities and methods applicable to epidemiologic research. Existing studies have examined the health impacts of social media, as shown in previous work [32] where researchers concluded that Tobacco Control Programs are ineffective in capitalizing on social media platform's potential. In addition, Thackeray et al examined the frequency of breast cancer-related tweets during BCAM [25] and concluded that Twitter could be a tool used for increasing health conversations to maximize health marketing. In the present study, we examined how new text mining techniques can be used to extract a user's race and ethnicity through lexical analysis, thereby providing a new opportunity to inform future studies to potentially address racial and ethnic health disparities. However, this work can be further expanded to examine differences across other demographic characteristics, as well as the investigation of disparities with respect to diseases other than cancer. Finally, understanding a social media user's demographic makeup also presents new opportunities for appropriately targeting health education materials.

Limitation

There were limitations of this study that should be considered. First, our findings provide only a glimpse of all tweets, focused on cancer-specific topics among users without private Twitter accounts during one year. Thus, there could very well be an underestimation of the frequency of cancer-focused discussion via Twitter. Relatedly, it is possible that tweets of interest were missed due to our choice of keywords or use of alternate terms and/or spellings of some words among the users. It is possible that we missed tweets of interest based on the keywords we have chosen to examine and, consequently, the true frequencies of cancer-related tweets may be higher than what we currently examined in the analysis. Nevertheless, our large-scale systematic examination of 779,653 unique Twitter users and their tweets contributed during a 9-month period still provides a meaningful glimpse into users' social media activity related to general or specific cancer topics. Due to the scope and length limit of this manuscript, we choose to report several representative case studies using the most popular cancer terms concerned by Twitter users. As demonstrated through these multiple case studies, commonly enabled by the proposed approach, the new method has the promise to be generically applicable for detecting, tracking, and comparing user interests regarding other cancer or disease topics. In addition, due to technical issues with our collection system, we were unable to retain collected tweets from the middle of May through the end of July 2014, which could have contributed to the very low frequency of use of the term "colorectal cancer". In addition, March, which is CRCAM, was not included in our collection period and could also contribute to the low frequency of the term "colorectal cancer." Another possibility is that not all public tweets were delivered from the Twitter public API; but there is no way to determine the likelihood of this possibility. The collection period excluding winter and post-holiday months (late January to March) could potentially miss important patterns that may emerge through the analysis of this time period.

And finally, because several regional, temporal, and country-specific factors may have some influence on the contents of information shared or communicated via Twitter, we went to considerable lengths to limit our dataset to US-based users. Ideally, we would have liked to filter our dataset by a Twitter-provided variable, distinguishing US-based users from non-US-based users. However, because Twitter does not provide this information, we chose to adopt an alternate method for the extraction of US users by looking at the "Location" portion of a user's profile. This is a free-text area provided by Twitter where users can input information such as New York or San Francisco, California, excluding users with non-US locations in their profile. This method was chosen for the following two reasons: (1) only a small fraction of users provide geo-tagged tweets, and (2) it is difficult to assume that geo-tagged tweets taken internationally do not belong to a US-national. Geo-tagging of tweets varies in location for a given user and, therefore, does not provide an accurate understanding of the location a user defines as home.

Conclusion

This study demonstrated that social media can serve as a very powerful and important tool in implementation and dissemination of critical cancer education and awareness messages to the community in real-time. These findings could help improve future social media studies, identify trends within groups of users, and target group-specific health education literature by learning users' characteristics through language differences. This study also introduced and tested a new methodology for identifying race and ethnicity among users of social media, which presents a unique opportunity to study risk profiles, risk factors and behaviors for several conditions by race and ethnicity and has significant implications in reducing disparities through targeted intervention and dissemination of evidence-based information tailored to specific racial and ethnic groups.

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Conflicts of Interest

None declared.

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Abbreviations

API: Application Programming Interface
BCAM: Breast Cancer Awareness Month
CRCAM: Colorectal Cancer Awareness Month
ID: identification
GPS: Global Positioning System
LCAM: Lung Cancer Awareness Month
LDA: Latent Dirichlet allocation
PCAM: Prostate Cancer Awareness Month
SES: Socioeconomic status

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Original Paper

Utilizing Nontraditional Data Sources for Near Real-Time Estimation of Transmission Dynamics During the 2015-2016 Colombian Zika Virus Disease Outbreak

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Abstract

Background: Approximately 40 countries in Central and South America have experienced local vector-born transmission of Zika virus, resulting in nearly 300,000 total reported cases of Zika virus disease to date. Of the cases that have sought care thus far in the region, more than 70,000 have been reported out of Colombia.

Objective: In this paper, we use nontraditional digital disease surveillance data via HealthMap and Google Trends to develop near real-time estimates for the basic (R_0) and observed (R_{obs}) reproductive numbers associated with Zika virus disease in Colombia. We then validate our results against traditional health care-based disease surveillance data.

Methods: Cumulative reported case counts of Zika virus disease in Colombia were acquired via the HealthMap digital disease surveillance system. Linear smoothing was conducted to adjust the shape of the HealthMap cumulative case curve using Google search data. Traditional surveillance data on Zika virus disease were obtained from weekly Instituto Nacional de Salud (INS) epidemiological bulletin publications. The Incidence Decay and Exponential Adjustment (IDEA) model was used to estimate R_0 and R_{obs} for both data sources.

Results: Using the digital (smoothed HealthMap) data, we estimated a mean R_0 of 2.56 (range 1.42-3.83) and a mean R_{obs} of 1.80 (range 1.42-2.30). The traditional (INS) data yielded a mean R_0 of 4.82 (range 2.34-8.32) and a mean R_{obs} of 2.34 (range 1.60-3.31).

Conclusions: Although modeling using the traditional (INS) data yielded higher R_0 estimates than the digital (smoothed HealthMap) data, modeled ranges for R_{obs} were comparable across both data sources. As a result, the narrow range of possible case projections generated by the traditional (INS) data was largely encompassed by the wider range produced by the digital (smoothed HealthMap) data. Thus, in the absence of traditional surveillance data, digital surveillance data can yield similar estimates for key transmission parameters and should be utilized in other Zika virus-affected countries to assess outbreak dynamics in near real time.

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KEYWORDS

Zika virus disease; digital disease surveillance; mathematical modeling; reproductive number; transmission dynamics

Introduction

Recent infectious disease outbreaks—including severe acute respiratory syndrome (SARS), Middle East respiratory syndrome (MERS), Ebola, and influenza A (H1N1)—have presented great challenges to the global public health community, including lack of basic epidemiologic knowledge to support important preparedness and control decisions. To address this gap, innovative surveillance methods have been developed over the last several years to leverage the increasing availability of digital data related to outbreaks. To date, many studies have retrospectively examined nontraditional digital data sources and have demonstrated their utility in estimating epidemic curves or changes in important epidemiologic parameters over time [1-3]. Such studies have provided a foundation for building near real-time prospective analytic techniques that can assess transmission dynamics in the absence of traditional data. These methodological developments fill a knowledge vacuum that may prove useful for public health decision making in the early stages of an outbreak.

The ongoing outbreak of Zika virus disease in Central and South America has attracted global attention due to its rapid geospatial growth as well as concerns over associated central nervous system complications [4,5]. Although Zika virus is primarily transmitted via *Aedes* mosquitoes, evidence of vertical and sexual transmission exists [6-8]. Likely introduced to the Americas in mid- to late 2013, the virus has since been propagated by the density of competent vectors throughout the region [8]. At present, approximately 40 countries in Central and South America have experienced local vector-borne transmission, resulting in nearly 300,000 total reported cases to date [9]. Of the cases that have sought care thus far in the region, about 70,000 have been reported out of Colombia, of which 17% were pregnant at time of clinical or laboratory diagnosis [9,10]. However, given the generally mild nature of Zika virus disease and subsequent lack of care seeking, reported cases undoubtedly comprise a small fraction of total cases [11,12].

Current prevention efforts focus on vector suppression [13], while interest in and efforts toward vaccine development are mounting rapidly due to increasing rates of Guillain-Barré syndrome following Zika virus infection and microcephaly in newborn babies born to women infected with Zika virus while pregnant [4,5]. Quantitative analyses designed to inform vaccine policies—in addition to other preparedness and control activities—are dependent on the transmission dynamics associated with the disease and, therefore, estimates for critical epidemiologic parameters are urgently needed for such decision making within the context of Zika virus disease.

In this paper, we use nontraditional digital disease surveillance data via HealthMap and Google Trends to develop near real-time estimates for the basic and observed reproductive numbers associated with Zika virus disease in Colombia as well as expected final outbreak size and duration. We then validate our results against traditional health care-based disease surveillance data and discuss the implications of our work on outbreak mitigation strategies in Colombia and assessment of transmission dynamics elsewhere in the region.

Methods

Cumulative reported case counts of Zika virus disease in Colombia were acquired via the HealthMap digital disease surveillance system, consisting of 28 unique nongovernmental media alerts between October 16, 2015 and April 16, 2016 [14]. The cumulative reported case curve obtained from these reports shows an unrealistic L-shape, presumably due to increased interest in reporting during recent weeks and lack of awareness during early weeks (Figure 1). By assuming that the total number of cases obtained from HealthMap was a reasonable approximation of reality for the given time period, we used Google search data to distribute cumulative reported case counts more realistically over time.

Although many cases of dengue and influenza go undetected, previous studies have shown that relevant Google search trends demonstrate high linear correlation with reported disease incidence over time [15,16]. Thus, we obtained weekly Google search fractions of the term “Zika” from Colombia via the Google Trends website (accessed on April 29, 2016). These search fractions are displayed weekly as normalized values that range from zero to 100, which reflect the level of nationwide search interest in the word “Zika” from January 4, 2004 (first available datum) to April 16, 2016.

We created a smoothed cumulative incidence curve (referred to as “smoothed HealthMap”) by scaling the Google search curve against the HealthMap-reported Zika cases [17]. The scaling constant was obtained by dividing the most recent total number of HealthMap-reported Zika cases by the total number of Google search fractions from May 31, 2015 to April 16, 2016. Perhaps due to initial delays in reporting, the first relevant uptick of the term “Zika” in the Google Trends data occurred during the week of May 31, 2015, approximately 20 weeks before the first HealthMap alert of Zika virus disease in Colombia. Because of this, May 31, 2015 was selected as the start date for modeling efforts using smoothed HealthMap data; April 16, 2016 (last available datum at time of manuscript preparation) was selected as the cut-off date.

Due to successful applications in other data-scarce (ie, cumulative incidence only) settings, the Incidence Decay and Exponential Adjustment (IDEA) model was used to estimate the basic reproductive number (R_0) and the discount factor (d) associated with the ongoing outbreak [2,18,19]. Both R_0 and d were solved for using nonlinear optimization to minimize the sum of squared differences (SSD) between reported (user-inputted) and modeled cumulative incidence (I) curves across multiple serial intervals (ie, outbreak generations). Figure 2 presents a formulation for I expressed in terms of R_0 and d, where t is the number of outbreak generations (ie, serial intervals) that have passed thus far and is inversely proportional to the serial interval length (ie, number of days per serial interval [SI]). Given that distribution for the SI associated with Zika virus disease had not yet been established, R_0 and d were solved for iteratively over a range of 14 deterministic lengths (10-23 days) [20].

These values of R_0 and d were then used to define maximum, minimum, and mean values for the observed reproductive number (R_{obs}), final reported outbreak size (I_{max}), and final reported duration (t_{max}).The observed number of secondary infections per infected individual for a given value of t (R_{obs}) was calculated using the following equation: $R_{obs} = R_0/(1+ d)^t$.

When d is greater than zero, R_0 does not equal R_{obs}. In such circumstances, disease incidence is nonexponential due to either planned or unplanned reductions in disease duration, contact rate, or infectiousness of cases [18]. Likewise, final reported outbreak duration (t_{max}) was calculated as follows [18]: $t_{max} \geq \ln(R_0)/\ln(1+ d)$.

Final reported outbreak duration can also be expressed in days by multiplying t_{max} by SI; however, in calculating I_{max}, original units (ie, outbreak generations) are used (Figure 3).

In the event that a viable vaccine is developed before the ongoing outbreak in Colombia ends (t_{max}), the following equation was used to assess the percentage of the susceptible population that would need to be immunized against Zika virus (%Vax) to eliminate transmission, assuming 100% vaccine efficacy: %Vax=1–(1/ R_{obs}).

After completion of the analyses on the digital surveillance data, we performed a validation study using traditional surveillance data obtained from weekly Instituto Nacional de Salud (INS) (National Institute of Health, Colombia) epidemiological bulletin publications [21]. The INS first reported incidence of Zika virus disease in Colombia on October 16, 2015. However, subsequent publications indicated that the outbreak likely began during epidemiologic week 32 of 2015 or earlier [22]. As result, August 22, 2015 was selected as a start date for modeling efforts using INS data. April 16, 2016 (date of the most recent publication at time of manuscript preparation) was selected as the cut-off date [22]. The analyses described previously for the smoothed HealthMap dataset were conducted on the INS dataset as well, resulting in R_0, d, R_{obs}, I_{max}, t_{max}, and %Vax estimates for both digital (smoothed HealthMap) and traditional (INS) cumulative reported case data.

Figure 1. Cumulative case curve of Zika virus disease in Colombia as captured by the HealthMap digital disease surveillance system. Linear smoothing was conducted to adjust the shape of HealthMap cumulative case curve using Google search data.

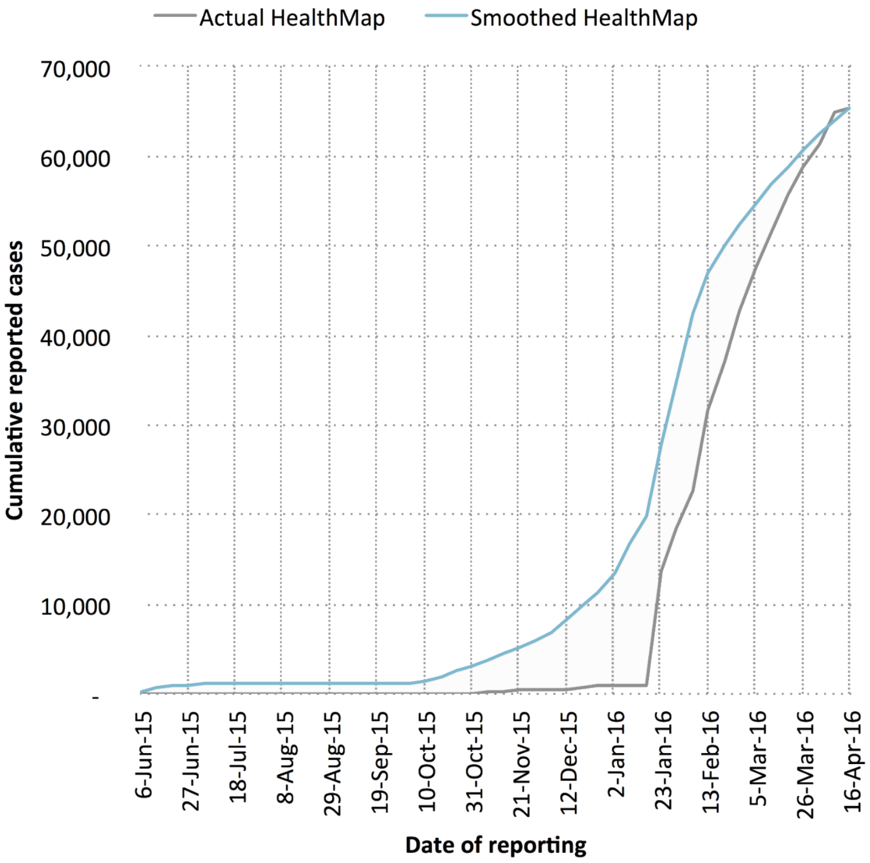


Figure 2. Cumulative incidence (I) expressed in terms of R_0 and d.

$$I = \sum_{t=0}^{t} \left[\frac{R_0}{(1+d)^t}\right]^t$$

Figure 3. Final reported outbreak size ($I_{\max}$) expressed in terms of R_0 and d.

$$I_{max} = \frac{exp\left(\frac{ln\,(R_0)^2}{4\,ln(1+d)}\right)\sqrt{\frac{\pi}{\ln\,(1+d)}}}{2} \times \left[erf\left(t_{max} - \frac{\ln(R_0)}{2\ln\,(1+d)}\right)\sqrt{\ln(1+d)} - erf\left(-\frac{\ln(R_0)}{2\ln\,(1+d)}\right)\sqrt{\ln(1+d)}\right]$$

Results

Example model fits for both digital (smoothed HealthMap; SSD=1.47×10^8) and traditional (INS; SSD=1.55×10^7) cumulative case data are shown in Figures 4 and 5 (SI=17 days). In general, the traditional data model fits (mean SSD=1.76×10^7) were superior to those derived from digital data (mean SSD=1.64×10^8).

Using the digital (smoothed HealthMap) cumulative case counts, we estimated a mean R_0 of 3.26 (range 1.91-5.05) and a mean d of 0.04 (range 0.01-0.07) across 14 deterministic serial interval lengths (range 10-23 days) (Figure 6). We then calculated a mean R_{obs} of 1.63 (range 1.31-2.05), a mean I_{max} of 85,546 cases (range 80,028-93,885 cases), and a mean t_{max} of 530 days (range 522-538 days; November 2016). Cumulative reported case projections using these modeled parameters are shown in Figure 7.

The traditional (INS) data yielded a mean R_0 of 5.36 (range 2.52-9.63) and a mean d of 0.07 (range 0.02-0.14) across 14 deterministic serial interval lengths (range 10-23 days) (Figure 8). Using these, we calculated a mean R_{obs} of 1.96 (range 1.45-2.58), a mean I_{max} of 77,386 cases (range 76,587-78,619 cases), and a mean t_{max} of 387 days (range 382-392 days; September 2016). Cumulative reported case projections using these modeled parameters are shown in Figure 9.

Although R_0 values calculated using the traditional (INS) data were general higher than those calculated using digital (smoothed HealthMap) cumulative case counts (SSD=82.14), R_{obs} values were quite similar across data sources (SSD=1.84). As a result, the digital (smoothed HealthMap) and traditional (INS) cumulative case data produced similar mean %Vax values of 0.39 (range 0.24-0.51) and 0.49 (range 0.31-0.61), respectively.

Figure 4. IDEA model fits against smoothed HealthMap cumulative case data for Zika virus disease in Colombia. A serial interval length of 17 days was used.

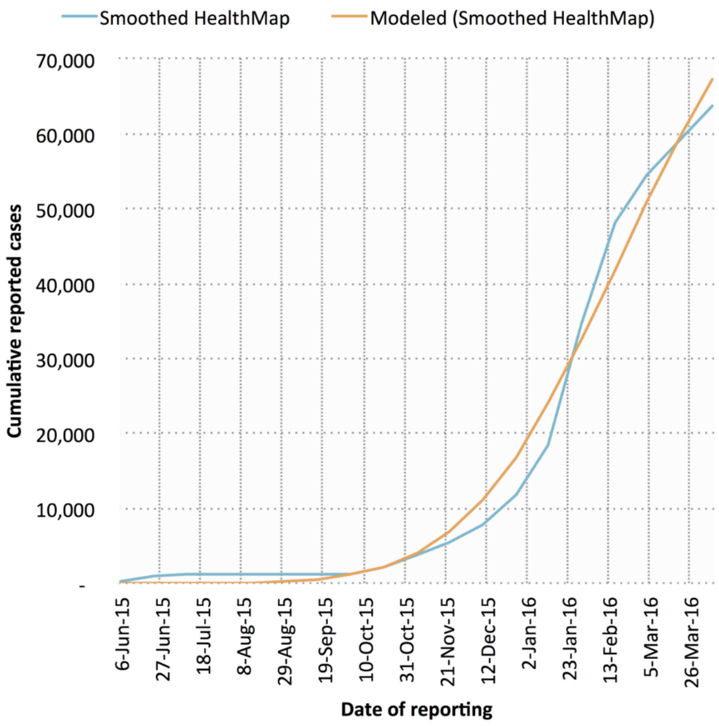


Figure 5. IDEA model fits against Instituto Nacional de Salud (INS) cumulative case data for Zika virus disease in Colombia. A serial interval length of 17 days was used.

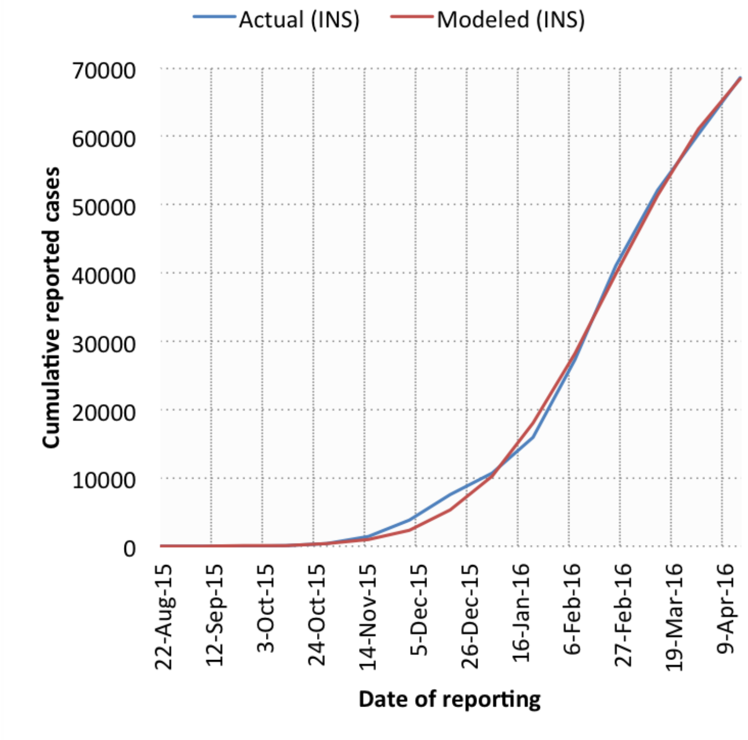


Figure 6. Modeled values for basic reproductive number (R_0), discount factor (d), and observed reproductive number (R_{obs}) using smoothed HealthMap cumulative case data. A total of 14 deterministic serial interval lengths were used; modeled values for each parameter are shown across all 14 serial interval lengths.

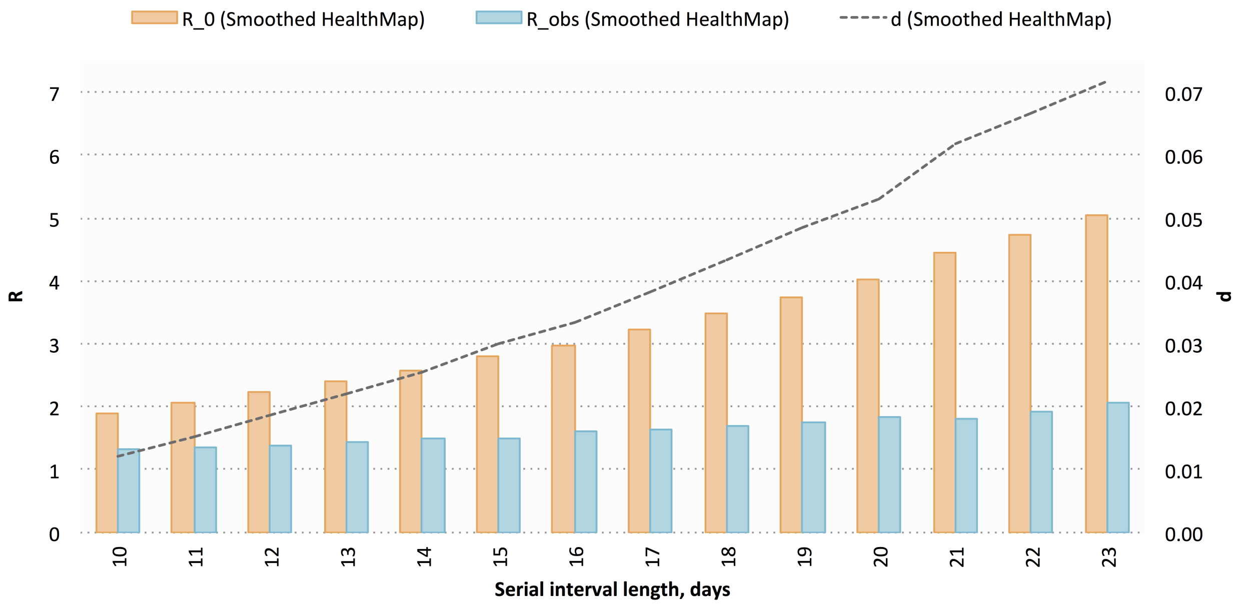


Figure 7. Cumulative case count projections using smoothed HealthMap cumulative case data. Projected minimum, maximum, and mean cumulative case counts are shown.

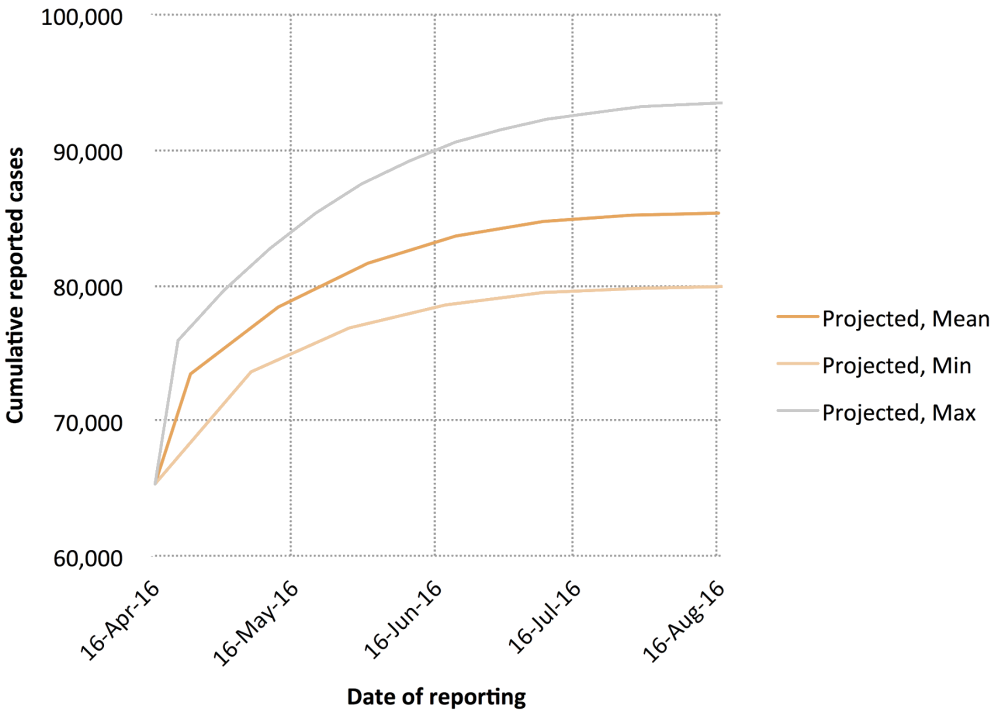


Figure 8. Modeled values for basic reproductive number (R_0), discount factor (d), and observed reproductive number (R_{obs}) using Instituto Nacional de Salud (INS) cumulative case data. A total of 14 deterministic serial interval lengths were used; modeled values for each parameter are shown across all 14 serial interval lengths.

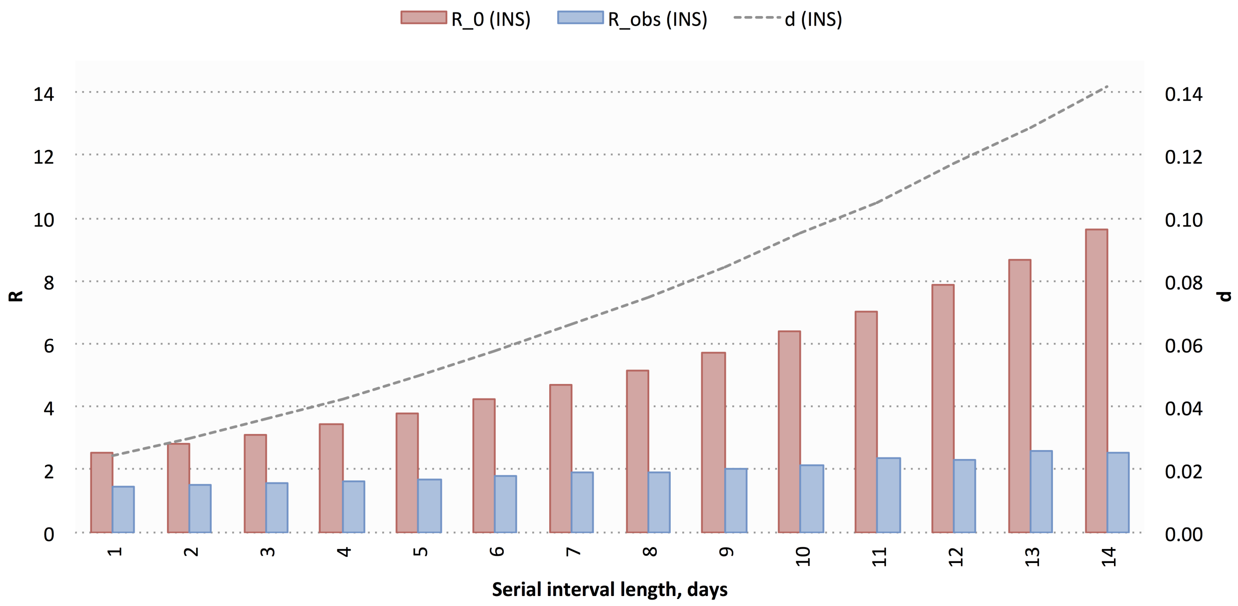
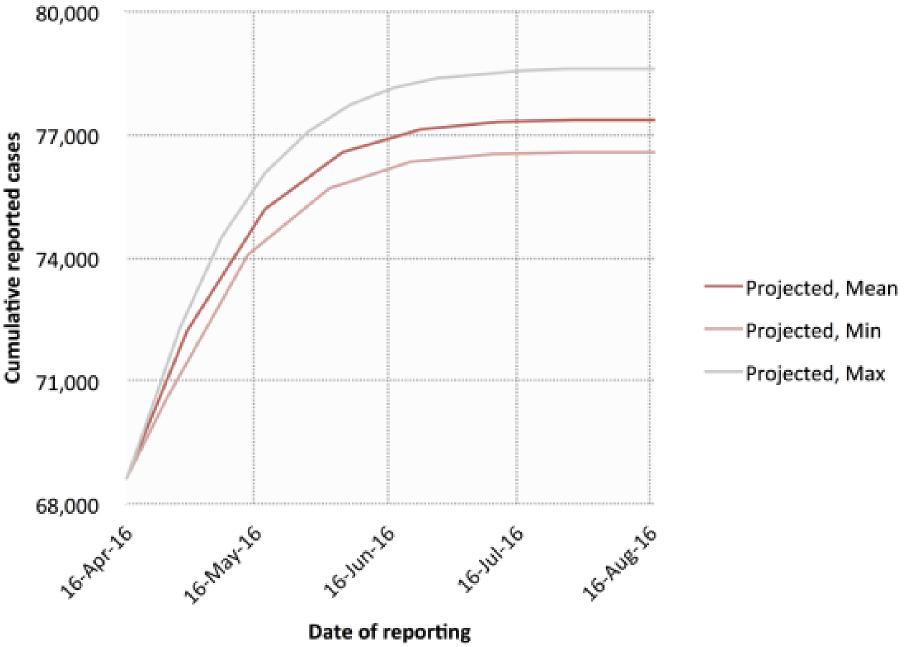


Figure 9. Cumulative case count projections using Instituto Nacional de Salud (INS) cumulative case data. Projected minimum, maximum, and mean cumulative case counts are shown.



Discussion

When depletion of susceptible individuals due to infection (ie, via death or immunity-conferred recovery) is small relative to the total population, basic reproductive numbers obtained using the IDEA model are comparable to simple SIR-type models [19]. Although they are especially suitable for use in data-scarce settings, SIR-type models—and, by extension, the IDEA model—cannot easily incorporate global dynamics, such as the importation and exportation of infectious agents (ie, vectors and humans) or significant climate events (ie, El Niño and La Niña). Nevertheless, others have demonstrated that simple SIR-type models perform similarly to complex mechanistic models when describing the transmission dynamics of vector-borne and water-borne diseases in localized contexts [23,24]. As a result, the IDEA model is a reasonable method for analyzing nationwide transmission dynamics of Zika virus disease in Colombia.

As defined by the IDEA modeling method, R_0 represents potential transmissibility of a given pathogen in a fully susceptible, naïve population; meanwhile, R_{obs} represents observed transmission in the face of existing interventions, as captured by d [2,18,19]. In this sense, the R_{obs} is similar to the effective reproductive number (R_t), which represents transmissibility in a population that is not fully susceptible. Mean modeled estimates for R_0 across both data sources were consistent with R_0 estimates for Zika virus disease in French Polynesia and with R_0 estimates for chikungunya and dengue [12,25,26]. Mean modeled estimates for R_{obs} were also comparable to R_t estimates for chikungunya and dengue [27,28]. To take into account the effects of ongoing transmission control efforts, R_{obs} was used instead of R_0 to calculate %Vax.

In this study, we found that using the traditional (INS) data yielded higher R_0 estimates than the digital (smoothed HealthMap) cumulative reported case counts. Nevertheless, because estimates for d were also higher, modeled ranges for R_{obs} and %Vax were comparable across both data sources. Similarly, the narrow range of possible case projections generated by the traditional (INS) data was largely encompassed by the wider range produced by the digital (smoothed HealthMap) cumulative reported case counts. Therefore, in the absence of traditional health care-based surveillance data, important epidemiologic parameters may be estimated using smoothed digital surveillance data as described here.

The methods used in this study are not without limitations. For both data sources, estimates for country-level case projections and I_{max} apply only to those that seek care; true caseloads are likely to be as much as five times higher than those that are reported [11,12]. Furthermore, because country-level data are utilized, in-country transmission heterogeneities are not captured. As geographic granularity of digital surveillance data improves, similar analyses should be conducted at smaller scales. Nevertheless, given that projection models are designed to serve as decision-support tools, estimating the number of cases that will report to hospitals and clinics over the next several months—even at the country level—is still valuable for the purposes of resource allocation. This may be especially pertinent with respect to diagnostic support for pregnant women presenting with clinical symptoms for Zika virus disease. To date, nearly 20% of all reported Zika virus disease cases in Colombia have been pregnant women; if the current rate holds, thousands more may be infected and seek care before the outbreak ends. However, the projections presented in this paper only apply in the event that circumstances remain unchanged (eg, no new interventions are put in place).

With improved compliance, vector suppression interventions (eg, elimination of standing water, exhaustive use of insect repellant) have the potential to bring this outbreak to a swift close, even in the absence of a vaccine. In the event that a viable vaccine can be developed before the outbreak ends, our estimates suggest that approximately half of the susceptible population would need to be immunized to confer herd immunity. Considering the growing body of evidence linking Zika virus infection during pregnancy to microcephaly in newborn babies, women of childbearing age should be given priority if the option becomes available [4,5].

Regardless of whether a vaccine reaches the market before the outbreak in Colombia ends, the data acquisition and modeling approach presented in this paper may still benefit other Zika-affected countries with limited capacity for government-implemented health care-based data collection. Although traditional surveillance data should be used preferentially, in its absence digital surveillance data can yield comparable estimates for key transmission parameters. It has been shown that digital surveillance data can be used retrospectively to assess transmission dynamics of well-understood pathogens (eg, *Vibrio cholerae*); however, our findings suggest that similar analyses can also be conducted in near real time for emerging infectious diseases [3]. Moreover, the epidemiologic parameters estimates from these analyses may be readily updated as new information emerges, enabling prospective tracking of transmission dynamics at the country level despite data scarcity.

Recent history has shown the need for rapid epidemiologic assessments to better inform intervention strategies in the face of a public health emergency. For effective evaluation of such interventions, baseline estimates for transmissibility—like those described in this study—must be established. Furthermore, changes in outbreak dynamics must be closely monitored in order to assess the impact of active interventions on disease transmission. Our approach offers an important alternative to guesswork based loosely on related diseases and previous outbreaks. Given the absence of traditional surveillance data and transmission heterogeneities across Central and South America, digital surveillance data can and should be used to conduct similar analyses for other Zika-affected countries in the months ahead.

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Conflicts of Interest

None declared.

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Abbreviations

%Vax: percentage of the susceptible population that would need to be immunized to eliminate transmission
d: discount factor
IDEA: Incidence Decay and Exponential Adjustment
I: cumulative incidence
Imax: final reported outbreak size
INS: Instituto Nacional de Salud

MERS: Middle East respiratory syndrome
R0: basic reproductive number
Robs: observed reproductive number
Rt: effective reproductive number
SARS: severe acute respiratory syndrome
SI: serial interval length
SSD: sum of squared differences
tmax: final reported outbreak duration

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Original Paper

Promoting a Hand Hygiene Program Using Social Media: An Observational Study

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Abstract

Background: Hand hygiene is an important component in infection control to protect patient safety and reduce health care-associated infection.

Objective: Our aim was to evaluate the efficacy of different social media on the promotion of a hand hygiene (HH) program.

Methods: The observational study was conducted from May 5 to December 31, 2014, at a 2600-bed tertiary care hospital. A 3-minute video of an HH campaign in 8 languages was posted to YouTube. The Chinese version was promoted through three platforms: the hospital website, the hospital group email, and the Facebook site of a well-known Internet illustrator. The video traffic was analyzed via Google Analytics. HH compliance was measured in November 2013 and 2014.

Results: There were 5252 views of the video, mainly of the Chinese-language version (3509/5252, 66.81%). The NTUH website had 24,000 subscribers, and 151 of them viewed the video (connection rate was 151/24,000, 0.63%). There were 9967 users of the hospital email group and the connection rate was 0.91% (91/9967). The connection rate was 6.17% (807/13,080) from Facebook, significantly higher than the other 2 venues (both $P<.001$). HH compliance sustained from 83.7% (473/565) in 2013 to 86.7% (589/679) in 2014 ($P=.13$) among all HCWs.

Conclusions: Facebook had the highest connection rate in the HH video campaign. The use of novel social media such as Facebook should be considered for future programs that promote hand hygiene and other healthy behaviors.

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KEYWORDS

social media; hand hygiene; infection control

Introduction

Since the World Health Organization (WHO) launched the first global hand hygiene (HH) campaign to protect patient safety in 2005, more than 130 WHO member states and 17,000 health care facilities have committed to improving HH [1]. Traditionally, printed posters were an important component in the multimodal HH-promoting strategies and other healthy behaviors in the work place [2]. However, there is typically no systemic evaluation to quantify how many people viewed printed posters, and changes in HH compliance may be due to the poster or other multimodal strategies to improve HH [3].

We have therefore questioned whether novel methods can be used to engage our health care workers (HCWs) and accurately measure the efficacy of an HH promotion. “Net generation” has been used to describe the generation who grew up in the era of electronic devices and social media [4]. A 2012 report from the Institute for Information Industry indicated that 74.5% of the population in Taiwan uses the Internet [5]. Thus, in addition to poster reminders, we aimed to promote an HH program in our institution via social media.

In Taiwan, the WHO’s HH program was centrally sponsored by the Centers for Disease Control (CDC) of Taiwan from 2009-2011 in three demonstration centers. After that, the program was distributed throughout the nation via HH certification programs [6]. In 2014, the National Taiwan University Hospital (NTUH) highlighted the HH program through a video campaign to remind our HCWs about the importance of HH and was launched on world HH day (May 5, 2014). Three different platforms were used to promote the video [7]: the hospital website, the hospital group email system, and a well-known Facebook site owned by a medical school student of the National Taiwan University (NTU). We compared the efficacy of promoting the HH program on these three different platforms.

Methods

Ethics Statement

This study was approved by the ethics committee of the NTUH. Informed consent was waived under the agreement of the committee (201501083W).

Setting

The NTUH (Taipei, Taiwan) is a university-affiliated medical center with 2600 beds. Alcohol-based hand hygiene equipment has been provided hospital-wide since 2004 [8]. A centrally sponsored HH program was conducted from 2009-2011.

Hand Hygiene Video

The video script was written by one of the authors (PSC) and produced by the FTIG Company (Taipei, Taiwan). The main actors were HCWs in the NTUH. Eight versions of the videos were produced in different languages, including the most common languages in Taiwan (Chinese, Hokkien, and Hakka) and languages commonly used by international patients (English, Japanese, French, Indonesian, and Vietnamese).

The 3-minute video covered three main topics: an introduction to the importance of HH and the commitment of the NTUH, a short drama to demonstrate five different moments for HH, and a dancing section that demonstrated the technique of HH.

Video Broadcast

The videos were uploaded to YouTube on the official site of the Center for Infection Control, NTUH. The videos can be found by searching for keywords such as “National Taiwan University Hospital (NTUH)” and “hand hygiene.” The videos were launched on May 5, 2014. The Chinese version was promoted through three sites: (1) the website of NTUH via an article introducing World HH day, (2) NTUH group email, and (3) the well-known Facebook site of a 6th year medical student at the NTU [7]. This student’s Facebook group, “Clerk: the life as a road blocker,” was started in 2013 and shared the life of a clerk who rotated in the training hospital. The video was shared with a comic who demonstrated the importance of HH on May 5, 2014.

Hand Hygiene Compliance

The method used to determine HH compliance was in accordance with WHO [2]. Covert observation were conducted by trained infection control nurses (ICNs). The HH observation was around 20 minutes in every ward. At least 6 HCWs, including physicians and nurses, were randomly selected. The ICNs would introduce themselves before the observation and give brief feedback right after the observation was completed. The compliance rate was calculated by the number of actual HH actions, divided by the number of required HH actions. The hospital-wide HH compliance rates were gathered and feedback from the chief and head nurse of every ward. HH compliance was checked annually in November, and the compliance rates in 2013 and 2014 were compared.

Statistics

The number of website views was determined by Google Analytics. The connection rate was calculated by the number of video views divided by the users subscribed to the specific platforms and compared by chi square test. A *P* value .05 was defined as statistically significant. The statistical analyses were performed using STATA 11.0.

Results

From May 5 to December 31, 2014, there were 5252 views of the video, mostly of the Chinese version (3509/5252, 66.81%) (see Figure 1). The production cost was US $6250, so the average cost per click during this period was US $1.20.

Figure 1. Screenshot of the video “5 moments for hand hygiene.”.

Efficacy of Three Different Promotions

Among the 3509 viewers of the Chinese version, 53.01% (1860/3509) was female and 46.99% (1649/3509) male. The main age group was among 25-34 years old, which accounted for 34.0% of the viewers. We used three different Internet-based platforms to promote the Chinese version of the video. At the hospital level, the official website of NTUH had 24,000 subscribers, and 151 of them opened the link to the video (connection rate: 0.63%, 151/24,000). A total of 9967 people received the hospital group email, and 91 of them opened the link to the video (connection rate: 0.91%, 91/9967). There was no feedback from the email or website promotions. On Facebook, there were 13,080 clicked to the site, and 807 opened the link to the video. The connection rate for Facebook (6.17%, 807/13,080) was significantly higher than from the other two platforms (*P*<.001 for both comparisons). On Facebook, 525 visitors (525/13,080, 4.01%) clicked on "Like" for the HH campaign and 21 visitors (21/13,080, 0.16%) shared the video (see Table 1).

Table 1. Views and feedback on the hand hygiene video that were traced to different applications.

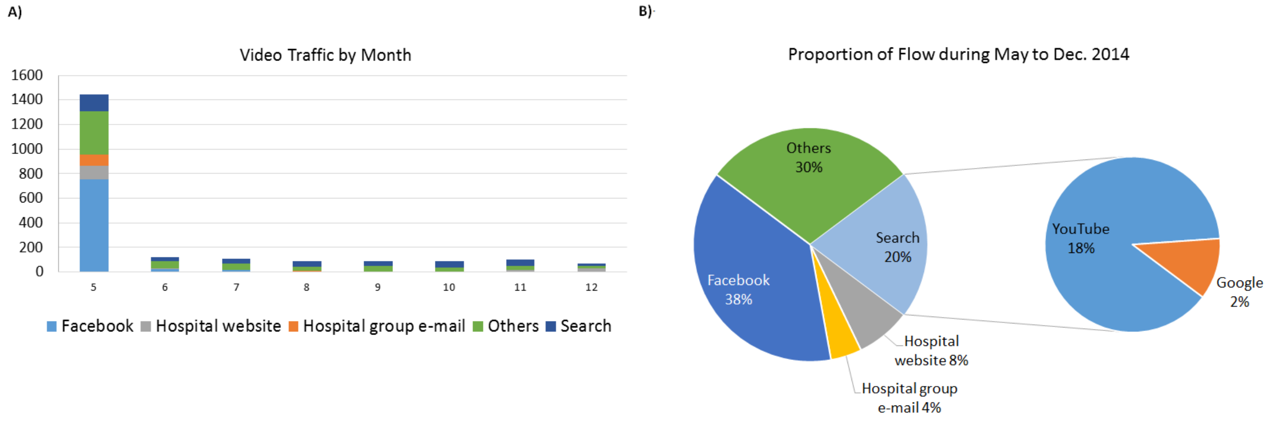
Application	Headlines (total message word counts)	Placement	Users/Visitors	Views	Interaction
NTUH Website	May 5, World Hand Hygiene Day (163)	Link	24,000	151	0
NTUH group email	May 5, World Hand Hygiene Day (163)	Link	9,967	91	0
Personal Facebook site	May 5, World Hand Hygiene Day (45)	Link	13,080	807	524 "liked"; 21 "shares"; 7 "recommends"

Time Series Analysis

On May 5, 2014, a press release was also sent from Public Relations Office of NTUH to 20 local newspaper offices. One e-newspaper reported this message that afternoon and provided the YouTube link. On the first day, except for the direct links to the Chinese version, most viewers were from the Facebook site (n=105), followed by NTUH website (n=19) and hospital group email (n=19), and e-newspaper (n=5). One traditional newspaper reported the news on the following day.

During the following year after the video launched (until Dec. 31, 2014), 69.68% (2445/3509) of the views of the Chinese version of the video were during the first month. After excluding 1259 direct links to the video (which cannot be readily tracked), 38.09% (857/2250) of the views were from Facebook, 7.60% (171/2250) from the NTUH website, 4.31% (97/2250) from the NTUH group email, 29.60% (666/2250) from other sources (eg, YouTube suggestions, e-newspapers, e-magazines), and 20.40% (459/2250) from search engines, including YouTube (407/2250, 18.09%) and Google (52/2250, 2.31%) (see Figure 2). The views of the video via search engines increased from 9.75% (141/1446) in May 2014 to 33.80% (24/71) in December 2014. The average time spent on the video was 2:40 minutes via the Facebook, 2:47 minutes via the NTUH, and 1:28 minutes via the group email.

Figure 2. (A) The number of views of the Chinese version of the hand hygiene video from May 5 to Dec 31, 2014 (views were excluded if the source could not be traced; "Others" included YouTube recommendations, e-newspapers, and e-magazines). (B) Proportion of traffic from different sites from May 5 to Dec 31, 2014.

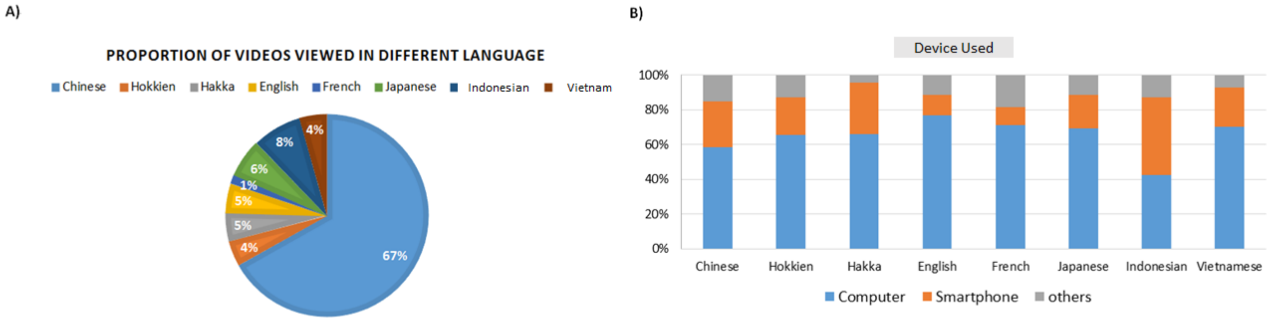


Comparison of Versions in Different Languages

Overall, the video was distributed in 49 countries, and on average, viewers spent 1.57 minutes on the 3-minute video. The Chinese version was the most popular (3509/5252, 66.81%), followed by the Indonesian version (414/5252, 7.88%) (see Figure 3). There were some differences in how different viewers accessed the video. For the English version, 7.4% (18/245) of the views were through Twitter and 1.2% (3/245) through Facebook.

Most visitors used computers to watch the video, except for the Indonesian version where a higher proportion was viewed by smartphone (187/414, 45.2%) than computer (174/414, 42.0%), although not statistically significant (*P*=.36) (see Figure 3).

Figure 3. Views of the hand hygiene video in different languages and with different devices. (A) Proportion of videos viewed in each of 8 languages. (B) Devices used to view the video in each of the 8 languages.



Hand Hygiene Compliance

The hospital-wide HH compliance improved from 83.7% (473/565) in 2013 to 86.8% (589/679) in 2014, although this change was not significant (*P*=.13) (Table 2). Among physicians, the HH compliance improved from 69.0% (69/100) to 81.1% (163/201) (*P*=.02).

Table 2. Hand hygiene compliance before and after the 2014 video campaign.

Compliance	2013, % (n/N)	2014, % (n/N)	*P* value
Total	83.7 (473/565)	86.7 (589/679)	.13
Physicians	69.0 (69/100)	81.1 (163/201)	.02
Nurses	87.9 (350/398)	89.9 (390/434)	.38
Others	80.6 (54/67)	81.8 (36/44)	.87

Discussion

Principal Findings

During the hand hygiene video campaign in 2014, the promotion on Facebook was significantly more successful than promotion on two traditional Internet-based communication tools, that is, the hospital website and group email.

Different marketing strategies have been used in the promotion of HH [9,10]; however, there is a growing influence of social media on health promotion [11]. For hand hygiene, Web-based interventions have been reported to promote hand washing during the flu season among the community [12]. In the health care setting, printed posters were traditionally used as reminders in the workplace [3]. This approach could be extended to the Internet (eg, video clips). The important issue is how to promote videos, instead of passively waiting for them to been seen. In this study, we demonstrated that social media could be a surrogate method to connect to our community of HCWs. Importantly, this new promotion tool allows quantification of the connection rate.

Through quantitative analysis, we revealed that connecting to the HH video is more efficient through Facebook than the traditional hospital website and group email. The difference in connection rate may be due to the fact that shared information among peers is an important influence on behavior [13]. The Facebook site, “Clerk: The life as a road blocker,” was run by a medical school student and followed by 13,080 users. Facebook interaction, including “Likes” and “Shares”, can create further discussion and connect to a greater possible audience. In contrast, the website and email would be more like a broadcast site without a method for further interaction.

In addition to the ability to connect to the right community and create interaction, social media also allows consumption and control, per the social media “4 Cs” (ie, connection, community, context, content) [14]. The word-of-mouth effect in social media, such as “like,” “share,” or “recommend” on Facebook, is controlled by all viewers and by the Facebook owner. We were fortunate to have a partner who received adequate infection control training and could provide professional feedback. However, other important online influencers may not have the same knowledge of infection control. Thus, there is an urgent need for the health care system to take a more proactive role in communicating with the net generation [15]. Thus, we could provide additional information about HH programs besides the video, which was designed to be short and catch viewers’ attention. However, special personnel are needed to create, maintain, and provide timely feedback on social media [16]. We hope that the current study stimulates interest in the analysis of cost and efficacy of using social media to promote infection control.

Of note, the proportion of the video viewers via Facebook decreased after the first month that the video launched. The potential pros of Facebook as rapid information sharing can also be a cons as the message may disappear rapidly. But while we stored the video campaign on the Infection Control Center’s YouTube site in December 2014, 34% of the traffic to the video was via search engine (eg, Google, YouTube). Thus, since search-engine optimization has been an important marketing tool [17], simple and frequently used keywords need to be planned early before launching a campaign.

Also from the point of view of marketing, the efficacy of a social media campaign would be considered as the return on investment (ROI). However, health care is different from commercial operations and online merchandise, so we cannot provide a traditional ROI as “cost per acquisition.” However, we calculated the equivalent cost per click as US $1.2, and this is within the average cost of online advertising [18].

There may have been some regional differences among our viewers. According to our analysis of the eight different versions of video, we found that those who viewed the Indonesian version had greater utilization of smartphones. This is consistent with the findings of a 2013 national survey in Taiwan, which found that new immigrants were more likely to own a smartphone than a computer (82.5% vs 61.4%) [19]. Thus, for future marketing of HH videos, we suggest that the material be tailored to suit the needs of different viewers and the characteristics of different electronic devices (eg, length of the video, formatting).

Limitations

A limitation of our study would be that HH behavior may be influenced by other interventions at the same time. In Taiwan, the national HH program was promoted by CDC, Taiwan, in 2012. There were no other concurrent interventions for HH after that within the institution. The HH compliance was also measured by professional ICNs, and objective compliance rate was used for evaluation.

Another limitation of this study is that we did not examine the use of multiple social media platforms. In particular, different geographical regions tend to prefer different social media sites, as is the case with Facebook and Myspace [20]. Surprisingly, the video had been distributed to 49 countries. Even though this effect may beyond the scope of this study, we are aware that video campaigns via novel social media can reach even larger populations beyond geographic boundaries. As Twitter had been used more frequently than Facebook in our English version, other social media platforms could also be considered for marketing an HH program, such as Twitter, blogs, mini-blogs, Instagram, Tumblr, Google$^+$, and Vimeo. Future research could focus on regional differences in the use of different social media websites.

Conclusions

Bernoff et al stated that social media “is a phenomenon of people connecting with each other and drawing strength from each other” [21]. This echoes the long-term goal of the HH program to empower our patients and create a safe environment in health care facilities. We expect that use of novel social media websites may play useful roles in the promotion of HH programs. Thus, starting a blog, building an online infection control community, or creating a dedicated Facebook page will allow us to engage more people and increase HH awareness.

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Conflicts of Interest

None declared.

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Abbreviations

CDC: Centers for Disease Control (Taiwan)
HCWs: health care workers
HH: hand hygiene
NTU: National Taiwan University
NTUH: National Taiwan University Hospital

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Notes from the Field

Considerations for Public Health Organizations Attempting to Implement a Social Media Presence: A Qualitative Study

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Abstract

Background: In the past decade, social media has become an integral part of our everyday lives, but research on how this tool is used by public health workers and organizations is still developing. Budget cuts and staff reduction in county departments have required employees to take on more responsibilities. These reductions have caused a reduction in the time for training or collaborating with others in the field. To make up for the loss, many employees are seeking collaboration through social media sites but are unable to do so because state departments block these Internet sites.

Objective: This study sought to highlight the key considerations and decision-making process for a public health organization deciding whether to implement a social media presence for their organization.

Methods: Using 3 structured interviews, 15 stakeholders were questioned on their personal experience with social media, experience within the context of public health, and their thoughts on implementation for their center. Interviews were coded using constant comparative qualitative methods.

Results: The following themes emerged from the interviews: (1) personal experience with technology and social networking sites, (2) use of social networking sites in public health, (3) use of social networking sites in work environments, (4) social networking sites access, (5) ways the Rural South Public Health Training Center could use social networking sites, and (6) perceived outcomes of social networking site usage for the Rural South Public Health Training Center (positive and negative).

Conclusions: The collective voice of the center showed a positive perceived perception of social media implementation, with the benefits outweighing the risks. Despite the benefits, there is a cautious skepticism of the importance of social networking site use.

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KEYWORDS

public health; social networking sites; professional development; training centers; Facebook; Twitter

Introduction

This research study was conducted with a focus on the Rural South Public Health Training Center (RSPHTC), a collaborative effort originally between the University of Florida (UF) and the Florida Agricultural and Mechanical University (FAMU). The training center's mission is to train public health workers with special emphasis on rural settings and human immunodeficiency virus/acquired immune deficiency syndrome (HIV/AIDS). A review of this training center's website, and the 37 others nationwide, reveals that 20 currently have a social media presence using Facebook; 5 of those maintain a Twitter page. Currently, these centers primarily use social media platforms for advertisement of center and community events, as well as offering links to other resources and research for specific areas of specialty.

This study provides an overview of factors common to many organizations related to the implementation of social media. While the term social media is often generally used in reference to Twitter and Facebook, a more specific term for this communication category is social networking sites (SNSs). SNSs are defined as Web-based services that allow individuals to (1) construct a public or semi-public profile within a bounded system, (2) articulate a list of other users with whom they share a connection, and (3) view and transverse their list of connections and those made by others within the system [1]. What makes these sites unique is not only that users can meet people they do not personally know, but that they are able to see and show their network [1].

For the purpose of this study, the focus on SNS centered on Facebook and Twitter due to their popularity. Like various SNSs, Facebook requires individual accounts; users have the ability to modify these accounts, ultimately affecting their potential contacts based on how they create their profile. Twitter is a micro-blogging SNS that has gained popularity in limiting users to write messages in 140 characters or less. Twitter, by allowing users to place a hashtag before a term creating a new searchable topic, has become valuable for professionals who want to network with people in their field and see specific topics regularly updated [2]. While Twitter has only been online since 2006, there is already growing research on its use in public health and by public health organizations [3]. Twitter users have demonstrated use by following health conferences, a developing health story, or learning new sources and Web links for future research [4]. Because of the internal system, using a hashtag, users can highlight specific words in their post that allow for grouping of posts. Thus, users can sort through all posts related to these words, which can help point them in new related directions of searching. The World Health Organization (WHO) used Twitter during a recent health scare, as the hashtag “H1N1” had nearly 12,000 followers [4]. This allowed WHO to update 12,000 people in addition to those to whom the information was forwarded every time there was news to report. Through a May 2013 search, the Centers for Disease Control and Prevention had over 162,000 Twitter followers, and a subgroup at one point had over 400,000 tweets.

Another important theme for one to consider, related to public health workers using SNS, is access. While much research highlights potential applications of SNS in public health, the subject is diminished when considering the access to, or lack thereof, this information to public health workers [5]. Recent budget cuts have halted opportunities for conferences and travel for further educational opportunities [6]. Budget cuts, as well as staff reduction of some county departments in Florida, place stress on the system and communities. Employees are now taking on more responsibilities and tasks beyond their scope of expertise, further reducing their time for training or collaborating with others in the field. These factors, and others, are pushing more formal and informal training online. Pursuing informal professional development through SNS, however, can be difficult as many state health departments, including Florida, block these sites on their Internet filters. The aim of this study was to record the decision-making process for a public health organization as it considered the implementation of social media to advance the center’s goals and mission, by focusing on the perspectives of varying stakeholders within a public health training center, in order to provide considerations for administrators/organizations when deciding to implement a social media presence.

Methods

This research study was conducted within a case-study model focusing on the RSPHTC’s potential implementation of a social media presence and followed a model of diffusion [7-9]. Rogers’ diffusion model has numerous aspects and perspectives, many of which provided the theoretical framework for this study. The diffusion of innovations theory is one that seeks to explain how, why, and at what rate new technology and ideas spread through a culture [7]. In essence, diffusion can be defined as a process in which a new innovation is communicated through a certain period of time, through various channels, among a social system [7]. Primarily, the diffusion model looks at 4 characteristics related to the diffusion of an innovation: elements of the innovation, types of decisions, the adoption process, and characteristics of adopters.

This project focused on the potential implementation of social media by the RSPHTC. Interviews of various stakeholders provided an account of the variables considered throughout the process. The interview questions were set in an interview guide created through instruments highlighted in the *Interview Guide Approach* [10]. The interview guide was created to more fully understand the knowledge, perceptions, and processes used by the RSPHTC regarding SNS implementation, in accordance with the framework of Rogers’ diffusion of innovations model. A total of 3 interviews were set up with each individual, recorded, and later transcribed verbatim, as described by the *Interview Guide Approach* [10]. The focus of the first interview is getting acquainted, developing rapport, and laying out the area that the researcher would like the interviewee to explore [11,12]. Between the first and second interview, the participant has had time to think more deeply about the experience, and, thus, the second interview is more focused and allows time to explore the experience in depth [11,12]. In the third interview, the researcher asks follow-up questions to fill in and clarify the account of the first 2 interviews, and the participant can add newly remembered information prior to moving on to new information [11,12]. Each interview was conducted face-to-face and recorded by the same individual (MH).

In applying Rogers’ diffusion model to the RSPHTC social media study, the interview questions were grounded thoroughly. The researcher asked questions related to all aspects of the innovation that could be considered by the stakeholders. The focus of these respective interviews with decision stakeholders included their definition and perceptions of social media, determining social media usage in public health, consideration of how social media can affect those within public health, and gauging perceived positive and negative implications for the implementation of social media for the center. Decision makers were chosen as the focus of this study because they are the individuals that would choose if public health workers could use social media or not.

Recruitment

This study followed the experiences of 15 stakeholders in the RSPHTC's decision-making process of considering social media implementation. To be interviewed, participants had to meet all three of the following inclusion criteria: (1) being members of the RSPHTC's management team or advisory board, (2) representing the 2 universities on the training center grant, and (3) being members who were given the responsibility to control day-to-day operations, or consult those making day-to-day decisions for the center (advisory board).

We recruited 15 subjects to participate in this investigation, by personal requests through email. These 15 members represented advisory board members and senior public health researchers and administrators at UF and FAMU. As the RSPHTC is a smaller organization with easily identifiable members prominent in the field of public health and university administration, extra effort was made to hide the specific identities of the participants in this study. In using a singular bound case, however, all thoughts of the SNS decision makers for the center were contained and reflective of the group. Collecting the final responses and sharing them without identifiers allowed the participants to speak more freely on the questions related to SNS implementation, its place within public health, and potential technology blocks imposed at the state and county levels. Each interview was coded into respective themes by trained qualitative researchers (MH & SHT).

Statistical Analysis

The results section of this study examined the replies of the stakeholders as a whole and separated the interview responses by themes, not by participant.

In total, 15 participants were interviewed three times each, for a total of 45 interviews. Each interview was transcribed and then coded using qualitative methods. To enhance the reliability of the coding process, 2 trained qualitative researchers both coded 3 interviews together to establish an initial code book, and then individually coded the entire set of interviews. At the conclusion of the initial data analysis, the researchers then compared their results, working the data from codes to larger themes.

While there are various methods within qualitative research to analyze data, the format used in this study was the constant comparison method. By using the constant comparison method of analysis, data can be reduced into manageable units and coded information. This method of analysis starts with examining the raw data, looking for key words across all interviews, and grouping segments of the responses into categories. From there, this method can be categorized into 4 states: comparing incidents applicable to each category, integrate categories and their properties, delimiting theory, and finally writing the theory or narrative [10]. What makes this method unique is that it is a continuous growth process, as each stage transforms itself into the next, while previous stages remain in operation throughout the analysis.

Results

Through the use of qualitative methods, the interviews with the RSPHTC stakeholders revealed six main themes in their responses: (1) personal experience with technology and SNS, (2) use of SNS in public health, (3) use of SNS in work environments, (4) SNS access, (5) ways the RSPHTC could use SNS, and (6) perceived outcomes of SNS usage for the RSPHTC (positive and negative).

Personal Experience With Technology and Social Networking Sites

In reviewing the interviews of the RSPHTC decision makers, there was a vast spectrum of personal SNS usage demonstrated. Prior to specifically discussing SNS usage and public health, various questions helped form a baseline of the stakeholders' collaborative knowledge and usage of technology in general. For the most part, many of the participants in Interview 1, when asked about what technology they use on a daily basis, listed the telephone, their desktop computer, and email as specific programs used. When asked about the technology they use in their job, 2 listed their phone, 4 listed their computer, and all 5 specifically mentioned email. One participant, when asked what program she used most on her computer, stated, "Just tons of email and some Word documents and that kind of stuff, I probably spend 2 hours a day just responding to emails." Another participant agreed and added, "Each day it takes me until lunch time to respond to all of my emails and phone calls. That is just how people communicate in public health." Another aspect of technology often mentioned in the interviews related to specific programs used in teaching, as many of the RSPHTC stakeholders and administrators are also professors.

One stakeholder interviewed seemed to be very passive about SNS in general and made numerous comments about the time needed to maintain a regular presence. Different than others interviewed, who often spoke on how using SNS helped them make connections and allowed them to communicate with others on their schedule, this stakeholder expressed that participating in SNS could be work and almost feel like "an obligation." This participant, when asked about personal SNS usage, stated "well, that's an interesting question because everybody around me uses them and they friend me, or they link me." She continued by clarifying her usage as, "I'm like 90% passive in my use because I just don't have the time to be active. It also does not really fit my personality to be actively putting things out there about myself." Ultimately this public health professional seemed content with the status of her friendships and how she communicates with the people in her life and primarily saw SNS as a barrier to friendships and not as a tool to make these connections stronger or more convenient.

In sum, the questions from Interview 1 that probed how the RSPHTC stakeholders use SNS in their personal life resulted in a varied mix of responses showing their collaborative commitment and indifference. Several people interviewed seemed to rely on SNS as a way to stay in touch with friends, past and present. Other people who were interviewed did not seem to be motivated to try and keep up with this growing social medium, content with how they currently communicate with others. Another set of comments, which revealed itself within this theme, related to participant questions on what exactly quantifies participation. Several of the stakeholders offered that they sometimes go onto SNS to look at pictures, see what friends and relatives were doing, but often not posting themselves or accepting the friend requests proposed. It can be said, however, that the RSPHTC decision makers all seemed familiar with SNS and their features. Furthermore, most were able to identify specific SNS by name, most citing Facebook, Twitter, and LinkedIn.

Use of Social Networking Sites in Public Health

In examining the responses of the RSPHTC workers from Interview 2, with regard to how they use SNS at work and within the field of public health, the answers were often difficult to distinguish between general public health and their personal work advancement. For the most part, many of the responses aligned to the stakeholders sharing how they make connections in the field of public health or their field of academia with SNS versus how to use, or teach how to use, the tools to directly help public health initiatives. The majority of answers described usage as participating in alumni groups, networking with known others who have similar sub-interests in public health, and overall professional development. There also seemed to be a connection of usage in a professional context, with personal usage, as those who incorporated SNS use into their daily lives with friends and family tended to be more determined to implement SNS for the center. The need to keep up with professional development, however, seemed to be a motivator for all, even for those who had previously answered personal use questions with responses indicating their natural tendency to be passive or indifferent to SNS usage. Primarily responses from Interview 2 could be broken down into people describing how they use SNS in the field and ultimately how it compares to the current methods of public health workers' professional development.

In addition to using SNS as a means to communicate with students and known colleagues, the RSPHTC stakeholders also addressed how they perceive these tools as a forum to interact with others in the field. Most (13/15) of the interviewees stated that they had never followed or tried to connect with someone in the field of public health that they did not already know personally. When wanting to see the work of another professional in the field, for the most part, they would just research their efforts on Google, read about new ideas in academic journals, or watch YouTube and webinar presentations. None of the participants had used a microblogging site, like Twitter, to follow an unknown person in public health. The concept of "following" an unknown person, on a professional or personal level, seemed to be a large deterrent for using a site like Twitter by everyone interviewed. Only 1 person questioned actually used Twitter, but she claimed to deliberately avoid public health discussions and professionals and follow only personal friends. She clarified by stating "When I'm on Twitter, that's kind of like my time. I'm really not focused on work or public health issues so to speak…I mean public health is part of my life all day long, but when I'm on Twitter at night I'm trying to kind of relax."

Use of Social Networking Sites in Work Environments

As the discussion turned from describing the general role of SNS in the field of public health toward how the RSPHTC could specifically use these sites to help public health workers, a theme of general work environment usage of SNS emerged. Most of the stakeholders interviewed, prior to considering how the RSPHTC could use these tools, shared their thoughts on the access, or lack of access, public health workers have to SNS. Many discussed the imposed block of SNSs through the state (Florida) public health network, which provides Internet access to county health departments, as a way to flush out their thoughts on how the RSPHTC might approach SNS implementation. Having limited access to the intended target audience during their work time seemed to cause a wide spectrum of thoughts on the value of creating an SNS presence. This discussion also, for several interviewed, touched on the subject of smartphones and their role during the workday for public health employees.

Social Networking Site Access

While some interviewed commented on how they did not want to discuss the state's ban of SNSs, often because they did not know enough of why the ban was there to begin with, others were willing to talk about it directly. One stakeholder interviewed made her opinions clear by saying "I think it should be lifted because I do think, more and more, there's a lot of good information that's out there on social media." She went on to elaborate that the ban "makes it tough on public health workers to stay up-to-date, as many do not want to look at these sites once they get home." This comment continued an ongoing theme others had mentioned in various ways, on questioning the interest level of public health workers to use their own time to use SNS in a professional way. Another person interviewed explained "public health workers are not like teachers, where their classroom is their domain, they just do what the state, or county tells them." Several others interviewed also alluded to the fact that many public health workers do not have the freedom to do things "their way" but rather need to stick with a scripted response so the public is often hearing 1 universal message.

As the discussion on whether state or county public health workers should have access to SNS during the workday continued, the perceived pros and cons emerged. One person interviewed stressed that getting information through SNS is in line with what people use every day. She stated "I think it's good technology, technology people are used to, and so it's really important they should be able to access information in that way." This same participant continued with her thoughts on potentially using SNS as a message board by public health workers willing to collaborate, or internally for a public health organization as a whole. She explained "these sites save time in the day so if you can just use them, go back and forth and have that collaboration, it makes it easier than trying to get a meeting together."

A tangential issue to access of SNS while at work, which was repeated by the majority of RSPHTC stakeholders interviewed, was the use of smartphones by employees. For many, the net outcome of this way of using the SNS (blocked computer for work and a smartphone for personal usage) resulted in not allowing for the positive aspects of SNS usage, while also not removing the potential negative aspects of SNS use by employees. One person explained that she used her smartphone at work on a “limited basis.” She said that she used the phone “sometimes for work, where I text people, or look up something in a meeting.” She also added, however, that “sometimes I use it to check my Facebook, personal email.” When asked how proportionate the times are between personal and professional usage, she laughed and said “oh, probably 80% personal.” When asked another follow-up question for her opinion of this usage related to work efficiency, she said “Yeah, I do not know if I would like it for the people who work for me, to do the same but I guess they do.” She continued by adding “it is just the way it is, we now all have supercomputers in our pockets.”

Ways the Rural South Public Health Training Center Could Use Social Networking Sites

When compiling the interview responses from Interview 3, which directly paired SNS and the RSPHTC, the vast majority of comments reflected that the RSPHTC stakeholders see this tool as a means for marketing and showcasing center activities. Currently, the website displays announcements of new educational sessions, courses, deadlines, and upcoming events. This website, however, does not have the ability to pop up new information on a stream like Facebook or Twitter, where people get newly updated information. To currently obtain the center’s announcements and marketing efforts, public health workers and community members would have to actively choose to check the website. The website does, however, have a feature allowing for people to sign up for email messages when new posts are made; however, to date no one has signed up for this feature.

Prior to describing perceived positive and negative outcomes for SNS usage, many also touched on logistical issues related to resources needed to properly manage SNS. When considering how the RSPHTC could set up SNS for long-term success, a great disparity arose between the 2 sites most referenced, Facebook and Twitter. Facebook, for many, was a tool that could be more controlled and would allow for attention given to a smaller group of people who are more closely affiliated with the center. Twitter, however, was seen as a tool that could potentially introduce the center to a larger audience but required a much more active participation and commitment. The difference of opinion for these 2 sites also reflected differences within the group on whether the mission of the center was to primarily focus on the regional aspect of training Florida public health workers with HIV/AIDS education or in its larger role as a national training center available to anyone online.

Perceived Outcomes of Social Network Site Usage for the Rural South Public Health Training Center

As RSPHTC stakeholders considered the impact of SNS usage (see Table 1) in Interview 3, the majority of responses continued to reflect the positive themes of marketing opportunities as well as using those efforts to reach certain younger demographics. A third and fourth subtheme that surfaced reflected the stakeholders’ positive impressions of the cost and ease of use of these sites. Finally, and usually only when asked specifically, some people interviewed considered the SNS that the RSPHTC could construct as a platform for public health workers to collaborate with one another in a formal and informal way.

While the RSPHTC decision makers were able to list several potential positive outcomes for tangible SNS usage now, or in the future, the responses for possible negative outcomes often reflected the fear of the unknown. Answers that reflected a specific negative condition created by SNS usage were rare; however, many of those interviewed seemed very concerned that perhaps they were missing an angle they had not considered. Supporting this mind-set, many people during their responses to these questions made mention of wanting to educate themselves more on how other training centers are using this model. Furthermore, there seemed to be a cost analysis for many in considering how many positive occurrences there need to be to balance out a potential negative occurrence that would reflect badly on the center or the 2 sponsoring universities. In the end, the set of questions from Interview 3 asking the RSPHTC decision makers to differentiate between the positive and negative outcomes resulted in more tangible responses for positive outcomes and a smaller sample of often fear-based answers for possible negative ones. This is not to say, however, there were no identifiable negative outcomes, as some mentioned concerns related to time, resources, inappropriate comments, and privacy.

Table 1. Most frequently mentioned positive and negative outcomes of SNS implementation perceived by RSPHTC stakeholders positive.

Positive	Negative
Marketing opportunities, for both public health workers and community members	Privacy
Reaching younger demographics	Dedicated resources for managing
Low cost	Stigma (related to HIV/AIDS focus)
Ease of use	Low level of discourse
Act as website portal	
Facilitate collaboration between public health workers or patient groups	

Discussion

Principal Results

As stated throughout this study, the opportunity to research an ongoing decision-making process, of very accomplished and distinguished public health professionals, is one many people within and outside the field of public health can learn from. Organizations that are not as well staffed, do not implement SNS usage, or do not have the experience of these professionals interviewed can be given a head start on the background of this innovation, as well as a long list of potential positive and negative ramifications to consider. For those who are advocates of social media, the worries of those who have not chosen to implement this for their organization can also be helpful as they can see perceived barriers whether they are accurate or not. This study, whether read from the perspective of the public health worker, administrator, or someone at the state health department level, illuminates issues that have not often been discussed beyond personal conversations. To date, however, the RSPHTC has chosen not to implement a social media presence, due to a lack of resources from cutbacks in the grant money funding the project.

Comparison With Prior Work

Public health organizations are slowly beginning to adopt the use of SNS. Analysis of SNS use shows that health departments and other public health organizations mainly use SNS as a way to disseminate health tips and information as well as information about specific organizations and events [13-18]. Unlike the current research, this study goes beyond the analysis of types of messages used on SNS and examines public health organizations' decision-making processes on whether or not to adopt SNS.

Limitations

The study examined only the SNS decision-making process at a single organization (RSPHTC); however, these 15 individuals are highly accomplished and experienced in their fields, making these results more broadly generalizable.

Conclusions

From the researchers' experience through all their conversations with individuals in public health, RSPHTC stakeholders, managers from counties throughout Florida, and those in the state health department who gave their time and official comments, there seems to be a lack of motivation and forum to have an open discussion on SNS implementation in the field of public health. Blocking aspects of the Internet for professional working adults, charged with protecting the public well-being of our entire society, is a significant philosophical issue. While removing the filter could potentially allow for computer viruses through the network, or employees making comments that reflect poorly on an organization, the fact is that many other fields and organizations have found ways to deal with these similar obstacles. However, pushing for more ways to incorporate SNS in the field of public health would not be as necessary if the majority did not see a need or did not want implementation. Having said that, the majority of people we interviewed seemed excited about the potential applications and often characterized the use of SNS as inevitable, making the lack of motivation for discussions moving the process along unclear. While there appears to be an environment of people discussing the Internet block among themselves, there seems to be a lack of open discussion with those at the state level. At this point, the potential implementation of more SNS use in public health stands at a tipping point, full of possible ways of application, further collaboration, and marketing and educational opportunities, but it lacks a singular voice with the ability to move the debate toward new policy. Hopefully, this study can create a foundation for many in the field to understand the current state of SNS in the field, as well as give a composite overview of many of the varied mind-sets on this innovation.

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Conflicts of Interest

None declared.

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Abbreviations

FAMU: Florida Agricultural and Mechanical University
RSPHTC: Rural South Public Health Training Center
SNS: social networking sites
UF: University of Florida

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Original Paper

Understanding Digital Technology Access and Use Among New York State Residents to Enhance Dissemination of Health Information

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Abstract

Background: Many state and local health departments, as well as community organizations, have been using new technologies to disseminate health information to targeted populations. Yet little data exist that show access and use patterns, as well as preferences for receiving health information, at the state level.

Objective: This study was designed to obtain information about media and technology use, and health information seeking patterns, from a sample of New York State (NYS) residents.

Methods: A cross-sectional telephone survey (with mobile phones and landlines) was developed to assess media and technology access, use patterns, and preferences for receiving health information among a sample of 1350 residents in NYS. The survey used random digit dialing methodology. A weighted analysis was conducted utilizing Stata/SE software.

Results: Data suggest that NYS residents have a high level of computer and Internet use; 82% have at least one working computer at home, and 85% use the Internet at least sometimes. Mobile phone use is also high; 90% indicated having a mobile phone, and of those 63% have a smartphone. When asked about preferences for receiving health information from an organization, many people preferred websites (49%); preferences for other sources varied by demographic characteristics.

Conclusions: Findings suggest that the Internet and other technologies are viable ways to reach NYS residents, but agencies and organizations should still consider using traditional methods of communication in some cases, and determine appropriate channels based on the population of interest.

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KEYWORDS

media; New York; Internet; health information; eHealth

Introduction

Interventions using digital technologies to improve health, known as eHealth interventions, have become a topic for theoretical discussion and practical application as an effective way to improve or enable health and health care among diverse populations [1-3]. Digital technology, especially the Internet, has become an increasingly popular health intervention tool because of its easy access on a variety of devices (ie, laptops, mobile phones, tablets) and is now a common resource to disseminate and find health information [2,4].

Recent statistics indicate that most people use the Internet [5,6]. In 2013, the Pew Research Center Internet Project Survey reported 85% of adults ages 18 and over are Internet users [5]. However, despite widespread use, variations by age, educational status, and household income remain [6]. National data show that mobile phone use has greatly expanded as well. Recent statistics show that 90% of adults in the United States own a mobile phone, and just more than half (58%) of Americans own a smartphone [7]. Nationally, smartphone ownership is most prevalent among 18-29 year olds (83%) and among those with higher education and income levels [7], which parallels Internet use. The rise in Internet use and smartphone ownership has also led to an increased use of social media (73% of online US adults [8]).

A number of health programs in recent years have used technologies such as text messages and smartphone apps [9,10], and several health interventions have incorporated social media channels [11-13]. Although data on Internet and mobile phone use is widely available at the national level, few states have attempted to collect information at the state level. Many media campaigns and programs that disseminate health information rely on the Internet, mobile phones, and social media channels to provide messages and information at the state level. In order to determine the tools and channels that are most effective in reaching target audiences, it is necessary to understand whether national patterns are representative of media and technology use at the state level and how access and usage may vary among subgroups of the state population.

Working with both internal and external partners, the New York State Department of Health protects the health, productivity, and well-being of all New Yorkers. Of strategic importance is improving the quality and availability of data. Central to this effort is the need for more reliable information about technology use pertaining to the increasingly diverse populations of New York State (NYS). To this end, the New York State Department of Health Office of Minority Health and Health Disparities Prevention (OMH-HDP), in partnership with the University at Albany School of Public Health and Bassett Research Institute, developed the New York State Media and Technology Use Survey study. The aim of the survey was to describe technology use, health information-seeking patterns, and preferences for receiving health information among a sample of NYS residents with oversampling of rural and Hispanic/Latino populations to facilitate future analyses of these subgroups. These subgroups are priority populations to OMH-HDP due to disparate health outcomes and a need to develop and disseminate effective health messages. The analyses for this paper focus on the overall sample of NYS residents; more detailed analyses of the rural and Hispanic/Latino respondents are presented in separate publications [14,15]. In this paper, we address the following questions:

1. What is the level of access to digital technologies, including computers, the Internet, cell phones, smartphones, and texting?
2. What is the frequency of use of various media channels, including email, search engines, online newspapers/magazines, social networking sites (SNS), online videos, video chat, Twitter, online bulletin boards (ie, Pinterest), text messaging, and smartphone apps?
3. What channels are preferred for receiving health information?
4. How do the answers to questions 1 through 3 vary by education, age, sex, ethnicity, race, income, and geographic area?

Methods

The New York State Media and Technology Use Survey is a cross-sectional telephone survey of a sample of NYS residents, ages 18 years and older. It was created to assess the media and technology access and use of NYS residents, along with health information seeking patterns and preferences. Siena Research Institute (SRI), a public opinion research center that conducts surveys, was hired for data collection. Interviews were conducted via a landline or mobile phone with English and Spanish language options available. Trained interviewers collected data by using the computer assisted telephone interviewing system to conduct telephone interviews. The survey was conducted from August 8 through November 4, 2013, and took about 10 minutes to complete. Institutional review board approval was obtained through the University at Albany Office of Regulatory and Research Compliance. This study was considered exempt from full review.

Sample

SRI purchased phone number lists generated using a random digit dialing methodology from Survey Sampling International. Random digit dialing was used for the landline sample to ensure selection of both listed and unlisted telephone numbers, whereas the mobile phone sample was retrieved from dedicated wireless telephone exchanges from within NYS. To ensure a sufficient number of rural respondents, a component of the landline sample targeted the 24 NYS counties not situated in a Metropolitan Statistical Area. Oversampling of Hispanic/Latino respondents was accomplished through a similar targeted random sampling of landlines in census tracts with at least a 20% concentration of Hispanic/Latino residents. Some rural and Hispanic/Latino respondents were also identified in the statewide samples of landlines and mobile phones. The sampling plan from these multiple frames produced a study population of 1350 adults, with 483 identified through their mobile phones.

Measures

The survey asked for demographic information such as geographic area (ie, city/urban, suburban, rural), age, race, ethnicity, sex, education level, employment status, income, number and ages of children, health insurance coverage, and number of doctor visits within the last year. Categories created for race were: White, Black/African American, Asian (ie, Asian Indian, Chinese, Filipino, Japanese, Korean, Vietnamese, Other Asian, Native Hawaiian, Guamanian or Chamorro, Samoan, and Other Pacific Islander), and Other/Multiple. For analyses, Asian categories were combined, and respondents who chose other or multiple categories were compiled into one group. For income, a not sure/missing category was created for respondents who refused to answer or were not sure. For other variables, refusals were changed to missing.

Questions on media and technology access and use included the number of working computers in the home, type of Internet access on these computer(s) (ie, dial up, high speed), whether respondents had cellular service throughout the past year, if they had a plan with unlimited texting, whether the phone was a smartphone, and on what device they typically access the Internet. If respondents reported not having Internet access or a mobile phone, or not using the Internet, a follow-up question was asked to establish the reason. Respondents with Internet access were then asked about Internet use and their frequency of use for a variety of Internet and phone-related activities. All respondents were asked the following: "How often do you do each of the following activities? Do not include times you spend doing these activities as part of your job or school." A range of activities was provided, such as sending or receiving email, using a search engine, using the Internet to read newspapers/magazines, visiting a SNS site, watching or uploading a video, using video chat, participating on Twitter, using an online bulletin board like Pinterest, receiving or sending a text message on a mobile phone, or using an app on a smartphone. Answer choices were: several times a day, once a day, several times a week, once a week, less than once a week, and never.

The following question was developed to assess respondents' preferences for receiving health information: "This survey is not providing any health information, but if an organization like the Department of Health wanted to provide health information to people in your community, how would you prefer getting the information? For each way of getting the information, rate your level of interest as low, medium, or high." The channels of communication to rate were: in-person meeting/workshop, mail to your home (eg, brochure), mobile phone app, text message on a mobile phone, website you could go to, email, social media (ie, Facebook), television, and radio. Channels were rotated in order to avoid any bias related specifically to the order of responses. A transition statement earlier in the survey where questions about health information began stated: "By health information, we mean information about health topics such as exercise, nutrition, immunizations, and where to find a health provider. We do not mean information about the treatment of specific medical conditions."

Analysis

Due to the complex sampling strategy, a weighted analysis was conducted utilizing Stata/SE (StataCorp, College Station, Texas). For this sample, weights were derived to adjust for the sampling procedures, which led to some individuals having greater or lesser probability of being included in the survey. A second stage of weighting was used to adjust the distribution of the sample's socio-demographic characteristics to match the characteristics of the population of NYS residents age 18 and over. Data were weighted for age, sex, region (ie, Upstate New York, Suburban New York City (NYC), NYC-Metro), rural status, race, ethnicity, education, and mobile phone status. Many respondents did not report income; therefore, data were not weighted for income. Chi-square tests were used to compare respondent groups through bivariate (unadjusted) analyses for key demographic variables: education, age, sex, ethnicity, race, income, and geographic area. Ordinal logistic regression and logistic regression were also used to run adjusted models with all demographics accounted for.

Results

Table 1 presents demographic data for the NYS sample in comparison to all NYS residents. The unweighted sample represents those who participated in the survey, while the weighted sample adjusts for the complex sampling design and also allows for inferences to be made to the general population of the state.

Table 1. Key demographics for the sample of New York State respondents (n=1350).

Demographics		NYS Demographics	Unweighted Sample (actual percent surveyed) N (%)	Weighted Sample (weighted estimates)
Education [16]				
	High school grad or less	41%	434 (32)	35%
	Some college/vocational degree	28%	366 (27)	31%
	College graduate or more	31%	537 (40)	35%
Age [17]				
	18-29	22%	289 (22)	23%
	30-49	36%	334 (25)	36%
	50-59	18%	248 (19)	17%
	60 or over	24%	455 (34)	25%
Sex [17]				
	Male	48%	594 (44)	48%
	Female	52%	751 (56)	52%
Ethnicity [18]				
	Hispanic, Latino/a, or Spanish origin	18%	412 (31)	17%
Race [18]				
	White	66%	836 (66)	65%
	Black/African American	16%	162 (13)	16%
	Asian	7%	71 (6)	8%
	Other/Multiple	11%	204 (16)	10%
Household Income [19]				
	Less than $25,000	24%	352 (26)	26%
	$25,000 to $49,999	21%	242 (18)	18%
	$50,000 to $74,999	17%	156 (12)	12%
	$75,000 or more	38%	301 (22)	23%
	Not sure/Missing	N/A	299 (22)	21%
Geographic Area [20]				
	City/Urban	88%	628 (47)	56%
	Suburban	(with urban)	272 (20)	33%
	Rural	12%	435 (33)	11%

Research Question 1: What is the level of access to digital technologies, including computers, the Internet, cell phones, smartphones, and texting?

A substantial portion (82%) of the sample reported having at least 1 working computer at home and of those, 1090 answered the follow-up question about whether they have Internet access on home computers; 91% reported having high-speed Internet, and only 19 (2%) respondents answered no.

All respondents were asked about their personal use of the Internet; 85% reported using the Internet at least sometimes. Of those, 53% reported using the Internet several times per day. While using a computer or tablet at home is the main way people reported usually accessing the Internet (62%), 29% indicated they use their cell phones to access the Internet. Respondents with lower education (P=.04), or who were younger (P<.0001), non-white (P<.0001), or nonrural (P=.006) were more likely to report using their mobile phone as their main way to access the Internet. A number of respondents (n=221) stated they never use the Internet for personal use (not related to school or work). For these respondents, the most common reasons for not accessing the Internet were: no interest in it (37%), no Internet access (17%), and feel that it is too hard to use (10%).

Overall, mobile phone ownership was very common with 90% of respondents indicating they had a mobile phone. Among the respondents who reported owning a mobile phone (n=1197), 63% had a smartphone, 79% had unlimited texting, and 8% did not have cellular service throughout the entire year.

In response to Research Question 4, computer and mobile phone access were compared by key demographic characteristics. Table 2 shows unadjusted and adjusted comparisons. While there were a number of significant findings in the bivariate analyses, once adjusted, results showed that age was an important predictor across all variables. Older people were less likely to report having home computers, broadband access, mobile phones, smartphones, and unlimited texting. Education and income were also important variables in predicting access to home computers and broadband connections, with higher levels resulting in increased access for both. There were fewer demographic differences for mobile phone and smartphone ownership, with age being the main predictor.

Research Question 2: What is the frequency of use of various media channels, including email, search engines, online newspapers/magazines, SNS, online videos, video chat, Twitter, online bulletin boards (ie, Pinterest), text messaging, and smartphone apps?

The most common activities included using email or search engines. Only 21% reported never using email, and only 17% reported never using a search engine. There were a number of activities that a large number of respondents reported never doing: using SNS like Facebook (40%), watching or uploading videos on a site like YouTube (40%), reading newspapers or magazines online (49%), and using video chat services like Skype (61%). Over two-thirds (75%) said they never used SNS for health purposes. Regarding activities specific to mobile phone use, only 17% reported never sending text messages; 26% reported never using mobile phone apps, and over half (56%) said they never used mobile phone apps for health purposes.

To further support findings in response to Research Question 4, Table 3 presents demographic comparisons of activities conducted using the Internet and mobile phones as reported by respondents. A majority of the sample reported never using Twitter (86%) and online bulletin boards like Pinterest (88%); therefore, those 2 activities are not included in the table.

While age was an important predictor of activities involving the Internet and mobile phones, education also appeared to be important, remaining significant even after adjusting for other demographics. Older respondents as well as respondents with lower educational attainment were less likely to report doing most of the activities listed. Some activities—such as online search engine use—could be predicted by income, yet others—such as text messaging—could not. Also of note is that Asian respondents appeared to be much more likely to engage in most activities than other races. Geographic area of residence or being Hispanic/Latino or male (with the exception of using online videos) did not appear to be a significant predictor for any activity after controlling for other demographics.

Research Question 3: What channels are preferred for receiving health information?

When asked about receiving health information from an organization, many respondents said they preferred getting information from websites. The general population (49%) rated websites as a high preference, more than any other channel of communication. After websites, the next most preferred channels were television (35%), mail (eg, brochure) (35%), and email (29%). Fewer respondents had a high preference for receiving health information via smartphone apps (25%), in-person meetings (25%), text messages (22%), radio (20%), and SNS (17%).

Table 4 presents comparisons for information preferences across demographics. There are a number of differences by demographics across all methods for receiving health information per the bivariate analyses. When adjusting for all demographics, some notable differences remained. Respondents with higher education were significantly more likely to prefer websites and email, but less likely to prefer TV, than those with lower education levels. Income was also a predictor, with respondents at higher incomes reporting a stronger preference for websites and email.

Table 2. Internet and mobile phone use and access for New York State respondents (n=1350 except where noted; weighted estimates, unadjusted and adjusted using logistic regression[1]).

		% working computer at home	% broadband access at home (n=1093)	% have mobile phone	% have unlimited texting (n=1197)	% have smartphone (n=1197)
Education		*P*<.0001	*P*=.0003	*P*=.0005	*P*=.0779	*P*=.0006
	High school graduate or less	66%	88%	85%	74%	54%
	Some college/vocational degree	84%**	93%	89%	82%	64%*
	College graduate or more	96%***	97%*	95%	80%	70%**
Age		*P*<.0001	*P*<.0001	*P*<.0001	*P*<.0001	*P*<.0001
	18-29	89%	97%	93%	90%	86%
	30-49	88%	96%	94%	85%	73%**
	50-59	82%*	92%**	96%	75%**	51%***
	60 or over	66%***	85%***	75%***	55%***	28%***
Sex		*P*=.0482	*P*=.6778	*P*=.0030	*P*=.1003	*P*=.0147
	Female	79%	93%	87%	76%	58%
	Male	85%	93%	93%	81%	67%
Ethnicity		*P*=.0441	*P*=.2314	*P*=.0002	*P*=.6391	*P*=.0008
	Non-Hispanic, Latino/a, or Spanish origin	83%	93%	91%	79%	61%
	Hispanic, Latino/a, or Spanish origin	78%	91%*	83%*	80%	73%
Race		*P*<.0001	*P*=.6919	*P*=.4203	*P*=.0157	*P*<.0001
	White	83%	93%	90%	75%	56%
	Black/African American	73%	90%	90%	89%*	73%**
	Asian	97%***	94%	91%	80%	93%**
	Other/Multiple	77%	94%	84%	83%	63%
Household Income		*P*<.0001	*P*<.0001	*P*<.0001	*P*=.1523	*P*=.0110
	Less than $25,000	68%	90%	86%	82%	60%
	$25,000 to $49,999	85%**	88%	89%	80%	63%
	$50,000 to $74,999	92%**	97%	97%*	77%	59%
	$75,000 or more	97%***	99%**	96%*	80%	73%**
	Not sure/Missing	73%	89%	83%	71%	55%
Geographic Area		*P*=.0006	*P*=.0018	*P*=.0007	*P*=.0235	*P*=.0003
	Urban	79%	94%	90%	80%	66%
	Suburban	89%	95%	93%	80%	64%
	Rural	75%	84%*	79%**	67%	43%

Reference group is the first group listed for each demographic characteristic.

[1] Unadjusted P-values of significance are indicated in the table.
Adjusted P-values of significance are noted as follows: *<.05; **<.01; ***<.0001

Table 3. Frequency of Internet- and mobile phone-related activities for New York State respondents (n=1350; weighted estimates, unadjusted and adjusted using ordinal logistic regression[1]).

		Internet use: % Never	Email: % Never	Search engine: % Never	Read news/mags: % Never	SNS: % Never	SNS for health: % Never	Use videos: % Never	Video chat: % Never	Texts: % Never	Apps: % Never	Health apps: % Never
Education		*P*<.0001	*P*<.0001	*P*<.0001	*P*<.0001	*P*<.0001	*P*=.0108	*P*<.0001	*P*<.0001	*P*<.0001	*P*<.0001	*P*=.8264
	High school or less	30%	40%	34%	70%	53%	69%	55%	77%	25%	43%	55%
	Some college/Vocational degree	12%***	17%***	14%***	46%***	34%**	73%	33%**	59%**	15%***	23%**	52%
	College graduate or more	3%***	6%***	3%***	29%***	31%**	82%	27%**	47%***	10%**	13%***	58%
Age		*P*<.0001	*P*<.0001	*P*<.0001	*P*<.0001	*P*<.0001	*P*=.2962	*P*<.0001	*P*<.0001	*P*<.0001	*P*<.0001	*P*=.0062
	18-29	4%	10%	5%	37%	14%	72%	15%	50%	1%	9%	47%
	30-49	7%***	13%	9%***	40%	28%***	78%	28%***	54%***	8%***	19%***	53%
	50-59	16%***	25%***	19%***	55%***	54%***	76%	45%***	72%***	18%***	28%***	74%**
	60 or over	35%***	40%***	38%***	67%***	69%***	76%	71%***	82%***	48%***	66%***	69%*
Sex		*P*=.2818	*P*=.0361	*P*=.0080	*P*=.0002	*P*=.4823	*P*=.3305	*P*=.0001	*P*=.0223	*P*=.0808	*P*=.0644	*P*=.2048
	Female	17%	24%	20%	53%	39%	74%	42%	61%	19%	30%	50%
	Male	12%	17%	14%	44%**	40%**	77%	35%*	61%	14%	21%	60%
Hispanic, Latino/a, or Spanish		*P*=.3955	*P*=.0282	*P*=.2321	*P*=.3031	*P*=.1661	*P*=.0001	*P*=.0087	*P*=.0264	*P*=.0536	*P*=.0530	*P*=.5566
	No	14%	20%	16%	48%	40%	79%	39%	60%	17%	25%	56%
	Yes	16%	25%	19%	51%	34%	61%	35%	62%	11%	28%	51%
Race		*P*=.0001	*P*=.0006	*P*<.0001	*P*=.0026	*P*=.0059	*P*=.1144	*P*<.0001	*P*<.0001	*P*=.0061	*P*=.0362	*P*=.8826
	White	14%	20%	16%	48%	43%	79%	41%	62%	19%	25%	58%
	Black/African American	23%*	28%	25%	56%	39%	76%	42%	67%	14%	30%	53%
	Asian	3%	5%	4%*	27%*	21%	65%	20%*	34%*	4%	16%	48%
	Other/Multiple	17%	26%	20%	49%	33%	64%	34%	59%	12%	30%	49%
Household Income		*P*<.0001	*P*<.0001	*P*<.0001	*P*<.0001	*P*=.7770	*P*=.0002	*P*<.0001	*P*=.0015	*P*=.0725	*P*<.0001	*P*=.0210
	Less than $25,0000	23%	31%	28%	57%	41%	60%	49%	65%	17%	34%	59%
	$25,000 to $49,999	14%	20%	13%**	53%	41%	72%	40%	67%	17%	34%	51%
	$50,000 to $74,999	5%*	9%*	4%***	31%	31%	90%***	24%	50%	16%	11%**	55%
	$75,000 or more	2%***	7%***	5%***	57%**	37%	81%*	26%*	51%	12%	9%**	54%
	Not sure/Missing	26%	33%	31%	34%	45%	79%**	49%	69%	23%	37%	72%**
Geographic Area		*P*=.0004	*P*=.0001	*P*=.0002	*P*=.0788	*P*=.0194	*P*=.1711	*P*=.0032	*P*=.0291	*P*=.0003	*P*=.0049	*P*=.7291

		Internet use: % Never	Email: % Never	Search engine: % Never	Read news/mags: % Never	SNS: % Never	SNS for health: % Never	Use videos: % Never	Video chat: % Never	Texts: % Never	Apps: % Never	Health apps: % Never
	Urban	16%	23%	19%	48%	38%	71%	39%	60%	16%	26%	55%
	Suburban	9%	14%	11%	47%	39%	82%	34%	58%	15%	19%	55%
	Rural	20%	29%	22%	57%	50%	77%	52%	75%	25%	45%	61%

Reference group is the first group listed for each demographic characteristic.

[1] Unadjusted P-values of significance are indicated in the table.
Adjusted P-values of significance are noted as follows: *<.05; **<.01; ***<.0001

Table 4. Preferred media channels for receiving health information for New York State respondents (n=1350; weighted estimates, unadjusted and adjusted using ordinal logistic regression[1]).

		Website: % High	TV: % High	Mail: %High	Email: % High	In-person: % High	Phone app: % High	Text: % High	Radio: % High	SNS: % High
Education		*P*<.0001	*P*=.0044	*P*=.4485	*P*<.0001	*P*=.0884	*P*=.0333	*P*=.0844	*P*=.8113	*P*=.1356
	High school grad or less	33%	43%	35%	24%	25%	21%	26%	21%	19%
	Some college/vocational degree	53%***	32%*	38%	29%*	29%	25%*	22%	20%	15%
	College graduate or more	62%***	29%**	32%	33%**	22%	27%	16%*	17%	15%
Age		*P*<.0001	*P*=.7332	*P*=.0851	*P*<.0001	*P*=.0120	*P*<.0001	*P*<.0001	*P*=.3081	*P*<.0001
	18-29	62%	33%	30%	33%	26%	37%	31%	19%	28%
	30-49	55%***	33%	32%	35%	24%	32%*	29%	19%	20%**
	50-59	51%***	39%*	37%*	27%*	32%	15%***	14%***	26%	12%***
	60 or over	28%***	36%	43%**	16%***	21%	9%***	7%***	17%	5%***
Sex		*P*=.2074	*P*=.1689	*P*=.0025	*P*=.6626	*P*=.8212	*P*=.1646	*P*=.9592	*P*=.4376	*P*=.6992
	Female	47%	36%	41%	27%	26%	24%	21%	19%	18%
	Male	51%	33%*	29%*	30%	25%	26%	22%	21%	16%*
Hispanic, Latino/a, or Spanish		*P*=.8131	*P*=.0002	*P*=.0002	*P*=.0083	*P*<.0001	*P*<.0001	*P*<.0001	*P*=.0949	*P*<.0001
	No	49%	33%	34%	27%	24%	23%	19%	19%	15%
	Yes	48%	44%*	44%**	36%	31%	36%*	32%	23%	27%*
Race		*P*=.0001	*P*=.0350	*P*=.0179	*P*=.0068	*P*=.0749	*P*<.0001	*P*<.0001	*P*=.0013	*P*<.0001
	White	49%	31%	34%	25%	23%	19%	15%	17%	11%
	Black/African American	55%*	42%*	41%	36%	30%	33%**	35%**	30%	23%*
	Asian	41%	35%	18%	31%	27%	37%*	21%	9%	26%**
	Other/Multiple	47%	47%*	44%	40%*	32%*	37%*	38%*	30%*	32%*
Household Income		*P*<.0001	*P*=.0073	*P*=.0359	*P*<.0001	*P*=.3229	*P*=.0019	*P*=.003	*P*=.3551	*P*=.1207
	Less than $25,0000	38%	40%	39%	27%	26%	22%	27%	22%	22%
	$25,000 to $49,999	52%	40%	30%	27%	24%	26%	23%	18%	14%*
	$50,000 to $74,999	56%*	32%	30%*	27%	23%	26%	12%**	20%	19%
	$75,000 or more	68%***	28%	31%*	40%***	22%	33%**	21%	21%	14%
	Not sure/Missing	34%	33%	34%**	21%	26%	16%	20%*	19%*	14%
Geographic area		*P*=.0178	*P*=.4264	*P*=.2260	*P*=.0167	*P*=.2434	*P*=.0011	*P*<.0001	*P*=.0582	*P*=.0040
	Urban	49%	36%	32%	32%	27%	28%	27%	22%	20%
	Suburban	53%	34%	38%*	27%	25%	23%	16%	17%	14%
	Rural	42%	32%	39%	20%	17%	13%	11%**	14%	10%

Reference group is the first group listed for each demographic characteristic.

[1] Unadjusted P-values of significance are indicated in the table.

Adjusted P-values of significance are noted as follows: *<.05; **<.01; ***<.0001

Discussion

Principal Findings

For this sample, there was high Internet and mobile phone use, and many respondents had high-speed Internet access. This group also reported a high level of engagement with Internet- and mobile phone-related activities, especially with texting. Thus, NYS respondents are similar in many ways to national samples regarding Internet use and mobile phone ownership. In fact, some percentages are identical; 85% of NYS respondents in this sample report using the Internet, compared to 85% nationally, and 90% of respondents have a mobile phone, compared to 90% nationally [5,21]. Considering these high numbers, it appears reasonable that organizations can use the Internet and mobile phones to disseminate health information and support interventions.

Still, there are some differences across demographics. Similar to national data noted in the Introduction section, this research found that those who are older, have fewer years of education, and are in lower income brackets are less likely to use the Internet. Age and income, and sometimes education, also seem to be important in explaining differences in usage of technologies and preferences for information. These results are similar to what has been found with national samples [22]. While national data show similar trends for smartphone use, income and education do not seem to impact smartphone use as much as age does in NYS. And, different from other research [23], in this sample, income was the biggest predictor of using SNS for health, as opposed to age; those with lower incomes were more likely to use SNS for health.

Despite the widespread access to digital technologies, these findings suggest there are many variations in what people *do* online and with their mobile phones. For instance, respondents were more likely to use text messages than SNS and, when compared to national results of the 2013 Pew Research Internet Project (73%), this sample used SNS less (60%) (SNS use for health was similar to that in other research, 25% compared to 32% [23]). It is also important to remember there are variations not measured here with respect to specific websites or tools. Different groups may prefer different SNS. For example, LinkedIn users tend to be highly educated and come from higher income households [24].

Given the variation among Internet and mobile phone activities, it is recommended that public health groups seeking to disseminate health information should consider specific technology access and use patterns and preferences of the target population when developing a communication plan. Although there are a number of new and unique channels, many NYS respondents preferred getting information from organizations on websites. Having a website where people can go for information is a useful strategy, with other channels such as text messages, social media, and videos used to not only publicize the website but to also provide alternative modes of communication. It is of interest that television and mail (ie, a brochure) were the second and third preferred modes of communication, showing that even with the increased utilization of digital technologies, traditional communication channels are still viable methods for sharing information. Of note, those who were older or reported less education were less likely to prefer websites and email.

Even though these data support the idea that digital channels for communication can effectively and efficiently reach many people, they may not be the only channels to use when disseminating health-related resources and information, especially for certain populations. Traditional information sources such as brochures, television, billboards, bus signs, and radio should be considered as well. Offline information sources could be developed to supplement any online information dissemination activities. This would allow better access for those who do not regularly interact with online or new technology platforms.

Further, the goals of any public health communication program or intervention should be evaluated using data to inform decisions about which information channels would be most effective at reaching the target population. It is also important to consider the pros and cons of each channel being considered. For instance, while many use social media to deliver information, the strength of social media is that people can interact with each other and provide user-generated comments and information. There are instances where this may be ideal, but this approach could also lead to issues such as misinformation.

Limitations

While this study provides important information from a sample of NYS residents, there were many complexities associated with the nature of a cross-sectional phone survey, compounded by the ever-changing dynamics of media and technology. Among them, there was limited time to conduct the survey. Questions were tested prior to finalizing the survey to ensure that the call lasted only 10 minutes. Although a substantial number of questions were asked, we did not have time to fully explore respondents' experiences using media and technology for health information. Sample selection was intended to target specific subpopulations (ie, Rural, Hispanic/Latino, mobile phone users). To ensure that the sample was representative of NYS, weighted adjustments were calculated to provide a more accurate depiction. In addition, interviewers did not ask about all possible communication channels. While questions referred to social media sites, respondents may not have considered sites like YouTube or blogs as belonging in that category. These channels could prove useful depending on the target population, and video-based sites like YouTube might be especially suitable to some groups. Finally, we asked about preferences for receiving information in a general way. It may be that responses could have been different if asked about specific health topics. However, we did provide guidance as to what we meant by "health information." It may also be that respondents interpreted "if an organization like the Department of Health" in different ways; people may not be familiar with the work of the Department of Health, or think it only has certain functions, such as tracking diseases. This may have impacted responses to this question.

Conclusions

This study represents an important first step in exploring media and technology use for public health purposes at the state level, but there is a need for future research on specific populations to examine how variables beyond the demographics presented here impact media and technology use, and health information-seeking activities and preferences. Factors such as language, culture, and health literacy could all potentially impact media and technology use and preferences for receiving health information. For example, there is a growing realization that even though there has been a decrease in the digital divide with respect to access, there is a growing divide regarding skills [25]. Additional research can also explore how preferences for information dissemination may vary by topic.

While there are limitations that must be considered when drawing conclusions from this study, the data collected suggests that people in NYS are online and engaged in technology use but may have unique preferences for receiving health information. When considering how to disseminate health information, it is important to ensure that the methods being used are appropriate for the target population. Technology is constantly evolving and trends are always changing. A SNS that may be popular today may be displaced by a new one in the future. Continued efforts to understand and stay abreast of technology use patterns and preferences for receiving health information will be an important goal as we consider ways to use digital technologies to improve public health.

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Conflicts of Interest

None declared.

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Abbreviations

NYC: New York City
NYS: New York State
OMH-HDP: Office of Minority Health and Health Disparities Prevention
SNS: social networking sites
SRI: Siena Research Institute

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Original Paper

Medical Institutions and Twitter: A Novel Tool for Public Communication in Japan

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Abstract

Background: Twitter is a free social networking and microblogging service on the Internet. Medical professionals and patients have started to use Twitter in medicine. Twitter use by medical institutions can interactively and efficiently provide public health information and education for laypeople.

Objective: This study examined Twitter usage by medical institutions.

Methods: We reviewed all Japanese user accounts in which the names of medical institutions were described in the user's Twitter profile. We then classified medical institutions' tweets by content.

Results: We extracted 168 accounts for medical institutions with ≥500 followers. The medical specialties of those accounts were dentistry and oral surgery (n=73), dermatology (n=12), cosmetic surgery (n=10), internal medicine (n=10), ophthalmology (n=6), obstetrics and gynecology (n=5), plastic surgery (n=2), and others (n=50). Of these, 21 accounts tweeted medical knowledge and 45 accounts tweeted guidance about medical practice and consultation hours, including advertisements. In the dentistry and oral surgery accounts, individual behavior or thinking was the most frequent (22/71, 31%) content. On the other hand, consultation including advertisements was the most frequent (14/23, 61%) in cosmetic surgery, plastic surgery, and dermatology.

Conclusions: Some medical specialties used Twitter for disseminating medical knowledge or guidance including advertisements. This indicates that Twitter potentially can be used for various purposes by different medical specialties.

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KEYWORDS

social media; Web 2.0; medical education; consultation guidance; advertisement

Introduction

Twitter is a free social networking and microblogging service on the Internet. Twitter has grown rapidly in popularity [1]. In medicine, increasing numbers of medical professionals and patients use Twitter. We first reported that Twitter networks of patients with cancer have developed so they can exchange information on Twitter [2]. Harris et al reported on tweets about diabetes mellitus by a local health department [3]. In addition to cancer, Twitter is used in various fields, such as dental pain surveillance [4], exploring misunderstanding or misuse of antibiotics [5], and monitoring influenza outbreaks [6-8].

Medical professions have started to use Twitter [9]. For example, some physicians or medical teams use Twitter to share medical information with the public [10-16]. Thus, Twitter use by medical institutions might interactively and efficiently provide public health information and education for laypeople. We could speculate that some of the needs and requests of the public cannot be met by typical medical practice. Thus, medical professionals may be able to conduct personalized educational activities. Furthermore, Twitter can contribute to improved satisfaction with health promotion and medical care.

Information about Twitter use by medical institutions is highly limited and the optimal methods of use remain unclear. In this study, we examined Twitter usage by medical institutions and Twitter's role in public medical information. This should assist medical institutions that use Twitter in making significant changes from noninteractive, 1-way publicity to interactive information exchange, wherein personal opinions, needs, and requests are disseminated and collected in the future.

Methods

Identifying Twitter Accounts

We searched Twitter profiles using a method detailed elsewhere [2]. Briefly, we searched every publicly available user profile on Twitter in Japan. The search words were "hospital" and "clinic" in Japanese. We reviewed all user accounts that included the names of medical institutions, aiming specifically at those with ≥500 followers. As in our previous study's methods, we included only such large "powerful" accounts [9]. The website used for the profile search was the 16 Profile Search beta version for Twitter [17]. The search was conducted on July 15, 2013. We classified the accounts using Twitter profiles. We excluded accounts that probably were not medical institutions. The accounts with medical institutions' names were categorized as medical institutions. However, in the case of medical staff, we categorized the accounts by professions. The people who had medical treatment in that medical institution were categorized as patients. Then, we classified the extracted medical institution accounts into the following categories: dentistry and oral surgery, cosmetic surgery, plastic surgery, dermatology, other surgery, and internal medicine including pediatrics.

We collected the latest tweets of the top 5 accounts in terms of number of followers for measuring longitudinal changes. We extracted tweets from 2012 to 2014. The website we used for collecting the latest tweets was TwimeMachine [18], which can collect a maximum of 3200 tweets. This search was conducted on November 5, 2015.

We searched the accounts of medical institutions in English-speaking countries for comparison with the accounts of medical institutions in Japan. The search words were "hospital" and "clinic" in English. We extracted the accounts with the top 10 number of followers, reading medical institution profiles. The website used for collecting the accounts of medical institutions in English-speaking countries was followerwonk [19]. The search was conducted on October 30, 2015. We referred to the URL of medical institutions if we could not extract information about the medical institutions from the Twitter profile alone.

Categorizing Tweets

We classified the medical institution tweets into 6 categories using the 100 most recent tweets. The categories were medical knowledge (category A); consultation guidance (including advertisements and newsletters from medical institutions; category B); suggestions from patients (category C); links to other home pages only (category D); individual behavior or thinking (category E); and tweets with multiple kinds of content (eg, tweets with a URL link to a home page and medical knowledge tweets from the same account, classified by YS, a medical informatics researcher; category F). In the most recent 100 tweets, the most categorized tweets from categories A to E were the account classifications. When categories A to E were almost equal, we classified the accounts as category F. The categories for tweets that the primary investigator (YS) could not categorize were decided by discussion with the secondary investigator (NH).

Analyzing Tweet Morphemes

Tweet morphemes in Japanese were analyzed using the method previously developed for frequency comparison of nouns by medical specialties [20]. Briefly, we collected 200 tweets and used the ChaSen (version 2.1 for Windows, Nara Institute of Science and Technology, Ikoma, Nara, Japan) morphological analysis system. We used the normal ChaSen dictionary in morpheme analysis, extracting only nouns from the tweets. Tweets were obtained January 11, 2014.

Results

Identifying Medical Institution Accounts

We identified 1211 Twitter accounts with ≥500 followers in which the keywords "hospital" and "clinic" were included in the profile. From those, we extracted 168 accounts by medical institutions using the following keywords in Japanese: *Byoin* (hospital) and *Shinryojo*, *Iin*, or *Kurinikku* (clinic) (Table 1). Among the 168 medical institutions, 30 had registered Twitter accounts in 2009, 110 in 2010, and 28 in 2011 (Figure 1). As of July 15, 2013, the median duration from the day Twitter accounts were registered to the last tweeted day was 1151 (range 596–1526 days).

Table 1. Categorized Twitter accounts (relevant Twitter accounts with ≥500 followers on July 15, 2013).

Type of Twitter account	Search words				Total no. of accounts
	Byoin (hospital)	*Shinryojo* (clinic)	*Lin* (clinic)	*Kurinikku* (clinic)	
Accounts related to medicine					
Medical institutions	30	6	67	65	168
Pharmacies	2	0	0	0	2
Doctors, dentists	86	12	39	53	190
Nurses, midwives	35	1	0	6	42
Paramedics (except nurses)	71	1	10	5	87
Other hospital personnel	68	4	3	7	82
Tweets about medical knowledge[a]	18	0	6	5	29
Patients	11	0	1	1	13
Total	321	24	126	142	613
Accounts unrelated to medicine	356	31	58	153	598
Total no. of accounts	677	55	184	295	1211

[a] The accounts’ proprietors were unknown.

The medical specialties of those accounts were dentistry and oral surgery (n=73), dermatology (n=12), cosmetic surgery (n=10), internal medicine (n=10), ophthalmology (n=6), obstetrics and gynecology (n=5), plastic surgery (n=2), and others (n=50; Figure 2).

We identified 190 Twitter accounts of doctors or dentists in this search, including 10 pediatricians. We searched “pediatrician” using 16 Profile Search beta version for Twitter on March 12, 2014 and identified 12 pediatrician accounts with ≥500 followers.

Table 2 shows the accounts with the top 10 number of followers in Japanese medical institutions. The medical specialties in the accounts having the top 10 followers were dentistry (n=3), cosmetic surgery (n=2), ophthalmology (n=1), therapeutic radiology (n=1), obstetrics and gynecology (n=1), dermatology (n=1), and internal medicine (n=1). Account 1 had the highest number of followers (n=169,407). There was a median of 3129.5 tweets, 29,865 followers, and 3.00 tweets per day.

Table 3 shows the top 10 accounts of medical institutions by number of followers in English-speaking countries. Those accounts were from 6 general hospitals, 3 children’s hospitals, and 1 cosmetic surgery clinic. There was a median of 9072 tweets, 213,314.5 followers, and 3.61 tweets per day.

Table 2. The top 10 accounts by number of followers of Japanese medical institutions.

No.	Account name	Hospital or clinic	Medical specialty	Prefecture	Date joined	Total tweets	Followers	Tweets/day[a]
1	@team_nakagawa	Hospital	General hospital (therapeutic radiology)	Tokyo	March 15, 2011	285	169,407	0.33
2	@Sanhujinka	Clinic	Obstetrics and gynecology	Kanagawa	April 7, 2010	81,753	90,906	68.41
3	@biyoudoctor	Clinic	Cosmetic surgery	Tokyo	September 20, 2010	4603	48,151	4.47
4	@SBCLASIK	Clinic	Ophthalmology	Tokyo	March 8, 2010	6303	45,063	5.15
5	@sbcmatsuoka	Clinic	Dermatology	Tokyo	September 24, 2010	1559	32,609	1.52
6	@GVBDO	Clinic	Dentistry	Gifu	May 21, 2010	31,568	27,121	27.43
7	@ryouki4181	Clinic	Dentistry	Osaka	July 6, 2010	1422	21,365	1.29
8	@suzuki1855	Clinic	Dentistry	Yamagata	November 9, 2009	1656	18,914	1.23
9	@Drponchi	Clinic	Internal medicine	Kanagawa	May 19, 2011	7370	16,852	9.35
10	@moriyukabc	Clinic	Cosmetic surgery	Mie	December 5, 2010	359	13,916	0.38
Median						3129.5	29,865	3.00

[a] Up to July 15, 2013.

Table 3. The top 10 accounts by number of followers of medical institutions in English-speaking countries.

No.	Account name	Hospital or clinic	Medical specialty	Country	Date joined	Total tweets	Followers	Tweets/day[a]
1	@MayoClinic	Hospital	General hospital	US	April 30, 2008	25,859	1,233,111	9.44
2	@HarvardHealth	Hospital	General hospital	US	March 4, 2009	2,898	998,726	1.19
3	@ClevelandClinic	Hospital	General hospital	US	March 14, 2009	27,644	542,697	11.42
4	@StJude	Hospital	Children's hospital	US	October 23, 2007	6,567	388,754	2.24
5	@HopkinsMedicine	Hospital	General hospital	US	February 7, 2009	11,469	329,343	4.67
6	@FUEHairClinics	Clinic	Cosmetic surgery	UK	August 10, 2013	738	97,286	0.91
7	@GreatOrmondSt	Hospital	Children's hospital	UK	October 22, 2009	20,703	82,405	9.41
8	@HospitalsApollo	Hospital	General hospital	India	October 25, 2010	26,494	77,120	14.47
9	@seattlechildren	Hospital	Children's hospital	US	September 4, 2008	6,675	55,531	2.56
10	@NIHClinicalCntr	Hospital	General hospital	US	February 6, 2009	3,111	52,221	1.27
Median						9072	213,314.5	3.61

[a] Up to October 30, 2015.

Figure 3 shows the top 5 accounts of medical institutions by number of followers in Japan. The therapeutic radiology account (account 1), with the most followers, tweeted 64 tweets in 2012 and had no tweets from 2013 to 2014. We could not collect tweets from an obstetrics and gynecology account (account 2) and a dermatology account (account 5) from 2012 to 2014 due to technology issues. Account 2 had more than 3200 tweets, none of which could be technically collected due to the large numbers of tweets from 2012 to 2014. We could not access account 5 on November 5, 2015.

Figure 3 shows the number of tweets by therapeutic radiology (account 1), cosmetic surgery (account 3), and ophthalmology (account 4) accounts (Table 2) from 2012 to 2014. All tweets from account 1 in 2012 were about the Fukushima nuclear accident and radiation exposure. Account 3 had 77 tweets with links to preoperative and postoperative photographs of all 536 tweets from 2012 to 2014 (14.4%). Account 4 was a clinic that performed LASIK eye surgery. The content of its tweets recommended LASIK surgery, provided information about appointment status in that clinic, and contained advertising. Over 3 years, 80.33% (960/1195) of their tweets contained their phone number.

Figure 1. Year of Twitter registration by 168 medical institutions, showing the number of Twitter registrations from 2009 to 2011 per half year. The first registration was in July 2, 2009. The latest registration was on November 27, 2011.

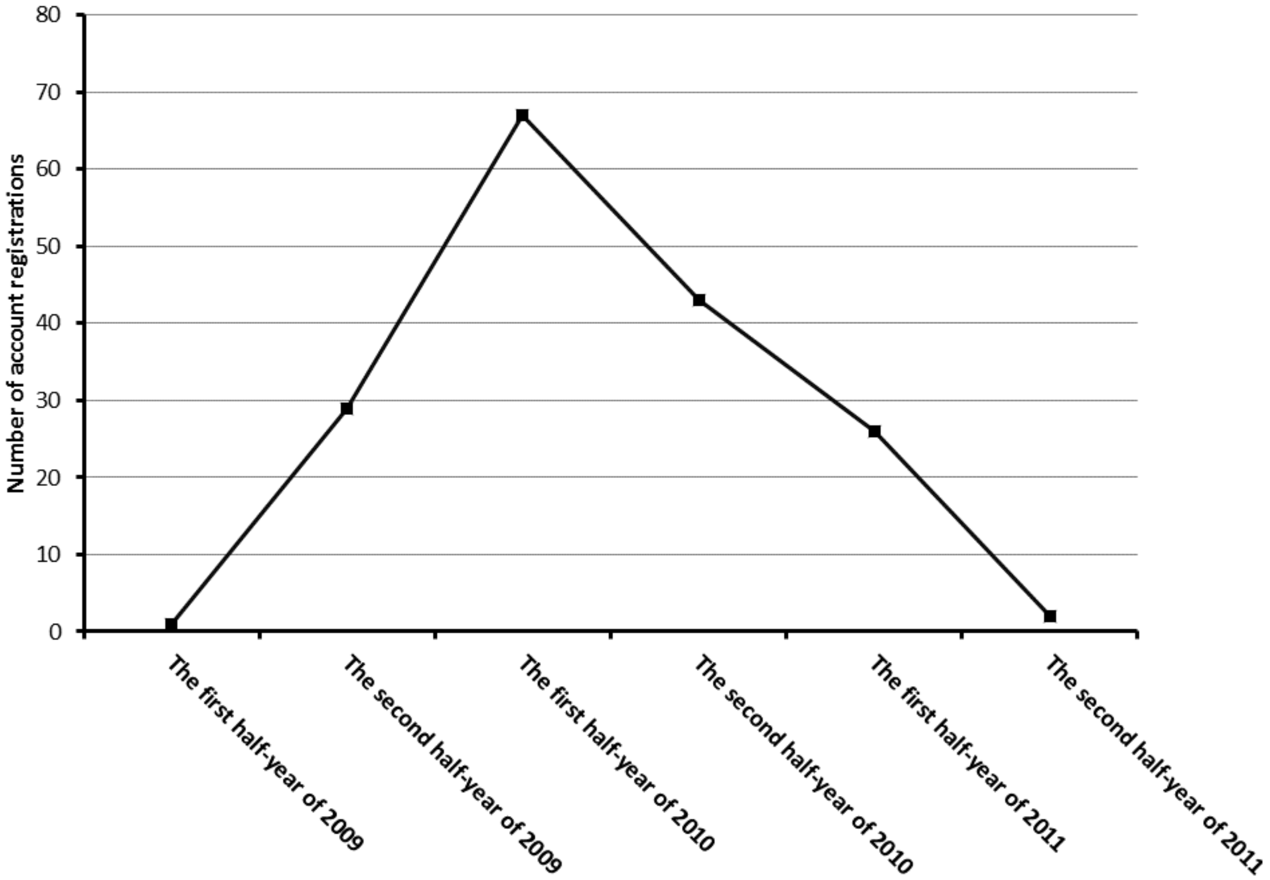


Figure 2. Number of Twitter accounts in each medical specialty. The medical specialties of general hospitals were included in the specialty accounts and not in “hospitals”.

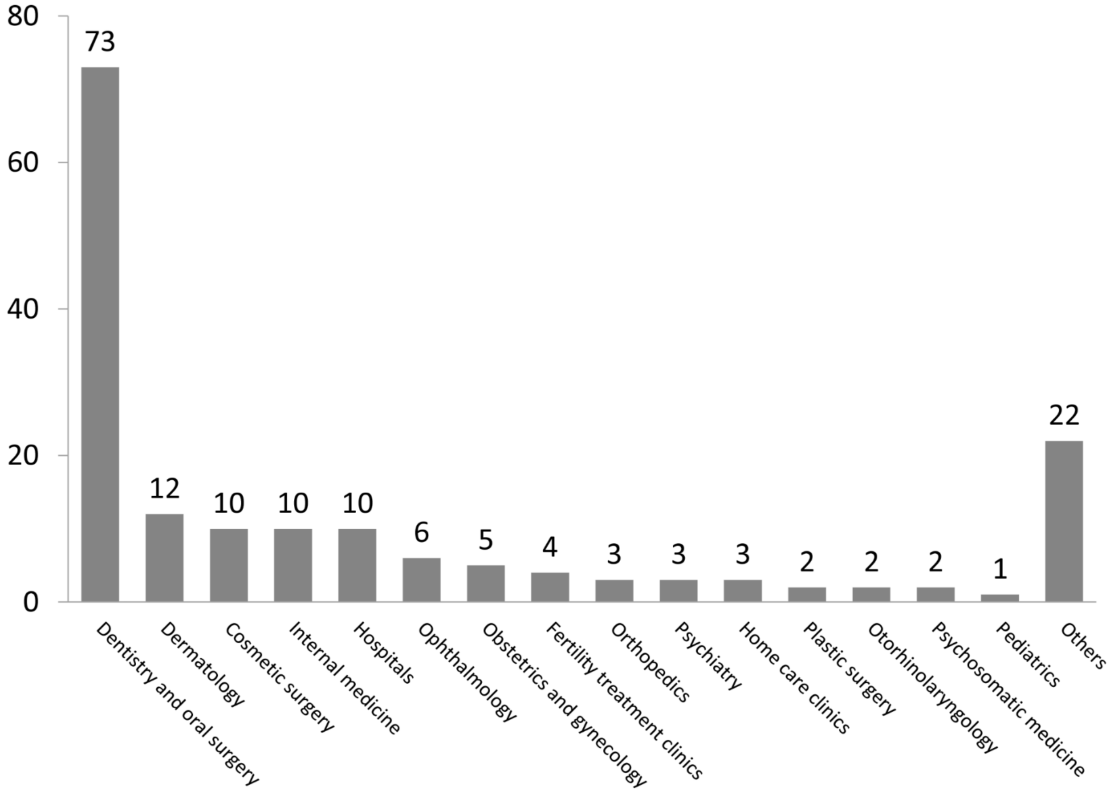
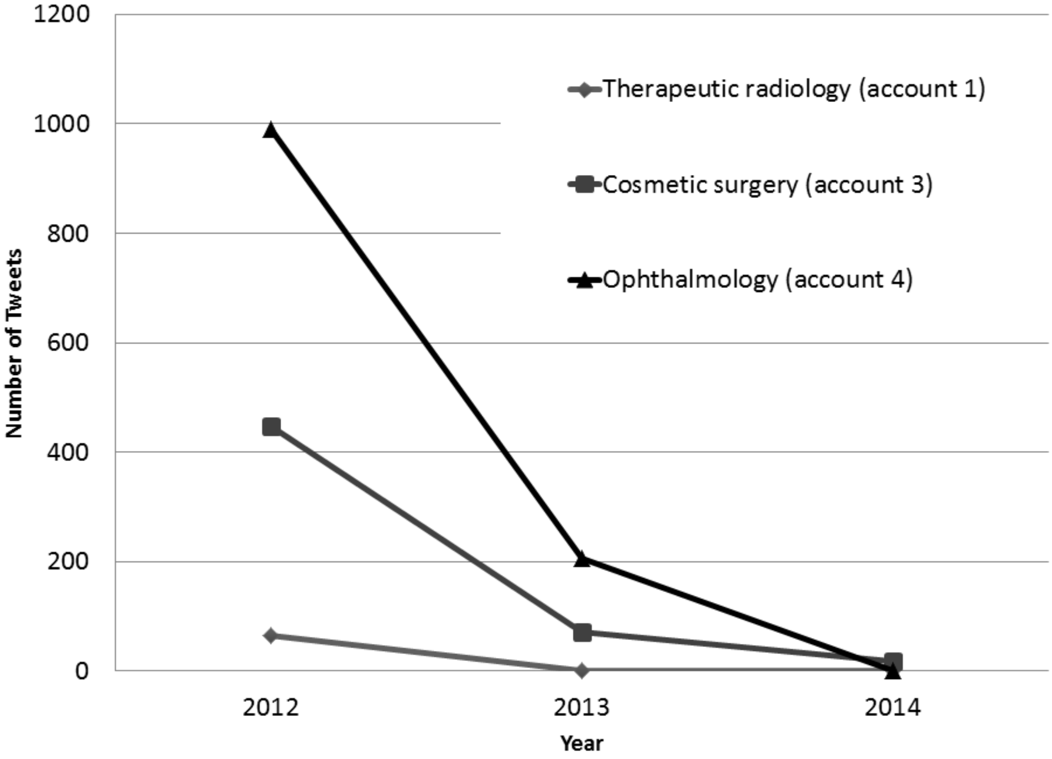


Figure 3. Number of tweets from medical institutions in Japan from 2012 to 2014 with content on therapeutic radiology (account 1), cosmetic surgery (account 3), and ophthalmology (account 4).



Categorizing Tweets

We classified tweets by medical institutions into 6 categories by content (see Table 4). Tweets about consultation guidance including advertisements and newsletters from medical institutions (category B) were most frequent. Figure 4 shows content classification of tweets in each specialty. In cosmetic surgery, plastic surgery, and dermatology, category B was the most frequent (n=14, 61%). In dentistry and oral surgery, category E was the most frequent (n=22, 31%). The accounts of 2 medical institutions were attempting to recruit dentists, dental hygienists, nurses, and others. Table 5 shows sample tweets.

Table 4. Number of tweets by categories of contents.

Category	Content	No. of tweets[a]
A	Medical knowledge	21
B	Consultation guidance, including advertisements and newsletters from medical institutions	45
C	Patients’ suggestions	3
D	Links only to home pages, blogs, etc	37
E	Individual behavior or thinking	37
F	Tweets with multiple types of content	20

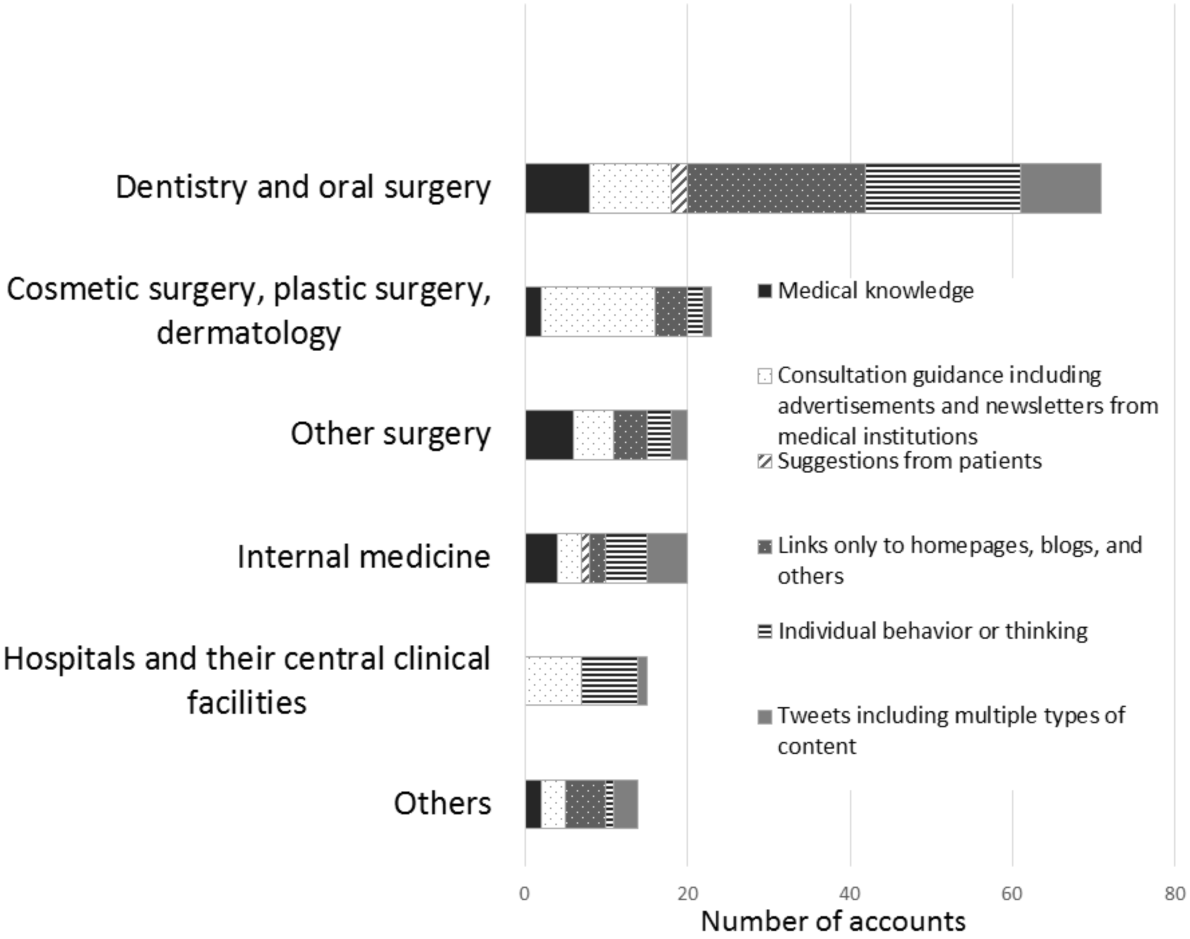
[a] A total of 5 accounts could not be accessed to obtain tweets on January 11, 2014.

Table 5. Sample tweets by content category.

Category	Account no.	Tweet sample[a]
A	1	Internal exposure to radioactive cesium through foods reminds us of “Minamata disease” caused by concentrated organic mercury in the food chain from Chisso Minamata factory. Those who ate fish polluted by organic mercury in high densities accumulated “liposoluble” organic mercury in their brain and frequently experienced neuropathy.
A		On the other hand, radioactive cesium seldom causes biological concentrations like organic mercury. Cesium is an alkali metal close to potassium. Taken into the body, cesium distributes evenly to all cells and is excreted in urine. This was established by analysis of euthanized domestic animals in Fukushima prefecture.
A		Cesium is excreted in urine like potassium. The amount of cesium in the body is halved at nine days in infants and at three months in adults. Unlike organic mercury, cesium is not accumulated in the body. Even when cesium is excreted, it exists on Earth because the half-life of cesium-137 is approximately 30 years.
A	2	Defining blood–brain barrier (BBB) disruption as a hyperdense lesion on the CT scan after endovascular therapy in acute ischemic stroke patients, BBB disruption is independently associated with lower rates of early major neurologic improvement, higher rates of mortality, and hemorrhagic complications. http://****
A	3	We call it a wedge-shaped defect when the sides of the teeth are sharpened. Clenching one’s teeth is the most common cause of wedge-shaped defects. Images→http://****
B	4	****clinic for liposuction and fat infusion! ****clinic is an expert in liposuction with more than 30 thousand cases. We have been chosen for techniques and trust.
B	5	We will start flu shots on October 15. We are accepting reservations from companies for flu shots. Call ** in charge.
C	6	[In patient's voice]: “I found this dentist. This dentist described the treatment I wanted and how to brush well. This dentist explained other things besides treatment, too. If I had brushed my teeth earlier, I would have better teeth. I regret that now.”
D	7	Our blog was renewed. [Report of cardiology training] at http://****
E	8	Let’s drink water because it’s hot.
E	9	I feel that it’s the end of the year due to increasing numbers of patients with hand injuries.
		I feel that it’s spring because of the number of infectious atheroma cases.
F	10	Anticancer activity of extract from grape seeds: Many studies suggest that an extract from grape seeds has anticancer properties. http://****
		Watching and doing dance performances are fun, even if we cannot do them. Everyone says, “If I was XX years younger, I would dance.” Let’s go dancing! Throw away your assumptions and prejudices.

[a] Japanese conversations were translated into English. The number of characters could be more than 140 because the tweets were translated from Japanese sentences.

Figure 4. Number of accounts by medical specialty tweeting content categorized as follows: medical knowledge; consultation guidance including advertisements and newsletters from medical institutions; suggestions from patients; links only to homepages, blogs, and others; individual behavior or thinking; and tweets including multiple types of content.



Analyzing Tweet Morphemes

The frequency of nouns per medical specialty is shown in Multimedia Appendix 1. In all specialties, words about doctor visits frequently appeared, such as "consultation," "appointment," "reception," and "closed," (n=23,919). Keywords unique to each specialty appeared frequently (Multimedia Appendix 1). Examples include "decayed tooth" in dentistry, "depilation" in cosmetic surgery, "surgical operation" in other surgery, and "influenza" in internal medicine. Advertisement words such as "campaign" and "inquiry" frequently appeared in cosmetic surgery.

Discussion

Twitter Use in Medical Institution Management

In this study, we classified Twitter accounts by medical practice, including dentistry and oral surgery, cosmetic surgery, plastic surgery, dermatology, other surgery, and internal medicine including pediatrics, and by tweet contents. Powerful accounts with ≥500 followers varied by clinical specialties, as did Twitter use indicators such as amount of active Twitter use. There were 179,857 medical institutions in Japan [21]. We identified 168 medical institution Twitter accounts with ≥500 followers. These accounted for 0.09% of all medical institutions in Japan. There were more dentistry and cosmetic surgery accounts, whereas there were fewer in internal medicine, surgery, and pediatrics (Figure 2). This result may have been affected by differing medical institution management by specialty and the Japanese medical insurance system. In Japan, medical costs are covered by universal insurance. People pay 10%-30% of medical care costs on their own [22-24]. Most medical practice is conducted under health insurance. However, some medical practices in cosmetic surgery and dentistry are not covered by health insurance; indeed, most practices in cosmetic surgery are not covered by insurance. Infertility and obstetric care are also not covered unless complications are diagnosed. Patients must pay the full amount of the medical expenses not covered by health insurance, and medical institutions can freely set the cost of uncovered practices. Therefore, improving brand images to maintain higher pricing of medical costs is of much greater financial interest to medical institutions conducting uncovered practices than it is to those conducting primarily covered practices. This suggests that the management of a medical institution affects the number of Twitter accounts and the contents of medical institution tweets. Future studies will allow appropriate interpretation.

Many of the top 10 Japanese accounts were medical institutions of cosmetic surgery and dental clinics, which frequently performed medical treatment not covered by health insurance.

This suggested that the accounts of cosmetic surgery clinics possibly used Twitter for advertising. Few of the accounts were from general hospitals, while many were from clinics. In comparison, many of the top 10 accounts from English-speaking countries were from general hospitals. The British Medical Association has published guidelines about social media use among doctors and medical students in the United Kingdom [25]. However, there are no such guidelines in Japan. Clinics can establish Twitter use policies rapidly and independently. In large general hospitals, the decision to use Twitter may be difficult. In addition, the tweets of some medical institutions decreased annually. The accounts of cosmetic surgery and ophthalmology clinics performing LASIK surgery might not have been attracting customers. In Japan, medical institutions temporarily used Twitter without defined purposes. It is necessary to perform detailed investigations on Twitter use by medical institutions.

Tweet Contents

Tweet contents were also markedly different between the specialties. For example, cosmetic surgery accounts, where most practices are not covered by insurance, tended to tweet consultation guidance, including advertisements. We also found advertisement tweets covering introductions to clinic operations, consultation hours, and working hours of the doctor in charge of operations. Of the tweets by cosmetic surgery accounts, 38% (9/24) were categorized as advertisements, defined as tweets with concrete prices or discounts. Most practices in cosmetic surgery are not covered by insurance and it is necessary to attract customers or collect patients. Thus, Twitter might be used as an advertising medium to attract cosmetic surgery patients. This supported our inference that medical institution management affected Twitter use.

On the other hand, the Twitter accounts of some specialties were used for medical knowledge and education. Words about pregnancy frequently appeared in the other surgery category, such as “uterus,” “spermatozoon,” and “infertility” (Multimedia Appendix 1). These Twitter accounts probably disseminated medical knowledge about pregnancy or infertility. There were 4 infertility treatment clinic accounts. In fact, 3 infertility treatment clinics tweeted frequently about infertility, 2 of them focusing on education for men. One of the infertility treatment clinics’ account was deleted because it could not be accessed for tweets, even though it specified disseminating medical knowledge about infertility in its Twitter profile. This is one example of medical knowledge education. In this area, Twitter might be a useful tool for disseminating medical knowledge. Pregnant women often use the Internet as an information source [26-28]. Obstetricians and gynecologists, midwives, nurses, and others may also educate pregnant women through Twitter.

Some Twitter accounts used Twitter for both attracting patients and disseminating medical knowledge. Words about dental practice frequently appeared in the dentistry and oral surgery accounts, such as “decayed tooth,” “implant” (*inpuranto* in Japanese), “orthodontic,” and “prophylaxis.” This indicated that dentistry and oral surgery accounts frequently tweeted about dental practice. Implants and most orthodontic care are not covered by health insurance; thus, those words about dental practice might frequently appear not only to disseminate medical knowledge about implants and orthodontic care but also to attract customers. Moreover, patient home prevention is the most important practice in preventive dentistry. Thus, dentistry and oral surgery accounts might disseminate information about preventive dentistry for patients with figures and photographs through Web links. In fact, the 57 dentistry and oral surgery accounts in this study had a Web link in their tweets. Because Twitter users frequently wish to share Web content and tweets are restricted to 140 characters in length, tweets frequently shortened URLs [29]. The details of medical information were explained through Web links in Twitter. Medical institutions might effectively disseminate medical information using Twitter with Web links in every specialty.

Use of Twitter in Internal Medicine, Pediatrics, and Surgery

In some specialties, such as internal medicine, surgery, and pediatrics, Twitter was seldom used. Of the 168 accounts, 83 (49.4%) were dentistry and cosmetic surgery accounts. In contrast, only 11 accounts (6.5%) were in internal medicine, pediatrics, and surgery. In those specialties, most medical practices in Japan are covered by medical insurance. Thus, the institutions likely do not need to attract customers or collect patients. In particular, there was only 1 pediatric Twitter account, which was significantly lower than in other specialties. Parents with small children often use Twitter because they have high Internet literacy [30,31]. We hypothesized that disseminating medical knowledge about pediatric practice to parents would be useful, but our study did not support this hypothesis. However, 3 children’s hospitals were included in the top 10 accounts by number of followers in English-speaking countries. Disseminating medical knowledge about pediatric practice to parents would be useful in English-speaking countries. We should investigate what medical institutions in English-speaking countries tweeted to demonstrate our hypothesis. We searched Twitter accounts for pediatricians a second time because of the lack of pediatric clinic accounts on Twitter in the first round of the study. We found 10 pediatricians among 190 doctor or dentist Twitter accounts, but 21 pediatrician accounts with ≥500 followers. We do not know the reasons for this inconsistency in the number of pediatric clinic and pediatrician accounts. However, first, it is possible that, in pediatrics, social media usability is not widely known. Second, other social media besides Twitter may have been more commonly used. It may be necessary to perform specific investigations on pediatricians and pediatric clinics. On the other hand, most patients in internal medicine and surgery are older or have a chronic disease. It may be difficult to disseminate medical information via Twitter to such elderly patients who do not use social media or the Internet. For these patients, it is likely that written dissemination of medical information will continue to be important.

Study Limitations

In this study, we first showed how medical institutions use Twitter and what they tweet. Nevertheless, several issues remain for discussion.

First, we conducted this study with power accounts (having ≥500 followers) as the focus. Thus, we might not have obtained the same results if we had included accounts with fewer followers. About 98% of Twitter accounts have fewer than 500 followers in Japan [32]. It is likely that some smaller accounts contribute to public health via Twitter. Therefore, such accounts should be investigated to provide a broad view of medical institutions' Twitter use.

Second, we did not examine the medical accuracy of tweets in this study. Several studies have examined deleterious and inaccurate information on websites and social media [33,34]. It will be necessary to investigate tweet medical reliability and accuracy of tweets. Although Twitter is a useful tool for communication, the dissemination of inaccurate medical knowledge by Twitter might negatively affect people. Thus, it is important to examine Twitter's potential negative impact in future studies.

Third, the results of this study depended on the search site; however, it remains unclear what Web search tools are sufficiently accurate and adequate. Some search sites for Twitter accounts exist, such as twpro, Twitter Search, and Twitter Profile Search [35-37]. Our preliminary search showed differences in search results between search sites (data not shown). We used 16 Profile Search beta version for Twitter for account searches for the following reasons. In this tool, AND, OR, and NOT searches were available. Furthermore, there were many kinds of output data, including account profiles, and number of tweets and followers, and the characteristics of search tools must be investigated in detail in future studies.

Fourth, we did not examine whether Twitter advertisements conformed to guidelines about medical institution advertising. Advertising by medical institutions is regulated by the Japanese Medical Care Act [38]. The Ministry of Health, Labour and Welfare provides guidelines for medical advertisements [39,40]. These detailed guidelines regulate specialties, licenses of specialists, and so on. Descriptions of curative effects, noting the number of times a doctor performed the operation, and showing before-and-after photographs are not permitted. It is also important for patients to know the medical cost. The guidelines state that advertisements emphasizing medical expenses should be regulated. There was a tweet that did not follow this guideline in the study. Thus, Twitter advertisements should be investigated to determine whether they follow medical advertisement guidelines.

Conclusions

The number of Twitter accounts by medical institutions and the tweet contents differed by medical specialty. Some Twitter accounts attracted customers or collected patients. On the other hand, some accounts provided medical knowledge. Thus, Twitter potentially can be used for various purposes by different medical specialties.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Twenty most frequently tweeted Japanese nouns in each medical specialty.

[PDF File (Adobe PDF File), 55KB - publichealth_v2i1e19_app1.pdf]

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Original Paper

Facebook Advertising Across an Engagement Spectrum: A Case Example for Public Health Communication

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Abstract

Background: The interpersonal, dialogic features of social networking sites have untapped potential for public health communication. We ran a Facebook advertising campaign to raise statewide awareness of Michigan’s newborn screening and biobanking programs.

Objective: We ran a Facebook advertising campaign to stimulate public engagement on the complex and sensitive issue of Michigan’s newborn screening and biobank programs.

Methods: We ran an 11-week, US $15,000 Facebook advertising campaign engaging Michigan Facebook users aged 18-64 years about the state’s newborn screening and population biobank programs, and we used a novel “engagement spectrum” framework to contextualize and evaluate engagement outcomes ranging from observation to multi-way conversation.

Results: The campaign reached 1.88 million Facebook users, yielding a range of engagement outcomes across ad sets that varied by objective, content, budget, duration, and bid type. Ad sets yielded 9009 page likes (US $4125), 15,958 website clicks (US $5578), and 12,909 complete video views to 100% (US $3750). “Boosted posts” yielded 528 comments and 35,966 page post engagements (US $1500). Overall, the campaign led to 452 shares and 642 comments, including 176 discussing newborn screening and biobanking.

Conclusions: Facebook advertising campaigns can efficiently reach large populations and achieve a range of engagement outcomes by diversifying ad types, bid types, and content. This campaign provided a population-based approach to communication that also increased transparency on a sensitive and complex topic by creating a forum for multi-way interaction.

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KEYWORDS

Internet; facebook; social media; facebook advertising campaign; social media engagement; health communication; social networking; biobanking; neonatal screening; infant; newborn screening

Introduction

Social networking sites have the potential to modernize core public health functions, including the delivery of essential services [1,2]. They can also be used to focus on specific populations, including some that are vulnerable and hard to reach [2]. Fostering ongoing, multi-way communication, these sites encourage new thinking about the role the public can and should play in public health. As tools for establishing and maintaining new virtual relationships and communities, they would also be well suited to accompany national health initiatives such as the Affordable Care Act, precision medicine, and learning health systems, perhaps catalyzing a new kind of personalized public health.

With more than a billion users, Facebook is the most popular social networking site in the United States and the world [2,3]. Facebook ads can reach and engage large, finely specified populations at relatively low cost [4-6]. Obtaining Web-based health information is a common practice among Internet users [7,8]. In addition, although some have found that samples drawn from social networking sites tend to overrepresent females and young adults [8], factors that do not significantly affect participation in social networking sites include household income level, race or ethnicity, and geographic location [9], suggesting Facebook's broad potential to reach a large and diverse audience.

In this study, we present an example of a recent public health Facebook advertising campaign, whose goal was to engage Michigan citizens on the topic of the state's newborn screening and large population biobanking programs. The results from this low-cost, short-duration campaign demonstrate potential for public health communicators to move beyond passive approaches to reach communications goals across a spectrum of engagement levels that include active participation by the public. The focus of the Facebook advertising campaign presented here is the Michigan BioTrust for Health (BioTrust), a population-based biobank run by the state's health department that functionally links public health practices and the research enterprise. The BioTrust's biobank is composed of residual dried bloodspots retained after newborn screening that can be linked to public health registries and other health information sources.

Biobanks such as this have raised legal and ethical questions around the limits of informed consent and the role of participants in unspecified research [10]. An ongoing critique of the open-ended storage and unspecified use is that ensuring participants have made an informed decision is nearly impossible, and lack of transparency has undermined trust in some large population biobanks. Lawsuits driven by privacy concerns in Texas and Minnesota led to the destruction of dried bloodspots stored by those state health departments [11]. Although efforts are underway to address these issues procedurally (eg, proposed revisions to the Common Rule announced in 2015 would require broad consent for or notification of secondary research), another key approach is to improve education and communication to maintain respectful participant partnerships and ongoing public engagement [12,13]. Social networking sites open possibilities for communication to occur organically, an outcome unlikely to be sparked by one-time notification or consent.

Michigan BioTrust for Health markets a biobank of more than 4 million deidentified dried bloodspots to health researchers. However, its participants are largely unaware of their participation. Less than half of Michiganders are aware of newborn screening and less than 5% are aware of the BioTrust [14]. Raising statewide awareness of Michigan's biobank is a challenging undertaking. The participant group is large and transient; the message is sensitive and complex [4].

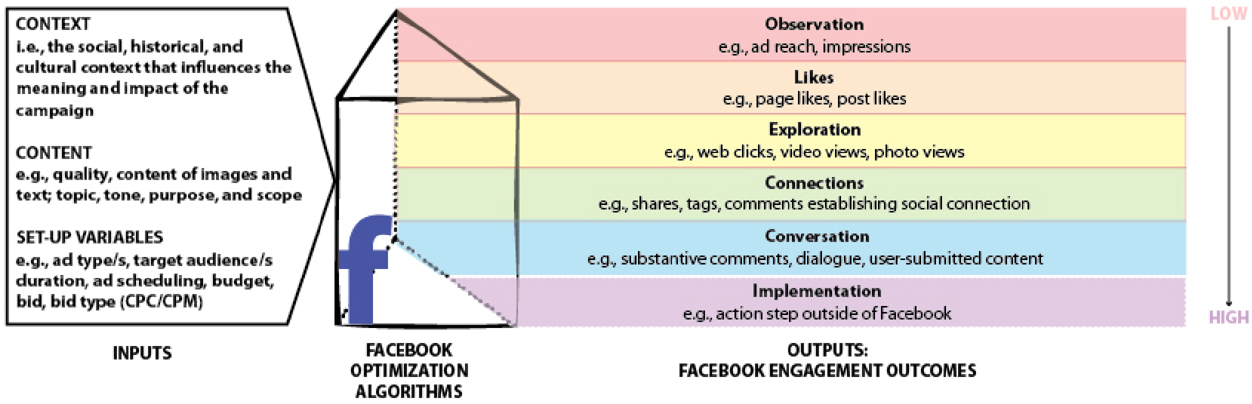
Various models have been used to describe and evaluate a hierarchy of engagement outcomes in social media [15-19]. Preece and Schneiderman [18], for example, propose a generalized "Reader to Leader framework" that describes engagement in terms of the way in which people may become active readers, contributors, collaborators, or leaders on Web-based social media forums. In a systematic review, Hrastinski [19] iteratively develops a six-stage classification scheme with definitions of participation ranging from "accessing e-learning environments" to taking part in dialogue. Neiger et al distinguish low (eg, likes), medium (eg, content sharing), and high social media engagement (eg, partnership, online action) in the context of Twitter [16,20].

Each of these frameworks highlights the potential for social media sites to achieve various modes of participation. Drawing heavily on the evaluation hierarchy described by Neiger et al, we developed a framework for examining a spectrum of Facebook engagement outcomes (Figure 1). We consider as inputs (1) context, (eg, the social, political, and cultural context in which the campaign occurs), (2) content (eg, quality and content of ads), and (3) setup variables (eg, ad type, target audience, budget, and so on). These are then processed through Facebook's optimization algorithms or the "prism" that leads to Facebook engagement. These can be classified along a spectrum ranging from low to high levels of engagement, wherein we have included, where possible, metrics specific to the Facebook advertising platform.

In the lower engagement range, Facebook users are observing (red), "liking" (orange), and exploring content by clicking on links to photos, videos, and websites (yellow). At these levels, a campaign's goals include reaching the targeted audience, establishing a community of followers to receive ongoing content, and delivering information. In the higher engagement range, Facebook users are establishing connections by sharing posts or commenting (green) and conversing on the Facebook platform (blue). Goals at the higher levels of engagement may include stimulating peer-to-peer content sharing, identifying and addressing questions and concerns from the public, or establishing partnerships. The highest level of engagement, which we have delineated as "implementation" (purple), is an action step taken outside of the Facebook domain (eg, attending an event, or enrolling in a research study.)

This Facebook ad campaign took a population-based approach to achieving engagement across the spectrum by creating a forum for multi-way interaction. In this paper, we present and apply the spectrum of Facebook engagement outcomes framework to describe the campaign. We then consider the implications of these results for public health communicators to move beyond passive approaches to achieve a range of communications goals.

Figure 1. A spectrum of Facebook engagement outcomes.



Methods

In the spring of 2015 the University of Michigan's Life Sciences and Society Program ran an 11-week Facebook advertising campaign, with a US $15,000 budget, to raise awareness and understanding of the state's newborn screening and biobanking programs among Michigan Facebook users aged 18-64 years.

Ad Content Preparation

Visual content for the ads included a graphic image of the state of Michigan, 2 animated, ~1-minute videos (using Sparkol VideoScribe software), and 35 photographs of Michigan biobank participants and parents. We took these photos in organized sessions in which we educated 80 individuals (biobank participants or parents of children with bloodspots in the biobank) about Michigan's newborn screening and biobank programs, and then asked them to create posters to share their thoughts. We photographed participants holding up posters they created from the suggested prompts: "Today I learned...;" "I hope...;" "I was spotted in [place of birth];" and "I'll share what I learned because...." Photographed participants were compensated with a US $25 cash card incentive and signed photo release forms that included permission to use images for educational, academic, and research purposes.

We also photographed participants pointing to Michigan locations on their hands, a familiar gesture in this mitten-shaped state. We used the tagline "Where were you spotted?" throughout the campaign, highlighting Michigan locations and soliciting comments from Facebook users indicating where in the state they or their children were born.

We used the University of Michigan School of Public Health logo as our profile image (which appears in all ads) to help establish credibility and to distinguish ourselves from the state health department and the BioTrust.

Ad Types and Ad Sets

Ad content is uploaded onto Facebook's Ads Manager. Using the Ads Manager interface, we selected the objective (ie, "ad type"), budget (total amount spent on an ad type), and "bid type," which determines how costs are incurred (ie, on a per-click or per-viewer basis) and how Facebook will promote the ad (Figure 1). Ad types correspond with advertising objectives defined by Facebook, including page likes, event responses, and app installs. Ad design features such as character limit, image size, and call-to-action buttons vary slightly across ad types. The ad type designation also affects how Facebook optimizes delivery of ads for maximum impact; for example, the type of ad that maximizes "video views" is more likely to be delivered to Facebook users who watch videos.

As shown in Figure 2, our campaign used 4 ad types: (1) A, "page likes," which encouraged users to like our Facebook page; (2) B, "clicks to website"; (3) C, "video views"; and (4) D, "page post engagement," boosting interactions such as comments, shares, and photo views. The campaign included a total of 8 ad sets that varied by budget, schedule, ad type, and bid type. Ad sets had "lifetime budgets" equally apportioned across their target audiences. All ads ran at the bid price automated by Facebook and incurred cost based on clicks (cost per click, CPC), except for ad set B2, which was set to a bid of US $2 per thousand impressions (cost per 1000 impressions, CPM).

Although no ad type aimed to achieve a single engagement goal exclusively, each ad set was designed to hit 1-2 primary engagement goals, noted in Figure 2. For example, "reach" was the primary goal of ad set B2, with inputs that prioritized reach over clicks. Likes were the main objective of ad set A. We designed ad sets B1-B2, C1-C2, and D3 to encourage exploration of our website, videos, and photo albums showing biobank participant perspectives. By incorporating Michigan themes and the comment prompt to input birthplaces, ad sets D1-D2 aimed to promote social connection. Incorporating a hashtag and photos sharing genuine public perspectives about biobanking, we developed ad set D3 to generate conversation.

The video ads are included in Multimedia Appendices 1 and 2; full photo albums can be viewed at facebook.com/mybloodspot.

Figure 2. Facebook ad set examples. All ads targeted Michigan residents aged 18-64 years. Ad set A1 included an additional audience of Michiganders aged 18-64 years interested in parenting. Ad set identifiers (A1-D3) correspond with Table 1 and references within the manuscript.

Target Audience

We focused our campaign on Michigan Facebook users aged 18-64 years. For all but one ad type (A1), we ran ads separately to 3 age groups: 18-30, 31-44, and 45-64 years, differentiating likely biobank participants and their peers from groups likely to include parents of young or adult biobank participants. Content was the same or very similar across age groups, but some language was tailored to address parents and participants specifically (eg, “Where were you spotted?” vs “Where was your kid spotted?”). The “page like” ad (A1) targeted 2 groups: Michigan Facebook users aged 18-64 years generally and those with an “interest” in “parenting, motherhood, or fatherhood.”

Budget and Timeline

We set a timeline for a US $15,000, 11-week campaign to allow us to investigate the 8 ad sets using 4 ad types. Whereas “page like” ads (A1) ran for all 11 weeks, all others ran for 1 to 3 weeks. Overall, we budgeted US $5625 on ads promoting clicks to our website; US $4125 on page like ads; US $3750 on promotion of videos; and US $1500 on “page post engagement” ads.

We spent the most on the ad type promoting website clicks because the site (mybloodspot.org) has more high-quality information on the newborn screening and BioTrust topics than could be conveyed in a single ad. We also dedicated a substantial portion of our budget to page like ads. “Likes” establish a base of followers who will see future page posts, help establish credibility, and increase viral exposure as friends see one another’s likes. At a threshold of 1000, they also allow communicators to view summary statistics reporting demographics and characteristics of fans provided by Facebook’s “Audience Insights” tool.

Planning and implementing the campaign took about 4 months total, requiring weekly team meetings and approximately 20 hours per week time investment from a dedicated staff person (the lead author) with prior experience in community and social media engagement on the Michigan BioTrust to design the communications plan, create ads and wall posts, run the campaigns, and moderate discussions. The staff person created ad content and the website before the campaign; while ads ran, she posted content to the page 1-3 times weekly and moderated discussions, posting 72 comments primarily to respond to questions and concerns. Once the content and communications plan were established, running the campaign took approximately 5-10 hours per week (1-2 hours per day).

Data Collection and Analysis to Evaluate Engagement

Facebook’s Ads Manager provides descriptive statistics from our campaign, including aggregated data reports on “General Metrics,” “Facebook Page Actions,” and “Video Actions.” These reports present metrics on performance and engagement outcomes such as reach, likes, and shares. The first 3 authors manually coded comments to distinguish those that established a social connection (eg, they tagged friends, identified their birthplace) from those that engaged in conversation about newborn screening or biobanking (eg, posting questions, opinions, feelings, personal experiences). Coders also recorded patterns of interaction: frequency of posts per user, length of discussion threads, and the number of participants in discussion threads. To examine themes of user discussion in greater detail, the authors conducted additional content analysis using ATLAS.ti, but these results will be reported in a future manuscript.

Upon consultation with the University of Michigan Institutional Review Board (IRB), this research project was deemed exempt from IRB oversight for human research participant protections.

Results

Overall Campaign Performance

The results of the Facebook advertising campaign overall are presented in Table 1. The campaign reached 1.88 million and led to 9186 page likes, 452 shares, and 642 comments. The average CPC in this campaign was US $0.17, and the CPM was US $0.21.

Level 1: Observation (Red)

The reach of a Facebook ad or campaign is determined not only by ad performance but also by the target audience, the bid, and competition with other ads in the marketplace. In this campaign, 7 ad sets ran with a CPC bid type, each reaching between 87,680 and 345,587 Facebook users. Using 1 ad set with a CPM bid type (B2), we reached 1.2 million Facebook users over 3 weeks.

Table 1. Facebook ad campaign performance

ID[a] Objective & Ad set	Budget, US $	Schedule	Reach	CTR[b], %	Page likes	Web clicks	Video views	PPE[e]	Shares	Comments
A1 Page likes	$4125	Weeks 1-11	146,179	3.57	9009					
B1 Web clicks: CPC[c] bid	$2250	Week 4	345,587	3.77	30	9563			267	99
B2 Web clicks: CPM[d] bid	$3500	Weeks 9-11	1.2 million	0.13	8	6395			25	1
C1 Video views: newborn screening	$1500	Week 3	134,521	0.87	23		85,283		17	—
C2 Video views: biobanking	$2250	Weeks 7-8	302,768	2.27	32		146,197		102	14
D1 Page post engagement: map	$375	Week 5	119,266	10.92	22			12,108	41	374
D2 Photo album engagement: “Where were you spotted?”	$375	Week 5	87,680	11.55	40			7445	—	130
D3 Photo album engagement: posterboard perspectives	$750	Week 6	173,121	9.41	22			16,413	—	24
Totals	$15,000	(All)	1.88 million		9186	15,958	231,480	35,966	452	642

[a] ID: identifier

[b] CTR: click-through rate

[c] CPC: cost per click

[c] CPM: cost per 1000 impressions

[e] PPE: page post engagement

The overall population of Michigan aged 18-64 years is 6.2 million [21]. Facebook identifies the size of our target audience—Michigan Facebook users aged 18-64 years—as 5.2 million. Our campaign reached 36% of this audience (1.88 million individuals). Demographic information about those individuals reached is limited to sex and age. Of individuals reached, 57% (~1.07 million) were female; Michigan’s population is 51% female. We also reached a disproportionately young population (57% reached were aged 18-34 years; see Table 2).

Table 2. Demographic insights into a Facebook ad campaign

Demographic variable[a]	Michigan FB[c] users 18-64 years Audience N=5.3 million %	Michigan FB users 18-64 years Ad reach N=1.88 million %	Michigan FB users 18-64 years Page likes N=~9200[d] %	Michigan population[b] (all ages) N=9.9 million %
Race/ethnicity				
African American	13	NR[e]	~17	14
Hispanic (all)	4	NR	~16	4
All other	83	NR	~67	82
Sex				
Female	53	57	~70	51
Male	45	42	~30	49
Age, years				
18-64	100	100	~100	63
18-24	23	28	~13	10
25-34	26	29	~24	12
35-44	19	22	~20	13
45-64	30	20	~41	28
Household income				
Less than US $50 K	70	NR	NR	51
US $50-$100 K	20	NR	~26	30
More than US $100 K	12	NR	NR (n<1000)	19
Families				
Child in home	NR	NR	~33	29
Parents (all)	32	NR	~71	NR
Education				
Less than diploma	NR	NR	NR	11
High school diploma	23	NR	~29	30
Some college	NR	NR	NR	24
Bachelor’s or associate’s degree	42	NR	~58	24
Advanced degree	5	NR	~12	10

[a] The table presents results from a Facebook ad campaign raising awareness about Michigan’s newborn screening and biobanking programs among Michigan Facebook users aged 18-64 years. Facebook’s ad creation tool is the source of information on the Facebook audience, Michigan Facebook users aged 18-64 years. Facebook’s ad management tool breaks down ad campaign reach by sex and age groupings. All figures are rounded.

[b] Michigan population source: US Census Bureau – State and County QuickFacts. Data derived from Population Estimates, American Community Survey, Census of Population and Housing, State and County Housing Unit Estimates, County Business Patterns, Nonemployer Statistics, Economic Census, Survey of Business Owners, Building Permits. Last revised: Tuesday, December 1, 2015, 16:11:42 EST.

[c] FB: Facebook

[d] Facebook’s “Audience Insights” tool provides information about monthly active Facebook users who have liked a page, provided that the population of a given category is greater than 1000. The N and percentages in this category are presented as estimates because the N is variable over time, owing to changes in user activity.

[e] NR: not reported.

Level 2: Likes (Orange)

We ran a “page like” ad (A1) throughout the 11-week campaign. In Figure 2, we show just one example of the 8 photographs submitted as potential permutations of the ad set; Facebook selected, monitored, tested, and ultimately optimized the reach of the most successful images to get the most page likes. At a cost of US $4125, the “page like” ad set garnered 9009 page likes, accounting for 98% of the 9186 page likes elicited by the ad campaign.

Ads elicited 1803 “post likes” as users liked advertised content (eg, videos or boosted posts). Page post engagement ads (D1-3) generated the most and least expensive post likes in this campaign (754).

Facebook’s “Audience Insights” tool suggests that the people who liked our page skewed heavily female: approximately 70% of those who liked versus 57% of those reached. Parents, Hispanic, and African American Facebook users were also heavily represented among those who liked our page. Divided into 4 age groups, the oldest demographic (45-64 years) had the highest proportion of likes (see Table 2).

Level 3: Exploration (Yellow)

Website click ads (B1-2), video ads (C1-2), and photo albums (D2-3) were created to facilitate deeper exploration and learning. Facebook users could engage with Web content, videos, and photo albums that included descriptions and public opinions of biobanking and newborn screening. Website click ads led to 15,958 clicks through to our website, at a cost of US $0.35 per website click. The website click ad that incurred CPM had a much lower click-through rate (CTR) than the same ad that incurred CPC: 0.13%, compared with 3.77%.

The campaign yielded 231,480 video views, a Facebook metric defined by video views lasting 3 seconds or more. On average, users watched 27.6% of the videos, with a total of 12,909 watching the videos from start to finish, at a cost of US $0.29 per 100% video view. Younger viewers were most responsive to video ads. Facebook reports “relevance scores” for individual ads, a metric on a 1-10 scale that factors in positive and negative user responses. The newborn screening and biobanking ads had relevance scores of 2 and 7, respectively, among older users, compared with 5 and 8, respectively, among users aged 18-30 years.

Photo album sets running for 2 weeks of the campaign elicited 23,858 “page post engagements.”

Level 4: Connection (Green)

Overall, our campaign’s Facebook ads were shared 452 times. Website click ad B1 prompted 59% of all shares (267); this ad ran for 1 week and also elicited 99 comments. “Shares” both broadcast and potentially help legitimize content; health messages may be perceived as more relevant when they are mediated through friends and personal contacts [22]. Shares also drive up an ad’s organic reach. Shares of an ad in set B1, for example, pushed its organic (unpaid) reach to 22,272.

The biobank video ran for 2 weeks and prompted 102 shares.

Page post engagement ads (D1-3) were especially effective for establishing “connection” and had “relevance scores” across all age groups of 9 or 10. The map ad consisted of a graphic image of Michigan and encouraged users to write their (or their child’s) place of birth in the comments. This ad ran 1 week for only US $375. It was shared 41 times and also garnered 374 comments responding to the prompt “where were you spotted?” to build social connection. The “Where Were you Spotted?” photo album also contained a prompt for Facebook users to enter their or their child’s birthplace in the comments. This ad generated 130 comments, 80% of which responded to the prompt, while 20% engaged in conversation about biobanking or newborn screening.

Level 5: Conversation (Blue)

Overall, 659 unique Facebook users contributed 709 comments during the ad campaign, with 642 commenting on ads directly. The vast majority of users posted 1 comment (92%), while 6.7% commented twice and 1% commented 3 to 6 times.

Discussion peaked in weeks 4-8 of the campaign, primarily in response to a Web click ad (B1, 99 comments); the photo albums (D2, 130 comments; D3, 24 comments); and the biobank video ad (C2, 14 comments).

Overall, 176 comments from 127 unique users engaged with the topics of biobanking and newborn screening. Comments included questions about consent, legality, research uses, and privacy rights; personal experiences with newborn screening; feelings of support and opposition; and intentions to opt out or continue participating in the BioTrust.

Comment threads related to public health topics ranged from 2 to 19 comments in length; among 55 threads, 62% were 2-3 comments long; 29% were 4-7 comments long, and 9% were 8-19 comments long. The campaign moderator contributed 15 wall posts and responded to comments 72 times, primarily to address questions and concerns.

Activity on the Facebook page decreased dramatically once advertising stopped, suggesting that ads were critical to both stimulating and maintaining user engagement.

Discussion

The campaign reached 1.88 million Facebook users, yielding a range of engagement outcomes across ad sets that varied by objective, content, budget, duration, and bid type, at a relatively low cost. The page promotion, Web click, and video ads achieved strong results aligned with their objectives: 9009 page likes (US $4125), 15,958 web clicks (US $5578), and 12,909 video views to 100% (US $3750), respectively. “Boosted posts” yielded 528 comments and 35,966 page post engagements (US $1500), with high response rates to comment prompts associated with the “Where were you spotted?” campaign tagline. Overall, the ads led to 452 shares and 642 comments, including 176 discussing newborn screening and biobanking.

As a field, public health has been called to task for underutilizing the value of harnessing the social characteristics of social networking sites to advance the social service of informing, educating, and empowering the public [1,2,17,20,22-25].

Low-level, one-way engagement has been identified as “the stage of engagement where most social media efforts in public health and health promotion languish or terminate” [16]. Dynamic, dialogic approaches open opportunities for the public to share content, ask questions, contribute, advocate, respond, and interact with a community of Facebook users. Public health communicators can in turn listen and respond, adapt messages, answer questions, and gauge and consider public sentiment. In this paper, we have presented a campaign that aimed to achieve engagement goals across 5 stages of engagement—reach, likes, exploration, connection, and conversation—and we have examined the results in a framework that aligns these results with Facebook advertising metrics and situates them in both context and process.

The campaign reached a very large number of individuals (1.88 million Facebook users), especially for a short-term campaign. Specifically, we reached 36% of our potential ~5.2 million Facebook user audience. More examples in the literature would be helpful to determine the typical proportional reach of Facebook ads targeting large populations, and the relative effects of time, budget, and ad settings on maximizing reach among a broad population. In this study, running an ad that incurred cost based on impressions rather than clicks significantly boosted the overall reach of the campaign. Further, overall, funding the campaign allowed us to build our audience and push information out that would not have otherwise been accessible to users.

The campaign's Facebook page ended the campaign with 9186 “likes” and the page promotion ad alone established a fan base in 11 weeks that surpassed those of related but much more well-known and established entities. For example, at the time, the University of Michigan School of Public Health had 7125 likes [26] and the Michigan Department of Health and Human Services had 8572 likes [27]. For further context, we did not approach the fan base of Shakira, with 104 million likes [28].

Other metrics often applied in evaluating Facebook ad performance are CTRs, CPC, and CPM. Benchmark CTRs vary widely by industry and ad type, but a Facebook ad sales representative suggested the goal of 3.0% for this 2015 campaign. Average metrics for nonprofits, according to a 2013 industry publication [29], were 0.21% CTR, US $0.19 CPC, and US $0.52 CPM. In a public health study of the effectiveness of Facebook ads for recruiting survey participants on young adult substance use, a 2011 campaign that cost US $6628 over 13 months reported a CTR of 0.05% and cost US $0.45 per click and US $0.35 per 1000 impressions [6]. Our campaign met or exceeded these values. The average CTR for ads in this campaign optimized for clicks was 4.54%. Page post engagement ads yielded CTRs of 9.41% to 11.5%. The average CPC was US $0.17, and the CPM was US $0.21.

The spectrum framework that we use incorporates metrics such as “clicks” (CTR, CPM, CPC) and “likes” that are readily available on the Facebook platform, and also includes “conversation” that can be analyzed quantitatively and qualitatively to achieve more robust and meaningful evaluation. In this campaign, Web click, video, and page post engagement ads prompted users to explore and discuss public health topics, creating an open and transparent forum for education and discussion of newborn screening and biobanking. Users posted 176 comments on these topics and engaged in 53 relevant discussion threads during the campaign. These patterns of interaction are indicative of participatory learning [19].

These outcomes indicate the potential for social media networking sites to innovate public health communications. Notably, however, raising awareness about Michigan's biobank initiative among its large population of participants and parents presented challenges and risks. The information was unfamiliar, complex, and sensitive. Thus, our campaign needed to present opportunities for users to explore information deeply and to interact, both with our organization and with peers. We used Facebook ads because they had the potential to reach a large audience quickly and economically and facilitate transparent discussion. The content, context, and tone of our awareness campaign were presumably important factors determining interest and engagement among users. The peculiar story of the Michigan BioTrust meant that the relevance of the information we delivered depended on the age and birthplace of the users and children of the users we reached, that conversation was likely sparked by diverging opinions and levels of comfort with the initiative, and that low levels of awareness likely made the information more difficult to deliver and digest.

Factors that have been found to affect engagement outcomes in the context of health promotion on social networking sites include privacy and stigma concerns associated with particular conditions (eg, sexually transmitted diseases, diarrhea); the purpose and utility of a Facebook page or organization (eg, support groups vs public awareness); and the context and content of subject matter [30-32]. Standardized metrics, well-defined terms, attention to context, and detailed reporting of processes will help health researchers to compare outcomes of social media engagement. The prism framework used here (Figure 1) might influence the way communicators plan and analyze the use of Facebook in health education and promotion. Communicators can strategically target engagement outcomes across the spectrum using variable ad types (objectives) and fostering user interaction. Low-level engagement can be valuable in itself or to stimulate higher-level engagement. Active “exploration” can be shallow or deep (eg, a photo view vs extensive reading) but the messaging is still one-way; the next step is to stimulate high-level, multi-way engagement to take advantage of the social aspects that distinguish social networking sites from traditional media [2,18,21-23] and to address the need for more evidence on approaches to stimulating interaction [15,16].

Limitations and Future Studies

Understanding Facebook as a communications platform is a time-intensive endeavor, and the lack of control over algorithms and certain organizational features can be challenging for public health communicators and researchers. A limitation to public health communication via Facebook is that the representativeness of the audience targeted and reached cannot be fully determined through typical epidemiological methods because of Facebook's restrictions on its release of population demographics. However, as a Facebook campaign begins to reach large fractions of the total population, the confidence that the campaign reached the full range of diversity in the population increases. Social networking analysis can provide insight into engagement and its social drivers, but was beyond the scope of this study. More research needs to be done on the dynamics of population-based communications using Facebook and its advertising infrastructure. This campaign ran for a relatively short time span (11 weeks), with minimal Facebook activity before and after the campaign; results might vary for an organization with a more steady, established, and ongoing social media presence. More studies are needed to test specifically how input variables (eg, ad types, bid type) affect engagement outcomes.

Conclusions

The presented case suggests public health communicators can use Facebook ads to spur actions and interactions with users across a spectrum of user engagement by creating ads with diverse ad types and multiple engagement goals. A wide set of inputs filtered through the "prism" of Facebook's algorithms for ad delivery yields an entire spectrum of engagement outcomes. Our results, mapped onto this spectrum of Facebook actions, indicate potential for social networking sites to bring the public into public health communications.

Facebook advertising campaigns can efficiently reach large populations and achieve a range of engagement outcomes by diversifying ad types, bid types, and content. This campaign provided a population-based approach to communication that also increased transparency on a sensitive and complex topic by creating a forum for multi-way interaction. By offering a platform on which individual citizens can access professionals and peers in an open forum, Facebook is a promising tool for meeting the arising objectives of personalized public health.

Acknowledgments

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Facebook video ad to raise statewide awareness of Michigan's newborn screening program.

[MOV File, 128MB - publichealth_v2i1e27_app1.mov]

Multimedia Appendix 2

Facebook video ad to raise statewide awareness of Michigan's large population biobank.

[MOV File, 130MB - publichealth_v2i1e27_app2.mov]

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Abbreviations

BioTrust: Michigan BioTrust for Health
CPC: cost per click
CPM: cost per 1000 impressions
CTR: click-through rate
IRB: Institutional Review Board

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Original Paper

Intragroup Stigma Among Men Who Have Sex with Men: Data Extraction from Craigslist Ads in 11 Cities in the United States

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Abstract

Background: Gay, bisexual, and other men who have sex with men (MSM) regularly experience homophobic discrimination and stigma. While previous research has examined homophobic and HIV-related intergroup stigma originating from non-MSM directed at MSM, less is known about intragroup stigma originating from within MSM communities. While some research has examined intragroup stigma, this research has focused mostly on HIV-related stigma. Intragroup stigma may have a unique influence on sexual risk-taking behaviors as it occurs between sexual partners. Online sexual networking venues provide a unique opportunity to examine this type of stigma.

Objective: The purpose of this study is to examine the presence and patterns of various types of intragroup stigma represented in Men Seeking Men Craigslist sex ads.

Methods: Data were collected from ads on Craigslist sites from 11 of the 12 US metropolitan statistical areas with the highest HIV/AIDS prevalence. Two categories of data were collected: self-reported characteristics of the authors and reported biases in the ads. Chi-square tests were used to examine patterns of biases across cities and author characteristics.

Results: Biases were rarely reported in the ads. The most commonly reported biases were against men who were not “disease and drug free (DDF),” representing stigma against men living with HIV or a sexually transmitted infection. Patterns in bias reporting occurred across cities and author characteristics. There were no variations based on race, but ageism (mostly against older men) varied based on the ad author’s age and self-reported DDF status; bias against feminine gender expression varied based on self-reported sexual orientation; bias against “fat” men varied by self-reported DDF status; bias against “ugly” men varied by a self-report of being good-looking; and bias against people who do not have a DDF status varied based on self-reported HIV status and self-reported DDF status.

Conclusions: Despite an overall low reporting of biases in ads, these findings suggest that there is a need to address intragroup stigma within MSM communities. The representation of biases and intragroup stigma on Craigslist may result from internalized stigma among MSM while also perpetuating further internalization of stigma for men who read the sex ads. Understanding patterns in the perpetuation of intragroup stigma can help to better target messages aimed at making cultural and behavioral shifts in the perpetration of intragroup stigma within MSM communities.

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KEYWORDS

stigma, online, MSM, Craigslist, sex ads

Introduction

Experiencing discrimination and stigma may have negative physical and mental health consequences for gay, bisexual, and other men who have sex with men (MSM). Research examining how discrimination among MSM is experienced has addressed two pervasive and often interacting forms of stigma: discrimination based on actual or perceived sexual orientation [1,2] and discrimination based on actual or perceived HIV status [3-5]. Experiences of homophobic or HIV-related stigma have been linked with increased suicide ideation [6-8], depression [6-9], substance use [10-13], and HIV risk [10,12-15] among MSM.

Another form of stigma that MSM may experience is intragroup stigma, defined as stigma within communities of MSM. Intragroup stigma may result from either the internalization of homophobic stigma among MSM or the heterogeneity of the MSM community. Communities of MSM contain a range of individual characteristics, such as race, age, HIV serostatus, etc, which could act as the basis for the generation of stigma within the MSM community. Research has examined how HIV stigma has been perpetuated among MSM; this type of intragroup stigma can lead to a rift or fracture within MSM communities with divisions based on HIV serostatus [16-18]. Intragroup stigma among MSM may also exist based on other characteristics, such as sexual orientation, race, class, gender identity, and body size; however, these other forms of possible stigma have received less research attention. Intragroup stigma among MSM is important to examine because it may have a different influence on health than intergroup stigma. Unlike intergroup stigma, intragroup stigma can be perpetuated by romantic and/or sexual partners, which may have implications for sexual risk and the negotiation of sexual encounters.

A useful source for examining intragroup stigma among MSM and between sexual partners is through Internet-based sex-seeking websites and apps. Online sex-seeking has become increasingly popular [19,20]; an estimated 40% of MSM in the United States have used the Internet to look for a sex partner [21-25]. Research suggests that MSM who have met their partners online report more sex partners [23,24,26,27], a higher prevalence of condomless anal intercourse [24,27,28], and a higher prevalence of sexually transmitted infections (STIs) [23,24,29-31]. However, research examining men seeking sex on Craigslist, a classified advertisements website, also states that the impact of online sex-seeking on MSM's sexual risk-taking behaviors depends on the number of ads posted and the success of those ads [32]. The Internet may also have some protective factors for sexual risk-taking, such as increased negotiation around sex [33-37]. The online environment allows men seeking sex to negotiate location and type of sex and enables disclosure of information, including serostatus, prior to meeting. In a study by Grov et al, men who met their most recent sex partner online were more likely to disclose their HIV status compared with men who had met their most recent partner at other public places [25]. One reason for this increased negotiation may be the anonymity of meeting online partners. However, the anonymity, invisibility, and lack of eye contact inherent in online interactions may also result in online disinhibition, allowing those seeking sex online to say things that they would not say face-to-face [38-40], including discriminatory or stigmatizing statements. In this study, we explore whether the authors of sex ads report biases in their ads as a measure of the presence of stigma internal to the MSM community. Understanding the presence and forms of internal stigma in sex ads has the potential to inform messages aimed at risk prevention and stigma reduction among those seeking sex in online forums.

Methods

Data were collected from 11 of the 12 metropolitan statistical areas (MSAs) with the highest HIV/AIDS prevalence in the United States, ranked by the Enhanced Comprehensive HIV Prevention Planning (ECHPP) project [41]. We chose MSAs with a high prevalence of HIV/AIDS to understand the presence and possible implications of intragroup stigma. The 12 MSAs include the cities of New York (New York), Los Angeles (California), Washington (District of Columbia), Chicago (Illinois), Atlanta (Georgia), Miami (Florida), Philadelphia (Pennsylvania), Houston (Texas), San Francisco (California), Baltimore (Maryland), Dallas (Texas), and San Juan (Puerto Rico). No Craigslist site exists for San Juan, so data were not collected. Data were extracted from ads on the Men Seeking Men section of the Craigslist sites from each of the cities.

Data collection was performed consecutively over 11 days (October 8, 2013 through October 18, 2013) with data collected from 1 city per day. After 2 data analysts developed a codebook with a list of variables for data extraction, they coded the first 50 ads for testing. Once the codebook was tested and finalized, a data analyst used the codebook to extract the data from the remaining ads. To minimize bias, data were collected from the first 200 ads listed before 2:30 PM (a randomly selected time) in each city's time zone, standardizing the time of day for which data were collected across cities. Ads that were not looking for sex (eg, ads selling sex toys) or where couples created an ad together were excluded. This allowed for the correct identification of author characteristics. The total sample size included 2200 sex ads (200 per city). No identifying information was collected, and there was no interaction between the data collector and the subjects. Data were extracted from ads, entered into an Excel (Microsoft Corp) spreadsheet, and imported into STATA version 13.1 (StataCorp LP) for analysis.

We collected two types of variables: self-reported characteristics of the ad authors and reported biases in the ads. Domains not mentioned were coded as such in the data set. Self-reported characteristics included race/ethnicity (white, black, Latino, Asian, other); age (entered as a continuous variable and later categorized into age groups 18-25, 26-35, 36-45, 46 and above); sexual orientation (homosexual, heterosexual, bisexual); HIV status (negative, positive); self-reported "disease and drug free" status ("DDF," "clean," "healthy"); and self-reported physical appearance ("good looking," "not good looking"). We use the terms "DDF," "clean," and "healthy" throughout this paper because those are the terms used by the sex ad authors. Since some characteristics were present in very few ads, categories were combined when analyzing the data. For characteristics, the race categories were combined to include only white, black, and other, and "DDF," "clean," and "healthy" were combined in one DDF status category.

Biases were defined as an ad in which the author specifically reported not wanting a characteristic in a sex partner or an ad that used stigmatizing language. The ad had to contain language stating "no X" or "X only," with X representing a specific characteristic. For example, an ad was coded as including a bias if it included language such as "no HIV positive guys" or "white men only." The following biases were collected: racism (saying no to black/Latino/Asian/other partners), ageism (saying no to a particular age group/range), weightism (saying no to "fat" or "underweight" men), heightism (saying no to tall or short men), transphobia (saying no to transgender people), physical appearance (saying no "ugly" men), gender expression (saying no "feminine" men or "no femmes"), HIV stigma (saying no "positive" men), and DDF status (saying must be "DDF," "clean," or "healthy"). DDF status was included as a bias because the terms "DDF," "clean," and "healthy" were considered stigmatizing language [34,42]. When a bias was present, it was entered into the codebook as a 1, and when it was not present it was entered as a 0. Data were analyzed using chi-square tests to determine variation in the demographic characteristics and biases across the 11 cities and across the demographic characteristics. Fisher exact tests were used when a demographic characteristic or bias was present fewer than 5 times. The alpha denoting significance was .05.

Results

Sample Characteristics

The self-reported characteristics of the ad authors are described in Multimedia Appendix 1. The majority of the ads had minimal information about author characteristics. Among ads that contained race or ethnicity (853/2200, 38.77%), 63.4% (541/853) of the authors were white, 17.1% (146/853) were black, and 19.5% (166/853) were of another race (including Latino, Asian, and those who reported as other). Reporting of race was significantly different across the 11 cities (*P*<.001), with Baltimore representing the highest percentage of authors self-reporting race (104/200, 52.0%). Among those who self-reported race, Philadelphia represented the highest percentage of authors identifying as white (46/57, 80.7%). Miami and Los Angeles had a smaller percentage of ads with authors self-reporting as white (Miami, 23/48, 47.9%; Los Angeles, 49/98, 50.0%), with more of the authors in these cities identifying as Latino (Miami, 16/48, 33.3%; Los Angeles, 35/98, 35.7%). Most ads reported age (1991/2200, 90.50%), and age reporting in ads varied significantly across the cities (*P*=.003). Among ads reporting age, the modal age group of the authors was 26 to 35 years (689/1991, 34.61%), with Chicago representing the highest percentage of ads in this age group (80/187, 42.8%). Sexual orientation was not reported in the majority of ads; of those that did report sexual orientation (174/2200, 7.91%), 77.6% (135/174) of the authors reported being bisexual, 18.4% (32/174) heterosexual, and 4.0% (7/174) homosexual. Reporting of sexual orientation varied significantly across the cities (*P*<.001), with 16.0% (23/200) mentioning sexual orientation in New York and only 2.5% (5/200) mentioning it in Houston. Self-reports of HIV status were also low, with 86.50% (1903/2200) not mentioning their status. Among the ads that did mention self-reported HIV status (297/2200, 13.50%), 97.0% reported a negative serostatus. These reports of HIV status varied significantly across the 11 cities (*P*<.001); only 9.0% (18/200) of ads in New York self-reported HIV status compared to 26.0% (52/200) in Los Angeles. In addition, among men who did report HIV status, ads in Baltimore (n=20) were more likely to report a positive HIV status (3/20, 1.5%) compared with other cities. Among ads that contained self-reported DDF status (698/2200, 31.73%), 85.8% of authors reported being "DDF," 13.9% reported being "clean," and 0.3% reported being "healthy." There were significant variations in DDF status across the cities (*P*<.001) with Houston representing the highest percentage of ads with authors describing themselves as "DDF," "clean," or "healthy" (73/200, 36.5%). The percentage of ads that contained reports of physical appearance (368/2200, 16.73%) varied significantly across the cities (*P*<.001) with Los Angeles and San Francisco representing the highest percentages of authors who reported being "good looking" (23.5% in both cities).

Reported Biases

Overview of Biases

Overall, there were very few explicit reports of biases. Bias against men who are not "DDF" was the mostly commonly reported, with 24.55% (540/2200) of ads mentioning the need for a "DDF," "clean," or "healthy" partner. There were also more biases against physical appearance than most other biases with 4.36% (96/2200) of ads containing bias against "ugly" men. Weightism, which almost exclusively comprised bias against "fat" men, was reported in 2.32% (51/2200) of ads. Bias against gender expression, comprising bias against "feminine" men, was reported in 1.9% of the ads. Among ads with ageist biases (34/2200, 1.55%), most reports were against older men (32/34, 94.1%). There was very little racial bias reported (7/2200, 0.32%); these biases were reported against white men (n=4) and black men (n=3). Homophobia was the lowest reported bias with only 1 ad (1/2200) expressing bias against homosexual men (0.05%). No ads contained reports of bias against height, transgender people, or HIV status.

Variations in Biases by City

Variations in reported biases by city are presented in Tables 1-3 and reported by region (Northeast, South, and Midwest/West). Variations in self-reported biases by city were only significant for 3 variables: bias against physical appearance (*P*<.001), ageism (*P*=.03), and bias against men who are not "DDF" (*P*<.001). Bias against physical appearance was highest in ads from Los Angeles (24/200, 12.0%) and lowest in ads from Baltimore (4/200, 2.0%). Out of 11 cities, 9 contained ads with ageism; no ageist ads were present in New York and Washington. Among ads containing ageism, ageist bias was most present in Los Angeles with 5.0% (10/200) of ads reporting ageism overall and 4.5% (9/200) of ads reporting ageism directed at older men. Bias against men who were not "DDF," "clean," or "healthy" was highest in Dallas (61/200, 30.5%) and lowest in Philadelphia (33/200, 16.5%).

Table 1. Biases stratified by Northeastern cities (N=800).[a]

Biases (*P* value)[b]	MSAs with the highest HIV prevalence in the United States—Northeast				
	Baltimore n (%)	New York n (%)	Philadelphia n (%)	Washington n (%)	Total n (%)
Racism (*P*=.43)	2 (1.0)	1 (0.5)	0 (0.0)	0 (0.0)	3 (0.4)
Ageism (*P*=.03)	3 (1.5)	0 (0.0)	3 (1.5)	0 (0.0)	6 (0.8)
Weightism (*P*=.10)	7 (3.5)	2 (1.0)	2 (1.0)	2 (4.0)	13 (1.6)
Physical appearance (*P*<.001)	4 (2.0)	10 (5.0)	9 (4.5)	6 (3.0)	29 (3.6)
Gender expression (*P*=.83)	5 (2.5)	3 (1.5)	2 (4.0)	3 (1.5)	13 (1.6)
Homophobia (*P*=.44)	0 (0.0)	0 (0.0)	1 (0.5)	0 (0.0)	1 (0.1)
DDF status (*P*=.001)	55 (27.5)	48 (24.0)	33 (16.5)	55 (27.5)	191 (23.9)

[a] n=200 in each city.

[b] *P* value is based on comparisons among all 11 cities.

Table 2. Biases stratified by Southern cities (N=800).[a]

Biases (*P* value)[b]	MSAs with the highest HIV prevalence in the United States—South				
	Atlanta n (%)	Dallas n (%)	Houston n (%)	Miami n (%)	Total n (%)
Racism (*P*=.43)	1 (0.5)	1 (0.5)	1 (0.5)	1 (0.5)	4 (0.5)
Ageism (*P*=.03)	1 (0.5)	1 (0.5)	3 (1.5)	4 (2.0)	9 (1.1)
Weightism (*P*=.10)	0 (0.0)	5 (2.5)	6 (3.0)	7 (3.5)	18 (2.3)
Physical appearance (*P*<.001)	6 (3.0)	11 (5.5)	7 (3.5)	5 (2.5)	29 (3.6)
Gender expression (*P*=.83)	2 (1.0)	5 (2.5)	3 (1.5)	4 (2.0)	14 (1.8)
Homophobia (*P*=.44)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)
DDF status (*P*=.001)	40 (20.0)	61 (30.5)	52 (26.0)	46 (23.0)	199 (24.9)

[a] n=200 in each city.

[b] *P* value is based on comparisons among all 11 cities.

Table 3. Biases stratified by Midwestern and Western cities (N=600).[a]

Biases (*P* value)[b]	MSAs with the highest HIV prevalence in the United States—Midwest and West			
	Chicago n (%)	Los Angeles n (%)	San Francisco n (%)	Total n (%)
Racism (*P*=.43)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)
Ageism (*P*=.03)	4 (2.0)	10 (5.0)	5 (2.5)	19 (3.2)
Weightism (*P*=.10)	9 (4.5)	3 (1.5)	6 (3.0)	18 (3.0)
Physical appearance (*P*<.001)	8 (4.0)	24 (12.0)	6 (3.0)	38 (6.3)
Gender expression (*P*=.83)	2 (1.0)	4 (2.0)	7 (3.5)	13 (2.2)
Homophobia (*P*=.44)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)
DDF status (*P*=.001)	45 (22.5)	49 (24.5)	56 (28.0)	150 (25.0)

[a] n=200 in each city.

[b] *P* value is based on comparisons among all 11 cities.

Variations in Biases by Sample Characteristics

Variations in biases by author characteristics are presented in Table 4. We found no statistically significant variation in biases based on the author's race; however, there was variation on at least one reported type of bias for all other characteristics. Although more than 98.08% (2166/2200) of all ads across age groups contained no reports of ageism, reported ageism varied significantly by the age of the ad author (*P*=.006); 2.9% (11/381) of ads authored by those aged 18 to 25 years contained ageism compared to those aged 36 to 45 years (1/537, 0.2%) and aged 46 years and older (5/384, 1.3%). Only men in the 26 to 35 years age group reported ageism directed at younger men (n=2). Ageism also varied based on DDF status. Ads authored by men who self-report as “DDF” were more likely to contain ageism (13/698, 1.9%) compared to those authored by men who did not mention their DDF status (*P*=.04).

Bias against feminine men varied significantly by the sexual orientation of the ad author (*P*<.001). Although 98.09% (2158/2200) of the ads across authors of all sexual orientations contained no bias against feminine men, 6.7% (9/135) of ads authored by bisexual men and 6.3% (2/32) of ads authored by straight men contained bias against feminine men. Men who identified as homosexual reported no bias against feminine men.

Bias against men who are not “DDF” varied by HIV status (*P*<.001) and self-reported DDF status (*P*<.001). Men who reported a negative HIV serostatus were more likely to report bias against men who are not “DDF,” “clean,” or “healthy” (96/288, 33.3%) when compared with men who report a positive HIV serostatus (2/9, 22.2%) or men who did not mention serostatus (532/1903, 27.96%). Among men who reported a DDF status, 39.4% (275/698) reported bias to be with men who report a DDF status. Among men who do not report a DDF status, only 17.64% (265/1502) report a bias for a partner who is “DDF,” “clean,” or “healthy.”

Weightism varied significantly by the DDF status of the author (*P*=.04); 3.2% (22/698) of ads authored by men who identify as “DDF” contained weightism compared to 1.9% (29/1502) of ads authored by men who did not report their DDF status. Bias based on physical appearance varied significantly by the author’s self-report of being “good looking” (*P*<.001). Men who report being “good looking” are more likely to report bias against “ugly” men (44/368, 12.0%) compared to men who do not mention physical appearance (52/1832, 2.84%). The difference in reports of homophobic bias by age group was statistically significant (*P*=.05), but this was not a substantial finding because only 1 ad reported homophobic bias and this author did not mention his age.

Table 4. Variations in biases by author characteristics for all cities (N=2200).

Characteristics of ad authors		Biases							
		Racism	Ageism	Weightism	Physical appearance	Gender expression	Homophobia	DDF	Total n
Race, *P* value		.11	.87	.06	.11	.09	.99	.79	
	White, n (%)	2 (0.4)	4 (0.7)	10 (1.9)	23 (4.3)	7 (1.3)	0 (0.0)	125 (23.0)	541
	Black, n (%)	0 (0.0)	4 (2.7)	6 (4.1)	1 (0.7)	7 (4.8)	0 (0.0)	35 (24.0)	146
	Other, n (%)	0 (0.0)	3 (1.8)	5 (0.9)	11 (2.0)	5 (0.9)	0 (0.0)	39 (7.2)	166
	Not mentioned, n (%)	2 (0.3)	23 (1.8)	30 (2.2)	61 (4.5)	23 (1.7)	1 (0.1)	275 (25.1)	1347
Age, *P* value		.35	.006	.85	.09	.10	.049	0.88	
	18-25, n (%)	0 (0.0)	11 (2.9)	10 (2.6)	20 (5.3)	12 (3.2)	0 (0.0)	96 (25.2)	381
	26-35, n (%)	0 (0.0)	17 (2.5)	17 (2.5)	39 (5.7)	17 (2.5)	0 (0.0)	177 (25.7)	689
	36-45, n (%)	1 (0.2)	1 (0.2)	9 (1.7)	21 (3.9)	6 (1.1)	0 (0.0)	131 (24.4)	537
	46+, n (%)	3 (0.8)	5 (1.3)	10 (2.6)	9 (2.3)	5 (1.3)	0 (0.0)	87 (22.7)	384
	Not mentioned, n (%)	2 (1.0)	0 (0.0)	5 (2.4)	7 (3.4)	2 (1.0)	1 (0.5)	49 (23.5)	209
Sexual orientation, *P* value		.10	.46	.30	.93	<.001	.99	.56	
	Homosexual, n (%)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	1 (14.3)	7
	Straight, n (%)	0 (0.0)	0 (0.0)	0 (0.0)	1 (3.1)	2 (6.3)	0 (0.0)	11 (34.4)	32
	Bisexual, n (%)	0 (0.0)	5 (3.7)	6 (4.4)	6 (4.4)	9 (6.7)	0 (0.0)	36 (26.7)	135
	Not mentioned, n (%)	7 (0.4)	29 (1.4)	45 (2.2)	89 (4.4)	31 (1.5)	1 (0.1)	492 (24.3)	2026
HIV status, *P* value		.26	.96	.77	.47	.89	.93	<.001	
	Negative, n (%)	2 (0.7)	5 (1.7)	8 (2.8)	16 (5.6)	6 (2.1)	0 (0.0)	96 (33.3)	228
	Positive, n (%)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	2 (22.2)	9
	Not mentioned, n (%)	5 (0.3)	29 (1.5)	44 (2.3)	80 (4.2)	36 (1.9)	1 (0.1)	532 (28.0)	1903
DDF status, *P* value		.13	.04	.04	.27	.37	.93	<.001	
	DDF, n (%)	3 (0.4)	13 (1.9)	22 (3.2)	5.6 (39)	15 (2.1)	0 (0.0)	275 (39.4)	698
	Not mentioned, n (%)	4 (0.3)	21 (1.4)	29 (1.9)	3.8 (57)	20 (1.8)	1 (0.1)	265 (17.7)	1502
Physical appearance, *P* value		.67	.10	.58	<.001	.21	.65	.14	
	Good looking, n (%)	1 (0.3)	10 (2.8)	10 (2.7)	44 (12.0)	10 (2.7)	0 (0.0)	91 (24.7)	368

Characteristics of ad authors		Biases							
		Racism	Ageism	Weightism	Physical appearance	Gender expression	Homophobia	DDF	Total n
	Not mentioned, n (%)	3 (0.2)	(24 (1.4)	41 (2.2)	52 (2.8)	32 (1.8)	1 (0.1)	449 (24.5)	1832
Total		7 (0.3)	34 (1.6)	51 (2.3)	96 (4.4)	42 (1.9)	1 (0.1)	540 (24.6)	2200

Discussion

Principal Findings

These findings provide insight into the representation of biases and intragroup stigma among MSM using Craigslist to seek sex with other men. Overall, very few biases were reported. This could be indicative of the unique formatting of Craigslist ads. Since there is no prescribed form for authors to complete, we found great variation in how ads were presented. In most cases, ads included very little information, resulting in limited reports of both author characteristics and biases. However, biases that were present still showed patterns and variation.

DDF bias was the most pervasive. The saliency of using the term “DDF” is consistent with previous research examining Craigslist Men Seeking Men sex ads [43]. The use of the terms “DDF,” “clean,” and “healthy” to describe people living without HIV or STIs is stigmatizing as it implies that those who are living with HIV or an STI are “diseased” and “dirty” [34,42,44]. We also found that men who described themselves as HIV negative or as “DDF” were more likely to also present a bias to be with men who are “DDF.” Similar patterns have been found in previous research; in a qualitative study examining men who posted sex ads on Craigslist, only men with an HIV negative serostatus used the term “DDF” [34]. When terms such as “DDF” and “clean” are used by MSM with an HIV negative serostatus to describe MSM living with HIV or an STI, it contributes to intragroup HIV-related stigma and can create further serostatus-based rifts within the community [16-18]. In addition, our findings showed more variation in stigma based on an author’s self-identified DDF status than any other characteristic, indicating that men who use this stigmatizing terminology may also be more likely to perpetuate other forms of stigma.

Another important finding from these data is that when men reported sexual orientation, most men identified as straight or bisexual; bias against feminine gender expression was only present in ads by these authors. This bias was only present in 1.9% of ads overall, but this finding provides insight into who is perpetuating bias against feminine gender expression. Previous research has identified a subgroup of non-gay-identified men on Craigslist who seek sex from other non-gay-identified men (who they may believe will present as more stereotypically masculine) [45-47]. The frequency of non-gay-identified men on Craigslist may be a result of the increased anonymity and invisibility of the online environment; Craigslist sex ads may be a more private way for non-gay-identified men to seek sex with men. The representation of bias against feminine gender expression may be reflective of the endorsement of hegemonic masculinity and stigma against men who deviate from expressing their masculinity in a way that is considered normative. The endorsement of hegemonic masculinity fails to recognize the fluid and nondichotomous nature of men’s gender expression [48], specifically defining masculinity in a way that is heterosexual [48-50]. Therefore, the endorsement of hegemonic masculinity exclusively by non-gay-identified MSM may indicate internalized stigma; this subgroup of men do not identify as gay, but their behaviors conflict with hegemonic masculinities because they are seeking sex with other men. While this representation of stigma may be an indication of the internalization of stigma, the bias against feminine gender expression may also be explained by a phenomenon where non-gay-identified men seek other men who are also non-gay-identified (who may be believed to present as more stereotypically masculine) because of a belief that there is a shared desire for privacy and nondisclosure about same-sex encounters [46]. Regardless of the reason behind why this subgroup presents it, this stated bias endorses hegemonic masculinity and stigmatizes those ad readers whose gender expression does not fit the stereotypical ideals of masculinity.

The presence of stigma in online sex ads may contribute to poor mental health and increased sexual risk for those who are seeking sex online. Men who have characteristics that are described in ads as undesirable may experience a fear of rejection, loneliness, and reduced self-esteem. These men may also perceive themselves as having less bargaining power when negotiating sex, possibly increasing sexual risk; previous research has examined how homophobic discrimination may influence behaviors associated with higher risk for HIV, including nondisclosure of HIV status [5,51,52] and condomless anal intercourse [11-14,53-55]. These biases may also contribute to internalized stigma among readers of the sex ads [5]. Previous research has found that internalized HIV stigma (the most prevalent form of stigma in this study) may lead to poor mental health outcomes, including depression and reduced self-esteem [3-5,56-58]. Internalized HIV stigma can also increase sexual risk-taking behaviors, including nondisclosure of HIV status to a sex partner [56,59,60] and increased drug use [60].

Limitations

The ad authors represented in this study are limited to men who are actively seeking sex partners online. Men who seek sex partners on Craigslist differ in characteristics from men seeking partners offline [25,61,62] and may differ from men seeking partners through other online or app-based venues. Therefore, the results cannot be generalized to all MSM. Furthermore, this study analyzed Craigslist sites from 11 cities with the highest HIV prevalence in the United States; thus they may not be generalizable to cities with low HIV prevalence or to nonurban areas. We are also unable to verify the authenticity of the information posted on the ads, including the identities of the ad authors. Research indicates that online dating profiles and sex ads may misrepresent MSM demographics [63] resulting in possible misreporting of data for this study. However, despite any possible misrepresentations, we were still able to examine the representation of stigma within ads that are on Craigslist.

Conclusions

Despite an overall low reporting of biases in ads, these findings provide insight into patterns of stigma represented on Craigslist Men Seeking Men sex ads. These findings suggest that there is a need to address intragroup stigma within MSM communities; it is important to focus on HIV-related stigma among MSM, but it is also useful to understand other forms of intragroup stigma and how they may influence mental health outcomes and sexual risk-taking behaviors, especially for MSM who are seeking sex online. Understanding patterns in the perpetuation of intragroup stigma can help to better target messages aimed at making cultural and behavioral shifts in the perpetration of intragroup stigma within MSM communities.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Descriptive statistics of sample characteristics.

[PDF File (Adobe PDF File), 79KB - publichealth_v2i1e4_app1.pdf]

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Abbreviations

DDF: disease and drug free
ECHPP: Enhanced Comprehensive HIV Prevention Planning
MSA: metropolitan statistical area
MSM: men who have sex with men
STI: sexually transmitted infection

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Original Paper

Factors Associated With Condom Breakage During Anal Intercourse: A Cross-Sectional Study of Men Who Have Sex With Men Recruited in an Online Survey

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Abstract

Background: Within the United States, HIV affects men who have sex with men (MSM) disproportionally compared to the general population. In 2011, MSM represented nearly two-thirds of all new HIV infections while representing less than 2% of the US male population. Condoms continue to be the foundation of many HIV prevention programs; however, the failure rate of condoms during anal intercourse among MSM is estimated to be 0.5% to 8%, and condom breakages leave those affected at high risk for HIV transmission.

Objective: Estimate the frequency of condom breakage and associated demographic and behavioral factors during last act of anal intercourse using data from a national online HIV prevention survey of MSM.

Methods: From March 19 to April 16, 2009, data were collected on 9005 MSM through an online survey of US MSM recruited through a social networking site. Using multivariable logistic regression and controlling for several demographic and sexual risk behaviors, we estimated odds ratios of the association between condom breakage and several risk factors.

Results: In the study, 8063 participants reported having at least one male sexual partner in the last 12 months. The median age of participants was 21 years (range 18-65). More than two-thirds (68.2%, 5498/8063) reported anal intercourse during last sex and 16.90% (927/5498) reported using a condom during last anal intercourse act. Condom breakage was reported by 4.4% (28/635) participants who engaged in receptive anal intercourse and 3.5% (16/459) participants who engaged in insertive anal intercourse, with an overall failure rate of 4.0% (95% CI 3.2%-6.0%). Age (adjusted odds ratio [aOR] per 5 years: 0.53 (95% CI 0.30-0.94), number of male sex partners (aOR per 5 sex partners: 1.03 (95% CI 1.00-1.08), and being high or buzzed during sex with a casual sex partner (aOR: 3.14, 95% CI 1.02-9.60) were associated with condom breakage.

Conclusions: Our results indicate condom breakage is an important problem for MSM that may be more common for younger men, for men with more partners, and during sex with casual partners after alcohol consumption or drug use. A better understanding of why condom breakage occurs more often in these groups is needed to improve educational efforts. Further, during this time of expanded interest in new condom designs, consideration should be given to how condom design might minimize breakage during anal sex.

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KEYWORDS

MSM; anal intercourse; condoms; condom failure

Introduction

Men who have sex with men (MSM) continue to be disproportionately affected by HIV/AIDS in the United States. MSM represent less than 2% of the male population in the Unites States, but male-to-male sexual contact remains the predominant mode of HIV transmission, accounting for an estimated 65% of all new HIV diagnoses in 2011 [1,2]. Further, since 2008, the proportion of HIV diagnoses attributable to male-to-male sexual contact and the rate of HIV transmission among MSM continued to increase while trends for other transmission categories and groups have remained the same or declined [1-3]. The high prevalence of condomless anal intercourse among MSM coupled with the fact that anal intercourse is associated with greater HIV transmission probabilities compared to vaginal intercourse provides some explanation of the large burden of disease experienced among MSM [4-9].

Despite suboptimal utilization, male condoms have been and remain a constant in HIV prevention programs due to their effectiveness in reducing transmission of HIV/STIs when used correctly and consistently [10-17]. To date, however, the US Food and Drug Administration has only cleared condoms for use during vaginal intercourse and has warned against the use of condoms during anal intercourse [18]. Because of the physiological differences between anal intercourse and vaginal intercourse, such as friction and compression, it is possible that condoms break differentially by application [19-20].

Condom failure, defined as breakage or slippage of a condom during intercourse, can obviate the prevention benefit of condom usage, but data on condom failure rates and condom failure during specific sex acts have produced a wide range of failure rates [10,21-28]. In two separate studies, D'Anna et al reported higher rates of condom breakage or slippage during vaginal intercourse among heterosexual couples (6%) compared to anal intercourse among MSM couples (3%) [22,23]. Other studies have shown similarly low rates of condom failure (per condom use) among those engaging in anal intercourse (2%-3%), compared to vaginal intercourse [10,24-26].

Data on predictors of condom failure among MSM is limited. Penile length and circumference, absence of lubricants, race, and lower socioeconomic status have all been associated with higher rates of condom failure [29,30]. Further identification of behaviors associated with condom failure is key in order to identify high-risk groups and behaviors that would benefit from targeted condom education. Using data from a national online HIV prevention survey of MSM, we aimed to document how often condom breakage was reported to occur during anal intercourse between MSM and to identify demographic and behavioral characteristics associated with condom breakage during an act of anal intercourse.

Methods

Recruitment and Ethics

We utilized data from the Barriers to Online Prevention Research survey of US MSM collected between March 19, 2009 and April 16, 2009. The methods have been previously reported [31]. Briefly, participants were recruited from MySpace, a large social networking site, using banner advertisements. Advertisements were directed at male users of MySpace18 years or older who resided within the United States. Once the banner advertisement was clicked, individuals were screened for eligibility and provided informed consent. Eligible participants included men 18 years or older who had at least one male sex partner in the past year and were residents of the United States. Eligible men were then asked to complete a Health Insurance Portability and Accountability Act-compliant online survey on SurveyGizmo (Boulder, CO). The survey took approximately 30 to 45 minutes to complete, and no compensation was provided to participants. The study protocol was approved by the Emory University Institutional Review Board.

Data Collection

Participants were asked a series of questions regarding demographics, sexual history, most recent sex act, and most recent sexual partner. Specifically, participants were asked to report the number of male sexual partners in the last 12 months and if they were high or buzzed during last act sex act. Participants were also asked questions pertaining to their most recent sex partner, such as if he was a main or casual partner. A main partner was defined as someone that the participant felt committed to above all others, and a casual partner was defined as one whom the participant did not feel committed to above all others. With regard to their last sexual partner, participants were asked whether they engaged in anal and/or oral sex with him, if a condom was used, and if the condom broke during last anal intercourse. A copy of the survey items relevant to the present study can be seen in Multimedia Appendix 1.

Our outcome measure, condom breakage, was assessed via a categorical response to two separate questions designed to capture both receptive and anal insertive sex acts. Men were first asked if they had receptive anal intercourse, insertive anal intercourse, or both during their last sex episode. Based on their responses, men were asked separately about condom use when they were the receptive and/or insertive partner. Questions were: "Did [your last sexual partner] use a condom the last time you had *receptive* anal sex?" and "Did you use a condom the last time you had *insertive* anal sex?" Responses for both questions included "He (I) did not use a condom," "He (I) used a condom part of the time," "He (I) used a condom the whole time," "He (I) used a condom but it broke," "Don't know," or "Prefer not to answer." Condom breakage was defined as answering "He (I) used a condom but it broke" for either insertive or receptive anal sex acts with the last male sex partner of the participant.

Data Analysis

Data were analyzed using SAS version 9.4 (SAS Institute). Participants included in the final analysis reported engaging in receptive or insertive anal intercourse with their last male partner in the past 12 months and using a condom during last anal intercourse. Bivariate analyses were conducted to examine unadjusted correlates of condom breakage. For continuous variables, a Wilcoxon rank-sum *z* test (two-sided) was used due to the nonnormally distributed nature of the variables. Statistically significant covariates (*P* value ≤.05) were included in the final model, as were variables found to be associated with condom breakage in previous studies [20-22,25,32,33].

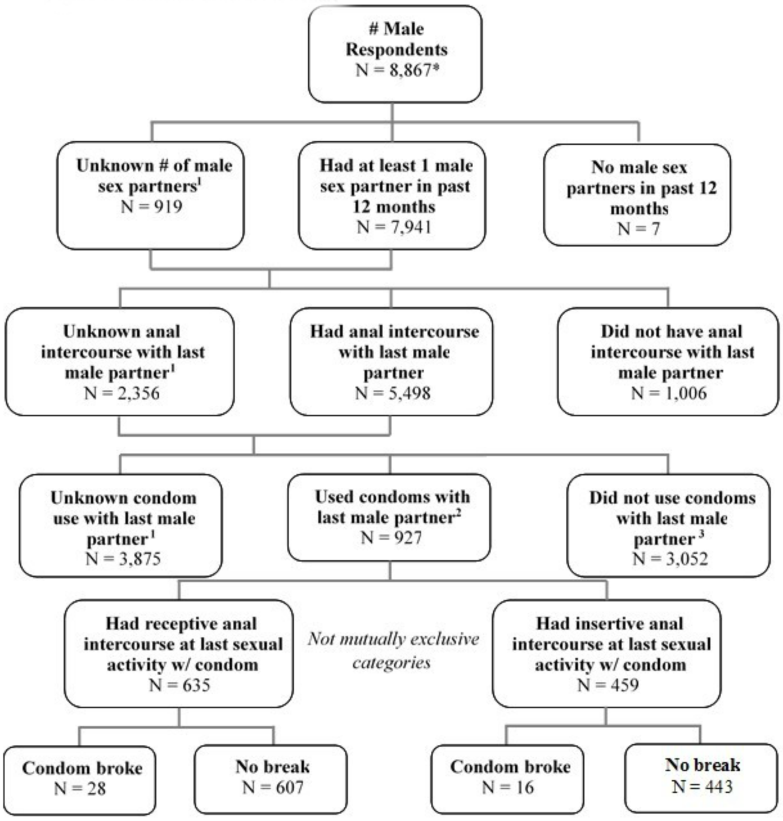
The dependent variable, condom breakage, was calculated as a proportion and modeled the event level for both receptive and insertive anal intercourse at last sex. Thus, one participant could contribute two observations (one for receptive and one for insertive sex) from his last sexual episode. Multivariable analysis was conducted using multivariable logistic regression controlling for repeated observations. Odds ratios and 95% confidence intervals were calculated for categorical variables. For continuous variables, odds ratios and confidence intervals per unit of 5 were calculated.

Results

A total of 9005 participants completed the initial screening questions and gave consent; 133 surveys were linked to duplicate IP addresses and were therefore excluded. Of the 8872 unique surveys completed, 62.0% (5498/8872) were completed by men who reported anal intercourse at last sex; 44.0% (3875/8872) did not know if they used a condom at last anal intercourse. A total of 10.4% (927/8872 of the surveys were completed by participants who reported condom use at last sex and thus were eligible for multivariable analysis. Figure 1 describes how participants were classified and identified for inclusion in the analysis.

Demographic information on the 927 participants who reported using a condom at last anal intercourse and the 3052 participants who reported not using a condom at last anal intercourse is provided in Table 1.

Figure 1. Inclusion criteria flowchart.



* Excludes 138 duplicate records with the same IP address.

[1] Includes participants who dropped out of the survey, refused to answer the question, didn't know, or skipped the question.

[2] Used condoms for either receptive or anal intercourse with another male at last sexual activity (this does not mean they had to use condoms for both anal and receptive intercourse if the participant was involved in both sexual activities).

[3] Participant did not use condoms for both receptive and insertive anal intercourse (if involved with both or either activities).

Table 1. Demographic and behavioral characteristics of men at last act of anal intercourse with a male sexual partner, stratified by condom use, among participants of an online HIV prevention survey, United States, March-April 2009.

Characteristics		Used condoms[a] (N=927) n (%)	Did not use condoms[a] (N=3052) n (%)	Total(N=3979) n (%)
Race/ethnicity [b]				
	Black/African-American	150 (16.3)	354 (11.7)	504 (12.8)
	Latino/Hispanic	365 (39.8)	962 (31.8)	1327 (33.7)
	White/Caucasian	281 (30.6	1375 (45.5)	1656 (42.0)
	Other[c]	122 (13.3)	331 (11.0)	453 (11.5)
Education				
	≤ High school diploma/GED	394 (43.4)	1269 (42.0)	1663 (42.3)
	> High school diploma/GED	516 (56.7)	1752 (58.0)	2268 (57.7)
Age (years), median (range)[b]		21.0 (18-65)	22.0 (18-65)	21.0 (18-65)
Sexual identity [b]				
	Heterosexual/straight	669 (72.6)	2366 (78.2)	3035 (76.9)
	Homosexual/gay	236 (25.6)	628 (20.8)	864 (21.9)
	Other[d]	17 (1.8)	32 (1.1)	49 (1.2)
Number of male sex partners in last 12 months, median (range)[b]		5.0 (1-365)	3.0 (1-365)	4 (1-365)
Type of MRMSP [b]				
	Main	448 (52.1)	2039 (71.1)	2487 (66.7)
	Casual	412 (47.9)	829 (28.9)	1241 (33.3)
Race/ethnicity of MRMSP [b]				
	Black/African-American	157 (17.2)	360 (12.0)	517 (13.2)
	Latino/Hispanic	298 (32.7)	793 (26.4)	1091 (27.9)
	White/Caucasian	366 (40.2)	1592 (53.1)	1958 (50.1)
	Other[c]	90 (9.9)	256 (8.5)	346 (8.8)
Racial concordance with MRMSP [e]				
	Yes	500 (55.4)	1695 (56.9)	2195 (56.5)
	No	403 (44.6)	1286 (43.1)	1689 (43.5)
Age of MRMSP, median (range)[b]		23 (18-70)	24 (18-70)	23 (18-70)
Age discrepancy with MRMSP				
	Participant is at least 5 years younger	232 (25.0)	740 (24.3)	972 (24.4)
	Participant is within 5 years in age	612 (66.0)	2045 (67.0)	2657 (66.8)
	Participant is at least 5 years older	83 (9.0)	267 (8.8)	350 (8.8)
MRMSP is an exchange partner [f]				
	Yes	28 (3.1)	64 (2.1)	92 (2.3)
	No	888 (96.9)	2977 (97.9)	3865 (97.7)
High or buzzed during sex [g]				
	Yes	225 (25.3)	681 (23.2)	906 (23.7)

Characteristics		Used condoms[a] (N=927) n (%)	Did not use condoms[a] (N=3052) n (%)	Total(N=3979) n (%)
	No	665 (74.7)	2259 (76.8)	2924 (76.3)
HIV status of MRMSP				
	HIV positive	32 (5.3)	116 (5.0)	148 (5.1)
	HIV negative	577 (94.8)	2186 (95.0)	2763 (94.9)

[a] Column percentages may not add up to 100% due to rounding; missing values were not included.

[b] *P* value ≤.05.

[c] Other races include Asian/Pacific Islander, Native American/Alaskan Native, multiple, and other races.

[d] Other sexual identities include bisexual and other.

[e] A participant is racially concordant with MRMSP if he/she reports the same race/ethnicity as the MRMSP.

[f] Exchange partner is defined as a partner with whom the participant had sex in exchange for things they needed (eg, money, drugs, food, shelter, or transportation).

[g] Includes being high or buzzed with alcohol, drugs not prescribed by a doctor, or both during sex.

Most participants were members of a racial or ethnic minority: 33.7% (1327/3979) were Hispanic, 12.8% (504/3979) were black non-Hispanic, and 11.5% (453/3979) were multiracial. Most reported having attended some college, and three-quarters of all participants were aged 18 to 26 years. The median number of male sex partners in the past 12 months was 3, and over half of participants' last male sex partners were casual partners. Nearly 20% (906/3979) of participants had used drugs or alcohol prior to engaging in sex at last sexual episode, and almost 2% (92/3979) of participants reported exchange sex with their most recent male sex partner.

Of the 927 participants included in the final analysis, 69.0% (635/927) reported using a condom during receptive anal intercourse and 50.0% (459/927) reported using a condom during insertive anal intercourse. Overall, condom breakage was reported in 4.0% (44/1094 , 95% CI 3.2%-6.0%) of the total distinct episodes of anal intercourse. Condom breakage was reported by 4.4% (28/635) participants who engaged in receptive anal intercourse and 3.5% (16/459) participants who engaged in insertive anal intercourse.

Results from the multivariable analysis are presented in Table 2. Younger age and being buzzed or high before or during sex with a casual partner were associated with condom breakage during last anal intercourse, while number of male sexual partners in the past year was marginally significant. Participants' odds of condom breakage increased 3% for every 5 male sex partners reported in the past year (adjusted odds ratio 1.03, 95% CI 1.00-1.08). Participants who reported being high or buzzed at last sex with a casual sex partner had 3 times the odds of condom breakage compared to participants who reported being high or buzzed at last sex with a main partner (95% CI 1.02-9.6). The odds of condom breakage were 0.53 for every 5-year increase in age of a participant (95% CI 0.30-0.94).

Table 2. Associations between demographic and behavioral factors and condom breakage among men who had anal intercourse with their last male sex partner, in an online HIV prevention survey, United States, March-April 2009.

Characteristics		Broken condom[a,b] (N=41) n (%)	No broken[a,b] condom (N=881) n (%)	Crude odds ratio (95% CI)	Adjusted odds ratio (95% CI)
Race/ethnicity					
	Black/African-American	10 (7)	139 (93)	1.95 (0.79-4.80)	2.13 (0.79-5.77)
	Latino/Hispanic	13 (4)	349 (96)	1.01 (0.4-2.34)	0.78 (0.29-2.08)
	Other[c]	8 (7)	113 (93)	1.92 (0.74-4.99)	1.98 (0.6-5.76)
	White/Caucasian	10 (4)	271 (96)	Referent	Referent
Education					
	≤ High school diploma/GED	19 (5)	374 (95)	1.32 (0.69–2.53)	0.84 (0.39-1.81)
	> High school diploma/GED	19 (4)	493 (96)	Referent	Referent
Age (year), median (range)[d]		20 (18-47)	21 (18-65)	0.69 (0.48-1.01)	0.53 (0.30-0.94)
Number of male sex partners in last 12 months [d]		6 (1-364)	4 (1-87)	1.05 (1.02-1.07)	1.03 (1.00-1.08)
MRMSP is an exchange partner [e]					
	Yes	4 (14)	24 (86)	3.93 (1.29-11.91)	0.63 (0.06-6.31)
	No	36 (4)	848 (96)	Referent	Referent
Type of MRMSP					
	Main	23 (5)	421 (92)	1.45 (0.74-2.81)	See interaction
	Casual	15 (4)	397 (96)	Referent	See interaction
High or buzzed during sex [f]					
	Yes	16 (7)	209 (93)	2.33 (1.20-4.56)	See interaction
	No	21 (3)	640 (96)	Referent	See interaction
Interaction, high or buzzed during sex					
	Casual partner	10 (9)	107 (91)	—	3.14 (1.02-9.60)
	Main partner	4 (5)	82 (95)	—	Referent
Interaction, not high or buzzed during sex					
	Casual partner	4 (1)	274 (99)	—	0.31 (0.08-1.27)
	Main partner	17 (5)	324 (95)	—	Referent

[a] Column percentages may not add up to 100% due to rounding; missing values were not included.

[b] Condom break is defined as a break in the condom during either insertive or receptive anal intercourse (or both) during last sexual activity with a male partner. No condom breakage is defined as no break in the condom at last sexual activity (with both insertive and receptive anal intercourse) with a male partner.

[c] Other races include Asian/Pacific Islander, Native American/Alaskan Native, multiple, and other races.

[d] Per 5-unit increase.

[e] Exchange partner is defined as a partner with whom the participant had sex in exchange for things they needed (eg, money, drugs, food, shelter, or transportation).

[f] Includes being high or buzzed with alcohol, drugs not prescribed by a doctor, or both during sex.

Discussion

Principal Findings

Results from our multivariable analysis of condom breakage among US MSM revealed an overall condom breakage rate of 4%. Condom breakage rates did not differ between participants who reported receptive and insertive anal intercourse. Younger age, a greater number of sexual partners reported in the last 12 months, and being buzzed or high at last sex with a casual partner were associated with condom breakage.

The overall condom breakage rate of 4% is in line with previous studies [10,14-18], but there is considerable variability among breakage rates from prior studies [33-40]. Golombok et al found a condom failure rate of 2% in a group of 283 homosexual couples in the United Kingdom, but the study focused on sexual activity among long-term couples, which does not represent the MSM population [19]. Our sample was younger, and more than half of sex partners were reported to be casual partners. A 6-month condom breakage risk of 31% was found in a cohort study of MSM in Atlanta, GA [35]. The high frequency of condom breakage found in the aforementioned Atlanta cohort study compared to other studies is likely due to the longer recall period (6 months), allowing for a higher number of sex acts to occur. Further, the study revealed 40% of black MSM reported breakage or incomplete use; the population was twice as likely to report condom breakage as white MSM. Similar point estimates were seen from our analysis; however, our sample size was not sufficient to assess the relationship. The wide variability of condom failure rates among these studies is most likely a reflection of the diverse population of MSM and sample sizes under study [36-40].

For every 5 male sexual partners, we found that the odds of condom breakage increased by 3%. There are likely user characteristics of participants with large numbers of sexual partners not captured by our survey that explain the statistical association with condom breakage. Participants with a larger number of male sexual partners might have engaged in more aggressive coital behaviors than those with fewer sexual partners, leading to greater stress on the condom [41,42]. Further, participants with a large number of male sexual partners may have a predisposition to inappropriately use lubricant, resulting in condom failure [43]. MSM who report high numbers of sexual partners represent a risk group commonly targeted for behavioral interventions, as having multiple sexual partners is an established risk factor for HIV acquisition [38]. Results from our study suggest that behavioral prevention interventions targeted to this high-risk group should also include more thorough condom education.

Several studies demonstrated that drug and alcohol use is associated with an increased risk of HIV acquisition among heterosexual men engaging in vaginal intercourse and MSM engaging in anal intercourse [44,45]. Alcohol use during sex is higher among casual partners compared to main partners; however, few studies have assessed the association between condom failure and partner type, modified by alcohol and drug use before or during sex [46,47]. Results from our study suggest that being high or buzzed during sex with a casual partner was associated with increased odds of condom breakage compared to being high or buzzed with a main partner. Alcohol and drug use may prolong ejaculation and thereby prolong sex, increasing the risk of condom failure [27]. Moreover, alcohol and drug use may impede the proper application and usage of condoms, increasing condom failure rates [27]. These results suggest that public health prevention interventions need to increase awareness of the effects of drug and alcohol use during sex, specifically targeting MSM who engage in sex with casual partners.

Limitations

There are several limitations to this study. Most notably, our respondents are not representative of all MSM in the United States. Due to the nature of the survey, participants had to be proficient with computers, making them more likely to have a higher education and income than the general population of MSM. Our study used a cross-sectional study design to evaluate condom breakage at last intercourse and therefore did not capture condom use or breakage over time. Safe sex behaviors fluctuate over time [31], making a prospective study more appropriate to capture the time-dependent nature of condom use and failure. We did not ascertain a history of lubrication use or lubrication use during last sex act. Therefore, our sample may represent men who were less likely to use lubrication, and thus, factors associated with condom breakage may actually be factors associated with lubrication use. The majority of studies that have evaluated condom failure define it as condom breakage or slippage during sex [36-39]. Our study only used condom breakage as a measurement of condom failure. Omission of condom slippage data resulted in our inability to report condom failure more generally. Our study uses older data; however, our finding of a condom breakage rate of 4% is in line with previous and more recent studies [10,14-18]. Finally, responses may have been affected by social desirability bias and recall bias, resulting in misclassification of outcomes [48].

Conclusion

Results from our study highlight condom breakage rates among a diverse sample of MSM from the United States. While condoms remain a strong component of prevention policy, our findings indicate condoms may not suffice as a sole means of reducing HIV transmission risk within the context of a high per-act transmission risk of anal sex [6]. Combining condoms with other prevention modalities such as preexposure prophylaxis can help mitigate risk that occurs after condom breakage [49]. Even in the context of preexposure prophylaxis, more efforts should be made to improve condom use practices that might lead to condom failure [49]. MSM who report a high number of sexual partners as well as those who use drugs and/or alcohol before or during sex with a casual partner are at an increased risk for condom failure and would benefit from targeted condom education programs to help mitigate their risks. As innovation continues to occur in the design of condoms, it will be important to consider if there are new types or designs of condoms that might decrease condom breakage during anal intercourse [49]. To best understand when, why, and how condom failures occur, further studies are needed to capture the time-dependent nature of condom use; these should include high-risk sexual behaviors; precoital factors, such as condom storage; and coital factors, such as duration of sex act and use of lubricants. As HIV continues to disproportionately affect United States MSM and anal intercourse remains a significant mode of HIV transmission, condom failure among this population needs to be addressed through multiple approaches.

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Conflicts of Interest

PS is editor-in-chief of JMIR Public Health and Surveillance. This paper was handled independently by an associate editor, with PS not involved in any decision-making. Other authors have nothing to declare.

Multimedia Appendix 1

Barriers to Online Prevention Survey.

[PDF File (Adobe PDF File), 231KB - publichealth_v2i1e7_app1.pdf]

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Abbreviations

MSM: men who have sex with men

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Original Paper

Exploring the Feasibility and Potential of Virtual Panels for Soliciting Feedback on Nutrition Education Materials: A Proof-of-Concept Study

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Abstract

Background: A changing and cluttered information landscape has put pressure on health organizations to produce consumer information materials that are not only factual but high quality and engaging to audiences. User-centered design methods can be useful in obtaining feedback from consumers; however, they are labor intensive and slow, which is not responsive to the fast-paced communication landscape influenced by social media. EatRight Ontario (ERO), a provincial nutrition and health support program of Dietitians of Canada, develops evidence-based resources for consumers and sought to increase user-centered design activities by exploring whether the standard approach to feedback could be replicated online. While online feedback has been used in marketing research, few examples are available in health promotion and public health to guide programming and policy.

Objective: This study compared a traditional in-person approach for recruitment and feedback using paper surveys with an Internet-based approach using Facebook as a recruitment tool and collecting user feedback via the Web. The purpose of the proof-of-concept study was to explore the feasibility of the approach and compare an online versus traditional approach in terms of recruitment issues and response.

Methods: An exploratory, two-group comparative trial was conducted using a convenience and purposive sampling. Participants reviewed a handout on healthy eating and then completed an 18-item survey with both forced-choice items and open-ended responses. One group viewed a hard-copy prototype and completed a paper survey and the other viewed a PDF prototype via Web links and completed a Web survey. The total days required to fulfill the sample for each group were used as the primary method of efficiency calculation.

Results: In total, 44 participants (22 per condition) completed the study, consisting of 42 women and 2 men over the age of 18. Few significant differences were detected between the groups. Statistically significant ($P \leq .05$) differences were detected on four attitudinal variables related to the document reviewed and include perceived length of the document, perceived attractiveness, likelihood of contacting ERO for food and nutrition questions in the future, and likelihood of recommending ERO to a friend. In all cases, the responses were more favorable to the document or ERO with the online group. All other variables showed no difference between them. A content review of the qualitative feedback found relative consistency in word use and number of words used, indicating relative parity in the amount of data generated between conditions. The online condition achieved its sampling target in 9 days, while the in-person method took 79 days to achieve the target.

Conclusions: An online process of recruitment through Facebook and solicitation of online feedback is a feasible model that yields comparable response levels to in-person methods for user feedback. The online approach appears to be a faster and less resource-intensive approach than traditional in-person methods for feedback generation.

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KEYWORDS

health communications; Facebook; marketing; nutrition; nutrition education; healthy eating; health education; design; study design; social media; user design; qualitative data; health promotion; public health

Introduction

A diverse and cluttered informational environment has placed pressure on health organizations to devise means to communicate with their audiences that attract attention to their messages and provide relevant advice. Social media has further complicated this challenge, introducing new opportunities and demands on organizations operating with limited resources as they try to attract an audience that is presented with increasing competition for its attention [1]. Attracting and holding consumer attention and engaging audiences requires strategic design considerations that differ from traditional health communications messaging where information flows are unidirectional, not multidirectional as is the case with social media. This new participatory media landscape requires attention to information quality and the health and eHealth literacy of audiences, but also to their preferences, interests, and the esthetic appeal of communications that take place within the media ecology [2]. Thus, it is critical that health organizations develop materials that take into account user preferences and interests and do so in a manner that is responsive, proactive, and consistent with the rapid media cycle available through social media. This study seeks to explore how social media can be used as a means of providing reliable consumer feedback on health promotion and nutrition education materials in an efficient manner compared with traditional face-to-face consultations with users.

Background

For health organizations, the requirements and expectations around their communications activities are growing amid limited resources (eg, time, money), which places ever-greater emphasis on the need to be efficient and effective in health communications campaigns. This requires attention to the needs and use contexts of the audience in the co-development of the message and determining the media forms that are best suited to delivering, exchanging, and co-creating messages [3]. User-centered design is an approach that seeks to create products and services that are based on the preferences, needs, and use patterns of the intended audience (users) and creates more relevant and potentially more used products and services [4]. While potentially helpful, such design methods are time and resource intensive, especially for organizations that serve broadly dispersed populations.

One way to gain user feedback in structured form is the virtual panel, which is a growing staple within the marketing profession [5]. Virtual panels go by many names (eg, customer advisory panels, online research panels, Internet access panels), but they typically are standing groups made up of recruited participants or volunteers who are typically called on to provide feedback on specific things over time [5]. Virtual panels and online surveys conceptually offer many advantages for health promotion. Virtual panels reach those who are not seeking support from a professional (eg dietitian), are not limited by geography in the same way, potentially reach a greater diversity of individuals, and may be a cost-effective means of nutrition education and research [6-8]. Social media adds to the opportunity for recruitment of participants and deployment of virtual panels for soliciting feedback on materials or engaging the public in health promotion campaigns [8-13].

Organizational Context and Setting

EatRight Ontario (ERO) is a province-wide program designed to provide residents of Ontario with increased access to evidence-based healthy eating information, educational outreach, and consultation through a variety of distance-bridging methods. ERO is a multiplatform free service providing dietitian and healthy eating support services to residents of Ontario through printed materials, a toll-free telephone dietitian advice line, email-a-dietitian service, Web-based resources, and social media. The ERO service is operated by Dietitians of Canada (DC) with funding from the Ontario Ministry of Health and Long Term Care. The materials and advice offered by ERO are developed by DC as part of the Practice-based Evidence in Nutrition (PEN) database and include a variety of modalities and media accessible through the ERO website, social media, phone, email, and mail.

At the time of this study’s deployment, the standard protocol for feedback gathering involved sharing early prototypes of materials under development to professional dietitians who volunteered to consult with their clients about various features related to the length, attractiveness, and perceived quality and usability of the materials. This approach required that a designated coordinator recruit volunteers, collect contact information from them, prepare and distribute materials in hard-copy form by mail to volunteers, send reminders, collect returned surveys or feedback forms completed by clients, the volunteers or both, and then manually collate the materials. This was perceived to be slow, inefficient, and potentially prone to error.

This study seeks to consider the differences associated with using a virtual panel approach to recruitment and deployment of a user feedback process compared with the standard in-person approach currently in use. The in-person approach has consisted of sending draft materials to dietitians in the field for feedback and who may also solicit feedback from among their clients. A switch to using online recruitment and feedback gathering holds the potential to improve the reach, speed, and potential to do more iterative reviews if found to be comparable to the current standard practice in the quality and quantity of feedback received. This proof-of-concept study seeks to explore this issue and provide guidance for future research.

Project Outline

The overall project included three components: (1) a review of the literature on virtual panels as a means of feedback elicitation and design critique of consumer-directed materials, (2) a review of the program options and developmental design of the intervention (ie, the means of soliciting feedback through online methods), and (3) a comparative experimental study exploring the outcomes of two methods of soliciting feedback. The results of the comparative analysis are reported here. The study employed a collaborative, participatory, and co-creative process between ERO, PEN, and the lead researcher (CN) reflecting the co-creative process that was of interest in the study. This enabled participation on the development of measurement items, outcome indicators, and in the sense-making process required to interpret the findings.

Social media offers a real-time manner of recruiting participants and soliciting feedback from potential users of materials under review, particularly because it can engage them directly, and their engagement might have ancillary benefits beyond the current project by having them associate with DC and ERO as brands. ERO has a broad and engaged following among the public and professionals alike through social media. The online approach to engagement was selected and designed based on an initial review of the current ERO online portfolio, to assess which of the three would be the most feasible option to start with. All three of the social media platforms have active users/followers. However, among the various options Facebook was selected as the medium of choice to begin the study.

ERO has extensive experience with using social media as communication tool and as a vehicle to try new means of engaging their audience through different media. As of September 2015, ERO's social media properties included 9261 "likes" on Facebook, 2338 subscribers to their YouTube channel (with multiple videos having been viewed more than 100,000 times and over 700,000 total views of all videos) and 9647 followers to their Twitter feed and over 15,000 subscribers to a newsletter that has used social media as a recruitment tool for attracting enrollment.

In reviewing the various options, the community that had formed through ERO's Facebook page was highly active with many different users posting responses to ERO's posts, questions, and events, suggesting it might be the best place to design and trial an engagement plan for recruitment of a panel. A separate FB group associated with ERO's page was established, and invitations were sent out to all page members (ie, those who had "liked" the page). Based on the study design, membership in this special group was capped at 24 people. Anyone who requested inclusion in the group up to this number was included; no selective recruitment was conducted. In considering future possibilities for ERO, Facebook also offered the most opportunity to develop and maintain a panel over time compared to other forms of social media engagement (eg, Twitter).

The study protocol received approval from the University of Toronto research ethics board (Protocol #00029006), and no adverse effects were reported during the study.

Methods

An exploratory, two-group comparative trial was conducted using a convenience and purposive sampling comparing the current model of feedback used by DC and the ERO service with a novel, online approach. In the first condition, the current standard approach for feedback elicitation was used. DC sent a message to its members requesting assistance with the study. Those dietitians who agreed to participate were to ask clients post-consultation if they would be interested in participating in the study, and those who indicated an interest were given the consent and information package to review. Consenting individuals were given a survey and hard-copy version of the information resource under review entitled *Healthy Eating Guidelines for Increasing Your Fibre Intake* (Multimedia Appendix 1) and completed the survey in a private space, sealed it in an envelope, and returned it to their dietitian to return to DC. This is consistent with the previous standard practice except that feedback was normally provided orally to the dietitian and the responses were not blinded to the dietitian. In this case, responses were blinded, which was more consistent with a true study and helped mitigate social desirability bias.

In the second condition, a request for participation message was posted on the ERO Facebook page with instructions for interested individuals to contact the ERO communications manager who was responsible for posting material to the Facebook page on behalf of ERO. Once the desired quota of 24 participants was reached, recruitment was closed. All interested participants were invited to a special subgroup of the Facebook page that was designed for the study and restricted as invite-only for the purposes of the study. A link to an electronic Web survey hosted on FluidSurveys was provided that had a preamble with the consent materials and an embedded link that opened up an electronic version of the document *Healthy Eating Guidelines for Increasing Your Fibre Intake* for users to review online. In both conditions, participants were given an opportunity to indicate if they wished to receive a complimentary Dietitians of Canada cookbook in acknowledgment of their participation.

Materials

An 18-item, self-administered survey that asked questions about usability, esthetics, health behavior, and demographic questions was developed for the study drawing on some of the questions used in past practice by DC in their previous resource reviews. The survey included the ethical consent information as a preamble, which allowed individuals to indicate their interest in participation and gain an understanding of the risks and benefits prior to participating in the study (Multimedia Appendix 2). The survey was not pre-tested and did not undergo any psychometric assessment due to its short size and straightforward opinion questions with open-ended responses. The online version of the survey was restricted to only those with a secure Web link to the Fluid Survey platform.

Recruitment

48 participants—24 in each condition—were recruited between February and April 2014 to participate in the study. A minimum sample size of 20 participants per condition was sought as the required number in this efficacy trial. To account for possible dropouts, the study oversampled with 48 initial recruited participants, of which 44 eventually completed the study with 4 who left the study prior to completion (2 per condition). Participants were recruited by two means: (1) standard practice through dietitians operating in Ontario via an in-person introduction to the study after the client has completed their

appointment or (2) an open invitation to join a research study panel subgroup on the ERO Facebook page sent from the ERO communications manager. In both circumstances, individuals were presented with an invitation letter (in person or via a secure, confidential channel such as an email address) that introduced the study, its goals, its risks and benefits, procedures, and appropriate contact information with instructions to indicate interest and consent to participate. If interest was indicated (verbally to the dietitian or via an affirmative response through email or through direct Facebook message), a formal consent form was presented using the appropriate media and participants either signed the form and returned it to the dietitian (Condition 1) or selected a check box on the Web form (Condition 2).

The study approach followed a model of exploration and testing used within innovation research that uses a concept called design thinking [14], whereby initial ideas are generated, then refined and the most plausible, trialable product is tested with rapid feedback to allow for adaptation of the design as necessary. This approach is aligned with Developmental Evaluation [9], where the evaluation design is tied to the intervention and co-developed to ensure appropriate fit, scope, and adaptability to suit context. The use of Facebook as the medium for recruitment and deployment of the study was seen as the first choice among different options, but ended up being the appropriate choice after testing (ie, there was a positive response that yielded the level of engagement desired from participants), so no alternative methods were sought as the full sample was recruited.

In both conditions, participants were offered a Dietitians of Canada cookbook from ERO as a form of recognition for their time and were asked to submit an email to the ERO communications manager requesting one if they wished.

Analytic Approach

Due to the small sample size and given the focus on efficacy and plausibility of the intervention (online vs standard forms of feedback), non-parametric tests (Mann-Whitney U) were conducted to determine any potential between-group differences. Standard demographic frequency calculations were used to collate the responses.

Qualitative comparisons were made using a content analysis to assess if there were any unique features of terms, language, or descriptive depth to the text. A word count was performed to see if there was any difference between the two groups.

Efficiency Considerations

Data collection was tracked to reflect the overall speed of delivery and response. Post-hoc review of coordination time spent on the study was used to determine amount of staff energy used to facilitate the study.

Results

Forty-four participants completed all aspects of the study, 22 in each condition with 2 participants who did not complete the entire survey; 42 women (95%) and 2 men (5%) completed the study. Age was calculated by range response (20 years per category), with all participants reporting falling between 19 and 70 years, with the mean age range of 31-50. No participants reported being under the age of 18 or over age 70. Differences between groups were detected on age and sex, with no men participating in the online group and a slightly higher mean age for those in the paper condition.

Quantitative Results

We conducted Mann-Whitney U comparisons to explore differences between each group on each of the variables using IBM SPSS Statistics 22.

Statistically significant ($P \leq =.05$) differences were detected on four attitudinal variables related to the document reviewed and include perceived length of the document (ie, number of pages) ($P=.027$), perceived attractiveness ($P=.022$), likelihood of contacting ERO for food and nutrition questions in the future ($P=.029$), and likelihood of recommending ERO to a friend ($P=.002$). Across all questions, the online group reported more favorable responses to questions than those in the in-person, paper-based condition. All other variables showed no comparative difference between them.

Qualitative Results

No discernable style difference was found in comparing the responses between the two groups across the three open-ended questions. Three open-ended questions were asked on the survey: (1) A supplemental item to Q3 requesting additional comments on the look of the handout, (2) “After reading the handout, tell us 1-3 changes that you want to make in your diet?”, and (3) “What would make this handout more useful to you?”

Some of the examples of the quote comparisons are included in Tables 1-3. Qualitative text is taken directly from the survey and has been edited only for formatting, not grammar. Table 1 presents some of the responses to the question, “What would make this handout more useful to you?”

With the first response, the total word count was 368 words across 10 responses to the item, (36.8 words per response, 45% question completion) with the online survey, compared with 321 words used across 13 respondents (24.7 words per response, 59% question completion) to the item in the paper survey. All other participants did not provide an answer to the question.

Table 2 profiles some of the responses to the item, “After reading the handout, tell us 1-3 changes that you want to make in your diet.”

Table 1. Usefulness of the handout: selected responses.

Online group	Paper group
I'm more of a visual type. I feel that if the steps to eating more fibre would be easier to retain and refer to if it was in a table type format. It would be great if you could get the meal plan to fit on one page. That way, people could easily pin it up or put it on their refrigerator.	I like the use of bulleted points and tables. As something you can print out from the Internet this is great. However, it looks like the formatting of this print handout has been done using HTML. The look is not at all optimal for a printed document in terms of layout, page breaks, and visual separation of elements. Double borders on a table looks terrible!
It is very clear and concise. Easy to read. Easy to use as a guide. One comment on the comparative table re: high fibre/low fibre diet. A couple of places have the same food item at the meal but they don't line up on either side.	Consider bolding headings to standout (eg, pg. 2 veg, fruit, legumes, nuts and seeds) - add pictures of food if possible - consider hyperlinks to move info on a certain food that someone might not know about eg, guava? - chart (meal breakdown) is good/helpful to see - more spacing between groups (topics) so they standout
Most people won't read past the first page.	To think about > - colour - print double sided on 17 x 11 P - fold - then it's just one piece of P
	1 - Good layout - PEN logo busy at the top (simplify logos > distracting) - maybe have choice of font sizes? (large for older people, medium for younger > you can then have better spacing for blocks + info)
I think it is a great handout	A few colours or highlighted areas - numbers instead of words

Table 2. Anticipated or intended behavior changes attributable to the handout: selected responses.

Online group	Paper group
Change my cereal, use a combination of flour and include more fibre in my snacks. Flax seed to my smoothie	I want to be more aware and make sure I am including the right foods to obtain my daily fibre since I deal with IBS symptoms
Add more fibre easily by swapping current food choices for those with a higher fibre content.	Instead of having juice at breakfast to have an orange or other piece of fruit with my cereal 2. to try and have oatmeal more
The handout listed a lot of the changes that we are currently making in our diet. I have not thought of using dried fruit as a snack. That is easy to transport and store. I will make that change. And I have not thought of added beans to a pasta sauce. I'm going to try that as well.	add + look for more variety in choices/meals - try to changes to recipes (substitutions to the every day) - read more labels
Simple substitutes for the foods I already eat for ones with more fibre - Chart was very helpful - Will make sure I am get "whole grains" not just "whole wheat"	Be more fearless in substituting 1/2 to full white flour to a multi-grain. Reference fibre counts. Get back on your Eat Right Ontario website to see the latest healthy recipes (especially using legumes)

For this question there was a difference in the number of words used with participants in the online group writing a total of 484 words (mean of 24.2 per response, 91% overall completion) and those in the paper group writing a total of 331 words (mean of 15 per response, 100% overall completion).

Table 3 highlights some of the comments made to the question, "What would make this handout more useful to you?"

Table 3. Usefulness suggestion responses.

Online group	Paper group
Make available on line	an extensive listing of foods and their gm of fibre. Fruits and vegetables
I recently learned that you can increase the amount of fibre intake all you want but it is not productive in your system if you are not drinking enough water. I think that should be stated somewhere or highlighted as an important factor esp for people using this type of diet to have more regular bowel movements. Water helps break down the fibre. It would be nice to have a link to recipes that include high fibre ingredients such as homemade granola bars, quinoa salad, etc	shorter to read - more point form - pictures, graphics + charts
You are on Facebook that is a big help for all that want the help.	if the information was condensed. Somehow to make the handout shorter > maybe 4 pages. more websites in the additional resource section to get more ideas on how to add more fibre to my diet - have more examples that are culturally sensitive if possible - more examples of fruits/vegetables with high in fibre
I would like to see more suggestions on how to make food substitutions! if you eat this now... here is what you can try to replace it with for more fibre.	Take out the 2-page chart, it didn't add much. Add a good recipe.

The two groups differed marginally on the completion rate, with the online group yielding 12 responses (55% item completion) and the paper group yielding 8 responses to the question (36% item completion). For word count, the online group overall number of words was lower with 205 (mean of 17 words per response) compared with the paper group with 245 words (mean of 30 words per response).

Efficiency Results

The ability to reach the quota of 22 participants (per condition) reflected a substantive difference between the two groups. The recruitment for both arms of the study began at the same time. For the in-person group, this began with emails and phone calls placed to dietitians requesting their assistance, which was consistent with the current practice. In the online group, a new study group or panel was recruited and the commencement of the study began with a posting to the group inviting participation in the survey. Sampling was completed for the online group in 9 days, while the paper-based group took 79 days. The time calculated included the registered completion of the survey notice via Fluid Surveys for the online group and the received postage or scanned return receipt date for the paper surveys. Factored into the calculation was the staff time, which included doing follow-up phone calls and emails to dietitians who were handling the in-person surveys, postage preparation, monitoring and tracking responses, and for recruitment of participants directly in the online condition.

Discussion

Principal Considerations and Findings

The many barriers to convening users, both logistically and methodologically, can impede health organizations' willingness and capacity to engage in appropriate user testing of health materials. Rapid shifts in the way the public engages with information and information providers through modalities like Facebook, Twitter, and other social media channels has posed additional challenges for health professional organizations as the media cycle is shortened with consumers wanting materials quickly and expecting to have an opportunity to engage with the content materials in a more reflexive, interactive manner. ERO was already engaged with their users in conversations and exchanges via Facebook and thus, it provided a logical set-up for the study.

Other studies of recruitment have found that Facebook is a viable and cost-effective method for recruitment of study participants in different contexts [15]. Bensley et al found that clients are interested in using Web tools for nutritional information and recommended that Facebook be considered a key tool to support that work [16]. Lohse found that Facebook was an effective means of recruiting low-income women via ads distributed through the social media site [9]. This study differed from Lohse because it built on an established relationship with the intended users who had already indicated interest through responding to a request posted to the study hosts' page, not an ad.

This study found no substantive differences in the nature and quality of feedback obtained through a survey delivered via a standard, in-person feedback process and one recruited through Facebook and deployed online. Further, the study demonstrated the feasibility of using social media as a recruitment tool and that comparable data could be collected through online methods to in-person methods. Statistically significant (.05) differences were detected on four attitudinal variables related to the document reviewed and include perceived length of the document, perceived attractiveness, likelihood of contacting ERO for food and nutrition questions in the future, and likelihood of recommending ERO to a friend. In all cases, the responses were more favorable to the document or ERO with the online group than the in-person group.

One of the differences detected between the two groups is with respect to the stated likelihood of using ERO materials or recommending its services (see Q10 and Q18 for specific item wording), with those in the online group reporting a greater likelihood to engage ERO further. This could be because the participants in the online group were recruited from an ERO-administered Facebook group, suggesting that prior interest in being connected to ERO could influence future considerations.

Another notable difference is that those in the online condition were more likely to suggest that the reviewed resource on healthy eating was "just right." This could potentially suggest that the ability to touch, hold, and see the entire document in an in-person environment influences the perception of the design characteristics of that document. This is a question for further research to determine the degree to which the medium for soliciting feedback is connected to the product media used in communication.

Limitations

This was an efficacy study aimed at exploring the feasibility and plausibility of using a virtual panel as a means of engaging users and soliciting quality, complete feedback in a comparative manner to the current standard of practice used by ERO. Although the study involved nutrition education materials developed by PEN, the focus was not to assess their educational impact, nor were the instruments used designed for such a purpose. The exploratory nature of the study and unknown possible outcomes meant that the sample size was low and thus the findings are not highly generalizable to other contexts. Further research will need to consider whether there are shifts in effects with greater numbers of participants.

Recruitment of participants through a Facebook group developed and administered by ERO could have introduced a positive bias to the responses to the survey. While the sample was non-random, both groups were drawn from consumers who fit the key demographics of ERO services on the measured variables. What the sample did not reflect was potential additional demographic groups, particularly those defined by cultural heritage, geographic location, and eHealth literacy or those in the community who were not able to or willing to engage community dietitians (for the in-person condition). Further research could explore whether these conditions are influential variables influencing the outcomes.

Another limitation is related to the population being researched and the gendered conditions in which most primary food decision making is being made, namely that women have been historically much more likely to engage with ERO than men in this role. Thus, it is unclear whether men would report similar things if equally represented in the sample. More research at a population level is needed now that the plausibility and efficacy has been explored through this study. While there are potential confounders that could influence the findings, the key is to understand that the overall viability and plausibility of comparing two different approaches and their implementation is sound even if the degree of impact of each method of response requires further study to delineate the full effects of each approach on the feedback received.

Conclusions

This study sought to determine if the virtual panel approach is viable, to assess any unique challenges in the study implementation, and to propose strategies based on the findings to do further research with larger populations and different contexts. In doing so, the study also explored a methodological approach that could be used directly by health professionals and social marketing researchers. Our findings build on earlier research that showed how Facebook could be a cost-effective means of recruitment for participants. Indeed, ERO has since adopted this method in their work since the completion of the study and is using it as part of ongoing practice for feedback solicitation and is considerably increasing the frequency and speed of feedback in shaping the design of their materials. Consistent with the findings in this study, the use of an online panel has saved considerable resources in terms of coordination and energy required to reach and engage users.

Using online engagement methods for user testing has the further benefit of engaging current and prospective clients in dialogue early and potentially building a relationship with them in a manner that extends beyond a simple transactional encounter. By using tools like Facebook, participants are invited to be part of an initiative, not just participate in a study or survey. This creates additional value for potentially lower costs, which is an important advantage when there are limited financial and human resources for health communications.

By creating a means for greater engagement and a responsive method of feedback elicitation, health promotion organizers create opportunities to be more effective and relevant in their messaging. Social media provides opportunity to get feedback within days and through direct engagement with users instead of relying on intermediaries—a process that can introduce timing constraints. If approached as an opportunity to engage users in the design of products, social media offers means to speed up the process of and reducing the barriers to creating health promotion products and services that are not only attractive and useful, but more effective overall.

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Conflicts of Interest

The principal investigator for the project was contracted by ERO to design and implement the study. No restrictions, expectations of results, or imposition of methods were given to the investigator. ERO staff actively participated in the selection of the methods, study design, item development, data gathering, and sense-making related to the findings.

Multimedia Appendix 1

Healthy eating handout that was reviewed.

[PDF File (Adobe PDF File), 816KB - publichealth_v2i1e18_app1.pdf]

Multimedia Appendix 2

Data collection survey.

[PDF File (Adobe PDF File), 1MB - publichealth_v2i1e18_app2.pdf]

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Abbreviations

DC: Dietitians of Canada
ERO: EatRight Ontario
PEN: Practice-based Evidence in Nutrition

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Original Paper

Development and Implementation of Culturally Tailored Offline Mobile Health Surveys

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Abstract

Background: In low and middle income countries (LMICs), and other areas with low resources and unreliable access to the Internet, understanding the emerging best practices for the implementation of new mobile health (mHealth) technologies is needed for efficient and secure data management and for informing public health researchers. Innovations in mHealth technology can improve on previous methods, and dissemination of project development details and lessons learned during implementation are needed to provide lessons learned to stakeholders in both the United States and LMIC settings.

Objective: The aims of this paper are to share implementation strategies and lessons learned from the development and implementation stages of two survey research projects using offline mobile technology, and to inform and prepare public health researchers and practitioners to implement new mobile technologies in survey research projects in LMICs.

Methods: In 2015, two survey research projects were developed and piloted in Puerto Rico and pre-tested in Costa Rica to collect face-to-face data, get formative evaluation feedback, and to test the feasibility of an offline mobile data collection process. Fieldwork in each setting involved survey development, back translation with cultural tailoring, ethical review and approvals, data collector training, and piloting survey implementation on mobile tablets.

Results: Critical processes and workflows for survey research projects in low resource settings were identified and implemented. This included developing a secure mobile data platform tailored to each survey, establishing user accessibility, and training and eliciting feedback from data collectors and on-site LMIC project partners.

Conclusions: Formative and process evaluation strategies are necessary and useful for the development and implementation of survey research projects using emerging mHealth technologies in LMICs and other low resource settings. Lessons learned include: (1) plan institutional review board (IRB) approvals in multiple countries carefully to allow for development, implementation, and feedback, (2) in addition to testing the content of survey instruments, allow time and consideration for testing the use of novel mHealth technology (hardware and software), (3) incorporate training for and feedback from project staff, LMIC partner staff, and research participants, and (4) change methods accordingly, including content, as mHealth technology usage influences and is influenced by the content and structure of the survey instrument. Lessons learned from early phases of LMIC research projects using emerging mHealth technologies are critical for informing subsequent research methods and study designs.

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KEYWORDS

mobile health; survey research; ethical review

Introduction

Electronic methods for capturing survey data have proven feasible [1] and efficient [2,3] in locales with the technical infrastructure to support their implementation [2,4]. In settings where the telecommunications and technology infrastructure may be uncertain or lacking and where Internet penetration may be lower, electronic means for capturing survey data is of limited utility [4]. Maximizing the benefits and efficiencies of electronic data capture in survey research in settings with limited technological infrastructure requires the decoupling of the means of collection (eg, mobile device, laptop computer) from the mechanism of transmission and storage of survey data (eg, via the Internet). Using a store-and-forward approach to data collection in resource-limited settings may offer an effective approach to survey research by achieving efficiency gains through mobile device-based data capture delayed synchronization of data [5-7] when access to the Internet becomes available.

Public health lessons from resource-challenged areas of the world increasingly inform practice in other areas, including higher-resourced communities. Knowledge translation from research into practice has long challenged public health [8]. Evidence-based interventions exist to reduce chronic disease mortality substantially by addressing common lifestyle and behavioral risks [9], but suffer from lack of implementation [10]. This gap between knowledge and practice – the “know-do” gap – is more pronounced in communities of need throughout the world [11]. Better understanding of local social and cultural circumstances may help reduce the know-do gap [12] and increasingly successful implementation of existing knowledge to reduce chronic illness requires community-based approaches [13]. Further, novel ways to achieve better engagement in communities with disparities frequently arise from global settings [14] that have demonstrated creative problem-solving when challenged with a wide range of barriers [15]. Such learning can directly benefit communities of need nested within wealthier nations [12], in part by recognizing that community circumstances warrant creativity in blending best-practice with local culture [16] to reduce preventable chronic disease mortality [17]. Creating, nurturing and supporting researcher-community partnerships are an essential component of this effective translation [18], though progress in bridging the know-do gap is improbable without the appropriate involvement of enabling technology and informatics support [19].

The Centers for Disease Control and Prevention (CDC), through its Prevention Research Centers (PRC) Program, established a thematic network, the Global and Territorial Health Research Network (Global Network) to conduct, share, and translate innovative chronic disease prevention research in low-resource settings. In the context of the Global Network, the University of Rochester partnered with the University of Puerto Rico to test the feasibility of an electronically-implemented survey of community attitudes toward participation in genetic research (Survey 1), a scientific area of increased importance [20]. The investigators used the same approaches for a separate electronic health (eHealth) survey (for new mothers) being developed with research partners in Costa Rica and the Dominican Republic (Survey 2). This report focuses on the field-testing of electronic surveys with offline, store-and-forward data capturing using Research Electronic Data Capture (REDCap), a widely-used data capture application developed for large-scale research projects [21]. Procedures, infrastructure concerns, and methodologies have been adapted from previous work and lessons learned [22-35] to meet the needs for maximum flexibility and usability in low-resource settings. Procedures for successful project implementation include ethical review, survey development, data collector training, pre-testing, pilot testing, and data management. In two low and middle income countries (LMIC) settings: Puerto Rico (Survey 1) and Costa Rica (Survey 2). The surveys were in initial development (pre-testing) and/or pilot testing phases and although the topical areas were different, the initiatives involved overlapping teams and lessons learned will continue to be useful across future initiatives with LMICs.

Methods

Ethical Review Process

Obtaining institutional review board (IRB) approval from all participating groups raises certain challenges [28]. For all research funded by US federal agencies and institutions, participating institutions in the United States and each participating country must have a Federal Wide Assurance (FWA) and approval from an Office for Human Research Protections (OHRP) registered IRB. The FWA provides a commitment by the institution to follow standard ethical guidelines for human subjects research (eg, the Belmont Report, the Declaration of Helsinki, or similar codes). To obtain an FWA, institutions must have a designated IRB registered with OHRP. A database of institutions with FWAs and IRBs that meet US human subjects’ protections guidelines for research is maintained by OHRP [36]. Each participating country outside of the United States may have its own required IRB for in-country research, which may not be approved by the US OHRP [28]. Thus, reviews by multiple IRBs may be required. Coordination of timing of reviews is critical to ensure that all are completed prior to study initiation. In addition, some IRBs may require approval by IRBs in the other participating countries prior to providing local approval, so it is critical for investigators to be aware of such local regulations and communicate documentation of approvals to each IRB within the required time frame [22,24,37,38].

Finally, investigators need to be aware of culturally-specific variations in what are acceptable research practices to produce a final protocol that meets regulatory requirements of each country. For example, in our prior work in the Dominican

Republic, paying subjects for completing surveys, a practice that is acceptable by US IRB standards was considered coercive by Dominican Republic IRB standards, though provision of a small thank you gift at the end of the survey was acceptable with the caveat that participants not be informed of the gift until after completing the survey. In addition, in partner Dominican Republic communities, providing written consent for participation was culturally unacceptable as it raised concerns about contractual requirements. Thus, investigators worked with all IRBs to develop an acceptable verbal consent procedure with documentation of consent provided by data collectors [22,24,27,28]. Understanding IRB requirements of all participating sites is critical to successful global partnerships for research [37].

The IRB process at the University of Puerto Rico (UPR/MSC) was another source of lessons learned. The initial request for IRB approval was submitted for the online/offline versions of the survey to be administered by means of iPads and facilitated by a member of the research team. Once the IRB approval was ready (see below), the team proceeded to collect data. Once data collection began, the team faced the challenge of implementing offline collection, as the study sites were in remote areas in Puerto Rico with limited access to an Internet connection. Not being able to use the printed, hard copy as an alternative to the electronic version was a setback that required an amendment to the original protocol and changes to the data collection schedule. The lessons learned here – to gain initial IRB approval for both electronic and paper versions of survey data collection - can help to avoid further delays in the study plan.

Participants

Survey 1

Participants in Survey 1 consisted of a convenience sample of 32 Puerto Rican residents who were engaging with their medical health care system in one of three Federally Qualified Health Centers (FQHCs) in rural areas of Northern Puerto Rico over a 2-week period. Potential participants were approached by project data collectors (see below) and, if agreeable, were provided an information letter about the purpose of the survey. Implementing the survey consisted of a face-to-face interview, using a digital tablet to enter responses.

Survey 2

In the development phase of the study prior to an actual pilot implementation of Survey 2, qualitatively pre-testing all the sections and items of the developing survey was accomplished with a convenience sample of 16 trainees who were participating in an National Institute of Health (NIH) funded eHealth training initiative, and who will later be data collectors using Survey 2 and offline data collection. This sample was mostly composed of highly educated persons (eg, health providers, technology experts) who will, later in the parent study, be responsible for administering the final version of Survey 2 in their own countries (Costa Rica, Honduras, and Dominican Republic). Feedback was obtained on content, wording, and device navigation (ie, using the REDCap mobile survey on a digital tablet).

Data Collectors

Survey 1

For the field work with Survey 1 in Puerto Rico, data collectors were six Puerto Rican-based staff who were participating in the Puerto Rico Testsite for Exploring Contamination Threats (PROTECT), a research project that follows a cohort of 1800 pregnant women in the northern Karst area of Puerto Rico and their exposure to environmental agents [39,40]. Biological samples for PROTECT, an IRB-approved study, include examination of the DNA for the PAX gene and for future genetic testing.

The PROTECT staff that participated in the field work with Survey 1 included one registered nurse and fieldwork coordinator with ample experience in research, one master’s degree nutritionist, a doctoral student with a master's in public health (MPH) degree and experience in field research, and the co-principal director for the PROTECT Community Engagement Core with a doctorate of philosophy (PhD) in policy analysis and research. The staff were all previously familiar with REDCap, although they had not yet used the mobile version.

Training activities included observation and a 3-hour workshop to become familiar with both the content of the survey as well as its online and offline implementation via the mobile REDCap protocol. Each staff was given a tablet and assigned a unique username. All staff members participating in the project completed human subject research protection training from the Collaborative Institutional Training Initiative (CITI) prior to the collection of any data.

Survey 2

Qualitative data collection for the pre-testing phase of Survey 2 was conducted by a senior US research project staff (behavioral scientist), who interactively presented a draft of the draft survey as part of a didactic module during a week-long short course in Costa Rica (see below) on online/offline digital data collection. During the module and in subsequent meetings, senior project staff documented qualitative feedback via field notes and confirmed common themes and item improvement ideas. At the same time, another senior project team member provided live support and feedback from the United States, including real-time problem-solving that led to lessons learned (eg, problems with offline/online synchronization, log-in credentials, and other functionality).

Instruments

Survey 1: From Mechanical Turk to Offline

The present fieldwork began with the development of a Spanish-language version of a survey initially available online at Mechanical Turk (mTurk), Amazon's crowdsourcing website [41-43]. The initial survey was assembled primarily from items validated in previous surveys. Reliability and validity have not yet been established, but it is currently in use in several of our initiatives and will be examined for reliability metrics in subsequent phases of project development. The Internet as a medium and, more recently, the use of “crowdsourcing” as a strategy, has greatly expanded the potential for low-cost timely survey research initiatives. Crowdsourcing is the paid (or often unpaid) “recruitment of an independent global workforce for the objective of working on a specifically defined task or set of tasks” [44]. Crowdsourcing is increasingly recognized as a legitimate strategy to engage with research subjects [45-47].

Spanish Back Translation Process

In order to create an equivalent, as well as culturally appropriate Spanish language version of the initial English version, it was first translated into Spanish, and then back translated into English using the Brislin method [48]. The team then compared the back-translated version with the original to identify problematic translations. These problematic translations were then examined by two native Puerto Rican speakers and edits were provided. Finally, a native Spanish speaker did a final edit of the entire survey before it was pre-tested. The Spanish version was pre-tested during the back translation process by six bilingual investigators from the United States and Puerto Rico for readability, skip patterns, formatting, and content. Committed partners and an organized and systematic approach facilitated the translation process. A barrier to the process was time to complete translation given that people were volunteering their time.

Research Electronic Data Capture (REDCap)

For the present field work, surveys were developed and implemented using the mobile (offline) application of REDCap, a software toolset and workflow methodology for electronic collection and management of research and clinical trial data [21]. The secure, Web-based application (whether online or offline) provides an intuitive interface for users to enter data and real-time validation rules (with automated data type and range checks) at the time of data entry. REDCap offers easy data manipulation with audit trails and functionality for reporting, monitoring and querying patient records, as well as an automated export mechanism to common statistical packages (SPSS, SAS, Stata, R/S-Plus).

The NIH-funded Clinical and Translational Science Institute’s (CTSI’s) informatics core, a unit of the University of Rochester's School of Medicine & Dentistry Academic Information Technology (AIT) Group, serves as a central facilitator for data processing and management. REDCap data collection projects rely on a thorough study-specific data dictionary defined in an iterative self-documenting process by all members of the research team, with planning assistance from the AIT-CTSI informatics core. The iterative development and testing process result in a well-planned data collection strategy for individual studies.

REDCap servers are housed in a local data center at the University of Rochester and all Web-based information transmission is encrypted. REDCap was developed in a manner consistent with Health Insurance Portability and Accountability Act (HIPAA) security requirements and is recommended to University of Rochester researchers by the University of Rochester Medical Center (URMC) research privacy officer and office for Human Subject Protection.

REDCap Mobile for Offline Data Collection

For the purpose of this fieldwork the REDCap application for offline data collection was used, because many surveillance sites will be remote and will have limited Internet access. Mobile offline data collection allows for real-time data collection and storage. Data are later “synced” or uploaded to an online server and added to the primary database.

Although software programs and hardware devices were not prospectively compared and tested with our LMIC project partners, we employed lessons learned from our previous work regarding reach and engagement considerations of eHealth strategies [49,50], and from the formative evaluation phase of one of our randomized controlled trials (RCTs) [51]. In this trial, surveys were developed and pretested for implementation with US English speakers with low health literacy across a large geographic area. This included formative evaluation (key informant interviews and focus groups, exploring offline data capture) and, later, process evaluation steps (tracking participant engagement) to determine how and under what circumstances various mHealth strategies increased project engagement. Platforms that were considered for survey implementation included: (1) use of a vendor to manage all online surveys with sophisticated programming and support, (2) use of a commercial product such as Survey Monkey, and (3) use of REDCap. REDCap was chosen as the mHealth platform because (1) it is HIPAA protected; (2) there is no cost to the project; (3) programming support is available; and (4)respondents who are located anywhere geographically can access it using any common device such as personal computers, laptops, tablets, or mobile phones with app capabilities.

The process of enabling the system began with survey instrument development on the REDCap website platform, and then offline module approval was obtained from the US institution’s REDCap administrator. This approval is in the form of a Quick Response Code (QR Code), which contains a unique identifier for each specific requester and is necessary for installation of the survey into the offline application. This QR Code is provided for each staff member collecting data in the field, and each QR code matches with each username. The ability to scan this QR code with the mobile device enhances the project’s ability to collect secure data in the field, including the facilitation of later data collection when offline. Failure to match in this way, however, results in a substantial data storage complication (a “metadata conflict”), whereby the username and the QR code do not match and data collection from that username cannot occur and/or data may be compromised. This code is scanned to each mobile device where the username is used (eg, mobile phones and tablets).

Where online connections are possible, the mobile application provides direct data entry into the REDCap environment on the institution’s server. In LMICs or other low-resource settings where there are limited wireless (WiFi) or cellular connections to ensure predictable online access, the mobile application provides the flexibility for offline data collection. This expanded ability to use digital devices to collect data also limits the need for paper surveys (except as a backup) and the risk of losing data. The portability is also maximized by the ability to be used on iOS and Android platforms (including tablets and mobile phones). With both online and offline options, there is capability for direct data entry, which reduces the time needed for further data management and analysis. Finally, although matching each portable device to unique users requires advanced planning and start-up time, registering each username individually allows for superior tracking of data collection by each data collector.

Survey 2: Maternal Health Information Communication Technology

A second survey development and implementation project continued to provide lessons learned for overall project methodologies (ie, formative evaluation for Survey 1 as well as Survey 2) regarding the refinement of the development of both the online and offline survey procedures. The Survey 2 goals in this second project ("MundoComm" based in Costa Rica and the Dominican Republic) include conducting qualitative and quantitative assessments of multi-level determinants of maternal health behaviors that can potentially be addressed through technological innovation, and identifying electronic readiness (e-readiness), defined as use and acceptability of current information communication technology resources (such as social media, texting, as well as earlier technologies such as radio) to guide project development.

During a week-long "short course" training in Costa Rica with teams from the Dominican Republic, Honduras, and Costa Rica, experiences with the offline digital tablet (iPad) demonstrations in vivo revealed new challenges, primarily that systematic upgrades to the REDCap platform at our US-based institution caused immediate problems in the current version accessible on the digital tablet. It was determined that additional or back-up strategies to save all data collected since the last upload/sync will need to be developed. Also, explaining the multi-step processes to gain initial online access at the US-based institution, the steps needed to ensure current access, survey administration, data syncing and trouble-shooting, were all challenging for both instructors and trainees.

Results

Survey 1

Selected survey results from Survey 1 with 32 respondents interviewed face-to-face in Puerto Rico with the offline REDCap mobile application (see below) can be found in Table 1. These pilot data, successful collection of which provided evaluation feedback regarding the utility of the offline REDCap survey process, included common demographic information (gender, age, race, ethnicity, education, religion), demographic information of interest to the project (general health status, economic indicators such as owning one's own house and/or vehicle), and process information on respondents' perceptions of the length of the survey, and understandability, which aided the project team in refinement of the instrument both for content and for implementation.

Table 1. Example variables demonstrating the feasibility of and feedback regarding offline data collection process (N=32).

Variable		% (n/N)
Gender		
	Males	31% (10/32)
	Females	69% (22/32)
Age in years		
	Mean (SD)	35.69 (12.39)
	Range	18-61
Ethnicity		
	Hispanic	100% (29/29)
Race[a]		
	White	80% (24/30)
	Black	13% (4/30)
	Other	27% (8/30)
Education		
	Less than high school	7% (2/29)
	High school	45% (13/29)
	Some college	21% (6/29)
	College	24% (7/29)
	Advanced	3% (1/29)
Religion		
	Christian	97% (28/29)
	Prefer not to answer	3% (1/29)
General health		
	Excellent	17% (5/29)
	Very good	31% (9/29)
	Good	28% (8/29)
	Average	21% (6/29)
	Poor	3% (1/29)
Own your own house		48% (14/29)
Own your own vehicle		59% (17/29)
Understood survey?		
	Totally disagree	28% (8/29)
	Agree	55% (16/29)
	Totally agree	17% (5/29)
Was the survey clear/ simple?		
	Totally disagree	24% (7/29)
	Disagree	10% (3/29)
	Neither agree or disagree	7% (2/29)
	Agree	45% (13/29)
	Totally agree	14% (4/29)

[a] Some selected more than one race.

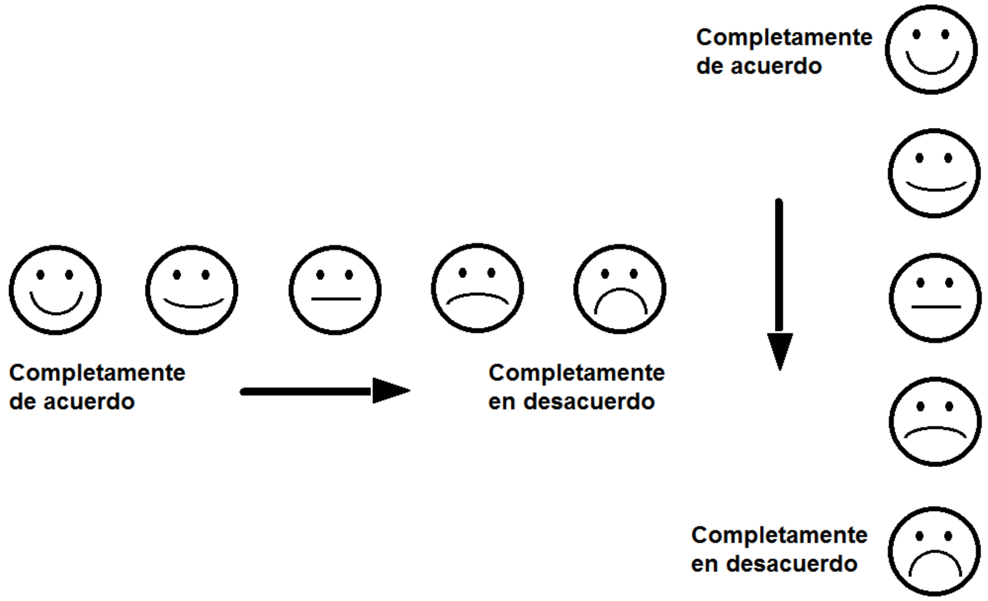
Feedback from data collectors during their 3-hour training workshop and before the pilot implementation included concerns that the survey was too long and that respondents would likely provide socially desirable responses to speed up the process. Changes to the instrument after pilot implementation resulted from additional feedback, including content related issues (item wording, skip patterns), as well as formatting and navigation issues related to the mobile offline version of the instrument. Data collectors reported that some aspects of the survey (eg, Likert scales) were too difficult for some respondents to understand. More than two thirds of the respondents with whom the survey was piloted, however, indicated that they felt the survey was understandable.

Survey 2

Pre-testing feedback on Survey 2, which was presented to 16 trainees at a week-long short course in Costa Rica (see above), included similar themes as those identified in feedback regarding Survey 1. Primarily, the participants reported that the survey was too long, item formats such as those presented as Likert Scales or similar ranking tasks, and layout were likely to be confusing to the target population of women in their maternal and child health research projects in their LMICs (Costa Rica, Dominican Republic, and Honduras). An interesting finding was that the Honduran team (n=4) felt strongly that the proposed layouts for the Likert scale items using pictures as aids should not go from left-to-right, as is common in US survey instruments (and even those commonly used in other LMICs), but rather from “top to bottom” (Figure 1).

All qualitative feedback from participants, as well as from LMIC partners and project personnel, will continue to be synthesized with process feedback from Survey 1 (the survey instrument as implemented in the medium of offline data collection), and content feedback (where overlap exists) to edit and pre-test subsequent iterations of Survey 2.

Figure 1. Pictoral ranking scale options.



mHealth Survey Development Challenges

A number of challenges to the development of our mHealth technologies for both online and offline survey data collection were noted. Implications and potential solutions were derived from a review of field notes, feedback from survey respondents and key informant interviewees, feedback from project partners in Puerto Rico and Costa Rica, and project team planning meetings (Table 2). A data collector’s individually assigned username can only used by that data collector, for both online and offline data collection. Therefore, it was decided that it is best to assign only one device to be used by each data collector. If more than one data collector will use a specific device, or more than one person will use a unique username (both possible but not advisable), then additional steps are needed to allow for this expanded functionality and additional training and quality assurance steps would need to be added.

Table 2. mHealth survey development challenges.

Problem	Implication	Potential solution
Institutional review board (IRB) approval process	Multiple IRBs and delays were challenges to both initial drafts of methods, and updated methods and instruments	Earlier engagement with IRBs and allotment of more time for ethical reviews and approvals Obtain ethical reviews from a centralized IRB process
Unique user identifications	Limits data collection options, such as one device for one collector only	Allow more users access to a single device (eg, a “generic” user ID log in)
Securing device	Although securing the device is meant as a security measure, all data are lost when the device sleeps, is turned off, or the application is accidentally closed	This security measure could be removed, or the device configured to never sleep[a]
Survey is too long	Respondents and collectors felt the instrument is too long and responses won't be valid	The survey will be revised for length and complexity of item response formatting (eg, simpler Likert scales)

[a] This remains a key training and quality improvement issue.

In addition, each data collector must “secure” the instrument prior to data collection (a step in the process of setting up each mobile device). Otherwise, when the device goes into “sleep mode” or the screen is accidentally turned off (screen), there is a risk of losing data already collected. Similarly, failure to match each device with appropriate permission codes can result in a “metadata error” and loss of collected data when attempting to sync the data. Clear protocols are needed to ensure that these steps are taken by all data collectors. For example, project procedures and checklists can be affixed to mobile devices (and included as a “read me” file after the device is activated) to remind data collectors and project staff of important details.

As can be expected in survey development between countries and cultures, several issues were identified, such as challenges with understanding certain survey item formats (eg, Likert scales), and feedback that the survey is “too long”. Finally, the mTurk Spanish version is still in development, and has therefore not been validated. Ongoing process evaluation will continue to identify and resolve these and other survey research implementation issues.

Discussion

Principal Findings

Electronic data capture is increasingly common in low and middle income resource settings because of the efficiencies introduced, speed, and convenience. Maximizing these benefits in survey research in settings with limited technological infrastructure and low resources means identifying low-cost mobile strategies with easy user interfaces, yet provide secure and efficient data management. Using a store-and-forward approach, where offline data capture can maximize mobility and reach, offers new successful methods and procedures for survey research.

In our early fieldwork for related public health initiatives, we have tested several electronic data capture modalities in a range of settings, including rural Puerto Rico, and with Latin American public health professionals in Costa Rica, including public health teams from other LMICs (Honduras and the Dominican Republic). This experience has generated several procedural and methodological lessons learned and insights for ongoing project development in our current and future projects in LMICs and other regions with low resources.

Lessons Learned

Lesson 1

While all cross-cultural research projects involving human subjects in multiple countries have expected multi-tiered ethical review processes [28], the complexities involved in newer digital data capturing methodologies mean that even more advanced planning and time will be needed for IRB approvals.

Lesson 2

In addition to testing the content of survey instruments and their items, extra time will be needed for testing the use of novel mHealth technologies (both hardware and software), including formative and process evaluation feedback, a consideration which has been noted in other mHealth development initiatives [51,52].

Lesson 3

It is important to incorporate the descriptions of usability and steps involved with mHealth technologies into the training of project staff and staff from the target regions. Communication with and input from project staff, partner staff, and research participants should be incorporated throughout the development, implementation, and feedback processes such as pre-testing, pilot testing, and early fieldwork [52].

Lesson 4

It is critical to be flexible and change methods accordingly, including both the content and the users’ experience. mHealth technologies influence and are influenced by the content and structure of the survey instrument and associated methods, so it is important to continue to adapt study methods based on this formative and process evaluation feedback [51-54].

Limitations

Our study has several limitations. First, our experience is limited to the sites as described, so generalizability is limited. Generalizability is further limited by the fact that with research in LMICs with the United States as a partner, there are typically specific requirements and additional regulatory considerations that add time and complexity to a study (eg, multiple ethical reviews, requirement for a partner with an FWA).

Second, mHealth strategies (hardware, software, research infrastructures, open source vs proprietary) used in the present research were not compared to other mHealth options a priori to select resources that would best meet project objectives. Such comparisons are often crucial for conducting mHealth research, especially in LMICs, in order to more fully protect the fidelity of the research. Additionally, the software and hardware described in the present study may not be available or optimal for LMICs. Future research could proactively conduct comparative effectiveness studies of similar methodologies to meet such needs.

Third, these are preliminary lessons learned at the early stages of two large studies. Insights gained from a retrospective examination of barriers and facilitators to a project's success may reveal different, even contradictory, conclusions. That said, our experiences are useful and practical and could inform the decisions researchers make around electronic data capture in low resource settings.

Conclusions

Electronic data capture offers an opportunity for low and middle income regions to participate in large research projects efficiently. Although no a priori comparisons for selection of optimal resources within LMICs were conducted, in the early phases of the project, along with our LMIC partners, we were able to successfully identify and implement feasible practical steps regarding the preparation of both software (online applications and services) and hardware (mobile devices) in advance of implementation of our large survey research initiatives. Survey development successfully incorporated both content development (with pre-testing and translation), and platform development for implementation (using REDCap for both online and offline implementation). Advantages and disadvantages to device and software choices, workflows, and user interfaces need to be weighed as part of necessary formative evaluation of the project [50]. These practical details also impact (and are impacted by) IRB issues, training details, and data management procedures.

There is growing evidence that mHealth strategies remove health care barriers in low and middle resource settings, so the dissemination of evidence-based mHealth methodologies is critical [53,54]. Immediate next steps will include full implementation of mHealth driven surveys in multiple LMIC and other low-resource settings, with plans for ongoing process evaluation to guide methodological improvements as needed. Future research in this area could focus upon further qualitative research to inform improvement and implementation [52], usability, privacy and confidentiality issues, best practices for training, and survey implementation fidelity.

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Conflicts of Interest

None declared.

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Abbreviations

AIT: Academic Information Technology
CTS: Clinical and Translational Science Institute
FWA: Federal Wide Assurance
HIPAA: Health Insurance Portability and Accountability Act
IRB: institutional review bard
LMIC: low and middle income countries
mTurk: Mechanical Turk
mHealth: mobile health
NIH: National Institutes of Health
OHRP: Office for Human Research Protections
PROTECT: Puerto Rico Testsite for Exploring Contamination Threats
REDCap: Research Electronic Data Capture
QR Code: Quick Response Code

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Original Paper

An International Study of the Ability and Cost-Effectiveness of Advertising Methods to Facilitate Study Participant Self-Enrolment Into a Pilot Pharmacovigilance Study During Early Pregnancy

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Abstract

Background: Knowledge of the fetal effects of maternal medication use in pregnancy is often inadequate and current pregnancy pharmacovigilance (PV) surveillance methods have important limitations. Patient self-reporting may be able to mitigate some of these limitations, providing an adequately sized study sample can be recruited.

Objective: To compare the ability and cost-effectiveness of several direct-to-participant advertising methods for the recruitment of pregnant participants into a study of self-reported gestational exposures and pregnancy outcomes.

Methods: The Pharmacoepidemiological Research on Outcomes of Therapeutics by a European Consortium (PROTECT) pregnancy study is a non-interventional, prospective pilot study of self-reported medication use and obstetric outcomes provided by a cohort of pregnant women that was conducted in Denmark, the Netherlands, Poland, and the United Kingdom. Direct-to-participant advertisements were provided via websites, emails, leaflets, television, and social media platforms.

Results: Over a 70-week recruitment period direct-to-participant advertisements engaged 43,234 individuals with the study website or telephone system; 4.78% (2065/43,234) of which were successfully enrolled and provided study data. Of these 90.4% (1867/2065) were recruited via paid advertising methods, 23.0% (475/2065) of whom were in the first trimester of pregnancy. The overall costs per active recruited participant were lowest for email (€23.24) and website (€24.41) advertisements and highest for leaflet (€83.14) and television (€100.89). Website adverts were substantially superior in their ability to recruit participants during their first trimester of pregnancy (317/668, 47.5%) in comparison with other advertising methods (P<.001). However, we identified international variations in both the cost-effectiveness of the various advertisement methods used and in their ability to recruit participants in early pregnancy.

Conclusions: Recruitment of a pregnant cohort using direct-to-participant advertisement methods is feasible, but the total costs incurred are not insubstantial. Future research is needed to identify advertising strategies capable of recruiting large numbers of demographically representative pregnant women, preferentially in early pregnancy.

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KEYWORDS

teratogen; surveillance; pregnancy; pharmacovigilance recruitment; advertisement

Introduction

Medication Use in Pregnancy

Maternal medication use during pregnancy is common [1] and is thought to have increased substantially over the last 30 years [2]. However, adequate nonconflicting clinical evidence concerning the fetal effects of maternal medication use in pregnancy takes many years to collect [3]. Safety data is therefore often lacking, particularly for newly marketed medications [3], and this may impact upon both maternal medication compliance [4] and health care professional prescribing [5]. The paucity of data and the potential consequences this may have for both maternal and fetal health, thereby identifies a clear need for improved pharmacovigilance (PV) research in the field. For ethical reasons, and in order to provide sufficient statistical power, this research is predominantly performed using post-marketing pharmacoepidemiological (PE) approaches [6]. However, many of the more commonly used PE methods have been associated with numerous biases and limitations [7] highlighting the need for novel PE approaches to pregnancy PV research.

Pregnancy Pharmacovigilance

The direct collection of health and medication use data from medicines consumers has proven beneficial in the monitoring of adverse drug reactions [8-10]. Therefore, gestational exposure and pregnancy outcome data collected in a prospective manner directly from pregnant women may provide a useful data source for pregnancy PV research. In 2009, a large collaborative European research program, the Pharmacoepidemiological Research on Outcomes of Therapeutics by a European Consortium (PROTECT) project [11], was funded with the aim of addressing key methodological limitations in PV/PE research. One of the specific aims of the PROTECT project was to explore the feasibility of enhancing the early detection of adverse drug reactions using modern communication methods to collect PV surveillance data. Through employing modern communication techniques in pregnancy PV research, such as website reporting, it may be possible to collect data from a large number of study participants in a manner, which is less researcher time intensive than some traditional epidemiological methods [12]. As data are collected directly from the patient, it may also be reasonable to expect fewer misclassification errors, particularly for socially sensitive details, such as use of alcohol, tobacco, or illicit drugs, or details regarding over-the-counter medication, which are not easily collected from population-based registers of health care data. More specifically for pregnancy PV studies, as self-reporting does not require notification of pregnancy to a health professional, data reported directly from a patient could be collected earlier in pregnancy; hence, providing surveillance over a time period not easily covered by some of the common PV/PE surveillance techniques.

Study Objectives

Given these potential advantages, the PROTECT pregnancy study was designed to explore whether pregnant women could be recruited to self-provide detailed information to an automated data collection tool, thereby enabling the prospective collection of gestational medication use, lifestyle details, and pregnancy outcomes. Here, we describe recruitment achieved by the direct-to-participant advertisement methods used to recruit participants to this study and compare their cost-effectiveness and the stage of pregnancy at which these methods recruited participants to the study.

Methods

PROTECT Pregnancy Study

The PROTECT pregnancy study is a prospective, non-interventional descriptive pilot-study of self-reported medication use and obstetric outcomes as provided by a cohort of pregnant women. The research protocol was created by a collaboration of public and private institutions, with researchers from public health authorities and academic institutions leading the research in each of the four study locations: Denmark, the Netherlands, Poland, and the United Kingdom. Ethical review of the study was required in Poland (Ethics Committee of the Poznań University of Medical Sciences) and the United Kingdom (National Research Ethics Service Committee North East - Sunderland). In the Netherlands as the data being collected were considered anonymous the study was granted an ethical review waiver from a regional research assessment board (Regionale Toetsingscommissie Patiëntgebonden Onderzoek, Leeuwarden), while in Denmark non-interventional epidemiological surveys are considered exempt from the requirement for ethical review [13].

Study Participants

All study participants were required to provide informed consent for participation. In Denmark, the Netherlands, and the United Kingdom informed consent to participate was provided electronically. In Poland, participants were required to provide hand signed declarations of consent via forms printed from the website and mailed to the local study team.

Participants were asked to provide information via a series of self-completed questionnaires using either a secure website or a telephone-based interactive voice recognition system (IVRS). Questionnaires were completed at study entry, over the duration of their pregnancy (completed every 2-4 weeks with the frequency decided by the participant at study entry) and shortly following the expected date of delivery (EDD) by website participants, or at study entry and shortly following the EDD only by IVRS participants. For pregnancies that ended prior to the EDD, participants reported they were no longer pregnant at their 2 or 4 weekly information request. Participants were also free to discontinue their participation at any stage, providing notification either by email or telephone.

For inclusion in the study participants were required to be currently pregnant, residing in one of four study countries, to have adequate natural language skills for that country, have internet or telephone access, and to be of legal age for the provision of their consent to participate (Denmark, Netherlands, and Poland – 18 years; United Kingdom – 16 years). In Denmark there was an additional requirement for participants to provide their civil registration number.

Study Sample Size

Because this was an exploratory pilot study, an arbitrary target sample size of 4800 women (1200 per study location) was selected with the goal of recruiting participants over a 104-week period. However, due to time delays in obtaining the necessary approvals the recruitment period was reduced to 70 weeks.

Study Recruitment and Data Collection

Participants were recruited from October 1, 2012 (recruitment week 1) until January 31, 2014 (recruitment week 70) in Denmark, the Netherlands, and the United Kingdom. Due to difficulties in arranging ethical approvals, the start date in Poland was further delayed until May 20, 2013 (recruitment week 34). Follow-up data, which are not further considered in this manuscript were collected from all participants until March 28, 2014. Participants received no incentives for enrolment or retention.

Recruitment Strategies

A key recruitment objective was to use direct-to-participant advertisements wherever possible to recruit women early in their pregnancy, and at low or no cost. In the first 18 weeks of the recruitment period, low/no-cost advertisement methods were used in Denmark, the Netherlands, and the United Kingdom. These included posting promotional discussion topics in pregnancy online forums (United Kingdom – no cost), placing small hyperlinks on pregnancy-related websites (Netherlands – no cost), displaying leaflets and posters in community pharmacies and/or obstetric/midwifery units (Netherlands and United Kingdom – printing and delivery costs), communication through a social media profile (Facebook United Kingdom – no cost), and banner advertising in a pregnancy-specific section of a popular health and wellbeing website (Denmark – low cost). Subsequently, additional funding was provided for higher cost advertising methods, which included large digital banners (Denmark), hyperlinks (Netherlands), and small picture/text graphics (United Kingdom) placed on prominent pregnancy specific websites, adverts in emails sent to registered users of widely used pregnancy/health information, and parenting websites (all locations), an advert aired on regional/digital-Internet television channels (Poland), a full-page article in a regional newspaper and pregnancy magazine (Poland), and paid advertising on a social media site (Facebook – targeting British women aged 16-45 with interests in children, pregnancy, and health). Several examples of the adverts used to promote the study are provided in the supplementary appendix.

Advertisement Method Cost-Effectiveness Analysis

To compare the international advertising costs, conversion of local currencies to Euros was performed using the exchange rate on March 10, 2014 (Euro:DKR 0.13, Euro:PZ 0.24, Euro:GBP 1.20, Euro:USD 0.72). Only advertising methods with associated costs (paid advertising methods) displayed via similar media platforms were grouped for comparison in this analysis. The cost-effectiveness of the various paid advertisement methods were compared as total cost per participant recruited (€ per participant).

Stage of Pregnancy at Enrolment Analysis

All participants were requested to provide their EDD. Using this, the date of the last menstrual period (LMP; EDD-280 days) was calculated and the date of enrolment was defined as being within the first (1-90 days post-LMP) or second/third trimester (91-280+ days post-LMP). The proportion of participants in their first trimester at enrollment was compared between study locations and paid advertisement methods using Poisson regression (*P*<.05 indicating statistical significance). Statistical analysis was performed using Stata Version 13.1 [14].

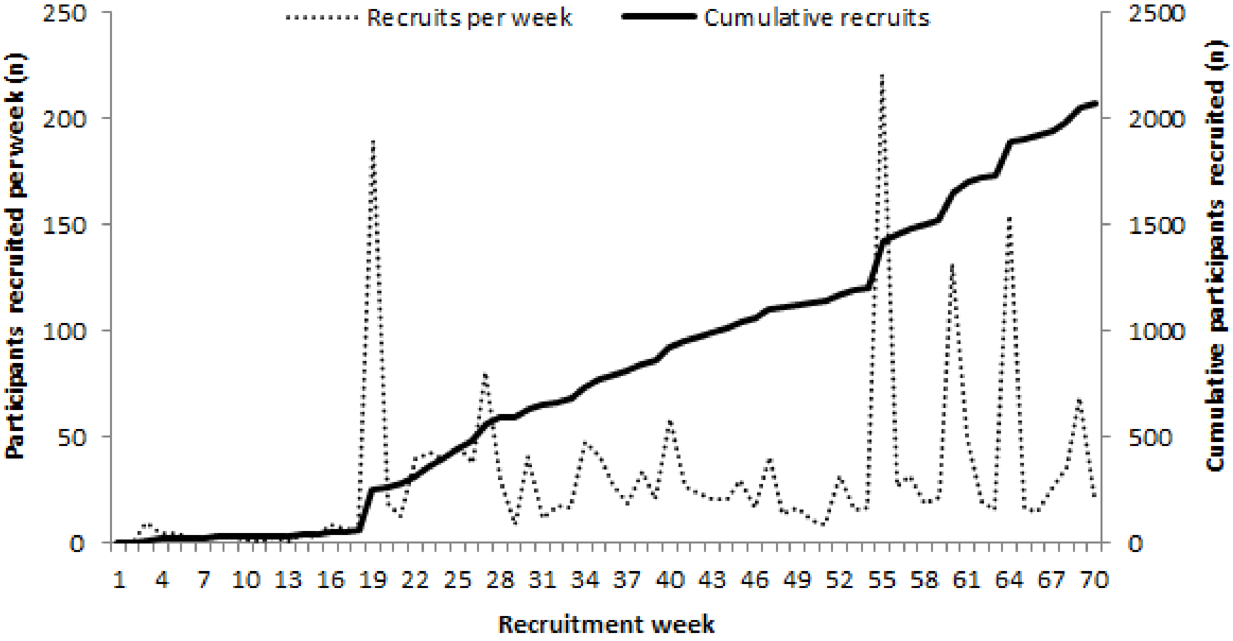
Results

Participant Recruitment

In total the advertisements generated traffic of 43,220 unique subjects to the study website and 14 calls to the IVRS over the 70-week recruitment period. Of these women, 5.83% (2521/43,220) self-enrolled and began data entry. However, 455, including 13 of 14 who chose to provide data via the IVRS, did not complete the study entry questionnaire. As insufficient information was available from these participants, and only a single participant used the IVRS system, only the details of the 2065 active study participants who completed the study entry questionnaire via the website are discussed further (Denmark n=639, Netherlands n=476, Poland n=241, and the United Kingdom n=709).

Figure 1 below describes the total number of active study participants joining the study in each week of the recruitment period. The low/no-cost advertisements used over the first 18 weeks of recruitment attracted a smaller than expected number of visitors to the website (n=1278), of which only 4% (52/1278) enrolled and provided study data. This prompted the use of higher cost advertisement methods, and Figure 1 clearly demonstrates the improvement in recruitment following their implementation (week 19+).

Figure 1. Timeline of participant recruitment (large scale email advertisements at weeks 19, 55, 60, and 64).



Also, clearly seen from Figure 1 are the large increases in recruitment, which were observed during weeks 19, 55, 60, and 64, which were mainly produced by the large scale email advertisement campaigns where in excess of 100,000 emailed adverts were broadcast.

Advertisement Method Cost-Effectiveness

Of the 2065 active study participants, 1867 were recruited through paid advertisements, which broadly fit into the following five categories: website advertisements, email broadcasts, leaflet promotions, television broadcasts, and social media advertisements. A description of the costs incurred for each of these categories, the number of participants recruited, and the resulting cost-per-participant is provided in Table 1. Where available we have also provided estimates of the total impact of the advertisements. For website/paid social media advertisements, we display the total number of advert impressions (ie, the number of times advertisement were displayed to users), for emails the total number broadcast, and for leaflets the total number printed.

Table 1. Number of active participants recruited by each of the paid advertisement methods.

Advertisement Methods	Denmark	Netherlands	Poland	United Kingdom	All locations
All Paid Methods					
Total expenditure (€)	9912.00	19,010.00	10,843.00	16,962.00	56,727.00
Participants recruited (n)	614	446	125	682	1867
Cost per participant (€)	16.14	42.62	86.74	24.87	30.38
Website					
Total expenditure (€)	9522.00	6002.00	276.00	576.00	16,376.00
Total impressions (n)	2,124,341	1,789	183,652	567,556	2,877,338
Participants recruited (n)	594	32	22	20	668
Cost per participant (€)	16.03	187.56	12.55	28.80	24.52
Email					
Total expenditure (€)	390.00	7412.00	5304.00	10,022.00	23,128.00
Total emails sent (n)	14,000	80,214	94,500	120,442	309,156
Participants recruited (n)	20	346	47	582	995
Cost per participant (€)	19.50	21.42	112.85	17.22	23.24
Leaflet					
Total expenditure (€)	-	5596.00	4355.00	6178.00	16,129.00
Total leaflets printed (n)	-	15,030	19,850	13,250	47,880
Participants recruited (n)	-	68	47	79	194
Cost per participant (€)	-	82.29	92.66	78.20	83.14
Television					
Total expenditure (€)	-	-	908.00	-	908.00
Participants recruited (n)	-	-	9	-	9
Cost per participant (€)	-	-	100.89	-	100.89
Paid Social Media					
Total expenditure (€)	-	-	-	186.00	186.00
Total impressions (n)	-	-	-	135,305	135,305
Participants recruited (n)	-	-	-	1	1
Cost per participant (€)	-	-	-	186.00	186.00

In total, €56,727 was spent on the paid advertising methods, which equated to €30.38 per active participant. In comparing the five broad categories of paid advertisements across all countries, the least cost-effective were social media (€186.00), television advertisements (€100.89), and leaflet advertising (€83.14), while website and email advertisements were the most cost-effective at €24.41 and €23.24, respectively. However, there were considerable international variations in the cost-effectiveness of the broad advertisement categories (Table 1). For example the cost-per-participant for website advertising in Denmark (€16.03), Poland (€12.54), and the United Kingdom (€28.80) was low in comparison with the Netherlands (€187.56), while for email advertising, costs in Poland were high (€112.85) in comparison with Denmark (€19.50), the Netherlands (€21.42), and the United Kingdom (€17.22). Leaflet advertising costs were found to be similar across the three study locations where they were used (Netherlands €82.29, Poland €92.66, United Kingdom €78.20).

Recruitment of Participants in Early Pregnancy

Of the 2065 active participants recruited to the study 23.0% (475/2065) were in their first trimester at enrolment. Table 2 reports the number of active participants recruited by gestational age at enrolment stratified by study location. A Poisson regression comparing the proportion of first trimester enrolled participants across the locations identified a statistically significant difference (*P*<.001) driven by the high proportion of first trimester active participants recruited from Denmark (309/330, 48.4%) in comparison with the lower proportions recruited from the Netherlands (48/476, 10.1%), Poland (48/193, 19.9%), and the United Kingdom (70/709, 9.87%).

Table 2. Stage of pregnancy at which active participants were recruited to the study (SOP, stage of pregnancy, participants recruited in the second or third trimesters had reached at least 13-weeks' gestation)

SOP	Denmark	Netherlands	Poland	United Kingdom	All Locations
	n (%)	n (%)	n (%)	n (%)	n (%)
First trimester	309 (48.4%)	48 (10.1%)	48 (19.9%)	70 (9.9%)	475 (23.0%)[a]
≤4/40	58 (9.1%)	2 (0.4%)	3 (1.2%)	0 (0.0%)	63 (3.1%)
5/40	53 (8.3%)	0 (0.0%)	4 (1.7%)	4 (0.6%)	61 (3.0%)
6/40	53 (8.3%)	2 (0.4%)	5 (2.1%)	4 (0.6%)	64 (3.1%)
7/40	37 (5.8%)	2 (0.4%)	5 (2.1%)	2 (0.3%)	46 (2.2%)
8/40	29 (4.5%)	4 (0.8%)	8 (3.3%)	7 (1.0%)	48 (2.3%)
9/40	23 (3.6%)	15 (3.2%)	0 (0.0%)	14 (2.0%)	52 (2.5%)
10/40	21 (3.3%)	9 (1.9%)	4 (1.7%)	8 (1.1%)	42 (2.0%)
11/40	20 (3.1%)	6 (1.3%)	9 (3.7%)	15 (2.1%)	50 (2.4%)
12/40	15 (2.4%)	8 (1.7%)	10 (4.2%)	16 (2.3%)	49 (2.4%)
Second/third trimester	330 (51.6%)	428 (89.9%)	193 (80.1%)	639 (90.1%)	1590 (77.0%)
Total	639 (100.0%)	476 (100.0%)	241 (100.0%)	709 (100.0%)	2065 (100.0%)

[a] Poisson regression (*P*<.001) identifies a significant difference between the four study locations in the proportion of first trimester participants recruited driven by the high proportion of Danish participants recruited in the first trimester.

Table 3 compares the ability of the five broad categories of paid advertisement methods to recruit participants in their first trimester. A second Poisson regression, which compared the proportion of first trimester enrolled participants across three of five advertisement categories (television- and social media–recruited participants excluded due to small sample sizes) identified a statistically significant difference (*P*<.001) driven by the high proportion of total first trimester active participants recruited by website advertisements (317/668, 47.5%) in comparison with the email (72/995, 7.24%) and leaflet advertisements (53/194, 27.3%). Although website advertisements recruited the highest proportion of first trimester participants overall, as they did in Denmark, Poland, and the United Kingdom, in the Netherlands only 18.8% (6/32) of participants recruited via website adverts were in their first trimester compared with 41.2% (28/68) of leaflet recruited participants.

Table 3. Overview of the number of study participants recruited in the first trimester (T1) by each of the paid advertisement methods stratified by study location.

Advertisement Methods	Denmark	Netherlands	Poland	United Kingdom	Total
Total participants recruited by paid advertising *n*	614	446	125	682	1867
Total recruited in T1 n (% of total)	299 (48.7%)	47 (9.87%)	28 (22.4%)	68 (10.0%)	442 (23.7%)
Website n T1/total by method (%)	296/594 (49.8%)	6/32 (18.8%)	8/22 (36.4%)	7/20 (35.0%)	317/668 (47.5%)[a]
Email n T1/total by method (%)	3/20 (15.0%)	13/346 (3.8%)	11/47 (23.4%)	45/582 (7.7%)	72/995 (7.2%)
Leaflet n T1/total by method (%)	-	28/68 (41.2%)	9/47 (19.1%)	16/79 (20.3%)	53/194 (27.3%)
Television n T1/total by method (%)	-	-	0/9 (0.0%)	-	0/9 (0.0%)
Paid Social Median T1/total by method (%)	-	-	-	0/1 (0.0%)	0/1 (0.0%)

[a] Poisson regression (*P*<.001) identifies a significant difference in the proportion of first trimester study participants recruited between the website, email, and leaflet advertisement methods, driven by the high proportion of first trimester participants recruited by website advertisements.

Discussion

Principal Findings

In this non-interventional study of self-reported gestational exposures and pregnancy outcomes we found that low/no-cost advertisements were unsuitable for recruiting a high number of study participants in a short period of time. Higher-cost advertisements improved recruitment considerably although the costs were not insubstantial. Email and website advertisements performed preferentially to the other methods in terms of costs-per-participant recruited and overall website advertisements were substantially superior at recruiting participants in the first trimester. However, we did identify international variations in both the cost-effectiveness of the various advertisement methods used and in their ability to recruit participants in early pregnancy.

Advertisement Cost-Effectiveness

We believe that our study represents the first attempt to assess the cost-effectiveness of direct-to-participant advertisement methods used in the recruitment of women to a pregnancy PV study. Available published data comparing the cost-effectiveness of different advertisement methods to recruit pregnant women to health research programs are limited [12,15,16]. One study showed advertising via social media (€25.00 per participant, based on 1,829,115 advert views over approximately 1 month, 624 clicks to the website, and 8 recruits) [15] to be more cost-effective than in our study (€186.00, based on 135,305 advert views over one month, 236 clicks to the website, and 1 recruit). Results from a second study were more consistent with our findings, suggesting that email advertising was the most cost-effective of the methods trialed [16], although in contrast to our findings website advertising was reported to be approximately three times less cost-effective than email advertising [16]. In addition, a final study identified a considerable reduction in total research costs, including recruitment costs, for studies conducted via the Internet in comparison with more traditional researcher interview techniques [12]. In this study, traditional researcher-led recruitment costs were approximated at €33 per participant, while Internet advertisement recruitment costs were lower than what we experienced overall (€24.52) at €11.68 per participant [12].

The key limitation of our cost-effectiveness analysis relates to the inability to account for any cumulative exposure to various advertisement materials. An additional limitation of the international comparisons specifically relates to the way in which we combined all the different advertisements used into five broad categories. For example, the website advertisements category combines cost-efficacy data from all the adverts placed in various locations on a variety of sites all with different levels of internet visibility (see Table 1). It is therefore plausible that the number of unique site visitors, which viewed the adverts varied between the websites that were grouped within this category. While it might have been expected that this would be controlled for by the cost of advertisement, with more prominent websites charging higher costs, we found this wasn't comparable internationally. It was possible to advertise in prominent positions on popular Danish websites at a lower cost than that required for advertising on Dutch, Polish, or British websites with similar levels of web visibility.

Recruitment of Participants in Early Pregnancy

One of the hypothesized advantages of collecting data from pregnant women recruited directly without the requirement for study promotion by a health care professional was that women could theoretically be recruited early in pregnancy, prior to seeking out any obstetric care. This was considered potentially beneficial in that it could provide surveillance over a gestational period not easily covered by traditional pregnancy PV/PE studies, collecting early pregnancy exposure and outcome data, which may otherwise be missed. Published data comparing the demographics of pregnant participants recruited through different advertisement methods are limited [17]. The single published study that we identified [17] did not investigate the differences in stage of pregnancy at enrollment for the various advertisement methods used. We therefore believe that our findings represent the first to demonstrate the variation in stage of pregnancy at enrollment by advertisement method.

It is likely that a main factor predicting an advertisement method's ability to successfully recruit participants in early pregnancy is the time at which women naturally interact with the media platforms on which advertisements are displayed. For example, email advertisements were mainly sent to registered members of online pregnancy or parenting clubs; although women in early pregnancy are not prevented from registering with these, it is probable that most only do so in later stages of gestation (>90 days post LMP – outside the first trimester) when more confident that the pregnancy is likely to continue to term. In contrast, pregnancy/parenting information websites may be commonly viewed by women in the early stages of pregnancy investigating pregnancy symptoms or using due date calculators.

Overall the results of our study identified that website advertisements recruited a significantly higher proportion of women in early pregnancy in comparison with the alternative methods. The results also identified a significant difference in first trimester recruitment by study location, a finding that we believe was mainly influenced by the high proportion of Danish study participants which were recruited through website advertising (~93%).

In this pilot study, most women were recruited beyond the first trimester, but this is still of potential value for direct-to-participant pregnancy PV/PE studies [18]. For example details of early pregnancy maternal exposures and lifestyle choices may still be collected, albeit retrospectively, and therefore with a possible risk of introducing misclassification or recall biases.

Future Research

For pregnancy PV studies specifically, the ability to detect increased incidences of rare gestational events such as specific congenital malformations among women taking a specific medication is dependent on the enrolment of a large study population. Prospective enrollment in early pregnancy is also considered advantageous as it is likely to minimize the introduction of some detrimental biases. Over the course of the PROTECT pregnancy study's 70-week recruitment period, we conservatively estimate that more than 3 million pregnancies would have been recognized by women residing in the four study locations [19]. We therefore only enrolled a small percentage of the total pregnant population, which raises concerns regarding the ability of these methods to recruit a sufficiently large enough sample size to test associations between exposures and rare clinical events. In addition, the advertisement methods we employed were much more likely to recruit women in the later stages of pregnancy, which may introduce selection, recall, and misclassification biases. While we remain optimistic that study participant self-reporting of medication use and obstetric outcomes will prove advantageous for pregnancy PV/PE studies, future research is needed to identify advertisement strategies which are able to recruit large numbers of demographically representative pregnant women, preferably early in pregnancy and at a low cost. While the recruitment strategy employed in this study aimed to exclusively employ direct-to-participant advertisement methods, it is possible that recruitment may be improved using study promotion through clinicians such as general practitioners/family doctors who are often the first health professional to speak to patients about pregnancy.

Conclusions

Of the various advertisement methods trialed in this pilot study, website and email advertisements were the most cost-effective, while website advertisements were the most suitable for enrolling participants in their first trimester. We believe these findings could prove useful for researchers looking to recruit a similar study cohort directly and without the intervention of health care professionals or academic researchers. However, our results also identify some concerns regarding the use of direct-to-participant advertisement methods as the sole strategy for recruiting women to a pregnancy PV study.

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Prior postings and presentations: Abstracts detailing findings from a preliminary analysis submitted and accepted for poster presentations to the 2014 2ndInternational Conference of the Organization of Teratology Information Specialists and the European Network of Teratology Information Services (OTIS/ENTIS) in Toronto, and the 30thAnniversary International Conference on Pharmacoepidemiology (ISPE) in Taipei.

Conflicts of Interest

None declared.

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Abbreviations

EDD: estimated due date
IVRS: interactive voice recognition system
LMP: last menstrual period
PE: pharmacoepidemiology
PV: pharmacovigilance
PROTECT: Pharmacoepidemiological Research on Outcomes of Therapeutics by a European Consortium
SOP: stage of pregnancy

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Viewpoint

The Importance of Computer Science for Public Health Training: An Opportunity and Call to Action

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Abstract

A century ago, the Welch-Rose Report established a public health education system in the United States. Since then, the system has evolved to address emerging health needs and integrate new technologies. Today, personalized health technologies generate large amounts of data. Emerging computer science techniques, such as machine learning, present an opportunity to extract insights from these data that could help identify high-risk individuals and tailor health interventions and recommendations. As these technologies play a larger role in health promotion, collaboration between the public health and technology communities will become the norm. Offering public health trainees coursework in computer science alongside traditional public health disciplines will facilitate this evolution, improving public health's capacity to harness these technologies to improve population health.

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KEYWORDS

digital health; public health; machine learning; computer science; health technology; chronic disease

Introduction

In 1915, the Rockefeller Foundation published a report by William Welch and Wickliffe Rose to delineate a knowledge base for public health practice in the United States and to design an educational system accordingly. While compiling this report, Welch, Rose, and other stakeholders struggled with the multidisciplinary nature of the field. Most professions are defined by a common disciplinary focus, but public health combines diverse disciplines to achieve a common goal [1]. Distinct from medicine and health care, public health focuses on promoting health and preventing disease at the population level. While a deep knowledge of biological and life sciences forms the core of medical training, public health requires a more comprehensive set of skills, including biology and life sciences, social sciences, public policy, and statistical reasoning [2].

The Council on Education for Public Health (CEPH), an independent agency recognized by the US Department of Education to accredit public health schools and programs, emphasizes five core areas that constitute the "intellectual framework" for public health professionals: biostatistics, epidemiology, environmental health sciences, health services administration, and social and behavioral sciences [3]. One of the CEPH's three objectives is to encourage—through periodic review, consultation, research, publications, and other means—making improvements in the quality of education for public health [4].

Since the formation of the CEPH in 1974, several reports have assessed the state of public health and made recommendations for public health education. In 1988, a US Institute of Medicine (now the National Academy of Medicine) report on the future of public health called for a greater emphasis on public health practice and relationships with academic disciplines outside of public health, including business administration and departments of physical, biological, and social sciences [5]. Following up on that report, in 2002 the Institute of Medicine again highlighted the need for public health schools to cross traditional boundaries and provide transdisciplinary training. This report specifically emphasized the need for training in computer skills and information technology [6]. Echoing these sentiments, *The*

Lancet Commission on the Education of Health Professionals for the 21st Century also stressed the need for the next generation of learners to “discriminate vast amounts of information and extract and synthesize knowledge that is necessary for clinical and population-based decision making” [7].

Many public health programs now offer specialization in public health informatics—the systematic application of information and computer science and technology to public health practice and research [8,9]. Nonetheless, curricula have rarely kept up with the data management and analytic requirements to understand the implications of new technologies [10]. One example of this is disease surveillance—a key responsibility of public health. Advances in information technology have spurred an evolution in our capacity to collect crucial information quickly, remotely, reliably, and cheaply. These technologies allow for the continuous real-time collection and analysis of health-related data. Both Google Search data and Twitter data have provided insights into disease surveillance and other “digital epidemiology” research questions [11-13].

The Digital and Mobile Health Revolution

Over the last few decades, the digital revolution has fueled technological progress and innovation. It is becoming clear that mobile devices will play a growing role in that process [14]. Smartphone penetration has surpassed that of personal computers, with estimates suggesting that usage will exceed 6 billion by 2020 [15]. With increases in smartphone usage, mobile phone apps have become a ubiquitous presence in users’ lives; most users report using at least 20 apps on their devices [16].

Health apps are particularly popular. A 2014 analysis estimated that there are over 100,000 health, fitness, and medical mobile apps, with the majority focusing on preventive areas such as healthy living, diet and exercise, addiction, stress, relaxation, and sleep [16]. Along with the growing presence of wearable technologies (eg, fitness trackers and smartwatches), these apps are contributing to a surge in the availability of health-related data. These apps collect tremendous information flows, in real time, and have the capacity to interact with the user, enabling changes in user behavior in response to user data.

Computation and Public Health: Machine Learning as an Example

One example of the potential for computational techniques to improve public health is machine learning. This methodological approach has emerged as a means of making sense of increasingly complex, high-volume big data such as those emerging from apps. Arthur Samuel, a machine learning pioneer, described this domain as the “field of study that gives computers the ability to learn without being explicitly programmed” [17]. Machine learning includes many different methods—regression, decision trees, neural networks, clustering, network analysis—that are more broadly categorized as either supervised or unsupervised learning. Although the field has existed for over half a century, recent progress has allowed for the development of real-world applications, including Google News clustering, Amazon product recommendations, and Facebook photo recognition. Recognizing the demand for machine learning expertise, trainees are flocking to the field; a graduate-level machine learning course is one of the most popular courses at Stanford University [18].

With the emergence of big data, machine learning is increasingly being used in real-world applications that are transforming industries. In 2013, IBM declared that the intersection of cloud computing, big data analytics, and learning technologies would usher in “a new era of cognitive systems where machines will learn, reason and engage with us in a more natural and personalized way” [19]. Large technology companies such as Amazon, Facebook, Google, IBM, and Microsoft have been at the forefront of this movement with investments in machine learning resources (including academic talent). Many smaller startups are also using these methods across a variety of sectors and receiving funding from investors [20]. In 2014, investors put US $309 million into artificial intelligence and machine learning startups across more than 40 deals [21]. Common applications of machine learning include Web search, spam filters, recommender systems, ad placement, credit scoring, and fraud detection [22].

Furthermore, an increasing number of health care stakeholders are recognizing that human-machine collaboration is critical for the development of cost-effective and potentially cost-saving solutions. Google, IBM, and Microsoft have partnered with a variety of health care organizations to implement machine learning solutions for complex problems including medication adherence, cancer treatment, and claims reimbursement. For example, Memorial Sloan Kettering Cancer Center is using IBM Watson Analytics’s cognitive computing technologies to provide oncologists and patients with tailored treatment options informed by clinical evidence and The Center’s highly specialized expertise. Google is working with Stanford University to investigate how machine learning can transform drug discovery by using data from a variety of sources to more accurately identify which chemical compounds could effectively treat a variety of diseases [23].

In the context of public health, computational methods such as machine learning could be used for both predictive and explanatory modeling, that is, identifying which individuals will benefit from an intervention, and better understanding the relationship between different exposures and health outcomes. In the realm of predictive modeling, machine learning could integrate data from a diverse set of sources—electronic health records, genomic sequencing, claims data, mobile sensors, and even social media—to better predict individuals at high risk for specific health conditions. Continually incorporating new data with minimal supervision will likely reduce the time and costs typically associated with building these insights. Once individuals have been identified, interventions and recommendations can be tailored based on personal preferences and feedback. Machine learning allows algorithms to continuously update so they become smarter and more personalized the more they are used. This data-driven approach is an improvement over traditional approaches in which individuals are stratified according to characteristics such as age, sex, and biomarkers to predict risk and recommend interventions.

The promise of machine learning approaches is beginning to be realized. Several technologies in development and in the market are using machine learning methods in concert with behavioral and biometric data to generate personalized suggestions that promote healthier lifestyles without any human involvement [24,25]. Although the literature on efficacy is limited, a recent study of a health-tracking app provided preliminary evidence on machine learning as a tool for behavior change [26]. The app automatically translates behavioral data into personalized suggestions that promote healthier lifestyle without any human involvement. Participants in the experimental group (those who received the app's personalized suggestions) walked significantly more and rated the suggestions more positively compared with the control group that received nonpersonalized suggestions from professionals. Although the sample size was relatively small and the time period relatively short, these results provide an optimistic outlook for machine learning and health.

Machine learning also has important implications for explanatory modeling and new insights into causality. While randomized controlled trials and experimental data are considered the criterion standard in epidemiology for causal inference, they are often criticized for a lack of external validity [27,28]. What works in a controlled research setting may not translate to an effective solution in practice. As data become increasingly complex, machine learning could help uncover patterns and identify trends, ultimately improving existing explanatory models and generating new causal hypotheses [29].

Although machine learning methods present an opportunity for public health, there are challenges and limitations to consider. Given that these methods generally use a diverse set of data in addition to traditional medical information, there are many concerns relating to data privacy. While the US Health Insurance Portability and Accountability Act protects medical information, existing laws in the United States do not cover data generated by most personalized health technologies. Special consideration must also be given to health inequities because innovative technologies often favor younger and affluent individuals over older, high-risk, and marginalized populations. These novel methods will also inevitably create tension between relying on algorithms and on human recommendations—the true potential of these technologies is their ability to augment rather than replace human expertise.

A Call to Action for Public Health Training

Big data, machine learning, and other computational techniques have the potential to provide insights into a broad set of public health topics including disease treatment, surveillance, and prevention. Chronic diseases, such as heart disease, stroke, cancer, diabetes, obesity, and arthritis, are the leading causes of death and disability in the United States and in much of the world. Motivating behavioral change related to physical activity, nutrition, tobacco, alcohol use, medication adherence, and mental health could alleviate a substantial portion of the chronic disease burden [30]. Personalized health technologies, specifically those incorporating machine learning, have shown promise in driving behavior change in these areas. If public health practitioners are serious about their commitment to disease prevention, they should follow the lead of health care and other industries in embracing big data and adopting machine learning methods.

A significant constraint in realizing public health value from big data, however, is a shortage of talent at the nexus between public health and computer science. Leading voices, including the Institute of Medicine, the US Centers for Disease Control and Prevention, and *The Lancet* have called attention to the need for information technology skills and have recommended public health curricula changes [6,7,10]. Although many public health programs offer statistical programming courses in SAS and STATA, for example, curricula generally do not include deeper computer programming skills. Some programs have options for specialized training in public health informatics, but gaps in skills and knowledge persist. Computer science disciplines have extended their focus to health, but public health schools have yet to fully embrace computer science. However, the incorporation of computer science into public health training is perhaps more critical than the adoption of public health as a focus for computer science: the role of well-trained public health professionals is essential to foster dialogue on important issues such as the methodological limitations and ethical implications of big data for health.

Public health schools have a history of collaboration and formal engagement with other fields, including medicine, law, nursing, social work, and business [31]. As formalized public health education in the United States celebrates its 100th anniversary, it is time to extend this collaboration to computer science and technology in order to more effectively and efficiently address today's pressing public health problems.

Conflicts of Interest

None declared.

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Abbreviations

CEPH: Council on Education for Public Health

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Original Paper

Development of the Health Atlas of Jalisco: A New Web-Based Service for the Ministry of Health and the Community in Mexico

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Abstract

Background: Maps have been widely used to provide a visual representation of information of a geographic area. Health atlases are collections of maps related to conditions, infrastructure or services provided. Various countries have put resources towards producing health atlases that support health decision makers to enhance their services to the communities. Latin America, as well as Spain, have produced several atlases of importance such as the interactive mortality atlas of Andalucía, which is very similar to the one that is presented in this paper. In Mexico, the National Institute of Public Health produced the only health atlas found that is of relevance. It was published online in 2003 and is currently still active.

Objective: The objective of this work is to describe the methods used to develop the Health Atlas of Jalisco (HAJ), and show its characteristics and how it interactively works with the user as a Web-based service.

Methods: This work has an ecological design in which the analysis units are the 125 municipalities (counties) of the state of Jalisco, Mexico. We created and published online a geographic health atlas displaying a system based on input from official health database of the Health Ministry of Jalisco (HMJ), and some databases from the National Institute of Statistics and Geography (NISGI). The atlas displays 256 different variables as health-direct or health-related indicators. Instant Atlas software was used to generate the online application. The atlas was developed using these procedures: (1) datasheet processing and base maps generation, (2) software arrangements, and (3) website creation.

Results: The HAJ is a Web-based service that allows users to interact with health and general data, regions, and categories according to their information needs and generates thematic maps (eg, the total population of the state or of a single municipality grouped by age or sex). The atlas is capable of displaying more than 32,000 different maps by combining categories, indicators, municipalities, and regions. Users can select the entire province, one or several municipalities, and the indicator they require. The atlas then generates and displays the requested map.

Conclusions: This atlas is a Web-based service that interactively allows users to review health indicators such as structure, supplies, processes, and the impact on public health and related sectors in Jalisco, Mexico. One of the main interests is to reduce the number of information requests that the Ministry of Health receives every week from the general public, media reporters, and other government sectors. The atlas will support transparency, information diffusion, health decision-making, and the formulation of new public policies. Furthermore, the research team intends to promote research and education in public health.

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KEYWORDS

Public health; health atlas; geographic information systems; geographic mapping; online systems; health information systems

Introduction

Information in health has become an asset for governments and institutions in many countries. Registers of health and disease events, inventories of health resources and infrastructure, medical records, and registers of preventive actions are only a few of the many sources of health data [1,2]. In the last twenty years, a lot of work has focused on the use of Geographic Information Systems (GIS) around the world [3]. These systems are defined as computer systems capable of assembling, storing, manipulating, and displaying geographically referenced information (ie, data identified according to their locations) [4]. However, their use in health information improved when they were used to support decisions on service implementation, epidemic monitoring, and public health interventions [5]. One of the applications of these systems is the generation of atlases, which are sophisticated tools capable of managing, storing, and showing spatial relationships. Atlases can be printed on paper, but are also available in electronic or Web-based, interactive or multimedia formats. In health, research has described the distribution of health actions and disease cases from a geographic standpoint, using aggregated information at country, state or county level, whether raw numbers or standardized rates [6]. Health atlases are a collection of maps related to health conditions which provide a unique method to analyze data and describe the magnitude of health problems, identify their relationships with social situations, determine conditioning factors, and support decision making from health authorities, government, non-government organizations, and the community.

The use of maps to show health information provides a visual representation of the distribution of a health situation or condition and its relation to many other environmental, dietary, and physical infrastructures, human resources, among many others [7]. For example, a geographic atlas was used in Spain to show mortality information that guided health authorities to focus their services where they were needed the most [8]. Another atlas was used in Taiwan to report mortality rates on oral cancer related to environmental risks [9], where they found a spatial correlation between the presence of some metals in the environment and the incidence of oral cancer. Another example is the Atlas of Reproductive Health that the Center for Disease Control (CDC) of Atlanta released in 2004 to show demographic and risk factors related to this topic [10]. More recently, a Web-based system was developed in Saudi Arabia to manage registry data for patients with diabetes [11].

In Latin America, there have been several efforts to develop health atlases from different perspectives and areas, such as the atlas of cancer mortality in Colombia, which shows the distribution of cancer mortality in a series of maps according to gender and state [12]. The Health Atlas of Mexico that was made in 2003, displays health and disease distributions according to state and counties, and was published in compact disc (CD) and in a Web-based platform [13]. The Web-based atlas developed at the Pan-American Health Organization in 2003 [14], and some other atlases devoted entirely to show the health conditions of specific states in one country, such as the one we report here, have been developed [15,16]. All of them served their respective ministries to make health-related decisions and take the corresponding actions with different results.

Since 2013, the government of Jalisco established a new law called *Law of Transparency and Public Information Access*, which compels all public offices to publish their operations and economic and management information related to the use of public resources [17]. This law also establishes that any citizen can request information from any state office and the officials must answer promptly or be sanctioned for the delay. For this reason, in 2014, the Health Ministry of Jalisco (HMJ) signed an agreement with the research team from the University of Guadalajara responsible for the project reported in this paper to provide information, and use this atlas as one of its main sources of information for purposes of the Transparency Law.

The interactive Health Atlas of Jalisco (HAJ) is a service created by the University of Guadalajara, Mexico, through a grant by the Council of Science and Technology of the Province of Jalisco. The HMJ provides approved information to feed the system and publishes it as a Web-based service. The aim of the service is to support health decision makers and inform media reporters and the general public with a collection of thematic maps that represent the main health indicators of the Province of Jalisco, based on data from 2010 to 2013. In addition, it serves to indicate the status of the health-related Millennium Development Goals established by the United Nations (UN) in the state [18]. Thus, the objective of this work is to describe the methods used to develop the HAJ, as well as show its characteristics and how it interactively works with the user as a Web-based service.

Methods

A multidisciplinary research team comprised of a physician, geographer, mathematician, and statistics specialist all working at the University of Guadalajara developed the HAJ. In total, the design and development of the HAJ took about two and a half years, which includes the time spent in making arrangements with the HMJ and the National Institute of Statistics and Geography (NISGI, INEGI in Spanish), the organizations that provided the data used as input to the system. The digital maps are generated using the Instant Atlas software [19], which creates an interactive, online tool for the end user to manipulate and display the atlas data as digital maps. To achieve this, the team generated the website, manipulated the input data, prepared the base maps, and gave the instruction set so the software could process the data and generate the mapping tool.

This work is based on an ecologic design in which the analysis unit was the municipality (county) of the state of Jalisco in Mexico. We created and published online a Geographic Health Displaying System in which we used HMJ´s official health database and databases from the NISGI as input to complete the project. For this purpose, we acquired a license for the Instant Atlas software as our base program to generate the interactive online application [19].

Scope

Jalisco is one of the 32 states (departments) of Mexico. It is located in the Central Western area of the country and it is the 7th biggest state in Mexico with an area of 78,588 km^2. Jalisco has 125 municipalities (counties), a population of more than 7.3 million people distributed in urban (87%) and rural (13%) areas, and ranks as the 4th most populated state in the country (6.5%). There are 3,750,041 women (51%) and 3,600,641 men (49%) in Jalisco, with a mean age of 25 years. In 2013, the gross domestic product of the state represented 6.4% of the country's total.

Analysis Units

While the main scope of the atlas is the state of Jalisco, its analysis units are the municipalities. There are 125 municipalities in the state with a mean distribution of 93.5 inhabitants per km^2. The municipality with the largest population is Guadalajara with 1,495,189 inhabitants on a surface of 187.91 km^2, only 0.23% of the state's surface. The least populated municipality is Ejutla with only 2082 inhabitants on a territory of 472.21 km^2, representing 0.60% of the state's surface. Ejutla has three times more surface than Guadalajara and a population density of 4.42 inhabitants per km^2, while Guadalajara´s density is of 7957 inhabitants per km^2. Thus, a great disparity in population distribution exists in Jalisco [20]. More than 50% of the population lives in only five municipalities: Guadalajara, Zapopan, Tlaquepaque, Tonalá (central region), and Puerto Vallarta (north coast region), with 1.49 million inhabitants in Tonalá and only 250,000 in Puerto Vallarta.

Variables

The atlas is divided into seven broad, health-related themes, where three of them (mortality, morbidity, and health infrastructure) are direct health indicators and four of them (demography, socio-economy, education, and living condition) are general health-related indicators. Each of the seven themes are composed of different health indicators (referred to as variables in the atlas) and broken down as follows: (1) demography (36 variables), (2) socio-economy (18 variables), (3) mortality (43 variables), (4) morbidity (59 variables), (5) health infrastructure (3 variables), (6) education (18 variables), and (7) living conditions (79 variables). Each variable generates a thematic map resulting in seven thematic maps and a total of 256 variables.

Most of the variables are represented in absolute numbers while some are shown as percentages, and a few as rates. The variables are not all represented in the same format because they were received them from the HMJ and the NISGI, and because we did not want to change the data so it reflected the real situation of the state according to those institutions.

There are two major regional divisions in the HAJ: the 12 sanitary regions made by the HMJ, and the 13 planning regions made by the Jalisco´s State Planning Office (JSPO, COPLADE in Spanish). The difference is because the HMJ divided the state more than twenty years ago for health service delivery purposes, whereas the Government of Jalisco, through the JSPO, divided the state about fifteen years ago for planning purposes. The regions of both divisions have different municipalities; therefore the results given by the atlas are different too. Given that, the user needs to verify which major division to select in order to receive the adequate information.

Information Sources

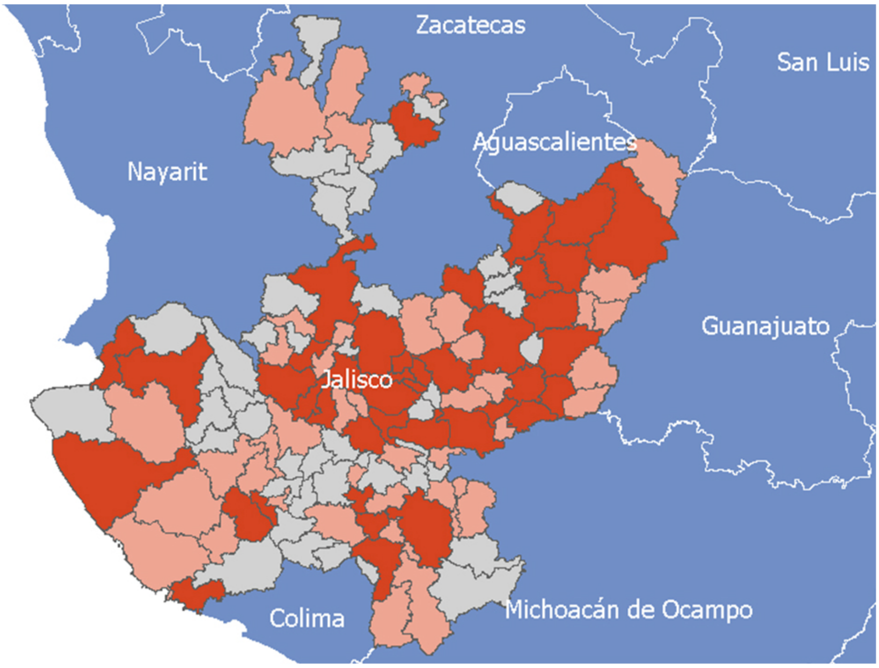
The information regarding health indicators was provided by the HMJ, who provided databases in datasheet format corresponding to mortality, morbidity, and health infrastructure of the state, divided by municipalities for the year 2013. In addition, information was extracted by mining the NISGI website [20], and demographic, socio-economic, education, and housing information corresponding to the 125 municipalities for the year 2013 was obtained. The information from both sources was retrieved in datasheet format and then manipulated to feed the GIS used in this project.

Procedures

Datasheet Processing and Base Maps Generation

Using the coding system provided by the NISGI in which each of the 125 municipalities has a unique code or number, we processed the datasheets received from the HMJ (118 health indicators) and collected from the NISGI website (138 general indicators). The 256 indicators were then processed as variables in datasheet format according to software specifications in order to generate the same number of tables that served as input. Each municipality was also assigned two region numbers according to the twelve sanitary regions and the thirteen JSPO regions that appeared as new variables on each table created (Multimedia Appendix 1). Three different base maps (data shapes) were then generated to be used in all the analytical categories, so we could combine them with the HMJ and NISGI's datasheets (Figure 1). The shapes were the maps of the territory analyzed according to its real geographical coordinates defined by the NISGI and also obtained through its website. The shapes were processed according to the project's specific needs and then prepared for the requirements of the software. The shapes are polygonal databases that save the data of the entire studied territory, in this case the state of Jalisco, and of all the municipalities within one registry (row) for each municipality in the "municipality code" field. Thus, each municipality was assigned to a row on the shape database and then the corresponding information of each one was captured on the same row, which would later be processed inside the software to generate the thematic maps.

Figure 1. Example of a data shape of the state of Jalisco, Mexico.



Software Arrangements

The data files were processed offline using Instant Atlas software [19] to combine data shapes and datasheets and generate the online files for the users. The software is capable of generating every necessary file to publish the map on the Web. For example, in the mortality category, the software generated more than 50 files that included the datasheet file (csv and xslt), the shape files (js), the image files (PNG, GIF, and JPEG), and the html files (html and css). The generated files were ready to upload into the Web server with no further manipulation,

Making Up the Website

The goal of the HAJ is to provide an open access, free service for the HMJ, health related decision makers, non-government organizations, and the community. As such, we generated a free, searchable website accessible through the Internet. The grant we received from the Council of Science and Technology of Jalisco allowed us to pay for the hosting and the URL name for two years.

Two hosting providers were contracted. The first was Wix that was used to prepare the overall interface of the project with general information about the research project, the research team, tutorials, and credits of the university and the collaborating and granting institutions. On this site, one section to publish the atlas was prepared but no files of the atlas were saved on this server. Instead, we made a link where the files were stored. The second is where we hosted and organized the files generated by the GIS software on the other contracted server where the link on the first server pointed. A local provider manages this server for security (check that all the files are secured and protected) and accessibility (managing the website) purposes. The contracts of both hosting services included the payment of the URL names for the site, so we did not have to pay for them separately. In 2014, we uploaded the generated files into the server and set the online version of the HAJ as well as the URL given, so it could be available for user review.

Results

General Characteristics and Technical Specifications of the HAJ

The HAJ is a Web-based service that provides a friendly environment for users to interact with health and general data, regions, and categories according to their information needs; the atlas generates thematic maps about the situation of the state for each health indicator and category requested (ie, the total population of the state or of a single municipality, grouped by age or sex). It is capable of generating and displaying more than 32,000 different maps by combining categories, indicators, municipalities, and regions, so users can select the entire province, one or several municipalities, and the indicator that they require. Then, the atlas generates and displays the requested map. Users can then print it or save it in PDF, spreadsheet, PNG or html formats. This represents a very large amount of information for the health ministry and the community of the state. Access to the atlas can be found on its website [21].

Selection of a Thematic Map

The main page of the HAJ (Figure 2) shows an introductory video that explains why the atlas was made and what it can be used for. The video plays automatically when the webpage is opened, but it can be paused or stopped at any time, shown in full screen or in the default small-frame setting. The logos of the institutions involved in the project and the grant credits are shown at the top of the page. The main menu is displayed under the logos. The five main menu options are Homepage (*Inicio*), Theme Selection (*Atlas*), Downloads (*Descargas*), Contact (*Contacto*), and More Info (*Más*). Each link takes the user to a different area.

To see the thematic maps users must get to the mapping tool. This can be done by following two paths. The first is selecting the Atlas option on the main menu that opens the Theme Selection page, which shows the previously mentioned categories and a general explanation of each. If a category is selected, the mapping tool on that category is displayed. The second is selecting a category from the submenu in the Atlas option on the main menu, which links directly to the mapping tool to choose data from the category selected.

Figure 2. Homepage of the Health Atlas of Jalisco showing the main menu and the introductory video.

Finaciamiento: Consejo Estatal de Ciencia y Tecnología de Jalisco y el Centro Universitario de Ciencias Sociales y Humanidades de la Universidad de Guadalajara

Colección de mapas interactivos sobre salud

El proyecto "Atlas de Salud del Estado de Jalisco" es apoyado y financiado por el Consejo Estatal de Ciencia y Tecnología de Jalisco (COECYT JAL) así como por el Centro Universitario de Ciencias Sociales y Humanidades de la Universidad de Guadalajara en México. Es el resultado del esfuerzo del Cuerpo Académico "Geografía de la Salud".

Enlaces a los portales de los principales usuarios de este Atlas:
Secretaría de Salud Jalisco (SSJ), Universidad de Guadalajara, Grupo Interinstitucional de Información en Salud, Instituto Nacional de Geografía y Estadística INEGI, así como otros organismos relacionados directa o indirectamente con la salud de la población.

El cuerpo Académico Geografía de la Salud de la Universidad de Guadalajara está conformado con profesionales de la salud pública y trabaja actualmente en proyectos simultáneos a este Atlas de Salud de Jalisco tales como el Atlas de Salud de América Latina y proyectos relacionados con la salud y territorio, entre otros.

The Mapping Tool

The site includes a tutorial on how to use the mapping tool; users must select the "More Info" option of the main menu and select the "Extras" option from the submenu. There, the "Video Tutorial" link opens an 8-minute video clip that explains how to use the mapping tool.

Interactive Characteristics

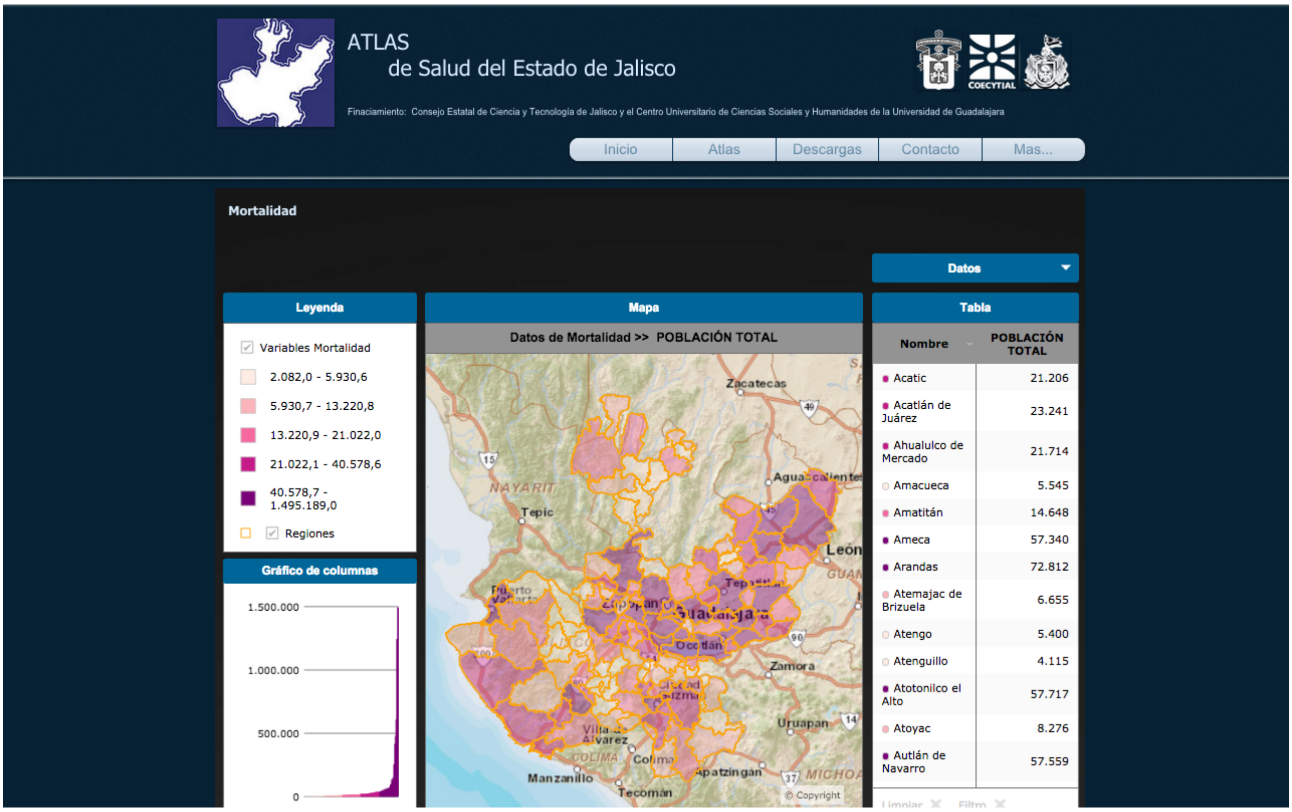
Whether the user selects the first or second path, the site directs him/her to the mapping tool. The mapping tool with the *Mortalidad* (mortality) category in the upper left corner of the screen is shown in Figure 3. There are four frames in the center of the screen. The mapping tool will display information on any element within the frame simply by moving the mouse over that element. Clicking on any element, however, produces a change in the map in the middle, as explained in Textbox 1.

Textbox 1. Description of the frames in the mapping tool.

Frame and description

1. The *Leyenda* (Legend) frame activates or deactivates the four layers displayed on the map (variables, regions, municipality limits, and the world street map) just by clicking their name on the Legend frame.
2. The *Gráfico de Columnas* (Bar Graph) frame shows a bar graph according to the variable selected, if any bar is selected it activates the corresponding region or municipality on the map.
3. The *Mapa* (Map) frame in the middle displays the map of Jalisco according to the variable and layer selected, and shows the quantification of the municipalities in color data groups. If the mouse is placed over a municipality, it shows its name and value, but if it is clicked, the map highlights its geographical limit here as well as in the other frames. In addition, the frame has a small box on the top left corner that allows the user to zoom in and out of the state, reset it to its original size or clean any selected filter.
4. The *Tabla* (Table) frame shows the names and values of all the municipalities of the state in two columns. If the mouse is placed on any of them, the atlas will display it on the map frame; but if it is clicked, the frame will highlight it and the map will zoom in on that municipality to take a closer look at it and the surrounding areas. In addition, the frame allows the user to scroll up and down to reach all the 125 municipalities of the state.
5. The last element of the mapping tool is the *Datos* (Data) button. When clicked, this button displays a new box that allows the user to select the type of region, sanitary or planning that will be displayed, and the category's variable data that will be displayed on the other four frames.

Figure 3. The mapping tool of the Health Atlas of Jalisco.



Finaciamiento: Consejo Estatal de Ciencia y Tecnología de Jalisco y el Centro Universitario de Ciencias Sociales y Humanidades de la Universidad de Guadalajara

Datos de Mortalidad >> POBLACIÓN TOTAL

Tabla

Nombre	POBLACIÓN TOTAL
Acatic	21.206
Acatlán de Juárez	23.241
Ahualulco de Mercado	21.714
Amacueca	5.545
Amatitán	14.648
Ameca	57.340
Arandas	72.812
Atemajac de Brizuela	6.655
Atengo	5.400
Atenguillo	4.115
Atotonilco el Alto	57.717
Atoyac	8.276
Autlán de Navarro	57.559

Data Retrieval per Health or Planning Regions

The aim of the mapping tool is to help users find information about a particular indicator of the health situation in the state of Jalisco. Thus, the first step is to select a category or theme from the Atlas menu (eg, mortality). Whenever a category is selected, the data set changes on the mapping tool, but this is not visible until the user clicks on the Data button where the data changes according to the category selected. The second step is to select a type of region by clicking on the Data button, and selecting *Regiones COPLADE* or *Jurisdicciones Sanitarias*; this action changes the elements on the Legend frame. The third step is to select a variable from the data box. In the case of the mortality category, it appears as *Datos de mortalidad* (mortality data), which displays a list of 43 variables that the user can select (eg, traffic accidents or diabetes). If a variable is clicked, the contents of all the other frames change to display data on that specific variable. Finally, the user can move over the map, legend, and graph bar frames to select the information required as needed.

Map Download and Visits

The mapping tool is not yet able to generate an output by itself, but the research team is currently working to provide a list of maps in PDF format of almost all the 256 indicators currently available on the website [22]. This map list will be available in the *Descargas* (Downloads) section of the main menu. Today, if a user wants a selected map that is not available in that section, he/she has to generate it with the mapping tool and then take a screenshot to obtain an image of it.

To date, the HAJ has received more than 1400 visits, most of them from HMJ health authorities that are testing the atlas function. In addition, there is a small visit counter on the main page just for information purposes; however, the hosting service provides detailed information of the visitors and their characteristics that will allow the team to identify them and the information they check in order to improve the service with time.

The research team is now engaged in analyzing the statistics reported by the HMJ and generating the maps of two separate years, 2000 and 2013. This will serve to compare and show any changes in the UN's millennium goals. We will also check how every municipality and health jurisdiction is doing. This aspect of the project should be complete by December 2015.

Discussion

Principal Findings

Here, we described how the HAJ was made and how it functions. The HAJ is a Web-based service that interactively allows users to review health indicators such as structure, supplies, processes and the impact on public health and related sectors, in order to request and identify opportunity areas and good practices in health services in Jalisco, Mexico. For example, users may use it to analyze the distribution of vaccines in the state and then make projections by age groups or life dimensions about the needs of the population for general care [23].

The atlas is intended to help the HMJ in (1) reducing the volume of information requests from the health sector of Jalisco; (2) maintaining available data from multiple sources with a different grouping or presentation; (3) presenting in map format a considerable volume of data for users with different interests; (4) unifying health data focalization criteria; (5) facilitating graphic and cartographic data representation; (6) integrating the new technologies for request consultation; and (7) supporting the consultation of data for health decision making.

One of the main interests of the HMJ is to reduce the number of information requests that the Ministry of Health receives every week from the general public, media reporters, and other government sectors. These requests are made through the transparency channels and the ministry is forced by law to answer fast and correctly. The atlas will support transparency, information diffusion, health decision-making, and the formulation of new public policies. Furthermore, the research team intends to promote research and education in public health.

Showing health information in map format helps us to analyze the spatial relations between health and geographic situations (eg, mountains, rivers, and water bodies) that can affect the area accessibility. This action cannot be easily done just by looking at a graphic chart or a table. These topographic elements can sometimes represent important barriers to the resources sent to an area and can represent a delay of hours or even days to reach some communities for the health personnel because they have to travel in small planes or helicopters, by walking or riding a horse.

In addition, displaying the health situation in a map can help the authorities to make decisions on a sanitary region or municipality that are more or less affected by a disease. This can be done, for example, by putting over a transparent layer with financial information or human resources that are closer to the areas in trouble. Finally, spatial-temporal analyses can show how conditions can change over time to find tendencies or future perspectives.

Limitations

Although we tried to gather the main health indicators, it is very difficult to have all of them because of confidentiality issues. The HMJ is very careful about releasing health data, in order to protect its users and personnel from information misuse or abuse. We were very clear on this matter and we only published a data collection from official sources and after receiving the authorization from the Ministry of Health.

Moreover, the service is not yet finished because users cannot generate an output map in PDF or JPEG format directly from the mapping tool. Instead, we created the Download section to make some maps available, but they may not comply with user needs. We will continue to work on these issues.

Another limitation is the level of aggregation. Here, we worked at the municipality level but the basic geographical-statistical areas (AGEB) level or blocks would be better. However, we are not sure if the data records at the HMJ are complete at those levels. In a second version of the atlas we are planning to work at the AGEB level, but then we will work with NISGI´s records. They make a population census every five years that gathers information at the house level, and we will try to reach that level.

Comparison with Prior Work

Different researchers have studied the use of GIS and/or Web-based maps and its usefulness has been proved as an accepted method to provide information to users and to support health decision makers in providing a better service [24]. As Wong and colleagues [25] have demonstrated, GIS have important implications for improving public health; they developed a system that keeps track of public water sources to make decisions on managing water systems. Though their system was not specifically an atlas, it provides geographic information through maps that show water system boundaries and support authorities in decision-making.

In Latin America and Spain, most of the atlases have been developed to analyze the mortality situation of the respective countries. Ocaña and colleagues [8], for example, developed the interactive Atlas of the Andalucía region in Spain. This atlas is very similar to the one we created in that it displays a series of maps focused on mortality rates from that region, and compares them to the rates of the entire country. It is available on the Web and intends to help evaluate interventions and identify territorial inequities in resource distribution. It was reported as the first interactive mortality atlas in Spain.

However, Colombia [12] and Bolivia [15] each developed health atlases that show not only mortality information, but also health indicators in general. They show health, social, and economic information in order to provide an integral perspective of the health situation in those countries as well as indicate the problems shared by several regions or municipalities. Brazil also published its atlas of human development; they published it online, and it shows health information on a municipal scale [26]. This atlas is based on the human development index of the UN and it is intended to evaluate the effect of public policies on the population due to the country’s international agreements and future perspectives. Of note, other atlases available on the Internet are also based in Instant Atlas software [19].

Conclusions

The HAJ was created to quickly review the profiles and tendencies in which health conditions, disease, and death indicators are distributed in the state as well as the services provided in different socio-economic contexts, geographical borders, and political and administrative limits.

These methods have been used recently to support health decision makers and inform the general public. Now, more institutions will be using maps to represent health situations because of its proximity to the analyzed areas [27], especially if researchers plan to use spatio-temporal, and cluster analyses [28].

As Iñiguez and Barcellos say [29], it is time for health geographers to start analyzing the health situation of population groups in a state or a region, which will help authorities to identify the distribution of problems according to environmental and life condition inequities [30]. Indeed, the next step of the research team is to address this.

Acknowledgments

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Variable (indicator) coding system according to regions and categories.

[XLSX File (Microsoft Excel File), 15KB - publichealth_v2i1e11_app1.xlsx]

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Abbreviations

AGEB: Basic Geographic-Statistical Areas
GIS: Geographic Information Systems
HAJ: Health Atlas of Jalisco
HMJ: Health Ministry of Jalisco
JSPO: Jalisco State’s Planning Office
NISGI: National Institute of Statistics and Geography
UN: United Nations

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Short Paper

Use of Electronic Health Records and Geographic Information Systems in Public Health Surveillance of Type 2 Diabetes: A Feasibility Study

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Abstract

Background: Data routinely collected in electronic health records (EHRs) offer a unique opportunity to monitor chronic health conditions in real-time. Geographic information systems (GIS) may be an important complement in the analysis of those data.

Objective: The aim of this study was to explore the feasibility of using primary care EHRs and GIS for population care management and public health surveillance of chronic conditions, in Portugal. Specifically, type 2 diabetes was chosen as a case study, and we aimed to map its prevalence and the presence of comorbidities, as well as to identify possible populations at risk for cardiovascular complications.

Methods: Cross-sectional study using individual-level data from 514 primary care centers, collected from three different types of EHRs. Data were obtained on adult patients with type 2 diabetes (identified by the International Classification of Primary Care [ICPC-2] code, T90, in the problems list). GISs were used for mapping the prevalence of diabetes and comorbidities (hypertension, dyslipidemia, and obesity) by parish, in the region of Lisbon and Tagus Valley. Descriptive statistics and multivariate logistic regression were used for data analysis.

Results: We identified 205,068 individuals with the diagnosis of type 2 diabetes, corresponding to a prevalence of 5.6% (205,068/3,659,868) in the study population. The mean age of these patients was 67.5 years, and hypertension was present in 71% (144,938/205,068) of all individuals. There was considerable variation in diagnosed comorbidities across parishes. Diabetes patients with concomitant hypertension or dyslipidemia showed higher odds of having been diagnosed with cardiovascular complications, when adjusting for age and gender (hypertension odds ratio [OR] 2.16, confidence interval [CI] 2.10-2.22; dyslipidemia OR 1.57, CI 1.54-1.60).

Conclusions: Individual-level data from EHRs may play an important role in chronic disease surveillance, namely through the use of GIS. Promoting the quality and comprehensiveness of data, namely through patient involvement in their medical records, is crucial to enhance the feasibility and usefulness of this approach.

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KEYWORDS

electronic health records; diabetes mellitus; geographic information systems; primary health care; health records; personal

Introduction

Nowadays, data collected by health care providers in electronic health records (EHRs) offer a unique opportunity to monitor acute and chronic health conditions in real-time [1]. Moreover, EHRs have the potential to become a cost-efficient, feasible, and sustainable source of data for continuous population health management [1]. One interesting way to analyze EHR-collected data is with the use of geographic information systems (GIS). GIS can track regional changes in disease incidence and prevalence, analyze the environmental and social determinants of health, identify health trends in local communities, and help plan interventions for populations with the greatest need of services [2].

GIS have the ability to give geographic context to EHR data and seem useful when conducting community-level health needs assessment. Indeed, geovisualization may be considered a preliminary stage in focusing public health efforts in high-need communities. Moreover, GIS are gathering increasing attention in the identification and analysis of high-risk areas for noncommunicable diseases, as is the case with “obesogenic environments” [3,4] and diabetes [2,5-7].

The main objective of this study was to evaluate the feasibility of using primary care individual-level EHR data and GIS, for public health surveillance of type 2 diabetes in Portugal.

Methods

Setting

This study was based in Lisbon and in the neighboring region of Tagus Valley, involving a total of 514 primary care centers. All centers were computerized and had an EHR in use. At the time of the study, there were three different types of EHR software in use at the primary care system, but one of them (named ‘SAM’, developed and funded by the Ministry of Health) was used in the great majority of primary care practices throughout the country. Data from primary care EHRs are currently gathered in local health data warehouses, one of which is in Lisbon.

In Portugal, health care is mostly publicly funded, and the majority of patients has a unique patient identifier and access to primary care services through the public primary care system. Use of the International Classification of Primary Care (ICPC-2) is common practice by primary care physicians in Portugal, especially for registering diagnoses and health problems in the EHR. Furthermore, current quality improvement indicators defined by the Ministry of Health are mostly dependent on the use of this classification.

Data Collection

Data collection was performed in September 2013 by the Information Technology department of the Regional Health Administration in Lisbon, from its data warehouse. The dataset provided was de-identified (a pseudonymised identifier was used for each patient). Individual-level data were collected on adult patients (≥20 years of age) with the diagnosis of type 2 diabetes (identified by having the ICPC-2 code for type 2 diabetes - T90 - in the EHR field ‘problems list’). Duplicates were removed from the dataset, as well as patients living outside of the study area of Lisbon and Tagus Valley. Variables collected were: age, gender, parish of residence, comorbidities, and cardiovascular complications. Data on comorbidities and cardiovascular complications were collected from the problems list, by the presence or absence of the corresponding ICPC-2 codes (comorbidities: obesity, T82; hypertension, K86 and K87; and dyslipidemia, T93; and complications: ischemic heart disease, K74 and K76; myocardial infarction, K75; transient cerebral ischemia, K89; stroke, K90; cerebrovascular disease, K91; and peripheral vascular disease, K92).

The study was approved by the National Data Protection Committee and by the Ethics Committee of the Regional Health Administration in Lisbon.

Data Analysis

R Studio software (version 3.0.2) was used for the statistical analyses. The ArcMap functionality of ArcGis (version 10; ESRI) was used to create cloropleth maps. The prevalence of diabetes by parish was mapped using a gray scale where the darkest tone represented the highest prevalence. The same method was applied to generate the comorbidities’ maps.

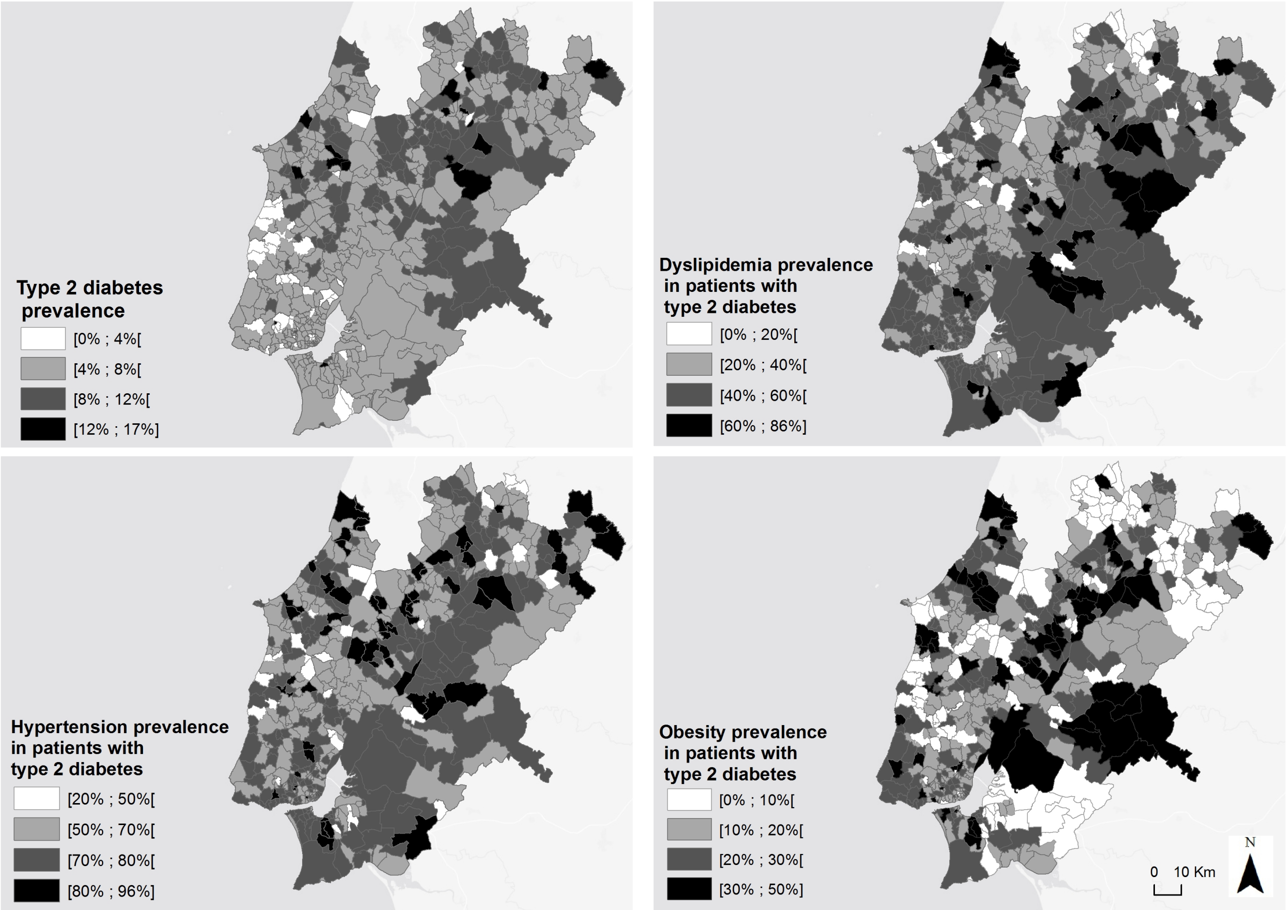
Results

Diabetes Prevalence

From a total of 3,659,868 individual records of people registered in the primary care centers studied, 205,068 had the diagnosis of type 2 diabetes, corresponding to a prevalence of 5.6% (205,068/3,659,868). The mean age of these patients was 67.5 years (standard deviation 11.7) and 49.8% (102,155/205,068) were female. The majority (190,912/205,068, 93.1%) of patients were 50 years of age or older.

Hypertension was present in 71% (144,938/205,068) of the patients with type 2 diabetes, obesity in 20% (41,473/205,068), and dyslipidemia in 45% (92,000/205,068); 19% (37,949/205,068) of the patients had none of these comorbidities. No cardiovascular complications were registered for 85% (173,227/205,068) of the patients. Ischemic heart disease was the most prevalent cardiovascular complication, being present in 7% of the patients (14,982/205,068), followed by stroke (9,152/205,068, 5%), peripheral vascular disease (7,683/205,068, 4%), and myocardial infarction (5,012/205,068, 2%). Transient cerebral ischemia and cerebrovascular disease were registered in less than 2% of the patients with diabetes (1,355/205,068 and 2,448/205,068, respectively).

Figure 1. Mapping of diabetes prevalence and comorbiditiesâ€™ distribution, by parish, in Lisbon and Tagus Valley. Image copyright: the authors.



Geographic Analysis

The maps of prevalence for diabetes, dyslipidemia, hypertension, and obesity showed considerable variation across the region of Lisbon and Tagus Valley, with some parishes showing higher proportions than others (Figure 1). Geographic analysis enabled the identification of high-prevalence areas for diabetes, hypertension, dyslipidemia, and obesity.

Discussion

Principal Findings

This study demonstrated the feasibility of collecting, analyzing, and geographically displaying EHR data. Our study showed a prevalence of diagnosed diabetes in primary care similar to previously reported estimates, as well as a high proportion of diagnosed hypertension, consistent with the literature [8]. One way to apply this information would be to focus initial public health efforts in areas where the prevalence of diabetes and comorbidities seems to be higher, analyzing and addressing possible reasons for that discrepancy, at the community-level.

Nevertheless, we found that individual-level data that is extractable from the primary care information systems in Portugal is still limited. We did not have access to data regarding schooling, socio-economic status (SES), diabetes medication, or biometric and lab data. Moreover, ethnicity data is not usually allowed to be collected in Portugal, hampering a comprehensive analysis of health care disparities in ethnic minority groups.

A more accurate and comprehensive GIS analysis was not possible due to lack of access to individual-level zip code of residence information or parish-level data on the social and environmental determinants of health (eg, schooling, SES, housing, walkability, green spaces, distance from grocery stores, fast food chains).

Furthermore, for comprehensive outcomes monitoring to occur, it should be possible to link data from primary care and hospital EHRs, as well as other health institutions (eg, pharmacies, labs) [9]. The integration of these sources of data, in combination with information on the social and environmental determinants of health, would have the potential to render a more complete picture of the health state of communities [2].

Unfortunately, a great amount of data remains siloed in institutions, fragmented, and generally inaccessible to the ones who could bring meaning to it: clinicians, public health workers, researchers, and, most importantly, patients. It is important that health-related data are increasingly treated as a public good and an essential element of a learning health care system.

Strengths and Limitations

This study had several strengths. It was the first in Portugal to analyze data routinely collected from EHRs, producing small-area maps of the distribution of diabetes and comorbidities, in an entire region. The large sample size and considerable amount of structured data ensure some robustness to the results. The results of our study need to be interpreted in the context of its cross-sectional design. Selection bias cannot be excluded, and two specific groups of individuals might be missing from our sample: people with health care accessibility issues, and people covered by private insurance, who do not normally use the public primary care services.

Finally, it is important to keep in mind that the interpretation of EHR data is generally subject to certain bias (eg, selection, misclassification, surveillance), and should be done skeptically, to distinguish real signals from random noise [10].

Implications for Clinical Practice, Research, and Health Policy

Given the potential of this approach to improve chronic disease surveillance, awareness should be promoted among policy makers regarding the importance of data access, ownership, security, privacy, quality, and comprehensiveness. Furthermore, buy-in from clinicians should be promoted, and every effort should be made for data entry not to be an extra burden in daily practice. A necessary condition to improve data quality and comprehensiveness is facilitating and streamlining its collection, with clinician-friendly EHRs, and patient involvement in data gathering and integration.

Future studies should explore the effects of small-area characteristics (eg, socioeconomic and environmental factors, health care services availability) on individual health, namely in regions where the burden of diabetes is higher. Analyzing the correlation of health outcomes with the social determinants of health may facilitate the implementation of targeted interventions and an optimal allocation of available resources. Furthermore, by identifying high-risk localities, public health efforts may be able to delineate and prioritize community-based strategies, an important element of the Chronic Care model.

Conclusion

In summary, primary care EHR data shows potential to be used in public health surveillance of chronic diseases, in particular with the help of GIS. Clinical data routinely collected in daily practice, when combined with information on the social and environmental determinants of health, has the potential to render a more complete picture of the health state of communities.

Conflicts of Interest

None declared.

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Abbreviations

EHRs: electronic health records
GIS: geographic information systems

ICPC: International Classification of Primary Care
SES: socio-economic status

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Original Paper

Availability and Accessibility of Student-Specific Weight Loss Programs and Other Risk Prevention Health Services on College Campuses

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Abstract

Background: More than one third of college students who are overweight or obese are in need of weight loss programs tailored to college students. However, the availability and accessibility of these programs is unknown.

Objective: The aim of this study is to examine the availability and ease of access to weight loss programs for students at 10 universities with the largest undergraduate enrollment.

Methods: The 10 public universities with the largest student bodies with a mean (SD) undergraduate enrollment of 41,122 (7657) students were examined. The websites of the universities were assessed to determine the availability of weight loss programs. Services for high-risk health needs common to university campuses (ie, alcohol and other drugs, victim services, sexual health, and eating disorders) were searched.

Results: Of the universities searched, 3 (30%, 3/10) offered weight loss programming, however, none met the predetermined criteria. Comparatively, all schools (100%, 10/10) offered no-cost and continual enrollment programming for the other high-risk health needs.

Conclusions: There are limited weight loss services available to undergraduate students compared with other university services. Collaboration between existing college health service providers is suggested for the delivery of appropriate programming for overweight and obese undergraduates wanting to lose weight.

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KEYWORDS

weight loss; student health services; students; universities

Introduction

College campuses provide a foundation for the development of lifelong behaviors for over 70% of young adults between the ages of 18 and 24 who enroll in college [1]. During the undergraduate years, young adults must adjust to multiple personal, social, and academic demands while trying to establish or maintain healthy lifestyle behaviors [2]. This adjustment can be challenging particularly when it comes to establishing healthy eating and exercise patterns [2]. Services offered on university campuses are a convenient resource for undergraduate students looking for assistance with the college adjustment. Undergraduate students' need for university-based health services has increased over the past 5 years, as evidenced in a 2013 survey of college counselors [3].

Services for high health risk needs, like alcohol and other substance use, eating disorders, sexual health services, and victim services are generally recognized as critical to ensure the health of undergraduate students and other university members. However, the prevalence of the high health risk needs requiring services on college campuses varies dramatically. For example, the prevalence of undergraduate students with alcohol use disorders ranges between 20.4% [4] to 31% [5]. According to the Centers for Disease Control and Prevention, 1 in 4 sexually active young adults between the ages of 19 to 24 years have a sexually transmitted disease [6]. Rates of sexual assault in undergraduates range from 1.9% to 7% in college populations [7]. With regards to eating disorders, 1.2% of undergraduate females report being diagnosed and/or treated for anorexia [7], 1% for bulimia [7], and 8.4% for binge eating disorder [8]. An additional 9% of young women meet Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-V) criteria for specified or unspecified feeding or eating disorder [9,10]. Comparatively, approximately 35% percent of college students are overweight or obese [7].

As with the services for high-risk needs described above, colleges have the unique opportunity to address weight and weight-related topics to further ensure the health of their student body. Average weight gain from college matriculation to graduation ranges from 3.5 pounds [11] to 9.5 pounds [12]. Of note, upon college matriculation, 22% of college students are already overweight, and 12% are obese [7]. With one-third of undergraduate students already at risk for negative health and psychosocial outcomes associated with obesity [13,14], relatively small weight gains can increase an individual's risk of having a body mass index (BMI) in the overweight or obese category [15]. These small gains may increase an individual's risk for type 2 diabetes, cardiovascular disease, and depression [16-19].

Despite this public health concern, there remains a need on campuses for weight management services tailored to undergraduates [20,21]. Behavioral health services for the treatment of obesity have lagged behind other on-campus high-risk health behavior services, including drug and alcohol use, risky sexual behavior, eating disorders, and victim services [22]. A 2013 survey of university-based registered dietitians found that over half of participating university dietitians felt it was important for their respective universities to offer structured weight loss programming for students [23]. An integrative approach to the treatment of overweight and obesity could provide an opportunity for counseling centers and health centers to collaborate by promoting the application of evidenced-based practices and access to mental health resources that individuals may need while losing weight. However, it is unclear what services are currently available for overweight and obese undergraduate students wanting to lose weight. No systematic assessment of weight loss programs specific to college students and offered on university campuses could be located in the literature.

Research suggests that weight gain [24] and access to weight-related services [25] are concerns for undergraduate students. A recent study reviewing causes of stress referenced in undergraduate student Facebook pages found weight gain was referenced in 10% of posts [24]. A qualitative study of undergraduate students found that students who felt they had greater access to fitness facilities and healthy eating options were more likely to use those services [25]. Despite this evidence, it remains unclear as to what weight loss services are available and accessible to overweight and obese undergraduate students wanting to lose weight.

This study examines the availability and ease of access of weight loss programs for undergraduate students compared to existing services for other high-risks health needs (ie, alcohol and other drugs, eating disorders, victim services, and sexual health).

Methods

Search Methodology

The 10 public universities with the largest undergraduate student bodies, with a mean (SD) undergraduate enrollment of 41,122 (7657.4) students, were identified using the 2013 US News and World Report College Guide [26]. Because undergraduate students may be more comfortable in programming specifically for students of their same age and demographic, particularly ones that do not include graduate students or faculty who may be their professors or advisors, we selected to focus on weight loss programs tailored specifically to undergraduate students. Similarly, health programing for other high-risk health services are traditionally tailored exclusively to the needs of undergraduate students; as such, we decided to use this same metric when examining weight loss programing. The Internet is ranked as the top source of gathering health-related information for college students [27]. Thus, a Web-based search was elected to search for university weight loss programs. Additionally, college students report trusting health information originating from their respective universities and university health centers [7,27]. For this reason, only websites with edu links were reviewed.

Structured searches of university pages using standardized search terms were conducted over a period of 4 months (July 2013 to October 2013). Search terms were typed into the university's main page by 3 independent coders (2 undergraduate and 1 graduate research assistants). Phone calls were placed to university health, counseling, and wellness centers to confirm the Web search findings.

Search terms were initially selected through a brief survey of undergraduate students that asked students to identify what term they would use to search for weight loss services on their campus. The suggested search terms were reviewed by 2 clinical psychologists and a registered dietitian with experience in the development and delivery of undergraduate weight loss programming, as well as by 2 undergraduate and 2 graduate research assistants. A total of 15 key terms were used to search for student-specific weight loss programs using the search box found on the home page of the respective universities: diet program, weight loss program, losing weight, fitness program, nutrition counseling, nutritionist, dietician, dietitian, exercise facility, weight watchers, student weight loss, student diet program, student weight loss program, weight management, and student weight management .

Search terms for traditional high-risk health services offered on university campuses (ie, alcohol and other drugs, victim services, sexual health, eating disorders) were included to compare the availability of these services to student weight loss services. These terms were also typed in the search box found on the home page of the respective universities.

Search terms were additionally typed into the search box on the student health services page and university counseling pages to ensure no programs were not found due to website-derived search algorithms unknown to the research team.

Establishment of Inter-Rater Reliability

The aforementioned clinical psychologists established criteria prior to the webpage reviews. In order to be coded as a weight loss program, the program must have been undergraduate student-specific, offered on campus, no additional cost, and delivered by university-funded treatment providers. Results were also coded as “related weight loss services” (missing one or more of the weight loss program criterion, fee-based weight loss program, nutrition counseling, personal training, research on college student weight loss or community-based weight loss program), or no weight loss program (group fitness programs, academic research with a focus outside the scope of college student weight loss, nutrition and physical activity handouts).

Two undergraduate and one graduate research assistant piloted the search terms on 4 large (undergraduate student enrollment greater than 30,000 students) test universities, which were randomly selected from a list of universities from the US News and World Report [26]. These 4 schools were not included in the final university sample pool. Terms were typed into the university search engine found on the university’s home page. Research assistants took a screen shot of the results and a screen shot of the first page of each link clicked on, in order to capture the content of the website at the time reviewed. After completion of coding, screen shots and coding of the content were reviewed and discussed between the coders. Coding decisions were confirmed under the direction of 2 clinical psychologists who have experience in the development and delivery of college weight loss treatments.

Results

Weight Loss Programs

Although the predetermined criteria were not met, the following 3 universities offered some weight loss programming: (1) University of Minnesota offered a weight loss program for their undergraduate students; however, the 12-week program for undergraduates cost US $250, (2) Florida International University offered an 8-week program for undergraduate students inspired by the Biggest Looser for US $80, and (3) University of Texas-Austin offered a 12-week program exclusively to graduate students for US $60. Phone calls placed to university health, counseling, and wellness centers verified the results. The aforementioned programs had discrete enrollment periods. Two other universities offered short-term programs, but there was no confirmed plan to continue those regularly beyond the planned dates of the one program. For the purpose of this paper those programs were not included.

Accessibility of Weight Loss Programs

The results of our findings are shown in Table 1. Coders spent a mean (SD) of 102.2 (21.0) minutes searching for weight loss programs using the15 search terms, and a mean (SD) of 8.2 (6.8) minutes per search term. Comparatively, coders spent a mean (SD) of 20.5 (2.9) minutes searching for 4 traditional university services and 5.1 (0.7) minutes per search term. Although the predetermined criteria were not meet, 3 universities offered student weight loss programs. Comparatively, all of the universities searched (100%, 10/10) offered free, university-sponsored, student-specific services for sexual health and victim services. We found that 90% (9/10) of the universities offered free, university-sponsored student-specific services for alcohol and other drug treatments; one school required a fee for assessment and treatment. In addition, 90% (9/10) universities offered free, university-sponsored student-specific services for eating disorders; one school provided screening and referred out to the community for treatment.

Discussion

Principal Findings

Three schools offered weight loss programming, however, none met the predetermined criteria. Comparatively, all schools offered no-cost and continual enrollment programming for the other high-risk health needs. Given the current prevalence of overweight and obesity among college students and the demonstrated weight gain during college, there is a need for obesity-related services on campuses. Universities have competing wellness priorities for their students, and they may designate resources for those behavior and health risks that have more immediate negative consequences such as suicide or alcohol-related death or injury [28-30]. Obesity treatment may be a lower priority as the consequences may not manifest until long after students leave the university. However, our findings indicate that some colleges are beginning to offer services specific to the treatment of obesity in their college populations.

The focus of weight management on college campuses may reflect changes in health services mandated by the Affordable Care Act (ACA). Students are now able to remain on their parents’ insurance until the age of 26 years old [31]. The extended insurance coverage is coupled with an increased focus on obesity prevention and weight loss under the ACA, which requires insurance providers to provide regular BMI screening, nutrition counseling, and other weight management services for no or little cost to the insured [32]. The 35% prevalence rate of overweight and obesity in undergraduate students [7] is comparable to or exceeds the prevalence rates of high-risk behaviors that have regularly provided no-cost services (10% for eating disorder [7-10], 20-30% for alcohol and other drug use [4,5], 25% of sexually transmitted disease [6], and 1-7% for sexual assault [7]). Given the shift in focus that we have seen nationally related to weight management due to the ACA, colleges have the opportunity to mirror these new initiatives.

Table 1. The largest public universities and the health services offered (N=10).

University	Number of students[a]	Weight loss program	Victim services	Sexual health	Alcohol and other drugs	Eating disorder treatment
University of Central Florida	51,269	0[b]	X[c]	X	X	R[d] (only screening offered)
Texas A&M	44,315	0	X	X	X	X
Ohio State	44,201	0	X	X	X	X
Penn State	40,085	0	X	X	R (fee)	X
University of Texas at Austin	39,979	R (fee; only for graduate students)	X	X	X	X
Florida International University	39,045	R (fee)	X	X	X	X
Arizona State University	38,735	0	X	X	X	X
Michigan State	37,988	0	X	X	X	X
University of Minnesota	34,449	R (fee)	X	X	X	X
University of Florida	33,168	0	X	X	X	X

[a] Academic year 2013-2014.

[b] 0 is no program.

[c] X is a program that meets established criteria.

[d] R is a related program that does not meet established criteria for program.

Despite these opportunities, colleges and universities are faced with a number of demands in terms of academic and health-related priorities and limited funds. Examining the barriers and facilitators on college campuses to delivering weight loss programming is an important step in understanding the broad scale implementation and acceptability of these programs. One on-going project, funded by the National Institutes of Health (DK 100916), is examining the efficacy of using social media and text messaging for delivering weight loss programming to college students on 2 different campuses [33]. In addition to examining weight loss and metabolic outcomes (ie, glucose, blood pressure, lipids), one primary aim of this project is to evaluate the implementation feasibility and sustainability infrastructure on college campuses for delivering weight loss programs tailored for students. This evaluation will include a cost effectiveness assessment as well as interviews with key administrative and student leaders on campus to provide data on both the facilitators and challenges to offering tailored weight management programs.

A 2011 analysis of the American College Health Association-National College Health Assessment (ACHA-NCHA) database found that the top two most trusted sources of health information were health center medical staff and health educators [34]. However, this same study found that these two sources of information were also the most under-utilized method of gathering health information [34]. While it is unclear why these on-campus resources are underutilized, it is possible that the nature of the Web search (eg, timely, cumbersome) may have been a barrier to utilization. Students relying on the Internet alone might struggle to find information about on-campus services. The cost of these programs may also reduce the likelihood that students will utilize the resources. We found weight loss programs exclusively for undergraduate students were available for a fee (US $60-$250) at 2 of the 10 universities included in this Web-based search (University of Minnesota and Florida International University).

For these and other reasons, a multidisciplinary approach to disseminating and marketing a weight loss program specific to college students is critical. Collaboration with the counseling center may be particularly important. The is concern that weight loss services on college campuses may promote disordered eating and/or eating disorders in a vulnerable college population [35]. Dieting is prevalent on college campuses: over 60% of college females and 36% of college males report they are trying to lose weight, and 48% of college females and 28% of college males reported dieting to lose weight [7]. Overweight and obese young adults who desire to lose weight are just as likely to develop an eating disorder as the general population [36], yet eating disorder treatment for this population is often over looked [23,37].

There is literature suggesting that there may be a common underpinning for both excessive weight gain and eating disorders. These shared experiences and characteristics are dieting, media use, body image dissatisfaction, and weight-related teasing [38,39]. Thus, it is not weight loss per se, but a combination of maladaptive behaviors and factors that may put an overweight or obese individual at risk for an eating disorder. College women, in particular, may use a combination of healthy and unhealthy weight loss practices [40]. Thus, a multimodal approach of social, environmental, and individual strategies coupled with media literacy and advocacy is needed for overweight and obese students wanting to lose weight [23,41]. It is critical that university health providers delivering weight loss programs for students be aware of the possibility of underlying eating disorders that may complicate the students' efforts to lose weight so that the appropriate treatment can be delivered to students [23,37]. The key is to provide education and evidence-based programs to teach safe, effective, and healthy ways of losing weight.

While many university health officials and administrators recognize the need for an environment that promotes healthy weight loss practices and relevant programming, there are a number of challenges faced by these key leaders on campus. There are competing priorities for resources, time, as well as other behavioral and health needs with more immediate consequences [28,29,42]. Unfortunately, outsourcing weight loss programming is likely not the solution to implementing weight loss programs for undergraduate students as traditional weight loss programs for adults. Young adults who attend weight loss programs tailored to adult populations attend fewer sessions and lose less weight than adults attending weight loss programs [43]. Many universities likely already have necessary components that would allow them to offer a systematic program to prevent and treat obesity. The key is to integrate these available services and personnel to provide education and evidence-based programs that are attuned to the potential for disordered eating behaviors in this population of overweight and obese students wanting to lose weight [40]. Programming that promotes a campus environment of positive body image and self-esteem may help overweight and obese and normal weight students who want to lose weight. For example, The Body Positive is a body image and health curriculum for high school students that promote physical and mental health through workshops, videos, and campus events. These types of programs could provide an interim solution prior to the launching of sustained weight loss program offerings.

Limitations

This study provides only a snapshot of the availability and ease of access to weight loss services on college campuses. Only the websites of the ten largest public universities were reviewed, limiting the search and possibly ignoring student weight loss programs available at smaller and/or private universities. Universities often update their webpages so that recent content is pushed to the top of searches, so it is possible that the results presented here were influenced by search mechanisms unknown to the study authors. Lastly and importantly, this study was not able to determine the extent of the utilization of available weight loss services by university students.

Conclusions

This study examined the avaliability and ease of access to weight loss programs for college students. The results highlight that there are limited weight loss services available and accessible to college students when compared to other university services, such as alcohol and other drugs, eating disorders, sexual health, and victim services.

Advocacy from student groups and collegiate administrators is called for to provide treatment and reduce stigma regarding accessing resources specific to weight loss for overweight and obese students wanting to lose weight.

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Conflicts of Interest

None declared.

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Abbreviations

ACA: Affordable Care Act
BMI: body mass index

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Original Paper

Mobile Technology for Empowering Health Workers in Underserved Communities: New Approaches to Facilitate the Elimination of Neglected Tropical Diseases

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Abstract

Background: As global mobile phone penetration increases, direct health information communication from hard-to-reach communities is becoming commonplace. Mobile health (mHealth) tools that enable disease control programs to benefit from this information, while simultaneously empowering community members to take control of their own health, are vital to the goal of universal health care.

Objective: Our aim was to highlight the development of the Liverpool mHealth Suite (LMS), which has been designed to address this need and improve health services for neglected tropical diseases being targeted for global elimination, such as lymphatic filariasis.

Methods: The LMS has two main communication approaches—short message service and mobile phone apps—to facilitate real-time mass drug administration (MDA) coverage, reporting patient numbers, managing stock levels of treatment supplies, and exchanging health information to improve the quality of care of those affected.

Results: The LMS includes the MeasureSMS-MDA tool to improve drug supplies and MDA coverage rates in real-time (currently being trialed in urban Tanzania); the MeasureSMS-Morbidity tool to map morbidity, including lymphedema and hydrocele cases (initially piloted in rural Malawi and Ghana, then extended to Ethiopia, and scaled up to large urban areas in Bangladesh and Tanzania); the LyMSS-lymphedema management supply system app to improve distribution of treatments (trialed for 6 months in Malawi with positive impacts on health workers and patients); and the HealthFront app to improve education and training (in development with field trials planned).

Conclusions: The current success and scale-up of the LMS by many community health workers in rural and urban settings across Africa and Asia highlights the value of this simple and practical suite of tools that empowers local health care workers to contribute to local, national, and global elimination of disease.

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KEYWORDS

mhealth; lymphatic filariasis; LF; elephantiasis; neglected tropical diseases; NTDs; community engagement; SMS; smartphones; apps

Introduction

A well-tested approach to achieving major health improvements for less fortunate and underserved people in developing countries is to actively involve the local community in the management, distribution, and advocacy of much-needed health practices [1,2]. A major example of this is seen in the world of parasite infection control with the very successful involvement of village personnel in the mass drug administration (MDA) activities of the anti-filarial chemotherapeutic agent, ivermectin, used for onchocerciasis (river blindness). This was termed “community-directed treatment with ivermectin” [3]. The direct involvement of the affected communities and those working in health within these communities (eg, village health workers, community drug distributors [CDDs]) has been an essential part of the global success of this and similar filarial disease programs such as lymphatic filariasis (LF) [4,5].

Here we present an additional way of empowering the local communities using current mobile phone technology developed at the Liverpool School of Tropical Medicine (LSTM) to specifically improve and enhance the implementation of national filarial disease programs. Mobile phones are arguably the most sophisticated form of modern technology to become universally available to underprivileged populations of the world, and the trend of using mobile phones to improve health services (mHealth) is rapidly increasing [6-9]. Mobile phone technology has to date been used in a wide range of health settings including data collecting and reporting, decision-making support for health workers, and delivering health information to the public (eg, appointment reminders, health quizzes).

Methods

The Liverpool mHealth Suite

The success of the tools we have developed—the Liverpool mHealth suite (LMS)—is attributed to the use of both local health workers’ knowledge and their own mobile phone handsets to generate primary data on treatment and morbidity. This has helped enhance the quality of health care they provide. The LMS tools focus on the parasitic disease LF (elephantiasis), which is one of the 17 neglected tropical diseases reported by the World Health Organization (WHO) and targeted for global elimination [4]. The LMS has been developed directly to enhance the mass drug administration (MDA) and patient care, currently referred to as morbidity management and prevention, components of the Global Programme to Eliminate Lymphatic Filariasis, as well as help prepare endemic countries for successful elimination verification.

Main Communication Approaches

We have adopted two main communication approaches to undertake these tasks (see Figure 1): short message service (SMS) communication and Internet communication.

SMS tools allow village health workers using readily available mobile phones with basic functionality (ie, not necessarily smartphones), which they use to send information, in the format of a standard SMS, to a local phone number. This SMS is received by a locally situated smartphone, which plays the role of the local server. We refer to this as the relay phone. The relay phone transmits the information to a central cloud-based server via the Internet using either WiFi or a local mobile Internet connection (via https) and further sends feedback to the health workers by SMS. Data received by the central server can be accessed via a Web browser, allowing real-time field collected data status, treatment needs, and other information of health activities occurring at the community level to be accessed in real-time.

Internet tools allow health workers to send and receive information (eg, text, pictures, location information) using mobile phone–based apps that are accessed via a local Internet connection. The health workers’ mobile phones communicate directly with the central server to facilitate the provision of essential medical care and supplies to remote locations in a timely manner. This also helps to instantly obtain current information on best care medical practices.

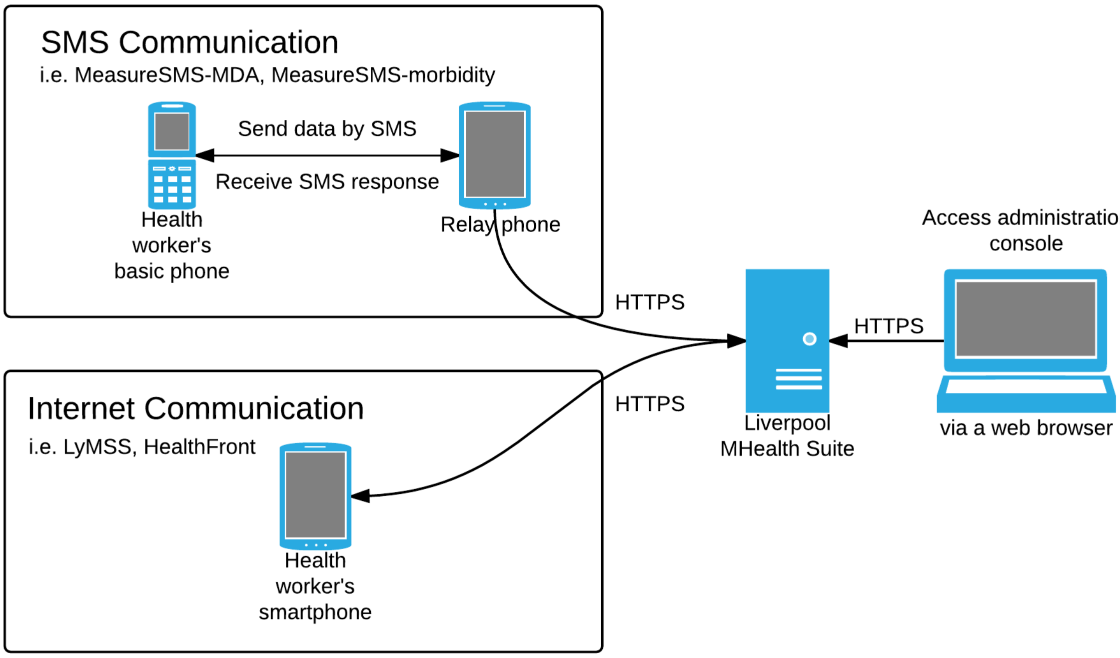
Both the SMS component and Internet component of the LMS differ from many of the mobile technology approaches previously developed. Formerly, these have been mainly top-down approaches where the communication is initiated by external or senior-level investigators, rather than being used by local health workers in the field. The LMS tools have been applied in both rural and urban settings by local health workers to acquire essential data that address four important national programmatic areas relating to the elimination of LF disease (see Table 1).

The first two programmatic areas use the MeasureSMS system to collate and report MDA treatment numbers (MeasureSMS-MDA) and morbidity information (MeasureSMS-Morbidity), including lymphedema and hydrocele cases, at the village and health center levels [10]. The second two programmatic areas make use of mobile phone apps to coordinate the distribution of lymphedema management supplies (LyMSS-lymphedema management supply system) and provide the most up-to-date health information to frontline health workers (HealthFront) and their supervisors. Details of each of these are outlined below.

Table 1. Summary of the tools included in the Liverpool mHealth suite.

№	Name of tool	Mode	Description
1	MeasureSMS-MDA	SMS	Reporting MDA treatment numbers and preliminary clinical case data at health facility level to help improve drug distribution and population coverage rates.
2	MeasureSMS-Morbidity	SMS	Reporting clinical case numbers, age, sex, condition, severity, and acute attacks at village and health facility level to help improve management and disability prevention services.
3	LyMSS	Internet	Maintaining a supply chain of morbidity care packages including wash basins, towels, soaps, and antibacterial creams to help ensure the provision of basic care to patients.
4	HealthFront	Internet	Providing up-to-date practical health information to health facility workers for managing clinical conditions to help improve the conditions and quality of life of patients.

Figure 1. The two main approaches of the Liverpool mHealth Suite (LMS).



Results

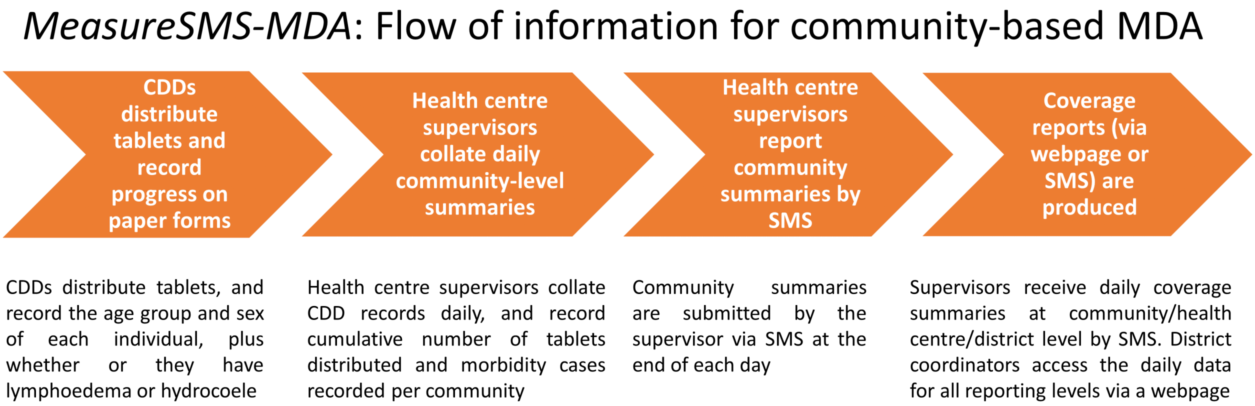
Areas of Application

Tool 1. Monitoring Mass Drug Administration Treatment Numbers and Preliminary Morbidity Case Detection

The MeasureSMS-MDA reporting tool is being used for real-time reporting of the number of people treated during MDA campaigns, plus the number of morbidity cases seen during the campaign (see Figure 2). Health facility/distribution post level treatment numbers, including the number of tablets distributed, and patient numbers are submitted to the MeasureSMS-MDA system via SMS by health workers at the end of each day of an MDA campaign, and these numbers are instantaneously viewable in a database via a Web browser. Health workers immediately receive an SMS message, which acknowledges both the receipt of their report, plus provides feedback on the progress of the campaign in their area (eg, reported cumulative coverage in relation to target coverage, or the number of tablets remaining at the facility). This real-time information sharing empowers both the health worker and MDA supervisors at the district or national level. The health worker, in receiving instant feedback on their progress, is able to determine how to more effectively manage their campaign to meet coverage targets. Further, the knowledge that their activities are being reviewed by more senior campaign members may lead them to feel more connected to the MDA program and thus more motivated to ensure its success. The MDA supervisors are empowered through gaining instant access to data, which will help them identify facilities or distribution posts that need additional assistance proactively rather than retroactively (eg, helping facilities acquire more tablets before their stock runs out).

The use of this tool is particularly important for countries starting or scaling up MDA implementation. Post-MDA treatment summaries can further help identify areas where drugs need to be targeted to improve coverage and help interrupt transmission. Further, it can provide a crude baseline of clinical case numbers on which to build more detailed information. This is important where there is a lack of information on disease prevalence. Figure 2 describes the flow of information during an MDA campaign in a rural setting where reports are made at health facility level and CDDs distribute tablets door to door.

Figure 2. Flow of information using the MeasureSMS-MDA system.



MeasureSMS-MDA: Flow of information for community-based MDA

CDDs distribute tablets and record progress on paper forms

Health centre supervisors collate daily community-level summaries

Health centre supervisors report community summaries by SMS

Coverage reports (via webpage or SMS) are produced

CDDs distribute tablets, and record the age group and sex of each individual, plus whether or they have lymphoedema or hydrocoele

Health centre supervisors collate CDD records daily, and record cumulative number of tablets distributed and morbidity cases recorded per community

Community summaries are submitted by the supervisor via SMS at the end of each day

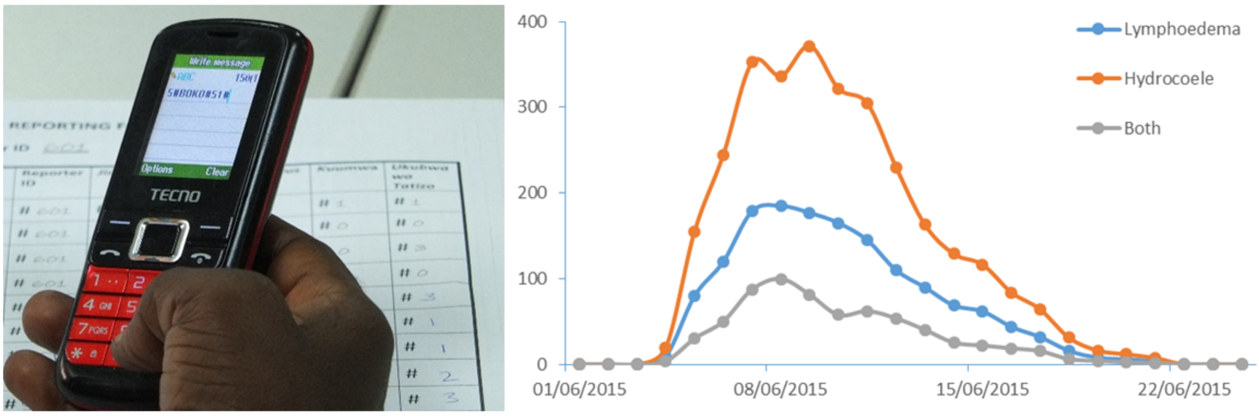
Supervisors receive daily coverage summaries at community/health centre/district level by SMS. District coordinators access the daily data for all reporting levels via a webpage

Tool 2. Morbidity Mapping and Epidemiology

The MeasureSMS-Morbidity reporting tool is used to improve information on LF patient numbers, including location, age, sex, clinical condition (ie, lymphedema, hydrocele), and details about severity of condition (ie, mild, moderate, severe) and episodes of acute attacks [10]. Data are sent in as a simple SMS message (one message per patient) by health workers during a community cross-sectional survey and are collated into a national disease database that is accessible by national and district health teams via a Web browser, secured with a username and password. The number of cases reported can be viewed in real-time, allowing the progress and quality of data to be monitored during the survey period. Figure 3 presents an example of a health worker writing an SMS message containing example patient data, as well as examples of the data that can be accessed via the MeasureSMS-Morbidity webpages (ie, a time series plot of reported cases) and a spreadsheet of the resulting data. To verify the quality of the reporting in relation to clinical condition and severity, a random sample of individuals (with sample size based on estimated positive predictive value, eg, [10]) are followed up by the district health team and medical doctor. This tool again empowers both the health workers who report the data and the individuals who oversee the data reporting by increasing the sense of data ownership and accountability, and opening the channels of communication between the health workers and the patients, plus the health workers and those overseeing the activity.

This tool is important in addressing the major challenge of estimating patient numbers in each endemic country and will help national LF elimination programs provide basic health care for those suffering from this disease [11]. The identification and management of cases needing surgery for hydrocele and care for lymphedema is also greatly improved by using MeasureSMS-Morbidity. Further, if implemented on a regular basis, the MeasureSMS-Morbidity system can be used to detect new cases and monitor the decline in prevalence over time. Case number data have become increasingly important and are now formally required by the WHO for the official verification. Thus, the MeasureSMS-Morbidity tool gives the community members a key role in contributing to the national programmatic success.

Figure 3. The MeasureSMS-Morbidity tool data entry and presentation.



Received At	Validation Code	Raw SMS	Patient ID	Location	HW ID	Gender	Age	Condition	Acute Attacks	Severity
06/06/15 09:35	ALL_OK	5#boko#4#m#44#l#3#2	5	boko	4	M	44	L	3	2
06/06/25 09:38	ALL_OK	6#tenge#4#m#62#h#0#0	6	tenge	4	M	62	H	0	0
06/06/15 09:38	HASH_ISSUE	6#tenge#10#f#l#1#1	6	tenge	10	F	l	1	1	0
06/06/15 09:40	ALL_OK	10#faya#4#f#58#l#4#3	10	faya	4	F	58	L	4	3
06/06/15 13:53	GENDER_ISSUE	6#TENGE#14#F#49#H#1#1	6	TENGE	14	F	49	H	1	1

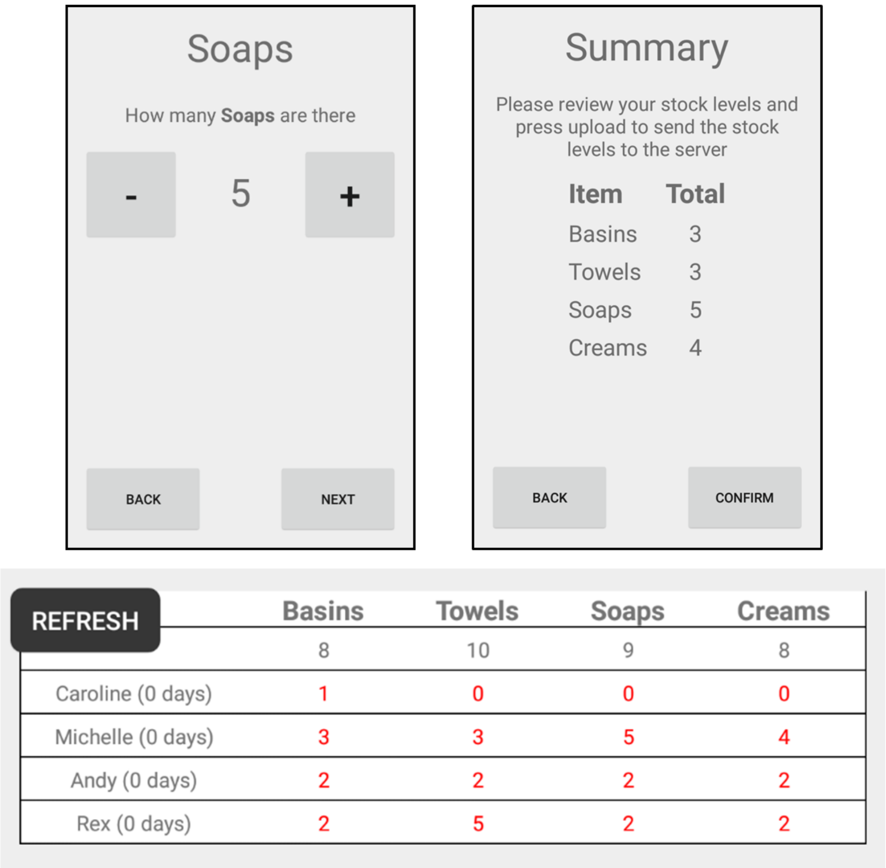
Tool 3. Delivery of Care to Patients

LyMSS is a lymphedema management supply system that makes use of mobile phone apps to help provide basic care packages (ie, towels, soap, antibacterial creams [12]) to those afflicted with the chronic disease and disfigurement that occur in LF patients. Currently, there is no sure way for central management and supply offices to know the local supply needs/demand or locally held basic care inventory (ie, by patients, community health workers, health centers) at a particular point in time. The LyMSS app allows health workers to submit regular inventory reports, which are instantly viewable by their local supply managers on their own mobile phones and by the national-level supply managers via a Web browser. Figure 4 presents an example of the supply manager app and reported levels of soaps in one of the study areas over a 6-month period. This information can then be used to direct supplies to where they are most needed in a timely manner and thus ensure patients have continuous access to the items that they need to effectively care for their condition. This system empowers the individuals involved in reporting and overseeing the stock levels to take ownership of the supply chain. The system does not dictate when supplies need to be distributed, as during its development it was acknowledged that the LyMSS users will have the most accurate knowledge of their own distribution rates and should therefore be encouraged to determine how and when the supply manager should supplement their supplies. The method and frequency of delivering supplies to patients was also determined by the local health workers to ensure these activities could fit easily into their usual activities.

While SMS-based stock management approaches have been shown to be successful in a number of applications [13,14], these tools are limited in their functionality. As smartphones are likely to become increasingly ubiquitous in even the most remote of settings [15], it is important to develop applications that use smartphones and thus extend the approach to activities that are not possible under an SMS model (eg, recording photographs of the patient's clinical condition). However, as not all locations are expected to have mobile data coverage at present, or data coverage may too expensive, a more basic SMS reporting approach may be more suitable for supply management purposes in these locations in the interim.

The LyMSS tool will become increasingly more important as morbidity management activities become the main focus of the LF elimination programs in endemic countries. The increased need for the provision of the basic kits and supplies from international sources will be especially important for community/home-based lymphedema management. It will be critical to keep track of the community needs to ensure the supply meets local demands. In a wider context, the availability and access to health care, aside from being one of the WHO criteria for countries to achieve elimination [12], is also a goal of the wider principle of strengthening health care access for all [16].

Figure 4. An example of the LyMSS stock entry app.



Soaps

How many **Soaps** are there

Summary

Please review your stock levels and press upload to send the stock levels to the server

Item	Total
Basins	3
Towels	3
Soaps	5
Creams	4

	Basins	Towels	Soaps	Creams
	8	10	9	8
Caroline (0 days)	1	0	0	0
Michelle (0 days)	3	3	5	4
Andy (0 days)	2	2	2	2
Rex (0 days)	2	5	2	2

Tool 4. Health Information for Best Care Practice

HealthFront is another vital LMS tool currently under development, which involves the provision of practical health information to health workers for decision making, particularly for those who are at the patient-health interface for LF and other neglected tropical diseases. Ready access of current practical information to health workers on clinical management will improve patients' health, as well as empower their status and ability. This new LMS tool will deliver regularly updated information to health workers. It will work most efficiently and effectively as a smartphone app in order to support more visual information in a user-friendly format. A simpler text-only based approach is also being considered to complement the smartphone app in order to accommodate those without smartphone access, thus ensuring that access to the most sophisticated mobile technology is not a barrier to health information and quality of care.

Recent Epidemiological and Program Implementation

MeasureSMS-Morbidity has been extensively field tested in both rural and urban environments, providing vital LF patient baseline data (Figure 5) [10]. In brief, in 2014 local health surveillance assistants (HSAs) in parts of Chikwawa district, Malawi (covering a population of 107,000), and volunteer community health workers (CHWs) in parts of Ahanta West district, Ghana (covering a population of 45,000), used the tool to identify LF lymphedema and hydrocele patients in their own health catchment areas. Although there was little difference in mobile phone ownership, large differences in mobile phone experience were observed between these two reporting groups: 100% (60/60) in Malawi had used their phones to send SMS text messages compared to 44% (14/32) in Ghana. Due to the nature of their work, all health workers involved were very familiar with community members in their catchment area, and patient identification was undertaken using a mixture of methods including prior knowledge, community gatherings, and household visits.

Post-study questionnaires were completed by the majority of health workers involved in both surveys, in which they were asked to identify any difficulties they had in undertaking the survey and further highlight the perceived benefits. In Malawi, 96% (43/45) of HSAs reported that they found it easy to submit data by SMS, stating that the greatest benefits were that information could be shared quickly (95%, 42/44). In Ghana, where health workers had less SMS experience, 55% (16/29) reported that it was easy to report by SMS with 72% identifying the speed of information sharing as its most beneficial feature (21/29). Locating patients, particularly hydrocele patients, was reported by both groups to be more difficult than the SMS reporting. However, during a focus group discussion in Ghana, they reported that the exercise enabled them to form stronger relationships with the LF patient community. The quotes below were provided by health workers during these two field tests as part of a semistructured questionnaire:

> *The community has been very happy with the programme and enjoyed it. There is great linkage between HSA (health surveillance assistant) and the community.* [Malawi]

> *It is fast information and it is easy to get good data in our catchment areas.* [Malawi]
>
> *The programme is very important because these patients will be assisted accordingly, it is encouraging relationship between HSA and the community.* [Malawi]
>
> *(The) community will profit from this method of surveillance.* [Ghana]
>
> *Now we know the cases, something can be done to help them.* [Ghana]

The MeasureSMS-Morbidity tool has recently been implemented in Dar es Salaam, Tanzania (approximately 4.5 million people), in order to test it in an urban environment and to further demonstrate its scalability. To facilitate this, a cascade training approach was adopted in which local CDDs identified cases using a house-to-house approach, and then CDD supervisors collated this information daily and reported it via SMS. This was the first survey in which the LF program staff used the MeasureSMS-Morbidity webpages to fully supervise the data being reported in real-time. Program staff have expressed their satisfaction in the tool as it was easy to set up and train health workers and it allowed them to instantly access the reported data via the Web, monitor the quality of the data, and provide feedback on the results to interested parties in a very short time frame. Preliminary data from this urban survey indicate a high LF morbidity burden in Dar es Salaam, with approximately 2000 lymphedema cases and 4000 hydrocele cases reported across the city. In recent months, additional rural implementations have been undertaken in parts of Ethiopia (covering approximately 450,000 people) and Malawi (covering approximately 0.5 million people), and a second urban application has been undertaken in Dhaka, Bangladesh (covering approximately 2.5 million people). Such a rapid increase in a short period of time clearly highlights that the tool is simple enough to be scalable across different settings.

Most importantly, these mapping tools help ministries of health establish the prevalence of disease in a given area, which is an essential component of the WHO dossier requirements [4]. These tools help LF programs prioritize, plan, and start treatment and care for patients. This is best exemplified in Malawi where hydrocele surgery camps and home-based lymphedema training started within months of the mapping being completed in the 2 most endemic districts of the country. In total, approximately 1850 hydrocele and 650 lymphedema cases were identified, and the Ministry of Health, with the support of LSTM through the Department of International Development UK funding, is now implementing an essential minimum care package. The distribution and use of this package was greatly enhanced through the mapping data, which informed where and what resources were required to implement the hydrocele surgeries and also to increase the training of health workers, community volunteers, and patients in home-based lymphedema care. Over the next 6 months, it is expected that all those with LF-induced hydrocele in these 2 districts of Malawi will have had or been offered surgery, and all lymphedema patients will be able to receive care. Plans to address the specific needs of the more severe cases and how to scale up the new LyMSS tool (see below) in collaboration with other international partners are underway. This is an extraordinarily powerful example of empowering local communities.

Implementation challenges varied between settings. As demonstrated in Ghana, mobile phone ownership does not necessarily equate to a familiarity with using the phone's SMS functionality; therefore, basic mobile phone training may be necessary in some areas. Poor mobile phone coverage has thus far proven to be a secondary issue in comparison to the lack of regular access to phone charging facilities, particularly in rural areas. This to date has delayed submission of data but not prevented it entirely; however, knowledge of the local telecommunication networks is vital to the success of this tool. For example, to date, the cost of sending an SMS message has been covered by LSTM. While the cost of a single message is nominal (eg, approximately £0.01 in Malawi), at scale it consumes a large proportion of the overall cost to complete the survey. To address this, the use of bulk prepaid SMS options, referred to as bundles, should be encouraged where possible. For example, in Malawi you can purchase 600 SMS messages for MK600 (approximately £0.50), resulting in very large savings. Prior to starting the survey, research should also be undertaken to select which mobile network the relay phone should use (if multiple networks are available), as network quality can vary substantially in the target area. To account for this, the MeasureSMS-Morbidity tool allows multiple relay phones to be used (and thus multiple networks), such that all information is collated in a single database regardless of which relay phone it was received by.

The LyMSS tool is currently being tested in Chikwawa, Malawi (Figure 6). The LyMSS was set up in this area following the implementation of the MeasureSMS-Morbidity tool, which highlighted the prevalence of disease in the area. A total of 11 HSAs are involved, and since receiving initial training in May 2015 during which they were provided with a low-cost smartphone (eg, Huawei Ascend Y330, approximately £40), they have been continuously supplying 62 lymphedema patients with basic supplies, with soaps and antibacterial creams in highest demand. During the initial set-up, some problems were experienced in the local mobile network, with the data connection weak or non-existent in key areas (ie, around the health facility where the health workers gathered to send their initial supply reports). An interim follow-up in October 2015, however, indicated that this issue had been resolved, either through improvements in the local network or an increase in the health workers' knowledge of areas where there was a sufficient signal. This was confirmed via a questionnaire, where only 2 of the 11 HSAs indicated that poor network had been an issue for them. A more pressing issue identified by the health workers was the issue of ensuring their phones were sufficiently charged in order to be able to send the reports. As much as 5 of the 11 HSAs did not have electricity in their homes, hence they generally used charging services at their local market. Phone credit was also identified as an issue as 8 of the 11 health workers had never used a smartphone prior to the study and were unfamiliar with mobile data tariffs. As with SMS, mobile data bundles were available for the chosen network (eg, 500MB for 30 days at MK2550, approximately £3), and during the training the HSAs were directed to use those. However, many

HSAs chose not to consistently make use of the bundles over the 5-month period, resulting in higher costs and an increased likelihood of running out of phone credit.

Despite these perceived problems, the HSAs were not prevented from submitting their weekly reports, although they were occasionally submitted a day or 2 late. To date, over 500 soaps and 250 antibacterial creams have been distributed to patients over a 6-month period. The HSAs have expressed their personal satisfaction in being able to follow through and assist the patients, believing that regular contact with the patients has strengthened their relationship and encouraged the patients to open up about their problems and needs. During a focus group discussion, they also reported that sending supply reports by the smartphone app saved them time, although they did still need to communicate via telephone to arrange to collect additional supplies when needed. Improvements to the app were suggested by the HSAs, indicating that the scope could be extended for use beyond a simple supply monitoring tool.

The first version of the MeasureSMS-MDA tool has been developed and is being tested in December 2015 in Dar es Salaam, whereas the HealthFront health information tools are currently under development with plans to test the app in 2016.

Figure 5. An example of the MeasureSMS-Morbidity training workshop.

Figure 6. An example of the LyMSS tool in action.

Discussion

Principal Considerations

We advocate that community involvement and empowerment are essential for improving the health of many millions of people in underserved health-poor and resource-poor regions of the world. Community empowerment is the foundation of the LMS we describe here, and these tools have the potential to be applied to many other neglected tropical diseases and health conditions. The essential components of these tools include the simplicity of the data format, combined with the ease of its transference through a technology that is now a standard component of everyday life. This community-based approach sets it apart from more complicated, often research-oriented systems that have been applied elsewhere.

Further, these tools can be readily expanded to cover very large populations in a relatively short time frame, as we have demonstrated in our recent work in Africa with the MeasureSMS-Morbidity tool. The ability to scale up a tool and integrate it into existing national and subnational systems, structures, and policies is an essential part of mHealth initiatives, yet many fail to achieve this [17-19].

Conclusion

As public health systems move more towards establishing universal health care for the populations of the developing countries [16], there will be a greater need for information obtained directly from local communities, many of which are geographically isolated. The role of new communication approaches driven by advances in mobile technology, such as the LMS described here, are therefore vital to improving the health of currently underserved populations.

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Conflicts of Interest

None declared.

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Abbreviations

CDD: community drug distributor
CHW: community health worker
HSA: health surveillance assistant
LMS: Liverpool mHealth suite
LSTM: Liverpool School of Tropical Medicine

LF: lymphatic filariasis
LyMSS: lymphedema management supply system
MDA: mass drug administration
SMS: short message service
WHO: World Health Organization

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Original Paper

Applying Sparse Machine Learning Methods to Twitter: Analysis of the 2012 Change in Pap Smear Guidelines. A Sequential Mixed-Methods Study

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Abstract

Background: It is difficult to synthesize the vast amount of textual data available from social media websites. Capturing real-world discussions via social media could provide insights into individuals' opinions and the decision-making process.

Objective: We conducted a sequential mixed methods study to determine the utility of sparse machine learning techniques in summarizing Twitter dialogues. We chose a narrowly defined topic for this approach: cervical cancer discussions over a 6-month time period surrounding a change in Pap smear screening guidelines.

Methods: We applied statistical methodologies, known as sparse machine learning algorithms, to summarize Twitter messages about cervical cancer before and after the 2012 change in Pap smear screening guidelines by the US Preventive Services Task Force (USPSTF). All messages containing the search terms "cervical cancer," "Pap smear," and "Pap test" were analyzed during: (1) January 1–March 13, 2012, and (2) March 14–June 30, 2012. Topic modeling was used to discern the most common topics from each time period, and determine the singular value criterion for each topic. The results were then qualitatively coded from top 10 relevant topics to determine the efficiency of clustering method in grouping distinct ideas, and how the discussion differed before vs. after the change in guidelines .

Results: This machine learning method was effective in grouping the relevant discussion topics about cervical cancer during the respective time periods (~20% overall irrelevant content in both time periods). Qualitative analysis determined that a significant portion of the top discussion topics in the second time period directly reflected the USPSTF guideline change (eg, "New Screening Guidelines for Cervical Cancer"), and many topics in both time periods were addressing basic screening promotion and education (eg, "It is Cervical Cancer Awareness Month! Click the link to see where you can receive a free or low cost Pap test.")

Conclusions: It was demonstrated that machine learning tools can be useful in cervical cancer prevention and screening discussions on Twitter. This method allowed us to prove that there is publicly available significant information about cervical cancer screening on social media sites. Moreover, we observed a direct impact of the guideline change within the Twitter messages.

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KEYWORDS

Twitter; machine learning; social media; cervical cancer; qualitative research

Introduction

Social networking websites have fundamentally changed the way in which individuals and organizations communicate with each other [1,2]. Almost 75% of adults on the Internet use online social networking sites, including Facebook and Twitter [3], which provide an opportunity for social interaction and a space to share ideas, opinions, and information [1]. Thus, the content shared ranges from news to personal experiences [4], with health-related information commonly shared and discussed. For example, in a recent survey of adults, a large majority (80%) of younger Americans reported that they would share their personal health information on social media sites [5]. Similarly, in our previous qualitative examination of a sample of Twitter messages about mammograms and Pap smears, we found that a substantial proportion of the top messages within a 1-month period were related to personal experiences within these cancer screenings [6]. Despite this, it is unclear whether the types of health communication on social media sites like Twitter contain reliable information or clear health promotion and/or improvement messages in the midst of millions of comments and discussions.

The immense volume of messages on social media sites (eg, more than 500 million Twitter messages sent every day) [7], preclude the use of traditional qualitative methods to analyze most of this text. Therefore, there is a need to apply new methodologies from computer science and statistics to examine this publicly available content. The so-called sparse machine learning techniques offer a way to examine and summarize large amounts of textual data [8], and therefore would be particularly insightful in studying the online social media content related to cancer prevention, screening, and treatment. This methodology is currently used to analyze such content for businesses (eg, to generate advertising that is tailored to specific online discussion topics) [9], but it is yet to be implemented in biomedical and cancer research.

For this paper, we sought to explore the feasibility of these machine learning approaches to analyze Twitter content about cervical cancer and Pap smears. Specifically, we examined Twitter messages about these topics before and after the US Preventive Services Task Force (USPSTF) guideline change on March 15, 2012 [10] (Table 1), using a sequential mixed method approach.

Table 1. Summary of changes in the USPSTF guidelines for Pap smear screening.

	Guideline prior to 2012	Updated guideline release in March 2012
Frequency of screening	At least every 3 years	Every 3 years
Age to begin screening	Within 3 years of initiating sexual activity, or age 21	Age 21
Human papillomavirus (HPV) testing	Insufficient evidence to make a recommendation	No HPV screening for those under age 30

Methods

Data Source

For this study, we gathered and stored messages from a specific online social networking site, Twitter, the second largest social networking site after Facebook.[11] Twitter allows individuals to share information in short text messages called “tweets” that are 140 characters or less. Twitter is largely a public forum where users follow real-time information, and accounts range from personal (from friends and family to celebrities and politicians) to organizational (including news sources, national associations, and local groups). Using an application programming interface from a third-party Twitter platform (Topsy©), we were able to access a large collection of more than 20,000 Twitter messages originating in the US about Pap smears and cervical cancer over a 3-year time period (ie, 2009-2012). We restricted our data collection to messages citing our cancer-specific query keywords (“Pap smear,” “Pap test”, or “cervical cancer”, including common misspellings).

Within the raw dataset, we calculated the raw frequency data for messages related to cervical cancer screening during an entire 6-month time period, that is, we examined the total number of occurrences of the keywords on Twitter from January 2012 to June 2012. We then divided the data into two distinct time periods: before (January 1, 2012—March 13, 2012) and during or after (March 14, 2012—June 30, 2012) the USPSTF guideline change.

Mixed Methods Analysis

As we wanted to establish the face validity of using newer machine learning methods to analyze Twitter data, we used a sequential mixed methods approach for our study by first completing a quantitative summarization of the data using sparse principal component analysis, followed by qualitative content analysis of example messages.

Sparse Principal Component Analysis

After downloading the data, we first used an exploratory quantitative analysis using machine learning algorithms. Machine learning encompasses a set of statistical and computational tools, which assist in extracting meaning and insight from very large collections of data (see Multimedia Appendix 1 for more information). We used “sparse’’ machine learning algorithms [12,13] as an alternative to extremely large volumes of keywords in the machine learning classification process (as in Latent Semantic Indexing) . The sparse algorithms attribute a zero weight to as many keywords as possible, limiting the result to a short list of keywords with strong interrelationships and the most representative messages using those keywords. Therefore, in practice, sparsity enables interpretability by an analyst [8,14].

Specifically, we used a linear algebraic factor-model approach called sparse principal component analysis (SPCA), which split the results into a number of distinct topics. Each topic was characterized by a short list of keywords that were all determined to be correlated. In addition, few Twitter messages that were most strongly and statistically associated with the topic were identified. In practice, SPCA was used both as a topic modeling algorithm (while considering the list of keywords) and clustering algorithm (while considering the example Twitter messages). This form of SPCA was used in our previous studies [14-16].

In order to apply the SPCA approach to Twitter data (as opposed to other forms of text data, like full news articles), we modified the list of stop-words in our algorithm. For example, the text attached to the symbol “@” from the result terms was removed as it represents a username on Twitter rather than a part of the message content itself, and the uniform resource locator (URL) addresses were also removed since they were not considered as intelligible text. Hashtags (“#”) were permitted as they allowed users to indicate that their messages were related to the same topic (eg, #cervicalcancer) but did not change the meaning of the tweet. We restricted our analysis to messages tagged as “English” in the main dataset (but we handled the remaining non-English messages as described in more depth below). Finally, we allowed retweeted (indicated by “RT”) messages within our dataset and only the original message as an individual tweet that could be categorized in the cluster analysis was included, but that message was weighted more heavily in the results based on its appearance in the dataset.

As an output of our analysis, the SPCA algorithm required fixed parameters such as number of topics, terms per topic, and tweets per topic for the results. Based on our previous work [8], we specified five keywords per topic, and we allowed the program to produce the total number of topics on the entire datasets. We compared the results for different models using 10, 15, and 20 tweets per topic to identify the one that explained the highest variation in the discussion topics. We used the cumulative Frobenius norm to find out which model explained the highest proportion of the variance with the fewest number of topics, to assess the best performing model [17].

On identifying the best model, we recorded the singular value criterion, for which higher values indicate a higher prevalence of the topic within the entire set of messages (ie, more messages similar to that topic within the entire dataset) and the five keywords most strongly associated with each topic, which were automatically generated from the algorithm. As we used a sparse approximation of principal component analysis, there was a small degree of shuffling in the topic order by singular value criterion.

Qualitative Analysis of Example Tweets

We used the example tweets and keywords from the quantitative machine learning SPCA to conduct a qualitative review of the output. In particular, we read all example tweets from the top 10 relevant topics in both the baseline and follow-up periods to determine the nature and cohesiveness of the topics. By use of open coding [18,19] we determined: (1) the primary discussion category of each topic, and (2) the percentage of tweets within that topic that were unrelated to the main message (noting the general content area of the off-topic message). Three members of the research team (CRL, GL, and US) independently read all the tweets to categorize the topics, informed by our previous qualitative methods in a similar dataset [6]. For example, we used broad categories of “health promotion” and “personal experiences with screening” to start the coding process, but allowed new categories to emerge as we read through all tweets independently. The coding team discussed the categorization of topics to generate consensus about the primary meaning of the messages in each topic, focusing mostly on the topic labels in which there was some baseline coder differences in categorization. The coding team also determined the final percentages of messages that pertained to the overall topic category (ie, the cohesiveness of the messages) of the topic. Finally, we selected a single example tweet that represented each topic category. The US member of the research team made the final decision on the categorization and cohesiveness of the topics in case of any disagreement within the coding team.

In a few cases, the results included non-English topics despite our attempt to limit the sample to English messages only. This is most likely because the “English” designation within the Twitter data is imperfect for some messages. Non-English messages most often involved the word “Pap” with a different meaning in another language—these were reported below but not analyzed in the qualitative phase of the study. In addition, some topics returned a smaller number of tweets than specified, largely due to the amount of retweeting of an identical message that was weighted more in the output.

Results

Figure 1 displays the total mentions or raw count data for the terms “cervical cancer” and “Pap smear” or “Pap test” in the 6 months surrounding the guideline changes. Immediately following the new USPSTF 2012 guidelines announcement in mid-March, there was an increase in messages containing “Pap smear” or “Pap test”: starting from around 300 mentions in the previous month and spiking to 1000 mentions when the announcement was released. In contrast, the search term “cervical cancer” fluctuated throughout the entire 6-month window.

Next, after dividing the Twitter messages into baseline and follow-up periods surrounding the guideline change, there were 2,549 messages about cervical cancer on Twitter in the baseline period and 4,673 messages in the follow-up period.

The clustering analysis revealed that the models gave similar results overall, with marginally better performance of 10 tweets per topic as more topics were generated (Figures 2 and 3), that is, overall the 10-tweet model explained the most variance in the discussion topics in the fewest number of topics, but this difference only emerged in explaining the last 10% or so of the variance rather than in the early topic differentiation.

The qualitative analysis of the 10 tweets per topic results are shown in Table 1 (preguideline change) and Table 2 (postguideline change). This analysis showed that about 20% of the content in both time periods was irrelevant, that is, two top topics in both the baseline and follow-up periods were non-English results or nonapplicable messages that used the word “pap” as an abbreviation for another idea.

In terms of the content of the topics that were generated, Table 2 also summarizes the primary category of each topic, the singular value criterion, the proportion of tweets that did not match the overall topic category, the 5 keywords most strongly associated with the topic, an example tweet, and other notes or comments about the topic. The qualitative analysis revealed that the most common topics were about cervical cancer screening promotion or health education.

In the baseline period, the top topic was about screening promotion, followed by information on anti-vaccination and that for individuals with abnormal test results. In these baseline results, 10–40% of the messages were different from the overall topic. In the follow-up period, three of the top topics were directly about the 2012 USPSTF guidelines, with very strong cohesiveness of these topics (ie, very few other messages besides USPSTF guideline information). Several of the message categories in the follow-up period expressed gratitude or relief about not having to have annual Pap smears any longer, which is a direct reflection of the updated 2012 USPSTF guideline stating that women with normal results can now wait 3 years between Pap smears. All the remaining top topics in the follow-up period were decidedly mixed without any single discussion topic dominating the messages.

Figure 1. Total mentions of January–June 2012.

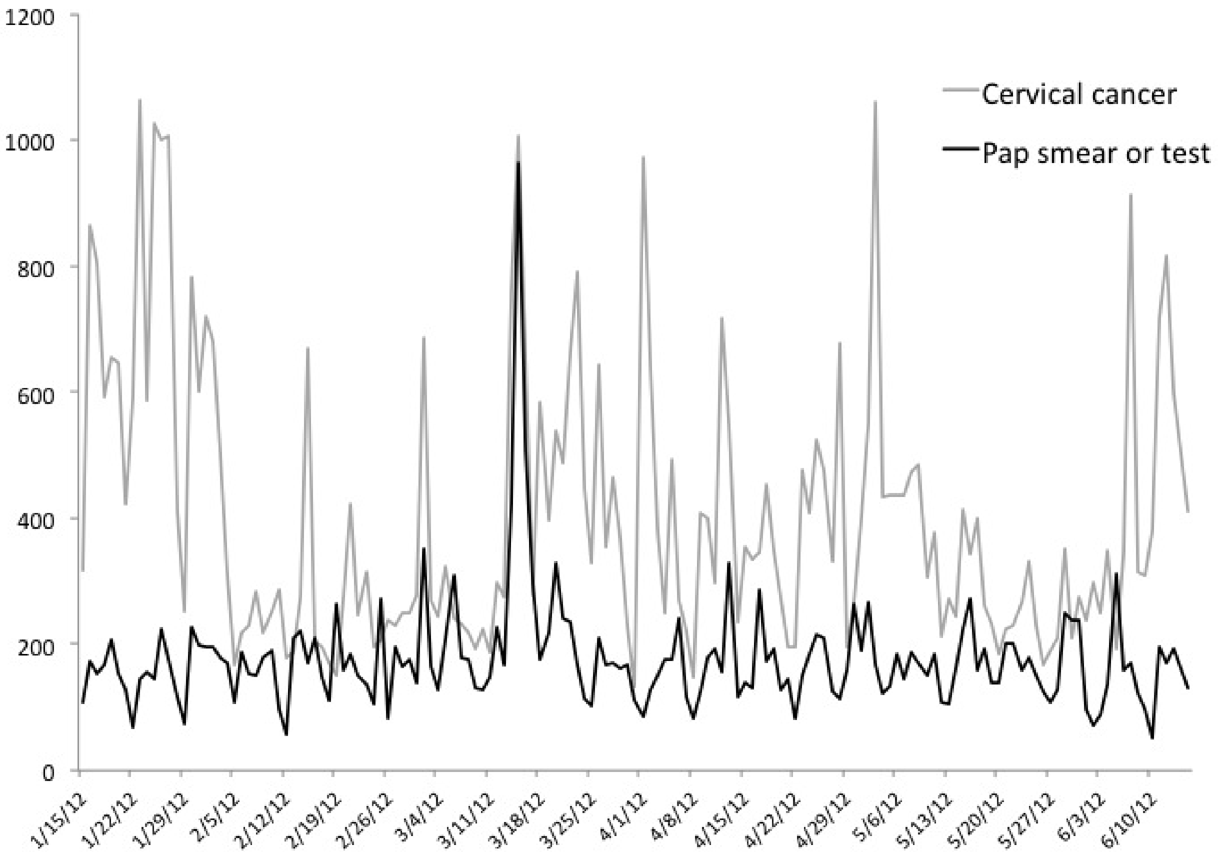

Figure 2. Baseline Frobenius norm plots comparing models specifying 10, 15, and 20 tweets per topic.

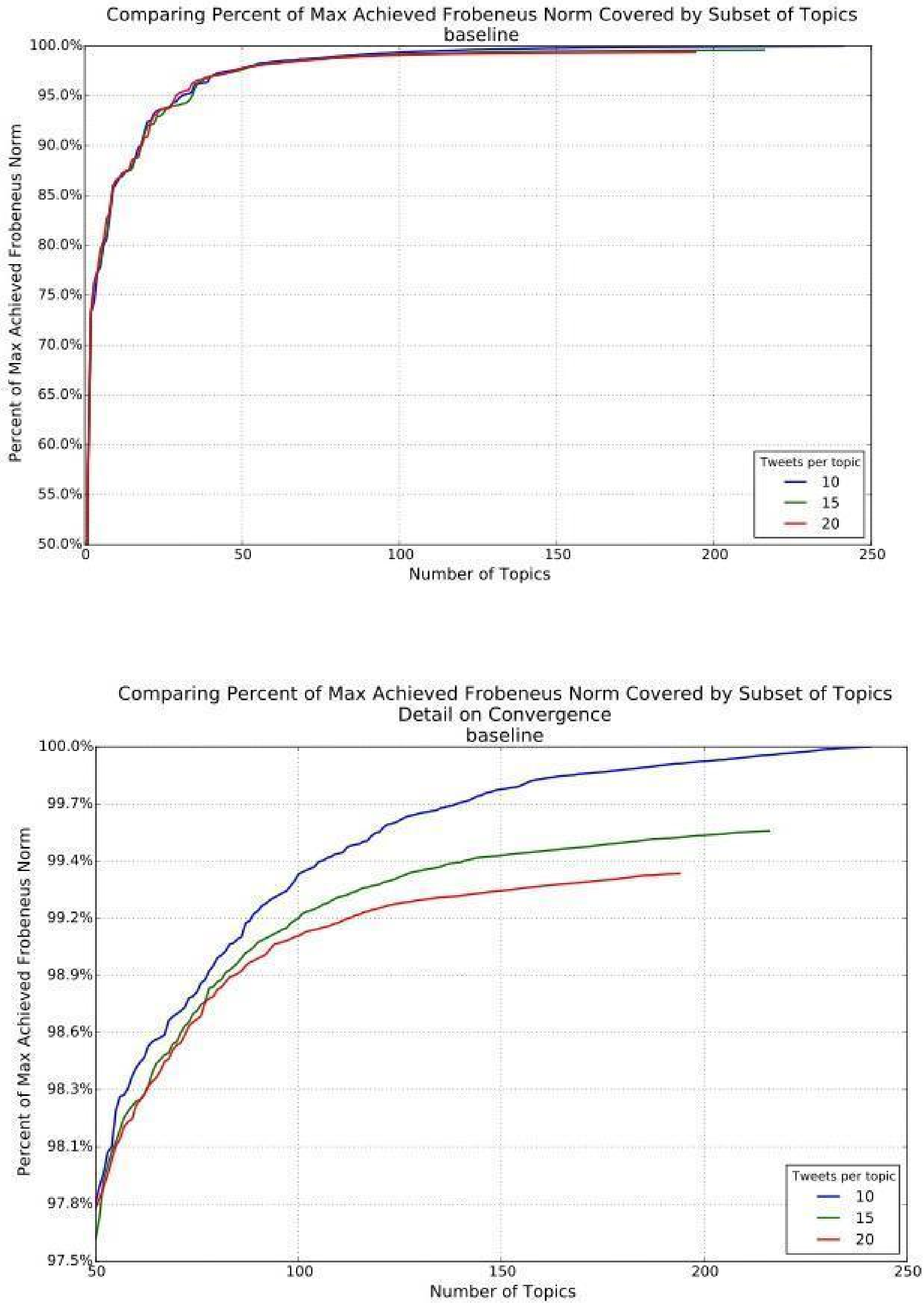

Figure 3. Follow-up Frobenius norm plots comparing models specifying 10, 15, and 20 tweets per topic.

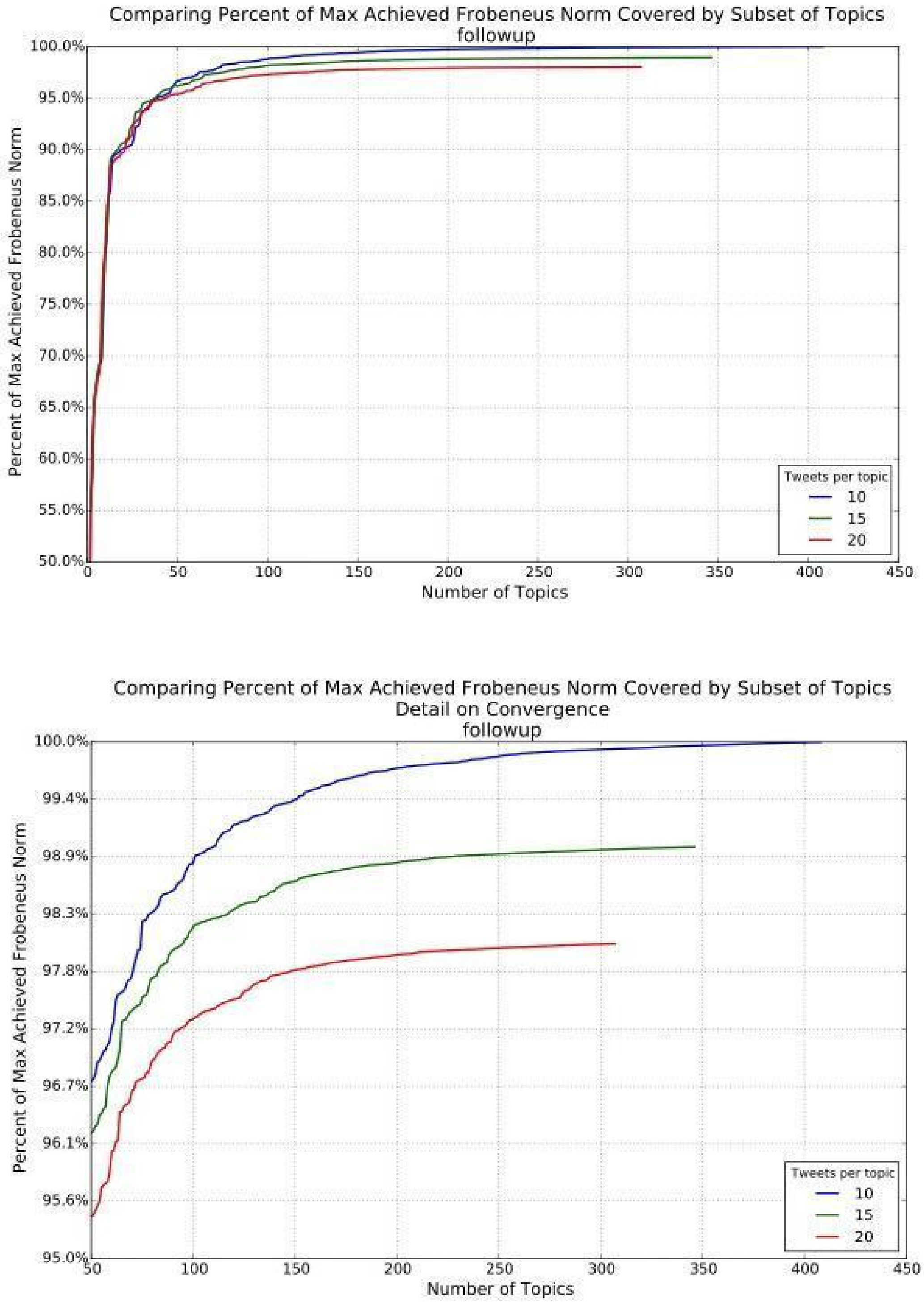

Table 2. Summary of top 10 topics in the baseline and follow-up periods.

Topic	Singular value	Proportion of messages off topic (%)	Example Tweet	Top 5 keywords	Information about "off-topic" tweets
Baseline period (before guideline change) from January 1–March 13, 2012					
Non-English	14.10	N/A	Non-English	Non-English	All non-English (Indonesian) tweets with key English words
Screening promotion	11.79	40	Get Tested For Cervical Cancer #cancer #cervicalcancer #paptest #HPV #HPVvaccine #women #health #womenshealth	study, women, #cancer, caught, #papsaveslives	Other 4 messages about cancer survival/cure rate
Education about abnormal test results	6.23	30	Learned in class: women who have an abnormal pap smear result and may have a B12 deficiency should be tested. It can cause a false positive! If you're under 26, the HPV vaccine can help prevent you from ever having to hear the words "abnormal Pap test results."	abnormal, doctor, recommended, chances, colposcopy	Other messages: 2 jokes; 1 survival rate
Anti-HPV vaccination information	8.03	40	This Foolish Cancer "Prevention" May Only Extend Your Life by 2.8 Days.	life, foolish, extend, days, #tdh	Other messages: 1 cancer awareness month; 1 education; 1 testimonial; 1 political
Report linking screening to increased survival	5.50	10	Regular Pap Smear Boosts Cervical Cancer Survival: Study: Screening is important even after HPV vaccine, experts say	survival, regular, boosts, health day, including	Other message: education about treatment
Jokes	7.54	30	I got scheduled for a pap smear today. Happy Valentine's Day." <== At least it's being touched on V-Day	doesn, period, dirty, scheduled, question	Other messages: 2 addressing HPV stigma; 1 education about screening
Education/Screening promotion	5.58	10	We're here, we're queer, pap smear! January is cervical health awareness month, read this: #PublicCervixAnnouncement	health, awareness, care, cdc, remind	Other message giving a personal opinion
Screening promotion with a personal song	8.02	10	Please retweet if you have ever had a Pap Smear (especially if you sang Footloose)	work, retweet, footloose, sang, laser	Other topic was political/unrelated
N/A Irrelevant	7.68	N/A	Smead Slash/Jacket, Letter, 11 Point, Blue, 25 per Pack (75431): 11 pt stock. Holds 8-1/2-inch W x 11-inch H pap...	holds, jacket, stock, letter, inch	Only 2 total tweets for this topic
Education/Screening promotion	5.32	10	It is Cervical Cancer Awareness Month! Click the link to see where you can receive a free or low cost Pap test....	annual, free, month, screening, appt	Other message a joke
Education/Screening Promotion	5.33	0	What are some ways to lower HPV risk: the usual know who you are having sex with, don't have sex, have sex later, get pap smears, std test	smears, told, prevention, kill, relying	Other messages: 5 about survival; 3 general education; 2 promotion
Jokes	4.99	30	All women (and any men who love women--which is all of you in some way!) please read this on Cervical Health Month/HPV This indian man taking my prescription is flirting with me hard. It's unnerving because he looks like that indian man that did my pap smear	man, love, chance, bono, chaz	Messages: 6 jokes (most referencing celebrities); 2 screening promotion; 1 education
Follow-up period after guideline change: March 14 to June 30, 2012					
News headlines about guideline change	11.59	0	New Screening Guidelines for Cervical Cancer - Fox News	guidelines, annual, screening, #cnn, corrected	Tweets mostly from news organizations

Topic	Singular value	Proportion of messages off topic (%)	Example Tweet	Top 5 keywords	Information about “off-topic” tweets
Non-English (relevant English key words)	14.97	0	Non-English	Non-English	All non-English (Indonesian) tweets with key English words for each tweet in this topic, including “abnormal” “pap smear” “HPV”
Non-English (relevant English keywords)	12.02	0	Non-English	Non-English	All non-English (Indonesian) tweets with key English words for each tweet in this topic, including “abnormal” “pap smear” “HPV”
News headlines on panel recommendations	9.89	20	Health panel: Pap tests needed only every 3 years: NEW YORK (Reuters Health) - Women only need to get a Pap test...	years, panel, health, women, safe	Other messages: 1 educational; 1 political
Health promotion – Female-to-female empowerment messaging	7.94	0	Ladies: Stop putting it off and go have a pap smear. A couple of minutes of discomfort and embarrassment might save your life. Seriously.	ladies, video, learn, defense, routine	All health promotion focused on prevention
Mixed category	7.82	N/A	You know you hate your job when you are excited to leave for two hours for a pap smear.	call, mom, hate, mammogram, dad	Messages: 4 jokes; 3 free resources for testing; 2 guideline change; 1 health promotion; 1 education about screening
Rejoice, no annual pap!	6.35	40	Women Rejoice: Time to Bid Farewell to Your Annual Pap Smear - The Atlantic http://t.co/eIsAegw5 #health	time, rejoice, bid, farewell, atlantic	Other messages: 1 political; 1 joke; 2 education
Mixed category	5.87	N/A	Encourage your mom to get a Pap test this Mother's Day! They're free at 19 PPIN health centers next week! Had The Talk w/ my 6YO: “One day you too shall become a woman & you'll cancel your pap smear to have your hair done.”	woman, free, maintain, order, pbr	Messages: 3 jokes; 4 resources for free Pap smear; 2 promotion for screening; 1 education
Mixed category	10.90	N/A	The Hairpin guide to abnormal pap smears is awesome. Sometimes, we just need facts about our health wrapped in bowties Making sense of your Pap test: #NWHW	rom, companion, pass, guide, citizenship	Only 7 messages in this topic: 2 education; 3 political; 1 opinion about OB-GYN career; 1 irrelevant
Mixed	11.66	N/A	CBC.Beauty Care: Hypnotherapy & Thin Prep Pap Smear	subjects, fundamental, cliffs notes, prep, praxis	Only 3 tweets in this topic: 1 non-English; 1 about Thin Prep Pap Smear; 1 irrelevant
Education about abnormal Pap smear results	8.50	30	If you have abnormal Pap or HPV test results, your doctor will suggest other tests to make a diagnosis. Pls RT	Abnormal, follow, common, procedure, colposcopy	Other messages: 3 education about screening
N/A irrelevant: Pap smears refer to paparazzi, not cervical cancer	11.09	10	Pap Smear: GIVING THE PAPARAZZI A TASTE OF THEIR OWN DISGUSTING MEDICINE #brilliant	paparazzi, tables, cameras, mag, faces	Mostly using “pap” as abbreviation for paparazzi
Mixed category	10.37	N/A	Phrases that a Bama girl never wants to hear: 1) We need to talk. 2) We found something on your pap smear. 3) Auburn just scored. I am answering tweets for this chat RT @XX: Women's #Health Wednesdays 5/2 12-2PM ET. Topic: Pap Test Talk. Join us and use #SCWHW	talk, send, photo, phrases, panic	Messages: 6 jokes; 4 invitations for Tweet Chat about Pap smears

Discussion

We successfully employed a sequential mixed-methods approach to analyze specific cervical cancer prevention and screening discussions on the online social media site “Twitter”—first using a quantitative topic modeling approach to parse the large text dataset, followed by qualitative analysis of the example Twitter messages that were pulled from the topic modeling.

Principal Findings

The machine learning methods provide statistically relevant terms, and indexing these to specific tweets was insightful, particularly when there is rich information shared through external links. However, while the resulting keywords from the quantitative approach were insightful, the true meaning of the messages was much more evident when we analyzed the full text examples for additional context. In other words, machine learning topic modeling required contextualization and content expertise, and much more significant adaptations to the algorithm would be needed to be able to replace human interpretation of the messages. Although the machine learning approach could not replace qualitative analysis altogether, it did allow for a more focused qualitative analysis, because it allowed us to prioritize the voluminous content available online.

Our study demonstrates that social media is a platform in which individuals shared direct information about the new 2012 cervical cancer screening guidelines from the USPSTF. In fact, a large proportion of the top topics in the follow-up period were solely dedicated to this shift in screening recommendations. The content of these topics was so distinct from the baseline topics that we feel confident that a machine learning approach can successfully detect such large public changes in dialogue. In addition, the information shared about the change in guidelines was mostly neutral or positive for eliminating the need to have a Pap smear every year. This finding appears to be more positive than other existing literature on women’s perceptions about the new guidelines, which found that a substantial proportion of women expressed concerns about increasing the intervals between screenings [20,21].

Our findings also demonstrated that a large portion of the cervical cancer messages on Twitter were about health promotion and education, beyond discussions about the 2012 screening guidelines. This included new science about the effectiveness of Pap smears and information (personal stories or lists of free screening sites) to encourage women to get Pap smears, which is consistent with our previous qualitative work [6]. We feel that this provides justification for public health and advocacy groups to continue harnessing social media for delivering messages about screening.

Limitations

Our small exploratory study has limitations. First, we chose one social media site, Twitter, which has a 140-character limit for each post. While Twitter represents a fast-growing platform for Web-based communication [22], Twitter users are likely to differ from the overall US population—as they are more likely to be younger (aged 18-29 years), from racial or ethnic minority groups (particularly African Americans) and living in urban or suburban areas [11]. In addition, it is not possible to easily automate the process of classifying Twitter messages by sender (such as from individuals vs. organizational accounts), nor we did not verify whether the messages in our analysis were from accounts that were active over a sustained period of time. Second, we are using only publicly available Twitter content—which is likely to represent the majority of content [23] but differs from privately shared messages. Third, we restricted our study to messages originating in the US, because we were interested in a change in national screening guidelines.

Finally, from a methodological standpoint, we faced some limitations in applying a novel approach, such as a few irrelevant sets of messages. While this is expected to a certain extent, future studies will be able to quantify the expected error when using these methods and perhaps additional refinements to minimize such error. The topic modeling and clustering approach also relies on a simple bag-of-words model of text, which ignores word ordering and natural-language semantic information. All analysis is based on patterns of associations between words. In addition, our method only captures the most prevalent associations between words; if a single word has multiple meanings in different contexts, the less prevalent patterns may be overlooked. Finally, we employed a model, which assumes that each message contains a single topic. Other approaches can identify a mixture of topics within a single message, but are computationally expensive [24,25]. Given that Twitter messages are so short, however, a single-topic model of a message appears to capture important and relevant information.

While preliminarily our findings imply that there is an interest in cancer screening discussions among the ever-growing population using online social media. Our work argues for further transdisciplinary study into cancer screening promotion via social media, whether in a peer-to-peer or in an expert-recommendation fashion.

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Authors' Contributions

AG and LEG performed the machine learning analyses, and CRL, US, and GL performed the content analysis.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Representing text numerically.

[PDF File (Adobe PDF File), 28KB - publichealth_v2i1e21_app1.pdf]

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Abbreviations

SPCA: sparse principal component analysis
USPSTF: US Preventive Services Task Force

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Rapid Surveillance Report

The Annual American Men's Internet Survey of Behaviors of Men Who have Sex with Men in the United States: 2014 Key Indicators Report

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Abstract

The American Men's Internet Survey (AMIS) is an annual Web-based behavioral survey of men who have sex with men (MSM) who live in the United States. The purpose of this Rapid Surveillance Report is to report on the second cycle of data collection (November 2014 through April 2015; AMIS-2014) on the same key indicators previously reported for AMIS (December 2013 through May 2014; AMIS-2013). The AMIS survey methodology has not substantively changed since AMIS-2013. MSM were recruited from a variety of websites using banner advertisements or email blasts. Adult men currently residing in the United States were eligible to participate if they had ever had sex with a man. We examined demographic and recruitment characteristics using multivariable regression modeling ($P<.05$) stratified by the participants' self-reported human immunodeficiency virus (HIV) status. The AMIS-2014 round of data collection resulted in 9248 completed surveys from MSM representing every US state. Participants were mainly white, 40 years or older, living in the US South, living in urban/suburban areas, and recruited from a general social networking website. Self-reported HIV prevalence was 11.34% (1049/9248). Compared with HIV-negative/unknown status participants, HIV-positive participants were more likely to have had anal sex without a condom with any male partner in the past 12 months (76.55% vs 67.17%; $P<.001$) and more likely to have had anal sex without a condom with their last male sex partner who was discordant/unknown HIV status (39.66% vs 18.77%; $P<.001$). Marijuana and other illicit substance use in the past 12 months was more likely to be reported by HIV-positive participants than HIV-negative/unknown status participants (26.02% vs 21.27%, and 27.26% vs 17.60%, respectively; both $P<.001$). The vast majority (86.90%, 7127/8199) of HIV-negative/unknown status participants had been previously HIV tested, and 58.23% (4799/8199) had been tested in the past 12 months. Sexually transmitted infection (STI) testing and diagnosis was also more likely to be reported by HIV-positive participants than HIV-negative/unknown status participants (71.02% vs 37.34%, and 20.59% vs 7.54%, respectively; both $P<.001$). HIV-negative/unknown status participants <40 years of age were more likely than those 40 years or older to have had anal sex without a condom, were more likely to report substance use, were less likely to have been HIV tested, but were more likely to been tested for and diagnosed with an STI. Compared with those from general social networking, HIV-negative/unknown status participants from a geospatial social networking website were more likely to have reported all risk behaviors but were more likely to have been HIV tested, STI tested, and diagnosed with an STI.

(JMIR Public Health Surveill 2016;2(1):e23) doi:10.2196/publichealth.5476

KEYWORDS

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

Notice to the reader: Rapid Surveillance Reports are brief reports, which primarily report new data in table format from an existing well-described surveillance system, making a methods (and sometimes an introduction) section redundant.

The idea of this new article type is to allow rapid publication of emerging trends, or continuous publication in regular intervals of public health relevant data. If a method or system description has been published previously in JMIR Public Health Surveill or JMIR Res Protoc, the report does not have to be peer-reviewed again (although in many cases they still are).

Introduction

The American Men's Internet Survey (AMIS) is an annual Web-based behavioral survey of men who have sex with men who live in the United States. The methods have been previously published [1]. Methods in AMIS-2014 are unchanged from the previously published manuscript unless otherwise noted below.

Recruitment and Enrollment

As in the prior year, AMIS participants were recruited through convenience sampling from a variety of websites using banner advertisements or email blasts to website members (hereafter referred to generically as "ads"). Men who clicked on the ads were taken directly to the survey website hosted on a secure server administered by SurveyGizmo. To be eligible for the survey, participants had to be 15 years of age or older, consider themselves to be male, reside in the United States, and report that they had oral or anal sex with a man at least once in the past (hereafter referred to as MSM). Persons who reported being <15 years of age or refused to provide their age were not asked any other screening questions. MSM who met the eligibility criteria and consented to participate in the study started the Web-based survey immediately. The full questionnaire for AMIS-2014 is presented in Multimedia Appendix 1. AMIS-2014 ran from November 2014 through April 2015, and resulted in 77,611 persons clicking on the ads and landing on the study's recruitment page (Table 1). Most were from a general social networking website (59,670/77,611, 76.88%). Nearly half (35,462/77,611 46.89%) of those who landed on the study's page started the screening process and 60.75% (47,149/77,611) were eligible. The most common reason for ineligibility was not ever having male-male sex. Nearly three-quarters (57,176/77,611, 73.67%) of those who were eligible consented to participate in the survey. There were 6.81% (1109/77,611) of the surveys determined to likely be from duplicate participants. Among unduplicated surveys, more than two-thirds (52,9790/77,611, 68.25%) were considered successful. Success was defined using an examination of completed survey sections [1]. Most successful surveys were among men who reported having sex with another man in the past 12 months (9248/10,359, 89.28%).

Measures and Analyses

For AMIS-2014 analyses, we categorized participants by recruitment website and based on target audience and purpose: gay social networking (n=2), gay general interest (n=4), general social networking (n=1), and geospatial social networking (n=2). We do not provide the names of the websites to preserve operator/client privacy, particularly where a website category has only one operator. The participants who were eligible, consented, unduplicated, successful, and reported male-male sex in the past 12 months were included in analyses of participant characteristics and behavior.

The following behavioral measures differed in AMIS-2014 from those previously published: both sexual behaviors (any condomless anal sex and condomless anal sex with a discordant/unknown status partner) were assessed for the past 12 months, binge alcohol drinking was not included, and substance using behaviors were recategorized. Human immunodeficiency virus (HIV) serostatus concordance was based on the participant's HIV status and the status of their sex partner. Discordant/unknown status was defined as either the participant or partner having unknown status or when one was HIV-negative and the other was HIV-positive. For substance-using behaviors in the past 12 months, we separated marijuana use from other illicit substance use. For AMIS-2014 all participants received questions on sexually transmitted infection (STI; chlamydia, gonorrhea, and syphilis) testing and diagnoses in the past 12 months. Participants could have been tested for an STI but not diagnosed with an STI. Persons who were diagnosed with an STI in the past 12 months all were considered to have been tested for an STI in the past 12 months.

The analysis methods for AMIS-2014 did not substantively differ from those previously published but are repeated in this report for clarity [1]. Overall chi-square tests were used to identify whether participant characteristics significantly differed between recruitment website types. Multivariable logistic regression modeling was used to determine significant differences in behaviors based on self-reported HIV status while controlling for race/ethnicity, age group, National HIV Behavioral Surveillance (NHBS) city residency, and recruitment website type. HIV-testing behaviors were only examined among those who did not report that they were HIV-positive and were also presented by participant characteristics. Multivariable logistic regression results are presented as Wald chi-square *P*-values to denote an independently significant difference in the behavior for each subgroup compared with a referent group. Statistical significance was determined at $P<.05$.

Results

Summary for AMIS-2014

Three-quarters (6819/9248, 73.73%) of participants included in this report were white, non-Hispanic, half (4676/9248, 50.6%) were ≥40 years of age, and their most common region of residence was the South followed by the West (Table 2). AMIS-2014 had participants from all US states and at least 100 participants from each of 27 states (Figure 1). Overall, 11.34% (1049/9248) of participants reported being HIV positive and 88.66% (8199/9248) reported being HIV negative or having an unknown HIV serostatus. There were significant differences in all participant characteristics based on where they were recruited (Table 2). Most of those differences were observed among participants recruited from geospatial social networking websites, who were less likely be white, less likely be 40 years or older, less likely to live in an NHBS city, more likely to live in the West, more likely to live in urban areas, and more likely to report being HIV positive.

Most participants had anal sex without a condom with another man in the past 12 months (Table 3). Compared with HIV-negative/unknown status participants, those who were HIV-positive were significantly more likely to report anal intercourse without a condom, including with male partners who were discordant/unknown status. Anal intercourse without a condom significantly differed by age group (HIV-positive and -negative/unknown status participants), recruitment website type (HIV-positive and -negative/unknown status participants), and race/ethnicity (HIV-negative/unknown status participants only).

More than one-quarter (273/1049, 26.02%) of HIV-positive participants reported using marijuana or other illicit substances in the past 12 months (Table 4). Compared with HIV-negative/unknown status participants, those who were HIV-positive were significantly more likely to report use of marijuana and other substances in the past 12 months. Marijuana or other illicit substance use significantly differed by age group (HIV-positive and -negative/unknown status participants), residence in an NHBS city (HIV-negative/unknown status participants only), and recruitment website type (HIV-negative/unknown status participants only).

HIV testing behaviors were only examined among those who did not report being HIV-positive. Most of those participants (7125/8199, 86.90%) had ever been previously tested for HIV infection, and just over half (4799/8199, 58.53%) reported being tested in the past 12 months (Table 5). HIV testing significantly differed by age group (ever tested), race/ethnicity (ever tested), residence in an NHBS city (past 12 months tested), and recruitment website type (past 12 months tested).

Compared with HIV-negative/unknown status participants, those who were HIV-positive were more likely to report being tested for and diagnosed with an STI in the past 12 months (Table 6). The most common STI diagnoses were syphilis (132/1049, 12.58%) and chlamydia (88/1049, 8.39%) among HIV-positive participants. STI testing significantly differed by age group, residence in an NHBS city and recruitment website type only for participants who were HIV-negative/unknown status. STI diagnosis significantly differed by age group (HIV-positive and HIV-negative/unknown status participants), race/ethnicity (HIV-negative/unknown status participants only), residence in an NHBS city (HIV-negative/unknown status participants only), and recruitment website type (HIV-negative/unknown status participants only).

Figure 1. Number of MSM participants in the American Men's Internet Survey by state, 2014.

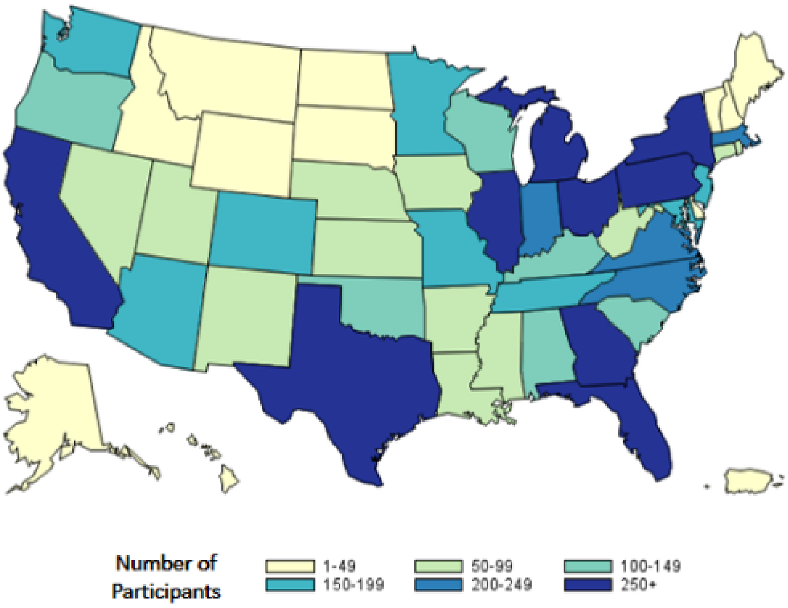

Table 1. Recruitment outcomes with different recruitment website types for the American Men's Internet Survey, United States, 2014.

			Recruitment Website Type							
	Total		Gay social networking (n=2)		General gay interest (n=4)		General social networking (n=1)		Geospatial social networking (n=2)	
Recruitment Outcomes	N	(%)	N	(%)	N	(%)	N	(%)	N	(%)
Clicked ad	77,611		1988		8372		59,670		7581	
Screened[a]	36,392	(46.89)	944	(47.48)	1293	(15.44)	26,576	(44.54)	7579	(99.97)
Ineligible[b]	14,285	(39.25)	171	(18.11)	523	(40.45)	11,356	(42.73)	2235	(29.49)
Not 15+ years of age[c]	10,219	(71.54)	118	(69.01)	340	(65.01)	8008	(70.52)	1753	(78.43)
Not male[c]	10,942	(76.60)	138	(80.70)	380	(72.66)	8494	(74.80)	1930	(86.35)
Not ever MSM[c,d]	13,776	(96.44)	167	(97.66)	510	(97.51)	11,073	(97.51)	2026	(90.65)
Not a US resident[c]	3733	(26.13)	22	(12.87)	161	(30.78)	2460	(21.66)	1090	(48.77)
Eligible[b]	22,107	(60.75)	773	(81.89)	770	(59.55)	15,220	(57.27)	5344	(70.51)
Consented[e]	16,286	(73.67)	574	(74.26)	595	(77.27)	10,821	(71.10)	4296	(80.39)
Unduplicated[f]	15,177	(93.19)	557	(97.04)	564	(94.79)	9960	(92.04)	4096	(95.34)
Success[g]	10,359	(68.25)	414	(74.33)	410	(72.70)	6913	(69.41)	2622	(64.01)
MSM past 12 months[h]	9248	(89.28)	377	(91.06)	369	(90.00)	5987	(86.60)	2515	(95.92)

[a] Proportion is of total who clicked ad. Includes those who started the screening questionnaire.

[b] Proportion is among total screened. Ineligible includes those who did not complete the screening questionnaire.

[c] Proportion is among total ineligible. Includes those who may not have responded to the question.

[d] MSM: men who have sex with men.

[e] Proportion is among eligible.

[f] Proportion is among consented. Unduplicated removes participants who were marked as duplicates using an Internet protocol address and demographic data matching.

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

[h] Proportion is among successes.

Table 2. Characteristics of MSM participants in the American Men's Internet Survey by recruitment website type, United States, 2014.

			Recruitment website type								
Participant characteristics	Total		Gay social networking (n=2)		General gay interest (n=4)		General social networking (n=1)		Geospatial social networking (n=2)		
	N	(%)	N	(%)	N	(%)	N	(%)	N	(%)	P -value[a]
Race/ethnicity											<.001
Black, non-Hispanic	415	(4.49)	11	(2.92)	21	(5.69)	225	(3.76)	158	(6.28)	
Hispanic[b]	1308	(14.14)	14	(3.71)	37	(10.03)	713	(11.91)	544	(21.63)	
White, non-Hispanic	6819	(73.73)	327	(86.74)	286	(77.51)	4643	(77.55)	1563	(62.15)	
Other or multiple races	706	(7.63)	25	(6.63)	25	(6.78)	406	(6.78)	250	(9.94)	
Age (years)											<.001
15-24	1389	(15.02)	21	(5.57)	47	(12.74)	857	(14.31)	464	(18.45)	
25-29	1221	(13.20)	24	(6.37)	48	(13.01)	612	(10.22)	537	(21.35)	
30-39	1962	(21.22)	40	(10.61)	86	(23.31)	1164	(19.44)	672	(26.72)	
40 or older	4676	(50.56)	292	(77.45)	188	(50.95)	3354	(56.02)	842	(33.48)	
Region											<.001
Midwest	1560	(16.87)	68	(18.04)	64	(17.34)	985	(16.45)	443	(17.61)	
Northeast	1933	(20.90)	117	(31.03)	55	(14.91)	1306	(21.81)	455	(18.09)	
South	3634	(39.29)	122	(32.36)	180	(48.78)	2369	(39.57)	963	(38.29)	
West	2110	(22.82)	69	(18.30)	65	(17.62)	1323	(22.10)	653	(25.96)	
US dependent areas	11	(0.12)	1	(0.27)	5	(1.36)	4	(0.07)	1	(0.04)	
NHBS city resident[c]											<.001
Yes	3553	(38.42)	137	(36.34)	206	(55.83)	2177	(36.36)	1033	(41.07)	
No	5695	(61.58)	240	(63.66)	163	(44.17)	3810	(63.64)	1482	(58.93)	
Population density[d]											<.001
Rural	2774	(30.00)	133	(35.28)	80	(21.68)	1902	(31.77)	659	(26.20)	
Urban/suburban	6300	(68.12)	241	(63.93)	285	(77.24)	4001	(66.83)	1773	(70.50)	
Self-reported HIV status											<.001
Positive	1049	(11.34)	23	(6.10)	32	(8.67)	554	(9.25)	440	(17.50)	
Negative	6992	(75.61)	277	(73.47)	303	(82.11)	4588	(76.63)	1824	(72.52)	
Unknown	1207	(13.05)	77	(20.42)	34	(9.21)	845	(14.11)	251	(9.98)	
Total	9248		377		369		5987		2515		

[a] Chi-square testing difference in characteristics between website type.

[b] Hispanic persons could have been of any race, including other or multiple.

[c] NHBS: National HIV Behavioral Surveillance System.

[d] There were 71 participants missing information needed to determine the population density of the area where they lived.

Table 3. Sexual behaviors with male partners of MSM participants in the American Men's Internet Survey, United States, 2014.

Participant characteristics	N in sample	Sexual Behaviors with male partners in the past 12 months Anal intercourse without a condom			Anal intercourse without a condom with a partner of discordant or unknown HIV status		
		n	(%)	*P* -value[a]	n	(%)	*P* -value[a]
HIV positive overall	**1049**	**803**	**(76.55)**	**<.001** [b]	**416**	**(39.66)**	**<.001** [b]
Race/ethnicity							
Black, non-Hispanic	92	69	(75.00)	.459	34	(36.96)	.253
Hispanic	172	134	(77.91)	.636	73	(42.44)	.893
White, non-Hispanic	716	546	(76.26)	REF	281	(39.25)	REF
Other or multiple races	69	54	(78.26)	.878	28	(40.58)	.794
Age (years)							
15-24	68	62	(91.18)	.038	38	(55.88)	.090
25-29	110	96	(87.27)	.226	65	(59.09)	.002
30-39	251	199	(79.28)	.086	111	(44.22)	.278
40 or older	620	446	(71.94)	REF	202	(32.58)	REF
NHBS city resident[c]							
Yes	464	361	(77.80)	.217	173	(37.28)	.291
No	585	442	(75.56)	REF	243	(41.54)	REF
Recruitment website type							
Gay social networking	23	18	(78.26)	.620	16	(69.57)	.007
General gay interest	32	24	(75.00)	.768	17	(53.13)	.478
General social networking	554	403	(72.74)	REF	192	(34.66)	REF
Geospatial social networking	440	358	(81.36)	.642	191	(43.41)	.002
HIV negative or unknown overall	**8199**	**5507**	**(67.17)**	**REF**	**1539**	**(18.77)**	**REF**
Race/ethnicity							
Black, non-Hispanic	323	202	(62.54)	.043	80	(24.77)	.121
Hispanic	1136	777	(68.40)	.377	276	(24.30)	.088
White, non-Hispanic	6103	4109	(67.33)	REF	1053	(17.25)	REF
Other or multiple races	637	419	(65.78)	.808	130	(20.41)	.323
Age (years)							
15-24	1321	870	(65.86)	<.001	334	(25.28)	.359
25-29	1111	820	(73.81)	<.001	193	(17.37)	.954
30-39	1711	1281	(74.87)	<.001	241	(14.09)	.572
40 or older	4056	2536	(62.52)	REF	505	(12.45)	REF
NHBS city resident[c]							
Yes	3089	2053	(66.46)	.300	607	(19.65)	.442
No	5110	3454	(67.59)	REF	932	(18.24)	REF
Recruitment website type							
Gay social networking	354	187	(52.82)	<.001	76	(21.47)	.318
General gay interest	337	219	(64.99)	.909	68	(20.18)	.680
General social networking	5433	3592	(66.11)	REF	825	(15.18)	REF
Geospatial social networking	2075	1509	(72.72)	<.001	570	(27.47)	<.001

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

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

[c] NHBS: National HIV Behavioral Surveillance System.

Table 4. Substance using behaviors of MSM participants in the American Men's Internet Survey, United States, 2014.

Participant characteristics	N in sample	Substance use behaviors in the past 12 months					
		Used marijuana			Used other substance(s)		
		n	(%)	*P* -value[a]	N	(%)	*P* -value[a]
HIV positive overall	**1049**	**273**	**(26.02)**	**<.001** [b]	**286**	**(27.26)**	**<.001** [b]
Race/ethnicity							
Black non-Hispanic	92	24	(26.09)	.549	19	(20.65)	.110
Hispanic	172	46	(26.74)	.468	44	(25.58)	.571
White non-Hispanic	716	181	(25.28)	REF	202	(28.21)	REF
Other or multiple races	69	22	(31.88)	.359	21	(30.43)	.400
Age (years)							
15-24	68	21	(30.88)	.988	17	(25.00)	.360
25-29	110	40	(36.36)	.082	34	(30.91)	.441
30-39	251	76	(30.28)	.771	91	(36.25)	.011
40 or older	620	136	(21.94)	REF	144	(23.23)	REF
NHBS city resident[c]							
Yes	464	123	(26.51)	.781	130	(28.02)	.573
No	585	150	(25.64)	REF	156	(26.67)	REF
Recruitment website type							
Gay social networking	23	7	(30.43)	.588	4	(17.39)	.316
General gay interest	32	10	(31.25)	.610	11	(34.38)	.255
General social networking	554	119	(21.48)	REF	134	(24.19)	REF
Geospatial social networking	440	137	(31.14)	.971	137	(31.14)	.353
HIV negative or unknown overall	**8199**	**1744**	**(21.27)**	**REF**	**1443**	**(17.60)**	**REF**
Race/Ethnicity							
Black non-Hispanic	323	60	(18.58)	.051	50	(15.48)	.060
Hispanic	1136	256	(22.54)	.586	212	(18.66)	.596
White non-Hispanic	6103	1274	(20.87)	REF	1051	(17.22)	REF
Other or multiple races	637	154	(24.18)	.123	130	(20.41)	.102
Age (years)							
15-24	1321	424	(32.10)	<.001	269	(20.36)	.160
25-29	1111	303	(27.27)	.005	259	(23.31)	.002
30-39	1711	411	(24.02)	.912	382	(22.33)	.002
40 or older	4056	606	(14.94)	REF	533	(13.14)	REF
NHBS city resident[c]							
Yes	3089	717	(23.21)	<.001	656	(21.24)	<.001
No	5110	1027	(20.10)	REF	787	(15.40)	REF
Recruitment website type							
Gay social networking	354	48	(13.56)	.032	39	(11.02)	.022
General gay interest	337	69	(20.47)	.985	55	(16.32)	.535
General social networking	5433	1095	(20.15)	REF	861	(15.85)	REF
Geospatial social networking	2075	532	(25.64)	<.001	488	(23.52)	<.001

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

referent (REF) group.

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

[c] NHBS: National HIV Behavioral Surveillance System.

Table 5. HIV testing behaviors of HIV-negative or unknown status MSM participants in the American Men's Internet Survey, United States, 2014.

Participant characteristics	N in sample	HIV testing behaviors					
		HIV tested ever			HIV tested past 12 months		
		n	(%)	*P* -value[a]	N	(%)	*P* -value[a]
Race/ethnicity							
Black non-Hispanic	323	287	(88.85)	.503	213	(65.94)	.221
Hispanic	1136	981	(86.36)	.544	706	(62.15)	.290
White non-Hispanic	6103	5299	(86.83)	REF	3454	(56.60)	REF
Other or multiple races	637	558	(87.60)	.469	406	(63.74)	.308
Age (years)							
15-24	1321	892	(67.52)	<.001	699	(52.91)	<.001
25-29	1111	997	(89.74)	.006	742	(66.79)	<.001
30-39	1711	1547	(90.41)	<.001	1037	(60.61)	.498
40 or older	4056	3689	(90.95)	REF	2301	(56.73)	REF
NHBS city resident[b]							
Yes	3089	2787	(90.22)	<.001	1992	(64.49)	<.001
No	5110	4338	(84.89)	REF	2787	(54.54)	REF
Recruitment website type							
Gay social networking	354	280	(79.10)	<.001	172	(48.59)	<.001
General gay interest	337	304	(90.21)	.054	188	(55.79)	.068
General social networking	5433	4662	(85.81)	REF	2881	(53.03)	REF
Geospatial social networking	2075	1879	(90.55)	<.001	1538	(74.12)	<.001
TOTAL	8199	7125	(86.90)		4799	(58.53)	

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

[b] NHBS: National HIV Behavioral Surveillance System.

Table 6. Sexually transmitted infection testing and diagnosis of MSM participants in the American Men's Internet Survey, United States, 2014.

		STI History in the past 12 months					
		Tested for any STI[a]			Diagnosed with any STI[a]		
Participant characteristics	N in sample	n	(%)	*P* -value[b]	N	(%)	*P* -value[b]
HIV positive overall	**1049**	**747**	**(71.21)**	**<.001** [c]	**216**	**(20.59)**	**<.001** [c]
Race/ethnicity							
Black non-Hispanic	92	72	(78.26)	.508	25	(27.17)	.905
Hispanic	172	129	(75.00)	.354	47	(27.33)	.687
White non-Hispanic	716	493	(68.85)	REF	120	(16.76)	REF
Other or multiple races	69	53	(76.81)	.867	24	(34.78)	.065
Age (years)							
15-24	68	57	(83.82)	.365	20	(29.41)	.968
25-29	110	94	(85.45)	.086	44	(40.00)	<.001
30-39	251	203	(80.88)	.583	67	(26.69)	.846
40 or older	620	393	(63.39)	REF	85	(13.71)	REF
NHBS city resident[d]							
Yes	464	344	(74.14)	.073	105	(22.63)	.326
No	585	403	(68.89)	REF	111	(18.97)	REF
Recruitment website type							
Gay social networking	23	13	(56.52)	.282	2	(8.70)	.302
General gay interest	32	24	(75.00)	.416	8	(25.00)	.154
General social networking	554	364	(65.70)	REF	81	(14.62)	REF
Geospatial social networking	440	346	(78.64)	.214	125	(28.41)	.246
HIV negative or unknown overall	**8199**	**3086**	**(37.64)**	**REF**	**618**	**(7.54)**	**REF**
Race/Ethnicity							
Black non-Hispanic	323	156	(48.30)	.272	35	(10.84)	.559
Hispanic	1136	553	(48.68)	.173	147	(12.94)	.007
White non-Hispanic	6103	2086	(34.18)	REF	378	(6.19)	REF
Other or multiple races	637	291	(45.68)	.470	58	(9.11)	.454
Age (years)							
15-24	1321	512	(38.76)	.033	109	(8.25)	.612
25-29	1111	579	(52.12)	<.001	136	(12.24)	.001
30-39	1711	754	(44.07)	.040	174	(10.17)	.021
40 or older	4056	1241	(30.60)	REF	199	(4.91)	REF
NHBS city resident[d]							
Yes	3089	1442	(46.68)	<.001	300	(9.71)	<.001
No	5110	1644	(32.17)	REF	318	(6.22)	REF
Recruitment website type							
Gay social networking	354	84	(23.73)	<.001	14	(3.95)	.173
General gay interest	337	109	(32.34)	.013	17	(5.04)	.107
General social networking	5433	1740	(32.03)	REF	284	(5.23)	REF
Geospatial social networking	2075	1153	(55.57)	<.001	303	(14.60)	<.001

[a] STI: sexually transmitted infection; includes chlamydia, gonorrhea and syphilis.

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

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

[d] NHBS: National HIV Behavioral Surveillance System.

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Conflicts of Interest

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

Multimedia Appendix 1

American Men's Internet Survey, 2014.

[PDF File (Adobe PDF File), 141KB - publichealth_v2i1e23_app1.pdf]

Reference

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Abbreviations

AMIS: American Men’s Internet Survey
HIV: human immunodeficiency virus
MSM: men who have sex with men
NHBS: national HIV behavioral surveillance system
STI: sexually transmitted infection

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