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Original Paper

Conurbation, Urban, and Rural Living as Determinants of Allergies and Infectious Diseases: Royal College of General Practitioners Research and Surveillance Centre Annual Report 2016-2017

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Abstract

Background: Living in a conurbation, urban, or rural environment is an important determinant of health. For example, conurbation and rural living is associated with increased respiratory and allergic conditions, whereas a farm or rural upbringing has been shown to be a protective factor against this.

Objective: The objective of the study was to assess differences in general practice presentations of allergic and infectious disease in those exposed to conurbation or urban living compared with rural environments.

Methods: The population was a nationally representative sample of 175 English general practices covering a population of over 1.6 million patients registered with sentinel network general practices. General practice presentation rates per 100,000 population were reported for allergic rhinitis, asthma, and infectious conditions grouped into upper and lower respiratory tract infections, urinary tract infection, and acute gastroenteritis by the UK Office for National Statistics urban-rural category. We used multivariate logistic regression adjusting for age, sex, ethnicity, deprivation, comorbidities, and smoking status, reporting odds ratios (ORs) with 95% CIs.

Results: For allergic rhinitis, the OR was 1.13 (95% CI 1.04-1.23; *P*=.003) for urban and 1.29 (95% CI 1.19-1.41; *P*<.001) for conurbation compared with rural dwellers. Conurbation living was associated with a lower OR for both asthma (OR 0.70, 95% CI 0.67-0.73; *P*<.001) and lower respiratory tract infections (OR 0.94, 95% CI 0.90-0.98; *P*=.005). Compared with rural dwellers, the OR for upper respiratory tract infection was greater in urban (OR 1.06, 95% CI 1.03-1.08; *P*<.001) but no different in conurbation dwellers (OR 1.00, 95% CI 0.97-1.03; *P*=.93). Acute gastroenteritis followed the same pattern: the OR was 1.13 (95% CI 1.01-1.25; *P*=.03) for urban dwellers and 1.04 (95% CI 0.93-1.17; *P*=.46) for conurbation dwellers. The OR for urinary tract infection was lower for urban dwellers (OR 0.94, 95% CI 0.89-0.99; *P*=.02) but higher in conurbation dwellers (OR 1.06, 95% CI 1.00-1.13; *P*=.04).

Conclusions: Those living in conurbations or urban areas were more likely to consult a general practice for allergic rhinitis and upper respiratory tract infection. Both conurbation and rural living were associated with an increased risk of urinary tract infection. Living in rural areas was associated with an increased risk of asthma and lower respiratory tract infections. The data suggest that living environment may affect rates of consultations for certain conditions. Longitudinal analyses of these data would be useful in providing insights into important determinants.

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KEYWORDS

population surveillance; respiratory tract infections; conjunctivitis, allergic; asthma; urinary tract infections; gastroenteritis; healthcare disparities; socioeconomic factors; social determinants of health; medical records systems, computerized; data collection; records as topic; primary health care; general practice; infectious diseases

Introduction

Urbanization as a Determinant of Health

There is a wide range of social determinants of health. Conurbation, urban, and rural living are important among these, although their different effects are still unclear [1]. Urbanization is increasing, and the United Nations has predicted that the world urban population will double between 2007 and 2050. Urbanization is an important determinant of health [2], as it may create incubators for infectious disease [3].

Factors associated with urban and rural living contribute to differences in respiratory and allergic conditions. Pollution, climate change, and pollen exposure are all associated with increased respiratory and allergic conditions [4-6]. Farm and rural upbringing have been shown to be protective against allergic rhinitis compared with urban living [7,8]. The same gradient has been reported for asthma in northern Europe [9]. However, asthma has also been shown to have an increasing incidence with higher levels of air pollution, but there is inconsistency between age groups for specific pollutants [10,11]. Pollen levels may also be important in precipitating exacerbations of asthma [12], and there may be a complex interaction between them and with the weather [13]. Much less is known about the impact of conurbation, urban, and rural living on upper respiratory tract infection (URTI), gastroenteritis, or urinary tract infection (UTI).

The UK Royal College of General Practitioners (RCGP) Research and Surveillance Centre (RSC) is one of the oldest sentinel networks and is in its 50th season of reporting infections and respiratory conditions [14,15]. This is a long-standing collaboration with Public Health England [16,17]. The network is recruited to be nationally representative and, at the time of this report, comprised over 1.6 million registered patients. The network's capabilities include reporting whether patients live in a conurbation, urban, or rural area.

Objective

We carried out this study to determine whether exposure to living in a conurbation (high-density living), urban (intermediate density, such as a city or town), or rural (least dense, such as the countryside) environment was associated with more presentations to a general practice (GP) of allergic (allergic rhinitis and asthma) or common infectious conditions. This investigation is the theme of the RSC's annual report on diseases. The annual report also includes the annual weekly rates of GP presentations of all our monitored conditions (Multimedia Appendix 1).

Methods

Design, Setting, and Ethical Considerations

We extracted data from 175 volunteer GPs that are members of the RCGP RSC, with a cohort of 1,602,366 patients registered for the first 6 months of the period of April 1, 2016 to March 31, 2017. All data are pseudonymized as close to source as possible. Data were coded with Read version 2 or Clinical Terms version 3 [18]. We only extracted coded data, not free text. Disease surveillance is part of standard health service activity, so no specific ethical approval was needed. No personal identifiers are held on the RCGP RSC secure network at the University of Surrey. We did not process the data of patients who had an opt-out code (2.2% of the RCGP RSC population).

Data Preparation

We determined a patient's urban classification by using a UK Office for National Statistics (ONS) lookup tool [19]. We did this on an individual-patient level basis using the ONS's Lower Super Output Area to estimate population density. Based on this lookup tool, if a patient's population was classified as mainly rural or largely rural, we classified them as living in a rural population. If a patient lived in an urban with significant rural, urban with city and town, or urban with minor conurbation area, we classified them as living in a city or town (referred to as rural throughout this paper). If a patient lived in an urban with major conurbation area, we classified them as living in a conurbation. These were based on the ONS Lower Super Output Area, which has a mean size in England and Wales of 1640, with population sizes ranging from 820 in South Cambridgeshire to 8250 in Oxford [20].

Our outcome variables, presentation to a GP for allergic and infectious conditions, were a composite of similar conditions grouped together, a method we adopted for the 2016-2017 annual report. To identify our outcomes, we used Read version 2 codes and Clinical Terms version 3 codes to extract the data. These codes are based on *International Classification of Diseases, Tenth Revision* codes. Allergic conditions were allergic rhinitis (including hay fever) and asthma. We divided infections into lower respiratory tract infections (LRTIs), comprising acute bronchitis, pneumonia, and pleurisy; URTIs, including tonsillitis, common cold, sinusitis, conjunctivitis, and otitis media; acute gastroenteritis (AGE); and UTI. We did not include influenza-like illness in this analysis, although data about these illnesses are contained in the annual report (Multimedia Appendix 1), as we plan a separate analysis taking into account vaccine exposure. Similarly, we excluded less-common conditions (eg, measles, mumps, scabies), although their weekly rates of GP presentation are included in the annual report.

In exploring the association between living area and allergic and infectious diseases, we adjusted for age, sex, ethnicity, and socioeconomic status using the Index of Multiple Deprivation (IMD). The IMD is the official measure of relative deprivation for areas in England. It uses 7 domains of deprivation to produce an overall measure (income, employment, education, health, crime, housing and services, and living environment) [21]. We grouped these variables as follows: sex (female was the reference group); age bands (1-4 years, 5-17 years, 18-64 years, and ≥65 years; the reference was 18-64 years); ethnicity (white ethnicity was the reference; we divided the others into Asian, Black, mixed, other, and unclassified ethnicities) using an ontological approach to maximize identification [22]; and deprivation. Using the IMD, we divided deprivation into quintiles (quintile 1, most deprived, was the reference).

From the cohort of 1,602,366 patients registered, we compiled and reported data on conurbation, urban, and rural living by age, sex, ethnicity, and IMD score. We also controlled for comorbid disease. We grouped comorbidities into the following groups: 0 comorbidities (reference), 1 to 2 comorbidities, and 3 or more comorbidities. We included the following as comorbidities: depression; hypertension; chronic obstructive pulmonary disease; rheumatoid arthritis; dementia; stroke or transient ischemic attack (grouped as cerebrovascular disease); acute myocardial infarction, angina, and coronary artery disease (grouped as ischemic heart disease); congestive cardiac failure; peripheral arterial disease; chronic kidney disease; diabetes mellitus; and atrial fibrillation. We also included and controlled for smoking status in our analysis, grouping smokers into active smokers (reference), ex-smokers, nonsmokers, and unknown, based on their latest recorded smoking habit. We used these comorbidities because they are quality and outcomes framework indicators that are used to rate GP performance [23,24]. These conditions are representative of common chronic diseases and likely to be consistently recorded between practices.

Statistical Analysis

To understand whether rural, urban, or conurbation living was associated with GP presentation for certain allergic or contagious diseases, we carried out a multivariate logistic regression, with rural, urban, or conurbation as the predictor variable and disease as the outcome variable. We report the odds ratio (OR) and 95% CI from the multivariate logistic regression [25] for conurbation, or urban compared with rural (reference). An OR greater than 1 implies greater odds of a patient living in a conurbation or an urban area presenting with the condition, and an OR of less than 1 suggests lower odds of a patient living in a conurbation or an urban area presenting with a condition, adjusting for other variables in the model. We created an aggregated table showing those conditions with significant results highlighted. Given the large number of models, we applied a Benjamini-Hochberg correction [26]. We also report probability (*P* value), which we calculated from the coefficients of the logistic regression.

In addition to the main effect of urban, rural, and conurbation living on GP presentation, we looked at the interaction of age band or sex and urban, rural, and conurbation living on GP presentation (see Multimedia Appendix 2 for detailed results). We also created forest plots for age bands and each of the conditions (Multimedia Appendix 3).

The analysis presented in the annual report (Multimedia Appendix 1) includes the following: (1) a map of the national distribution of RCGP RSC practices; (2) summary tables showing the conditions we monitor (median age, using horizontal box and whisker plots; sex distribution of our monitored conditions; ethnicity distribution, comparing white versus all other ethnicities; median IMD, using a horizontal box and whisker plot; and conurbation, urban, and rural distribution of our monitored conditions); and (3) weekly GP presentation rates of the conditions monitored by the RCGP RSC. Population denominators were based on the population registered in the participating practices in December. The weeks are numbered using the International Organization for Standardization system [27].

Results

Population

The RCGP RSC network population consists of 1,602,366 people. Older (>65 years: n=68,378, 25.01%), less deprived (IMD score ≥3: n=274,349, 25.62%), and less ethnically mixed (white: n=204,954, 20.8%; black: n=528, 1.00%) populations live in rural areas. In comparison, younger (25-44 years: n=182,322, 40.7%), ethnically mixed (black: n=44,690, 88.7%; Asian: n=30,827, 67.4%), and more deprived (IMD score <3: n=280,714, 52.81%) populations live in conurbations (see Multimedia Appendix 2, table B.7, and Multimedia Appendix 3, figures C.5-C.7).

Main Effect

Those living in a conurbation, in comparison with a rural area, had greater odds of presenting to a GP with allergic rhinitis (OR 1.29, 95% CI 1.19-1.41; *P*<.001) but had lower odds of presenting with asthma (OR 0.70, 95% CI 0.67-0.73; *P*<.001) and LRTI (OR 0.94, 95% CI 0.90-0.98; *P*=.005).

Those living in urban, compared with rural, areas had greater odds of presenting to a GP with allergic rhinitis (OR 1.13, 95% CI 1.04-1.23; *P*=.003), URTI (OR 1.06, 95% CI 1.03-1.08; *P*<.001) and AGE (OR 1.13, 95% CI 1.01-1.25; *P*=.03). On the other hand, urban dwellers were less likely to present to a GP with UTI (OR 0.94, 95% CI 0.89-0.99; *P*=.02; Table 1). Figure 1 displays these main effects in more detail.

Interaction Effects

We found no interactions between sex and living area, although we did find 4 interactions for age band and living area, using rural and working age (18-64 years) as reference groups. Children aged 0 to 4 years living in urban areas were more likely to present to a GP with asthma than were adults aged 18 to 64 years living in rural areas (OR 1.42, 95% CI 1.20-1.68; *P*<.001).

Table 1. Odds ratios (ORs) and 95% CIs of the main effect of conurbation and urban living (rural is the reference) on the 6 conditions of interest.

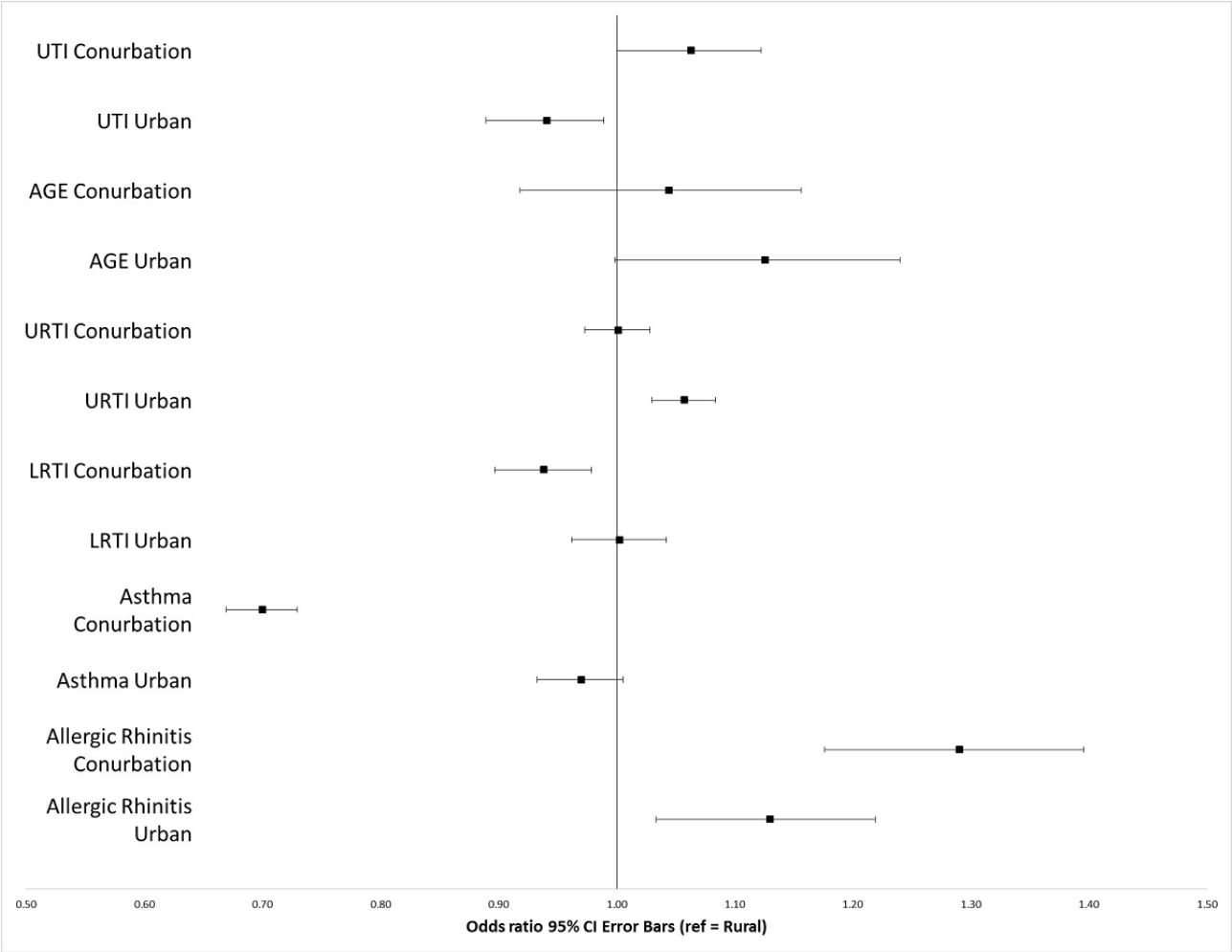
Conditions of interest	Conurbation		Urban area	
	OR (95% CI)	*P* value[a]	OR (95% CI)	*P* value[a]
Allergic rhinitis	1.29 (1.19-1.41)[b]	<.001[b]	1.13 (1.04-1.23)[b]	.003[b]
Asthma	0.70 (0.67-0.73)[c]	<.001[c]	0.97 (0.93-1.01)	.11
Lower respiratory tract infection	0.94 (0.90-0.98)[c]	.005[c]	1 (0.96-1.04)	.89
Upper respiratory tract infection	1 (0.97-1.03)	.93	1.06 (1.03-1.08)[b]	<.001[b]
Acute gastroenteritis	1.04 (0.93-1.17)	.46	1.13 (1.01-1.25)[b]	.03[b]
Urinary tract infection	1.06 (1.00-1.13)[b]	.04[b]	0.94 (0.89-0.99)[c]	.02[c]

[a]*P* value adjusted using Benjamini-Hochberg correction.

[b]OR>1 and significant adjusted *P* value.

[c]OR<1 and significant adjusted *P* value.

Figure 1. Forest plot showing odds ratios for various allergic and infectious diseases based on living area. AGE: acute gastroenteritis; LRTI: lower respiratory tract infection; ref: reference; URTI: upper respiratory tract infection; UTI: urinary tract infection.



From the results of the logistic regression (Multimedia Appendix 4), we could infer the odds of children in certain areas presenting with asthma. For example, there was a 27% decrease in the odds of 0- to 4-year-olds presenting with asthma if they lived in rural compared with urban areas. Children aged between 5 and 17 years were more likely to consult for URTI than adults aged 18 to 64 years living in rural areas (OR 1.06, 95% CI 1.02-1.11; *P*=.01). On the other hand, children aged 0 to 4 years living in urban areas were less likely to present with AGE than were adults aged 18 to 64 living in rural areas (OR 0.84, 95% CI 0.72-0.98; *P*=.03). Over-65-year-olds living in urban areas were less likely to consult for URTI (OR 0.92, 95% CI 0.88-0.97; *P*<.001) and AGE (OR 0.85, 95% CI 0.72-0.99, *P*=.04) than was our reference group (Table 2). Children aged 0 to 4 years

living in a conurbation were more likely to consult for URTI (OR 1.25, 95% CI 1.19-1.31; *P*<.001) than were 18- to 64-year-olds living in rural areas. Children aged 5 to 17 living in conurbations were more likely to consult for asthma (OR 1.14, 95% CI 1.05-1.23; *P*=.001), LRTI (OR 1.32, 95% CI 1.18-1.47; *P*<.001), URTI (OR 1.25, 95% CI 1.20-1.31; *P*<.001), and AGE (OR 1.64, 95% CI 1.36-1.98; *P*<.001) than was our reference group. Additionally, those aged over 65 living in conurbations were more likely to consult for asthma (OR 1.29, 95% CI 1.21-1.39; *P*<.001) and LRTI (OR 1.14, 95% CI 1.08-1.21; *P*<.001) than was our reference group (Table 3).

Table 2. Odds ratios (ORs) and 95% CIs of the main effect of urban (rural is the reference) and interaction terms of urban area with age band (18-64 years is the reference) on the 6 conditions of interest.

Conditions of interest	0-4 years		5-17 years		≥65 years	
	OR (95% CI)	*P* value[a]	OR (95% CI)	*P* value[a]	OR (95% CI)	*P* value[a]
Allergic rhinitis	0.81 (0.63-1.04)	.09	0.93 (0.83-1.05)	.23	1.08 (0.94-1.25)	.29
Asthma	1.42 (1.20-1.68)	<.001	1.05 (0.98-1.13)	.18	0.96 (0.91-1.02)	.18
Lower respiratory tract infection	0.99 (0.91-1.08)	.85	1.11 (1.00-1.23)	.06	1.03 (0.99-1.09)	.17
Upper respiratory tract infection	1.03 (0.99-1.08)	.16	1.06 (1.02-1.11)	.01	0.92 (0.88-0.97)	<.001
Acute gastroenteritis	0.84 (0.72-0.98)	.03	1.01 (0.84-1.22)	.92	0.85 (0.72-0.99)	.04
Urinary tract infection	1.100 (0.87-1.38)	.43	1 (0.86-1.17)	.97	0.98 (0.91-1.05)	.58

[a]*P* value adjusted using Benjamini-Hochberg correction.

Table 3. Odds ratios (ORs) and 95% CI of the main effect of conurbation (rural is the reference) and interaction terms of conurbation with age band (18-64 years is the reference) on the 6 conditions of interest.

Conditions of interest	0-4 years		5-17 years		≥65 years	
	OR (95% CI)	*P* value[a]	OR (95% CI)	*P* value[a]	OR (95% CI)	*P* value[a]
Allergic rhinitis	0.84 (0.65-1.07)	.16	0.94 (0.83-1.05)	.27	0.99 (0.85-1.17)	.94
Asthma	1.08 (0.90-1.29)	.43	1.14 (1.05-1.23)	.001	1.29 (1.21-1.39)	<.001
Lower respiratory tract infection	0.98 (0.90-1.07)	.68	1.32 (1.18-1.47)	<.001	1.14 (1.08-1.21)	<.001
Upper respiratory tract infection	1.25 (1.19-1.31)	<.001	1.25 (1.20-1.31)	<.001	1.02 0.97-1.08()	.40
Acute gastroenteritis	0.94 (0.80-1.10)	.45	1.64 (1.36-1.98)	<.001	0.93 (0.78-1.12)	.45
Urinary tract infection	1.13 (0.89-1.43)	.31	1.04 (0.89-1.22)	.61	1.02 (0.94-1.10)	.63

[a]*P* value adjusted using Benjamini-Hochberg correction.

Discussion

Principal Findings

Patients living in conurbations or urban areas were more likely to consult for allergic rhinitis and URTI, after adjustment for age, sex, ethnicity, socioeconomic status, comorbid disease, and smoking status. The OR of presenting with allergic rhinitis increased with population density. While living in rural areas was associated with an increased risk of asthma and LRTI, both conurbation and rural living were associated with an increased risk of UTI.

Age and living environment interacted when predicting the GP presentation rates of these conditions. Children living in urban areas were more likely to consult for asthma (0-4 years) and URTI (5-17 years) than were 18- to 64-year-old adults living in rural areas (our reference group). Additionally, children living in conurbations were more likely than our reference groups to consult for URTI (0-17 years), LRTI, asthma, and AGE (5-17 years). Over-65-year-olds living in conurbations were also more likely than our reference group to consult for asthma. The risk of AGE was increased in 18- to 64-year-olds living in rural areas in comparison with 0- to 4-year-olds and over-65-year-olds living in urban areas. Rural living for 18- to 64-year-olds was associated with an increased risk of URTI compared with over-65-year-olds living in rural areas.

Comparison With Prior Work

Conurbation and urban living was associated with increased presentation with allergic rhinitis to a GP. This is consistent with previous research finding that allergic rhinitis is more common in urban areas and conurbations [8,28].

Those living in conurbations had higher odds of consulting for UTI. Conurbation living is arguably very different from rural living. For example, the population density is higher [29], the nightlife is more active [30], and the levels of risky sexual behavior are higher in conurbations [31,32]. As one of the risk factors for UTIs in women is sexual intercourse [33-35], the lifestyle of conurbation living may explain this finding. However, more research is needed to test this.

The results also showed that those living in rural areas were more likely to present with LRTI and asthma. Some studies have found that urban living is associated with increased odds

of developing asthma [36], whereas others have found that rural living increases the odds [37]. Clearly more research is needed to identify environmental risk factors for developing asthma. Risk factors for LRTI vary across different studies. For example, risk factors for developing LRTI in children have been found to be pollution, poor ventilation [38], living in urban areas, and parental smoking [39,40]. In older people, difficulty taking medication and poor mobility were risk factors [41]. Based on these risk factors, it is difficult to understand our findings, as pollution and poor ventilation are more likely to be factors found in conurbations. However, looking at preventive factors for developing LRTI may explain the results. For example, research has found that influenza vaccination can be a protective factor against LRTI [41,42]. Furthermore, some studies have found that individuals living in rural areas are less likely to obtain preventive health services such as the influenza vaccine [43-45]. This may possibly explain our findings, although more research is needed.

Infectious diseases are associated with population density [3]; therefore, the increased odds of AGE in adults aged 18 to 64 years living in rural areas does not fit with previous research. A possible explanation may be related to food-borne illness. Risk factors for certain food poisoning–related bacteria include eating restaurant-prepared food, eating undercooked food, drinking raw milk, having contact with farm animals, and travelling abroad [46,47], factors that may be associated with rural living [48,49].

Implications of the Findings

Living in a conurbation or an urban area leads to an increased risk of allergic rhinitis and URTI in all people, and an increased risk of URTI, LRTI, asthma, and AGE in children. These results are in line with previous research, as densely populated areas have been associated with the rapid spread of infectious diseases such as the severe acute respiratory syndrome virus and avian flu [3]. Future research should therefore focus on aiming to reduce infection spread in high-density populations.

Furthermore, population density and traffic in conurbations may increase the rates of allergic rhinitis and asthma [4-6]. Increasing the number of green spaces may be an important preventive measure [50], as they have been found to prevent higher rates of asthma [51,52] and allergic rhinitis [53,54].

Strengths and Limitations

We derived the data from a network of general practitioners in which the population in question is large and is representative of the whole of England. This large and representative population allows us to link morbidity to ethnicity, living environment, and socioeconomic status. Patterns found from this dataset can be applied to the whole population.

Further, data quality in the RCGP RSC for infections and allergic conditions is assured through data quality feedback to RSC member practices. More recently, we have introduced financially incentivized training and practice-specific comparative feedback via a dashboard [55], modelled on the principles of audit-based education [56].

The limitations of this study were that not everyone who has infectious or allergic diseases will go to their GP, meaning that actual rates of illness may have been higher in the general population. Furthermore, although we worked hard to ensure accuracy of our data, there were instances where conditions were not recorded accurately. Additionally, the allergic conditions we investigated tend to be chronic conditions, with peaks of exacerbations. We did not control for episode type in our analysis, which may have confounded rates of GP presentation for asthma and allergic rhinitis.

Conclusions

Overall, we found that different allergic and infectious conditions were associated with rural, urban and conurbation living. A longitudinal study of RCGP RSC data may provide insights, particularly around changes in pollutant emissions or other variations in exposure, on the effect of the environment on allergic and infectious conditions.

Acknowledgments

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Authors' Contributions

SdeL created the idea for the study, proofread the work, was director and guarantor for the data, and assisted with clinical knowledge, system design, and problem solving. CM carried out data extraction and statistical analysis for this study and the supplementary report, and drafted the introduction, methods, and results sections. RW edited the introduction, methods, and results sections, wrote the discussion, and formatted the manuscript. MJ designed the statistical analysis method. AJE and GS reviewed the manuscript. RB designed and developed much of the database structure and carried out much of the data extraction. IY and MH acted as liaison with practices and provided coordination. FMF was project manager. IR was Joint Medical Director of RCGP Clinical Innovation and Research.

Conflicts of Interest

None declared.

Multimedia Appendix 1

RCGP RSC Annual Report 2016-2017.

[PDF File (Adobe PDF File), 5MB - publichealth_v4i4e11354_app1.pdf]

Multimedia Appendix 2

Data tables.

[PDF File (Adobe PDF File), 77KB - publichealth_v4i4e11354_app2.pdf]

Multimedia Appendix 3

Additional figures.

[PDF File (Adobe PDF File), 581KB - publichealth_v4i4e11354_app3.pdf]

Multimedia Appendix 4

Logistic regression output.

[PDF File (Adobe PDF File), 83KB - publichealth_v4i4e11354_app4.pdf]

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Abbreviations

AGE: acute gastroenteritis
GP: general practice
IMD: Index of Multiple Deprivation
LRTI: lower respiratory tract infection
ONS: Office for National Statistics
OR: odds ratio
RCGP: Royal College of General Practitioners

RSC: Research and Surveillance Centre
URTI: upper respiratory tract infection
UTI: urinary tract infection

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Original Paper

Establishing a Demographic, Development and Environmental Geospatial Surveillance Platform in India: Planning and Implementation

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Abstract

Background: Inadequate administrative health data, suboptimal public health infrastructure, rapid and unplanned urbanization, environmental degradation, and poor penetration of information technology make the tracking of health and well-being of

populations and their social determinants in the developing countries challenging. Technology-integrated comprehensive surveillance platforms have the potential to overcome these gaps.

Objective: This paper provides methodological insights into establishing a geographic information system (GIS)-integrated, comprehensive surveillance platform in rural North India, a resource-constrained setting.

Methods: The International Clinical Epidemiology Network Trust International established a comprehensive SOMAARTH Demographic, Development, and Environmental Surveillance Site (DDESS) in rural Palwal, a district in Haryana, North India. The surveillance platform evolved by adopting four major steps: (1) site preparation, (2) data construction, (3) data quality assurance, and (4) data update and maintenance system. Arc GIS 10.3 and QGIS 2.14 software were employed for geospatial data construction. Surveillance data architecture was built upon the geospatial land parcel datasets. Dedicated software (SOMAARTH-1) was developed for handling high volume of longitudinal datasets. The built infrastructure data pertaining to land use, water bodies, roads, railways, community trails, landmarks, water, sanitation and food environment, weather and air quality, and demographic characteristics were constructed in a relational manner.

Results: The comprehensive surveillance platform encompassed a population of 0.2 million individuals residing in 51 villages over a land mass of 251.7 sq km having 32,662 households and 19,260 nonresidential features (cattle shed, shops, health, education, banking, religious institutions, etc). All land parcels were assigned georeferenced location identification numbers to enable space and time monitoring. Subdivision of villages into sectors helped identify socially homogenous community clusters (418/676, 61.8%, sectors). Water and hygiene parameters of the whole area were mapped on the GIS platform and quantified. Risk of physical exposure to harmful environment (poor water and sanitation indicators) was significantly associated with the caste of individual household (P=.001), and the path was mediated through the socioeconomic status and density of waste spots (liquid and solid) of the sector in which these households were located. Ground-truthing for ascertaining the land parcel level accuracies, community involvement in mapping exercise, and identification of small habitations not recorded in the administrative data were key learnings.

Conclusions: The SOMAARTH DDESS experience allowed us to document and explore dynamic relationships, associations, and pathways across multiple levels of the system (ie, individual, household, neighborhood, and village) through a geospatial interface. This could be used for characterization and monitoring of a wide range of proximal and distal determinants of health.

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KEYWORDS

geospatial surveillance; health and nonhealth data harmonization; spatial epidemiology; participatory GIS; caste, socioeconomic transition; ground truthing; built environment

Introduction

Background

Inadequate administrative health data, suboptimal public health infrastructure, rapid and unplanned urbanization, environmental degradation, and poor penetration of information technology make the tracking of health and well-being of populations in the developing countries challenging [1-4]. Health surveillance capacities remain one of the major barriers in collating contextual evidences for identifying the pathways of health problems and assessing the true magnitude of the socioeconomic impact of diseases; new technologies and innovations hold promise for finding solutions in such environments [1,2,5,6]. Surveillance of behavioral, socioeconomic, and environmental determinants of health is further limited in terms of capacity to develop infrastructure and collect and interpret the information in resource-constrained settings [1,6,7].

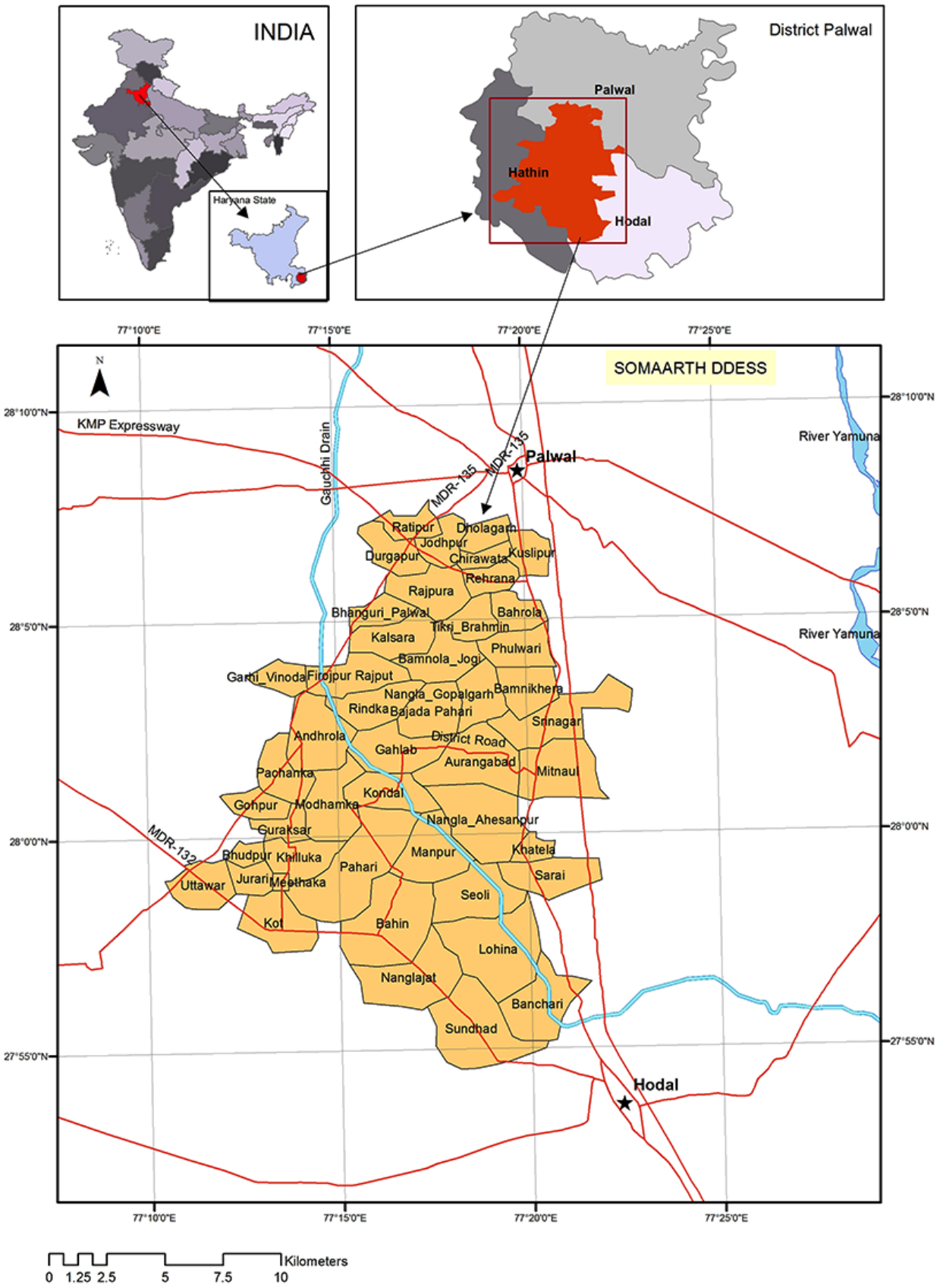
The US Center for Disease Control and Prevention has recently advocated for the establishment of comprehensive surveillance architectures for emerging infectious diseases and chronic conditions, particularly those associated with lifestyle, incorporating wider (distal and proximal) determinants of health and well-being [2]. Integrative surveillance of diverse environmental factors with a “whole-of-society” convergence framework is likely to be informative of the factors that contribute to occurrence, sustenance, and progression of communicable and noncommunicable diseases [8].

A geographic information system (GIS) enables an integrated comprehensive surveillance platform that allows rapid integration of data from disparate sectors and sources with the potential to contribute to improving the understanding of diverse disease exposures [9-16]. Although geospatial technologies have been explored and experimented with in several studies conducted in developed countries [12], there is limited experience from the developing countries due to reasons like lack of georeferenced administrative health datasets and postal codes, unavailability of trained technical manpower, and the complex morphologies of human habitations, particularly rural settings [17-21].

Between 2009 and 2015, the International Clinical Epidemiology Network (INCLEN) Trust International established a comprehensive SOMAARTH Demographic, Development, and Environmental Surveillance Site (DDESS) in a rural North Indian setting (District Palwal, Haryana). As a surveillance platform, SOMAARTH (the word SOMAARTH is a Sanskrit word meaning synergy between economic development and health) DDESS aims to allow monitoring and interpretations of synergetic and complex relationships between the environment, society, regional development, economics, and

health status of the population over time (Multimedia Appendix 1).

Figure 1. Location of the SOMAARTH Demographic, Development, and Environmental Surveillance Site (DDESS).



Building on the existing global experiences, this paper describes the feasibility of establishing a GIS-integrated surveillance

platform, SOMAARTH DDESS, and shares the learnings gained in the context of a resource-constrained rural North Indian setting.

Surveillance Site Location, Coverage, and Characteristics

The SOMAARTH DDESS (District Palwal, Haryana, India) is located about 80 km from the Delhi border on the Delhi-Agra National Highway 2 (NH-2). This site is located between 27°53′59.46″N to 28°7′30.02″N latitude and 77°10′2.95″E to 77°22′47.35″E longitude spanning over 251.7 sq km of area (Figure 1) and includes 51 villages from 3 administrative blocks (Hodal, Hathin, and Palwal) of the district. As per the 2011 census, the decadal population growth rate of Palwal district was 25.7% as against the Indian national average of 17.7%; over three-quarters (77.3%) of the district population is rural [22]. The climate of the study area can be classified as arid steppe hot according to Köoppen-Geiger Classification system [23]. The Western Peripheral Expressway (Kundli-Manesar-Palwal Expressway) traverses through the northern tip of the study site, and the proposed Special Economic Zones along the expressway are projected to boost local industrial and business growth [24].

Methods

Tools and Techniques

Google Earth open source imagery and Survey of India Palwal district map of 1:50,000 scale were utilized for preparing the initial maps. QuickBird very high-resolution (<1 m), multispectral, radiometrically corrected, and projected satellite imagery for the period March-May 2012 was procured from the National Remote Sensing Centre, India.

Environmental Systems Research Institute Arc Map Version 10.3 (ESRI, Redland, CA, USA) [25] and QGIS Version 2.1 (QGIS Development Team) [26] software were used for GIS analysis. MetOne E-sampler 9800 for ambient particulate matter ($PM_{2.5}$) and meteorological data (wind speed and direction, temperature, and relative humidity), UCB-PATS+ for household $PM_{2.5}$, MAXIM i-buttons for stove usage monitoring, and DJI Phantom-1 for recording particle dispersion and temperature inversions were utilized for establishing an air quality monitoring system.

Surveillance Architecture

SOMAARTH surveillance platform architecture was established for tracking the distal and proximal determinants of health through 3 key surveillance activities (Multimedia Appendix 2): (1) development and built environmental surveillance that encompasses land use, including commercial, industrial, institutional, educational, transportational, and contextual structures; (2) demographic and health surveillance, including size, structure, distribution, and population health; and (3) physical environmental factors including the indoor and outdoor air quality, ambient metrological data (ie, temperature, humidity, and wind direction), and water and sanitation.

A three-tier surveillance architecture was conceived using geospatial interfacing to enable incorporation of domain-specific areas, including the following layers: data collection (input layer), data management (application layer), and data harmonization (database layer). Datasets were prepared to permit relational documentation across each layer and to dynamically integrate additional information from research projects, health facilities, and institutional records in a timely manner as datasets were made available to the research team.

Data System Development Steps

A multidisciplinary expert group, the Central Coordination Team, was formed; it comprised specialists from the fields of public health, epidemiology, pediatrics, geospatial science, human geography, anthropology, environmental science, urban planning, management, and social sciences. The Central Coordination Team guided the establishment processes and the development of a conceptual framework. For surveillance site selection, a rural area circumscribed by the three major roads and having potential for rapid economic development was identified. Official permission from the state government and district administration was gained prior to undertaking field activities. Prior approval from the competent state or national authorities and from the community leaders is mandatory for setting up the demographic surveillance sites [27]. The progress of the SOMAARTH surveillance platform consisted of four major steps: (1) site preparation, (2) data construction, (3) data quality assurance, and (4) data update and maintenance system.

Step 1: Site Preparation (18 months, October 2009-March 2011)

Developing the surveillance platform was a long-term commitment and required continuous support from the local stakeholders including community members. Initial contact with the village community and administration was established (October 2009), and a partnership was forged over a period of 18 months with the local community leaders through village-level community meetings. Stakeholder engagement established the networks required to later undertake participatory mapping and census processes within the villages.

Three field teams were constituted: Census, GIS, and Environment teams. Teams comprised lead personnel with public health (n=5), geography (n=2), and environmental science (n=1) backgrounds; for field staff, local residents with graduate and undergraduate qualifications were hired (Census, 38; GIS, 11; Environment, 3). Project personnel were trained through 3 separate structured 2-week training programs, which included classroom sessions (20% time) along with hands-on fieldwork (80% training time). A village mapping listing manual, census enumeration guide, and GIS mapping guidelines were prepared to ensure consistency in data collection processes across the site. Separate microplans for collecting datasets pertaining to geospatial, demographic, and environmental domains were prepared, and instruments were finalized after a team of 4 investigators (NKA, MV, FA, and RKS) and 6 field staff piloted field activities in 5 villages over 12 working days.

Step 2: Data Construction (38 months, March 2011-April 2014)

In the absence of administrative datasets, baseline datasets were constructed for establishing a comprehensive surveillance platform (Figure 2).

Figure 2. The SOMAARTH Demographic, Development, and Environmental Surveillance Site (DDESS) data system: development and integration of demography, development, and environmental parameters. UID: unique identification number; GIS: geographic information system.

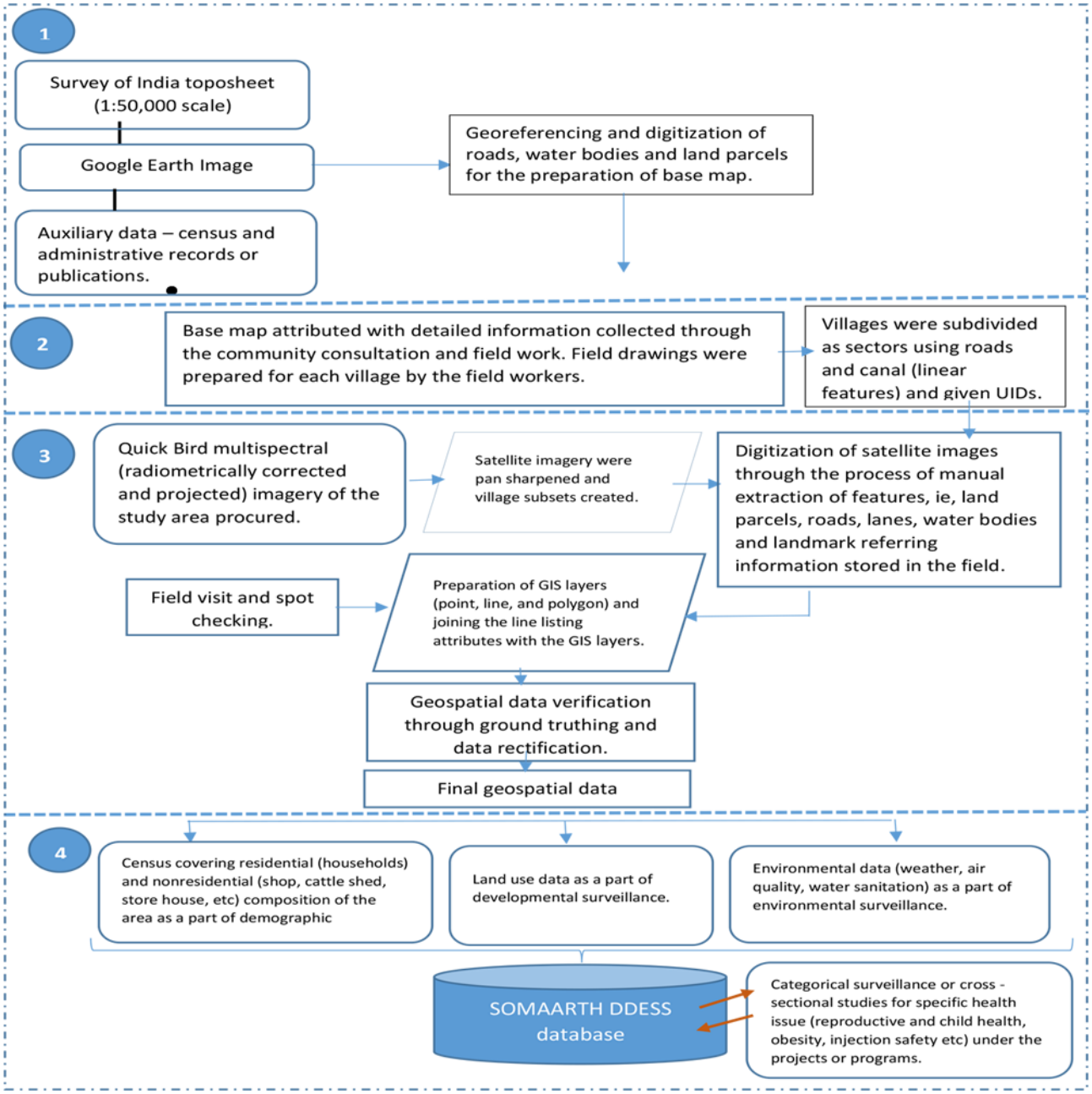
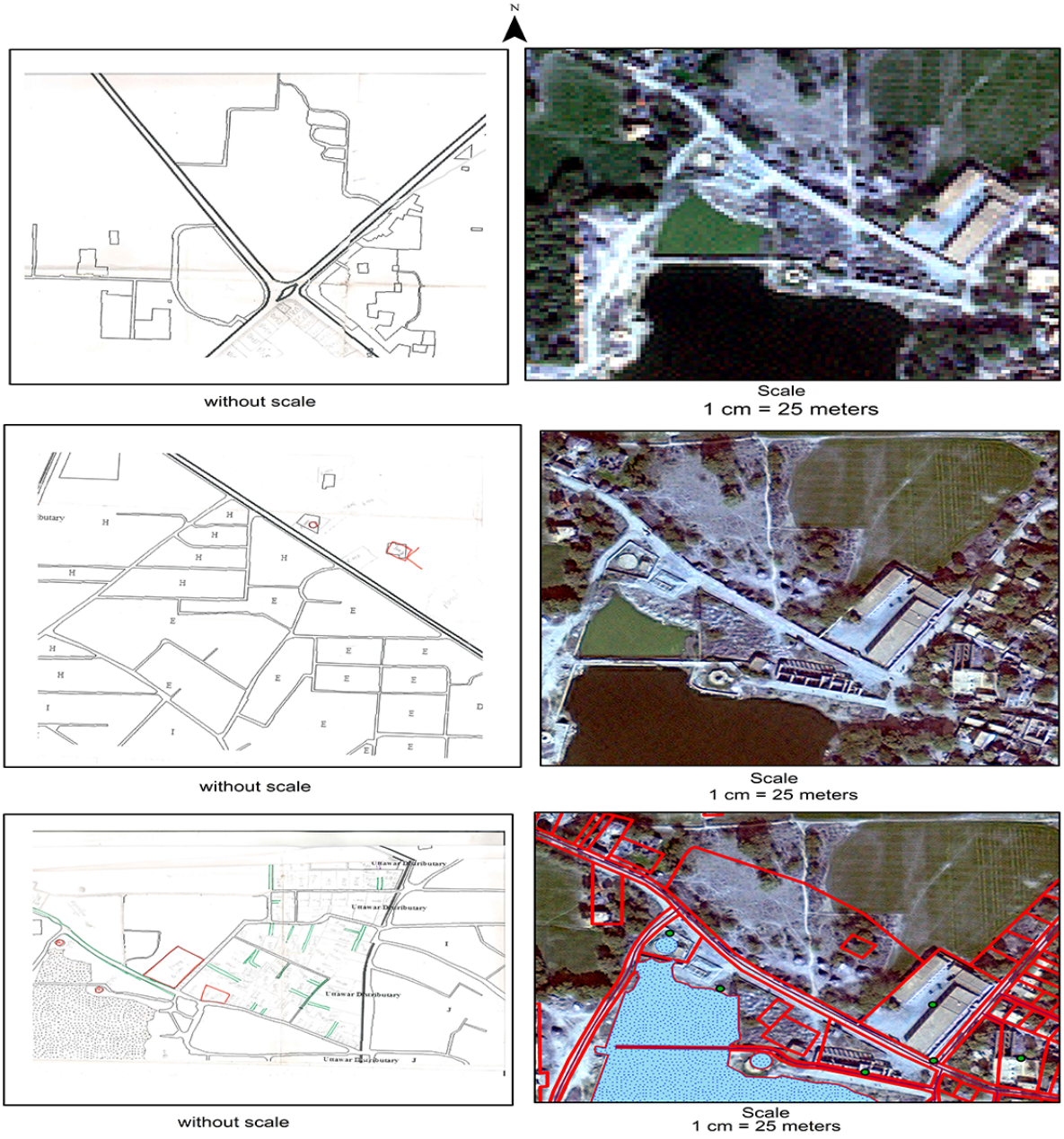


Figure 3. Stepwise development of geospatial datasets at SOMAARTH Demographic, Development, and Environmental Surveillance Site, Palwal, India.



Characterization of Rural Environment Through Participatory Mapping and Line Listing (12 Months, March 2011-February 2012)

Participatory mapping and line listing were undertaken simultaneously, covering the residential, nonresidential, vacant, and ruined land parcels. Before starting the data collection processes, base maps [28] were prepared by the GIS Associates utilizing the Survey of India toposheet (scale 1:50,000) and Google Earth imagery depicting locations of major roads and water bodies for all 51 villages. A team of 2 field workers (a mapper and lister) per village collected the information using hard copies of base maps and a line listing tool through community consultations, followed by the field work. Field workers identified the main entry point of the village; oriented themselves as per the directions provided on the hard copy of the base map; and following the left-hand rule, systematically captured roads, lanes, water bodies, and landmarks to prepare a detailed field drawing of the village.

Participatory mapping assisted in the subdivision of villages into sectors, resulting into around 50-500 (population of approximately 100-2000 persons) contiguous land parcels in the core habitation area and taking roads as a boundary of demarcation. However, outer village sectors were sparsely built (0-50) land parcels. Sectors were given unique alphabetic identification codes in a systematic clockwise order. Using the left-hand rule, all the residential, nonresidential, and vacant land parcels within each sector were mapped in the form of polygons of relative sizes and shapes of area as informed by the property owner or respondent (Figure 3). Each land parcel occupied in the residential, nonresidential, or mixed activities was given a unique identification number (UID) based on location by prefixing the sector identity and unique numbers in sequential

manner following the left-hand rule. This systematic approach later helped in developing location-based addresses for each household and nonresidential features of the study villages. The line list prepared for each land parcel consisted of the following details: structure type as per construction (mud, cement, brick) and usage (residential or nonresidential or vacant or ruined), ownership, head of household, religion, caste, gender, and age composition of household members. The Field Supervisor conducted 10% random field-based checks stratified according to the task accomplished by the primary field workers, and the lot quality assurance approach was adopted for accepting or rejecting the lot.

In Figure 3, top two and middle left images show stepwise development of a field drawing and comprise a framework map depicting major roads digitized from Google Earth; an outlining of village sectors; and a field drawing depicting roads, water bodies, and land parcels, respectively. Furthermore, middle right and bottom two images show stepwise development of geospatial data and comprise a multispectral Quick bird satellite image (raw); a processed (pan-sharpened) image for digitization; and digitized road, water body, and land parcel layers overlaid on the processed image, respectively.

Geospatial Data Construction (26 Months, September 2011-October 2013)

The analog participatory maps (field drawings) having contextual details of the villages and the line listing having compositional details proved helpful in satellite-based digitization processes for constructing digital, georeferenced, spatial datasets. Due to the lack of property delineation and informal settlements [20,21], automated digitization [29] was not possible for our area; therefore, manual digitization was adopted through combining visual interpretation of satellite imagery and participatory maps [30]. QuickBird multispectral satellite imagery was pan sharpened for improving the spectral quality for digitization processes (see Figure 3). Data was projected in the Universal Transverse Mercator coordinate system (Zone 43N). Different features were stored as separate feature classes, that is, sector (polygon), roads (polygons, line), water bodies (polygons), land parcels (polygon), wells (point), canal and drains (polygon), railway line (line), and burial places and landmarks (point). Land parcel features with their location UID and composition data collected during line listing were joined with the GIS layers. Digitization for all 51 villages was done by a team of 3 GIS research associates. The Program Officer (GIS) conducted a random cross-checking of 10% of the land parcels stratified for every sector in the village in order to take corrective steps.

Demographic and Health Data Collection (26 Months, March 2012-April 2014)

Hard copies of high-resolution GIS maps and line listing attributes were supplied to the census teams to operationalize the census of residential and nonresidential features using 2 separate tools in a systematic manner. The sectorwise high-resolution GIS maps (<1:200 scale) facilitated in work allocation and monitoring of census operations. Census forms were tagged with their respective location UID marked on the GIS map. Core variables collected for the residential structures were as follows: basic land parcel information, demographic details of the inhabitants, household structure, details of construction materials, socioeconomic status (SES), domestic animals and other assets owned by the household, water availability and usage, toilet facilities, sanitation, and waste management practices. The self-reported health parameters covered were as follows: details of mental and physical disability, behavioral issues, substance abuse (smoking, alcohol, and other substances), health-seeking patterns, and individuals with a chronic disease (an illness lasting for more than last 6 months) in the household. Core variables for nonresidential land parcels were land use typology and waste management besides the structural features and ownership. Regular structured coordination-cum-troubleshooting interaction occurred between GIS and Census teams every week to detect temporal changes and other feedbacks on the maps in a real-time manner; these meetings helped in the regular rectification of both census and GIS data.

Physical Environmental Data Collection

Weather and Air Quality Data Collection (Ongoing Since May 2011)

Environmental scientists led the establishment for air quality data monitoring, which covered point-based recording of real-time ambient air quality ($PM_{2.5}$) and other meteorological attributes (ie, temperature, humidity, and wind direction) at 2 fixed locations within the site. GIS maps helped in the site selection for establishing a small weather station within the surveillance site. The system for $PM_{2.5}$ air quality monitoring at the ambient level was upgraded to drone-based observations for monitoring the dispersion of particles ($PM_{2.5}$) at different altitudes and measurement of temperature inversions. Personal exposure monitoring was also carried out in selected female subjects (primary cook) from the site villages [31]. Latitude and longitude information was used for integrating weather and air quality data with the geospatial datasets.

Drinking Water and Sanitation Mapping (November-December 2015)

Baseline assessment of two critical components of the village environment (ie, drinking water supply and sanitary conditions of the rural communities) was performed. This survey was undertaken by a geographer with the help of a field worker hired from the local community. SOMAARTH GIS data were used for creating base maps for mapping water and sanitation status, drinking water pipe lines, drainage system (drainage channel and their quality), and liquid and solid (litter) waste spots (ie, open litter of large size covering more than 1 m diameter). Locations of water stagnation and spilling areas were also mapped on the hard copies of GIS maps and later updated within the geospatial datasets.

Land Use Mapping (March 2012-April 2014)

GIS Associates assigned an adapted system of land use categorization [32] to each land parcel. The resulting land use classification system included 3 levels. Level I representing “Built-Up Land,” “Agricultural Land,” “Water Bodies,” “Waste Land,” and “Vacant Land.” For example, Built-Up (Level I) was further refined to Level II to include the classifications of

"Residential," "Commercial," "Industrial," "Institutional," "Utilities," "Services," "Transportation," and "Agricultural and Others." Subsequently, Level II categories were further refined into a Level III classification. The attribute table within the GIS village layer included all land parcels that were characterized within the village. There was another project going on in the area: "Foundational Work for a Brain-to-Society Diagnostics for Prevention of Childhood Obesity and its Chronic Diseases Consequences." As part of this project, GIS mapping of food environment was done in 9 villages to identify exposures influencing the food intake of study subjects (children aged 6-12 years) [33].

Step 3: Data Quality Assurance (26 Months, April 2013-December 2015)

The geospatial data so constructed was subsequently reassessed for land parcel position (location, size, and shape) and attribute accuracy through ground-truthing–based verification exercises. Temporal changes that emerged during the course of the data construction were also incorporated in this exercise.

The methodology for verification of geospatial datasets through community-based ground-truthing was formulated through a pilot study conducted at 6 surveillance villages. Villages for pilot study were selected through a stratified random sampling process as per size (large, >1000 land parcels and small, ≤1000 land parcels) and settlement pattern (linear, circular): 2 each from large linear and large circular groups and 1 each from small linear and small circular groups. Within each selected village, 5.1% (455/8901) samples of total land parcels across all land use categories were selected, keeping the minimum sample size of 30 land parcels per village. The pilot exercise resulted in the development of 2 verification tools (land parcel and road assessment tools) and the associated operational manual. These tools were applied across the DDESS for data verification and refinement of the GIS maps. Discrepancies were recorded and highlighted on the hard copy maps. Refinement of land parcel delineation was done by capturing vacant land adjoining the existing structures (buildings). An updated road network was prepared for the entire DDESS and characterized according to a predefined typology (ie, highway, village road, public and private lanes), surface (ie, metalled, unmetalled, semimetalled), and surface quality (ie, good, average, poor).

After the completion of the verification exercise, the census forms were tagged with the updated geospatial UIDs and rechecked manually to ensure that the census form was accurately integrated with the corresponding geospatial data. The geospatial dataset was again verified using onscreen tools, topology functions, and ground-truthing processes before sending it for entry into the SOMAARTH surveillance data management software. A team of 8 field workers under the supervision of the 3 GIS research associates worked in this activity for 16 months, between February 2014 and May 2015.

Step 4: Data Update and Maintenance System

Data collected on the hard copy forms were entered in the specially designed SOMAARTH DDESS software (SOMAARTH-1) developed on HTML or cascading style sheet user interface, personal home page programming language with MySQL database management system. Software included modules on registration of land parcels, user management, survey, quality assurance, query building, reporting (including tabular and graphical), cohort, and multiple project management. Recently updated integrated Web- and Android-based data collection capabilities have made SOMAARTH-1 software a robust package for handling data collection, storage, management, and analysis for large volumes of longitudinal datasets. Considering the large surveillance area, volume, and variety of datasets, 3 data update strategies were put in place: (1) real-time update of datasets under individual projects; (2) annual update covering temporal changes in the land parcels and 6 vital demographic events, including migration (immigration, emigration), birth, death, pregnancy registration, changes in marital status, and change in the head of households; and (3) complete data collection wave (census) covering all data components (ie, built environment, demographic, and health) every 3 years. SOMAARTH DDESS was prepared for its first annual update after completion of the baseline round of census in May 2018.

Results

Description of Data Constructs

Some of the unique geospatial data constructs available within the SOMAARTH platform were physical environment (land parcel, water bodies), social (road, rail, public places, religious places), and services (child and mother care centers, rural banks, health facilities, educational institutes, cremation grounds or burial places, others; Table 1). There were a total of 47,007 land parcels spread across 51 villages; these were characterized as residential (26,363/47,007, 56.08%), nonresidential (18,118/47,007, 39.54%), and mixed (2528/47,007, 5.38%) land parcels. The number of land parcels varied between 25 and 3279 per village (median 587; mean 922 [SD 857]) depending on the average population size (mean 3916 [SD 3673]) per village (median 2603; range 89-18,249; Multimedia Appendix 3).

Demographic and health datasets of 199,702 persons residing at the SOMAARTH DDESS were nested within the geospatial dataset. Granular datasets on village- and neighborhood-level ambient air quality ($PM_{2.5}$) were available from year 2012 onwards.

Almost all the villages (48/51, 94%) had ponds locally called *johar*. All the villages were accessible through metalled roads, with an average road density of 2.8 km per sq km of surface area. Moreover, 18 villages had public health facilities; however, every village had one or more private providers (n=234), most of whom were informal or nonqualified. The median distance of public health facilities in the villages, where they were available, was 370 m (range 142 m-1282 m) from the center of the village built-up area. All the 231 water bodies within the SOMAARTH DDESS were highly polluted due to the dumping of solid and liquid wastes generated by the local inhabitants.

Table 1. The SOMAARTH Demographic, Development, and Environmental Surveillance Site geospatial database: physical, social, and service constructs of the area.

SOMAARTH GIS[a] constructs, data domain, and details or local names	GIS representation	Villages, n	GIS features, n
Physical environment			
Land parcel			
Residential	Polygon	51	26,363
Nonresidential	Polygon	51	18,116
Mixed	Polygon	51	2528
Water bodies			
Pond	Polygon	48	231
Irrigation channels, distributaries, or drainage system (km)	Line	33	135.6
Wells	Points	42	322
Road (km)			
Road	Line	51	707.2
Lane (public)	Line	51	473.9
Lanes (private)	Line	51	82.3
Railroad	Line	2	3.7
Social			
Public places			
Chaupal	Point and Polygon	47	319
Community center	Point and Polygon	18	21
Religious places			
Temple	Point and Polygon	40	248
Mosque or Eidgah	Point and Polygon	16	94
Madrassa	Point and Polygon	8	12
Others			
Old age home	Point and Polygon	13	13
Monuments or landmark	Point	10	15
Service			
Anganwadi child and mother care center	Point and Polygon	49	198
Rural bank or mini bank or automated teller machine booth	Point and Polygon	11	17
Kabristan or Shamshaanghat or cremation ground	Point and Polygon	42	64
Health facilities			
Community health center	Point and Polygon	1	1
Primary health center	Point and Polygon	2	2
Subcenter	Point and Polygon	18	18
SOMAARTH clinics	Point and Polygon	5	5
Veterinary clinic	Point and Polygon	16	16
Public dispensary or Ayurvedic clinic	Point and Polygon	4	4
Educational institute			
School	Point and Polygon	49	172
College	Point and Polygon	5	8
Others			
Water boosting station	Point and Polygon	36	48

SOMAARTH GIS[a] constructs, data domain, and details or local names	GIS representation	Villages, n	GIS features, n
Village revenue office	Point and Polygon	9	9
Bus depot or stand	Point and Polygon	3	3
Railway station	Point and Polygon	2	2
Petrol pump	Point and Polygon	10	15
Post office	Point and Polygon	7	7
Police station	Point and Polygon	2	2

[a]GIS: geographic information system.

Table 2. Concentration of habitations: villagewise distribution of the Nearest Neighbor Index.

Settlement typology	Nearest Neighbor Index	Village distribution, n (%)
Highly clustered	0-0.5	35 (68.6)
Clustered	0.6-0.9	15 (29.4)
Random	1.0	0
Regular	>1.0	1 (2.0)

On average, each village had 12 ([SD 9]; median 8; range 2-41) permanent litter areas and 75 wastewater stagnation points ([SD 39]; median 61; range 26-143 per village), and open defecation sites were marked in 43 villages. Food environment mapping carried out in 9 villages recorded 382 food stores with an average of 42 ([SD 40]; median 27; range 8-133) food stores per village.

Preliminary analysis of the settlement pattern using Nearest Neighbor Index (NNI) [34] indicated a clustered pattern (NNI<1.0) in 98% (50/51) villages; of them, 35 villages had highly concentrated settlements (NNI<0.5), and only 1 small village (Bazara Nagla) had an NNI of >1.0 (Table 2 and Multimedia Appendix 3). The cumulative area of the structural concentration of 51 villages was 2127 hectares (2127/23,788.7, 8.94%), encompassing 80.79% (37,979/47,007) of the total constructed land parcels (Multimedia Appendix 3).

Space and Time Monitoring

The updated information on fine administrative boundaries (village, hamlets, land parcels) of the study area was missing from administrative records [35]. Official census maps (1:2 km scale) of the SOMAARTH area showed the boundaries of only 43 revenue villages; the district planning map helped delineate 4 additional small villages. The participatory GIS mapping process helped in the identification of 4 more small habitations (locally known as *nagla*) to make a total of 51 villages in the SOMAARTH DDESS. The absence of a formal subdivision of villages was a hindrance to the data collection process as the shape and size of the villages were organic and without any land use system.

Using geospatial tools, villages within the SOMAARTH site were subdivided into 760 sectors (range 5-26 sectors per village), with the area varying between 0.03 and 791.5 hectares. In a setting where no postal code system was in place, UIDs were created based on the georeferenced land parcels. Each enumerated land parcel was allotted a 19-digit-long UID covering the country, state, district, administrative block, village, sector, and land parcel number. Individuals were nested within the land parcel and given a computer-generated random 9-digit UID. Land parcel IDs had fixed geographies, whereas individual UIDs were kept independent to locations. All these were done with the objective of establishing a space, individual, and time monitoring system within the surveillance platform.

The social (caste categories such as schedule castes or tribes, backward communities, and general category) and economic (rich, middle, and poor classes) profile (socioeconomic profile) of all 676 sectors having households was assessed. Depending on the overall prevalence of socioeconomic classes in the SOMAARTH DDESS, if a sector had 1.5 times the average prevalence of a particular social or economic class, the sector was labeled as a dominant sector. Of all sectors, 61.8% (418/676) had a dominant caste and 34.8% (235/676) had a dominant economic class, with heterogeneity observed within and across the villages. Social class (ie, caste) was the major determinant of sector composition.

Ground-Truthing–Based Data Verification and Refinement

Ground-truthing helped in the identification of both systematic and random errors in spatial and nonspatial data. Ground-truthing revealed that the data had positional and attribute errors, inconsistencies in land parcel boundary delineation, and lack of documentation of the vacant parcels. These errors had further escalated due to the temporal changes that occurred over 2 years between participatory mapping and preliminary verification exercise starting from 2011 to 2013. Out of the site-wide total land parcels, 23.53% land parcels (11,064/47,007) had size-related, 11.64% (5474/47,007) had shape-related, and 11.14% (5237/47,007) had location-related inaccuracies. In addition, 7990 vacant land parcels were left undocumented during the initial data collection exercise. In 12.09% (5687/47,007) of the land parcels, temporal changes like new construction (4640/5687, 81.6%) had occurred, with over three-fourth of these changes occurring during previous

6-24 months. The geospatial data of 1263 km of roads, including lanes and community pathways, was classified as per road typology, surface, and quality during the field visits. The final verification round conducted after the refinement of the data indicated that 4.90% (2303/47,007) of the land parcels still had positional inaccuracies due to the errors in size (141/47,007, 0.29%), shape (47/47,007, 0.09%), and location (2115/ 47,007, 4.50%) of the land parcels; 57.70% (1329/ 2303) of these errors recurred due to incorrect demarcation of individual property boundaries. Another 0.49% (235/47,007) of the land parcels were detected to have errors in attributes, and 184 more vacant land parcels were identified in this round.

Physical Exposure to Harmful Environment

Physical exposure to harmful environment was assessed using two indicators calculated based on the geospatial mapping of the solid waste mounds and liquid waste spots in all of the 676 sectors having 32,631 households falling under the SOMAARTH DDESS area. The density of solid waste mounds and stagnant liquid waste puddles (both ≥1 m in diameter) within the sectors was calculated per 100 residents (median 2.7; 95% CI 4.2-5.4; range 0-60.9; Multimedia Appendix 3), and the Euclidian distance of households from the nearest solid waste dump or liquid waste puddle (in meters) was calculated for each of the households (median 29.4 m; 95% CI 64.2-67.9; range 1.5 m-2830.8 m). Village sectors were categorized as per the dominant socioeconomic classes of people living within them (proportion of a particular category more than 1.5 times the SOMAARTH average). The waste density and proximity variables calculated through GIS analysis were integrated with the socioeconomic data. The resultant analysis helped in characterizing the household-level condition of environmental sanitation vis-a-vis socioeconomic profile of the sectors. Table 3 presents the associations of sector-wide dominant social (caste) and economic classes with the harmful environmental indicators. Harmful environmental indicators such as higher sector waste density and household proximity (closeness) were significantly associated (P=.001) with the sector-wide dominant caste class. Waste spots were located at maximum distance from the plots or households in sectors inhabited by rich households.

Proximity (closeness) of the households to waste spots was examined using structural equation modeling [36] to explicitly describe the direct and indirect roles of various social and environmental determinants. The SES of the household was not found to be related to household proximity to waste spots either directly or indirectly after modeling for SES- and caste-dominant sectors and density of waste spots in the sector while adjusting for various household behavioral factors (household liquid and solid waste disposal practices, presence of a toilet, and source of drinking water within the households). However, the caste of the household was significantly associated with proximity to waste spots (P<.001). This effect was mediated through the SES dominance and waste density of the sector when adjusted for the previously mentioned household behavioral covariates (Figure 4). However, no significant association was found between household SES and proximity to waste spots (Table 4).

As part of another ongoing study [33], the nutrition (thinness and stunting) of a cohort of 612 children in the age group of 6-12 years was associated with the proximity of waste spots to the household, and the effects were mediated through caste dominance of the sector and religion of the household. The mediational effect was observed after adjusting for biologic factors like maternal height and sibship of the index child (Personal communication, Neha Gupta et al 2018—under publication).

Table 3. Relationship between socioeconomic class-dominated sectors (population subgroups) and environmental sanitation indicators.

Dominant[a] sector	Value, n (%)	Sector waste density[b], median	Nearest waste distance from the household[c], median (m)
Caste			
General	182 (26.9)	2.42[d]	30.9[d]
Other backward castes	236 (34.9)	2.9[d]	29.8[d]
Scheduled castes or scheduled tribes	110 (16.3)	2.6[d]	28.0[d]
Socioeconomic status			
Rich	102 (15.1)	2.3	31.5[d]
Middle	20 (3.0)	2.9	27.4[d]
Poor	113 (16.7)	2.8	30.0[d]

[a]Dominant caste and socioeconomic status: a sector having 1.5 times the average prevalence of a particular economic or social class of the whole SOMAARTH Demographic, Development, and Environmental Surveillance Site.

[b]Sector waste density: number of solid waste mounds and stagnant liquid waste puddles (both >1 m in diameter) per 100 residents of a sector.

[c]Nearest waste distance from the household location (meters): distance of the nearest solid waste dump or water puddle (both >1 m in diameter), whichever was nearer.

[d]Significant at P=.001 (Kruskal-Wallis test).

Figure 4. Structural equation model: mediational association between the caste of the household and sector-level environmental indicator, as well as social and economic dominance. SES: socioeconomic status.

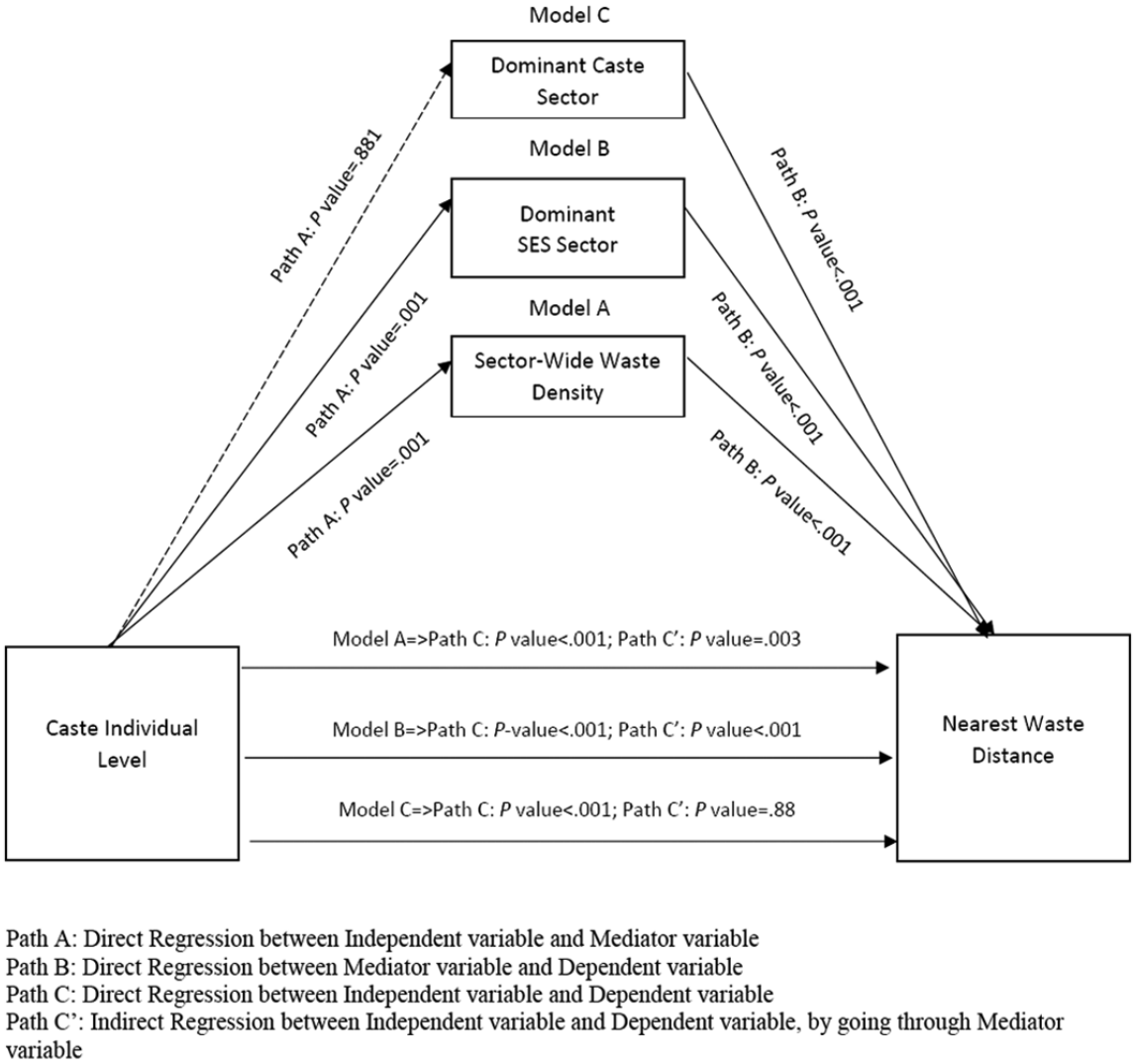


Table 4. Structural equation model: mediational association between the caste of the household and sector-level environmental indicator, as well as social and economic dominance.

Covariates	Mediator variables, *P* value		
	Sector-level waste density (Model A)	Dominant SES[a] sector (Model B)	Dominant caste sector (Model C)
Source of drinking water	Not significant	<.001	Not significant
Availability of toilet	<.001	<.001	.001
Liquid waste disposal	Not significant	Not significant	Not significant
Solid waste disposal	<.001	Not significant	.001
SES class	Not significant	Not significant	Not significant

[a]SES: socioeconomic status.

Data Construction Cost

The total cost incurred in building SOMAARTH DDESS over the span of 7 years (2009-2015) was US $810,809 (12.6% spent on building the GIS infrastructure, including baseline data; 56.8% on census data construction; 8.2% on environmental monitoring; 4.6% on developing SOMAARTH software for census data storage; 5.2% on office essentials, including travel; 3.5% on other logistics or communication; and 10% on office utilities). The total cost of constructing the geospatial infrastructure, including baseline datasets, was US $102,666 (46% spent on technical staff salary, 26% on field worker salary, 7% on purchase of satellite imagery and GIS software, and 20% on office infrastructure and travel costs).

Discussion

Principal Findings

The unique features of the SOMAARTH DDESS are its architecture and capability to capture, store, and harmonize comprehensive datasets pertaining to the built environment, land use, access, weather and air quality, food environment, education, water and sanitation (liquid and solid waste), and health care services (public and private) for studying the individual-, household-, and community-level exposures and outcomes. Baiden [7] stated that the available surveillance platforms in developing countries such as MATLAB (Bangladesh), Filabavi (Vietnam), and Rakai (Uganda) are mostly the extension of surveillance systems for specific interventions. Similarly, the available literature on the methodology for the development of geospatial datasets reflects only the development of base maps for a particular intervention [17,18,37,38]. In contrast, we have described the methodology and architecture for building a GIS-integrated, comprehensive surveillance platform that can handle diverse health, developmental, and environmental issues in a convergent manner.

The overall approach and construct of the geospatial-enabled surveillance was feasible due to collective inputs from the interdisciplinary and transdisciplinary teams. Several authors have recently called for greater collaboration between disciplines to enrich research and explain the interaction and dynamics of environment, health, and well-being of individuals and societies, particularly in low- and middle-income countries [10,13,19]. Mixed methods involving participatory mapping, satellite imagery, and quantitative survey were adopted for capturing the accurate context and detailed composition of the study area. Participatory mapping can be achieved through several methods [28,37,38]. In our case, participatory mapping was achieved by utilizing the base maps (framework map) for overcoming the limitations of asymmetry (cartographic inaccuracies) and lack of reusability arising from hands-on mapping [28,30]. High-resolution satellite data along with community inputs helped in the identification of 4 new villages that were not present in official administrative records. Government records pertaining to fine administrative boundaries (village, hamlets, land parcels) are not regularly updated [19,35] and provide only aggregated data for revenue villages in developing countries. The community involvement provided insight into the local knowledge system, cultural practices, traditions, and customs [28], which were reflected in the organization of habitations and adjoining physical environment, identification of marginalized unnotified population groups, and access to traditional and cultural resources as well as community nomenclature, for example, *chaupal* (public places), *johad* (pond), *kos minar* (historical landmark), and *phirni* (ring road around the village).

Geospatial features were manually extracted from the pan-sharpened, high-resolution Quick bird satellite imagery. Makanga's [38] research showed that manual digitization is the most effective and a cheaper way for health GIS data constructions at low-resource settings. For simplifying the task of mapping in morphologically complex villages, we adopted principles of spatial generalization [39] for the delineation of land parcels and village boundaries. Unlike the urban areas, the process of geocoding could not be applied in most of the rural areas of developing countries as postal codes for properties were not available [40].

The systematic methodology adopted for subdividing the villages into sectors on the lines of urban areas helped in building a system for georeferenced UIDs as well as in identifying socially homogenous community clusters (418/676, 61.8%, sectors) within the villages (Table 3). The computed physical exposure to harmful environment (proximity to waste spots) was significantly associated with the caste of the household, a social class indicator within the villages; the effect was mediated through SES dominance and waste spot density of the sector. Household behavioral factors like the source of water, presence of a toilet, and waste disposal practices were directly affecting these relationships. (see Table 4). These environmental factors, in turn, had the potential to influence the health and nutrition of the household members [41]. The INCLEN SOMAARTH surveillance platform was being used to prospectively assess the health outcomes of the national flagship intervention program "Clean-India (Swatch Bharat)" [42]. Projects implemented at the SOMAARTH DDESS have the potential to harness granular data related to diverse aspects of demography, development, and environment. Multimedia Appendix 4 shows coarse-resolution administrative maps of the surveillance villages that were the only spatial data available with the government. The top left and right maps are fine-resolution sector map and built-up area map, respectively, of surveillance villages that helped characterize land use; the middle one shows liquid and solid waste spots mapping that was overlaid on the land use map, and the bottom one depicts the location of food stores and their distance from the water-stagnant areas.

The community- and household-level exposure details could, therefore, be used to explain and quantify diverse societal determinants of health; profiling of sociocultural and economic status of sectors within villages also opened up opportunities for designing and implementation of complex intervention studies incorporating social determinants [14-16].

Several studies have highlighted the possibilities of generating erroneous geospatial data and exposure misclassification due to the nonavailability of valid and quality administrative data and the absence of thorough ground-truthing exercises [43-45]. The settlement pattern was highly compact across the site (see Table 2); 80.79% (37,979/47,007) of the total built structures were concentrated in 8.94% (2127 hectare/23788.7 hectare) of the total area, which was consistent with previous observations from developing countries [46]. Also, the empirical datasets reflected rapid expansion of built-up area in adjoining agricultural belts. Ground-truthing exercises were, therefore, kept as an integral step in the methodology for addressing the potential positional, attribute (location, size, and shape), and temporal discrepancies [43,44]. The first round of geospatial data verification revealed that 88.50 % (41,601/47,007) of the total land parcels were accurately marked for their location, but only 64.5% (30,320/47,007) of the land parcels were correctly

mapped in terms of their relative size and shape. We faced the additional challenge of nonavailability of physical demarcation in almost one-third (27.0%, 12,692/47,007) of the land parcels. The physical demarcation of land parcels affected image interpretation and, thus, the quality of land parcel data. Ground-truthing of the land parcel data in rural settings of countries like India shall, therefore, remain an essential step for finalizing spatial datasets [43]. However, as reported earlier, the use of satellite imagery resulted in high degrees (>95%) of positional accuracies for features such as water bodies and roads [45].

A licensed proprietary software Arc GIS 10.3 (ESRI, Redland, CA, USA) along with the open source (QGIS) software was used to expedite the digitization of large volumes of geospatial data without adding burden on limited financial resources. Similar strategy for cost minimization was also tried at other resource-constrained settings [47]. Although we could not perform any direct comparison for cost incurred in developing similar surveillance platforms in other low- and middle-income countries, investments in SOMAARTH-like comprehensive platforms are likely to be far more useful than establishing categorical surveillance systems criticized for their limited capacities and sustainability [2].

We identified three major challenges in building fine-resolution geospatial datasets for a surveillance system in a scientific manner in resource-constrained settings. First, administrative health datasets were not available, and varied spatial data frames were followed at different data sources; therefore, the high-resolution vectors prepared through satellite imagery could not be properly integrated with the administrative datasets. Due to such problems, the recent report from National Institute of Advanced Studies [48] has advocated the initiation of a unified spatial framework under National GIS in the country; geocoding is not possible in these areas due to the lack of an address system in rural areas. Second, due to the compact nature of the settlement in our villages, we faced difficulty in using Global Positioning System (GPS) [17,21]. In the absence of GPS coordinates, characterization of satellite imagery was a challenging task. Third, there was a shortage of skilled personnel for long-term work engagements in rural areas [19,20]. Although a period of 5 years was required to set up SOMAARTH DDESS, we believe that based on the learnings, subsequent endeavors can be accomplished in much shorter periods using Web GIS and advanced GPS recorders.

Way Forward

The granular data generated through the SOMAARTH surveillance platform could be harnessed in designing complex research studies taking into account social determinants of diseases and health; furthermore, environmental and behavioral interventions could be targeted at subvillage and household levels [49-52], which are presently constrained due to data unavailability. The land use datasets could also be harmonized with the available international GIS-integrated surveillance sites [53] to promote multicentric spatial epidemiological studies.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

SOMAARTH website—www.sommarth.org.

[PNG File, 225KB - publichealth_v4i4e66_app1.png]

Multimedia Appendix 2

Architecture of the SOMAARTH Demographic, Development, and Environmental Surveillance Site.

[PNG File, 548KB - publichealth_v4i4e66_app2.png]

Multimedia Appendix 3

Supplementary file; profile of villages at SOMAARTH DDESS, Palwal, India.

[PDF File (Adobe PDF File), 153KB - publichealth_v4i4e66_app3.pdf]

Multimedia Appendix 4

Detailed context and composition stored in the SOMAARTH Demographic, Development, and Environmental Surveillance Site geospatial data layers.

[PNG File, 119KB - publichealth_v4i4e66_app4.png]

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Abbreviations

DDESS: Demographic, Development, and Environmental Surveillance Site
GIS: geographic information system
GPS: Global Positioning System
INCLEN: The International Clinical Epidemiology Network
NNI: Nearest Neighbor Index
$PM_{2.5}$: particulate matter 2.5
SES: socioeconomic status
UID: unique identification

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Original Paper

Issues in Building a Nursing Home Syndromic Surveillance System with Textmining: Longitudinal Observational Study

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Abstract

Background: New nursing homes (NH) data warehouses fed from residents' medical records allow monitoring the health of elderly population on a daily basis. Elsewhere, syndromic surveillance has already shown that professional data can be used for public health (PH) surveillance but not during a long-term follow-up of the same cohort.

Objective: This study aimed to build and assess a national ecological NH PH surveillance system (SS).

Methods: Using a national network of 126 NH, we built a residents' cohort, extracted medical and personal data from their electronic health records, and transmitted them through the internet to a national server almost in real time. After recording sociodemographic, autonomic and syndromic information, a set of 26 syndromes was defined using pattern matching with the standard query language-LIKE operator and a Delphi-like technique, between November 2010 and June 2016. We used early aberration reporting system (EARS) and Bayes surveillance algorithms of the R surveillance package (Höhle) to assess our influenza and acute gastroenteritis (AGE) syndromic data against the Sentinelles network data, French epidemics gold standard, following Centers for Disease Control and Prevention surveillance system assessment guidelines.

Results: By extracting all sociodemographic residents' data, a cohort of 41,061 senior citizens was built. EARS_C3 algorithm on NH influenza and AGE syndromic data gave sensitivities of 0.482 and 0.539 and specificities of 0.844 and 0.952, respectively, over a 6-year period, forecasting the last influenza outbreak by catching early flu signals. In addition, assessment of influenza and AGE syndromic data quality showed precisions of 0.98 and 0.96 during last season epidemic weeks' peaks (weeks 03-2017 and 01-2017) and precisions of 0.95 and 0.92 during last summer epidemic weeks' low (week 33-2016).

Conclusions: This study confirmed that using syndromic information gives a good opportunity to develop a genuine French national PH SS dedicated to senior citizens. Access to senior citizens' free-text validated health data on influenza and AGE responds to a PH issue for the surveillance of this fragile population. This database will also make possible new ecological research on other subjects that will improve prevention, care, and rapid response when facing health threats.

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KEYWORDS

Centers for Disease Control and Prevention; nursing homes; syndromic surveillance; pattern recognition; Delphi technique; sentinel surveillance

Introduction

Background

Population in developed countries is aging [1], and the French population follows this trend. In France, by 2050, 22.3 million people will be aged over 65 years compared with 12.6 million in 2005, an increase of 80% in 45 years. Between 2013 and 2050, the senior population will grow more than the population as a whole. Similarly, life expectancy at birth in France, one of the highest in the world, is projected to surpass 86 years for men and 90 for women [2].

This increase will then have to be anticipated and will affect care and related costs [3]. It is, therefore, essential to improve our knowledge of this senescence process to help prevent increase in pathologies, and improve quality of life at extreme ages.

In spite of this major expected evolution of population, ecological research on this aged population is still limited [4]. Case or ad hoc studies do not consider individual variability and cannot analyze health issues as a whole. Data then need to be recorded for quite a long time and on a daily basis, helping to address this lack of knowledge. This has to be done in a natural way, in a professional environment with caregivers and medical staff [5].

As until now, follow-up studies on senior citizens were conducted using cohorts that were costly to set up and follow [6-8]. Data are occasionally stored, even if the follow-up is long and based on auto-questionnaires or planned interviews with health professionals. This approach does not allow describing in detail the daily life of this population and storing health evolutions throughout the residents' whole stays.

New Data

On the contrary, nursing homes (NH) offer this possibility of tracking and recording them daily as health professionals feed these information for their proper use and, this time, without any memory bias [9]. These new data as well as their uses suggest innovative approaches to improve health knowledge.

Korian (Paris, France) as the first private NH European group has these kinds of data. This enterprise holds 290 NH and approximately 3.92% (290/7394) [10] of the French NH network, distributed all over the country, mostly in urban areas (see Multimedia Appendix 1). A professional data warehouse (DWH) set up in 2010 hosts half the company's French residents' population data. Their health follow-ups are recorded daily from 126 NH. For every new resident admitted in one of the NH, a personal electronic resident medical file (PERMF) is set up. Data are then collected at various times: at admission (admission date, medical history, marital status, birth date, tastes, and habits), on a daily basis (new pathologies, chronic disease evolution, date of death, and drug prescriptions), or just after specific medical or health care professional visits. Items include diagnosis, outcomes, as well as sociodemographic information.

Objectives

Elsewhere and a little earlier, during the early 2000s, surveillance systems (SS) [11-19] showed that professional data could also be used for health and alert surveillance [20-26]. Here, professional data use for SS was only done using point data analysis (going to the emergency, 911, and Web queries) [19,25,26] and not during a long-term follow-up of the same people, and even more, not dedicated to senior citizens.

As we have just seen, data gathered by different NH professionals offer the opportunity of following the residents' situations on the flow and on a daily basis and, through this process, of building syndromic surveillance data. The objective of this study was to build and assess an influenza and acute gastroenteritis national ecological NH public health (PH) SS describing and validating the Base du Bien Vieillir (BBV), that is, Aging Well database architecture. Thus, through a new health data building paradigm, we engineered an NH syndromic surveillance system (SSS) based on already validated criteria [11,13], hopefully opening the way to new research and knowledge about the senescence process.

Methods

Data Collection

All data are transmitted from 126 NH in real time to a national server using the group intranet. Records collected from the PERMF server are anonymized (see Multimedia Appendix 2) when sent to the BBV server, keeping track of every resident even when moving from one NH to another. After this first step, BBV is built through an extract, transform, and load (ETL) process of health and sociodemographic data. (see Multimedia Appendix 3 for details). Following this second step, all residents have two types of data:

1. Gender, age, and GIR (Groupe ISO Ressources; english: Group International Standardization Organization Resource Group), a French autonomy-level rating indexed to government benefits [27-32] at the NH entry
2. Daily care information fed on the flow by the caregivers and the medical staff, whenever deemed useful, that is, their syndromic information and, finally, hospitalizations and death

At the same time, every Sunday, all residents' daily care information is aggregated to count the weekly number of syndromes per NH.

By extracting data for all residents of the PERMRF database from its inception, from November 1, 2010, to mid-February 2017, and adding every new resident entering one of the NH networks every week, a *one-week moving* cohort of residents followed during their entire NH life course was built opening the way for our SSS. Even if most residents of this cohort were followed during their entire NH life course, syndromic data could be left-truncated for people whose data were entered before the inception of the information system (IS) or right-truncated for people whose data were entered later.

At the IS core, the data transmissions table containing key information about the residents' care was fed on a daily basis. Data take the form of big size character fields (of up to 4000 characters). Extracting these and using residents and NHs' indexes and data transmissions dates (see Multimedia Appendix

3 for a complete example), we were able to track all residents through two dimensions. Over time—every day with syndromic data—and space—every NH with syndromic data—with queries and text mining, building their syndromic life course, beginning at their date of entry and ending with their last available data transmission or death. The BBV then has two nested time frames: by day for every resident and by week for every NH.

Ethics Approval and Consent to Participate

The use of this database in the frame of epidemiological studies has been authorized by the French National Commission for Data protection and Liberties. The Institut du Bien Vieillir, which became the Foundation Korian of Well Ageing, filed a declaration of conformity to a baseline methodology, which received an agreement number in March 2017: 2.041.050, in accordance with the Act n 78–17 of January 6, 1978 on Data Processing, Data Files, and Individual Liberties. All residents are informed at their NH entry about their electronic health record (EHR) and their right to oppose its use. Although the primary purpose of this medical research was to generate new knowledge, this goal did not take precedence over the rights and interests of the NH residents. All the new generated information was extracted from already existing data and was deidentified and anonymized when necessary to protect their health and rights.

Building the Acute Respiratory Infection and Influenza-Like Illness and Acute Gastroenteritis Syndromes

With a multistep learning and text mining (MSL-TM) process (see Multimedia Appendix 3 for the 4-phase process) of the data transmissions file similar to what was experimented in the study by Cohen at al [33], using problems' list logic [34-36] and pattern matching with the SQL-like operator [37], 24 syndromes were implemented [38-49], following the SurSaUD (Sanitary Surveillance of Urgencies and Deaths) SSS method [16]. Starting with acute respiratory infection and influenza-like illness (ARI-ILI) and acute gastroenteritis (AGE) syndromes (see Multimedia Appendix 3 for 2 examples and the syndromes' list), extracting directly hospitalizations and deaths, this NH IS kept for every resident, every day, in every NH, from none to 26 daily syndromes whenever appropriate (see Multimedia Appendix 3 again for full details of the whole process [50-61]).

The Surveillance Tools Framework

Syndromic Systems attempt to detect outbreaks through statistical analysis of aggregated cases data to improve on competent clinicians in detecting early-stage or small outbreaks [62]. It focuses on data collected before clinical diagnosis or laboratory confirmation [63]. Statistical laws are then defined to give an answer to the question "knowing the average number of expected events during a period of time, what is the probability to observe the current situation?" [62].

The SSS generation was designed using a *Pentaho* extraction platform for all the ETL processes [64] and is described in Figure 1. It follows the Centers for Disease Control and Prevention (CDC) Working Group recommendations [11,13].

The whole process was done in 4 steps: first, the ILI and AGE syndromes built through the MSL-TM process [65]; second, the weekly ILI and AGE syndromic data aggregation and the time series (TS) generation with their statistical alerts using the R *surveillance* package [66,67]; third, the Sentinelles data joining, the ARI-ILI and AGE French surveillance gold standard [68]; and finally, the alerting system interfacing the *surveillance* package [66,67] statistical alerts with the NH general practitioners (GPs) coordinators signals, eventually reporting to the Health Regional Agencies (HRA).

It is only after the final step that epidemiologists in the national public health agency's regional units (HRA in Figure 1) are asked to choose an alert level for the regions they are in charge of: non-epidemic, pre/post epidemic, or epidemic [68]. A public health alert will then be defined as such by the public health agency Santé publique France (SPF) after every signal has been verified and validated [69] (for further details, see Multimedia Appendix 4 [22,67-76]). Relevant information for French epidemiologists since January 2016 at a regional level includes the Sentinelles (2.1% of French private GP) as well as the OSCOUR (Organization of the COordinated Surveillance of Urgencies; 88% of French hospital emergency departments make up the Coordinated Health Surveillance of Emergency Department network) and SurSaUD (95% of French emergency GP consultations) data but also local specific surveillance data such as NH ARI clusters' surveillance.

Syndromic Data Analysis

Data Flow Buildup and Stabilization

As explained above, we computed weekly counts of ILI and AGE cases as well as hospitalizations and deaths as with *Sentinelles*, avoiding week and weekend days' heterogeneity [77]. Then, with the *ggplot* function of the *ggplot2* R package [78] used with local regression curves fitted to the NH data (Figure 2) [79], we were able to track yearly tendencies as well as inconsistent data not reflecting the seasonal spikes during winter.

Assessing the syndromic data flow over time, by computing the summary statistics of deaths, hospitalizations, ARI-ILI and AGE weekly syndromes' counts during the 3 periods (ie, from November 1, 2010, to November 1, 2011; then from November 1, 2011, to November 1, 2012; and finally from November 1, 2010, to February 26, 2017), we chose to exclude the first year's data from this analysis (see Table 1).

Figure 1. The nursing homes acute respiratory infections and influenza-like illness and acute gastroenteritis surveillance tools framework. BBV: Base du Bien Vieillir (ageing well database); ILI: influenza-like Illness; AGE: acute gastroenteritis; MSL: multi-step learning; TM: text mining; TS: time series; GP: general practioner; HRA: Health Regional Agencies.

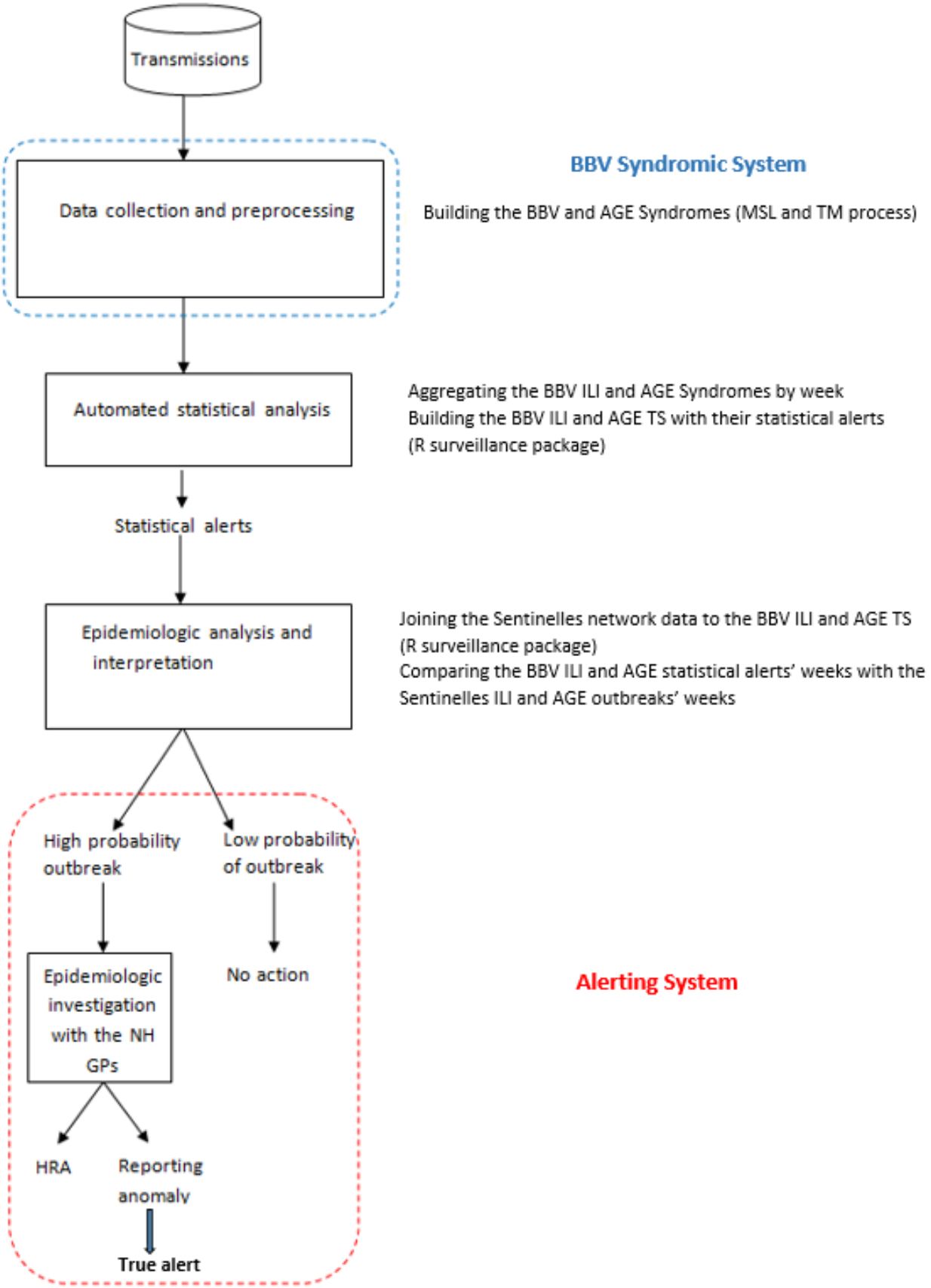

Figure 2. Acute gastroenteritis, acute respiratory infections, deaths and hospitalizations data flow buildup and stabilization in 11 regions covering France between November 1, 2010, and February 26, 2017. AGE-DIAR: acute gastroenteritis and diarrhea; ARI-ILI: acute respiratory infection and influenza-like illness.

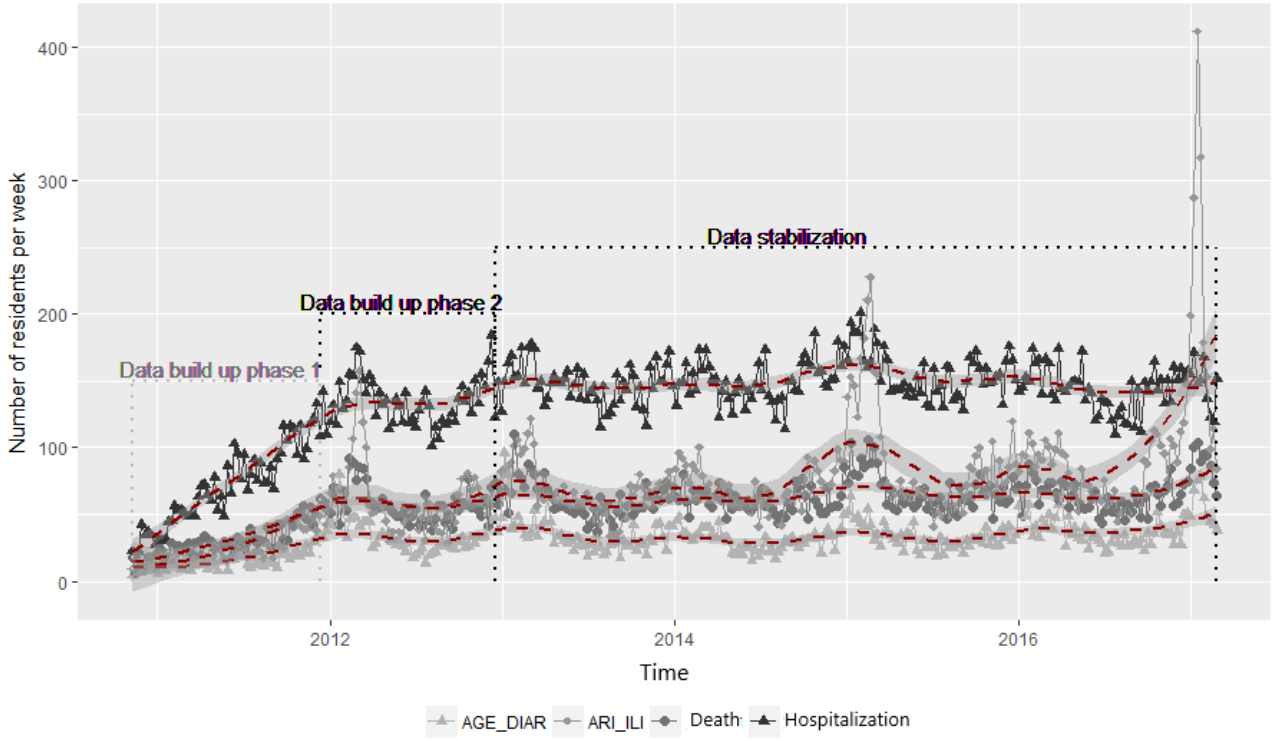

Table 1. Assessing the Base du Bien Vieillir (BBV) four syndrome's weekly counts.

Period	Minimum	Q1	Median	Mean	Q3	Maximum
Phase 1	4	16	24.5	33.45	42.25	118
Phase 2	13	40.5	55	70.92	109.25	184
Stabilization	15	48	67	82.72	124	412

Building the Acute Respiratory Infection and Influenza-Like Illness and Acute Gastroenteritis Time Series

The ARI-ILI and AGE TS were built by aggregating all NH weekly syndromes counts. The choice of a statistical method to analyze these then rested on definitions of statistical alerts, adapting the BBV SSS data to fit French public health infrastructure and available SS data sources [80], here data of the ARI-ILI and AGE Sentinelles network [22]. Although the Sentinelles network used the Serfling method [70,71] relying on disease incidence levels of preceding years, we used the CDC steady favorite, the CUSUM (cumulative sums) methods, not drawing on data from preceding years but just from preceding weeks and 1 recent method, the Bayes method allowing fine tuning [72]. For further details, see Multimedia Appendix 4.

Quality-Precision

Following the process described in the Building the Acute Respiratory Infection and Influenza-Like Illness and Acute Gastroenteritis Time Series subsection, the whole procedure was reviewed over 3 weeks of data transmissions: one in mid-August 2016 when there was no epidemic and two in January 2017 at the ILI and AGE epidemics weeks' peaks, respectively, according to the Sentinelles network [81], computing the percentage of miscoded ARI-ILI and AGE syndromes among the extracted data transmissions defined as such [26].

Stability

The idea here was to check the syndromic flow stability in quantity (the syndromes counts) and quality (several different recurring syndromes) during the complete period and for all 126 NH, computing the weekly syndromes frequencies for every NH.

The syndromic data flow stability was traced by designing 3 chronic diseases and 1 often-chronic ailment indexes [82] built as follows: whenever a resident had diabetes or a cardiovascular problem or depression or fell, the resident's transmission date and syndromic event type were set apart. Then, a similar event during a 200-day period after this resident's syndromic event was searched for, defining 4 syndromic ratios for the 6 years from the year 2011 up to February 27, 2017. For further details, see Multimedia Appendix 5.

Flexibility-Timeliness-Representativeness-Usefulness

Adaptability and reactiveness of the system were evaluated during the outbreak and routine periods according to the CDC surveillance systems guidelines [18,15,26]. Representativeness, completeness, and usefulness were assessed using the distribution description of ILI cases by time and origin during this last flu season, as well as by rating sex, age, and GIR at entry and age at illness missing data [13].

Surveillance Algorithms' Quality

All surveillance methods involve building first, time series with the weekly number of cases and second, statistical indicators used as thresholds. Here the 4 algorithms were compared by using the *algo.quality* function for Bayes [72] and rebuilding it for the early aberration reporting system (EARS) algorithms. This quality is defined by 4 numbers—the number of true positive (TP), false positive (FP), true negative (TN), false negative (FN)—and 4 criteria—the *sensitivity* [83] sometimes called recall [84] as the ratio of epidemic weeks correctly identified; the *specificity*, as the ratio of nonepidemic weeks correctly identified; the Euclidean distance between the perfect method with *specificity=sensitivity=1* and ours $(distance=((1-specificity)^2+(sensitivity-1)^2))^{1/2}$; and finally, the *precision* or *positive predictive value* (PPV), as the ratio of epidemic weeks correctly identified among the weeks defined as epidemic (with statistical alarm) [13].

Results

The Cohort

As explained in the Data Collection subsection, by extracting all residents already there on November 1, 2010, and then by adding those entered every week in one of the 126 NH, a cohort of 41,061 residents (Figure 2) was built with 12,983 men (31.61%, 12,983/41,061) of mean age 84.33 years and 28,083 women (68.39 % 28,083/41,061) of mean age 85.82 years.

The Acute Respiratory Infection and Influenza-Like Illness and Acute Gastroenteritis Syndromes and the Surveillance Inside Korian

As described in Building the Acute Respiratory Infection and Influenza-Like Illness and Acute Gastroenteritis Syndromes subsection, the BBV syndromic algorithm extracted all ARI-ILI and AGE cases in addition to hospitalizations and deaths, every week, from November 1, 2010, to mid-February 2017 and built the 4 TS. Using the BBV ARI-ILI and AGE syndromic TS, we were able to track the last flu season (winter 2016-2017) early on, even before the epidemic and compare our syndromic counts with the Korian GPs' number of cases. The first ones were usually much greater than the second ones, as several syndromic cases could identify the same resident over time, but both of them were always strongly correlated.

Syndromic Data Analysis

Checking the Data Flow During Time

We managed to highlight 3 different phases in the NH data flow as shown in Figure 2 and Table 1 with two buildup phases during the first 2 years of the IS implementation. As seen below, between the first and the second year, the median and mean weekly syndromes' counts more than doubled. For that reason, we excluded the data of the first year from the syndromic data analysis.

The Acute Respiratory Infection and Influenza-Like Illness and Acute Gastroenteritis Time Series

In the *surveillance* package, both Bayes' (see Figures 3 and 4) and EARS_C3s' algorithms with alpha=.025 (see Figures 5 and 6) used the 12 former ARI_ILI (Figures 3 and 5) and AGE (Figures 4 and 6) NH weeks' counts to define *alarm weeks* (red triangles). *Outbreak weeks* (green vertical lines) were defined according to the ILI and AGE Sentinelles data during the same period (from January 1, 2011, to January 16, 2011). Finally, the blue dotted lines were the upper limits at which alarms were triggered with both algorithms.

Senior citizens suffer much more of either ARI-ILI or AGE than the general population all year long and even in summer. This often results mechanically in triggering statistical alerts long before the general population epidemics. It can be seen in Figures 3 and 5 for ARI_ILI and Figures 4 and 6 for AGE where the red triangles (the SSS alarm weeks) appear always before the green bars (the Sentinelles' network outbreak weeks). It is especially true for ARI-ILI during the 2013 to 2014 and 2015 to 2016 winters and for AGE during the 2013 to 2014 winter with both algorithms.

Quality-Precision

To compute the percentage of miscoded ARI-*ILI* and *AGE* syndromes, all ARI-ILI and AGE syndromic data were extracted during 3 weeks: one in mid-August 2016, the 33rd week (third column) when there was neither flu nor AGE epidemic, and two in January 2017, the third and first weeks, at the ILI and AGE epidemics weeks' peaks, according to the Sentinelles network (second column). Then, each ILI and AGE syndromic data transmission was examined, rating it as correct, adding to TP, or incorrect, adding to FP (see Table 2).

The precision was best during epidemic weeks' peaks: 98% and 96%, respectively, as ILI and AGE versus 95% and 92% in summer, and there were very little FP. For example, for ILI FP, " his son has flu," "emergencies overloaded with flu cases," "no flu symptoms," "could they take care of my girl who has flu?", and finally, "serrure dégrippée," which means *unjammed* in French but has the same word stem "gripp" as flu, were excluded. We had already excluded the word " grippé" in this context, which means *jammed* for a lock. In addition, by checking the flu cases, we found 67 flu tests mentions using nasal swabs, adding 21% new cases. For AGE FP, "vomited without diarrhea" (2 times, as both words are needed to classify as an AGE syndrome) and "diarrhea protocol if fever" were excluded.

Figure 3. The influenza-like illness (ILI) Base du Bien Vieillir time series (TS) using the Bayes' alarm algorithm with 12 weeks upstream and the ILI Sentinelles outbreaks. NH: nursing homes. Green ellipses highlight a nice overlapping of alarm and Sentinelles' network weeks or when the algorithm seems better, whereas red ellipses when this is not the case.

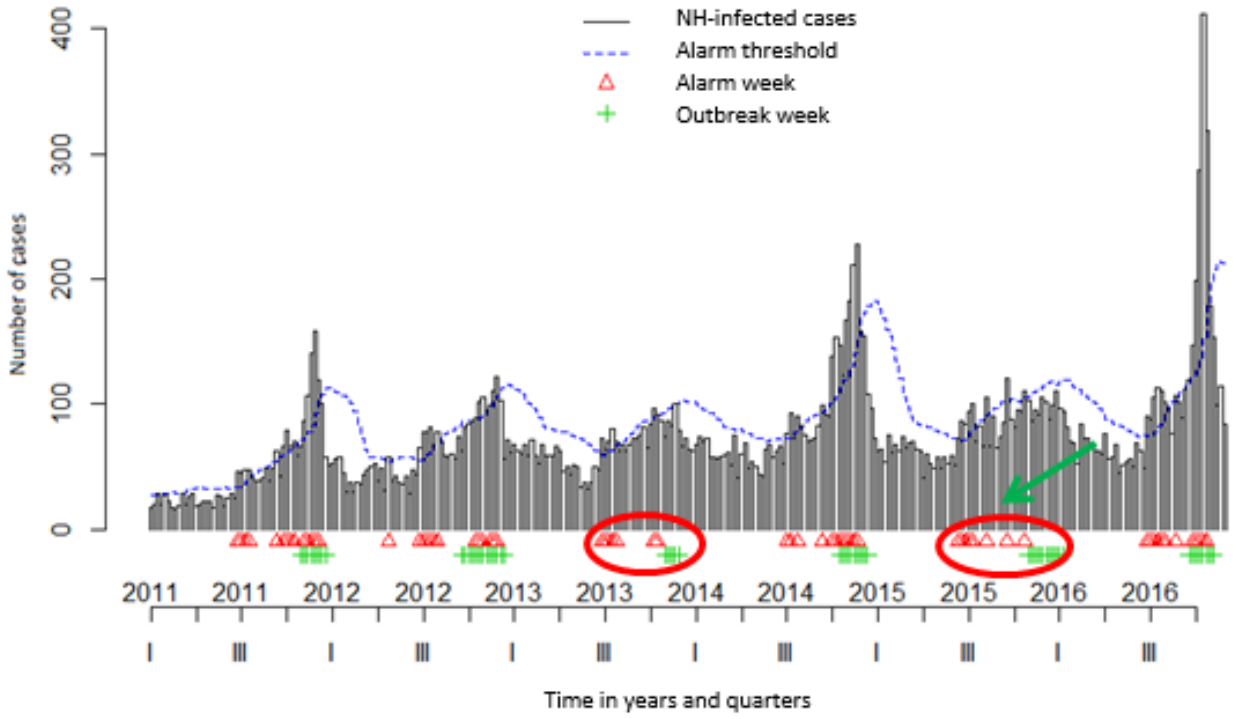

Figure 4. The acute gastroenteritis (AGE) Base du Bien Vieillir (BBV) time series using the Bayes' alarm algorithm with 12 weeks upstream and the AGE Sentinelles outbreaks. NH: nursing homes. Green ellipses highlight a nice overlapping of alarm and Sentinelles' network weeks or when the algorithm seems better, whereas red ellipses when this is not the case.

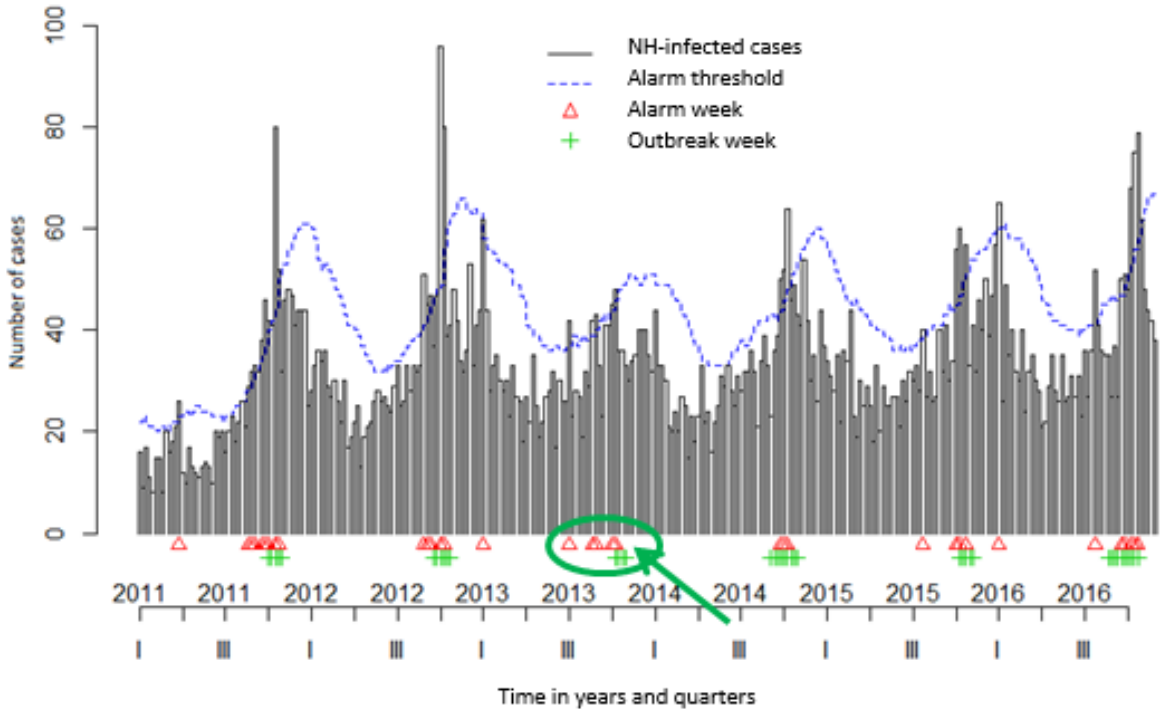

Figure 5. The influenza-like illness (ILI) Base du Bien Vieillir (BBV) time series using the EARS_C3's alarm algorithm with 12 weeks upstream and the ILI Sentinelles outbreaks. NH: nursing homes. Green ellipses highlight a nice overlapping of alarm and Sentinelles' network weeks or when the algorithm seems better, whereas red ellipses when this is not the case.

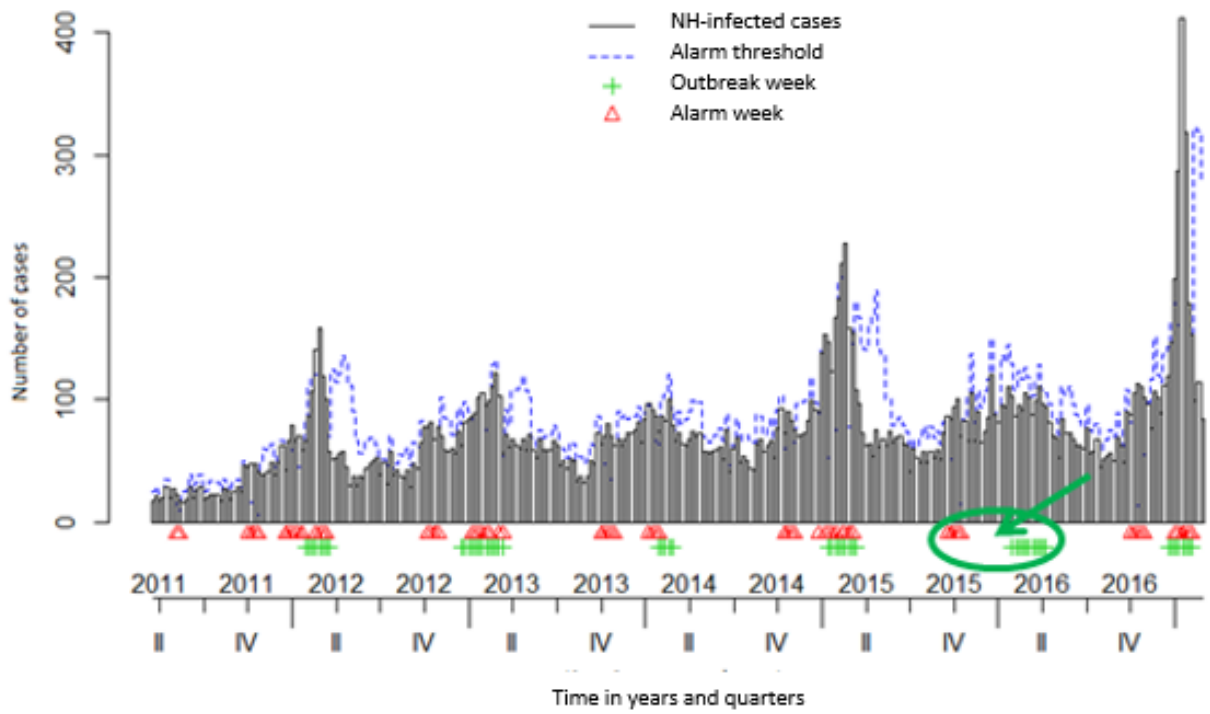

Figure 6. The acute gastroenteritis (AGE) Base du Bien Vieillir (BBV) time series using the EARS_C3's alarm algorithm with 12 weeks upstream and the AGE Sentinelles outbreaks. NH: nursing homes. Green ellipses highlight a nice overlapping of alarm and Sentinelles' network weeks or when the algorithm seems better, whereas red ellipses when this is not the case.

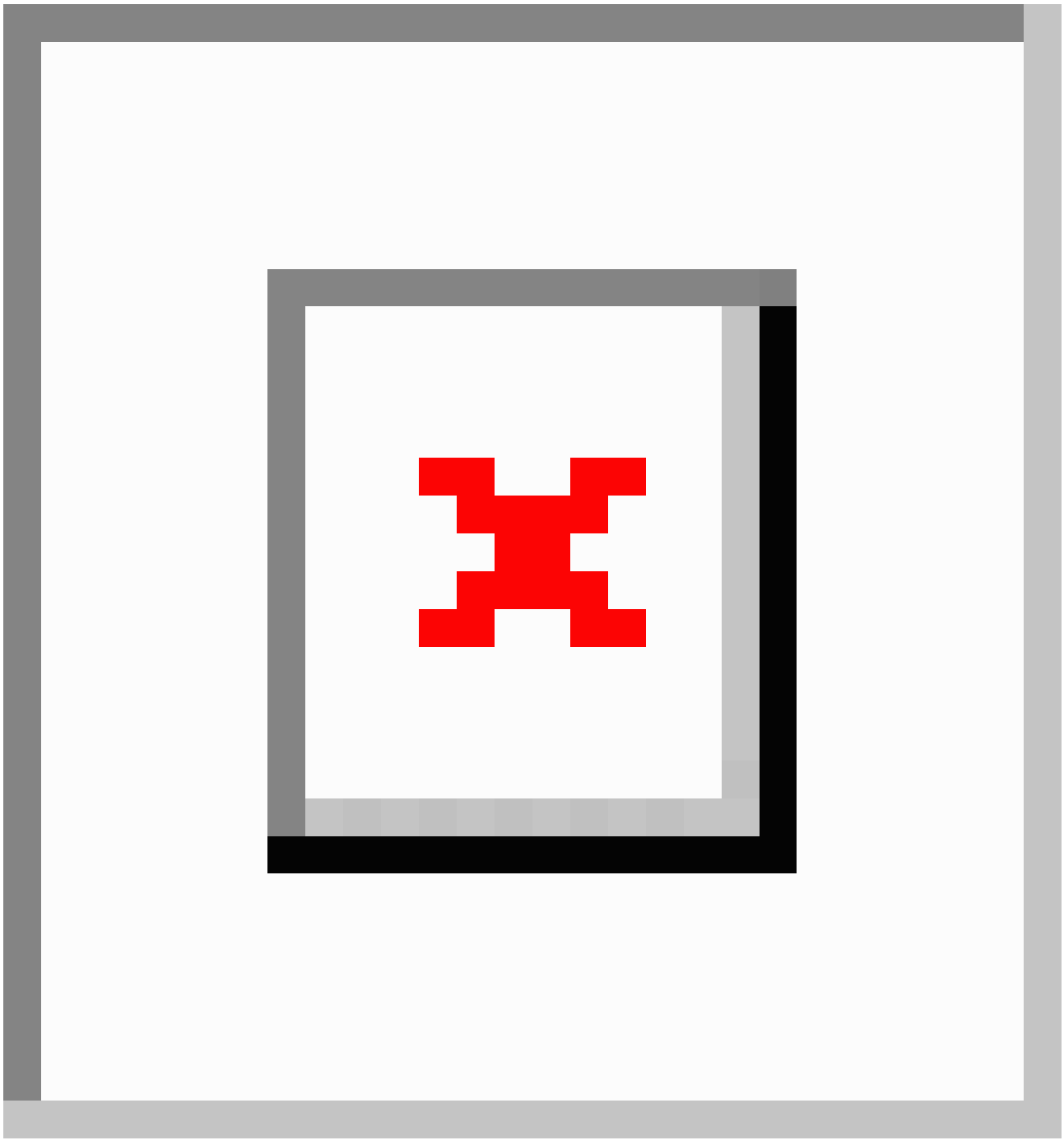

Table 2. Assessing Base du Bien Vieillir (BBV) influenza-like illness (ILI) and acute gastroenteritis (AGE) syndromes data transmissions precision during 3 periods: last summer (2016: 33rd week), the Last ILI (2017: 3rd week) and (2017: first week) epidemics weeks' peaks.

Disease	Epidemic period	Week of study	Residents with syndromes, n	Residents with syndromes x transmission days, n	Residents with influenza-like illness or acute gastroenteritis, n	False positive	True positive	Precision[a] or positive predictive value
ILI	No	sem33-2016	5399	10,631	56	3	53	0.95
AGE	No	sem33-2016	5399	10,631	26	2	24	0.92
ILI	Yes	sem03-2017	6013	12,215	318	5	313	0.98
AGE	Yes	sem01-2017	5862	11,933	68	3	65	0.96

[a]Precision=TP/(TP+FP).

Stability

As detailed in this section, the data transmission stability was evaluated by studying the weekly syndromes' frequencies for every NH from November 1, 2010, as well as the ratio of weeks with syndromic data transmissions:

1. The weekly 26 syndromes frequencies averaged over the number of NH (126) ranged from 21.45 to 180.57 (mean=88.5, SD=22.8).
2. The ratio of weeks of data transmissions per NH was built by computing the number of data transmissions weeks versus the data transmissions weeks span and ranged from 89% to 100% (mean=100%, SD=1%). Only 1 NH had a ratio of less than 95%.

Finally, the syndromic data flow over time studied with 3 chronic illnesses and falls syndromes distributions showed great stability (see Multimedia Appendix 5 for further details).

Flexibility-Timeliness-Representativeness-Usefulness

Table 2 showed the flexibility and reactiveness of our syndromic system during epidemic periods, following at the same time the increasing number of cases, going from a weekly population of 5399 to 6015 without losing any precision, from 95% to 98%. As shown this winter, by using the NH indexes and regions, the flu epidemic was followed geographically, week after week, starting from the beginning, detecting where the epidemic was most intense, tracking the most severe cases and related hospitalizations and deaths.

Great geographic heterogeneity was detected between regions in terms of ratios of infected; the Rhone valley (Rhone Alpes) and south (Sud) being the most afflicted with 24% and 19% and the southeast (Sud-Est) being the least afflicted with only 9%. There was also great variability in terms of population characteristics, for example, those from the southwest were the oldest afflicted at a mean age of 89.7 years, whereas the southern residents were the youngest at 87.6 years, 2 years and a month difference being quite a lot given the mean duration of residents' stay. Finally, among 1800 residents with a flu transmission, only 1 had no personal data.

Surveillance Algorithms' Quality

The 3 surveillance package EARS's algorithms as well as Bayes' algorithm were compared for both diseases. For every algorithm, the CI level defines the threshold used to trigger statistical alarms. We used a CI level of 0.001 for EARS_C*i*, *i=1, 2, 3* and also a CI level of 0.025 for EARS_C3 and Bayes' algorithms. 0.001 is the EARS_C3 default level, whereas 0.025 is the Bayes' algorithm default level (see the algorithm quality in Table 3). The EARS_C3 with alpha=0.025 gave the best results for both diseases (in italics in Table 3). Nevertheless, the Bayes' algorithm seemed better to define alarm weeks when epidemics were less intense as for ILI 2015 to 2016 and AGE 2013 to 2014 seasons, as there were fewer lag weeks between the Bayes' alarm weeks and the Sentinelles outbreak weeks (green arrows were added in Figures 3-6 to highlight this trend).

Either with ILI or AGE TS, mostly coherence between NH data and the Sentinelles data could be witnessed. In addition, only 12 weeks of data (see Table 3) were needed to detect outbreaks, most of the time several weeks ahead of Sentinelles' outbreaks. This was especially true for the last flu season (winter 2016 to 2017 in Figures 3 and 4).

Table 3. Comparing the surveillance algorithms' quality on Base du Bien Vieillir (BBV) influenza-like illness (ILI) and acute gastroenteritis (AGE) time series with ILI and AGE Sentinelles' outbreaks detection, by using early aberration reporting system (EARS).

Disease and algorithm	Number of weeks	True positive	False positive	True negative	False negative	Sensitivity or recall	Specificity	Distance[a]	Precision[b] or positive predictive value
Influenza-like illness									
Bayes[c]	12	22	44	210	32	0.407	0.827	0.617	0.333
EARS_C1[d]	7	6	12	248	48	0.111	0.954	0.890	0.333
EARS_C2[d]	9	13	26	232	41	0.241	0.899	0.766	0.333
EARS_C3[d]	12	19	31	225	35	0.352	0.879	0.659	0.380
EARS_C3 [c]	*12*	*26*	*40*	*216*	*28*	*0.482*	*0.844*	*0.542*	*0.394*
Acute gastroenteritis									
Bayes[c]	12	16	18	251	23	0.410	0.933	0.594	0.471
EARS_C3[d]	12	16	13	258	23	0.410	0.952	0.607	0.592
EARS_C3 [c]	*12*	*21*	*26*	*245*	*18*	*0.539*	*0.904*	*0.471*	*0.447*

[a]Distance=sqrt ((1-spec)^2 + (sens-1)^2) is the Euclidean distance of (specificity, sensibility) from (1, 1).

[b]Precision=TP/ (TP+FP) is the true positives ratio among the positives.

[c]CI with alpha=.025. Italicization indicates the best results, and therefore, the best method to detect both ILI and AGE.

[d]CI with alpha=.001.

Discussion

Principal Findings

We built and assessed a national ecological NH PH SS dedicated to senior citizens. By using a national network of 126 NH and extracting all sociodemographic as well as daily medical data from EHRs, a cohort of 41,061 residents was built. Through textual analysis of clinical narratives (CNs), we implemented ARI_ILI and AGE syndromes. We also engineered related TS by computing weekly head counts. Alarms with EARS_C3 and Bayes algorithms on these, over a 6-year period, allowed us to forecast the 2016 to 2017 influenza outbreak by more than 2 weeks; as can be seen in Figure 5, our statistical alarms were triggered in December, whereas the influenza epidemic according to SPF started only in January.

With just 4 tables, this IS of a new kind showed that it is possible to follow almost every resident every day, where he or she is, during his or her entire NH life, hopefully selecting most of his or her ARI-ILI and AGE health events, from NH entry until death or exit. Furthermore, each relevant syndrome is defined by 2 syndromic representations: either a simple additive syndromic image, that is, its 4 Boolean [65] syndromic components allowing whatever filtering, or its literal expression for further textual analysis or in-depth health questioning. By this whole process, free textual information extracted from CN was shaped into numerical data for further statistical or machine learning analysis.

In this study, we engineered a real NH SSS on qualitative data, offering immediate accessibility without adding any extra work to medical staff [11]. By using SQL-like pattern matching [37] and Delphi-like experts' consensus [57,58] on the data transmissions file, we followed last season ARI-ILI and AGE epidemics and found almost in real time that the flu dramatically reached NH residents, tracking them geographically and timely, searching for flu-related hospitalizations and deaths. Preventing disruptions of medical tasks and medical and paramedical staff turnover by predicting even 1 or 2 weeks ahead, the epidemic intensity could greatly improve the NH human resources management over time and help to prevent sanitary disasters by strengthening hygiene measures, for example.

As explained in [12], early detection of outbreaks can be achieved in 3 ways: first, by prompt recognition and reporting of disease case reports. Here, we could find most of flu and AGE cases by syndromic descriptions fed in the data transmissions table. Second, by improving the ability to recognize patterns indicative of a possible outbreak early in its course, using analytic tools, counting syndromes by NH, and building time series with the surveillance package. Third, by exploiting data that can signify an outbreak earlier in its course. More specifically, adding hospitalizations and deaths syndromes to the ARI_ILI, AGE syndromes allowed us to assess the flu and AGE outbreaks intensities as well as their severities long before the French health authorities this last season and follow precisely and locally the residents' syndromic population because of the NH and residents' indexes.

This framework with its 3 components, wholly described in Figure 1, has shown its efficacy as a public health SS for early detection of outbreaks. By bringing to light new data not available elsewhere when needed, this SSS improves NH ARI-ILI epidemics' knowledge. Its tools' efficacy could even be quantified by assessing syndromes' precision, stability, flexibility, timeliness, representativeness, and finally algorithms' quality [12,66].

For the AGE data, even with lots of cases, a good correlation could be found for every winter season between the NH alarm weeks and Sentinelles outbreak weeks (as shown in the last row in Table 3 by the small distance value of 0.471). The first ones almost always precede the latter by several weeks, except for the 2014-2015 winter where the AGE epidemic essentially reached senior citizens in NH [85]. During last winter, the AGE outbreak started at the same time as in other NH in France.

Limitations

This SSS using mostly the transmissions' qualitative data is neither exhaustive as some syndromes may still not be described in the SSS nor complete, as medical staff may not have fed all syndromic information on some day for whatever reason. So, ILI and AGE syndromic data recall, what proportion of cases in classes were correctly assigned to their classes [65], could not be assessed. At this moment, the syndromic information depends essentially on the medical staffs' available time and dedication to feed the system as shown in the Results section Syndromic Data Analysis subsection Stability subsubsection, where 1 NH had a ratio of data transmissions weeks of 89%, with 293 weeks of data transmission over a total span of 329 weeks.

As soon as the cold season begins, elderly people may get a respiratory syncytial virus (RSV), similar to very young children. In fact, RSV is a common cause of acute respiratory illness in older adults as the risk of serious respiratory infection increases with age [86,87]. Usually, RSV spreads quickly just before flu or at the same time and is largely indistinguishable from influenza based on clinical presentation alone [50,51,86]. It is rather a recurring problem in older adults causing 2% to 5% of adult community-acquired pneumonia [88]. Triggering an alarm even for RSV would allow to quickly organize care for the residents.

Then, by following our syndromic ARI_ILI data, 2 trends could be traced, one starting in early November, maybe the RSV, followed by another one later, starting usually in December as this year or later as last year. Depending on the flu epidemic characteristics and as ARI, ILI, and RSV could not be distinguished in our text mining algorithm, a flu threshold could be detected whenever appropriate or several weeks ahead. As can be seen, during the 2013-2014 and 2015-2016 winters, between the first alarm weeks and the outbreak weeks, quite long times elapsed [89,90], but as not really reaching elderly people, there was not something clear to find. However, during the 2014-2015 and 2016-2017 winters, we found a much better correlation between the two, the first ones, probably because of RSV, always preceding the latter by approximately 8 weeks (Figures 3 and 4), thus often triggering alarms before those of the Sentinelles network.

At the same time, we found proportionately much more ILI new cases with our SSS than with the Sentinelles network, especially for this last influenza season (see the last ARI-ILI surge at the beginning of 2017 in Figures 3 and 4). As a type A influenza virus, it reached people older than 75 years much more than the rest of the French population [81]. Then, as soon as clusters of NH ARI cases appeared, many flu tests had to be done to label residents as flu positive or negative. Moreover, even as some tests were negative, they derived from the flu epidemic health protocol and were mandatory to HRA hygienic safety measures [91-95], increasing the number of cases still more.

Nevertheless, as detailed above, fewer lag weeks were found with the Bayes' algorithm and even an overlap of alarm weeks and outbreak weeks for the ILI 2015-2016 (Figure 3) and AGE 2013-2014 (Figure 5) epidemics and nothing like that with the EARS_C3 algorithm (Figures 4 and 6). We could try in the following years to mix both algorithms as done in the study by Baroukh [96] for Salmonella and decide triggering an alarm whenever 1 of the 2 algorithms reaches its alarm threshold, probably improving both sensitivity and specificity. Alternatively, as in the new MASS (Module for the Analysis of SurSaUD and Sentinelles' data) system [68] designed by SPF, we could combine 3 statistical methods and 3 different data sources, used since January 2016 to define the public health alerts.

Finally, the epidemiologic analysis and interpretation steps (Figure 1) were not fully automated. Some work still needs to be done, especially the whole Sentinelles data extraction process. Some similar job was done before on another project [96,97].

Conclusions

Outbreak alerts are more reliable when systems focus on specific syndromes that reflect high-probability events such as influenza [62], as could be seen in this real-life experiment. However, there is always room for improvement, as the aggregation of ARI and ILI as well as RSV constraint shows. Nevertheless, this IS gives already a rich and detailed *syndromic* image of these residents. Moreover, as syndromes are modular and the *Pentaho* platform [64] allows extraction from different data silos, it will be possible to add new syndromes, maybe RSV, whenever needed and to adapt them to the new IS that is twice as big and due next year.

This study follows another work on CN using textual analysis and clearing the way for this syndromic health IS design [98]. Tracking flu and AGE epidemics seasons almost in real time and following their impact especially during this last year acute flu season has helped to show the usefulness of this SSS. In addition, the (November 2010-June 2016) syndromic data were used to build ARI_ILI and AGE algorithms, and nothing had to be added or retrieved to follow these last season epidemics' trends, so these algorithms exhibited flexibility, adaptability, stability, and timeliness.

This study highlights some differences between the NH residents' population and the general population, which hampers a better correspondence between NH alarm weeks and Sentinelles outbreak weeks. The main challenges here are extending the syndromic IS, improving the syndromes descriptions, as well as better taking into account NH residents' distinctiveness. Monitoring flu and AGE using the BBV IS could give way to a real SS for all senior citizens in France. For example, there are incoming discussions between Korian and HRA about targeting RSV besides flu and handling what differentiates them.

Korian NHs are already working with HRA at a local level, exchanging clinical data with them whenever outbreaks are

detected. This data sharing could then be extended with syndromic data integration, resulting in HRA reactiveness improvement [99]. Indeed, syndromic data are always available before, even if less precise. NH residents as a whole are a frail and captive population functioning as an ever-increasing reservoir for any contagious illness [100,101]. It is then essential to be able to prevent with all possible disposable tools any health catastrophe in the near future.

This syndromic IS offers a real opportunity for finding new ways to seniors' functioning modelization and opens, hopefully, the path toward specific clinical hypotheses formulation. Other works included studying the use of this IS applied to other public health problems such as frequent falls or falls with casualties [102] but also working toward a better life ending with cancer [103]. Ultimately, the aims are removing all preventable deaths and improving the residents' end of life with more autonomy, less pain, and an improved quality of life, translating this new knowledge into health benefits for seniors everywhere.

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Authors' Contributions

TD and LJ had full access to all the data in the study and take responsibility for the integrity of the data and the accuracy of the data analysis. All authors contributed to the study concept and design, critically revised the manuscript for important intellectual content, and supervised the conduct of the study. TD oversaw the data extraction and analysis as well as statistical analysis, and LJ obtained funding.

Conflicts of Interest

LJ does not have any financial competing interests to report, but he is a member of the Korian Aging Well Committee.

Multimedia Appendix 1

The Korian nursing home network in France.

[PDF File (Adobe PDF File), 81KB - publichealth_v4i4e69_app1.pdf]

Multimedia Appendix 2

The anonymization process.

[PDF File (Adobe PDF File), 19KB - publichealth_v4i4e69_app2.pdf]

Multimedia Appendix 3

The Base du Bien Vieillir (BBV) acute respiratory infection and influenza-like illness and acute gastroenteritis syndromic information building process in 4 phases: the 4 BBV tables, 2 syndromic examples, and the BBV 26 syndromes list.

[PDF File (Adobe PDF File), 93KB - publichealth_v4i4e69_app3.pdf]

Multimedia Appendix 4

How public health alerts are defined: statistical alerts according to the Sentinelles network; true alerts according to the MASS system; and how the surveillance package works.

[PDF File (Adobe PDF File), 57KB - publichealth_v4i4e69_app4.pdf]

Multimedia Appendix 5

Details about syndromic data-flow stability rating syndromic data flow stability over time with 4 syndromes frequencies: diabetes, cardiovascular problems, depression, and frequent falls.

[PDF File (Adobe PDF File), 52KB - publichealth_v4i4e69_app5.pdf]

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Abbreviations

AGE: acute gastroenteritis
ARI: acute respiratory infection
ARI-ILI: acute respiratory infection and influenza-like illness
BBV: Base du Bien Vieillir
CDC: Centers for Disease Control and Prevention
CN: clinical narrative
CUSUM: cumulative sums
EARS: early aberration reporting system
EHR: electronic health record
ETL: extract, transform, and load
FN: false negative
FP: false positive
GIR: groupe ISO ressources - ISO resources group
GP: general practitioner
HRA: Health Regional Agencies
ILI: influenza-like illness
IS: information system
MSL-TM: multistep learning and text mining
NH: nursing homes
PERMF: personal electronic resident medical file
PH: public health

PPV: positive predictive value
RSV: respiratory syncytial virus
SPF: Santé publique France
SQL: standard query language
SS: surveillance system
SSS: syndromic surveillance system
SurSaUD: Sanitary Surveillance of Urgencies and Deaths
TN: true negative
TP: true positive
TS: time series

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Original Paper

Real Time Influenza Monitoring Using Hospital Big Data in Combination with Machine Learning Methods: Comparison Study

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Abstract

Background: Traditional surveillance systems produce estimates of influenza-like illness (ILI) incidence rates, but with 1- to 3-week delay. Accurate real-time monitoring systems for influenza outbreaks could be useful for making public health decisions. Several studies have investigated the possibility of using internet users' activity data and different statistical models to predict influenza epidemics in near real time. However, very few studies have investigated hospital big data.

Objective: Here, we compared internet and electronic health records (EHRs) data and different statistical models to identify the best approach (data type and statistical model) for ILI estimates in real time.

Methods: We used Google data for internet data and the clinical data warehouse eHOP, which included all EHRs from Rennes University Hospital (France), for hospital data. We compared 3 statistical models—random forest, elastic net, and support vector machine (SVM).

Results: For national ILI incidence rate, the best correlation was 0.98 and the mean squared error (MSE) was 866 obtained with hospital data and the SVM model. For the Brittany region, the best correlation was 0.923 and MSE was 2364 obtained with hospital data and the SVM model.

Conclusions: We found that EHR data together with historical epidemiological information (French Sentinelles network) allowed for accurately predicting ILI incidence rates for the entire France as well as for the Brittany region and outperformed the internet data whatever was the statistical model used. Moreover, the performance of the two statistical models, elastic net and SVM, was comparable.

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KEYWORDS

electronic health records; big data; infodemiology; infoveillance; influenza; machine learning; Sentinelles network

Introduction

Background

Influenza is a major public health problem. Outbreaks cause up to 5 million severe cases and 500,000 deaths per year worldwide [1-5]. During influenza peaks, large increase in visits to general practitioners and emergency departments causes health care system disruption.

To reduce its impact and help organize adapted sanitary responses, it is necessary to monitor influenza-like illness (ILI; any acute respiratory infection with fever ≥ 38°C, cough, and onset within the last 10 days) activity. Some countries rely on clinical surveillance schemes based on reports by sentinel physicians [6], where volunteer outpatient health care providers report all ILI cases seen during consultation each week. In France, ILI incidence rate is then computed at the national or regional scale by taking into account the number of sentinel physicians and medical density of the area of interest. ILI surveillance networks produce estimates of ILI incidence rates, but with a 1- to 3-week delay due to the time needed for data processing and aggregation. This time lag is an issue for public health decision making [2,7]. Therefore, there is a growing interest in finding ways to avoid this information gap. Nsoesie et al [8] reviewed methods for influenza forecasting, including temporal series and compartmental methods. The authors showed that these models have limitations. For instance, influenza activity is not consistent from season to season, which is a problem for temporal series. Alternative strategies have been proposed, including using different data sources, such as meteorological or demographic data, combined with ILI surveillance network data [9-11] or big data, particularly Web data [12]. With over 3.2 billion Web users, data flows from the internet are huge and of all types; they can be from social networks (eg, Facebook and Twitter), viewing sites, (eg, YouTube and Netflix), shopping sites, (eg, Amazon and Cdiscount), but also from sales or rentals website between particulars (eg, Craigslist and Airbnb). In the case of influenza, some studies used data from Google [2,4,9,13-16], Twitter [17,18], or Wikipedia [19-21]. The biggest advantage of Web data is that they are produced in real time. One of the first and most famous studies on the use of internet data for detecting influenza epidemics is Google Flu Trends [13,22], a Web service operated by Google. They showed that internet users' searches are strongly correlated with influenza epidemics. However, for the influenza season 2012-2013, Google Flu Trends clearly overestimated the flu epidemic due to the announcement of a pandemic that increased the internet users' search frequency, whereas the pandemic finally did not appear. The lack of robustness, due to the sensitivity to the internet users' behavioral changes and the modifications of the search engine performance led to stop the Google Flu Trends algorithm [2,23,24].

Some authors updated the Google Flu Trends algorithm by including data from other sources, such as historical flu information for instance or temperature [2,13-16]. Yang et al [2] proposed an approach that relies on Web-based data (Centers for Diseases Control ILI activity and Google data) and on a dynamic statistical model based on a least absolute shrinkage and selection operator (LASSO) regression that allows overcoming the aforementioned issues. At the national scale, the correlation between predictions and incidence rates was 0.98.

The internet is not the only data source that can be used to produce information in real time. With the widespread adoption of electronic health records (EHRs), hospitals also produce a huge amount of data that are collected during hospitalization. Moreover, many hospitals are implementing information technology tools to facilitate the access to clinical data for secondary-use purposes. Among these technologies, clinical data warehouses (CDWs) are one of the solutions for hospital big data (HBD) exploitation [25-28]. The most famous is the Informatics for Integrating Biology & the Bedside (i2b2) project, developed by the Harvard Medical School, which is now used worldwide for clinical research [29,30]. In addition, it has been shown that influenza activity changes detected retrospectively with EHR-based ILI indicators are highly correlated with the influenza surveillance data [31,32]. However, few HBD-based models have been developed to monitor influenza [7,33]. Santillana et al proposed a model using HBD and a machine learning algorithm (support vector machine [SVM]) with a good performance at the regional scale [7]. The correlation between estimates and ILI incidence rates ranges from 0.90 to 0.99, depending on the region and season.

Objectives

It would be interesting to determine whether HBD gives similar, better, or lower results than internet data with these statistical models (machine learning and regression). To this aim, we first evaluated HBD capacity to estimate influenza incidence rates compared with internet data (Google data). Then, we aim to find the best statistical model to estimate influenza incidence rates at the national and regional scales by using HBD or internet data. As these models have been described in the literature, we focused on two machine learning algorithms, random forest (RF) and SVM, and a linear regression model, elastic net.

Methods

Data Sources

Clinical Data Warehouse eHOP

At Rennes University Hospital (France), we developed our own CDW technology called eHOP. eHOP integrates structured (laboratory test results, prescriptions, and International Classification of Diseases 10th Revision, ICD-10, diagnoses) and unstructured (discharge letter, pathology reports, and operative reports) patients data. It includes data from 1.2 million in- and outpatients and 45 million documents that correspond to 510 million structured elements. eHOP consists of a powerful search engine system that can identify patients with specific criteria by querying unstructured data with keywords, or structured data with querying codes based on terminologies. eHOP is routinely used for clinical research. The first approach to obtain eHOP data connected with ILI was to perform different full-text queries to retrieve patients who had, at least, one document in their EHR that matched the following search criteria:

1. Queries directly connected with flu or ILI were as follows:
   - "flu"
   - "flu" or "ILI"
   - "flu" or "ILI", in the absence of "flu vaccination"
   - "flu vaccination"
   - "flu" or "ILI", only in emergency department reports
2. Queries connected with flu symptoms were as follows:
   - "fever" or "pyrexia"
   - "body aches" or "muscular pain"
   - "fever or pyrexia" or "body aches or muscular pain"
   - "flu vaccination"
   - "fever or pyrexia" and "body aches or muscular pain"
3. Drug query was as follows:
   - "Tamiflu"

The second approach was to leverage structured data with the support of appropriate terminologies:

1. ICD-10 queries were as follows: J09.x, J10.x, or J11.x (chapters corresponding to influenza in ICD-10). We retained all diagnosis-related groups with these codes.
2. Laboratory queries were as follows: influenza testing by reverse transcription polymerase chain reaction; we retained test reports with positive or negative results because the aim was to evaluate more generally ILI symptom fluctuations and not specifically influenza.

In total, we did 34 queries. For each query, the eHOP search engine returned all documents containing the chosen keywords (often, several documents for 1 patient and 1 stay). For query aggregation, we kept the oldest document for 1 patient and 1 stay and then calculated, for each week, the number of stays with, at least, one document mentioning the keyword contained in the query. In this way, we obtained 34 variables from the CDW eHOP. Multimedia Appendix 1 shows the queries and the number of concerned stays. We retrieved retrospective data for the period going from December 14, 2003 to October 24, 2016. This study was approved by the local Ethics Committee of Rennes Academic Hospital (approval number 16.69).

Google Data

For comparison with internet data, we obtained the frequency per week of the 100 most correlated internet queries (Multimedia Appendices 2 and 3) by French users from Google Correlate [34], and we used this information to retrieve Google Trends data. Unlike Google Correlate, Google Trends data [35] are available in real time, but we had to use Google Correlate to identify the most correlated queries to a signal. The times series passed into Google Correlate are the national flu time series and the regional flu time series (Brittany region) obtained from the French Sentinelles network (see below). The time period used to calculate the correlation is from January 2004 to October 2016. We used the R package gtrendsR to obtain automatically Google Trends data from January 4, 2004 to October 24, 2016 [36,37].

Sentinelles Network Data

We obtained the national (Metropolitan France) and regional (Brittany region, because Rennes University Hospital, from which EHR data were obtained, is situated in this region) ILI incidence rates (per 100,000 inhabitants) from the French Sentinelles network [38-40] from December 28, 2002 to October 24, 2016. We considered these data as the gold standard and used them as independent historical variables for our models.

Data Preparation

Based on previous studies that included datasets with very different numbers of explanatory variables according to the used statistical model [2,7], we built two datasets (one with a large number of variables and another with a reduced number of selected variables) from eHOP and Google data, for both the national and regional analyses (Figure 1).

Each one of these four datasets was completed with historical Sentinelles data. Therefore, for this study, we used the following:

1. eHOP Complete: this eHOP dataset included all variables from eHOP and the historical data from the Sentinelles network with the ILI estimates for the 52 weeks that preceded the week under study (thus, from t-1 to t-52).
2. eHOP Custom: this eHOP dataset included the 3 most correlated variables between January 2004 and October 2016 from eHOP for the ILI signal for week t, −1 (t-1), and −2 (t-2), and historical information from the Sentinelles network with ILI estimates for t-1 and t-2.
3. Google Complete: this Google dataset included the 100 most ILI activity-correlated queries from Google Trends and historical information from the Sentinelles network with ILI estimates for t-1 to t-52.
4. Google Custom: this Google dataset included the 3 most ILI activity-correlated queries between January 2004 and October 2016 from Google Trends for t, (t-1), and (t-2) and historical data from the Sentinelles network with ILI estimates for (t-1) and (t-2).

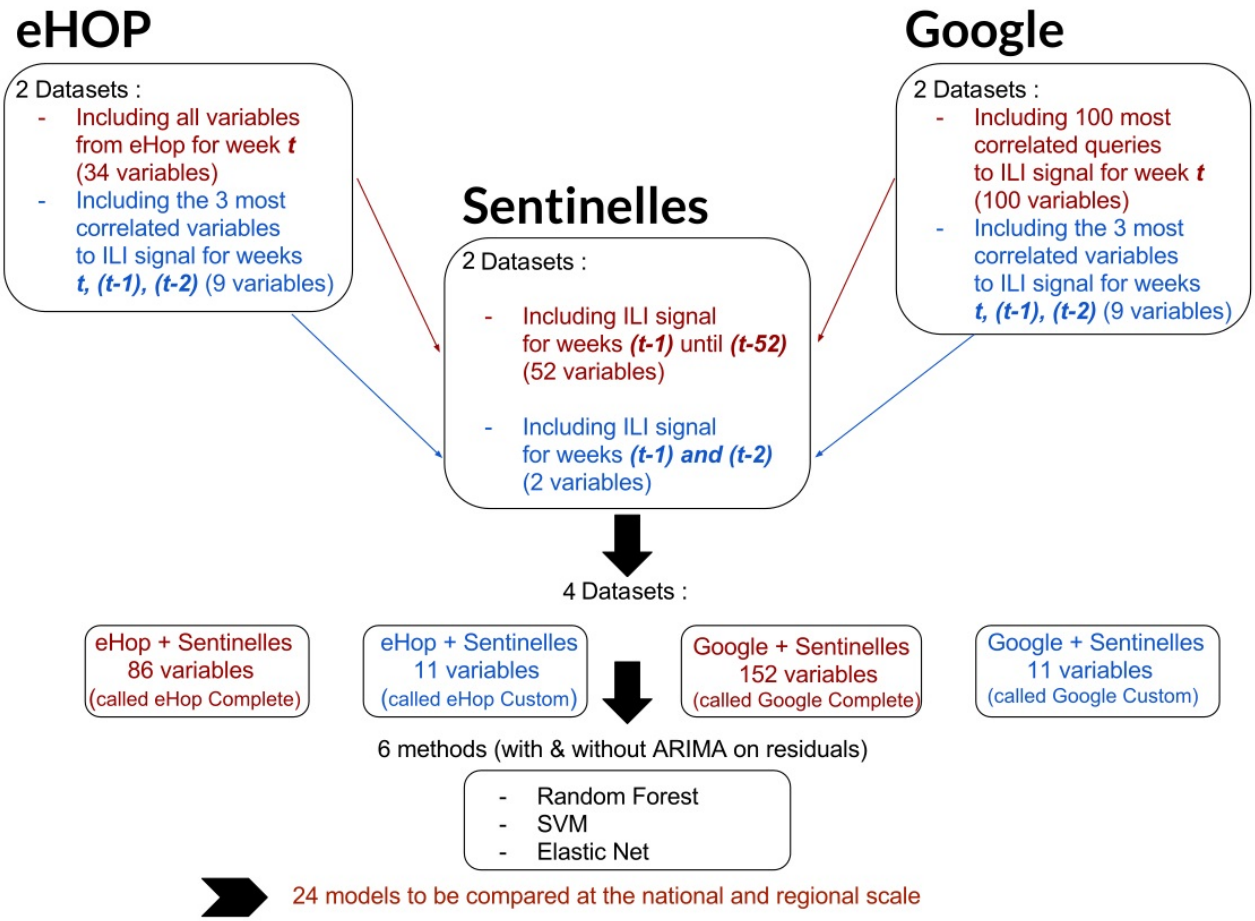
Statistical Models

Our test period started on December 28, 2009 and finished on October 24, 2016. We fitted our models using a training dataset that corresponded to the data for the previous 6 years. Each model was dynamically recalibrated every week to incorporate new information. For instance, to estimate the ILI activity fluctuations for the week starting on December 28, 2009, the training data consisted of data from December 21, 2003 to December 21, 2009.

Elastic Net

Elastic net is a regularized regression method that takes into account the correlation between explanatory variables and also a large number of predictors [41]. It combines the penalties of the LASSO and Ridge methods, thus allowing keeping the advantages of both methods and overcoming their limitations [42,43]. With datasets that may have up to 152 potentially correlated variables, we performed the elastic net regression analysis using the R package glmnet and the associated functions [36,44]. We fixed a coefficient alpha equal to.5 to give the same importance to the LASSO and Ridge constraints. We optimized the shrinkage parameter lambda via a 10-fold cross validation.

Figure 1. Schematic representation of the study design, including the data preparation and data modeling steps. ILI: influenza-like illness; SVM: support vector machine; ARIMA: autoregressive integrated moving average.



Random Forest

RF model combines decision trees constructed at training time using the general bootstrap aggregating technique (known as bagging) [45]. We used the R package randomForest to create RF models with a number of decision trees equal to 1500 [36,46].

Support Vector Machine

SVM is a supervised machine learning algorithm that can be used for classification or regression analyses [47]. Unlike multivariate regression models, SVM can learn nonlinear functions with the kernel trick that maps independent variables in a higher dimensional feature space. As Santillana et al [7], we used the linear kernel and optimized the cost parameter via a 10-fold cross validation with the R package e1071 [36,48].

Validity

Elastic net is a model that fulfills some assumptions on residuals. Means and variances must be constant, and residuals must be not correlated. Thus, residuals are called white noise. To test the stationarity and whiteness, we used Dickey Fuller's and Box-Pierce's tests available from the R packages tseries and stats [36,49]. When assumptions were not respected, we fitted residuals with a model of temporal series, called autoregressive integrated moving average (ARIMA) model. For RF and SVM, assumptions on residuals are not required. However, for comparison purpose, we tested them with the ARIMA model on residuals (Multimedia Appendices 4 and 5). We also assessed the calibration of the models by plotting the estimates against the real observations and by adding the regression line [50] (Multimedia Appendices 6 and 7).

Evaluation

We compared our ILI estimates with ILI incidence rates from the Sentinelles network by calculating different indicators. The mean squared error (MSE); Pearson correlation coefficient (PCC); variation in the height of the epidemic peak (ΔH), which corresponds to the difference between the height of the ILI incidence rate peak during the epidemic period estimated by the models and the height estimated by the Sentinelles network; and prediction lag (ΔL), which corresponds to the time difference between the ILI incidence rate peak estimated by the models and the peak estimated by the Sentinelles network, were calcuated. For the global comparison (ie, the entire study period), we calculated only the MSE and PCC. We calculated the four metrics only for the epidemic periods (plus 2 weeks before the start and after the end of the epidemic). The start and end date of epidemics were obtained from the Sentinelles network [39]. Indeed, clinicians want to know when an epidemic starts and finishes, as well as its amplitude and severity. Therefore, interepidemic periods are less important. We also calculated the mean of each indicator for each influenza season

to assess the model robustness. We also added two indicators to the mean of (ΔH) and (ΔL): the mean of |ΔH| and |ΔL|. We used the mean of (ΔH) to assess whether the models tended to underestimate or overestimate the peak calculated by the Sentinelles network, and the mean of (ΔL) to determine whether the predictions made by our models were too late or too in advance relative to the Sentinelles data. The mean of |ΔH| and |ΔL| allowed us to assess the estimate variability.

Results

Principal Results

Here, we show the results we obtained with the four datasets and three models—RF, SVM, and elastic net+residuals fitted by ARIMA (ElasticNet+ARIMA). The model on residuals was required to fulfill the assumptions for elastic net but not for the RF and SVM models. All results are presented in Multimedia Appendices 4 and 5. Moreover, we present two influenza outbreaks, including the 2010-2011 season (flu outbreak period for which the best estimates were obtained with all models) and the 2013-2014 season (flu outbreak period for which the worst estimates were obtained with all models; Multimedia Appendix 8). The calibration plots are in presented in Multimedia Appendices 7 and 9.

National Analysis

Dataset Comparison

PCC ranged from 0.947 to 0.980 when using the eHOP datasets (Multimedia Appendix 8) and from 0.937 to 0.978 with the Google datasets. MSE ranged from 2292 to 866 for the eHOP and from 2607 to 968 for the Google datasets. The mean PCC values during epidemic periods varied from 0.90 to 0.96 for the eHOP and from 0.87 to 0.96 for the Google datasets. The mean MSE values ranged from 7597 to 2664 for the eHOP and from 9139 to 2805 for the Google datasets.

Model Comparison

The eHOP Custom dataset gave the best results with the SVM model and ElasticNet+ARIMA (Multimedia Appendix 8). The SVM model and ElasticNet+ARIMA showed similar performance concerning the global activity (PCC=0.98; MSE, <900) and also during epidemic periods (mean values), although PCC decreased (0.96) and the MSE increased (> 2500). Both models tended to overestimate the height of the epidemic peaks (ΔH=6 with SVM; ΔH=26 with ElasticNet+ARIMA), but the SVM model was slightly more accurate (|ΔH|=19 for SVM; |ΔH|=30 for the ElasticNet+ARIMA model). Conversely, the SVM model showed a larger prediction lag (ΔL=+0.83). Figure 2 illustrates the estimates obtained with the best models (SVM and ElasticNet+ARIMA with the dataset eHop Custom).

The same figure with the dataset Google Custom is presented in Multimedia Appendix 10. In the same way, there is a figure with eHOP Custom and Google Custom datasets with the model ElasticNet+ARIMA presented in Multimedia Appendix 11.

For the outbreak of 2010-2011, eHOP Custom using ElasticNet+ARIMA gave the best PCC (0.98) and the best MSE (1222). With this model, there was a slight overestimation of the height of the epidemic peak (ΔH=23) and a prediction lag of 1 week. For the 2013-2014 outbreak, eHOP Custom using SVM gave the best PCC (0.95) and MSE (996), as well as the best ΔH (19) and prediction lag (1 week; Multimedia Appendix 8).

Regional Analysis

Figure 3 shows that ILI incidence rate variations were more important at the regional than the national level. For this reason, PCC decreased and MSE increased by the order of magnitude. The same figure with the dataset Google Custom is presented in Multimedia Appendix 12.

Dataset Comparison

PCC ranged from 0.911 to 0.923 (Multimedia Appendix 8) with the eHOP and from 0.890 to 0.912 with the Google datasets. MSE varied from 2906 to 2364 and from 3348 to 2736 for the eHOP and Google datasets, respectively. During epidemic periods, the mean PCC value ranged from 0.83 to 0.86 and from 0.70 to 0.83 for the eHOP and Google datasets, respectively. The mean MSE values ranged from 7423 to 5893 for the eHOP and from 9598 to 7122 for the Google datasets.

Model Comparison

Like at the national scale, eHOP Custom allowed obtaining the best PCC and MSE, and the SVM (PCC=0.923; MSE=2364) and ElasticNet+ARIMA (PCC=0.918; MSE=2451) models showed similar performances (Multimedia Appendix 8). Similar results were obtained also for the mean values during epidemic periods. Nevertheless, the PCC decreased (0.86 for SVM and 0.84 for ElasticNet+ARIMA), and the MSE increased (6050 for SVM and 5999 for ElasticNet+ARIMA). Both models tended to underestimate the height of the epidemic peaks (ΔH=−60 with SVM; ΔH=−32 with ElasticNet+ARIMA). The SVM model gave better PCC and MSE than the ElasticNet+ARIMA model, but ElasticNet+ARIMA was slightly more accurate for the epidemic peak height (|ΔH|=60 for SVM; |ΔH|=38 for the ElasticNet+ARIMA model). Although both models had a prediction lag (ΔL=+0.3), the ElasticNet+ARIMA model absolute lag value was smaller than that of SVM (|ΔL|=0.7; |ΔL|=1). For the 2010-2011 outbreak, eHOP Complete using the RF model gave the best PCC (0.92) and MSE (4263); with this model, there was a slight peak underestimation (ΔH=−40) but no prediction lag. For the 2013-2014 epidemic, the best PCC (0.78) and MSE (2113) were obtained with the Google Complete dataset and the ElasticNet+ARIMA model; there was a slight epidemic peak height underestimation (ΔH=−26) and 1 week of prediction lag.

Figure 2. National influenza-like illness (ILI) activity retrospective estimates obtained using the eHOP Custom dataset and the elastic net model with residuals fitted or the support vector machine model compared with the ILI activity levels from the French national Sentinelles networks. Global signal and 2010-2011 and 2013-2014 outbreaks are presented. SVM: support vector machine.

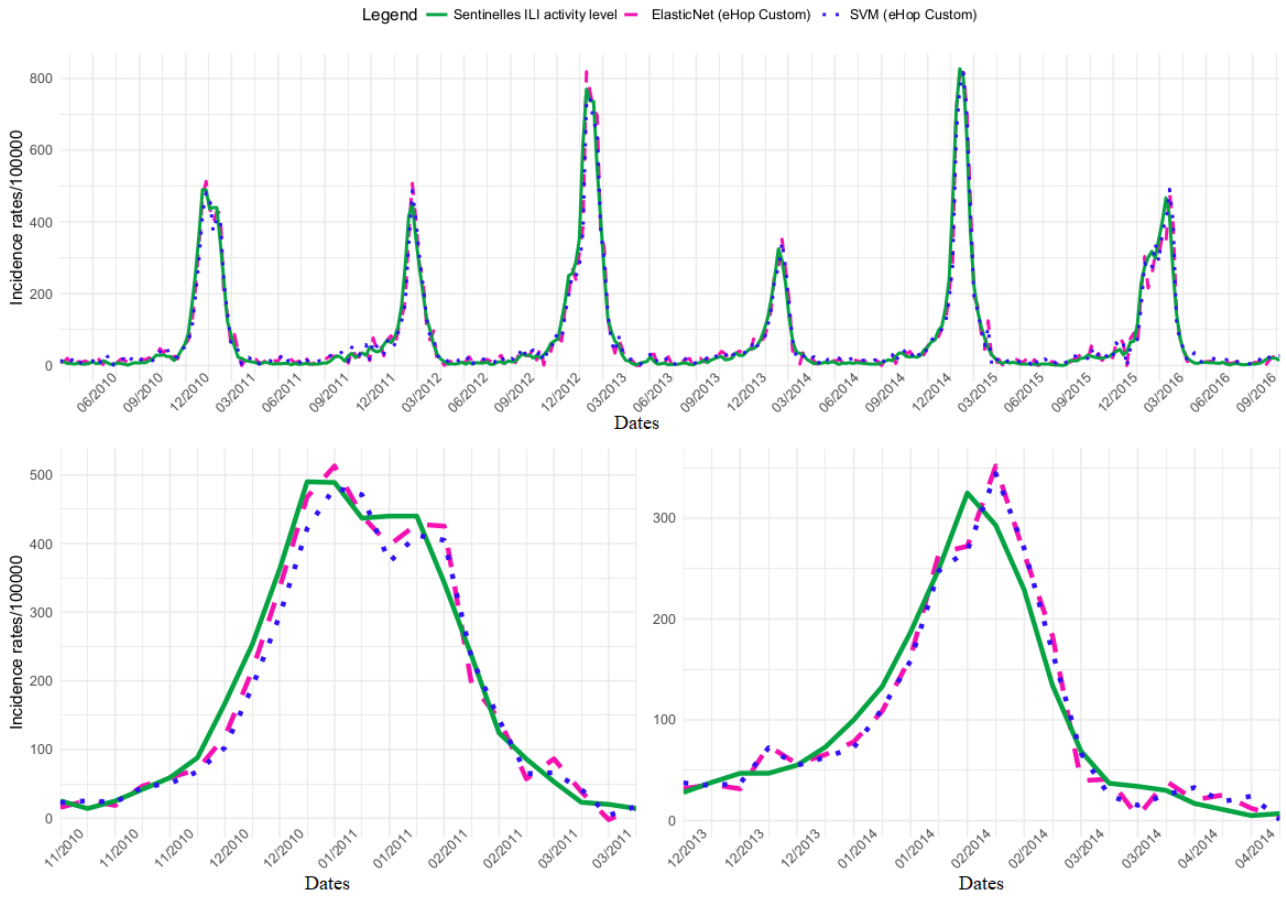
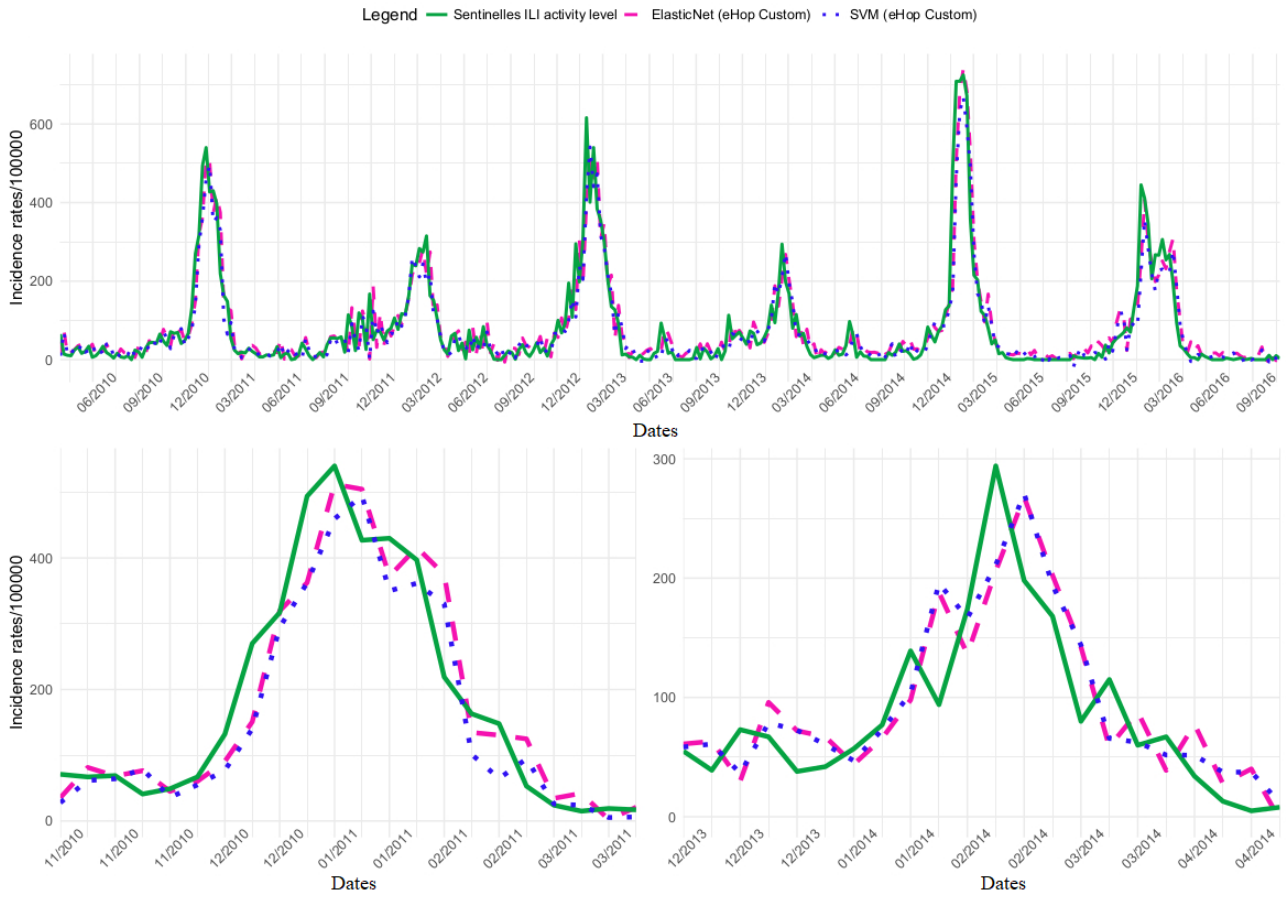


Figure 3. Regional influenza-like illness (ILI) activity retrospective estimates obtained using the eHOP Custom dataset and the elastic net model with residuals fitted or the support vector machine model compared with the ILI activity levels from the French regional Sentinelles networks. Global signal and 2010-2011 and 2013-2014 outbreaks are presented. SVM: support vector machine.



Discussion

Data

Here, we show that HBD in combination with flu activity-level data from a national surveillance network allows accurately predicting ILI incidence rate at the national and regional scale and outperform Google data in most cases. The correlation coefficients obtained for the French data are comparable to those reported by studies on US data [2,7]. At the national and regional level, the best PCC and the best MSE during the entire study period or during epidemics were obtained using the eHOP Custom dataset. Moreover, the PCC and MSE values obtained with the eHOP datasets were better than those obtained with the Google datasets, particularly at the regional level (PCC 0.911-0.923 vs 0.890-0.912; MSE 2906-2364 vs 3348-2736, respectively; Multimedia Appendix 8). However, the national signal is smoother and less noisy than the regional signal; the contribution of other data sources, such as hospital data or Web data, in addition to historical influenza data is more important at the regional level (Multimedia Appendices 4 and 5). The contribution of these external sources being less important at the national level, the differences observed between hospital data and Web data at this scale could be more significant.

Like internet data, some HBD can be obtained in near real time, especially records from emergency departments that are available on the same day or the day after. This is the most important data source for our models using eHOP datasets. Some other data, such as laboratory results, are available only on a weekly basis; however, they are not the most important data source for our models.

Moreover, in comparison to internet data, HBD have some additional advantages. First, data extracted from CDWs are real health data can give information that cannot be extracted from internet data, particularly information about patients (sex, age, and comorbidities) [51]. In addition, an important clinical aspect is to determine the epidemic severity. With HBD, it is possible to gauge this parameter by taking into account the number of patients who were admitted in intensive care or died as the result of flu. Second, some CDW data (particularly emergency department discharge summaries and laboratory test results) can confirm that people were really affected by influenza or ILI symptoms. On the other hand, people can make internet queries not because they are ill, but for other people, for prevention purposes or just because it is a topical subject. Third, HBD could also be used to estimate the incidence rates of diseases that do not generate internet activity (eg, diseases without or with little media coverage or that are not considered interesting by the general population). Fourth, there is a spatial decorrelation between internet data and the regional estimates that were not observed with the eHOP data. It is quite reasonable that hospital-based data give a better estimate of regional epidemics, although currently, we have only data from Rennes

University Hospital that might not be representative of the entire Brittany region.

A major HBD limitation is that, generally, clinical data are not publicly available. In our case, we could only access the Rennes University Hospital HBD. However, the epidemic peak in Brittany could have occurred earlier or later relative to the national peak, and this could have introduced a bias in our estimation. We can hypothesize that ILI estimates, particularly nationwide, might be improved if we could extract information from HBD in other regions. In the United States, a patient research system allows aggregating patient observations from a large number of hospitals in a uniform way [52]. In France, several initiatives have been developed to create search systems. For instance, an ongoing project (Réseau interrégional des Centres de Données Cliniques) [53] in the Northwest area of France associates six University Hospital centers (Angers, Brest, Nantes, Poitiers, and Rennes et Tours) and Orleans Regional Hospital Centre, thus collecting data on patients in the Bretagne, Centre-Val de Loire, and Pays de la Loire regions. This corresponds to 15.5% of Metropolitan France and 14.4% of the entire French population. Another way to aggregate patient data could be a cloud-based platform, and we are currently setting up this kind of architecture; this platform will integrate two University Hospital centers, Brest and Rennes, the French health reimbursement database (Système national d'information interrégimes de l'Assurance Maladie) and registries, such as the birth defect registry or cancer registry.

Statistical Models

Regarding the statistical models, we show that SVM and elastic net with ARIMA model are fairly comparable with PCC ranging from 0.970 to 0.980 at the national scale and from 0.890 to 0.923 at the regional scale. The SVM and elastic net models in combination with the eHOP custom dataset were the most robust models, although they did not always give the best results. Indeed, they showed the best performance in term of PCC and MSE for the global signal and also for the mean values. Nevertheless, these models have some limits. The main limitation of the SVM model is the very slow parameter optimization when there are many variables. With the SVM model, it can be important to preselect the important variables to reduce the dataset size to improve the optimization speed. For this, one needs a good knowledge of the available data, which may be difficult when using big data. On the other hand, elastic net shows good performance with many variables, which is an advantage when the most relevant variables to estimate ILI incidence rates are not known in advance. The elastic net model is a parametric model that fulfills certain assumptions on residuals, differently from the SVM model. With elastic net, residuals must be fitted to have a statistically valid model. Nevertheless, if we had to choose a model, we would prefer SVM with the eHOP Custom dataset because it has a better PCC than elastic net at the regional scale.

Another limitation is that indicators are better for the global period than for epidemic periods. This implies that models are less efficient during flu outbreaks, while clinical concerns are higher during epidemics when good estimates of the outbreak starting date, amplitude, and end are needed.

Finally, the results of our models with Web data may have been overestimated due to the way we obtained data from Google Correlate. Indeed, Google Correlate used information that we did not have at the beginning of our test period. The time period for our time series passed into Google Correlate is from January 2004 to October 2016. But, the beginning of our test period for our models is January 2010. To be more precise, we should recalculate the correlation coefficients for each week to predict with the data available at that time.

In the same way, to custom datasets, we calculated the 3 most correlated variables on a time period including our test period. To compare the results, we built another dataset from eHOP, including the 3 most correlated variables to ILI regional signal between December 2003 and December 2009 (before our test period), and we applied an ElasticNet+ARIMA model. In this way, we kept 2 variables on the 3 present in the eHOP custom dataset. The difference does not seem significant (Multimedia Appendix 6), but it would be interesting to test this hypothesis with all models at the national and regional scale with Google and eHOP custom datasets.

Perspectives

Future research could address clinical issues not only nationally or regionally but also at finer spatial resolutions such as a city like Lu et al did [54], a health care institution or in subpopulations. Indeed, by predicting epidemics, it will be possible to organize hospitals during epidemics (eg, bed planning and anticipating overcrowding). Moreover, in this study, we compared internet and HBD data; however, hybrid systems could be developed to take advantage of multiple sources [55,56]. For instance, internet data might avoid the limit of the local source linked to the choice or availability of HBD. Data collected by volunteers who self-report symptoms in near real time could be exploited [57]. Similarly, by combining models, we could retain the benefits of each of them and improve the estimates of ILI incidence rates. For example, we could use another algorithm, such as stacking [58], to concomitantly use the SVM and elastic net models. We could also test other kernels than the linear kernel for SVM models. Finally, we carried out a retrospective study using various models with clinical data in combination with the flu activity from the Sentinelles network to estimate ILI incidence rates in real time. Our models need now to be tested to determine whether they can anticipate and predict ILI incidence rates.

Conclusions

Here, we showed that HBD is a data source that allows predicting the ILI activity as well or even better than internet data. This can be done using two types of models with similar performance—SVM (a machine learning model) and elastic net (a model of regularized regression). This is a promising way for monitoring ILI incidence rates at the national and local levels. HBD presents several advantages compared with internet data. First, they are real health data and can give information about patients (sex, age, and comorbidities). This could allow for making predictions on ILI activity targeted to a specific group of people. Second, hospital data can be used to determine the epidemic severity by taking into account the number of patients who were admitted in intensive care or died as a result

of flu. Third, hospital data (particularly the emergency department discharge summaries and laboratory test results) can confirm that people were really affected by influenza. Finally, HBD could also be used to estimate the incidence rates of diseases that do not generate internet activity. Although massive data cannot take the place of traditional influenza surveillance methods at this time, they could be used to complete them. For instance, real-time forecasting is necessary for decision making. It can also be used to manage the patients' flow in general practitioners' offices and hospitals, particularly emergency departments.

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Authors' Contributions

CP, GB, AL, and BCG conceived the experiments; CP conducted the experiments and analyzed the results.

Conflicts of Interest

None declared.

Multimedia Appendix 1

eHOP queries (with the number of concerned hospital stays from 2003 to 2016).

[PDF File (Adobe PDF File), 21KB - publichealth_v4i4e11361_app1.pdf]

Multimedia Appendix 2

The 100 most correlated Google queries at national level.

[PDF File (Adobe PDF File), 15KB - publichealth_v4i4e11361_app2.pdf]

Multimedia Appendix 3

The 100 most correlated Google queries at regional level.

[PDF File (Adobe PDF File), 14KB - publichealth_v4i4e11361_app3.pdf]

Multimedia Appendix 4

Accuracy metrics for all seasons obtained with all models for the national scale.

[PDF File (Adobe PDF File), 72KB - publichealth_v4i4e11361_app4.pdf]

Multimedia Appendix 5

Accuracy metrics for all seasons obtained with all models for the regional scale.

[PDF File (Adobe PDF File), 80KB - publichealth_v4i4e11361_app5.pdf]

Multimedia Appendix 6

Comparison between two datasets with ElasticNet + ARIMA model: Dataset 1 corresponds to the dataset called eHOP Custom used in the paper and including the 3 most correlated variables to ILI signal between December 2009 to October 2016 (our test period). Dataset 2 includes the 3 most correlated variables to ILI signal between December 2003 to December 2009 (before our test period).

[PDF File (Adobe PDF File), 25KB - publichealth_v4i4e11361_app6.pdf]

Multimedia Appendix 7

National calibration.

[PNG File, 185KB - publichealth_v4i4e11361_app7.png]

Multimedia Appendix 8

Accuracy metrics for the 2010-2011 (flu outbreak period for which the best estimates were obtained with all models) and 2013-2014 (flu outbreak period for which the worst estimates were obtained with all models) seasons. PCC and MSE for the global period (Global) and mean values (Means) of all indicators for each model during the epidemic periods. In bold, the best results for each dataset. a. Data for the whole France. b. Data for the Brittany region.

[PDF File (Adobe PDF File), 52KB - publichealth_v4i4e11361_app8.pdf]

Multimedia Appendix 9

Regional calibration.

[PNG File, 202KB - publichealth_v4i4e11361_app9.png]

Multimedia Appendix 10

National ILI activity retrospective estimates obtained using the Google Custom dataset and the Elastic Net model with residuals fitted (pink dashed line) or the SVM model (blue dotted line) compared with the ILI activity levels from the French national Sentinelles networks (green solid line). a. Global signal. b. 2010-2011 and c. 2013-2014 outbreaks.

[PNG File, 142KB - publichealth_v4i4e11361_app10.png]

Multimedia Appendix 11

National ILI activity retrospective estimates obtained using the Google Custom dataset and the Elastic Net model (blue dotted line) or eHOP Custom dataset and the Elastic Net model (pink dashed line) compared with the ILI activity levels from the French national Sentinelles networks (green solid line). a. Global signal. b. 2010-2011 and c. 2013-2014 outbreaks.

[PNG File, 142KB - publichealth_v4i4e11361_app11.png]

Multimedia Appendix 12

Regional ILI activity retrospective estimates obtained using the Google Custom dataset and the Elastic Net model with residuals fitted (pink dashed line) or the SVM model (blue dotted line) compared with the ILI activity levels from the French regional Sentinelles networks (green solid line). a. Global signal. b. 2010-2011 and c. 2013-2014 outbreaks.

[PNG File, 159KB - publichealth_v4i4e11361_app12.png]

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Abbreviations

ARIMA: autoregressive integrated moving average
CDW: clinical data warehouse
EHR: electronic health record
HBD: hospital big data
ILI: influenza-like illness
LASSO: least absolute shrinkage and selection operator
MSE: mean squared error
PCC: Pearson correlation coefficient
RF: random forest
SVM: support vector machine
ΔH: epidemic peak
ΔL: prediction lag

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Increasing Active Transportation Through E-Bike Use: Pilot Study Comparing the Health Benefits, Attitudes, and Beliefs Surrounding E-Bikes and Conventional Bikes

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Abstract

Background: The emergence of electric pedal-assist bicycles (e-bikes) presents an opportunity to increase active transportation by minimizing personal barriers of engaging in physical activity.

Objectives: The aim of this study was to assess the beliefs of individuals using e-bikes for active transport and report preliminary biometric measurements while using e-bikes for physical activity compared with conventional bikes.

Methods: Participants used both conventional bicycles and e-bikes to compare energy expenditure while riding on the study route. Apple smart watches were used to track each participant's heart rate, distance, speed, and time while riding both bicycles. A total of 3 survey instruments were used to estimate beliefs: one administered before riding the bicycles, a second administered after riding a conventional bike, and the final survey completed after riding an e-bike. Survey instruments were constructed using constructs from the theory of planned behavior.

Results: The study sample (N=33) included adults aged between 19 and 28 years. Paired *t* test analysis revealed that participants believed a conventional bike was more likely than an e-bike to benefit their physical health (P=.002) and save them money (P=.005), while an e-bike was perceived to be more likely than a conventional bike to save them time (P<.001). Paired *t* test analysis revealed participants significantly agreed more with the statement that they could ride an e-bike most days (P=.006) compared with a conventional bike. After participants traveled approximately 10 miles on each type of bicycle, participants' mean average heart rate while riding the e-bike was 6.21 beats per minute lower than when riding the conventional bike (P=.04), but both were significantly higher than resting heart rate (P<.001).

Conclusions: This pilot study suggests that e-bikes are an active form of transportation capable of providing much of the cardiovascular health benefits obtained during conventional bike use. E-bikes may help reduce some of the obstacles to conventional bike use, such as increased transportation time, decreased convenience, and physical fatigue.

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KEYWORDS

physical activity; bicycling; obesity; physical fitness; cardiorespiratory fitness

Introduction

Background

Physical inactivity has been identified as a contributing factor to obesity, which is currently a leading public health issue in developed nations [1-3]. Health authorities have promoted active transportation as one possible response to addressing this epidemic [4]. Active transportation includes transportation activities that are human-powered, such as biking to work. This is distinct from many intentional exercise or fitness activities in that the purpose of active transport is primarily to get from one location to another. Substantial research in the fields of transportation, health, and psychology has helped to identify a variety of factors associated with engaging in active transport behaviors, including features in the built environment [5,6], age and gender [7], and attitudes and beliefs in a culture [8]. Though active transportation may be a promising approach to addressing obesity, it is not without its barriers. Active transportation can be made difficult because of barriers such as lack of safe walking and cycling paths, long commuting distance, limited current fitness level, lack of time, and inclement weather [7]. These barriers may be divided thematically into 2 classes: personal factors (eg, too much effort to ride a bike or a desire to wear normal clothes without getting to work sweaty) and environmental factors (eg, dangerous road or traffic conditions) [9]. As these barriers limit consistent and sustainable active transportation, innovative methods of active transportation that help to reduce or even eliminate such barriers are of interest to public health professionals.

In recent years, e-bikes have emerged, presenting a potential opportunity to encourage active transportation while reducing personal barriers to active transportation [10-12]. E-bikes operate through a small electric motor that acts as a pedal-assist, only providing assistance when the rider pedals. Because of this feature, the rider can theoretically still obtain at least a portion of the physical activity benefits of conventional cycling while reducing some of the traditional personal barriers to commuting with a conventional bicycle. Commuters may not want to exert the effort required to ride a conventional bicycle, may need to travel a longer distance, or may desire to wear normal clothing without arriving to their destination sweaty. In addition, individuals may have limited time or may not have the stamina to make the trip with a conventional bicycle. In each of these cases, the added assistance of the pedal-assist electric motor in e-bikes may reduce these barriers while still providing a portion of the health benefits associated with conventional cycling [12,13].

E-bikes also have the added benefit of being environmentally friendly, as they do not produce carbon emissions or noise pollution akin to their motorized vehicle counterparts [14,15]. In addition, they are not like motorcycles or other motorized scooters in that they can generally be ridden on bike paths and in bike lanes. If adopted widely enough, e-bikes could, therefore, reduce congestion in traffic as well as car parks, as they can also be parked with traditional bicycles.

On account of the relatively recent introduction of e-bikes, the current literature surrounding e-bikes is somewhat limited. To date, the majority of e-bike studies have focused on issues concerning safety [16-26]. Some research, however, has been focused on the potential physical health benefits of e-bikes and their potential to reduce personal barriers to traditional cycling. For example, results from a Web-based survey demonstrated that those using an e-bike to ride to work report an ability to ride greater distances while perspiring less, suggesting that e-bikes may reduce some of the personal barriers of traditional cycling [27]. Being able to ride greater distances was also confirmed in another Web-based survey of e-bike users [28]. A review of e-bike literature supports the idea that e-bikes are related to beneficial physical activity but that they also may be more dangerous than a traditional bike [29].

One study also suggested that e-bikes may have an added benefit of promoting health among individuals otherwise reluctant to engage in physical activity [30,31]. Previous e-bike studies with such populations (older individuals, obese or overweight individuals, and those who may be impacted by physical injury or impairment) have largely focused only on safety [32,33], though one study has examined e-bike use among untrained, overweight individuals [13].

Heart rate and energy expenditure is likely lower with an e-bike compared with what would be observed with a conventional bicycle, and this has been confirmed in 2 small studies, with sample sizes of 18 and 12 [34,35]. Another study of 8 individuals suggests that e-bike use results in lower oxygen consumption and exercise intensity but that moderate physical activity is still achieved [10]. Similarly, a study of 10 trained and 10 untrained individuals revealed that though power output, exercise intensity, and energy expenditure were lower with assistance from the electric motor, the exercise intensity was sufficiently high to achieve the standards for moderate-intensity health-enhancing physical activity [12]. Recent studies also suggest that e-bike commuting may improve metabolic fitness such as glucose tolerance [36] and that riders experience lower levels of perceived exertion and higher levels of enjoyment [31].

Despite these findings, there is limited research in the current literature regarding the attitudes, beliefs, and perceptions of e-bikes and their potential health benefits compared with those of conventional bikes. For this reason, an assessment of the attitudes and beliefs toward their use is needed, as even if beneficial for health reasons, it remains unclear if individuals would adopt this technology or perceive it to be of limited value.

Objective

The purpose of this pilot study was to compare e-bikes with conventional bicycles. More specifically, this study sought to answer 2 research questions: (1) what proportion of the health benefits are retained when using an e-bike as compared with using a conventional bicycle? and (2) what are the attitudes and beliefs toward e-bikes after riding one and how do those compare with attitudes and beliefs toward conventional bicycles? In particular, this study aimed to understand attitudes and beliefs regarding personal factors that may prevent active transportation events.

Methods

Participants

A total of 33 participants were recruited to this pilot study through announcements in undergraduate public health courses at a large private university in the state of Utah in the United States. Cycling in this area is relatively common, with the modal share for biking to work in Utah being 0.8% in 2014, making it the 11th-highest in the country [37]. Eligibility was limited to individuals between the ages of 18 and 65 years. Exclusion criteria included the inability to complete a survey in English, the inability to ride a bicycle at moderate to vigorous intensity for 10 miles (approximately 16 km), or a medical condition preventing moderate exercise.

Procedures

The institutional review board at Brigham Young University approved this study. Individuals desiring to participate first completed an informed consent form and then received an email link to a baseline survey with items relating to demographics, physical activity level, cycling history, as well as attitudes and beliefs about biking. Participants were then assigned a day and time to meet at a bike-park stall in the university campus. At the stall, participants were provided a heart rate monitor and global positioning system (GPS) device, a bicycle helmet, and a conventional bicycle. Participants were given instructions related to bicycle safety and bike path etiquette. They were also provided with a healthy snack and water bottle to ensure they had energy and water. Participants kept the water bottle. Participants were shown a map of the regional dedicated bike path and received detailed directions for the intended 10-mile path of travel. The bike path was generally flat, and elevation change during the ride was relatively minimal. Participants were then instructed to ride the prescribed bike path route at a comfortable speed. After completing the first ride, participants were emailed a link to a second survey with items relating to their experience, attitudes, and beliefs of riding the conventional bicycle on the study route. On a second day, participants returned to the same location to ride the study route again—this time using an e-bike. Rides were separated by an average of 6 days. Participants were again provided a heart rate monitor, GPS device, bicycle helmet, basic instructions related to bicycle safety and bike path etiquette, and a refresher on bike path directions for the same study route. In addition, participants were given instructions for the safe riding and operation of an e-bike. After completing the second ride, participants were emailed another link to the survey designed to measure their experience, attitudes, and beliefs of riding the e-bike on the study route. Participants completed rides between November 2016 and June 2017, with the majority taking place in April and May.

Instruments and Measurements

Both conventional bicycles and e-bikes were used in this study to establish a comparison between participant's energy expenditure while riding the study route. The conventional bikes were recreational mountain bikes equipped with 21 speeds, disc braking systems, and adjustable seat heights. The e-bikes were Specialized Turbo 2016 models equipped with 9-speeds, front suspension, disc braking systems, and adjustable seat heights.

Apple brand smart watches were used to track each participant's heart rate, distance, speed, and time while riding both the conventional bicycle and the e-bike. A comparison of participants' heart rate was used as a proxy measure to estimate health benefits retained during e-bike use compared with conventional bike use. Specifically, estimated maximum heart rate (MHR) was calculated by subtracting the mean age of the study group from 220. The estimated MHR was then used to establish a target average heart rate range for moderate-intensity physical activity. This range was calculated based on the target heart rate recommendations from the Centers for Disease Control and Prevention for moderate-intensity physical activity [38]. The free version of Strava, a mobile app using GPS technology available via the App Store for iOS and Apple Watch platforms, was used to measure speed and distance. During the e-bike rides, 2 participants experienced technical difficulties with the e-bikes in which the batteries were not functioning properly and, therefore, not providing assistance for the full duration of the ride. Because of this, the time, speed, distance, and heart rate measurements for these 2 participants were excluded from analysis. In addition, the heart rate measurement function of the Apple watches did not work properly for 2 participants, and their heart rate measurements were therefore excluded from analysis.

A total of 3 survey instruments, developed using the Web-based survey software provided by Qualtrics, were used in this study. Survey 1—administered before riding either of the bicycles—was used to gather basic demographic information (eg, age, ethnicity, education, income), typical personal transportation methods (eg, bus or train, car, bicycle), cycling history and experience data (eg, whether or not the participant owns a bicycle or e-bike), and information about general attitudes and beliefs regarding bicycles (eg, obstacles to riding a bicycle, social stigma). The information about attitudes and beliefs gathered in survey 1 was used to inform the development of questions in survey 2 and survey 3. Survey 2—administered after completing the ride on the conventional bike—assessed agreement with prosocial benefits of bicycle use using a 5-point Likert scale (eg, health, environment, saving time or money), social support for using cycling as a method of transportation (eg, feeling embarrassed to use a bicycle for transportation purposes), and the likelihood of using a bike under adverse conditions (eg, cold, rain, darkness, fatigue, hilly terrain, and so on). Survey 3—administered after completing the ride on the e-bike—was used to collect the same information as survey 2, but all the items reflected the participants' experience, attitudes, and beliefs related to riding an e-bike. The questions in survey 2 and survey 3 were identical except for the fact that survey 2 asked the questions in relation to conventional bicycles, while survey 3 asked the questions in relation to e-bikes. The surveys were also subjected to standard face and content validity assessments.

The theory of planned behavior (TPB) was used as a basis for the development of the surveys [39,40]. Within the TPB, a subjective norm is an individual's perception of social normative pressures or relevant others' beliefs that an individual should

or should not perform a particular behavior. In the case of biking, subjective norms could include perceived pressures to ride or not ride a bicycle (or e-bike). Attitudes reflect an individual's perception or belief regarding the extent to which, for example, riding a bike will be a benefit (behavioral belief) and, secondarily, the extent to which the individual desires the outcome (outcome evaluation). Finally, the perceived behavioral control construct represents an individual's assessment of his or her own ability to ride a bike (or e-bike) in the context of potential external barriers (eg, bad weather). These constructs provided a framework for the development of all study surveys.

Analysis

All statistical analyses were performed using SAS version 9.4 (SAS Institute Inc). Descriptive statistics were used to summarize demographic data from survey 1. Paired *t* test statistics were calculated to compare beliefs of conventional bicycles and e-bikes as well as to compare mean heart rate and speed between conventional bicycle and e-bike use. Heart rates from each ride were also compared against the resting heart rate. A separate set of paired *t* test statistics of heart rate data stratified by gender was also conducted.

Results

Demographics

The majority of the participants were aged between 20 and 24 years, with the average age being 22 years. Most identified themselves as non-Hispanic whites. Most participants had completed college, but had not graduated, and approximately three-quarters of the study sample reported an annual income of less than US $30,000. Complete demographic information can be found in Table 1.

Table 1. Demographics of participants (N=33).

Demographics	n (%)
Age (years)	
18-19	3 (9)
20-24	27 (82)
25-34	3 (9)
Race	
Asian	2 (6)
White	31 (94)
Ethnicity	
Not Hispanic or Latino	33 (100)
Gender	
Male	20 (61)
Female	13 (36)
Education level	
High school or GED[a]	1 (3)
Some college (not graduated)	27 (82)
2-year college degree	2 (6)
4-year college degree	3 (9)
Annual household income[b]	
Less than 30,000	24 (73)
40,000-49,999	1 (3)
60,000-69,999	1 (3)
70,000-79,999	1 (3)
100,000 or more	6 (18)

[a]GED: General Educational Development.

[b]All values are in 2017 US $.

Table 2. Transportation methods (N=33).

Transportation methods	n (%)
Participants own the following	
Bike	20 (61)
E-bike	0 (0)
Car or truck	24 (73)
Motorcycle or motor scooter	1 (3)
What is your most frequent method of transportation?	
Walk	12 (36)
Bicycle	5 (15)
Drive	15 (46)
Public transportation	1 (3)
How do you usually get to and from the following locations?	
School	
Walk	19 (58)
Bicycle	8 (24)
Public transportation	0 (0)
Drive	6 (18)
Social engagements (parties, religious events, concerts, sporting events)	
Walk	6 (18)
Bicycle	2 (6
Public transportation	1 (3)
Drive	23 (70)
Other	1 (3)
Work	
Walk	11 (33)
Bicycle	4 (12)
Public transportation	0 (0)
Drive	17 (52)
Other	1 (3)
Stores or shops	
Walk	1 (3)
Bicycle	4 (12)
Public transportation	0 (0)
Drive	27 (82)
Other	1 (3)
What obstacles are the most challenging in using bicycles for transportation purposes (select all that apply)?	
Safety concerns	10 (30)
Lack of dedicated bike paths	10 (30)
Decreased convenience	12 (36)
Time	13 (39)
Physical exertion	4 (12)
Inclement weather	14 (42)
Cost	6 (18)

Transportation methods	n (%)
Perceived negativity associated with biking	1 (3)
Other (open-ended)	
Lack of bike racks at destination	1 (3)
Time of day and darkness or cold	1 (3)
Do you consider using a bicycle for transportation to be viewed negatively among your peers?	
Definitely not	17 (52)
Probably not	11 (33)
Might or might not	4 (12)
Probably yes	1 (3)
Definitely yes	0 (0)
What benefits do you see in using bicycles for transportation? (open-ended)	
Cheaper	15 (45)
Environmentally friendly	12 (36)
Exercise	23 (70)
Fun	5 (15)
Faster than walking	5 (15)
Can get exercise and transport at same time	4 (12)
No time spent looking for parking	3 (9)

Transportation Methods

Responses to survey items about transportation methods revealed that 61% (20/33) of individuals owned a bicycle, while 73% (24/33) owned a car or truck and no participants owned an e-bike. Participants reported using a car or truck for transportation for an average of 17 days (median: 20 days) in a normal month and using a bike an average of 8.52 days (median: 1 day). Driving a standard motorized vehicle and walking were the 2 most frequent methods of transportation among study participants. Only 15% (5/33) of individuals reported biking as their most frequent method of transportation, but approximately one-third (12/33) indicated they rode a bike 2 or more times per week. A total of 7 participants indicated that they had previously ridden an e-bike. The majority of participants either walked or biked to school (university); however, most participants reported driving to social engagements, work, and stores or shops. When asked about which obstacles prevented riding a bicycle, 42% (14/33) identified inclement weather, followed by time, decreased convenience, lack of dedicated bike paths, and safety concerns. Finally, when asked about the perceived benefits associated with using a bicycle for transportation, 70% (23/33) of respondents cited exercise. Complete information on transportation methods can be found in Table 2.

Attitudes

Participants generally felt that using conventional bicycles and e-bikes for transportation purposes would help the environment, benefit their physical health, benefit their mental or emotional health, and save them money (Table 3). Paired *t* test analysis revealed that participants believed that a conventional bicycle was more likely than an e-bike to benefit their physical health (P=.002) and save them money (P=.005). Conversely, participants believed that the e-bike was more likely than a conventional bicycle to save them time (P<.001).

Participants also generally felt that improving the environment, improving their physical health, improving their mental or emotional health, saving money, and saving time were “extremely good” (Table 4). Paired *t* test analysis showed that these feelings did not change from the conventional bicycle ride to e-bike ride (all P values >.05). Note that a few participants elected not to respond to these questions, as indicated in the table.

Subjective Norms

When asked about the subjective norms related to riding a conventional bicycle or an e-bike for transportation purposes, participants generally agreed that their parents, friends, people who care about them, and people they look up to are supportive of them (Table 5). Paired *t* test analysis indicated that these feelings did not change when comparing the conventional bicycle with the e-bike (all P values >.05).

Perceived Behavioral Control

Paired *t* test analysis revealed that compared with their views after riding the conventional bicycle, participants significantly agreed more with the statements that they could ride an e-bike on most days (P=.006), in the cold (P<.001), when they are tired (P=.007), when they are dressed in formal attire (P<.001), when carrying personal effects (backpack, groceries, books, etc; P=.03), on longer trips (P=.006), and on steep or hilly terrain (P<.001).

Table 3. Behavioral beliefs (N=33).

Behavioral belief[a]	Descriptive statistics, mean (SD)		Paired *t* test: bike versus e-bike	
	Bike	E-bike	Mean difference	*P* value
Complete the following statement: Riding a bike or an e-bike for transportation purposes would…				
Help the environment	1.48 (0.67)	1.39 (0.56)	0.09	.52
Benefit my physical health	1.09 (0.29)	1.58 (0.79)	−0.48	.002
Benefit my mental or emotional health	1.33 (0.54)	1.42 (0.56)	−0.09	.41
Save me money	1.42 (0.66)	1.94 (0.93)	−0.52	.005
Save me time	3.18 (1.10)	2.12 (1.02)	1.06	<.001

[a]Variables were coded using the following logic: 1=extremely likely, 2=somewhat likely, 3=neither likely nor unlikely, 4=somewhat unlikely, 5=extremely unlikely.

Table 4. Outcome evaluations (N=33).

Outcome evaluation[a]	Descriptive statistics, mean (SD)		Paired *t* test: bike versus e-bike	
	Bike	E-bike	Mean difference	*P* value
Please note your feelings toward the following statements:				
Improving the environment is…	1.27 (0.52)	1.23 (0.43)[b]	0[b]	>.99[b]
Improving my physical health is…[c]	1.03 (0.18)[c]	1.03 (0.18)[b]	0[d]	>.99[d]
Improving my mental or emotional health is…	1.00 (0)	1.07 (0.25)[d]	−0.07[d]	.16[d]
Saving money is…	1.09 (0.29)	1.09 (0.30)[c]	0[c]	>.99[c]
Saving time is…	1.21 (0.48)	1.19 (0.40)[c]	0.03[c]	.57[c]

[a]Variables were coded using the following logic: 1=extremely good, 2=somewhat good, 3=neither good nor bad, 4=somewhat bad, 5=extremely bad.
[b]n=31.
[c]n=32.
[d]n=30.

Table 5. Subjective norms (N=33).

Subjective norms[a]	Descriptive statistics, mean (SD)		Paired *t* test: bike versus e-bike	
	Bike	E-bike	Mean difference	*P* value
Please note your feelings toward the following statements:				
My parents are supportive of me riding a bike or an e-bike for transportation purposes	1.06 (0.24)	1.12 (0.33)	−0.06	.16
My friends are supportive of me riding a bike or an e-bike for transportation purposes	1.21 (0.42)	1.12 (0.33)	0.09	.08
People who care about me are supportive of me riding a bike or an e-bike for transportation purposes	1.09 (0.29)	1.09 (0.29)	0	>.99
People I look up to are supportive of me riding a bike or an e-bike for transportation purposes	1.09 (0.29)	1.18 (0.39)	−0.09	.08

[a]Variables were coded using the following logic: 1=true, 2=false.

Table 6. Perceived behavioral control (N=33).

Perceived behavioral control[a]	Descriptive statistics, mean (SD)		Paired *t* test: bike versus e-bike	
	Bike	E-bike	Mean difference	*P* value
I believe that I can ride a bike or an e-bike for transportation purposes...				
Most days	1.97 (0.88)	1.55 (0.71)	0.42	.006
In the cold	3.15 (1.25)	2.52 (1.25)	0.64	<.001
In the heat	1.94 (0.93)	1.73 (0.94)	0.21	.15
In the rain	3.3 (1.38)	3.09 (1.26)	0.21	.27
In the snow	4.15 (1.12)	4 (1.15)	0.15	.30
In the daylight	1.21 (0.48)	1.09 (0.29)	0.12	.10
In the dark or at night	2.52 (1.33)	2.15 (1.23)	0.36	.08
When I am tired	2.39 (1.12)	1.88 (0.93)	0.52	.007
When I am dressed in casual attire	1.3 (0.59)	1.21 (0.42)	0.09	.37
When I am dressed in formal attire	3.45 (1.3)	2.7 (1.26)	0.76	<.001
When traffic is heavy	2.42 (1.17)	2.18 (1.18)	0.24	.19
When traffic is light	1.42 (0.9)	1.24 (0.61)	0.18	.08
When there is a dedicated bike lane	1.27 (0.45)	1.18 (0.39)	0.09	.26
When there is a dedicated bike path	1.15 (0.36)	1.09 (0.29)	0.06	.32
When I am rushed or in a hurry	2.85 (1.39)	2.33 (1.34)	0.52	.05
When I am with a group of friends	3.24 (1.37)	2.82 (1.47)	0.42	.06
When carrying personal effects (backpack, groceries, books, etc)	2.97 (1.38)	2.48 (1.28)	0.48	.03
On shorter trips (<1 mile)	1.36 (0.90)	1.36 (0.70)	0	>.99
On longer trips (>1 mile)	2.12 (1.11)	1.61 (1.06)	0.52	.006
On flat terrain	1.09 (0.29)	1.12 (0.33)	−0.03	.57
On steep or hilly terrain	2.42 (1.15)	1.64 (0.93)	0.79	<.001

[a]Variables were coded using the following logic: 1=strongly agree, 2=somewhat agree, 3=neither agree nor disagree, 4=somewhat disagree, 5=strongly disagree.

Distance, Time, Speed, and Heart Rate Metrics

Participants traveled approximately 10 miles (approximately 16 km) while following the dedicated path. Paired *t* test analysis (Table 7) revealed participants completed the course on an average of 14 min and 34 s faster when using e-bikes as opposed to conventional bicycles (*P*<.001). The mean average speed of travel on the e-bike was faster than on the conventional bicycle (*P*<.001), as was the mean maximum speed of travel on the e-bike (*P*<.001). Participants' mean average heart rate during the e-bike ride was lower than that during the conventional bike ride (*P*=.04; see Figure 1). The average heart rate above resting during the e-bike ride was 51.76 beats per minute (bpm), which is 89% (51.76/57.97) of the average heart rate above resting during the conventional bike ride. When looking at the mean heart rate by gender, the trends were similar in direction and magnitude. In paired *t* test analyses, the mean average heart rate for males and females during the e-bike ride was lower than that during the conventional bike ride; however, these findings were not statistically significant (*P*=.11 and *P*=.24, respectively). The mean MHR of participants during the rides was higher while on the conventional bicycle compared with the e-bike, but this difference was not statistically significant (*P*=.26). The mean average heart rate during both the conventional bike ride and the e-bike ride was faster than the mean resting heart rate. Both were also significantly higher than the resting heart rate (*P*<.001). With a mean age of 22 years, participants' estimated MHR was 198 bpm (this was calculated using the formula 220−age as described in the Methods). The target average heart rate range for moderate-intensity exercise (50%-70% of MHR) was then calculated to be 99 bpm to 138.6 bpm (0.5×198=99; 0.7×198=138.6) [38].

Table 7. Comparison of distance, time, speed, and heart rate metrics (n=31).

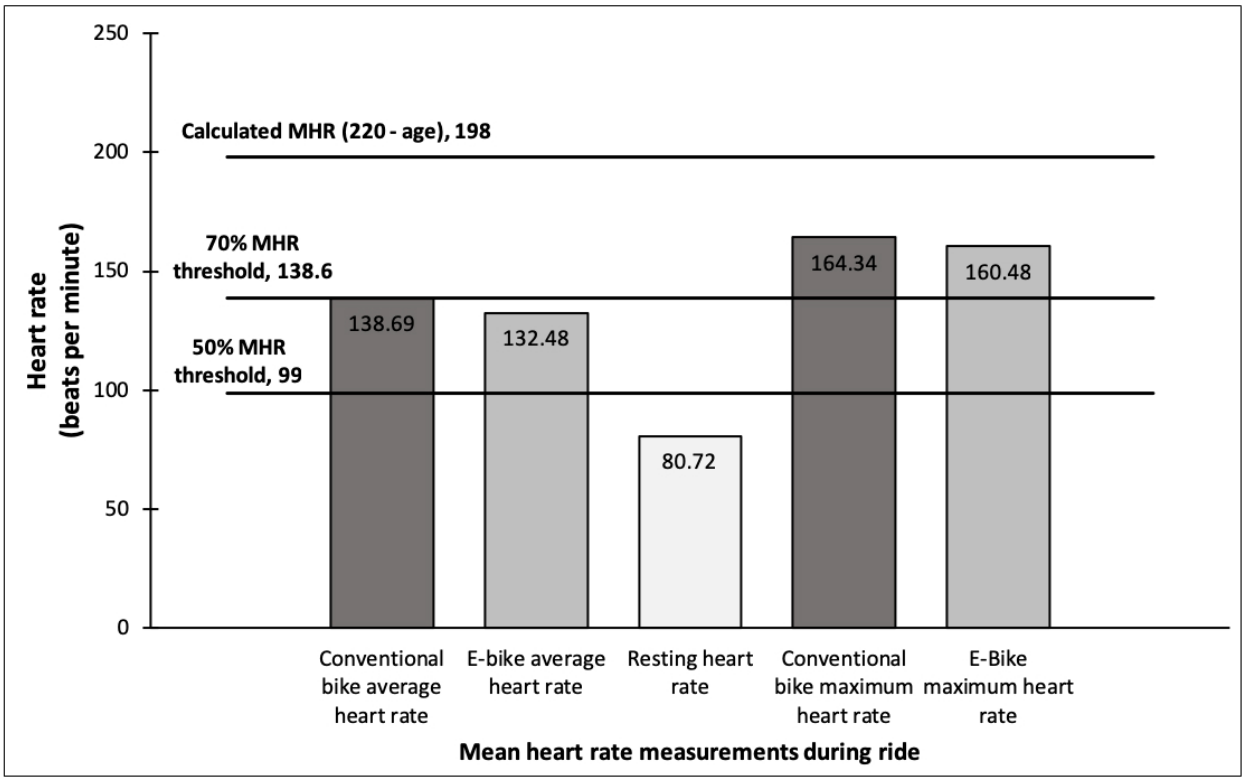
Metric	Descriptive statistics, mean (SD)		Paired *t* test: bike versus e-bike	
	Bike	E-bike	Mean difference	*P* value
Ride duration (minutes:seconds)	53:37 (10:55)	39:02 (6:24)	14:34	<.001
Average speed (miles per hour)	12.26 (1.94)	16.37 (2.27)	−4.11	<.001
Top speed (miles per hour)	21.86 (3.96)	27.02 (2.44)	−5.15	<.001
Average heart rate[a] (bpm[b])	138.69 (16.59)	132.48 (14.10)	6.21	.04
Maximum heart rate[a] (bpm)	164.34 (17.74)	160.48 (16.31)	3.86	.26
Resting heart rate[a] (bpm)	80.72 (15.02)	N/A[c]	N/A	N/A
Resting heart rate versus average heart rate (conventional bike ride)[a] (bpm)	N/A	N/A	−57.97	<.001
Resting heart rate versus average heart rate (e-bike ride)[a] (bpm)	N/A	N/A	−51.76	<.001

[a]n=29.

[b]bpm: beats per minute

[c]N/A: not applicable.

Figure 1. Comparison of heart rate metrics. MHR: maximum heart rate.



Discussion

Principal Findings

The purpose of this study was to compare e-bikes with conventional bicycles in answering the following questions: (1) what proportion of the health benefits are retained when using an e-bike as compared with using a conventional bicycle? and (2) what are the attitudes and beliefs toward e-bikes after riding one and how do those compare with attitudes and beliefs toward conventional bicycles? While significant differences in heart rate were measured between conventional bicycle and e-bike use, results indicate that both equated to significantly higher heart rates than were recorded at rest. In particular, when using average heart rate as a proxy for the health benefits of cycling, e-bike use retained 89% of the cardiovascular health benefits gained from riding a conventional bike. Furthermore, mean scores indicate that participants' average heart rate was well within the target heart rate range of 50% to 70% of MHR for moderate-intensity physical activity (132.48 bpm, or approximately 67% [132.48/198] of estimated MHR) while

riding the e-bike [38]. Therefore, e-bike use in this study retained the majority of the cycling cardiovascular health benefits and met established biometric thresholds for cardiovascular fitness. This finding is comparable with a similar finding in another study, in which e-bike users reached a mean heart rate of 69% and 67% of an estimated MHR in the ECO (eco support) and POW (power support) of the e-bike models used [35]. The findings from this study confirm the findings in previous studies that e-bikes can satisfy requirements for moderate-intensity physical activity [10,12,13,31,34-36]. In particular, the trends of the mean heart rate measurements were comparable with other studies, with the e-bike mean heart rate being lower than the mean heart rate on a traditional bike or a bike without electric motor assistance [34,35]. However, mean heart rate measurements did vary somewhat, which may be explained by the participants being required to stop and get off the bike in one study (lower mean heart rates) [35] or the hilly environment of the other study (higher mean heart rates) [34].

In general, participants' attitudes toward conventional bicycles differed in several distinct ways as compared with e-bikes. In relation to physical health benefits and cost-saving measures, participants favored the conventional bicycle. These findings are understandable as heart rate results did indeed show that riding the conventional bicycle required increased physical exertion, and the retail price of the e-bikes used in this study was approximately 5 times higher than the retail price of the conventional bicycles. However, participants reported comparatively more favorable attitudes toward e-bike use on several survey items. First, participants indicated that e-bikes were more likely to save them time—a belief backed by the results showing an increase in speed when riding an e-bike. Next, participants indicated they were more likely to ride e-bikes for everyday use in adverse conditions, including cold weather, when physically tired, when dressed in formal attire, when carrying personal effects, on longer trips, and on steep or hilly terrain. When taken together, these results demonstrate a belief that e-bikes are easier to ride, similar to the finding in a previous study that e-bikes are more enjoyable to ride and result in lower levels of perceived exertion [31]. Therefore, this study supports the idea that e-bikes may act as a catalyst in helping individuals clear some of the personal barriers to active transport cycling. Additional research in this area may be useful to understand the causes of these attitudes, including separately analyzing data from individuals who own bicycles, prefer bicycles as a mode of transportation, and those who use them frequently.

Limitations

Challenges encountered during the bicycle-riding portion of this study included technical difficulties with the e-bikes and the Apple Watches. During the e-bike rides, 2 participants experienced technical difficulties with the e-bikes in which the batteries were not functioning properly and, therefore, not providing assistance for the entire duration of the ride. Because of this, the time, speed, distance, and heart rate measurements for these 2 participants were excluded from the analysis. These issues may have also affected the participants' views of the bikes' functionality. In addition, the heart rate measurement function of the Apple Watches did not work properly for 2 participants' and their heart rate measurements were, therefore, excluded from the analysis. Also, GPS tracking data gathered through the Strava app on each Apple Watch are prone to some error, yielding distance measures that varied slightly between participants, despite all participants riding the same route. These variations were examined and determined to be random, equally distributed across both the conventional and e-bike rides, and impacted measures by less than 0.2 miles over the course of the ride.

One potential bias in this study is a social desirability bias. Social desirability bias drives an individual to answer in a way that makes them look more favorable to the experimenter or to society. Participants may have sensed that researchers wanted the e-bikes to be viewed more positively and may have answered accordingly. The surveys were, however, administered online so the participants could answer questions in private. A future study could randomly assign some participants to ride the e-bike first, and some to ride the normal bike first, to mix up the order and perhaps reduce this bias. Recall bias may also have influenced participants' responses, as participants took the surveys at varying times and may have remembered their experience differently as a result of this variation. This, however, is not expected to be a large bias, as participants are likely to accurately remember such a unique experience.

The survey that collected demographic information asked participants to report a combined annual household income. Despite being university students, 6 participants reported household incomes above US $100,000, likely because they were still living at home and reported their parents' incomes. A future study among university students should ask for a personal income, as that will likely be of greater interest to researchers. Finally, the study population was neither very diverse nor very large, even for a pilot study, making its findings less generalizable to other populations. A future, larger study should seek out a more diverse population regarding age, race or ethnicity, and income level. The limited sample for this pilot study is not likely to have impacted the biometric estimates, but it could have had an effect on the measures of attitudes and beliefs.

Conclusions

This pilot study suggests that e-bikes are an active form of transportation capable of providing much of the cardiovascular health benefits obtained during conventional bike use. Participants reported that they were more likely to use an e-bike for everyday transportation than a traditional bike and were still able to meet established criteria for moderate-intensity physical activity during e-bike use. While still providing an opportunity for physical activity, these findings suggest that e-bikes may help reduce several key personal factors known to be obstacles to conventional bike use, such as increased transportation time, decreased convenience, and physical fatigue. These findings also suggest that public health officials should advocate for the daily use of e-bikes as a novel means of meeting physical activity recommendations through active transportation, all while mitigating the effects of traditional barriers to active transport cycling. E-bike manufacturers could also frame their product development and marketing practices in light of these findings by seeking to develop more cost-friendly e-bike options

and by marketing their e-bikes as a means of reaching activity guidelines while avoiding inconveniences of traditional cycling. E-bike manufacturers could also expand their marketing to individuals who may be otherwise reluctant to engage in physical activity, such as older or overweight individuals.

As this is a pilot study, these results would benefit from being confirmed in a larger and more representative sample. In addition, future studies would benefit from including other energy-expenditure outcome measures, such as human power output and tests related to oxygen consumption. Future research should explore how e-bike use might improve environmental health indicators by potentially decreasing reliance on standard motorized vehicles and fossil fuels, decreasing noise and air pollution, and relieving traffic and parking congestion. Future studies would benefit from the application of a similar research design to populations who may be less inclined to use active forms of transportation, such as older individuals, obese or overweight individuals, and those who may be impacted by physical injury or impairment. In addition, this study could also be extended to the use of electric pedal-assist mountain bikes, or eMTBs, on soft-surface and off-road trails.

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Conflicts of Interest

None declared.

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Abbreviations

bpm: beats per minute
E-bike: electric pedal-assist bicycle
eMTB: electric pedal-assist mountain bicycle
GED: General Educational Development
GPS: global positioning system
MHR: maximum heart rate
TPB: theory of planned behavior

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Original Paper

How Twitter Can Support the HIV/AIDS Response to Achieve the 2030 Eradication Goal: In-Depth Thematic Analysis of World AIDS Day Tweets

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Abstract

Background: HIV/AIDS is a tremendous public health crisis, with a call for its eradication by 2030. A human rights response through civil society engagement is critical to support and sustain HIV eradication efforts. However, ongoing civil engagement is a challenge.

Objective: This study aimed to demonstrate the use of Twitter data to assess public sentiment in support of civil society engagement.

Methods: Tweets were collected during World AIDS Days 2014 and 2015. A total of 39,940 unique tweets (>10 billion users) in 2014 and 78,215 unique tweets (>33 billion users) in 2015 were analyzed. Response frequencies were aggregated using natural language processing. Hierarchical rank-2 nonnegative matrix factorization algorithm generated a hierarchy of tweets into binary trees. Tweet hierarchy clusters were thematically organized by the Joint United Nations Programme on HIV/AIDS core action principles and categorized under HIV/AIDS Prevention, Treatment or Care, or Support.

Results: Topics tweeted 35 times or more were visualized. Results show a decrease in 2015 in the frequency of tweets associated with the fight to end HIV/AIDS, the recognition of women, and to achieve an AIDS-free generation. Moreover, an increase in tweets was associated with an integrative approach to the HIV/AIDS response. Hierarchical thematic differences in 2015 included no prevention discussion and the recognition of the pandemic's impact and discrimination. In addition, a decrease was observed in motivation to fast track the pandemic's end and combat HIV/AIDS.

Conclusions: The human rights–based response to HIV/AIDS eradication is critical. Findings demonstrate the usefulness of Twitter as a low-cost method to assess public sentiment for enhanced knowledge, increased hope, and revitalized expectations for HIV/AIDS eradication.

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KEYWORDS

community; human rights; social network; infodemiology; infoveillence; Twitter

Introduction

Background

The United Nations' sustainable development goals (SDGs) seek a holistic and balanced approach to social, economic, and environmental aspects of development [1,2]. The SDGs emphasize the need to advance and complete the objectives set forth by the millennium development goals (MDGs), including a call to end the HIV/AIDS pandemic by 2030 [1,3,4]. An effective response to the pandemic's end demands critical, dedicated, and sustained action. However, the SDGs [2] have a broad health goal that does not recognize HIV/AIDS as a distinct focus area [1-3]. This is a result of the vertical prioritization of HIV/AIDS during the 2000 to 2015 MDG period [4] that reduced the allocation of resources from other important health issues [1,2,5]. With limited visibility in the post-2015 agenda and lack of additional resources to scale up efforts [1,6], achieving the 2030 eradication goal is of great concern.

The MDGs resulted in the expansion of 15 million people living with HIV/AIDS (PLWH) on life-saving antiretroviral (ARV) drugs [1,3,4,7]. Although the need to scale up and sustain these biomedical solutions is recognized, human rights issues (eg, stigma, marginalization, and discrimination) still serve as pervasive barriers to successful adoption of the goal to end new HIV infections by 2030 [3,8]. However, if HIV/AIDS is not perceived as an ongoing global health emergency, the necessary services and resources to sustain and expand eradication efforts will rapidly diminish. Grassroots activism [8-10] and civil society mobilization [10,11] are critical driving forces for the advancement of human rights and play a major role in the global response to HIV/AIDS [12]. Early in the pandemic, civil society organizations understood the limitations of a solely biomedical focus and need to advance a human rights approach, which resulted in the global scale-up of access to ARVs [3,11]. Further strengthening of the human rights response can support and sustain eradication efforts. According to the Joint United Nations Programme on HIV/AIDS (UNAIDS), strong civil society engagement is critical to the eradication of HIV/AIDS [11,12]. Ongoing human rights–related efforts, which include giving voices to PLWH and empowering marginalized populations, are essential for the successful mobilization of treatment and prevention resources [10]. In fact, the SDGs demand grassroots activism [4,8,9,11] and call for a greater investment and support of civil society to achieve the eradication goal [1,2,13]. Effective civil society activism [8,11] must engage advocacy networks, private and public institutions, and global policy makers to advance the 2030 campaign [14]. However, the life cycle of activism [8,9,12] and its ability to sustain influence and engage citizens is one of the greatest challenges and opportunities to the eradication of HIV/AIDS. Furthermore, the success of civil society activism [8,9] lies in exploration of public sentiment to guide the effective exchange of information for improved knowledge, increased hope, and revitalized expectations [11,12].

Objective

The utilization of social networking sites (SNSs) for civil society activism [8,9] is a promising approach to help sustain and drive HIV/AIDS-related social movements. SNSs, such as Twitter, have played a vital role in the organization of global movements [15]. Twitter is a very powerful and popular microblogging communication tool [16]. Users share information through 280-character messages called tweets. Information is disseminated through direct messages or the forwarding (retweeting) of messages for broad propagation [15,17]. In the field of infodemiology and digital surveillance (infoveillance), Twitter is effectively used to predict disease outbreaks, including the flu and HIV, and has informed a variety of public health efforts [18-20]. Public sentiment, expressed in tweets, provides a wealth of information to be used by public health professionals, politicians, governmental entities, activists, and computer scientists; to engage in purposeful discussions; and to play active roles on a variety of topics [11,16,17]. Moreover, Twitter has the capability to identify health beliefs and to support interventions and health campaigns for improved motivation and behavior. Twitter is also used effectively to assess and address health information needs during disease outbreaks, such as Ebola [15,17,21,22]. With more than 645 million registered users and the distribution of more than 58 million tweets daily, Twitter is a reliable source to track public sentiment and guide discussions for effective health awareness campaigns [14,17,21]. Public motivation is essential to sustain the global HIV/AIDS response and to achieve our global eradication goals. This study aimed to demonstrate the use of Twitter to explore HIV/AIDS public sentiment at 2 separate time points [15] to help guide social movements in support of HIV/AIDS eradication efforts, which are guided by UNAIDS core action principles of a comprehensive HIV/AIDS response [23] and commitments necessary to reach the 2030 goal of HIV prevention, treatment, care, and support. World AIDS Day, held on first of December every year, provides an ideal opportunity to assess public sentiment as people unite worldwide to support PLWH, to honor those lost, and to combat HIV/AIDS [24]. Our study provides a unique and in-depth analysis of World AIDS Day tweets in 2014 and 2015.

Methods

Tweet Corpus

During the World AIDS Days of December 1, 2014, and December 1, 2015, tweets about HIV/AIDS were collected from Twitter via a Google Chrome–based version of NCapture, a Web crawler that captures internet-based text [25]. The streaming application programming interface allowed for the capture of a limited sample of all tweets (eg, 18,000 tweets per 15 min) [25]. To overcome the challenges of time and amount limits, tweets were collected in 15-min intervals for a representative sample [25]. Keywords were used for searching tweets that mentioned HIV/AIDS (eg, #HIVtreatment, #HIVservices, #HIVprogramming, and #HIVprevention). Additional data elements collected were time stamps, content, and geographical locations from IP addresses, usernames, message type (unique or retweet), and followers (number of disseminated) [25]. English language tweets were included in the analysis, with 39,940 unique tweets (10,027,038,772 users) in 2014 and 78,215 unique tweets (33,370,938,359 users) in 2015.

Natural Language Processing

Natural language processing was conducted to identify and depict topics of collected tweets about HIV/AIDS. Tweets were cleaned and transformed to a vector form and N-gram [25]. An N-gram is a subsequence of N items in a given sequence from characters to words. The N-gram method was used to compute a tweet term–frequency dictionary [25]. Notepad++v7.2.2 developed by Don Ho and Weka 3.7 developed by the University of Waikato in New Zealand both are open source software reduced the dimensionality for the algorithmic processing of the data. Snowball stemmers were used to apply the stemming algorithm, Porter algorithm, an affix-removal approach, which was applied through Weka [25]. To further remove dimensionality, stemming was conducted to identify a word root and to remove suffixes and prefixes. Tweet topics were detected and summarized through descriptive statistics (eg, frequency, defined as the aggregate number of times a topic is tweeted), classification, visualization, and clustering.

Hierarchical Rank-2 Nonnegative Matrix Factorization Algorithm and Rank-2 Nonnegative Matrix Factorization

Clustering, the process of grouping a set of words into classes of similar topics, was conducted [26]. Hierarchical rank-2 nonnegative matrix factorization (HierNMF2) was used to determine the semantic organization of tweeted words [26,27]. Data were analyzed with the Python 2.7 software by the Python Software Foundation and were treated independently and analyzed separately by years. Tweet topic clusters were generated by HierNMF2 and visualized into tree nodes for 2014 and 2015 data to illustrate the topic structure. The HierNMF2 used for clustering generated a hierarchy of tweet themes into binary trees [26]. The hierarchy is automatically detected but does not always result in a balanced tree (Figure 1). A node-splitting rule was also employed to determine tree nodes to split from the original binary nodes. This methodology allows for the determination of tree structures. Data for each time point (2014 and 2015) were split into 2 clusters, creating a binary tree [26]. Rank-2 nonnegative matrix factorization (NMF) was applied to generate the hierarchical tree structure. Each cluster created nonleaf nodes (nln). A score was computed for each nln using rank-2 NMF [26,27]. The nln with the highest scores were then split into leaf nodes (ln) of 2 or more well-separated topics. Specific details of algorithm development have been previously published by a coauthor (DK) [26,27].

Thematic Analysis

A coding framework was used to interpret and explore the data and to identify perceptions of the HIV/AIDS pandemic. Tweet hierarchy raw data clusters were characterized based on words in each cluster of nln and ln by subject matter experts (MO and RB; Figure 1). Hierarchical cluster analysis occurred iteratively, based on cluster content (eg, *cluster words*: "fight, today, support, cure, love"; *associated theme*: Combat HIV/AIDS). Major themes were refined through review and discussion, with our experts (MO and RB), to shape the final coding structure. Themes were organized based on UNAIDS core action principles (eg, *theme*: Combat HIV/AIDS; *principle*: Safeguard Human Rights) for guiding a comprehensive response to HIV/AIDS (Table 1). Themes were then categorized according to the commitments necessary to reach the SDG's 2030 goal [4]: Prevention, Treatment or Care, and Support (eg, *theme*: Combat HIV/AIDS; *principle:* Safeguard Human Rights; *commitment area*: Support).

Ethics committee approval was not required for Twitter analysis because tweets are deidentified with no identifiable information obtained.

Figure 1. An illustration of a nonleaf node N (Blue) and its 2 potential children split L (left) and R (right) in red into leaf nodes (primary analysis phase).

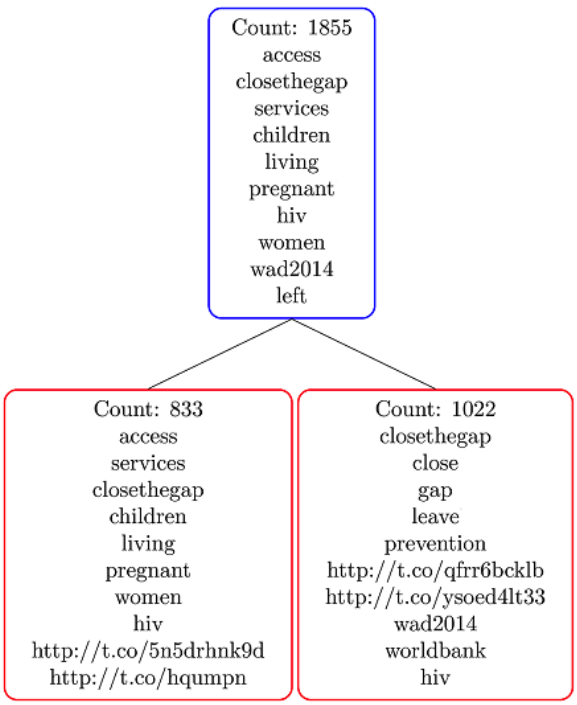


Table 1. Thematic analysis of 2014 and 2015 World AIDS Day tweet hierarchy.

Hierarchy—degree levels in hierarchy		Themes			World AIDS Day 2014	World AIDS Day 2015
2014	2015	Comprehensive Global Response to HIV/AIDS			Representative example tweets	
		UNAIDS[a] Core Actions		Prevention, Treatment or Care, and Support		
1	2	Prevention	Decrease Vulnerability of Acquiring HIV/AIDS	Informational Resources from Governmental Organizations	infographics, AIDS.gov	white house, AIDS.gov
4	5	Prevention	Decrease Vulnerability of Acquiring HIV/AIDS	Halt Infections	accessible, affordable, vaccine partnerships	epidemic, averted
5	4	Prevention	Decrease Vulnerability of Acquiring HIV/AIDS	AIDS-Free Generation	Close the gap	aids free gen, children
4	—	Prevention	Decrease Vulnerability of Acquiring HIV/AIDS	Prevent HIV/AIDS	aids prevention, HIV facts	—
5	3	Treatment or Care	Access to Services	Treatment for HIV/AIDS	Access, children, pregnant women services, closing the gap	treat, people
4	1	Treatment or Care	Access to Services	Save Lives: Infected and At Risk	cure	treatment for all
—	3	Treatment or Care	Access to Services	Impact of the HIV/AIDS Pandemic	—	millions, lives-end, children, can avert, infections-save, world
1	1	Treatment or Care	Expand Programs	Efforts for Targeted HIV/AIDS Eradication	facts, wipe homophobia, today	save, join, treatment for all
3	6	Treatment or Care	Expand Programs	Fast Track the End of the Pandemic	today, end, epidemic	unaids, fast track, treatment, response, assessing
4	2	Support	Safeguard human rights	Spread HIV/AIDS awareness	cure, love, sending, support, fight, amfar[b]	awareness, spread, end aids
5	3	Support	Safeguard human rights	Recognition of the Pandemic	unaware, United States, hiv	Aware, disease
4	1	Support	Safeguard human rights	Honor People Living with HIV/AIDS (PLWH)	honor, memory, continuing, lost, affected	living, people, positive, statement
4	2	Support	Safeguard human rights	Expression of HIV/AIDS Solidarity and Consciousness	wear, ribbon, close the gap	tee shirt ribbon
2	5	Support	Safeguard human rights	Combat HIV/AIDS	fight, today, support, cure, love	fight, helping
3	2	Support	Safeguard human rights	Support PLWH	sending, support, fight, cure	support, living, and people
4	2	Support	Partnerships and Alliances	Commitment to End the Pandemic	renew, vow, longer	statements, discrimination, make
2	5	Support	Partnerships and Alliances	Celebrities or Industries	mac[c] cosmetics viva glam, mac aids Fund	Kasper, rappers, Victoria Beckham
2	2	Support	Eliminate Stigma and Discrimination	Reduce Stigma	Lgbt[d], facts	stigma, end
—	3	Support	Eliminate Stigma and Discrimination	Discrimination of PLWH	—	discrimination, living, people

[a]UNAIDS: Joint United Nations Programme on HIV/AIDS.

[b]amfAR: American Foundation of AIDS Research.

[C]MAC: Make-up Art Cosmetics.

[d]LGBT: lesbian, gay, bisexual, and transgender.

Results

Response Frequencies

The geographic spread of HIV/AIDS-related tweets on World AIDS Days 2014 and 2015 spanned the globe (Figure 2). Top disseminators were United Nations agencies followed by celebrities, including singers, models, actors, and US governmental organizations and political figures.

Topics tweeted 35 times or more were aggregated. Response frequencies were generated and compared for increased and decreased frequency between 2014 and 2015. Results show increased frequency in tweets associated with an integrative approach to HIV prevention, treatment, and care (eg, community). An increase was also observed in the frequency of tweets associated with the recognition of barriers to HIV/AIDS eradication (eg, stigma). A moderate decline was observed in tweets associated with ending the epidemic (eg, fast track) and the provision or utilization of services (eg, access). A significant decrease in tweet frequency associated with combating the epidemic (eg, fight) was also observed (Figure 3).

Hierarchical Clusters of Tweets

World AIDS Day 2014 tweets were clustered into a binary tree: Informational Resources from Governmental Organizations versus Efforts for Targeted HIV/AIDS Eradication. The tweet cluster of *Efforts for Targeted HIV/AIDS Eradication* led to 2 nln. First, Reduce Stigma (nln) followed in order of descent by (1) Fast Track the End of the Pandemic (nln), (2) Expression of HIV/AIDS Solidarity and Consciousness (nln), (3) AIDS-Free Generation (ln), (4) Treatment for HIV/AIDS (nln), and (5) Recognition of the Pandemic (ln). Second, Combat HIV/AIDS (nln) followed in order of descent by (1) Celebrities or Industries (ln), (2) Support PLWH (nln), (3) Honor PLWH (nln), (4) Prevent HIV/AIDS (nln), (5) Spread HIV/AIDS Awareness (nln), (6) Commitment to End the Pandemic (ln), and (7) Save Lives: Infected and At Risk and Halt Infections (ln; Figure 4).

Figure 2. World AIDS Days 2014 and 2015: geographic location and top disseminators.

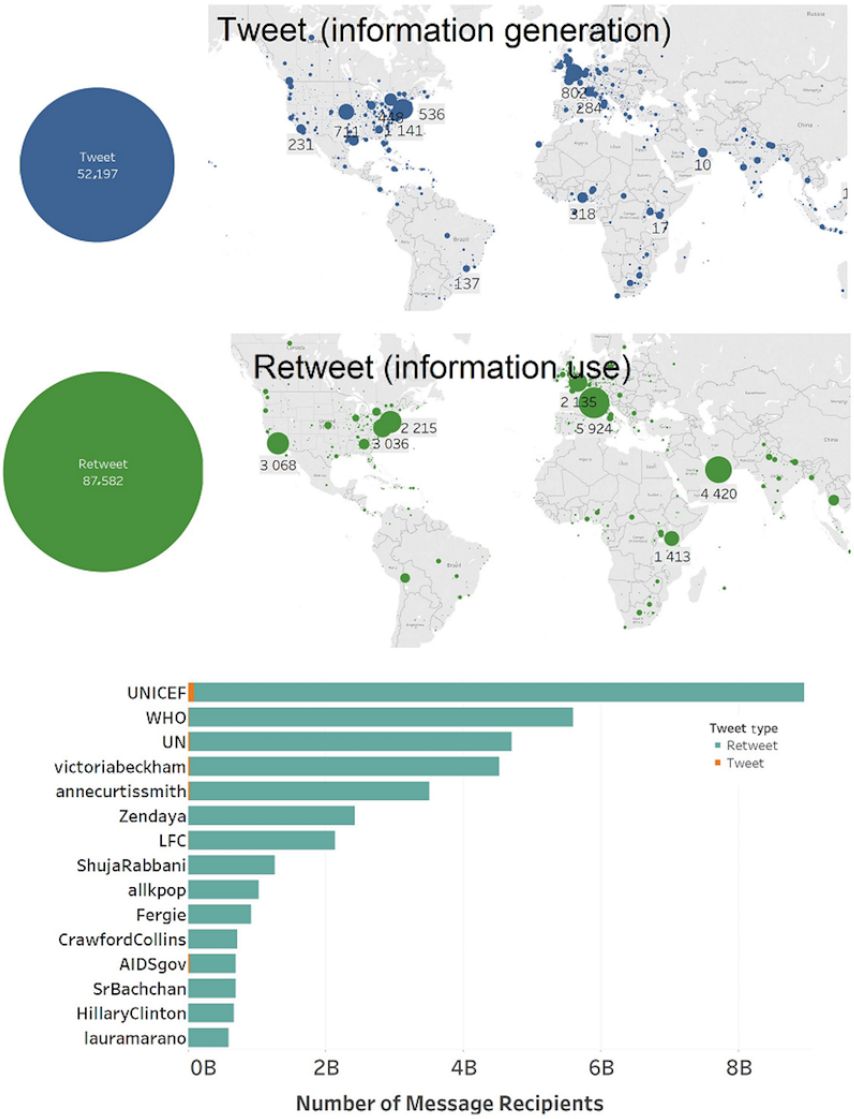


Figure 3. Shift in HIV/AIDS public sentiment: World AIDS Day tweets from 2014 to 2015.

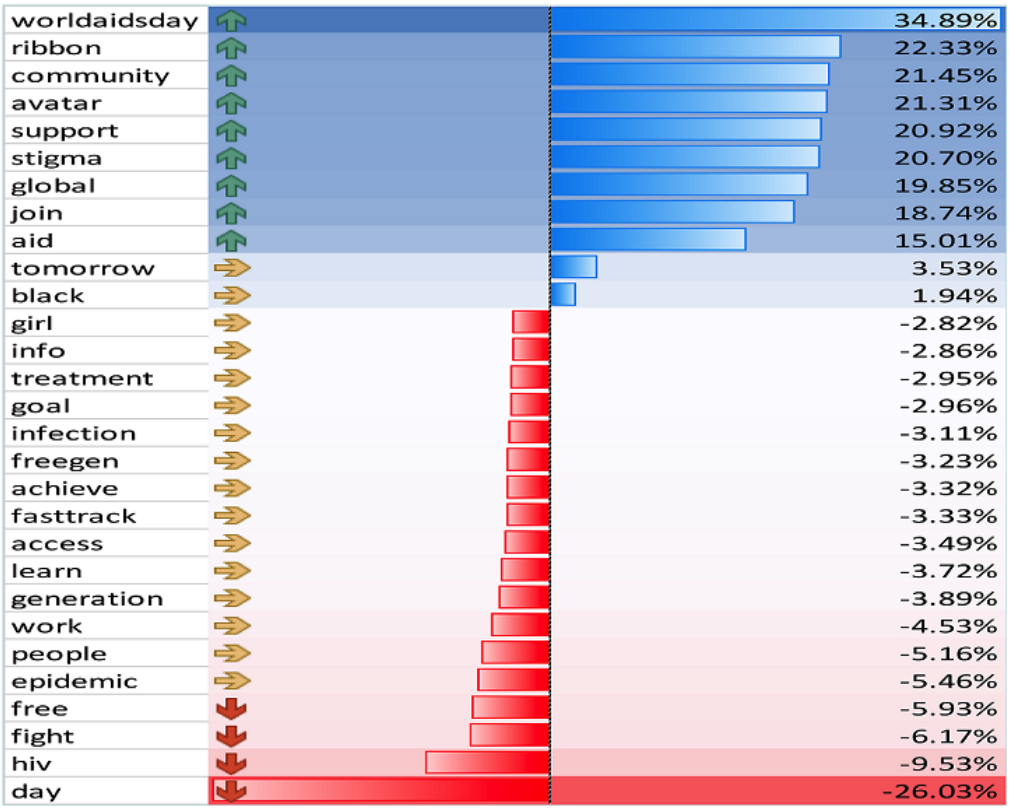


Figure 4. World AIDS Day 2014 tweet hierarchy.

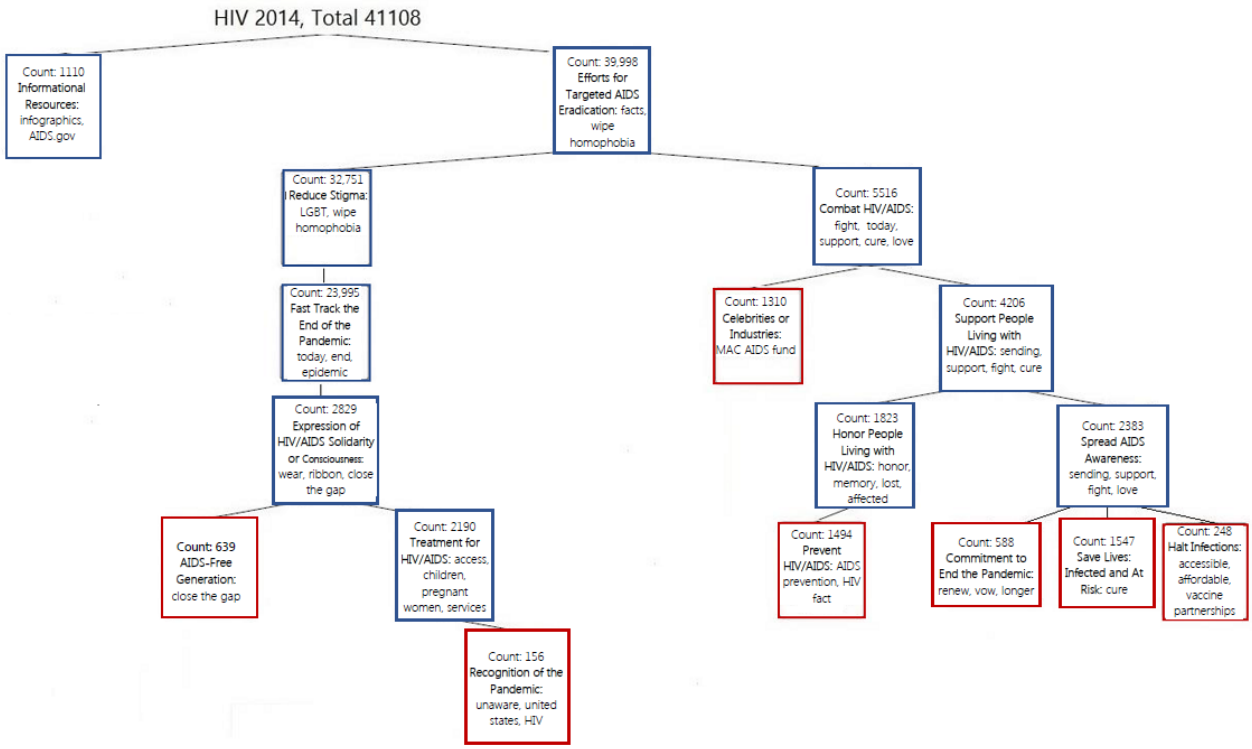
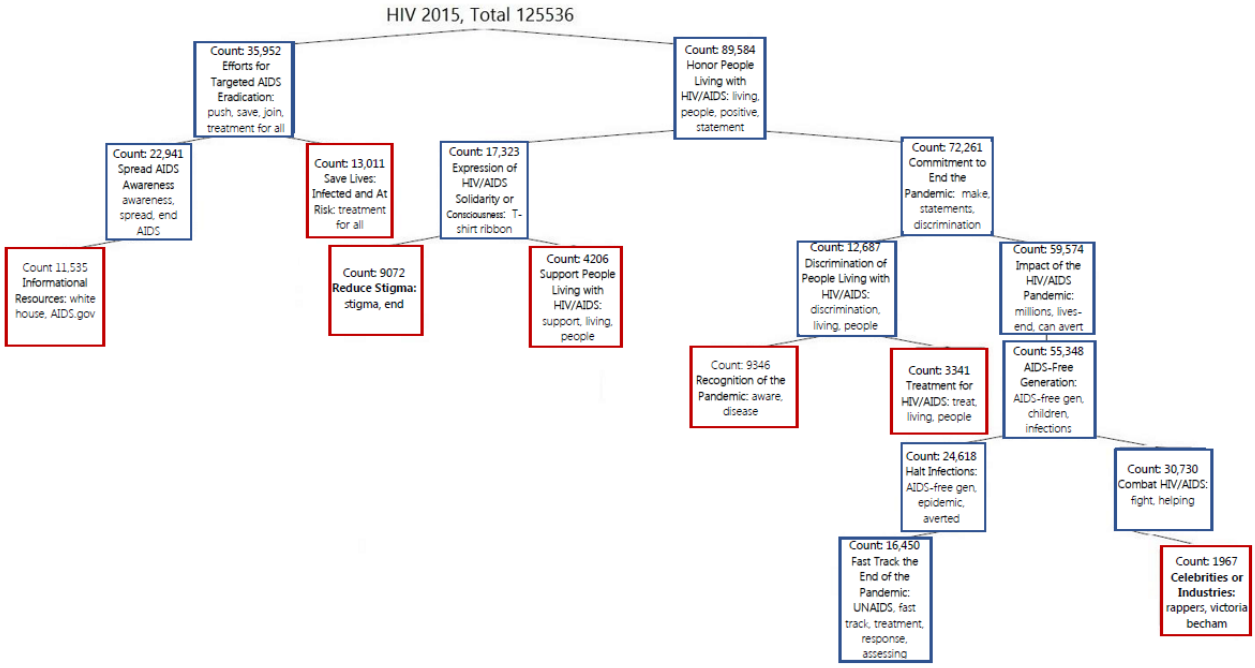


Figure 5. World AIDS Day 2015 tweet hierarchy.



World AIDS Day 2015 tweets were clustered into a binary tree: Efforts for Targeted AIDS Eradication versus Honor PLWH. The tweet cluster of *Efforts for Targeted HIV/AIDS Eradication* followed in order of descent by (1) Save Lives: Infected and At Risk (ln), (2) Spread HIV/AIDS Awareness (nln), and (3) Informational Resources from Governmental Organizations (ln). The tweet cluster of *Honor PLWH* followed in order of descent by (1) Expression of HIV/AIDS Solidarity (nln), (2) Reduce Stigma (ln), and (3) Support PLWH (ln) versus Commitment to End the Pandemic (ln) followed in order of descent by (4) Discrimination of PLWH (nln), (5) Recognition of the Pandemic (ln), and (6) Treatment for HIV/AIDS (ln) versus Impact of HIV/AIDS Pandemic (ln) followed in order of descent by (7) AIDS-Free Generation (nln), (8) Halt Infections (nln), and (9) Fast Track the End of the Pandemic (nln) versus Combat HIV/AIDS (nln) followed in order of descent by (10) Celebrities or Industries (ln; Figure 5).

Thematic Analysis

Prevention

In Prevention, 1 overarching theme emerged. The theme was *Decrease Vulnerability of Acquiring HIV/AIDS* and included the individual themes of (1) Informational Resources from Governmental Organizations, (2) Halt Infections, (3) AIDS-Free Generation, and (4) Prevent HIV/AIDS (2014 only).

Treatment or Care

In Treatment or Care, 2 overarching themes emerged: *Access to Services*, including the individual themes of (1) Treatment for HIV/AIDS (2015 increase), (2) Save Lives: Infected and At Risk (2015 increase), and (3) Impact of the HIV/AIDS Pandemic (2015 only), and *Expand Programs*, including the individual themes of (1) Efforts for Targeted HIV/AIDS Eradication and (2) Fast Track the End of the Pandemic (2015 decrease).

Support

In Support, 3 overarching themes emerged: *Safeguard Human Rights*, including the individual themes of (1) Spread HIV/AIDS Awareness (2015 increase), (2) Recognition of the Pandemic (2015 increase), (3) Honor PLWH (2015 increase), (4) Expression of HIV/AIDS Solidarity and Consciousness (2015 increase), (5) Combat HIV/AIDS (2015 decrease), and (6) Support PLWH; *Partnerships and Alliances*, including the individual themes of: (1) Commitment to End the Pandemic (2015 increase) and (2) Celebrities or Industries (2015 decrease); and *Eliminate Discrimination and Stigma*, including the individual theses of (1) Reduce Stigma and (2) Discrimination of PLWH (2015 only; Table 1).

Discussion

Principal Findings

HIV/AIDS is one of the greatest challenges to sustainable social, economic, and civil society development and affects all sectors of our society [1,6,11,28]. Strong civil engagement to drive social change remains critical to HIV/AIDS eradication [3,11]. This study demonstrated how the analysis of social media data, specifically Twitter, could inform purposeful discussions for effective civil society engagement. Our thematic analysis of the World AIDS Days 2014 and 2015 Twitter hierarchies identified public sentiment on a variety of human rights– and biomedical-related topics. The majority of themes fell primarily under Support, followed by Treatment or Care, and then Prevention. In fact, the theme *Prevent HIV/AIDS* was present only in 2014. Prevention words were not present in the 2015 hierarchy. An absence of this theme may reflect treatment as prevention because of the uptake of pre-exposure prophylaxis. This may indicate the need for purposeful discussion, as prevention needs are not only biomedical. Human rights–based prevention approaches will ensure a more permanent and

sustainable solution to achieve HIV eradication. The future cost of daily ARVs in developing countries is not sustainable [7]. Therefore, the revitalization of human rights–based initiatives is a priority. Early in the pandemic, human rights–based approaches focused on health equity and worked with populations living with and affected by HIV to expand ARVs in the pipeline to halt the spread of HIV [7,29]. The need exists for the constant engagement of civil society [7,11,12] in purposeful discussions to revitalize prevention campaigns [14].

Under Treatment or Care, the theme of *Impact of the Pandemic* was seen only in 2015. The emergence of this theme may reflect a heightened awareness or the recognition of the pandemic's effects on those infected and affected. The theme of *Efforts for Targeted HIV/AIDS Eradication* remained as a primary level theme in both years. In 2014, tweets discussed the elimination of homophobia and knowledge about HIV/AIDS. Tweets from 2015 discussed treatment, saving lives, and joining efforts. Although discrimination was present in 2015, the recognition of homophobia was seen only in 2014. This may indicate a need for purposeful discussion, particularly on the importance of supporting key populations [30]. The theme of *Fast Track End of the Pandemic* decreased 3 levels on the hierarchy in 2015. In 2014, tweets discussed the end of the pandemic, an indication of action and words of excitement. In 2015, tweets called for an assessment of the HIV/AIDS response. With 2015 marking the end of the MDGs, this may reflect our shortfall of the 2015 goals and the need for improved effort under the SDGs [3].

In 2015, all themes increased on the hierarchy under Support, except *Combat HIV/AIDS*, which decreased 3 levels. This theme comprises action words necessary to end the pandemic, including fight and support. The shift may be an indicator of lost enthusiasm, similarly discussed under Treatment or Care. It is also important to note the absence of such words based on our response frequency analysis. Decreases were observed in tweets associated with efforts to eradication (eg, AIDS-free generation). This may further reflect the need to re-engage the public in purposeful discussions and to reinvigorate grassroots efforts [10]. The theme *Reduced Stigma* remained a second-level tweet in 2015, with 2014 data acknowledging the lesbian, gay, bisexual, transgender, and queer community and 2015 data discussing the need to end stigma [8,11,30,31]. Maintaining this discussion is critical, as key populations are disproportionately affected by HIV/AIDS. Key populations are criminalized, marginalized, and plagued with stigma [32] and contribute to HIV risk [8,31]. Essential services for prevention are often unavailable to these groups [30]. Furthermore, HIV-associated stigma also contributes to poor HIV treatment and care access [30]. The theme of *Discrimination of PLWH* emerged in 2015. This may potentially reflect the November 2014 UNAIDS Fast-Track Strategy report, with zero discrimination recognized as the main target to end HIV/AIDS [3]. However, in the 2015 data on recognition of stigma and discrimination, tweets were not focused on key population or high-risk groups [3,8,30]. Results indicate the need for ongoing discussion on such barriers, as civil society plays a major role in the support of marginalized populations [11,12,31].

Hierarchical differences also revealed absence of tweets in 2015 mentioning women. This is of great concern; issues of gender minorities must be addressed or eradication efforts may be thwarted. The focus on key populations does very little to change gender inequality [33]. Women are only considered key when they are pregnant, nursing, or members of other high-risk groups (eg, sex workers) [3]. This approach, which neglects women living with HIV and other vulnerable women, fails to transform norms, beliefs, and perceptions about women's rights to health and well-being [33]. In fact, 2014 tweets mentioned women only in the context of motherhood. Women comprise over 60% of PLWH globally [33]. The biological and social factors that make them most vulnerable to HIV infection must be addressed. Persistent discussions about women's rights remain critical for eradication.

Strengths and Limitations

The generalizability of this study is limited because of the English-only analysis and the use of 1 SNS (ie, Twitter) [15]. We did not include composed tweets, only those disseminated through tweeting or retweeting. For a more in-depth analysis of social media data, future studies should explore other SNSs and analyses in other languages. Twitter's global and pervasive spread of information can support civil society engagement [15,22]. With the limitation of our dataset to data collection on 1 day out of each year and data analysis of only 2 consecutive years, our study lacked the power to assess trends. Future studies should include data collection days before and after World AIDS Day for multiple years to apply dynamic topic modeling to the data to effectively monitor change over time. Due to the randomness of tweets and potential of specific contents to go viral, generalizations of missing themes over time may be a consequence of the nature of Twitter and not actual changes in perceptions. Nevertheless, Twitter data have the potential to supplement traditional survey methods and provide tremendous insight into understanding public beliefs and sentiment.

Conclusions

Our ambitious targets are critical to the pandemic and are possible with the support of technology and social media outlets such as Twitter [15,16]. Civil society's human rights–based approaches and responses can be limited by material resources [11,12]. The low cost and ubiquitous spread of information through SNSs can diminish such barriers. The vision of zero new HIV infections, zero discrimination, and zero AIDS-related deaths must be transformed into tangible milestones and end points [1,6], and social media can help support these efforts [3,16,21,22].

Our study's demonstration of Twitter utilization to explore HIV/AIDS public sentiment can guide targeted social movement campaigns aimed to address grassroots level barriers and heighten public motivation necessary to drive eradication. We also demonstrated the feasibility of the use of cost-effective social networking technologies to identify health-related communication and the utilization of such platforms to support improved outcomes. In fact, with the ever-increasing amount of social media data and the unique and refined analytic approaches such as ours, HIV/AIDS researchers and global health professionals will soon be able to build upon and enhance their methods, to accurately monitor and support a variety of HIV-related issues, and outcomes.

Acknowledgments

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Authors' Contributions

All authors assisted in the data interpretation, manuscript drafting, revising of important intellectual content, and final manuscript approval.

Conflicts of Interest

None declared.

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Abbreviations

ARV: antiretroviral
HierNMF2: hierarchical rank-2 nonnegative matrix factorization
ln: leaf nodes
MDG: millennium development goal
nln: nonleaf nodes
NMF: nonnegative matrix factorization
PLWH: people living with HIV/AIDS
SDG: sustainable development goals
SNS: social networking site
UNAIDS: Joint United Nations Programme on HIV/AIDS

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Original Paper

Dynamics of Health Agency Response and Public Engagement in Public Health Emergency: A Case Study of CDC Tweeting Patterns During the 2016 Zika Epidemic

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Abstract

Background: Social media have been increasingly adopted by health agencies to disseminate information, interact with the public, and understand public opinion. Among them, the Centers for Disease Control and Prevention (CDC) is one of the first US government health agencies to adopt social media during health emergencies and crisis. It had been active on Twitter during the 2016 Zika epidemic that caused 5168 domestic noncongenital cases in the United States.

Objective: The aim of this study was to quantify the temporal variabilities in CDC's tweeting activities throughout the Zika epidemic, public engagement defined as retweeting and replying, and Zika case counts. It then compares the patterns of these 3 datasets to identify possible discrepancy among domestic Zika case counts, CDC's response on Twitter, and public engagement in this topic.

Methods: All of the CDC-initiated tweets published in 2016 with corresponding retweets and replies were collected from 67 CDC–associated Twitter accounts. Both univariate and multivariate time series analyses were performed in each quarter of 2016 for domestic Zika case counts, CDC tweeting activities, and public engagement in the CDC-initiated tweets.

Results: CDC sent out >84.0% (5130/6104) of its Zika tweets in the first quarter of 2016 when Zika case counts were low in the 50 US states and territories (only 560/5168, 10.8% cases and 662/38,885, 1.70% cases, respectively). While Zika case counts increased dramatically in the second and third quarters, CDC efforts on Twitter substantially decreased. The time series of public engagement in the CDC-initiated tweets generally differed among quarters and from that of original CDC tweets based on autoregressive integrated moving average model results. Both original CDC tweets and public engagement had the highest mutual information with Zika case counts in the second quarter. Furthermore, public engagement in the original CDC tweets was substantially correlated with and preceded actual Zika case counts.

Conclusions: Considerable discrepancies existed among CDC's original tweets regarding Zika, public engagement in these tweets, and actual Zika epidemic. The patterns of these discrepancies also varied between different quarters in 2016. CDC was much more active in the early warning of Zika, especially in the first quarter of 2016. Public engagement in CDC's original tweets served as a more prominent predictor of actual Zika epidemic than the number of CDC's original tweets later in the year.

(JMIR Public Health Surveill 2018;4(4):e10827) doi:10.2196/10827

KEYWORDS

Centers for Disease Control and Prevention; public engagement; Twitter; time series analysis; Zika epidemic; social media; twitter; infodemiology; infoveillance

Introduction

The World Health Organization (WHO) has stated that health is one of the most fundamental human rights [1]. Social media have increasingly become critical venues for the public to seek, share, and discuss information about health and diseases. Owing to their low cost, easy access, and broad reach, social media have also been increasingly adopted by health professionals and agencies to enhance public health communication [2]. For example, social media have been utilized to monitor food safety and food-borne pathogen outbreak, such as *Escherichia coli* O157 [3,4], to develop Web-based campaigns to quit smoking in different countries and regions (United States, Canada, and Hong Kong) with various social media platforms (Facebook, Twitter, and WhatsApp [5]); promote exercise, fitness, and healthy lifestyle (WeChat health campaign in China [6]; fitness campaign in New Orleans, LA [7]); raise public awareness and engagement regarding air quality and pollution [8]; and understand and monitor public discussion of controversial topics such as antimicrobial resistance [9].

Many government agencies and health officials (eg, WHO and US Centers for Disease Control and Prevention, CDC, as well as other local health departments) have also been adopting and utilizing social media to disseminate information, communicate with the public, and understand public opinions and concerns, especially during health emergency and crisis. Europe has developed a Web-based media and crisis communication framework for influenza [10]. The WHO and CDC utilized Twitter and Instagram during the Zika outbreak [11]. New York City monitored Zika, Hepatitis A, and Ebola discussion in social media and conducted risk communication with the general public [12].

Evidently, for many infectious disease epidemics, it has been demonstrated that Web-based discussion in social media can be an imperative indicator of the actual disease severity and help health officials to more accurately evaluate the time-sensitive epidemic situation when actual case counts are still being gathered and verified [13-15]. Time series analysis is a versatile and powerful modeling framework to link Web-based discussion and reveal the disease dynamics, as demonstrated by the extant research on various epidemics [16-18].

The 2016 Zika epidemic provides a great opportunity to investigate and evaluate the CDC's role and responsiveness on social media. Zika was a relatively new infectious disease, which affected men and women, fetuses, and infants with multiple transmission routes. However, the general public usually had very little knowledge and understanding about it. In 2016, Zika caused 5168 confirmed noncongenital cases in the 50 states and Washington DC in the United States, and much higher case number in US territories [19]. Twitter is the major social media outlet for the CDC, with a total of 67 official CDC–associated Twitter accounts covering a wide variety of health- and disease-related topics. Former CDC director Dr. Tom Frieden was active on Twitter and hosted live Twitter chats with general public [20], including a recent 1-hour live chat regarding Zika in February 2016.

Despite CDC's prominent Web-based presence and efforts, inaccurate information regarding Zika proliferated on social media and outperformed the CDC (and other legitimate sources such as the WHO) by a large margin [21]. Studies have shown a substantial topic discrepancy between public concern and the CDC's response to Zika on Twitter [22-25]. Another less addressed aspect is the low rate of public engagement (measured by the number of retweets and replies) on social media, where social media should be a Web-based platform for public engagement and interaction [26], not just one-directional news outlet [8,27,28]. Furthermore, currently there is no study on the temporal variability in the CDC's response to different epidemic stages of Zika for the entire year of 2016, its potential impact on public engagement, and quantification of information dissemination, as the CDC did not finalize and publish the complete 2016 Zika case counts in the entire United States until March 2018 [19].

Thus, there is a substantial knowledge gap in quantifying and understanding the interaction among Zika epidemic, the CDC's dynamic response on social media (Twitter), and public engagement to the CDC's effort, as well as potential discrepancy among these hierarchies during different stages of the Zika epidemic. More specifically, original CDC-initiated tweets regarding Zika represent the government agency's responsiveness to the Zika epidemic. Retweets and replies to CDC's original tweets quantify public engagement in the discourse about Zika in Twitter. Between the 2, retweets enhance Zika-related news and information discourse by replying information to other users, whereas replies imply more in-depth cognitive processing of this topic and contribute to the direct interaction with CDC [29].

To address these issues, this study aims to quantify the CDC's responsiveness on Twitter and corresponding public engagement during different stages of the 2016 Zika epidemic. We then identify potential discrepancy among them using time series analysis and information theory measurements. The results and insights gained from this study will reveal the effectiveness of CDC's efforts in disseminating information on social media and help develop more effective Web-based communication strategies to inform public and combat fake information in health-related topics.

Methods

Data Collection and Preparation

We collected all English tweets with the keyword "Zika" published between January 1, 2016 and December 31, 2016, using the Gnip Twitter application program interface. Corresponding retweets and replies received by these tweets were also collected. In addition, all tweets from 67 accounts affiliated with CDC in 2016 were collected. Zika case counts in the 50 US states and territories during the entire 2016 have been retrieved from the official CDC Zika case report website [29] and CDC's final report of the 2016 Zika epidemic in the United States [19].

Four time series were extracted from the original tweets (both Zika-related and all tweets initiated by CDC), retweets, and

replies (only to Zika-related CDC-initiated tweets). In addition, 2 additional time series of US Zika case counts (both 50 states and 50 states plus territories) were obtained [19]. Given that the dates of tweets, retweets, replies, and case counts were not entirely consistent (eg, the CDC may not tweet about Zika every day and may not publish case count on a regular basis), these time series were first standardized into weekly basis. The data were aggregated in weekly periods to ensure that each time series has the same 52 data points for further analysis and comparison. Monthly resolution was not adequate to perform successive time series analyses (because each quarter only had 3 data points) while daily resolution required an extra step of data interpolation (because each day did not necessarily had Zika tweets and case reports), and weekly basis was well balanced and should provide the highest signal-to-noise ratio in this study. To establish a baseline scenario, we computed the weekly number of tweets with any topic from all CDC accounts and identified the top topics tweeted by CDC in 2016. Using these data, we could calculate the ratio between weekly tweets with the keyword of Zika and all tweets from the CDC, which demonstrated the relative importance of Zika on the CDC's social media agenda. This estimate also helped reveal and assess the CDC's responsiveness to Zika at different stages of the epidemic.

Univariate Time Series Analysis

Original Zika tweets from the CDC, corresponding retweets and replies, and Zika case time series were plotted, visualized, and examined for stationarity. After the initial screening, we discovered a substantial temporal variability in the number of original tweets, retweets, and replies, as well as Zika cases. None of these time series was stationary. To characterize such large temporal heterogeneity, we divided the entire year of 2016 into 4 quarters and performed further analysis within each quarter. Furthermore, we calculated the ratio between Zika tweets and all tweets from the CDC as a measurement to quantify the relative importance of Zika among various health-related topics from the CDC's perspective.

These quarterly time series were first modeled as autoregressive integrated moving average (ARIMA) models to reveal any potential temporal characteristics such as linear trend, seasonality, or temporal autocorrelation [16]. The following equation:

shows the form of an ARIMA model with variable X_t, difference term L, and parameters (p, d, q) (Equation 1). The 3 parameters p, d, and q corresponded to autoregressive, differencing/integrated (L), and moving average components of the ARIMA model, respectively. The optimal model was then chosen by minimizing the Akaike Information Criteria (AIC) value among all possible competing models with different parameters. The Zika case counts were excluded from this analysis because most of the domestic Zika cases in 2016 were travel-related and could not be well characterized by the ARIMA model, and modeling the temporal dynamics of Zika was not an aim of this study.

Multivariate Time Series Analysis

We calculated the lagged correlation between 2 time series using the cross-correlation function (CCF) at different stages represented by 4 quarters in 2016 to identify and quantify the potential temporal discrepancy among Zika case counts, CDC's original tweets, and public engagement in these tweets (ie, retweets and replies to CDC's tweets). Specifically, we compared time series of Zika case counts with that of original CDC tweets to understand the CDC's responsiveness to the disease outbreak. In addition, time series of Zika case counts and that of retweets and replies were compared with discovered different levels of public engagement in reaction to the Zika epidemic. Their respective CCFs were computed for each of the 4 quarters in 2016. Given that the original CDC tweets were always highly correlated with retweets and replies, we also evaluated the dynamic change of public engagement by calculating the ratio between the number of CDC's original Zika tweets and the number of retweets or replies across different stages. In addition, we calculated the mutual information between 2 time series using Dirichlet-multinomial pseudo count Bayesian estimate of Shannon entropy, a more informative metric than the CCF to reveal the potential mutual information between 2 time series and quantify whether the number of original CDC tweets about Zika and retweets and replies received by them had adequate mutual information with actual Zika case counts.

We constructed the ARIMA with External Variable (ARIMAX) model for original CDC tweets, retweets, and replies in each quarter of 2016, respectively. The ARIMAX model was a multivariate extension of the ARIMA model and incorporated an effective external variable (ie, Y_t , representing a time series of Zika case counts in this study):

The univariate ARIMA model and multivariate ARIMAX model were then compared to see whether including external variable actually increased the model performance by decreasing the AIC value. The ARIMAX model was constructed on the basis of the corresponding optimal ARIMA model in the univariate time series analysis section. In other words, ARIMAX and ARIMA models should have exactly the same p, d, and q parameter values to correctly assess the effect of the external variable. This revealed whether public engagement in CDC's original tweets significantly corresponded to the domestic Zika epidemic. We then tested whether the number of original CDC tweets, retweets, or replies could serve as an imperative indicator of actual Zika case (or *vice versa*) in different stages by applying the Granger causality test. The terms that needed to be first differenced in the Granger test were determined from the corresponding ARIMA or ARIMAX model (ie, where parameter d is nonzero).

Results

Descriptive and Univariate Time Series Analysis Results

Among all tweets sent by the CDC in 2016, Zika was the third most tweeted health topic, totaling >6000 tweets (including 4000 original tweets and another 2000 retweets by other CDC–associated Twitter accounts), and was just behind HIV/AIDS and sexually transmitted disease in entire 2016 (Figure 1). As there might be overlap between topics (eg, Zika/sexually transmitted disease, Zika/Vaccine, HIV AIDS/Pre-exposure prophylaxis, HPV/Vaccine, etc), a specific tweet could belong to multiple topics. Thus, Zika was a highly ranked and important health topic in 2016 according to the CDC. Among all 67 CDC–associated Twitter accounts, 21 tweeted about Zika in 2016. More than 60% (3663/ 6104) of Zika-related tweets were posted by @CDCgov, @CDCTravel, @CDCGlobal, and @CDCEmergency; these 4 were also the most active Twitter accounts that disseminated Zika-related information consistently through all 4 quarters in 2016. Although Zika was one of the hot topics tweeted by the CDC, there was substantial temporal heterogeneity in the CDC's tweeting pattern regarding Zika. More than 84.0% (5130/6104) of all Zika tweets were published in the first quarter of 2016, with 5.6% (342/6104), 7.5% (458/6104), and 2.4% (146/6104) for the subsequent quarters, respectively (Figure 2). The top left of Figure 2 shows the number of all tweets sent from all CDC–associated Twitter accounts during 2016 (solid black line) and Zika-related tweets (dashed blue line); the top right shows the number of Zika-related tweets (solid black line) and Zika case counts in 50 states and DC (solid red line); the bottom left shows retweets to CDC's Zika tweets; and the bottom right shows replies to CDC's Zika tweets. As a comparison of the temporal dynamics, domestic Zika case percentages in 50 states and DC were 10.8% (560/5168), 26.0% (1343/5168), 52.8% (2728/5168), and 10.4% (535/5168) in the 4 quarters, and case percentages in 50 states, DC, and overseas territories were 1.70% (662/38,885), 5.91% (2298/38,885), 58.46% (22,732/38,885), and 33.92% (13,189/38,885) in the 4 quarters (Figure 3). Data were obtained from the CDC Morbidity and Mortality Weekly Report [19]. Thus, the Zika epidemic dynamics was substantially different from the CDC's tweeting dynamics in 2016, as Zika case counts were actually the lowest in the first quarter of 2016.

Figure 1. The top 15 most tweeted health topics by the Centers for Disease Control and Prevention (CDC) in 2016. STD: sexually transmitted disease TB: tuberculosis; CVD: cardiovascular disease; PreP: Pre-exposure prophylaxis; HPV: Human papillomavirus.

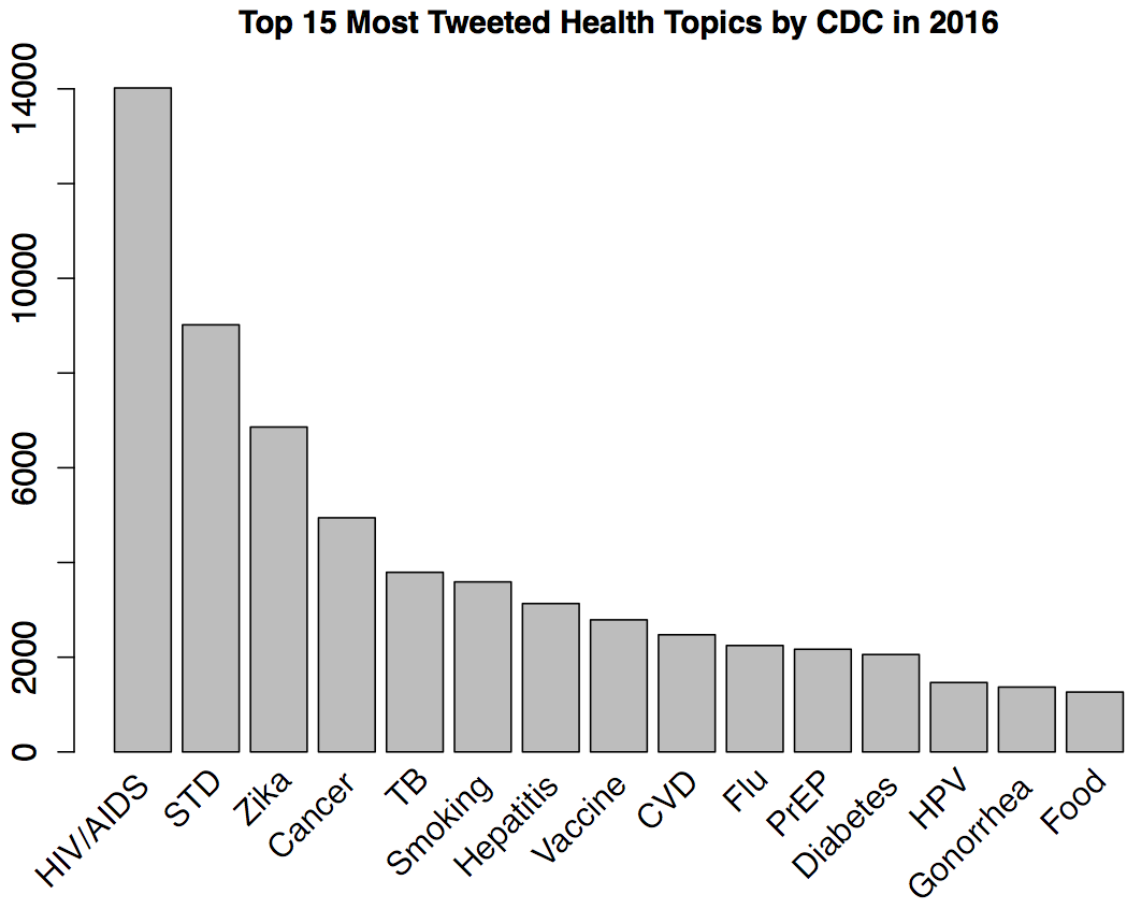


Figure 2. The time series of Zika tweets from the Centers for Disease Control and Prevention (CDC), corresponding retweets, replies, and all original tweets from the CDC in 2016.

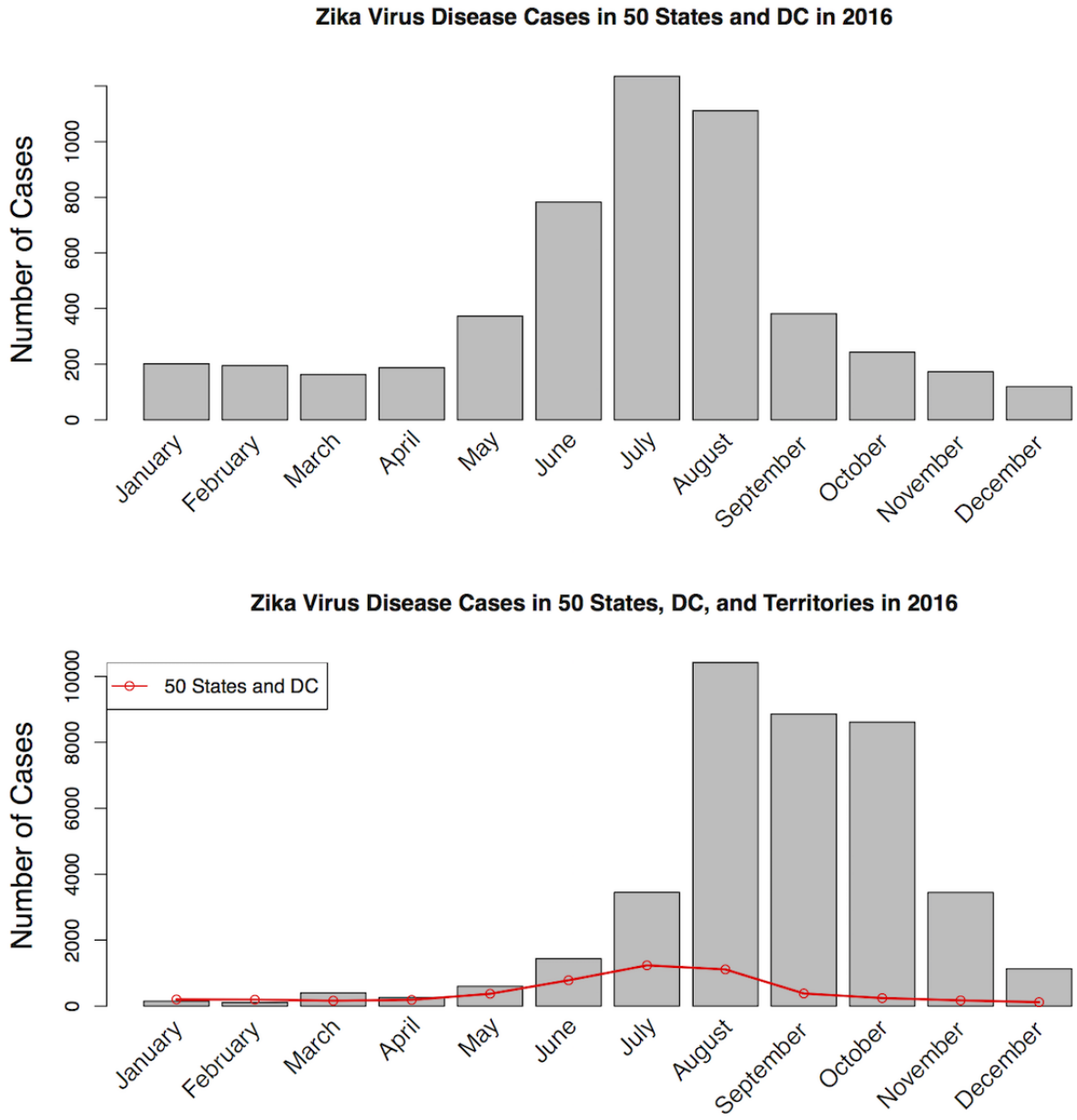
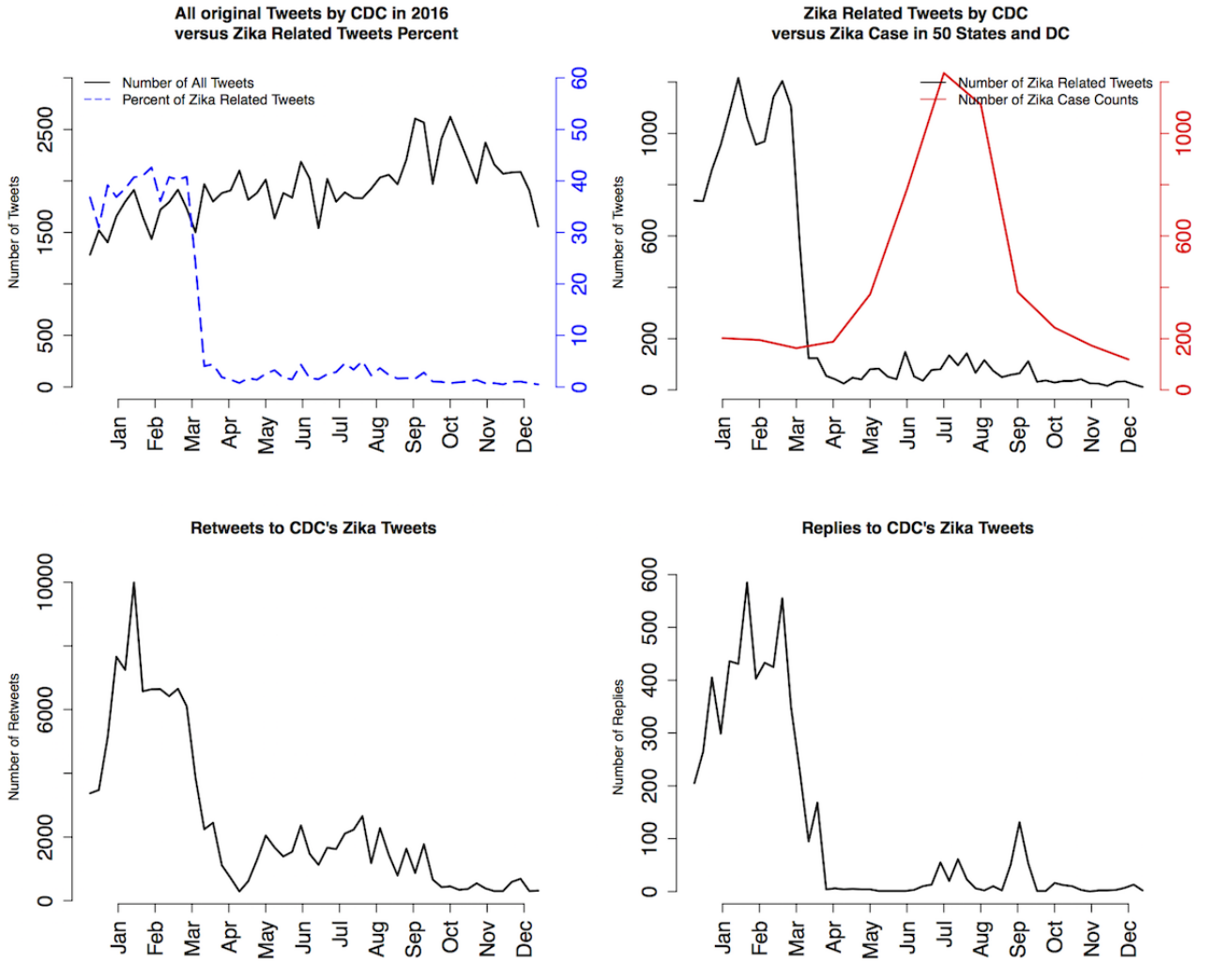


Figure 3. Noncongenital Zika virus disease cases in 50 states/DC and both 50 states/DC and territories in 2016. CDC: Centers for Disease Control and Prevention.



Zika was unequivocally the most tweeted health topic of the CDC in the first quarter and was mentioned in almost 50.0% (3052/6104) of all tweets in that quarter, dwarfing both HIV/AIDS- and sexually transmitted disease-related tweets; this substantial temporal heterogeneity was also demonstrated by the distinct ARIMA models in each quarter (see Table 1, the first column for original tweets). The optimal ARIMA model in the first quarter was with parameter *p*, *d*, *q*=2, 0, 3, indicating that the optimal time series model with the minimized AIC value for original tweets did not need differencing (*d*=0, order of differencing being 0, that is, already stationary and does not need further differencing), and with autoregressive and moving average term *p*=2 (indicating autoregressive time lag of 2) and *q*=3 (indicating moving average order of 3), respectively. The parameters associated with optimal ARIMA models in the next 3 quarters were *p*, *d*, *q*=2, 1, 3 (second quarter), 1, 1, 1 (third quarter), and 2, 0, 3 (fourth quarter), respectively.

Retweets of and replies to the original Zika tweets from the CDC generally followed the similar temporal characteristics, where the first quarter had the largest number of both retweets and replies (Figure 2, lower left and lower right, respectively). The optimal ARIMA models were again distinct across the 4 quarters in 2016, for both retweets (Table 1, the second column) and replies (Table 1, the third column). The only similarity was retweets in the first and the second quarter, both of which had the same parameterization (*p*, *d*, *q*=2, 1, 3). Comparing among ARIMA models for original tweets, retweets, and replies, there were only 2 pairs with the same model parameterization—original and retweets in the second quarter (both with *p*, *d*, *q*=2, 1, 3) and retweets and replies in the third quarter (both with parameter values *p*, *d*, *q*=2, 1, 2). These results revealed a substantial temporal variability across different quarters of 2016 and among original tweets, retweets, and replies.

Multivariate Time Series Analysis Results

As shown in Figure 4, strong temporal correlations were discovered between original Zika tweets from the CDC and retweets, as well as between original Zika tweets from the CDC and replies in all quarters of 2016. Most retweets and replies were centered at zero, indicating that general public's interaction with original CDC tweets was usually synchronized. Figures 5-7 provide the plots of the CCF between Zika case and each of the following variables: original Zika tweets from the CDC, retweets, and replies in each quarter of 2016, respectively.

Table 1. Mutual Shannon information entropy, Autoregressive Integrated Moving Average or Autoregressive Integrated Moving Average with External Variable model parameters, and Akaike Information Criteria values in different quarters of 2016.

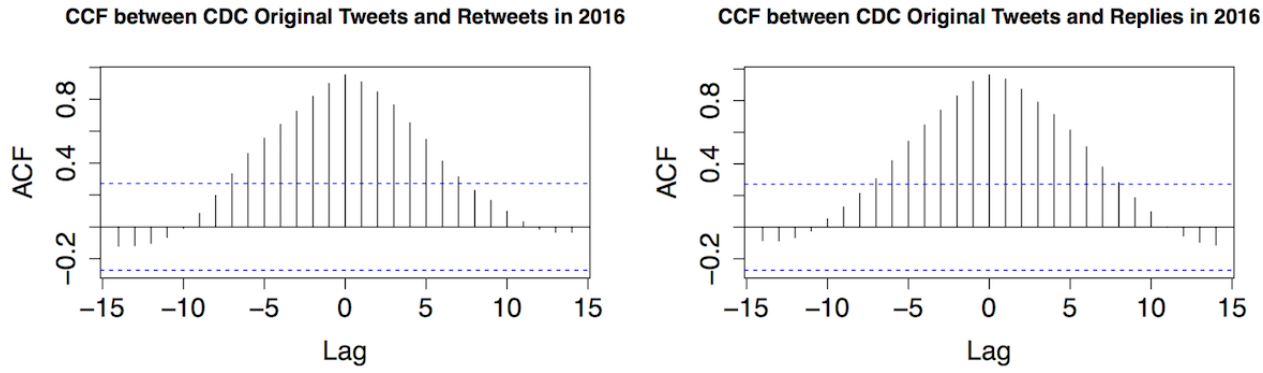
Quarters		Original + Case	Retweeting without commenting + Case	Reply + Case
Q1				
	Mutual Info	0.04	0.01	0.09
	ARIMA(X)[a] Par	2, 0, 3	2, 1, 3	2, 0, 2
	dAIC[b]	–2.25[c] (976.61, 974.36)	–1.88[c] (1341.51, 1339.63)	–1.21[c] (950.05, 948.84)
Q2				
	Mutual Info	0.13	0.17	0.29
	ARIMA(X) Par	2, 1, 3	2, 1, 3	0, 1, 1
	dAIC	0.96 (722.54, 723.50)	–0.88[c] (1207.14, 1206.26)	1.88 (709.18, 711.06)
Q3				
	Mutual Info	0.02	0.08	0.02
	ARIMA(X) Par	1, 1, 1	2, 1, 2	2, 1, 2
	dAIC	1.95 (719.51, 721.46)	1.82 (1172.01, 1173,83)	–0.62[c] (738.76, 738.14)
Q4				
	Mutual Info	0.01	0.07	0.01
	ARIMA(X) Par	2, 0, 3	0, 1, 2	0, 0, 1
	dAIC	–0.59[c] (453.28, 452.69)	1.62 (917.84, 919.46)	1.97 (353.23, 355.20)

[a]ARIMA(X): Autoregressive Integrated Moving Average (with External Variable).

[b]dAIC: difference in Akaike information criterion.

[c]Negative dAIC value indicates better performance of the ARIMAX model compared with its corresponding ARIMA model; hence, including Zika case counts improves the model performance.

Figure 4. The cross-correlation function (CCF) between original Centers for Disease Control and Prevention (CDC) Zika tweets, retweets, and replies in 4 quarters of 2016. ACF: autocorrelation function.



For original Zika tweets and Zika case counts, strong temporal correlations were observed in the first, second, and fourth quarter. In the first quarter, CDC's tweets regarding Zika preceded actual case counts for approximately 7-10 days, indicated by the substantial lag of 7, 8, 9, and 10 (Figure 5, top left). In the second quarter, CDC's tweets were ahead of the case for approximately 2 weeks (Figure 5, top right). In the fourth quarter, CDC's tweets were behind Zika case for approximately 1-3 days (Figure 5, bottom right). In the third quarter, there was no substantial correlation between the 2 time series. These results revealed that the CDC was very active during the early stage of the Zika epidemic (especially February

2016) on social media when the actual case number was low (Figure 2, top right).

The similar pattern was also observed between retweets and Zika cases (Figure 6). The first quarter demonstrated a strong temporal correlation between the 2, whereas there was no substantial correlation in the fourth quarter. In other words, the general public was more engaged in retweeting to help disseminate the information during the first half of 2016.

The correlation between replies and Zika cases was also explored and demonstrated (Figure 7). Replies preceded case counts for about a week in the first quarter, indicating the general public's strong interests in discussing Zika and interacting with the CDC on Twitter; this active engagement decreased as time went by. By the fourth quarter of 2016, replies were about 10 days behind actual cases.

In addition, we calculated the mutual information to explore mutual dependence between Zika cases and each of these activities on Twitter—original Zika tweets from the CDC, retweets, and replies, from an information perspective (Table 1). In the first quarter, replies had the highest mutual information (0.09) with Zika cases, which was even higher than original Zika tweets from the CDC (0.04) and retweets (0.01). Nevertheless, all these mutual information (ie, Shannon information entropy) were low, indicating a potential discrepancy between the discussion of Zika on Twitter and actual epidemic. In the second quarter, replies, retweets, and original Zika tweets from the CDC had 0.29, 0.17, and 0.13 mutual information with Zika cases, respectively, serving as the highest mutual information of all 4 quarters in 2016. In the third quarter, retweets had the highest mutual information with Zika cases (0.08), followed by both original tweets and replies tied at 0.02. In the fourth quarter, retweets got the highest mutual information again (0.07), followed by original tweets and replies with very low mutual information (0.01). In general, retweets and replies had even more mutual information with Zika cases compared with CDC's original Zika tweets. Thus, the CDC's tweeting pattern was an inferior indicator of the Zika epidemic than public engagement in its tweets as illustrated by the patterns of retweets and replies.

The mutual information does not consider potential temporal characteristics such as lag or trend. Therefore, we further quantified whether including an external variable of Zika case counts could increase the ARIMA model performance (Table 1). The analysis results showed that in the first quarter, all ARIMAX models outperformed their ARIMA counterparts by a large margin (difference of AIC [dAIC]=–2.25, –1.88, and –1.21 for original Zika tweets, retweets, and replies, respectively; dAIC was the difference of AIC values between ARIMAX and ARIMA models, and negative dAIC value indicated better performance of the ARIMAX model, that is, including an external variable increased the model predictability). Although Zika case counts were the lowest in the first quarter, they still highly correlated with the temporal dynamics of Web-based discussion of Zika. Including Zika case counts only improved the ARIMAX model for retweets (dAIC=–0.88) in the second quarter, for replies (dAIC=–0.62) in the third quarter, and for original Zika tweets from CDC (dAIC=–0.59) in the fourth quarter. These findings provided further evidence to confirm the large temporal variability and differences in the CDC's response to Zika and public engagement in their responses on Twitter.

In addition, we evaluated whether Zika case could be Granger cause of original CDC tweets, retweets, and replies, or *vice versa*. The Granger causality test revealed that case count was not Granger cause for original Zika tweets from the CDC in any quarter, and *vice versa*. Thus, the correlation between CDC's Zika tweets and actual Zika cases was not strong. Retweets, however, could serve as Granger cause of Zika cases for order from 1 to 5 (P=.05, .04, .02, .01, and .04, respectively) in the first quarter; this coincided with previous findings that retweets had a very high correlation with Zika cases in the first quarter (Figure 6). Similarly, replies also served as Granger cause in the first quarter for order 3, 4, and 5 (P=.03, .01, and <.001, respectively). Furthermore, replies served as Granger cause again in the fourth quarter for order 1 (P=.04). In contrast, Zika case counts in the third quarter could be Granger cause for replies with order 2 and 3 (P<.001 for both orders) but not *vice versa*. This was the only exception when Zika cases served as Granger cause for Twitter discussion. It is important to note that Granger causality only provided statistical evidence for potential causality and did not guarantee actual causality. For example, replies as Granger cause in the first quarter did not mean replies to CDC's tweets "caused" Zika cases in the United States. Therefore, we should interpret that replies preceded Zika cases and had a strong association with Zika case counts at selected orders. Furthermore, the temporal heterogeneity in Granger test results showed variability across different quarters in 2016.

Figure 5. The cross-correlation function (CCF) between original Centers for Disease Control and Prevention (CDC) Zika tweets and domestic Zika cases in 4 quarters of 2016. ACF: autocorrelation function.

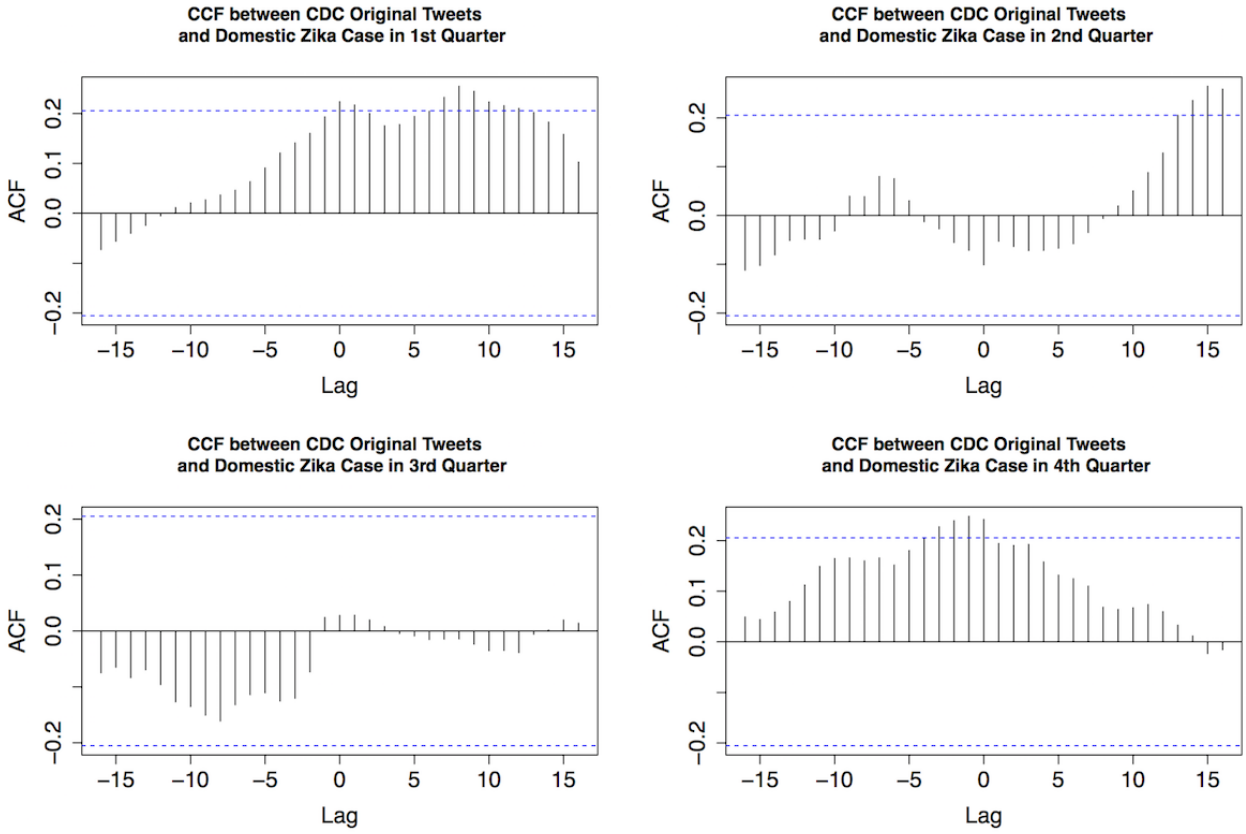


Figure 6. The cross-correlation function (CCF) between retweets to Centers for Disease Control and Prevention (CDC) Zika tweets and domestic Zika cases in 4 quarters of 2016. ACF: autocorrelation function.

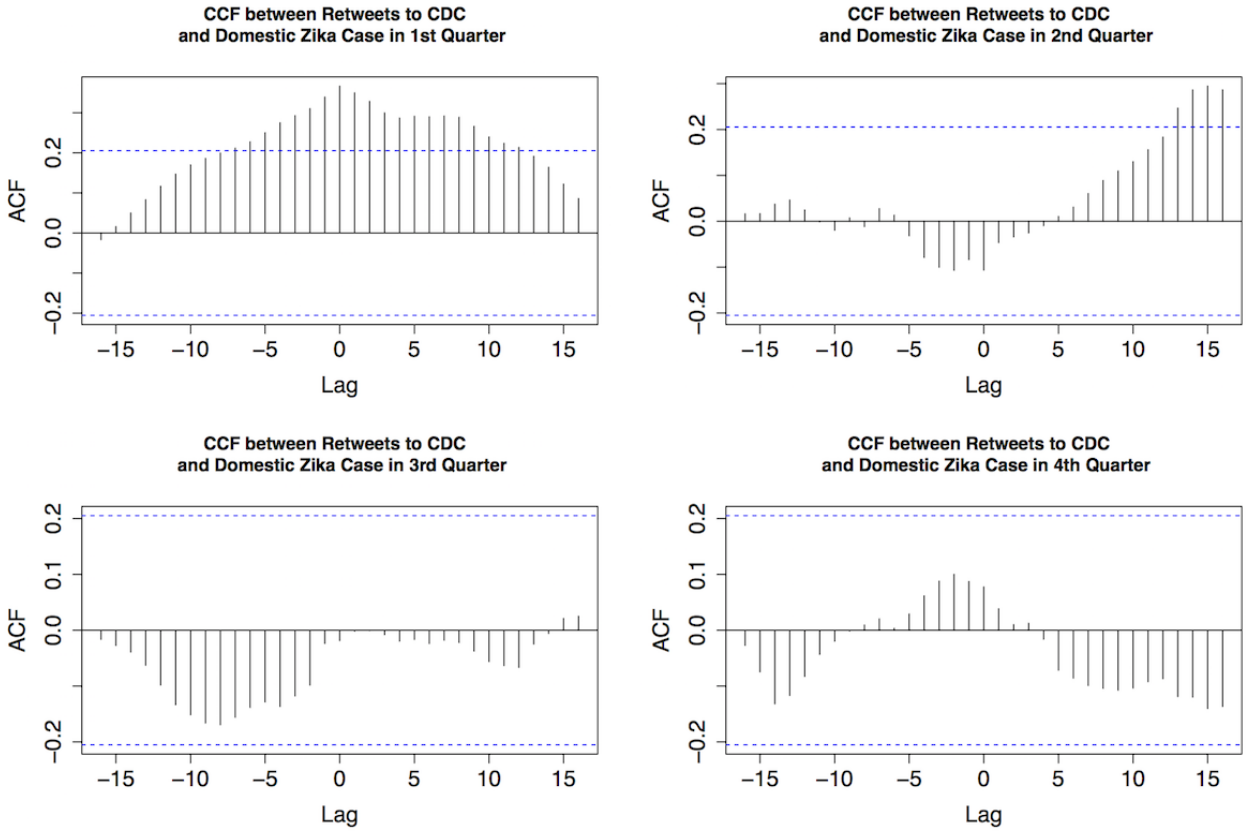
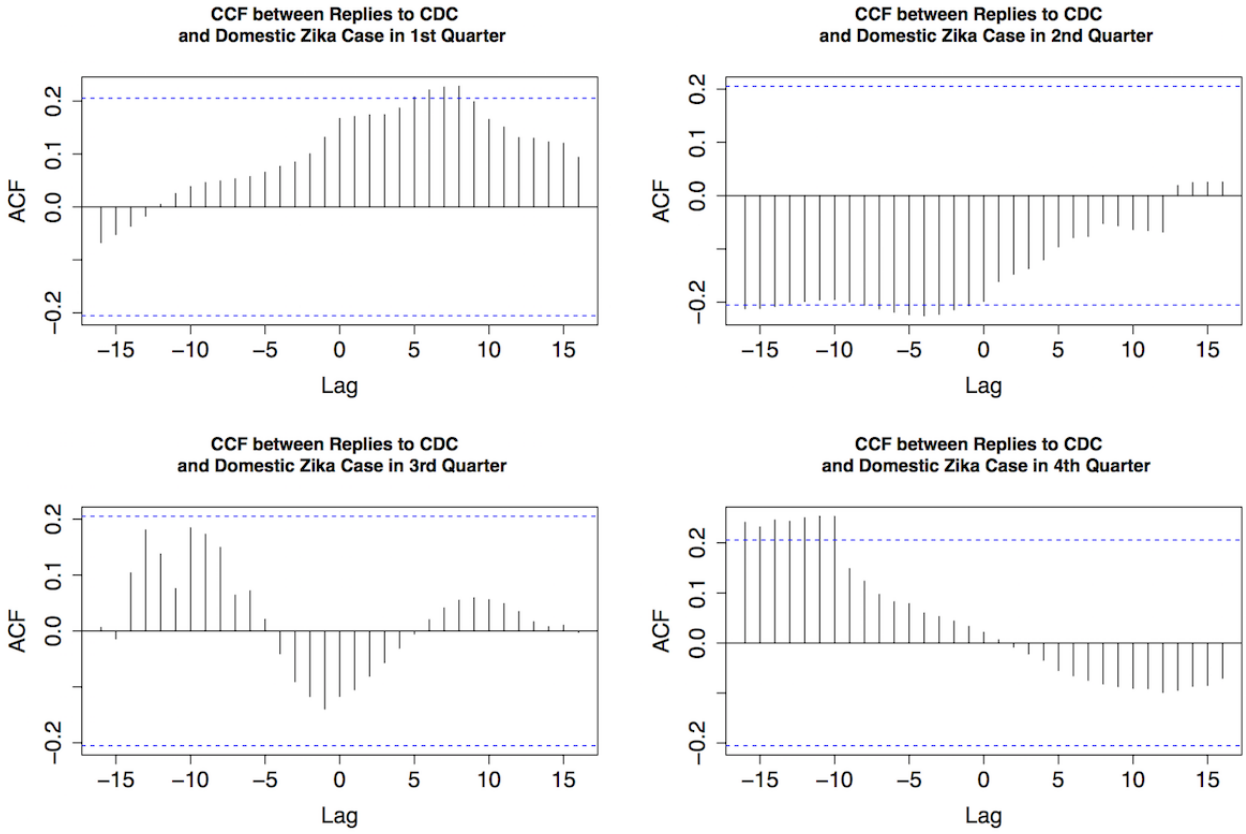


Figure 7. The cross-correlation function (CCF) between replies to Centers for Disease Control and Prevention (CDC) Zika tweets and domestic Zika cases in 4 quarters of 2016. ACF: autocorrelation function.



Discussion

This study is the first of its kind that specifically investigates the temporal variability in CDC's tweeting activities regarding Zika. More importantly, it links the temporal variability of Zika cases in the United States to that of CDC's social media responses and public engagement in those social media messages. In general, we discovered substantial discrepancy among CDC's tweets regarding Zika, public engagement, and actual Zika epidemic in different stages of the epidemic in 2016. As shown by our findings, there was a substantial discrepancy between CDC's response to Zika in Twitter and the Zika epidemic. When Zika case counts were low in the United States during the first quarter of 2016, CDC was very active in disseminating information about Zika by sending out >84.0% (5130/6104) of all its 2016 Zika tweets. The CDC and its former director Dr Frieden even hosted 1-hour Twitter chat on February 16, 2016. All these activities correlated with active public engagement, as retweets and replies were also the highest among all quarters. Thus, the CDC was effective in the early warning of the upcoming epidemic of Zika and successfully gained public attention during the first quarter of 2016. However, when Zika case counts started to increase sharply in the second and third quarters of 2016, CDC's Zika-related tweets decreased substantially and did not catch up with the Zika case counts. Nevertheless, public engagement in discussion of Zika on social media could be influenced by some other factors such as news source, personal familiarity with the disease, and potential opinion leaders who may not necessarily be health-related. All these could be future directions to expand this study.

While public engagement in CDC's Zika tweets (ie, retweets and replies) also decreased dramatically in the second and third quarters of 2016, it was significantly associated with Zika cases, as revealed by the performance of corresponding ARIMAX models (compared with the original ARIMA models). When more case counts (including both transmitted cases and travel-related cases) were reported in Florida since late July and from Summer Olympics in Brazil between August 5 and 21, 2016, retweets and replies to CDC's Zika tweets increased again substantially, demonstrating public's growing and recurrent awareness of this emerging health issue. The dynamic public engagement in CDC's Zika tweets was generally different among quarters and was also substantially influenced by and usually preceded the Zika epidemic. Therefore, public engagement in CDC's Zika tweets was generally a more prominent predictor of the actual Zika epidemic than CDC's tweets later in the year.

Different from previous studies that have used social media discussion trend to predict and adjust the actual disease dynamics [13,16,18,30-33], this study used Zika case counts and epidemic to infer the Twitter discussion dynamics and revealed dynamic changes throughout the year; we made this decision because the majority of domestic Zika cases in the United States were travel-related and highly stochastic [19]. Therefore, they could not be accurately captured by statistical models such as ARIMA or ARIMAX. Using social media discussion to predict the actual disease dynamics is, thus, more

useful for locally transmitted diseases, such as influenza, rather than travel-related diseases.

This study has several limitations. First, we did not investigate the actual content and user identities of retweets and replies. One of the future directions is to investigate the content of these messages by using topic modeling [24] and natural language processing [34]. It will be especially valuable to examine the patterns of replies to understand the public's responses toward the original tweets. For example, it will be interesting to examine if public responses are neutral, synergistic, or antagonistic. Another potential route was to investigate retweeting or replying network, identify potential opinion leaders, and assess their roles in disseminating health-related information from legitimate sources such as the CDC and WHO.

In this study, we focused on public engagement in CDC's tweets (ie, retweets and replies). Nevertheless, it represents a relatively small portion of public engagement in the general topic of Zika compared with all Zika-related tweets. An extension of this study could investigate the temporal dynamics of all Zika-related retweets and replies and compare them with public engagement in CDC's Zika tweets. Similarly, the number of original Zika tweets from the CDC were relatively low especially after the first quarter in 2016, which might influence time series analysis results (and it was also the reason we chose weekly but not a daily resolution in this study). A potential remedy was to include the temporal dynamics of all Zika-related tweets as a reference in the future study and contrast that with the CDC's tweeting pattern.

Acknowledgments

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Conflicts of Interest

None declared.

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Abbreviations

AIC: Akaike Information Criteria
ARIMA: Autoregressive Integrated Moving Average
ARIMAX: Autoregressive Integrated Moving Average with External Variable
CCF: Cross-correlation Function
CDC: Centers for Disease Control and Prevention
dAIC: difference in Akaike information criterion
WHO: World Health Organization

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Original Paper

Characterizing Tweet Volume and Content About Common Health Conditions Across Pennsylvania: Retrospective Analysis

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Abstract

Background: Tweets can provide broad, real-time perspectives about health and medical diagnoses that can inform disease surveillance in geographic regions. Less is known, however, about how much individuals post about common health conditions or what they post about.

Objective: We sought to collect and analyze tweets from 1 state about high prevalence health conditions and characterize the tweet volume and content.

Methods: We collected 408,296,620 tweets originating in Pennsylvania from 2012-2015 and compared the prevalence of 14 common diseases to the frequency of disease mentions on Twitter. We identified and corrected bias induced due to variance in disease term specificity and used the machine learning approach of differential language analysis to determine the content (words and themes) most highly correlated with each disease.

Results: Common disease terms were included in 226,802 tweets (174,381 tweets after disease term correction). Posts about breast cancer (39,156/174,381 messages, 22.45%; 306,127/12,702,379 prevalence, 2.41%) and diabetes (40,217/174,381 messages, 23.06%; 2,189,890/12,702,379 prevalence, 17.24%) were overrepresented on Twitter relative to disease prevalence, whereas hypertension (17,245/174,381 messages, 9.89%; 4,614,776/12,702,379 prevalence, 36.33%), chronic obstructive pulmonary disease (1648/174,381 messages, 0.95%; 1,083,627/12,702,379 prevalence, 8.53%), and heart disease (13,669/174,381 messages, 7.84%; 2,461,721/12,702,379 prevalence, 19.38%) were underrepresented. The content of messages also varied by disease. Personal experience messages accounted for 12.88% (578/4487) of prostate cancer tweets and 24.17% (4046/16,742) of asthma tweets. Awareness-themed tweets were more often about breast cancer (9139/39,156 messages, 23.34%) than asthma (1040/16,742 messages, 6.21%). Tweets about risk factors were more often about heart disease (1375/13,669 messages, 10.06%) than lymphoma (105/4927 messages, 2.13%).

Conclusions: Twitter provides a window into the Web-based visibility of diseases and how the volume of Web-based content about diseases varies by condition. Further, the potential value in tweets is in the rich content they provide about individuals'

perspectives about diseases (eg, personal experiences, awareness, and risk factors) that are not otherwise easily captured through traditional surveys or administrative data.

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KEYWORDS

Twitter messaging; disease; prevalence; public health surveillance; social media

Introduction

Communities are increasingly identified as a driver of health, yet our ability to track changes in the health of communities has been limited by the nature of community-level data. These data are typically survey-based or derived from administrative health care claims. In both of these cases, delays in data availability can preclude timely interventions. Social media channels, like Twitter, offer a new opportunity to track regional health trends by observing health-related communication generated by the public and for the public [1-7].

There is an opportunity to determine how emerging digital data sources are complementary (ie, social media data have similar findings to traditional health data sources) and augmentative (ie, social media provides new real-time information about health not available in data collected through traditional means). To better quantify the value added by social media for public health surveillance, an understanding of how much data exist about different health conditions is needed. High prevalence conditions that affect much of a population may be underrepresented on the Web, whereas low prevalence conditions could be discussed more frequently on Twitter. Further, it is likely that there are different drivers (eg, disease morbidity and mortality, celebrity news, acuity, and stigma) that may influence the volume of Web-based health conversations.

To better characterize health-related tweet volume and content, we compared the volume of Twitter messages about common diseases with the prevalence of the disease determined from inpatient and outpatient claims. We then characterized the public perception of common diseases by identifying the content (words and themes) most frequently associated with each condition.

Methods

Context

This was a retrospective analysis of publicly available data about health conditions posted on Twitter in Pennsylvania. This study was approved by the University of Pennsylvania Institutional Review Board.

We collected tweets originating from Pennsylvania related to 5 of the top causes of death in the United States. The causes of death were then further divided into subcategories: heart disease (heart disease and hypertension), diabetes, stroke, cancer (breast, skin, lung, lymphoma, leukemia, prostate, pancreatic, and ovarian), and chronic lung disease (asthma, chronic obstructive pulmonary disease, COPD).

Data Sources

Twitter Data

Twitter is a social media platform that allows users to send and receive short messages called “tweets.” At the time of data collection, tweets were limited to 140 characters; this limit was doubled to 280 characters in 2017. All tweets were collected via the Twitter Application Programming Interface (API) as described in Preotiuc-Pietro et al [8]. First, the Twitter Streaming API was used to collect a random 1% sample of public tweets from 2012-2015. This initial dataset was then filtered to contain only geolocated tweets or tweets originating from users with nonempty location fields in their profile. The county of origin of each tweet user was determined, and the dataset was filtered to obtain only tweets for users in Pennsylvania. To increase the sample size of tweets from the state, all unique user IDs were recorded, and the Twitter search API was used to extract timelines (each user’s prior 3200 tweets) filtered by timestamps ranging from 2012-2015.

Disease Keywords

The dataset analyzed was filtered for messages containing at least 1 keyword referencing a disease. The lexica of keywords (Multimedia Appendix 1) for each disease was derived from the Consumer Health Vocabulary [9] and supplemented by the authors of the study. The precision of the keyword filtering was estimated for each disease via a correction factor derived from a manual review of the tweets. The correction factor was then used to calculate corrected message counts.

Tweet Location

All tweets used in this analysis were classified as originating from a county in Pennsylvania. The tweets were mapped to a county using a combination of coordinates and the user-provided location field as per the method described in Schwartz et al [10]. For county mapping, we identified if coordinates were present with the tweet. If coordinates were present, these were used to identify the county of origin via the Google Maps API. For tweets without coordinates, we used the location field provided in the user’s profile to identify the county. When the field contained only a city or city nickname, it was mapped to a county as long as it met the following criteria: at least 90% of the population in all the cities with that name are in 1 specific city. For example, “Chicago” would get mapped to Chicago, Illinois, because greater than 90% of the population in all cities named “Chicago” in the United States are located in Chicago, Illinois. “Springfield” would not be mapped, as there are approximately 50 different regions named “Springfield” in the United States of similar population density. The same process in the previous step was used if the county name was listed without a specified state. Cities that were among the top 1000

English or Spanish nouns, verbs, and adjectives were not considered.

Deriving Topics About Individual Diseases

Utilizing all messages from the dataset, 200 topics (ie, groups of co-occurring words) were generated using the Mallet implementation of latent Dirichlet allocation (LDA). The input data for LDA were filtered to remove all disease keywords along with all words used by less than 5% of tweet authors.

The topic distribution of each message was then calculated as described in Schwartz et al [11]. The Pearson correlation between topic distribution and a binary label of whether or not the tweet contained the disease mentioned was calculated. All correlations were corrected for false discovery rate using the Benjamini-Hochberg procedure.

Organizing Topics into Themes

We created 10 themes by clustering the 200 LDA topics using nonnegative matrix factorization of the LDA topics derived from the messages. We identified the resulting clusters of topics as "themes." The LDA topics specify the probability of each word given each topic. Nonnegative matrix factorization provides a weighted value indicating how much each topic, and hence each word in each topic, contributes to each theme. Theme distributions for each message were then calculated in the same manner as described previously for the topic distributions, using Bayes' rule to compute p(theme|word). The resulting themes were manually labeled as follows: News, Research, Slang or Popular Culture Reference, Environment, Diagnosis and Survivorship, Treatment, Diet and Prevention, Awareness, Risk Factor, and Personal Experience.

Statistical Analysis

Disease Prevalence

Outpatient and inpatient hospitalization claims were retrieved from 2013 and 2014 claims data from the Pennsylvania Health Care Cost Containment Council. Claims corresponding to each disease were identified using the primary and secondary diagnostic codes that were encoded via the corresponding International Classification of Diseases, 9th edition. The codes pertaining to a specified disease were determined using the grouping provided by Clinical Classification Software developed as part of the Healthcare Cost and Utility Project [12]. Disease prevalence is defined as the number of unique patients in each county that have a claim related to a given disease divided by the total population of the county. The average of those county-level prevalences was used as the state prevalence for each disease.

Adjusted Message Counts and Correction Factors

Due to ambiguity in some of the disease lexica, the message counts for each disease need to be scaled to reflect that many uses of terms such as "heart attack" or "stroke" are metaphorical or refer to other subjects such as golf "stroke." The scaling is accomplished via a correction factor based on the manual review of tweets by 2 researchers using the methods outlined in Weeg, et al [13].

To calculate the correction factor for a disease, a sample of 30 tweets for each keyword were sampled. Those tweets were then classified as being a reference to a disease or not a reference to a disease. The percentage of tweets from the sample pertaining to a disease was identified as the correction factor for that keyword, w_k. To calculate the corrected message count for a disease (Figure 1), the product of the correction factor, w_k, and the number of messages containing that keyword, n_k, are summed for all keywords for a single disease.

Comparing Tweet Volume to Disease Prevalence in Pennsylvania

We used summary statistics to compare the volume of posts on Twitter with the disease prevalence in Pennsylvania for those conditions.

Associating Disease with Themes

The distribution of themes was investigated using 2 different metrics: the probability of the theme given the disease and the pointwise mutual information (PMI) between the disease and theme (Figure 2). The probability of the theme given the disease provides insight into the most prevalent topics of conversation for the given disease.

The PMI of a disease and theme provides a measure of how often a disease and theme co-occur relative to how often the 2 would co-occur if independent of one another. This provides insight into theme-disease co-occurrence that may be somewhat rare but is significantly different from random chance.

Figure 1. Equation for deriving a disease's corrected message count.

$$correctedmessagecount = \sum_{k=1}^{K} w_k n_k$$

Figure 2. Equation for deriving the pointwise mutual information between a disease and a theme. PMI: pointwise mutual information.

$$PMI = \log \frac{p(theme,disease)}{p(theme)p(disease)}$$

Results

Tweet Volume and Disease Prevalence Comparison

Tweet Volume

The initial sample of tweets from Pennsylvania consisted of 408,296,620 tweets. The data were filtered for messages containing disease-related language, resulting in a dataset containing 226,802 messages. This estimated size of this dataset was further reduced to 174,381 messages after correction factors were applied to the disease message counts. Breast cancer (n=39,156), stroke (n=53,858), and diabetes (n=41,615) were the most frequent conditions represented in the dataset (Table 1).

Correction Factors and Corrected Message Counts

Of the 14 diseases, we identified only 2, COPD and stroke, with a correction factor below 90% (Table 1). Messages containing terms related to pancreatic and ovarian cancer were always a direct reference to the disease. References to stroke were nonmedical or references to other health topics, such as heat stroke, 84.88% (45,716/53,858 messages) of the time.

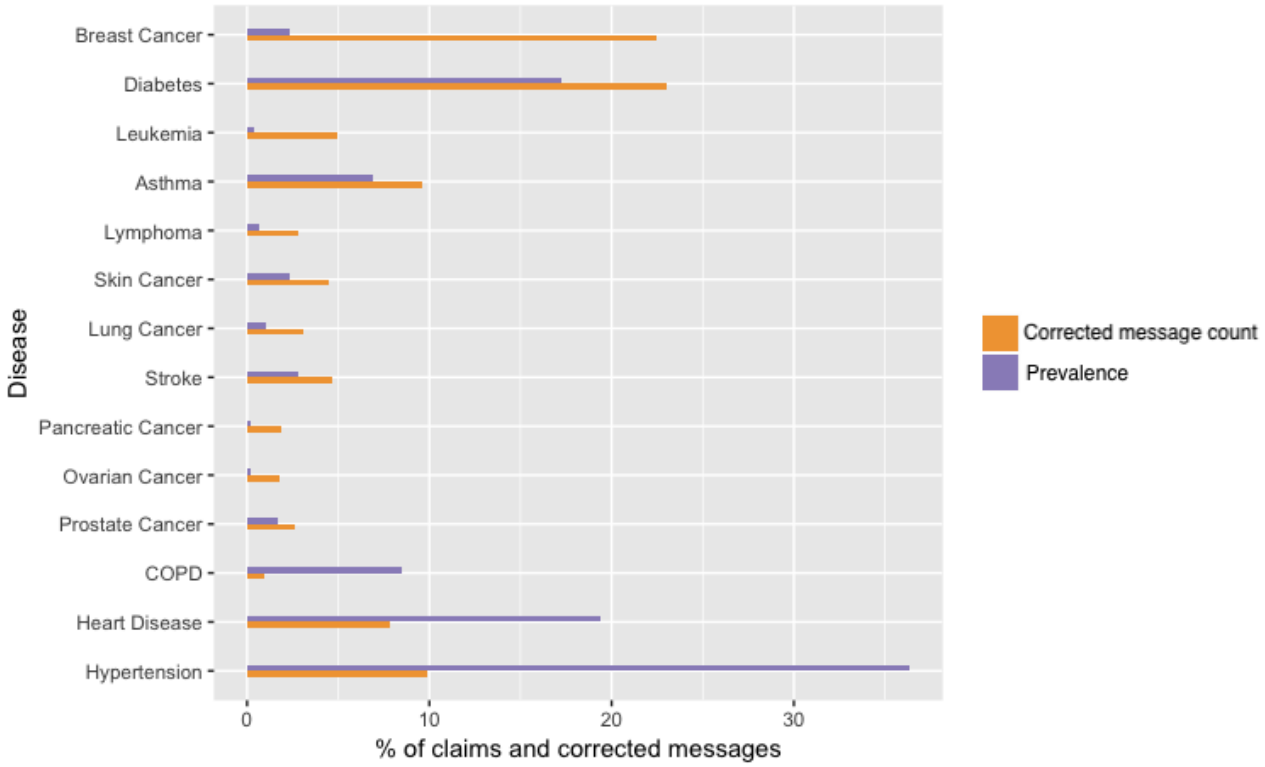
Comparing Tweet Volume to Disease Prevalence in Pennsylvania

When comparing prevalence to corrected message counts (Figure 3) we identified that hypertension (17,245/174,381 messages, 9.89%; 4614,776/12,702,379 prevalence, 36.33%), COPD (1648/174,381 messages, 0.95%; 1,083,627/12,702,379 prevalence, 8.53%), and heart disease (13,669/174,381 messages, 7.84%; 2,461,721/12,702,379 prevalence, 19.38%) were underrepresented on Twitter. Breast cancer was overrepresented when comparing corrected message counts and prevalence (39,156/174,381 messages, 22.45%; 306,127/12,702,379 prevalence, 2.41%).

Table 1. Characteristics of the study sample: tweet data and user data.

Disease	Message count, n	Correction factor, %	Corrected message count, n	Users, n
Cancer				
Breast cancer	39,169	100	39,156	19,960
Leukemia	9129	95.1	8682	5855
Lung cancer	5745	92.6	5317	3719
Lymphoma	5276	93.4	4927	2758
Ovarian cancer	3063	99.9	3060	1212
Pancreatic cancer	3231	100	3231	1189
Prostate cancer	4487	100	4487	2311
Skin cancer	7866	99.9	7859	4048
Chronic lung disease				
Asthma	18,082	92.6	16,742	10,185
Chronic obstructive pulmonary disease	2137	77.1	1648	726
Diabetes	41,615	96.6	40,217	16,321
Heart disease				
Heart disease	14,740	92.7	13,669	7992
Hypertension	18,404	93.7	17,245	12,203
Stroke	53,858	15.1	8141	34,298

Figure 3. Proportion of messages versus prevalence. COPD: chronic obstructive pulmonary disease.



Characterizing Tweet Topics About Individual Diseases

For each disease, we identified all statistically significant ($P<.001$) correlations between topics and a binary label indicating whether or not a message contained a reference to the disease. Topics most correlated with asthma were related to first-person accounts of managing the disease (*attack* and *inhaler*), discomfort associated with the disease (*can't* and *breathe*), or conditions that pose additional risk *(pollution, mold,* and *dust)* such as allergens. The majority of topics associated with cancer referenced some variety of charity campaign (*pink, ribbon,* and *bracelet*) or awareness effort (*support, awareness, October,* and *pink*). Topics related to stroke were rarely related to cerebrovascular accident, but more often related to other definitions of stroke (eg, golf stroke, paint stroke, and heat stroke). Diabetes, heart disease, and hypertension messages were correlated with topics that focused on disease management (*weight loss, insulin,* and *reduce stress*) and lifestyle choices (*diet* and *exercise)*. Complete topic word clouds for each disease can be found in Multimedia Appendix 2.

Characterizing Tweet Themes Across Diseases

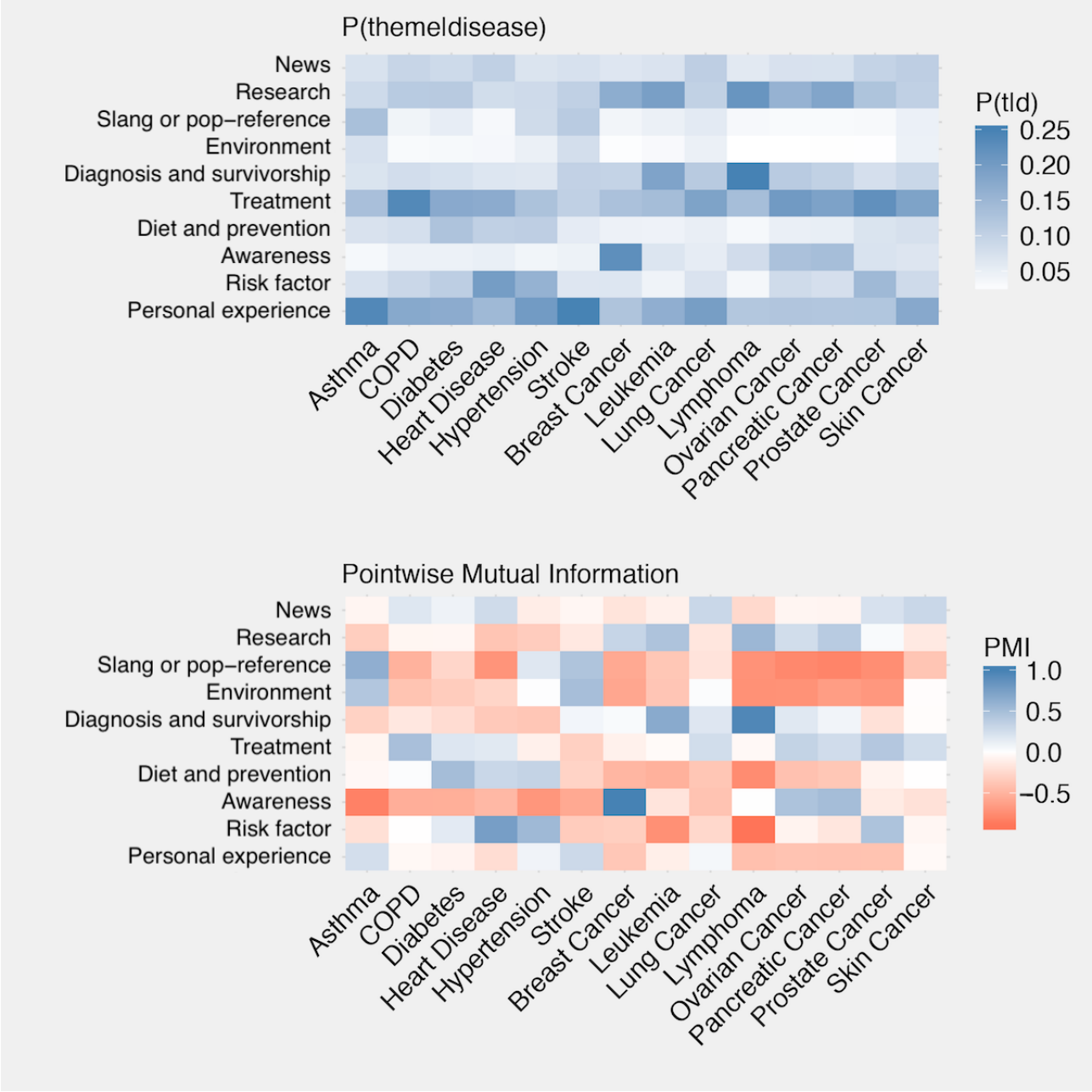
Probability of Theme Given Disease

The probability of a theme given the disease provides insight into the most prevalent topics of conversation for a specific disease (Figure 4). We identified that messages referencing breast cancer were more likely to be about disease *awareness* (9139/39,156 messages, 23.34%). Heart disease messages mostly focused on *risk factors* such as stress, sleep, and obesity (1375/13,669 messages, 10.06%). In most cases, asthma messages referenced a *personal experience*.

Pointwise Mutual Information

PMI provides a measure of association between the theme and the disease (Figure 4). We found that diagnosis was a small proportion of the theme distribution for each disease. However, if diagnosis or survivorship is mentioned, it is much more likely to be mentioned in conjunction with lymphoma and leukemia than with the other diseases (PMI 0.67-0.96). Similarly, a relationship between the *risk factors* theme and hypertension and heart disease was found (PMI 0.54-0.77).

Figure 4. Theme distribution. P(t|d): probability of theme given disease; COPD: chronic obstructive pulmonary disease; PMI: pointwise mutual information.



Discussion

Principal Findings

There is increasing focus on the potential for big data from digital sources in health care. There are challenges associated with using these sources, as they are not always collected for the purposes of health tracking.

We explored the potential for using Twitter to better understand the Web-based conversation about common health conditions. We identified that in some cases, traditional health metrics are associated with the volume of tweets for a given disease. Although traditional methods of determining disease prevalence are robust, they are often delayed in availability because the process for data acquisition and tracking to determine reliable and valid estimates is considerable. Twitter data are available in real-time, much faster than traditional methods, and with significant volume providing a measure of public discourse about health. While tweets would not replace traditional surveillance in the way initially posed by Google flu trends [14], they do provide something unique that prevalence statistics do not; a narrative about patient and public thoughts, knowledge, and experiences with health. Twitter provides context to the conversation surrounding disease and allows for characterization of public discussion of high prevalence conditions. We identified that individuals are using Twitter to talk about several diseases, although variation exists in the frequency of disease mention and the content.

We observed that people are using Twitter for talking about the most common health conditions in Pennsylvania. Prior work has demonstrated the use of Twitter to monitor influenza [15], postpartum depression [16], concussion [17], epilepsy [18], and

migraine [19]. The prevalence of disease has been correlated with the frequency of Twitter posting across a variety of diseases [13,20].

We also identified variability in disease mentions and the specificity of terms. This finding provides us with several insights. First, heart disease and stroke cannot be analyzed without preprocessing owing to the ambiguity of many of the keywords associated with the diseases. To resolve these varying issues, other methods will need to be developed to filter out much of the noise associated with these diseases. However, this finding also assures us that the majority of the language we find associated with other diseases can be analyzed using the open vocabulary methods previously described with minimal preprocessing.

Although disease prevalence often coincides with disease mention on Twitter, we found significant variability. The frequency of mentions of breast cancer on Twitter was several orders of magnitude higher than lung cancer, although lung cancer has a higher rate of death and relatively similar prevalence. Breast cancer has a large social media presence owing to awareness and charity campaigns in conjunction with a large community base from those affected by the disease. Lung cancer is tweeted about less often and is often the result of a pop culture reference from television or a celebrity death.

Traditional metrics provide detailed information about prevalence but not insights about people's understanding, concerns, and questions about health and disease. Our analysis identified several underlying themes that are specific to some diseases. Asthma tweets included references to personal experiences for both the person with asthma as well as parents expressing concern for their children's asthma issues. Although the largest portion of tweets for the different types of cancer analyzed often referenced charity and awareness, we observed that across diseases in our sample, cancer conditions had the largest portion of tweets about diagnosis.

Our findings also give insight into potential opportunities for using Twitter to inform public health and health communications practices. Future work could examine temporal relationships between Twitter volume and semantic data and traditional health data over larger timeframes and at varying timescales. Meaningful temporal relationships may indicate that Twitter data have value as an additional signal to augment existing surveillance systems, allowing for more precise health tracking and timely interventions.

Twitter data could enhance community building and engagement. Prior work by Neiger et al [21,22] found that more two-way communication on Twitter between public health entities and individual citizens led to an increase in action and awareness that, in turn, resulted in an improvement in community health. Providing local and state public health entities with more accurate information on the public discourse surrounding health could enhance communication and contribute to the more effective dissemination of pertinent and timely health information to the public.

Finally, understanding the interaction between social media use and individual health can identify opportunities for targeted interventions. Prior work by Park et al [23] showed that interventions targeting the perception of social media interaction have the potential to positively impact individual health. We have shown that it is possible to capture a measure of public perception of individual diseases at the community level via analysis of topics and themes. These methods can be translated to individual subjects, where disease perceptions could be tracked over time and compared with actual measures of health, potentially identifying opportunities for intervention.

Limitations

We compared data from Twitter for 2012-2015 with disease prevalence from 2014, so there may be some variability by year in these estimates. We evaluated unadjusted data from 1 state, so this may not be representative of the conversation about health conditions across other states or geographic regions. Twitter data primarily originate from urban areas; hence, data may not be the most representative sample across the state of Pennsylvania. Future work could explore variations in language on Twitter relative to the size of geographic regions, socioeconomic factors (eg, race, income, urban or rural), and variations in news events or other triggers. Although our correction method eliminates nondisease references, it does not account for metaphorical and joking tweets. This impacts diseases such as heart disease, diabetes, and hypertension.

The precision of the disease keyword filtering, which is the number of selected tweets that were relevant, is reasonably estimated by the corrected message count. However, the recall of the disease keyword filtering, which is the number of relevant tweets that were selected, is difficult to determine owing to the nature of the data and the subjectivity of relevance in the context of health-related tweets. Hopkins et al [24] provides 3 different models for estimating recall: a hand-coding approach similar to the corrected message count presented here, a supervised learning approach for individual document classification, and a supervised learning approach to estimate document category proportions. Evaluating these methods in terms of cost and accuracy is beyond the scope of this study but should be considered for future work to provide more robust measures of keyword-filtered data quality.

Location identification accuracy is difficult to measure for user-defined locations owing to the relative ambiguity of the data provided. The procedures used to estimate user-defined location provide a "soft" measure of accuracy, but more work is needed to ensure appropriate representation. Additionally, a very small proportion of tweets contains location information, thus, the sample may not be representative of the general Twitter landscape in Pennsylvania. Methods such as those detailed in Liang et al [25] should be considered in future studies to correct for sampling bias.

Conclusions

We identified that the volume of tweets is often related to rates of health conditions across a state. The semantic content provided from Twitter provides insight into public perception and awareness of disease beyond what is available through traditional measures of disease prevalence.

Acknowledgments

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Consumer Health Vocabulary search terms: This study focuses on 14 diseases and each disease is represented by a lexicon of disease related terms. The appendix contains each of the 14 diseases along with the 274 terms which comprise the lexica.

[XLSX File (Microsoft Excel File), 55KB - publichealth_v4i4e10834_app1.xlsx]

Multimedia Appendix 2

Correlation between topic and disease.

[PNG File, 940KB - publichealth_v4i4e10834_app2.png]

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Abbreviations

API: application programming interface
COPD: chronic obstructive pulmonary disease
LDA: latent Dirichlet allocation
PMI: pointwise mutual information

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Original Paper

Analysis of the Regionality of the Number of Tweets Related to the 2011 Fukushima Nuclear Power Station Disaster: Content Analysis

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Abstract

Background: The Great East Japan Earthquake on March 11, 2011, triggered a huge tsunami, causing the Fukushima Daiichi nuclear disaster. Radioactive substances were carried in all directions, along with the risks of radioactive contamination. Mass media companies, such as television stations and news websites, extensively reported on radiological information related to the disaster. Upon digesting the available radiological information, many citizens turned to social media, such as Twitter and Facebook, to express their opinions and feelings. Thus, the Fukushima Daiichi nuclear disaster also changed the social media landscape in Japan. However, few studies have explored how the people in Japan who received information on radiation propagated the information.

Objective: This study aimed to reveal how the number of tweets by citizens containing radiological information changed regionally on Twitter.

Methods: The research used about 19 million tweets that included the terms “radiation,” “radioactivity,” and “radioactive substance” posted for 1 year after the Fukushima Daiichi nuclear disaster. Nearly 45,000 tweets were extracted based on their inclusion of geographic information (latitude and longitude). The number of monthly tweets in 4 districts (Fukushima Prefecture, prefectures around Fukushima Prefecture, within the Tokyo Electric Power Company area, and others) were analyzed.

Results: The number of tweets containing the keywords per 100,000 people at the time of the casualty outbreak was 7.05 per month in Fukushima Prefecture, 2.07 per month in prefectures around Fukushima Prefecture, 5.23 per month in the area within Tokyo Electric Power Company, and 1.35 per month in others. The number of tweets per 100,000 people more than doubled in Fukushima Prefecture 2 months after the Fukushima Daiichi nuclear disaster, whereas the number decreased to around 0.7~0.8 tweets in other districts.

Conclusions: The number of tweets per 100,000 people became half of that on March 2011 3 or 4 months after the Fukushima Daiichi Nuclear Plant disaster in 3 districts except district 1 (Fukushima Prefecture); the number became a half in Fukushima Prefecture half a year later.

(JMIR Public Health Surveill 2018;4(4):e70) doi:10.2196/publichealth.7496

KEYWORDS

Fukushima nuclear disaster; Twitter messaging; radiation; radioactivity; radioactive hazard release; geographic location; information dissemination

Introduction

Fukushima Daiichi Nuclear Disaster

On March 11, 2011, the Great East Japan Earthquake struck off the coast of Tohoku, bringing a huge tsunami that brought catastrophic destruction along the Pacific-facing coast of Tohoku and Kanto regions, causing the Fukushima Daiichi nuclear disaster. As a result, a large quantity of radioactive materials leaked, causing radioactive pollution of the water. The radiation levels caused by the Fukushima Daiichi nuclear disaster threatened not only human health but also agriculture and fishing industry. Further, it had psychological impacts on the long-term refugees forced to leave their homes within the "difficult-to-return zone" or "restricted residence zone" in the areas surrounding the Fukushima Nuclear Power Plant.

Information Diffusion

Soon after the disaster, public opinions are formed through various platforms including social network services (SNS) [1]. The Fukushima Daiichi nuclear disaster was reported immediately by the mass media, including newspapers, TV stations, and internet news sites. Citizens witnessed the terrible sight of the nuclear plant disaster and learned the radiation dose in various areas, along with other information on radiation. Many expressed their emotions and opinions related to the nuclear plant disaster and radiation as well as shared information on the same using SNS, such as Twitter and Facebook. Therefore, information spread rapidly.

The information sharing on social media had far-reaching positive impacts, including real-time property and high diffusibility. Thus, consumers of information are simultaneously contributors of information [2]. However, it became a problem at the Fukushima Daiichi nuclear disaster that the information that spread rapidly included misleading reports such as claims that iodine is useful for treating radioactivity as a replacement of stable iodine. Stable iodine is used for thyroid exposure reduction under a doctor's prescription, but iodine was used for a person who did not have to take it. Taking in a toxic substance included in iodine and iodine in large quantities caused a health risk. People need to obtain correct information quickly in times of disasters, such as the Fukushima Daiichi nuclear disaster. As mentioned above, however, incorrect information on the radiation spread rapidly as well.

For confirmed truths and false rumor propagation in social media, false rumors tend to receive more questions; thus, it has been reported that it is possible to distinguish between them [3]. In addition, it has been reported that inaccurate information on social media is later modified by other users, so harmful and incorrect rumors are not particularly enhanced by using social media [4].

However, to distinguish between confirmed truths and false rumors, it is necessary to gather a lot of data using aggregate analysis of social media. Real-time false information and rumors at the time of a disaster require time to be modified by confirmed truths, so it is expected that they will possibly lead to temporary confusion and harm. The spread of wrong information on radiation was regarded as a problem in the Fukushima Daiichi nuclear disaster. Incorrect information needs to be addressed to ensure that citizens are not confused when a disaster such as the Fukushima Daiichi nuclear disaster occurs. We believe that it is necessary for citizens to get accurate medical information quickly in the event of a catastrophe.

Twitter

Twitter was the largest microblogging service, with about 200 million users, as of March 2011 [5]. Twitter is an information service through which users can post short messages called "tweets." Tweets are short but condensed personal messages with a 140-character limit designed for rapid reporting from mobile devices [6]. In Twitter, for the purpose of reading tweets, it is necessary to follow the users. Thus, the users can read tweets posted by followees (following users) and propagate information by showing the timeline of the follower (followed users) tweets posted by oneself. Posted tweets are displayed on the follower's timeline in a chronological order and are updated dynamically. Thus, tweets can be read by several followers immediately as they are posted.

Information on Twitter is characterized by its real-time availability and high information propagation power. As tweets must be not more than 140 characters in length, posting is easier compared with other SNS types. Users can post daily events and random thoughts as well as obtain regional information immediately. Compared with other SNS types, approval is unnecessary for following relations on Twitter, and information can be acquired easily according to one's interest except where a user opts to maintain a private timeline. In addition, information spreads easily through the "retweet" function that enables users to quote others' tweets. Other features include embedding of geographic information (latitude and longitude) in tweets and posting using "bots" programs that enable automatic and scheduled posting. Geographic information will be attached to a tweet only if that user permits sending location information. Figure 1 shows the rate of utilization for each generation on Twitter [7]. Teenagers are the largest group with available access to Twitter, where availability tends to decrease with age. The usage rate of Twitter varies according to age, and as the age increases, the utilization rate decreases. The limitations of Twitter research, in general, are to gather a lot of tweets with geographical information and to surely collect the tweets of all ages. Therefore, it is difficult for Twitter analysis to grasp the information dissemination situation of all ages.

Twitter, launched in July 2006, began to be used in Japan on April 23, 2008. The number of Japanese users increased rapidly after new mobile sites were established across Japan in October 2009. Figure 2 shows the changes in the number of Twitter users and Facebook users in Japan [5,8]. The active user is defined as a monthly active user on Twitter. In March 2011, the average daily number of tweets reached about 18 million, and Twitter was used for safety confirmation and information exchange in the aftermath of the Fukushima Daiichi nuclear disaster as conventional information and communication infrastructures suffered severe damage.

Figure 1. Rate of utilization for each generation on Twitter in Japan.

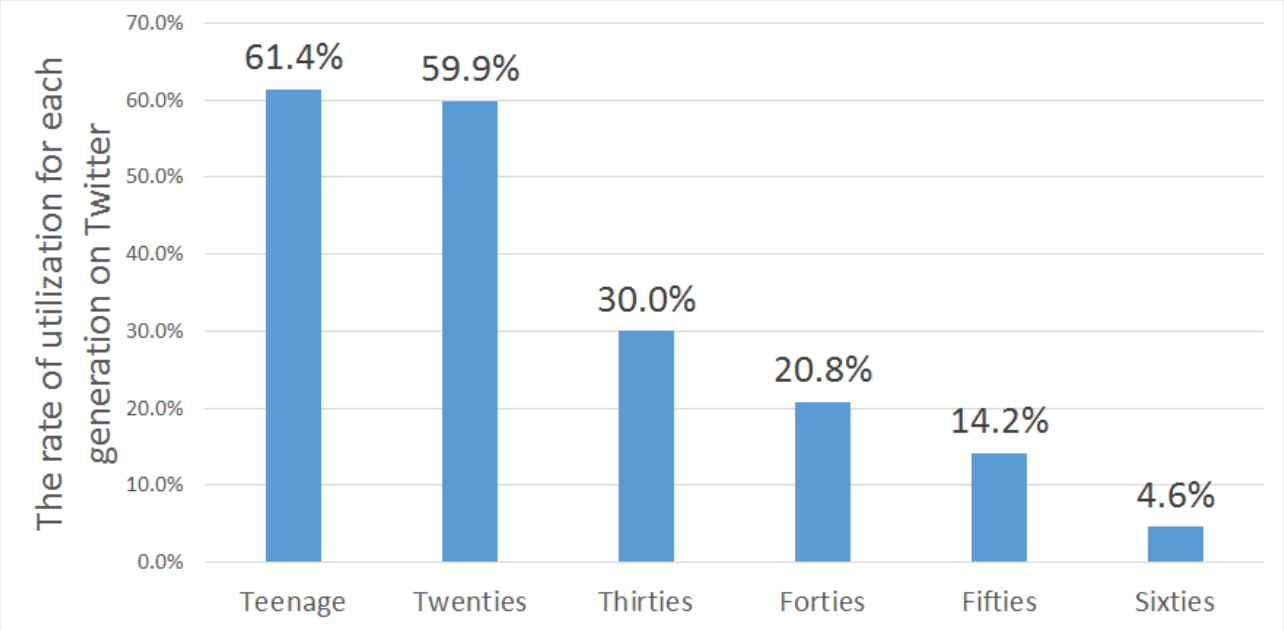
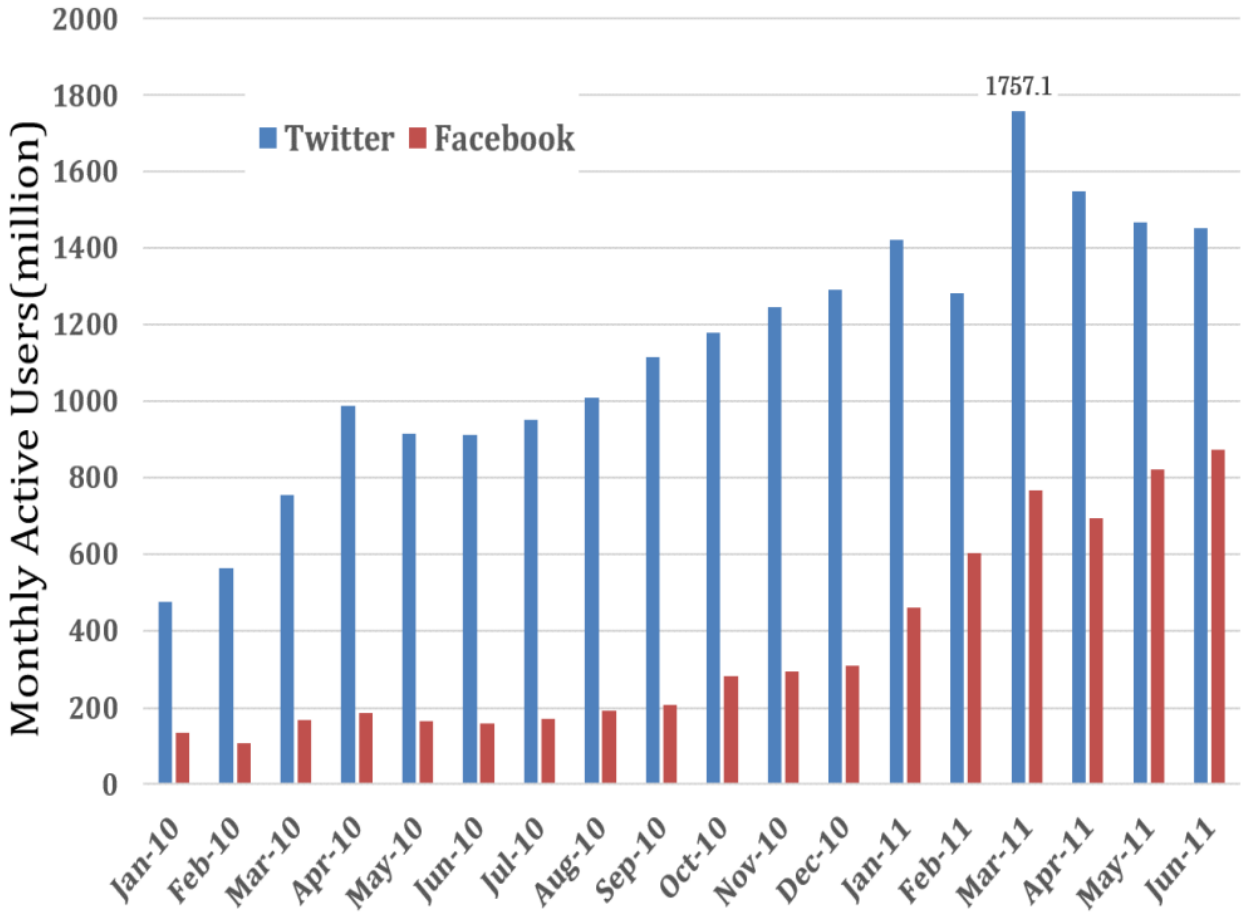


Figure 2. The number of active users on Twitter and Facebook.



Mendoza et al analyzed Twitter information immediately after the occurrence of 2010 Chile earthquake. As a result, it became clear that the most tweets were generated immediately after the earthquake occurred [3]. Qu et al conducted information analysis on the disaster sent by the Chinese microblogging site Sina Weibo after the occurrence of Yushu earthquake in 2010. It became clear that disaster-related situation update messages were the second most generated tweets[9]. Acar et al reported that people indirectly influenced by the Great East Japan Earthquake in 2011 had been tweeting about indirect and future

outcomes of the earthquake, including nuclear plant disaster-associated risks [10]. These three papers indicate that tweets on nuclear disaster were transmitted as situation update information by those who were affected by indirect earthquakes immediately after the earthquake occurred. Also, it is conceivable that the number of tweets will increase as one gets closer to the disaster occurrence area. Acar et al have reported that people affected by direct disasters tend to tweet survival-related topics [10]. People who were influenced by the direct earthquake would have thought that nuclear disaster information is a survival-related topic after information on nuclear plant disaster-associated risks was transmitted to disaster occurrence areas through Twitter and media. As a result, it seems that information on radioactive contamination increased even in areas affected directly. By this means, tweets on radioactive contamination are considered to cause regional differences. As for the information on radioactive contamination, it is expected that there will be a change in the amount of information over time as well as a regional difference in information, such as that in the tweet information that has occurred in the case of a big earthquake so far. However, after the occurrence of a disaster, analyses of changes in the number of tweets on regional radiation information and regional differences have not been conducted.

Objective

Xin Lu and Christa Brelsford analyzed tweets from February 28 to March 7, 2011 (before the Tohoku earthquake on March 11, 2011) and from March 14 to March 21, 2011 (after the earthquake), reporting distinctive changes in patterns of interactions in Web-based communities that had been affected by a natural disaster compared with communities that had not been affected [11]. Thomson et al analyzed tweets with the hashtag #fukushima, reporting that close to 70% of synthesis-derivative tweets (whereby tweets and other third-party-sourced information is passed on wholesale) were based on highly credible sources [12,13]. However, at the time of the disaster, there were few studies that investigated the temporal change in tweet number and its regionality with respect to radiation emitted among Japanese people. This study aimed to reveal how the number of tweets by citizens containing radiological information changed regionally on Twitter.

Methods

Research Objects

We analyzed 45,829 tweets, extracted from approximately 19 million tweets that contained any or all of the terms “radiation,” “radioactivity,” and “radioactive materials” and that were posted from 0:00 on March 11, 2011, to 23:59 March 10, 2012, on Twitter, as research objects. These tweets were chosen based on containing latitude and longitude information. The total population in each prefecture was used for the total population in each district [14].

Classification of Districts

Japan was classified into 5 districts in reference to use trend analysis of Twitter after the Great East Japan Earthquake [15]. Table 1 and Figure 3 show the definition and classification of the districts.

Fukushima Prefecture with the Fukushima Nuclear Power Plant was the catastrophic area set as district 1. The prefectures around district 1 were the damaged areas categorized under district 2. The prefectures receiving electric power supply from Tokyo Electric Power Company, excluding district 1 and 2, were the indirectly damaged areas included in district 3. The prefectures outside districts 1 to 3 were the nondisaster areas set as district 4. Finally, areas outside Japan were the other areas categorized as district 5. The study specified the places where tweets were posted according to their geographic information (latitude and longitude). Usoinfo reverse geocoder version 1.1 software was used to convert latitude and longitude information into the address of a corresponding point [16]. The districts where tweets were posted were then specified according to their addresses, and their distribution was mapped. This study did not use the tweets in district 5.

Comparison of Number of Tweets per 100,000 People in Each District

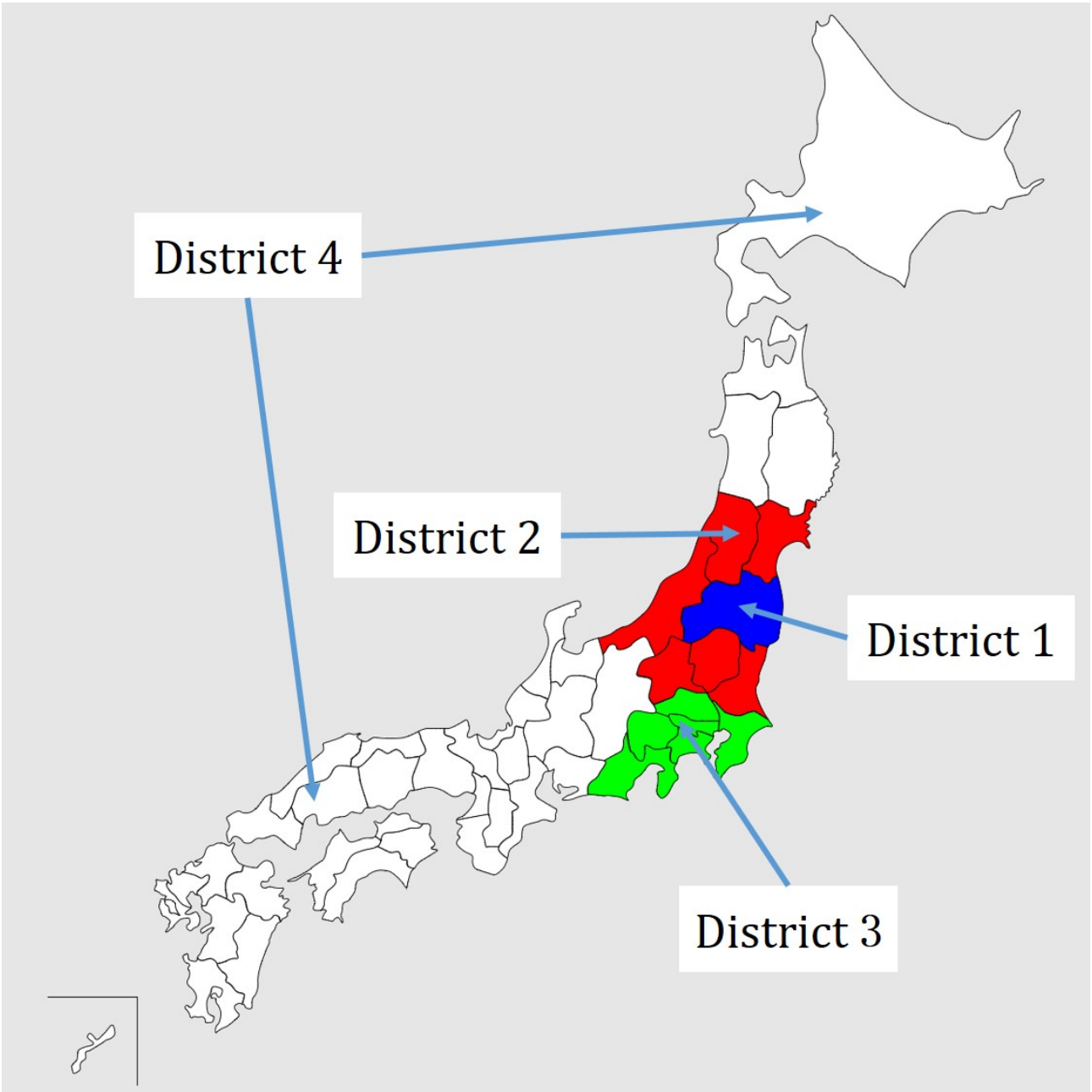
This study compared the number of tweets per 100,000 people every 1 month to solve the problem that the population was different in each district. In each district, the number of tweets in 1 month in a population of 100,000 people was counted using the total population and number of tweets in 1 month in each district. A month was defined as a 30-day period, beginning from 00:00 of March 11 to 23:59 of the 29th day; that is, the second month started at 0:00 of April 11 and so on. The study comprised 3 steps. First, we visualized how the number of tweets per 100,000 people in each district changed with each passing month after the Fukushima Nuclear Plant disaster. The districts were then compared in terms of tweeting trends. Second, we excluded bots to compare only the tweets posted by actual citizens for each district and visualize the changes in the civic interest toward radiation. Third, we compared the number of tweets based on that of tweets in March in each district shortly after the start of the Fukushima Nuclear Plant disaster. The relative number of tweets every month was then calculated to express the increase and decrease in the number of tweets. The percentages informed a visualization of how the number of tweets in each district changed after the Fukushima Nuclear Plant disaster, including the tweet to population ratio.

Table 1. Definition and classification of the districts of Japan according to trend analysis of Twitter after the Great East Japan Earthquake.

District	Definition	Prefectures
District 1	Catastrophic area (Fukushima Nuclear Power Plant location)	Fukushima
District 2	Damaged area (Prefectures around Fukushima)	Miyagi, Yamagata, Ibaraki, Gumna, Niigata, Tochigi
District 3	Indirectly damaged area (Prefectures in Tokyo Electric Power Company except district 1 and 2)	Saitama, Chiba, Tokyo, Kanagawa, Yamanashi, Shizuoka
District 4	Nondisaster area (Prefectures except district 1-3)	Other prefectures
District 5	Foreign countries and the sea	N/A[a]

[a]N/A: not applicable.

Figure 3. Locations of the districts of Japan classified according to trend analysis of Twitter after the Great East Japan Earthquake.



Results

Total Population and the Number of Tweets in Each District

Table 2 shows the number of tweets and total population in each district. Number of tweets was most numerous in district 3 (indirectly damaged area), and population size was greatest in district 4 (nondisaster area). Furthermore, tweets per population was highest in district 1 (catastrophic area).

Comparison of Number of Tweets per 100,000 People in Each District

Figure 4 shows the number of tweets per 100,000 people in each district. In district 1 (blue line), the number of tweets rose rapidly shortly after the Fukushima Nuclear Plant disaster outbreak. In district 3 (green line), the trend was a gentle rise throughout the year after the Fukushima Nuclear Plant disaster outbreak. In district 2 (red line) and 4 (purple line), the number of tweets decreased gradually throughout the year after the Fukushima Nuclear Plant disaster outbreak. Meanwhile, all districts showed an increase in the number of tweets in January 2012.

Table 2. Number of tweets and total population in each district according to trend analysis of Twitter after the Great East Japan Earthquake.

District name	Number of tweets	Population	Tweets per population (%)
District 1	1956	2,029,064	0.10
District 2	2042	12,877,060	0.02
District 3	34,152	40,246,646	0.08
District 4	6136	72,904,582	0.01
District 5	1543	N/A[a]	N/A

[a]N/A: not applicable.

Figure 4. Number of tweets per 100,000 people in each district according to trend analysis of Twitter after the Great East Japan Earthquake.

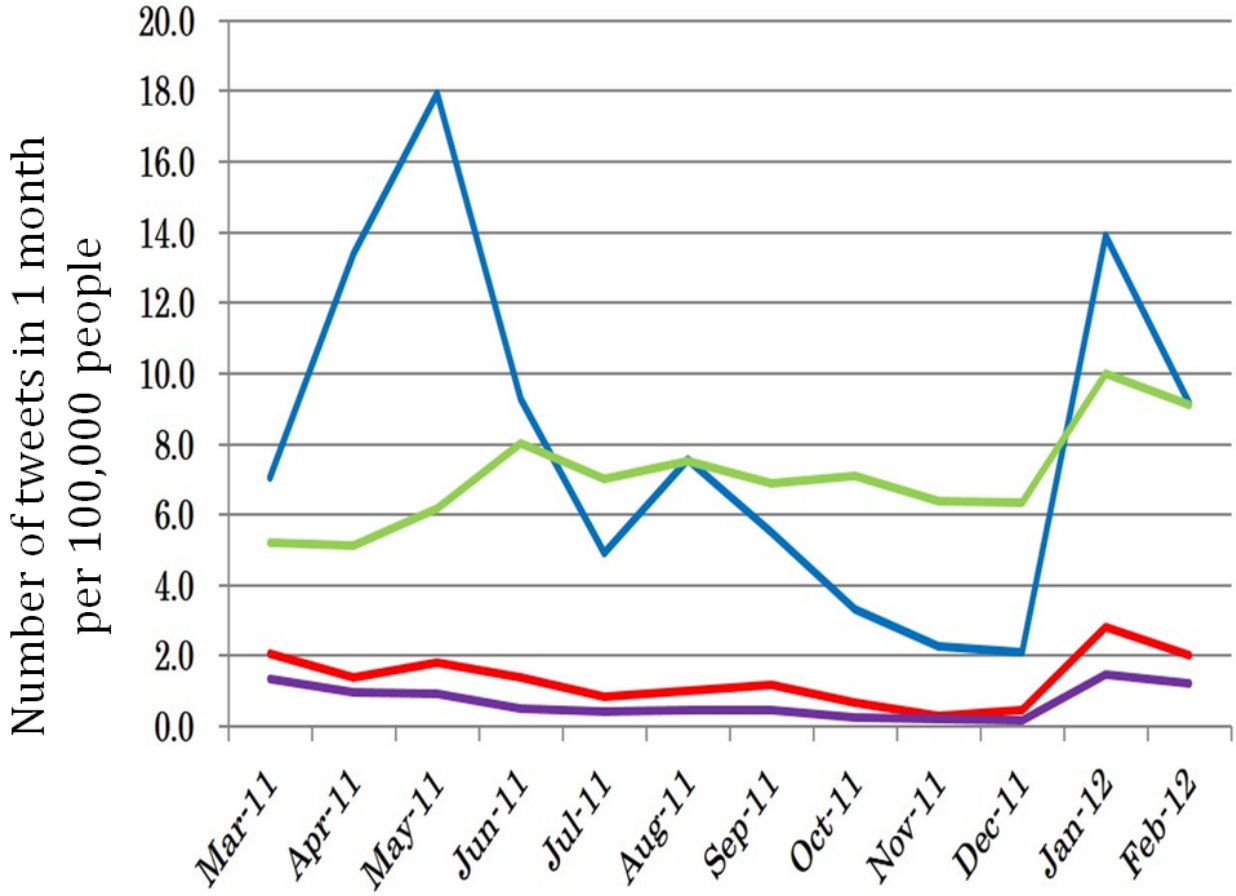


Figure 5. Number of tweets per 100,000 people in each district according to trend analysis of Twitter after the Great East Japan Earthquake.

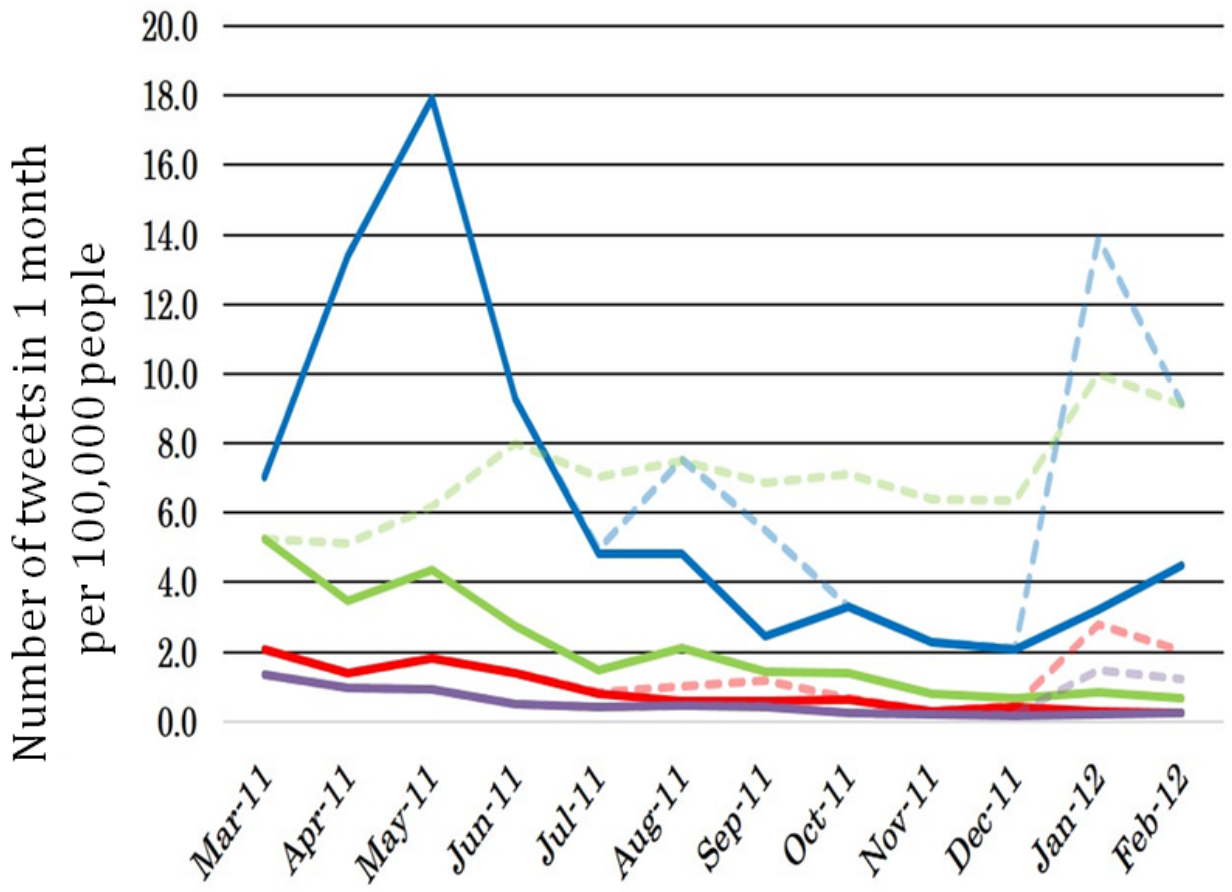


Figure 5 shows the number of tweets per 100,000 people in each district. Tweets posted automatically were removed. The dotted lines of the graph express the number of all tweets per 100,000 people, whereas the solid lines express the number of tweets excluding those posted automatically. A solid line and a dotted line separated by a distance indicate that the percentage of tweets posted automatically had the majority in a certain district. In district 1 (blue lines), the dotted and solid lines overlap each other at the point where the number of tweets increased rapidly after the occurrence of first Fukushima Nuclear Power Plant disaster. Therefore, the number of tweets increased in this period because the number of tweets posted by citizens increased. Meanwhile, in district 3 (green lines), the number of all tweets per 100,000 people increased through the year, but the number of tweets excluding those posted automatically decreased after the Fukushima Nuclear Plant disaster. As such, the number of tweets increased in district 3 because of automatically posted tweets, but the ratio of tweets posted by citizens decreased gradually.

Comparison of the Relative Number of Tweets in Each District

Figure 6 shows the ratio of the number of tweets in each month based on the number of tweets in each district when the Fukushima Nuclear Plant disaster occurred. In district 1 (blue line), the number of tweets increased to about 2.5 times 2 months after the Fukushima Nuclear Plant disaster outbreak. Meanwhile, in districts 2 (red line) and 4 (purple line), the number of tweets decreased slowly after the Fukushima Nuclear Plant disaster outbreak. District 3 (green line) showed an increase throughout the year. All districts showed an increase in the percentage of the number of tweets in January 2012.

Figure 7 presents the trends in each district, excluding tweets posted automatically, based on the number of tweets at the time of the Fukushima Nuclear Plant disaster outbreak.

In districts 2 (red solid line), 3 (green solid line), and 4 (purple solid line), the number of tweets decreased to half of that in March by July (4 months after the Fukushima Nuclear Plant disaster outbreak). The same decrease was seen in district 1 (blue lines), but in September or half a year after the Fukushima Nuclear Plant disaster outbreak. The ratio of the number of tweets continued to decrease until December, although this trend did not apply to district 1 (blue solid line) in January 2012.

Figure 6. Ratio of the number of tweets in each month based on the number of tweets in each district at the time of Fukushima Nuclear Plant disaster.

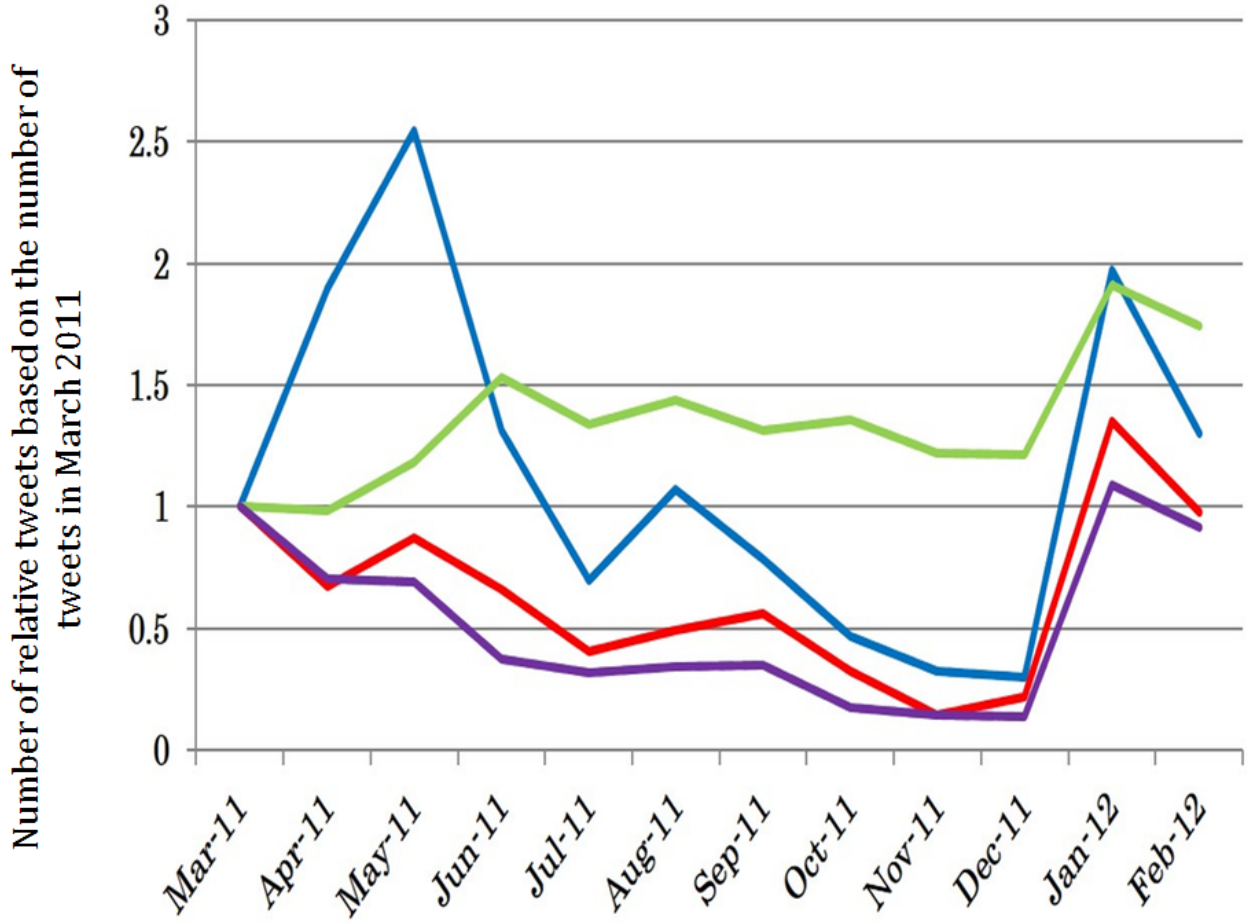
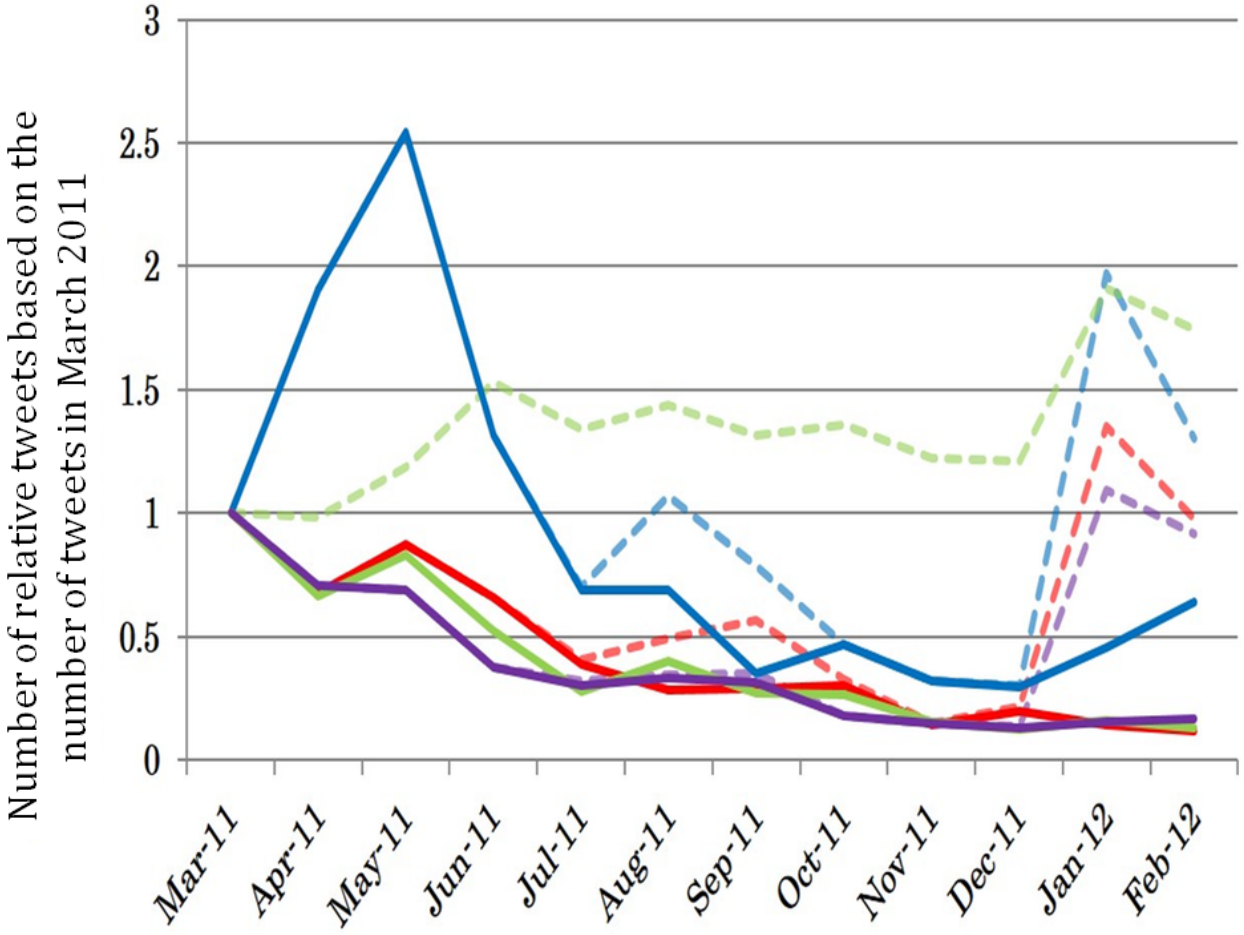


Figure 7. Ratio of the number of tweets in each month based on the number of tweets in each district at the time of the Fukushima Nuclear Plant disaster.



Discussion

Increase in Tweets on Radiation in Each District in May 2011

In 3 districts (except district 4), the number of tweets increased in May, or 2 months after the Fukushima Nuclear Plant disaster outbreak. Especially in district 1, the number of tweets increased to approximately 2.5 times compared with the March 2011 numbers. This trend coincided with the reports in May on the meltdown at Fukushima Nuclear Power Station No. 1 that relayed information on the high concentration of water contamination from a part of the soil in Fukushima. The main radioactive nuclide released from the nuclear power plant was iodine-131, which can increase the risk of thyroid cancer as epidemiologically demonstrated just after the Chernobyl disaster [17]. The news also covered the death of an employee on site at the Fukushima Nuclear Power Plant. These news reports may have stimulated civic interest in radiation, evidenced by the increase in number of tweets on the leak of highly concentrated radioactive material outside of Fukushima Nuclear Power Plant, on the geographic distance of the nuclear workstations, and on the health risks or potential fatality of radiation in the Fukushima Nuclear Plant disaster.

Increase in Number of Tweets on Radiation Doses in January in Each District

Automatically posted tweets increased in each district in January, and many of them indicated radiation doses in certain areas. This trend may indicate the uneasiness of the public regarding radiation, which had been shown to be fatal to humans. A survey conducted during March 12-15, 2012 on the internet with 1793 parents with small children living in the Tohoku region, Kanto region, and Kansai region reported that a total of 73.3% of the surveyed Japanese parents experienced anxiety after the Fukushima Nuclear Plant disaster, and 52.7% of parents in the Fukushima Prefecture experienced “strong anxiety” that was higher than that reported from other regions [18]. A survey to quantify emotional responses for 284 British nationals in Japan reported that 16% met the criteria for distress, 29.7% reported high anxiety relating to the incident, and 30.4% reported high anger [19]. Therefore, the citizens sought information on radiation in their area of residence for their peace of mind.

According to the needs of the citizens in each district, municipalities began to measure the radiation dose, and the results were transmitted through various media. As a result, tweets on radiation dose increased.

Limitations of the Study

This study has 3 limitations, as detailed below.

Civic Movement

The study period was set as the year after the disaster occurred. In this period, the entry and exit of people happened frequently; there was fluidity in the tweeting population. Refugees were moved to shelters; volunteers entered disaster-affected areas, and nuclear workers were brought into the plant and its environs. In other words, the places where citizens lived could be different from the places where they posted tweets, such as their workplace.

Immediately after the disaster, migration of citizens is taken into consideration as it is considered that there are not many citizens flowing in and out. However, because it is thought that citizens were flowing in and going out over more than 1 month, it is not possible to consider this point in this research; thus, we think that it is necessary to consider countermeasures.

Number of Twitter Users

We used the total population of 47 prefectures to calculate the number of tweets per 100,000 people in each district. However, the utilization ratio on Twitter differs according to age and is not equal. Therefore, the differences in the age composition of the population in each district generated deviation, and the ratio of the number of tweets per 100,000 people in each district may be not representative of the entire population. It would be necessary to consider the age composition in each district in a future study.

Number of Tweets With Geographic Information

The extracted 45,829 tweets with latitude and longitude information represent a small fraction of the 18 million tweets on radiation. Furthermore, the retweets were not given special attention. In future work, retweets on Twitter merit investigation, especially the relationship between original tweets and retweets, to show which tweets attracted public interest with respect to the need for information on radiation. It is difficult to increase the number of tweets including latitude and longitude information. We believe that we can gather more data by collecting information on latitude and longitude using information sent through other SNS and analyzing it along with Twitter data. In investigating the concern, we think that it is necessary to analyze the degree of impression of information on radiation and perform a regionality analysis on ambiguity; thus, we would like to analyze emotions as well. It is also necessary to analyze how the interest spreads. In the future, we also need to investigate the retweet information, which is the information spreading function of Twitter, and analyze the communication of medical information on Twitter.

The existence of not only accurate medical information but also erroneous medical information on the Web may hinder accurate medical information from being obtained quickly in the event of a disaster. In this study, tweet information including the phrases “radiation,” “radioactivity,” and “radioactive substance” within the target period was analyzed for the change over time of the tweet number. However, it seems that the information includes erroneous medical information. How this kind of information spreads cannot be clarified in this research. We would like to clarify how information among users will spread by analyzing retweet information in the future.

Conclusion

The purpose of this study was to reveal how the dissemination of information on radiation changed within the year immediately after the first Fukushima Nuclear Plant disaster. District 1, or the district closest to the disaster site, showed the highest frequency of related tweets 2 months after the disaster (up to June 2011). In districts outside district 1, a high volume of radiation-related tweets was found only in March 2011, after which information sharing on this aspect decreased gradually.

The number of tweets per 100,000 people became half of that on March 2011 3 or 4 months after the Fukushima Daiichi Nuclear Plant disaster in 3 districts except district 1 (Fukushima Prefecture 9); the number became half in Fukushima Prefecture half a year later.

Conflicts of Interest

None declared.

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Abbreviations

SNS: social network services

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Original Paper

Strategies to Increase Latino Immigrant Youth Engagement in Health Promotion Using Social Media: Mixed-Methods Study

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Abstract

Background: Generating participant engagement in social media applications for health promotion and disease prevention efforts is vital for their effectiveness and increases the likelihood of effecting sustainable behavior change. However, there is limited evidence regarding effective strategies for engaging Latino immigrant youth using social media. As part of the Avance Center for the Advancement of Immigrant/Refugee Health in Washington, DC, USA, we implemented Adelante, a branded primary prevention program, to address risk factors for co-occurring substance use, sexual risk, and interpersonal violence among Latino immigrant adolescents aged 12 to 19 years in a Washington, DC suburb.

Objective: The objectives of this study were to (1) characterize Adelante participant Facebook reach and engagement and (2) identify post content and features that resulted in greater user engagement.

Methods: We established the Adelante Facebook fan page in October of 2013, and the Adelante social marketing campaign used this platform for campaign activities from September 2015 to September 2016. We used Facebook Insights metrics to examine reach and post engagement of Adelante Facebook page fans (n=743). Data consisted of Facebook fan page posts between October 1, 2013 and September 30, 2016 (n=871). We developed a 2-phased mixed-methods analytical plan and coding scheme, and explored the association between post content categories and features and a composite measure of post engagement using 1-way analysis of variance tests. $P<.05$ determined statistical significance.

Results: Posts on the Adelante Facebook page had a total of 34,318 clicks, 473 comments, 9080 likes or reactions, and 617 shares. Post content categories that were statistically significantly associated with post engagement were Adelante program updates ($P<.001$); youth achievement showcases ($P=.001$); news links ($P<.001$); social marketing campaign posts ($P<.001$); and prevention topics, including substance abuse ($P<.001$), safe sex ($P=.02$), sexually transmitted disease prevention ($P<.001$), and violence or fighting ($P=.047$). Post features that were significantly associated with post engagement comprised the inclusion of photos ($P<.001$); Spanish ($P<.001$) or bilingual ($P=.001$) posts; and portrayal of youth of both sexes ($P<.001$) portrayed in groups ($P<.001$) that were facilitated by adults ($P<.001$).

Conclusions: Social media outreach is a promising strategy that youth programs can use to complement in-person programming for augmented engagement. The Latino immigrant youth audience in this study had a tendency toward more passive social media consumption, having implications for outreach strategies and engagement measurement in future studies. While study findings confirmed the utility of social marketing campaigns for increasing user engagement, findings also highlighted a high level of engagement among youth with posts that covered casual, day-to-day program activity participation. This finding identifies an

underexplored area that should be considered for health messaging, and also supports interventions that use peer-to-peer and user-generated health promotion approaches.

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KEYWORDS

social media; health promotion; Latinos; immigrants; adolescent; Hispanic Americans; emigrants and immigrants; adolescent health

Introduction

Background

Social media has numerous applications for health promotion and disease prevention efforts, and the benefits of using social media for public health communication have been documented [1-4]. Results of health promotion efforts delivered via social media or using digital technologies have demonstrated increases in health knowledge [5-7], have assisted users with chronic disease management [8], and have led to improvements in health-related practices [9,10]. The use of digital technologies, such as mobile phone-based interventions, has also achieved outcomes such as increased adherence to treatments and increased engagement with behavior change interventions [11]. Social media platforms have been highly useful for increasing peer, social, and emotional support [12-22] and for reaching marginalized and underserved audiences while also connecting low-literacy groups [23-32] to information and resources.

Generating participant engagement is vital for effective health promotion whereby, through captivating an audience's attention, we can go beyond simply reaching an audience to influencing sustainable changes in health behaviors [33]. However, engagement is an understudied area, and there are gaps in the literature regarding strategies that lead to greater engagement, especially among underserved populations [34-37]. Research has indicated that participants are more likely to be engaged when there is connectivity and multiple points of contact between participant and program; participation is easy yet rewarding; and participants are interested in and identify with the messages being conveyed or a program's brand [34]. Engagement of youth populations plays an integral role in healthy cognitive, social, and emotional development; can provide opportunities for the acquisition of skills and increased confidence; and can result in youth contributing to their communities [35-45].

Social media has many attributes that may potentially increase engagement for health promotion and disease prevention programs. First and foremost, social media is ubiquitous and can reach very large audiences, enabling broad dissemination of health information and messaging [46-49]. Social media messages can be highly personalized and tailored to the interests of specific audiences, including peer groups. Social networks can also be leveraged to further amplify dissemination, increase interaction with other users from a targeted group [47,50-53], and augment the credibility of information shared between known contacts [54,55]. Importantly, social media can be used to augment in-person programming to increase the effectiveness of health promotion programs seeking to change health-related behaviors [2,4,56-59].

Similar to the general public, youth populations appear to be amenable to receiving health-related information on social media [31,60-62]. Thus, understanding tactics that can increase engagement in health promotion programs for young audiences via social media will ensure effective use of this tool. Identifying predictors of social media engagement can guide the development of content and use of features that have high appeal for young audiences. Past research has identified some strategies for successful user engagement, including encouraging high levels of social media activity, individual user interaction, and interaction through posing questions or calls to action; using multimedia content; highlighting celebrity involvement; tagging users in posts; targeting messages to specific audiences; using strategic message framing; leveraging targeted outreach campaigns; using humor or shock appeals; and storytelling. However, few studies have focused on social media engagement for Latino immigrant adolescents [63-68].

Latino adolescents are an important and growing population in the United States. The United States Census Bureau estimated that, by 2050, Latinos will constitute 34% of the US adolescent population between the ages of 10 and 19 years [69]. Yet Latino adolescents continue to experience numerous health disparities, have more limited engagement in health promotion, and have lower rates of health care utilization [70-80]. Despite pervasive access to mobile technology and widespread use of social media by Latino adolescents, there is little evidence establishing the best ways to engage with this audience using social media, highlighting the importance of further exploration of this area [1,81-90]. The literature base exploring engagement through social media of Latino *immigrants*, a subgroup of Latinos who have more recently immigrated to the United States, is even more limited. The immigrant subgroup should be distinguished from Latino subgroups that have a more established presence in the United States, sometimes for generations. Recent immigrants tend to be harder to reach with health promotion programs, since they are more likely to experience a unique set of risk factors that contribute to health disparities [91-93]. Social media outreach has the potential to engage Latino immigrant adolescents in health promotion efforts, contributing to youth-centered initiatives that use tested engagement strategies and more meaningful experiences for this group of young people [38].

Objective

In this study, we explored Facebook engagement for a branded primary prevention intervention for Latino immigrant youth, called Adelante [94]. The study aims were to (1) characterize Adelante participant Facebook reach and engagement and (2) identify post features and content that resulted in greater user engagement. Ultimately, we sought to formulate predictors of

user engagement that would inform future prevention programming and youth outreach strategies using social media.

Methods

Adelante Youth Intervention and Social Media

We developed and implemented the 4-year Adelante primary prevention program to address risk factors for co-occurring substance use, sexual risk, and interpersonal violence among Latino immigrant adolescents, aged 12 to 19 years, living in Langley Park, Maryland, a community close to Washington, DC [94]. Adelante was grounded in an adapted positive youth development (PYD) framework, using a multilevel, asset-based approach for risk prevention [95,96]. Adelante addressed the following PYD constructs: *competence*, *confidence*, *connection*, and *contribution* (detailed elsewhere) [94,97]. The Adelante intervention consisted of in-person youth and parent programming, case management for high-risk youth and their families, and a social marketing campaign [98]. Adelante also applied innovative engagement strategies, whereby in-person activities intersected with the Adelante social media network, and participants also created user-generated digital media content informed by the Adelante brand and a foundation laid by previous activities and research [94,97-103].

We applied social marketing and branding principles for the development and implementation of Adelante components that sought to engage participants in the Adelante brand and program, increase receptivity to prevention messages, and, ultimately, improve Latino adolescent risk-preventive attitudes, norms, and behaviors [104-106]. As part of the overall engagement strategy, we implemented a 1-year social marketing campaign [98] that incorporated digital and print media advertisements, social media outreach, and the creation of user-generated content in collaboration with Adelante youth ambassadors [102]. Given youths' affinity for digital media, the Adelante program had an active social media presence as a strategy for disseminating prevention messages, engaging the target youth audience in the Adelante brand, and increasing peer-to-peer and peer-to-program connectivity.

This study built on previous research by using Facebook Analytics tools (Facebook, Inc, Menlo Park, CA, USA) to identify post content and features that were associated with higher engagement among fans of the Adelante program's Facebook page. This study expanded our understanding of predictors of engagement that can be applied to future health promotion and disease prevention initiatives with similar Latino immigrant audiences.

Study Population

The study population comprised fans of the Adelante Facebook page, which predominantly included Latino immigrant adolescents aged 12 to 19 years. We recruited fans from the in-person Adelante program and their immediate social networks, which we implemented in the community of Langley Park, Maryland. Langley Park is a low-income, mostly foreign-born (67.6%) Latino (80%) community [107]. A recent study by Cleary and colleagues estimated that, among adolescent Latinos aged 12 to 17 years, 66% were recently arrived immigrants, having lived in the United States for 3 years or less, with a large representation from El Salvador (46.53%), Guatemala (32.86%), and Honduras (10.41%; SC, unpublished data, 2017).

Adelante Program Facebook Fan Page

The Adelante Facebook fan page was established in October 2013, and the Adelante social marketing campaign used this platform for a portion of the campaign's activities from September 2015 to September 2016. We used the fan page for ongoing program-related posts, such as recruiting for programs or events; showcasing programmatic activities; disseminating information about social issues or initiatives; sharing information about health, social services, or educational resources and opportunities; and providing opportunities for Adelante staff or peers to provide social support to participants. The social marketing campaign disseminated health-risk and prevention information via social media (related to substance use, sexual risk, and interpersonal violence), and sought to further engage youth through targeted outreach and messaging using advertisements and user-generated video content that featured Adelante youth; contests; highlights of youth stories and achievements; and links to news stories of interest, websites, blog posts, and other resources. We also occasionally boosted posts to explore the utility of this strategy for increasing reach and engagement.

Data Collection and Metrics

Data for this study consisted of Facebook posts on the Adelante fan page between October 1, 2013 and September 30, 2016. We used Facebook Insights metrics to examine the reach and post engagement of Adelante Facebook page fans. Metrics for reach were number of page fans, number of posts, total reach, organic reach, and paid reach. Facebook defines reach as "the number of unique people who see a post" and engagement as "reacting to, sharing, or commenting or clicking on any content" [108]. Paid reach refers to the number of unique people who see a post as a result of advertisements, whereas organic reach does not involve advertisements. We created a composite post engagement dependent variable by summing post clicks, reactions, comments, and shares. Adelante research methods and protocols underwent the George Washington University Institutional Review Board review and approval process for the protection of human subjects (study number 111139; Washington, DC, USA).

Data Analysis

We developed a 2-phased mixed-methods analysis plan that enabled us to combine quantitative Facebook analytics and assessment of post features with qualitative data from Facebook posts (text, media, and graphics). We exported Facebook data into an Excel database version 2013 (Microsoft Corporation) using NCapture (QSR International Pty Ltd). In phase 1, we coded the data quantitatively using a coding scheme that assigned numeric values to post features, such as purpose of the post or language used (Spanish, English, or both; Table 1). In phase 2, we qualitatively coded post text and media, as well as text and media of external links included in the post.

Table 1. Post content and features coding scheme (phases 1 and 2).

Phase and content	Features
Phase 1	
Language used	English, Spanish, bilingual
Post tone	Positive, negative
Purpose of post	Program announcement, program activity sharing, health or social service promotion, internship or educational opportunity advertisements, health education or promotion, contest, youth achievement or story highlight, news story sharing, awareness raising or social issue advocating, and campaign messaging
Phase 2	
Prevention topic	Sexual health: sexually transmitted diseases, pregnancy and birth control, safe sex (condom use, abstinence), risk prevention; violence: partner violence, bullying, peer violence or fighting, risk prevention; substance abuse: factual information, risks of substance use, risk prevention; mental health: factual information, symptoms, sources of help, risk prevention
Positive youth development framework construct	Confidence; contribution (attitudes and action); competence (athletics, civic action, school, family, multicultural efficacy); connection (romantic partner, community, social and cultural, school, friends and peers, family)
People portrayed	Individuals or groups; gender (male, female, both male and female); adults and youth

Posts were coded according to prevention topic, PYD construct, people portrayed in the post, and whether the post was boosted or not (Table 1). For the qualitative coding, we used NVivo software version 16 (QSR International Pty Ltd). After qualitative coding was complete, we used NVivo software to convert qualitative coding to a quantitative format. We then combined this quantitative dataset with the quantitative dataset from phase 1 for analysis.

Following data coding, we examined the distribution for the post engagement dependent variable and all independent variables. All variables were not normally distributed but did have a similar pattern (or shape) of distribution. Given the nonnormal distribution, and with all of the assumptions being met, we decided to use the nonparametric Mann-Whitney *U* test to identify statistically significantly different median scores between groups (yes or no for a particular post content or feature) for post content category or feature (dichotomous independent variables) by post engagement (continuous dependent variable). We conducted the analysis using IBM SPSS version 19 (IBM Corporation). $P<.05$ determined statistical significance.

Results

The Adelante Facebook page reached a total of 743 fans with 871 posts. The total reach was 247,212 users, including an organic reach of 163,698 unique users (representing 850 posts) and a paid reach of 83,514 unique users (representing 21 posts). A total of 213 posts were made as a part of the 1-year social marketing campaign. Regarding overall engagement metrics, there were 34,318 post clicks, 473 post comments, 9080 post likes or reactions, and 617 post shares.

As Table 2 shows, posts that provided updates about program activities that had occurred recently garnered a lot of interest from Adelante Facebook fans. These posts tended to occur during, or immediately following, program activities, and the posts usually contained photos of youth participating in group activities that were facilitated by an adult. The images in program update posts also portrayed youth enjoying time with their peers in groups of male and female youth, which reflects scenarios of how youth in the study community most commonly socialize. Statistically significant differences in engagement for posts targeting PYD constructs of connection-peer and competence-physical activity can be explained by youths' interest in a highly popular program activity—soccer teams and tournaments—which were promoted on social media (Table 3). Fans were also interested in seeing youth participating in career workshops and internships (competence-workplace) and youth contributing to their communities through volunteering or community cleanups (contribution-action). Posts that showcased Adelante youths' personal stories and achievements were also engaging to Facebook fans.

Posts that were part of the Adelante social marketing campaign were also engaging to youth. These posts often contained photos, videos, and branded advertisements that portrayed local Adelante youth, whom participants knew firsthand, thus likely increasing youth interest. These posts also included content that promoted PYD-informed messages, and disseminated information related to health promotion and risk prevention. The most engaging topics included in posts were substance abuse prevention (a main focus of the Adelante program), safe sex and sexually transmitted disease prevention, and violence prevention—specifically, fighting. Topics that were less engaging were mental health, pregnancy prevention, bullying, and partner violence, which are very surprising given our experience working with this population.

Table 2. Results: post content variables and user engagement.

Post content (independent variable)	Posts, n (%)	*P* value (dependent variable)
Post purpose		
Program announcement or reminder	229 (26.3)	.53
Program updates	235 (27.0)	<.001
Service or resource promotion	89 (10.2)	.17
Health education or promotion	93 (10.7)	.52
Contest	32 (3.7)	.32
Youth Achievement showcase	49 (5.6)	.001
News link	92 (10.6)	<.001
Social issue awareness raising	143 (16.4)	.79
Campaign post	213 (24.4)	<.001
Prevention topic		
Substance abuse	73 (8.4)	<.001
Mental health	46 (5.3)	.10
Safe sex	30 (3.4)	.02
Sexually transmitted diseases	24 (2.8)	<.001
Pregnancy prevention	31 (3.6)	.11
Violence-bullying	29 (3.3)	.40
Violence-fighting	13 (1.5)	.047
Violence-partner	15 (1.7)	.20
Positive youth development framework constructs		
Competence	173 (19.9)	.31
Competence-physical activity	30 (3.4)	.005
Competence-school	24 (2.8)	.50
Competence-workplace	40 (4.6)	.003
Confidence	172 (19.7)	<.001
Connection	365 (41.9)	<.001
Connection-family	38 (4.4)	.22
Connection-peer	184 (21.1)	<.001
Contribution	87 (10.0)	.87
Contribution-action	33 (3.8)	.04

Adelante program participants comprised a mixture of very recently immigrated adolescents to the United States and slightly less recently immigrated youth. Given the makeup of the study community and program participants, Adelante staff emphasized the importance of using a mixed-language strategy for social media outreach, which mirrored in-person programming. Youth Facebook fans tended to show more engagement with posts that were either bilingual or in Spanish. Program update posts and campaign-specific posts incorporated the use of both Spanish and English, and this approach appears to have resonated well with this audience. Interestingly, there was no difference in engagement between posts that had a positive tone and those that had a negative tone.

Table 3. Results: post feature variables and user engagement.

Post feature (independent variable)	Posts, n (%)	*P* value (dependent variable)
Multimedia content		
Video	88 (10.1)	.25
Photo	574 (66.0)	<.001
External link	193 (22.2)	<.001
Language used		
English	241 (27.7)	.56
Spanish	171 (19.6)	<.001
Bilingual	380 (43.6)	.001
Post tone		
Positive	480 (55.1)	.001
Negative	82 (9.4)	.001
People portrayed		
Female only	108 (12.4)	.05
Male only	110 (12.6)	.43
Male and female	254 (29.2)	<.001
Group of youth	342 (39.3)	<.001
Individuals	140 (16.1)	.61
Adults	298 (34.2)	<.001

Discussion

Principal Findings

Social media use has become increasingly popular among young audiences, and Latino youth in the United States have been found to have nearly universal use of social media, making this method of communication essential for public health programs targeting this population [79,82]. Youth-oriented programs that incorporate social media outreach and engagement strategies extend beyond traditional in-person programming by opening a door to youth in the broader community who want and need health-related programming. This is particularly relevant for addressing health disparities among populations, such as recently arrived immigrants, who are more likely to be unaware of or disengaged from traditional health programming and potentially experience numerous barriers to participation.

Results for study aim 1 indicate that social media appears to be a useful tool for engaging Latino immigrant youth in health promotion programming. These levels of reach and engagement are on par with those seen in other studies examining health promotion efforts using social media [2,57-59,63-66]. Given that there are limited efforts targeting Latino immigrant adolescents through social media engagement, it is difficult to compare engagement observed in this study with that of other studies. However, this pilot effort serves as a starting point by which we can gauge reach and engagement of future efforts; it also provides guidance on content, features, and strategies to include in subsequent interventions. Despite the existence of numerous barriers to participation in traditional in-person programming, we were able to achieve a reasonable level of engagement through the Adelante Facebook page. This amplified the in-person programming, permitted the dissemination of branded prevention messages to youth, and combatted potential social, linguistic, and cultural isolation that this group of youth experiences through increased interaction with peers and program implementers in the Adelante digital network.

When characterizing social media consumption, Adelante youth Facebook fans tended to be more passive consumers of social media content, as opposed to active content contributors. Fans seemed more willing to interact with posts through clicks and likes but were potentially more hesitant to comment, share posts with their networks, or independently post user-generated content. This finding is consistent with other research and the phenomenon of “online identity management” described by Fergie et al, whereby youth described a complex vetting process to ensure that social media content they created was in line with their online persona [109]. Future youth programming should consider this finding and take steps to examine the concordance between youths’ personal brands and the established program brand, and how they intersect. Otherwise, this is a potential barrier for programs that ask youth to use their personal digital networks for dissemination of peer-to-peer prevention messages, such as the Living the Example youth ambassadors drug prevention program [110]. The more limited commenting and sharing by youth in our study may also indicate a potential hesitance among youth to be more actively engaged (sharing and commenting) on fan pages that are potentially viewable by a public audience. Future programs reaching high-risk youth populations should consider using Facebook closed groups instead of fan pages to increase the interactivity and engagement

of youth in the group [111]. In contrast to our previous research with this population, which suggested that this audience would be interested in social media-based contests, contest-related posts did not produce significant user engagement. This may be explained by the audience's patterns of passive social media consumption, discussed above. The contests sought to reward active engagement (likes or reactions, shares, comments, and user-generated content), but this call to action may have been incompatible with youth preferences of "lurking" on social media instead of engaging more actively. Future efforts should consider this potential tendency of passive social media consumption when determining programmatic targets and when deciding on mechanisms to increase engagement (eg, contests, posing questions, requesting post comments and shares, or use of closed groups).

Past research has identified some strategies for successful user engagement, including high sustained levels of social media activity [63] and targeted social media campaigns [64]. Results from study aim 2 highlighted that, for this audience, engagement was achieved both for posts that captured ongoing, day-to-day Adelante program activities and for planned, targeted social marketing campaign posts that featured local youth in campaign imagery. Building on this audience's affinity for seeing themselves and their friends in posts, youth were more engaged in posts that highlighted program-related group activities that showed them and their friends having fun. These posts almost always included photos of program-related activities, which included interactive prevention workshops, academic tutoring, playing sports, user-generated video development, or being involved in other recreational activities. These posts also portrayed youth who were in the Facebook fans' proximal peer networks and program activities taking place at familiar locations within their immediate community setting. The Adelante Facebook page served as a social extension of the in-person programming, where youth could see their friends and stay in touch. The success of certain post features, such as program updates or campaign posts, could be, in part, explained by the portrayal of recognizable youth from their community and school, and the use of local community visual imagery. For future efforts, we recommend collaboration with audience members in order to capture compelling imagery for posts and incorporation of audience-engaged content to result in higher engagement. We also recommend strategic incorporation of prevention messaging or other health promotion content into regular casual, habitual posts that keep participants connected with their friends. Furthermore, these findings bode well for interventions seeking to use peer-to-peer models for health promotion via social media.

Social media has also become an important mechanism for conveying health information, making audience engagement paramount for the utility of this strategy [5-7,31,47,60-62]. According to study aim 2 results, posts that resonated with this audience featured health and prevention information related to substance abuse, sexually transmitted disease prevention and safe sex, and violence prevention. Lack of engagement in certain topics, such as mental health and pregnancy prevention, was surprising, given that these topics were expressed as priorities by Adelante youth. Further analysis will be needed to explain diminished engagement for these topics. Regardless, we think that it is important for future efforts to carefully consider how health information can be packaged to increase the likelihood that young Latino immigrant audiences will consume this media and subsequently be exposed to the intended prevention messaging.

Our campaign formative research indicated that a mixed-language strategy would be the best option for this audience. For posts overall, Spanish-language and bilingual posts were more engaging than English-language posts, supporting our use of a mixed-language strategy, especially for communities that are diverse in terms of primary language spoken (English or Spanish) and have a large bilingual audience segment. Higher engagement with Spanish-language content for posts overall supports the finding from our formative research, where we were advised to "lean" toward more Spanish if we wanted to reach everyone, with the rationale that even English-dominant youth understand Spanish. Our prior research also suggested that the use of positive tone in posts would be more appealing to youth; however, we did not see any statistically significant differences in engagement between posts with a positive tone and posts with a negative tone.

Limitations

The findings of this study should be interpreted in view of its limitations. Adelante intervention participants were predominantly Central American immigrants between the ages of 12 and 19 years living in a low-income, majority foreign-born, and Latino community. While study results are likely useful for research with other Latino adolescent subgroups, results may not necessarily be generalizable to these groups. Furthermore, while a sizeable proportion of Adelante Facebook fans were known participants in the program, some fans were not; it is possible that some fans who were engaged through social media outreach were not from our target audience in terms of geographic location, exact age group, or ethnicity.

Results should also be interpreted within the constraints of the study's design; this social media outreach effort was a pilot demonstration, not a study of intervention outcomes. Thus, with no comparison group or behavioral measures, we are limited in the attribution of campaign effects and in the ability to determine health behavior change beyond initial engagement. Furthermore, youth from the target audience were users of numerous social media platforms, including Snapchat, Instagram, Twitter, and Kik Messenger, to name a few. The Adelante program did also cross-promote messages across platforms, particularly on Instagram and Twitter; however, this study examined only Facebook posts, which is likely an underrepresentation of audience engagement with overall Adelante social media outreach efforts.

Conclusions

Results from this study indicated that the use of social media is a promising strategy for engaging young Latino immigrants in health promotion efforts. Through gaining an understanding of what post content and features are most appealing to young Latino audiences, social media outreach programmers can offer multiple opportunities for addressing health disparities among

populations with additional barriers to engagement. Social media habits that include more passive consumption of posts should be considered when conceptualizing future social media outreach strategies and developing measures of engagement that are appropriate for these passive consumption habits. Interventions should consider approaches that can increase participant comfort with more active engagement, such as augmenting privacy through closed social media groups for certain activities where active engagement is sought. Additionally, social media prevention messages and posts should be created in collaboration with community youth, increasing the likelihood that the messages will resonate with this audience and will be compatible with youths' social media engagement habits. This approach would also be more likely to result in posts with content and features that are most engaging for the intended audience.

The literature describes many efforts that seek to disseminate health-related messaging and engage audiences through formal social marketing campaigns. While our study confirmed the utility of campaign posts for youth engagement, our study also highlighted the high level of appeal of posts that covered more casual, day-to-day activities of program youth. Youth were particularly interested in social media posts insofar as they were an extension of the in-person programming: the youth could see the activities that were happening, see photos of themselves or their friends, and feel like part of this peer network. We recommend that programs include online efforts that intersect with in-person programming as a strategy to augment youth engagement. This is a relatively unexplored area that public health practitioners may consider as a mechanism for disseminating health promotion and risk prevention messaging.

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Conflicts of Interest

None declared.

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Abbreviations

PYD: positive youth development

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Original Paper

Quality of HIV Websites With Information About Pre-Exposure Prophylaxis or Treatment as Prevention for Men Who Have Sex With Men: Systematic Evaluation

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Abstract

Background: Knowledge and uptake of high-efficacy HIV prevention strategies such as pre-exposure prophylaxis (PrEP) and treatment as prevention (TasP) remain low among men who have sex with men (MSM) who are at the highest risk for HIV infection in the United States. Electronic health (eHealth) interventions are promising tools for disseminating information about these critical yet underutilized strategies and addressing key barriers to uptake among target populations. However, existing HIV prevention websites are understudied and unevaluated.

Objective: This study aimed to systematically review and evaluate existing HIV websites that include information about PrEP or TasP for MSM.

Methods: From March 2018 to May 2018, 2 trained research assistants (RAs) entered relevant key words and phrases into 3 commonly used search engines and applied exclusion criteria to all returned results to identify 31 websites included in this review. RAs independently scored each website for authority, usability, interactivity, and PrEP/TasP-related content based on a standardized rating scale and then averaged the results.

Results: No website received a perfect score in any of the 4 categories, and the average website score was 62% (37/60). Less than a quarter of the websites (23%, 7/31) received a score of more than 75% (7.5/10) for content. Approximately two-thirds of the websites (65%, 20/31) received a score of 50% (5/10) or lower for interactivity. The average score in usability was 68% (6.8/10) and in authority was 69% (6.9/10). Other deficiencies observed included difficulty locating relevant content and lack of information targeting audiences with the highest likelihood of HIV infection.

Conclusions: Existing HIV prevention websites with information about PrEP or TasP for MSM fail to provide adequate content as well as present that content to users in an interactive and audience-conscious way. Future eHealth interventions should attempt to rectify these deficiencies to successfully engage and educate MSM at high risk for HIV regarding prevention strategies.

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KEYWORDS

pre-exposure prophylaxis; treatment as prevention; sexual and gender minorities; telemedicine; African Americans; Hispanic Americans; HIV

Introduction

Background

Gay, bisexual, and other men who have sex with men (MSM) in the United States continue to be disproportionately affected by HIV and AIDS. Even though MSM make up only 2% of the national population, they accounted for almost 70% of all new HIV infections in 2015 [1]. Furthermore, black/African American and Hispanic/Latino MSM alone accounted for approximately 70% of those new infections among MSM [1]. The Centers for Disease Control and Prevention (CDC) predicts that if new HIV diagnoses persist at current rates, 50% of black/African American MSM and 25% of Hispanic/Latino MSM will become infected with HIV in their lifetimes [2].

Pre-exposure prophylaxis (PrEP) and treatment as prevention (TasP) are 2 high-efficacy approaches recommended by numerous health organizations for addressing the HIV epidemic among MSM who are high-risk, defined here as MSM from demographics with high rates of new infections [3,4]. PrEP involves the daily ingestion of an oral single-tablet combination antiretroviral (ARV) by HIV-negative individuals and has been consistently shown to decrease the likelihood of HIV acquisition by more than 90% if taken as directed [3,5,6]. TasP entails the use of ARVs by HIV-positive individuals to decrease their viral load and thereby prevent the transmission of HIV and can be almost 100% effective if the HIV-positive partner's viral load is successfully suppressed [4,7,8].

However, uptake of these critical strategies remains low among those at the highest risk for HIV infection in the United States, including all MSM and particularly black/African American and Hispanic/Latino MSM. A recent study of a national cohort of HIV-negative MSM reported that in 2017 just 13% were on PrEP, although more than 60% were appropriate candidates [9].

Meanwhile, we were unable to find any peer-reviewed data on the proportion of HIV-positive MSM nationally who were engaging in TasP, or who were virally suppressed and considered preventing HIV transmission to be a motivation for their care. Looking at viral suppression data alone, the CDC reported that as of 2014, just 51% of HIV-positive MSM had a suppressed viral load [1].

Despite the scarcity of comprehensive data, various studies have investigated PrEP uptake and viral suppression for particular racial/ethnic and geographic subgroups of MSM. Based on the CDC's guidelines and data, although 44% of people who could benefit from PrEP were black/African American, just 1% of those individuals were prescribed PrEP; furthermore, only 3% of Hispanics/Latinos were prescribed PrEP, despite accounting for approximately 25% of those who could benefit from a prescription [10]. Meanwhile, in 2015, black/African American MSM had the lowest percentages of viral suppression of any racial or ethnic group, followed by Hispanic MSM [11]. Trends in uptake also seem to vary by geographic area, adding regional disparities to racial ones. For example, in 2016, 23% of high-risk MSM reported taking PrEP in Washington state, which is much higher than the national average [12]. Just 4% of young black/African American MSM in Atlanta, Georgia, reported taking PrEP in 2015 [13].

Despite numerous public health campaigns for MSM as well as a national HIV prevention plan targeting black/African American and Hispanic/Latino MSM specifically, uptake of PrEP and TasP by these men remain well below federal expectations and public health goals [14]. New and innovative approaches are urgently needed to encourage high-risk MSM to engage with important and underutilized HIV prevention strategies. Web-based media currently occupies a central place in the dissemination of many types of information and has likewise emerged as a highly promising option for public health. Often termed electronic health or *eHealth*, Web-based interventions have the potential to help address key barriers to PrEP and TasP uptake for MSM, even where more traditional campaigns have had limited successes [15-18].

Among the various barriers to PrEP and TasP use among MSM from populations with the highest rates and the highest risk of HIV infection, previous research has identified a number specifically related to the presentation of health information. For example, black/African American and Hispanic/Latino MSM frequently reference lack of access to health resources and low health literacy as important obstacles to their consideration of HIV prevention methods [19-24]. Notably, eHealth has been found to increase health literacy and is also highly accessible to these target populations [25]. Internet access has become ubiquitous for most Americans, and websites and mobile apps are consistently utilized by MSM across all racial and ethnic groups [26-28]. Another commonly cited barrier to PrEP and TasP uptake among MSM of color is a lack of targeted outreach. Qualitative research among MSM on the acceptability of eHealth interventions for HIV prevention and treatment indicates that eHealth would be acceptable to or even preferred by them [29]. Studies have additionally demonstrated eHealth to be cost-effective as well as highly acceptable to MSM [17,30-32].

As a result, biobehavioral HIV researchers have begun using eHealth to disseminate prevention information to marginalized populations, and numerous websites dedicated to HIV prevention currently exist on the internet. However, existing websites vary widely in terms of quality and content, and to our knowledge, they have never been systematically studied or reviewed.

Objective

The purpose of this systematic evaluation is to assess the accessibility and breadth of existing websites with information about PrEP or TasP for MSM, with a focus on the racial and ethnic groups at the highest risk; use these data to draw conclusions about the current use of eHealth for HIV prevention; and form recommendations for future directions.

Methods

Study Design

From March 2018 to May 2018, searches using 9 key words or phrases (black, African American, Hispanic, Latino, gay, bisexual, MSM, treatment as prevention, and pre-exposure

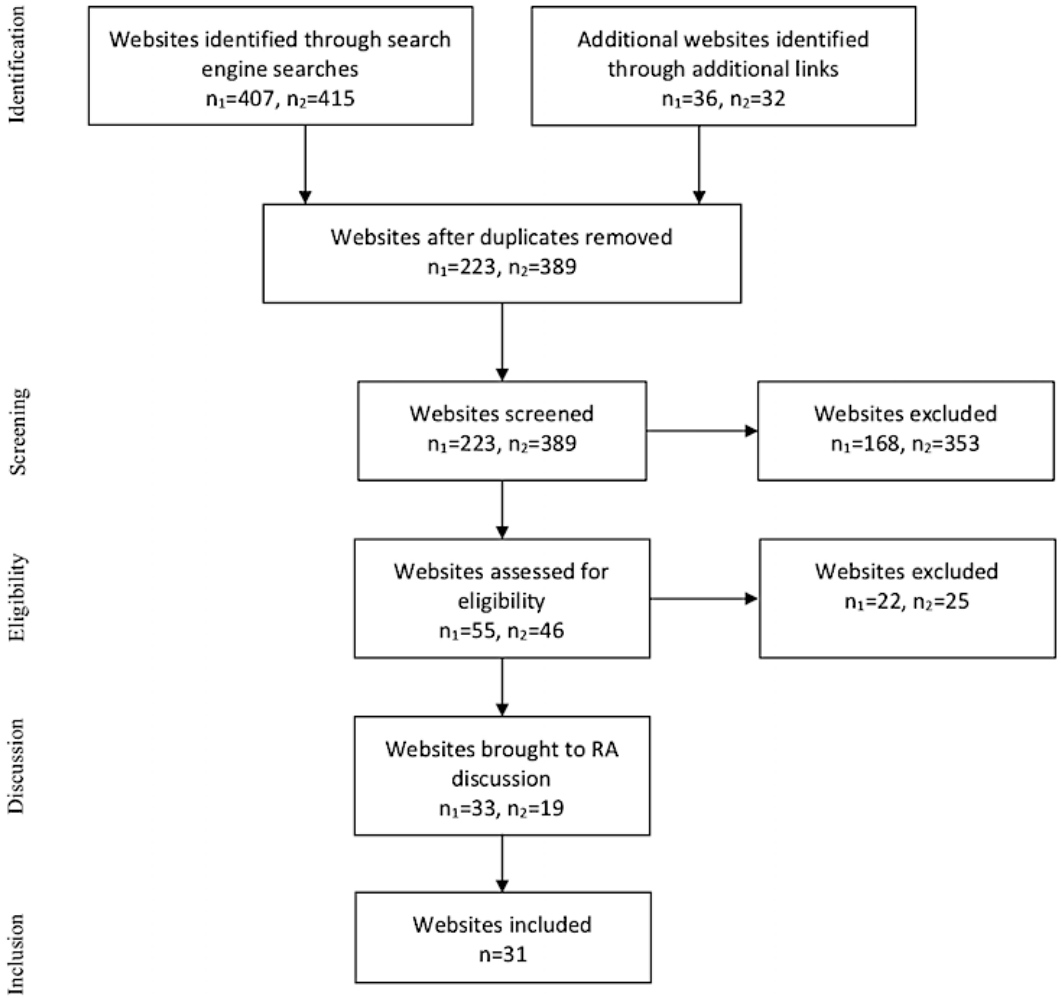
prophylaxis) were conducted on 3 commonly used search engines (Google, Bing, and Yahoo). To have the broadest reach while remaining relevant, the terms were entered as follows: [black OR "African American" OR Hispanic OR Latino] AND [gay OR bisexual OR "men who have sex with men"] AND ["treatment as prevention" OR "pre-exposure prophylaxis"]. Race and ethnicity terms were included because the initial goal of the project was to look at websites specifically for populations at the highest risk of HIV infection in the United States, meaning black/African American and Hispanic/Latino MSM; however, given how few websites focus on MSM of color, the eligibility criteria were expanded to websites for MSM more broadly.

The results of these searches were extensively reviewed for websites that primarily focused on HIV/sexually transmitted diseases and prevention methods, provided information on PrEP or TasP, provided information on MSM (at least 1 paragraph), appeared to be geared toward patients rather than providers, and offered an English language version. If websites identified through the initial search contained links to additional websites, the additional websites were also screened for inclusion. The websites included were determined by 2 trained research assistants (RAs) who conducted independent searches, compared results, and resolved any discrepancies. The process returned 31 websites relevant to this review (refer to Figure 1).

Scoring

The RAs independently scored each website on measures of usability, authority/credibility, interactivity, and PrEP-/TasP-related content. The criteria for these 4 categories were adapted from Whiteley et al's review of sexual health websites for adolescents as well as the *American Library Association Standards for Web Evaluation*, where applicable [33,34]. The scoring categories of usability, authority, and interactivity were all measured using 10 criteria worth 1 point each (contains feature=1, no feature=0) for a possible total of 10 points per category and 30 points in combination. The content of each website was rated on 15 criteria each worth 2 points (addresses category in-depth=2, addresses category briefly=1, does not address category=0) for a total of 30 points. RAs compared scores and resolved differences of 5 or more total points out of the 60 possible points through discussion. Website scores were then averaged between RAs and converted into percentages.

Figure 1. Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) diagram showing the website selection process by 2 raters. RA: research assistant.



Website usability ratings were based on whether the website included working internal hyperlinks (ie, the majority of internal hyperlinks worked and any broken links did not impair access to relevant information), working external hyperlinks, a search mechanism, an option for fewer graphics or text only, an option for a different language or languages, a heading or subheading referencing PrEP or TasP, a site map, and easily accessible information on PrEP and/or TasP (ie, information within 2 clicks from the website homepage) and whether the website did not require personal user information or additional software.

For authority, each website was rated based on whether it provided clarity regarding the organization responsible for the website content, a clear description of the organization's goals, enough information to verify the legitimacy of the organization, a statement that the content of the website had the official approval of the organization, a statement that the organization was the copyright holder of the website, authorship of some content by a medical or health professional, citations or clarity of authorship of some website content, references to the CDC guidelines for PrEP or TasP, updated content within the past year, and updated content within the past 6 months.

Website interactivity was based on inclusion or exclusion of the following components: video, audio, animation, or click-through modules; quizzes, polls, or surveys; a mobile app or mobile-adaptive website design; the ability to share information through email or text; the ability to share information through social media (eg, Facebook, Twitter); ability to email or text an expert or volunteer; ability to call or otherwise speak with an expert or volunteer; available message board or chat rooms; ability to contact the organization with questions; and inclusion of user-generated content in some capacity.

Content was assessed on the basis of whether the website included general information about PrEP, general information about TasP, information about PrEP eligibility, an accurate definition of PrEP, information about side effects and safety of PrEP, information about PrEP efficacy, an accurate definition of postexposure prophylaxis, local testing or provider information, additional resources, an accurate definition of TasP, information about TasP efficacy, information about viral load and being undetectable, information about side effects and safety of TasP, information that specifically addressed black/African American individuals, and information that specifically addressed Hispanic/Latino individuals. The content criteria were taken from the CDC guidelines for PrEP and TasP and augmented with information from Truvada and the National Institutes of Health.

Qualitative Analysis

Finally, the results of the scoring process were reviewed, and themes that had emerged throughout the search were considered. The RAs also assessed whether each website provided information specifically for black/African and Hispanic/Latino MSM; for a lesbian, gay, bisexual, transgender, queer, and sexuality/gender-nonconforming (LGBTQ+) audience; and for people of color (POC) as well as the geographic scope of the website (ie, whether the information was primarily regional, national, or global in scope), and then, they grouped the websites accordingly. Audience groupings were based primarily on the mission statements the websites provided. Websites with mission statements that discussed targeting LGBTQ+ people, for example, were placed in the LGBTQ+ audience group. Due to the nature of this review, we did not need to receive institutional review board approval.

Results

Main Findings

None of the 31 websites reviewed received a perfect score in any category. When considered together, the mean total website score was 62% (37/60). The total website score for individual websites ranged from a low of 35% (21/60) to a high of 87% (52/60). Among the 10 websites with the highest scores, 100% (10/10) scored above average for content, 90% (9/10) for authority, and 80% (8/10) for interactivity and usability. Of these websites, 3 websites (Poz, Positively Aware, and Plus Magazine) were publications providing news and other relevant content to people with HIV (refer to Table 1).

The lowest mean category score was in interactivity, with the average website scoring just 48% (4.8/10) and satisfying less than one half of the category criteria. Aids*info*, which received an interactivity score of 40% (4/10), serves as 1 example of a website with a roughly average level of interactivity. Alongside many of the other websites, Aids*info* failed to allow users to share information through social media, text messaging, or email; to include nontext content such as video and animation; and to provide a message board or other platform for user-driven commenting. In contrast, The Body and Poz were outliers in interactivity, with high scores in this category (85%, 8.5/10) and easy ways of sharing content, surveys or polls, a platform for users to comment on website content, and even a message board for conversation between users on user-proposed topics.

Usability scores averaged 68% (6.8/10). No website required user information, almost none required additional software, and most had working internal and external hyperlinks. However, several websites lacked a search bar, a site map, and/or an option for a different language.

The mean score for authority was 69% (6.9/10). BETA, scoring highly with 85% (8.5/10) in authority, was one of the few websites to provide a list of authors of website content as well as authors' medical or health credentials. On the other hand, even well-designed and aesthetically pleasing websites such as Keep it Real with PrEP (35%, 3.5/10) failed to provide sufficient information about the organization running the website, citations or sources, and clarity of authorship. Keep it Real with PrEP was also 1 of 4 websites (13%, 4/31) that did not provide evidence of updated content within the past year, which is concerning given the consistently changing nature of PrEP and TasP guidelines. Notably, no website provided a statement expressing that website content had the official approval of the organization supporting the website, and a number of websites included statements explicitly denying responsibility for their content.

Table 1. Usability, authority, interactivity, and content scores for included websites ranked in descending order.

#	Website	Usability[a], score (%)	Authority[a], score (%)	Interactivity[a], score (%)	Content[b], score (%)	Total[c], score (%)	Audience
1	The Body	8 (80)	8.5 (85)	8.5 (85)	27 (90)	52 (87)	National
2	Poz	7 (70)	7.5 (75)	8.5 (85)	26 (87)	49 (82)	National
3	Aidsmap	8.5 (85)	8 (80)	5.5 (55)	25.5 (85)	47.5 (79)	Global
4	HIV.gov	7 (70)	7.5 (75)	5 (50)	85 (25.5)	45 (75)	National
5	Avert	8 (80)	7.5 (75)	65 (6.5)	22 (73)	44 (73)	Global
6	Positively Aware	6.5 (65)	8 (80)	4.5 (45)	25 (83)	44 (73)	National
7	BETA	5.5 (55)	8.5 (85)	4.5 (45)	25 (83)	43.5 (73)	Regional
8	GMFA[d]	7.5 (75)	7.5 (75)	5 (50)	23.5 (78)	43.5 (73)	National; LGBTQ+[e]
9	Plus Magazine	7 (70)	7.5 (75)	6 (60)	22 (73)	42.5 (71)	National
10	Project Inform	7 (70)	6.5 (65)	5.5 (55)	22 (73)	41 (68)	Regional
11	Black AIDS Institute	6.5(65)	8.5 (85)	4 (40)	21.5 (72)	40.5 (68)	National; POC[f]
12	NASTAD[g]	7 (70)	7.5 (75)	5 (50)	21 (70)	40.5 (68)	Global
13	Aids*info*	7 (70)	7 (70)	4 (40)	21.5 (72)	39.5 (66)	National
14	HIV and Hepatitis	5.5 (55)	8 (80)	3.5 (35)	22 (73)	39 (65)	Global
15	HIV=	8 (80)	7 (70)	5 (50)	19 (63)	39 (65)	Global
16	GMHC[h]	7 (70)	8 (80)	3.5 (35)	19.5 (65)	38 (63)	Regional
17	UNAIDS[i]	6.5 (65)	8 (80)	5.5 (55)	16 (53)	36 (60)	Global
18	What Works in Youth HIV	7 (70)	6 (60)	5.5 (55)	17.5 (58)	36 (60)	National
19	Golden Rule Services	6 (60)	6 (60)	3.5 (35)	20 (67)	35.5 (59)	Regional; POC
20	AVAC[j]	7 (70)	8 (80)	4.5 (45)	15.5 (52)	34.5 (58)	Global
21	Georgia CAPUS[k]	5.5 (55)	7 (70)	4 (40)	17.5 (58)	34 (57)	Regional
22	Keep it Real with PrEP	6.5 (65)	3.5 (35)	6 (60)	16.5 (55)	32.5 (54)	Regional
23	The Pitt Men's Study	6 (60)	6.5 (65)	5 (50)	15 (50)	32.5 (54)	Regional
24	How I Value Life	6 (60)	4.5 (45)	5.5 (55)	15 (50)	31 (52)	National
25	Hudson Valley Center	6 (60)	7.5 (75)	3.5 (35)	13 (43)	30 (50)	Regional
26	amfAR[l]	7.5 (75)	7.5 (75)	3.5 (35)	11 (37)	29.5 (49)	Global
27	NMAC[m]	5.5 (55)	7.5 (75)	4 (40)	12.5 (42)	29.5 (49)	National; POC
28	Resource Center	8 (80)	7 (70)	3 (30)	10 (33)	28 (47)	Regional; LGBTQ+
29	My PrEP Experience	7.5 (75)	2.5 (25)	5.5 (55)	10.5 (35)	26 (43)	Regional
30	Connected Boston	6 (60)	5 (50)	1 (10)	9 (30)	21 (35)	Regional; POC; LGBTQ+
31	PrEP for Sex	6.5 (65)	3 (30)	3.5 (35)	8 (27)	21 (35)	Regional
	Averages	6.8 (68)	6.9 (69)	4.5 (48)	18.5 (62)	37 (62)	—

[a]Score out of 10.

[b]Score out of 30.

[c]Score out of 60.

[d]GMFA: Gay Men Fighting AIDS

[e]LGBTQ+: lesbian, gay, bisexual, transgender, queer, and sexuality/gender-nonconforming.

[f]POC: people of color.

[g]NASTAD: National Alliance of State and Territorial AIDS Directors.

[h]GMHC: Gay Men's Health Crisis.

[i]UNAIDS: The Joint United Nations Programme on HIV and AIDS.

[j]AVAC: AIDS Vaccine Advocacy Coalition.

[k]Georgia CAPUS: Georgia Care and Prevention in the United States.

[l]amfAR: The Foundation for AIDS Research.

[m]NMAC: The National Minority AIDS Council.

Deficiencies in Accessible and Original Website Content

The average content score was 62% (18.6/30), meaning that the average website presented less than two-thirds of the information making up our content criteria. Furthermore, content about PrEP and TasP was often difficult to locate even when provided by the website. Although the majority of the websites (84%, 26/31) included headings or subheadings about PrEP or TasP, relevant information was frequently decentralized and could only be feasibly located using a search bar. RAs spent approximately 1 hour on each website to assign a content score, likely much longer than the amount of time that would be spent by an average user. Our scoring criteria failed to capture this time-consuming process of accessing information.

The websites also varied in their proportion of original versus outsourced content, another important theme observed during scoring but not encompassed by the scoring criteria. Some websites served primarily as aggregating tools, pulling articles or parts of articles from other organizations and rarely producing their own content. For example, the Pitt Men's Study relied heavily on articles from a number of other sources, whereas text from the CDC website could be seen on a number of other websites. In contrast, Positively Aware is known for the guides it compiles on HIV drugs, Aidsmap designs their own factsheets and infographics, and Project Inform creates original booklets on PrEP, to provide just a few examples. Eight of the websites in this review provided information about PrEP only, whereas 23 included information about both PrEP and TasP. No website exclusively offered content about TasP.

Websites for Lesbian, Gay, Bisexual, Transgender, Queer, and Sexuality/Gender-Nonconforming Populations and Racial and Ethnic Minorities

Only 2 websites focused on members of the LGBTQ+ community more broadly and just 3 on POC. Furthermore, the only website that stated that it intended to target black/African American and Hispanic/Latino MSM, Connected Boston, was a regional website with the lowest total score among all of the websites (35%, 21/60). Nevertheless, the average overall scores in those 2 groups as well as the more general websites were all within 5% points: 59% for LGBTQ+-focused websites, 60% for POC-focused websites, and 63% for the rest of the websites.

Regional, National, and Global Websites

A total of 12 websites were primarily focused on a particular region of the United States, whereas 11 websites targeted a national audience and 8 operated globally. The areas covered by the websites labeled *regional* included cities such as Boston, Sacramento, and San Francisco as well as programs within Pittsburg, Dallas, and the Hudson River Valley. Some regional websites also covered whole states, for example, New York. One national website targeted people living in the United Kingdom, whereas the rest were US-based.

The regional websites scored substantially lower than the national and global websites overall as well as in every individual category. The average regional website scored 59% (5.9/10) for authority and 52% (15.5/30) for content, with an average total of 53% (31.9/60). In contrast, the national websites averaged 73% (7.3/10) for authority, 72% (21.6/30) for content, and 69% (41.1/60) total, and the global websites averaged 77% (7.8/10) for authority, 63% (19/30) for content, and 65% (38.8/60) total.

Discussion

Principal Findings

The goal of this study was to systematically identify and assess existing websites providing information about PrEP or TasP for MSM. Overall, the 31 websites reviewed exhibited various deficiencies across all 4 categories of authority, usability, interactivity, and content. The average score in each of the categories was below 75% (ie, the average website met less than three-fourths of the category criteria), and more than half of the websites (16/31) scored 75% or lower in all the 4 categories.

Shortcomings in terms of website content and interactivity were particularly apparent and concerning. The average website contained less than two-thirds of the content included in our scoring criteria (63%, 18.6/30). This score is especially disappointing given the limited nature of the information our criteria considered for the content category. In addition, the information on the websites was often difficult to locate, linked to other websites, reposted rather than original, or lacked citations, with implications for usability and authority as well as content. Notably, websites with information about both PrEP and TasP scored higher not only in the content category but also in authority and interactivity, suggesting a potential connection between overall website quality and content quality that could be explored in future research.

Furthermore, few existing websites directed their content toward populations at high risk, including LGBTQ+ individuals and POC as well as certain regional communities. Not only did this review find only 1 website geared toward black/African American and Hispanic/Latino MSM, but that website received the lowest average score out of all 31 websites considered. Additional websites are also needed to provide information on PrEP and TasP for LGBTQ+ populations more broadly. In addition, although regional websites did exist, they consistently scored lower than national and global sites on every measure, pointing to the need to develop more comprehensive, high-quality websites with location-specific content. Most were also based in urban areas, whereas barriers to HIV prevention and care remain high in some rural areas.

Finally, the websites and Web-based content that do exist have little value if the target populations are not finding and sharing it. Our report that the interactivity category had the lowest

average score (48%, 4.8/10) underlines general calls to present health information in a more intuitive and accessible way—precisely the concerns that have, in theory, motivated the use of eHealth. Furthermore, this problem was almost ubiquitous across websites; excluding the 3 highest-scoring websites, the average interactivity score would have been as low as 40% (4/10). Getting people to read and understand HIV prevention information remains a substantial barrier to PrEP and TasP uptake among MSM, and existing HIV websites need to do a better job of encouraging high-risk men to engage with their content about prevention.

Recommendations

Some of the deficiencies discussed in this review could be easily rectified with changes to basic site design, whereas others would require more substantial additions to content or comprehensive considerations regarding website audience. The inclusion of a functioning search bar and sitemap, for example, could help users navigate content and increase usability. In addition, website creators should be conscious of the amount of misinformation available on the internet and the accompanying skepticism of users and take steps to prove and highlight their credibility. Potential options to this end include citations for facts and statistics, articles authored by qualified medical professionals, and general transparency surrounding sources of website information and analysis.

In terms of user engagement, this review suggests that developers should utilize a wider variety of media such as videos and animations and choose their use of text carefully. Embedding links to allow users to share website content through social media and email is technologically relatively simple, highly ubiquitous in other fields, and critical not only for interaction with existing users but also for the engagement of new users. Finally, websites should carefully evaluate their intended purpose and target audiences. Most pressingly, given the risk levels, the extreme lack of existing websites for LGBTQ+ and POC should be rectified. More websites are needed to provide relevant content for LGBTQ+ individuals generally and black/African American and Hispanic/Latino MSM most of all. These changes should also help in the critical consideration of the quality, breadth, and depth of the information the websites create and collate.

Limitations

As with all internet-based research, the availability and content of websites may change over time. Although RAs included all the results that appeared in their searches, additional websites regarding PrEP and TasP promotion may not have been captured in this review, for example, because they were not *live* or well established during the research phase. We also recognize that all websites included were in English, limiting our ability to provide commentary for an international audience. In addition, the measure that we modified based upon the work of Whiteley et al needs to be validated, which was beyond the scope of this study. Finally, as discussed above, the scoring criteria used did not account for a number of potentially relevant factors such as the ease of accessing information and the existence of incorrect information on websites. We suggest the future development and validation of an updated and standardized way to evaluate websites as well as social media and other eHealth campaigns.

Conclusions

This review provides a much-needed evaluation of the state of Web-based information about PrEP or TasP for MSM. Our findings emphasize deficiencies in interactivity and content across HIV prevention websites. In particular, website content needs to be more easily accessible and engaging as well as place a greater emphasis on those at the highest risk for HIV infection, namely, black/African American and Hispanic/Latino MSM. Moving forward, eHealth campaigns should consider this analysis to more successfully present HIV prevention information to these marginalized populations. An interactive website with population-specific information about PrEP and TasP developed for and by black/African American and Hispanic/Latino MSM could help these men increase their knowledge about and uptake of critical HIV prevention strategies.

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Conflicts of Interest

None declared.

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Abbreviations

amfAR: The Foundation for AIDS Research
ARV: antiretroviral
AVAC: AIDS Vaccine Advocacy Coalition
CDC: Centers for Disease Control and Prevention
eHealth: electronic health
Georgia CAPUS: Georgia Care and Prevention in the United States
GMFA: Gay Men Fighting AIDS
GMHC: Gay Men's Health Crisis
LGBTQ+: lesbian, gay, bisexual, transgender, queer, and sexuality/gender-nonconforming
MSM: men who have sex with men
NASTAD: National Alliance of State and Territorial AIDS Directors
NMAC: The National Minority AIDS Council
POC: people of color
PrEP: pre-exposure prophylaxis
RA: research assistant
TasP: treatment as prevention
UNAIDS: The Joint United Nations Programme on HIV and AIDS

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Original Paper

Quantification of HIV-1 RNA Among Men Who Have Sex With Men Using an At-Home Self-Collected Dried Blood Spot Specimen: Feasibility Study

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Abstract

Background: Suboptimal antiretroviral therapy (ART) adherence and disengagement in care present significant public health challenges because of the increased probability of HIV transmission. In the United States, men who have sex with men (MSM) continue to be disproportionately affected by HIV, highlighting a critical need to engage high-risk MSM living with HIV who are not engaged or retained in care.

Objective: The aim of the study was to assess the feasibility of at-home blood self-collection and laboratory quantification of HIV-1 RNA viral load (VL) to report laboratory-based VL outcomes and compare self-reported and laboratory-reported VL

Methods: Between 2016 and 2017, 766 US HIV-positive MSM enrolled in a Web-based behavioral intervention were invited to participate in an at-home dried blood spot (DBS) collection study using HemaSpot-HF kits (Spot On Sciences, Inc, Austin, TX) for laboratory-quantified VL.

Results: Of those invited to participate, 72.3% (554/766) enrolled in the DBS study. Most (79.2%, 439/554) men enrolled reported attempting to collect their blood, 75.5% (418/554) of participants mailed a DBS specimen to the research laboratory, and 60.8% (337/554) had an adequate blood sample for VL testing. Of the 337 specimens tested for VL by the laboratory, 52.5% (177/337) had detectable VL (median: 3508 copies/mL; range: 851-1,202,265 copies/mL). Most men (83.9%, 135/161) who returned a DBS specimen with laboratory-quantified detectable VL self-reported an undetectable VL during their last clinical visit.

Conclusions: Home collection of DBS samples from HIV-positive MSM is feasible and has the potential to support clinical VL monitoring. Discrepant laboratory HIV-1 RNA values and self-reported VL indicate a need to address perceived VL status, especially in the era of treatment as prevention. Most participants were willing to use an at-home DBS kit in the future, signaling an opportunity to engage high-risk MSM in long-term HIV care activities.

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KEYWORDS

HIV-1; viral load; dried blood spot testing; men who have sex with men

Introduction

Background

Suboptimal antiretroviral therapy (ART) adherence and intermittent engagement in care present significant public health challenges because of the increased probability of HIV transmission resulting from high HIV-1 RNA viral load (VL) [1-5]. It is critical to assess strategies to monitor VL among individuals living with HIV who are not consistently ART adherent. In the United States, men who have sex with men (MSM) continue to be disproportionately affected by HIV; in 2016, MSM accounted for 66.79% (26,570/39,782) of all HIV diagnoses and 82.69% (26,570/32,131) of diagnoses among men [1]. Among US MSM known to be living with HIV in 2014, 74.07% (265,280/358,151) had received any care, 57.66% (206,523/358,151) were retained in care, and 61.16% (219,043/358,151) of those in care achieved viral suppression, although engagement in care and viral suppression were lowest among younger MSM and black MSM [6,7]. Research and program initiatives have aimed to increase both the number of MSM who are tested and who engage in care after an HIV diagnosis [8-10]. At-home rapid HIV self-testing has provided another option for MSM to be tested, and studies have shown that MSM are willing to self-test rather than use traditional testing sites because of stigma, privacy-related concerns, and the ability to test at any time [11-13]. There is a similar need for VL self-testing or sample collection approaches to be developed for MSM living with HIV that can support traditional HIV clinical care and increase the proportion of virally suppressed MSM living with HIV.

The Mailed-Spot (M-Spot) study assessed the feasibility of home self-collection of dried blood spot (DBS) specimens for laboratory quantification of VL among US white, black, and Hispanic MSM living with HIV who participated in a Web-based behavioral intervention [14]. Because MSM commonly use the Internet and smartphone apps for sexual and health purposes, Web-based and mobile settings provide an opportunity for engagement and obtaining biologic specimens in behavioral research [15-17].

Study Objectives

We report feasibility and VL outcomes among MSM living with HIV who received a novel DBS collection kit for at-home blood self-collection and laboratory quantification of VL.

Methods

Study Overview

MSM participating in Sex Positive! (parent study), a national Web-based behavioral intervention, were invited to take part in the M-Spot study following completion of the original study. The parent study's protocol has been described previously [14]. Briefly, eligible participants in the parent study were (by self-report) biologically male and identified as a male or genderqueer; aged 18 years or older; white, black, or Hispanic; able to read and respond in English; a US resident; HIV-positive; not virally suppressed (>200 copies/mL) in the past year or reported past-month suboptimal ART adherence [18]; and had condomless anal sex with an HIV-negative or unknown status male partner in the past 6 months.

Ethics Statement

The institutional review board (IRB) at Public Health Solutions in New York, NY, approved all study procedures. The IRB at Johns Hopkins University in Baltimore, MD, approved all laboratory-related procedures. Participants provided consent by clicking a button at the end of the Web-based consent form to indicate that they had read the consent page and agreed to participate. A Certificate of Confidentiality was obtained from the National Institute of Mental Health to protect the privacy of participants enrolled in this study.

Participants

For the M-Spot study, men received an email recruitment solicitation within a week of completing the parent study's 12-month follow-up survey. The email contained a link that redirected them to a brief, secure screening survey. Those ever diagnosed with hemophilia, or who were currently taking anticoagulation medication, were excluded.

Study Procedures

Consenting participants were mailed a package containing one HemaSpot-HF device (DBS kit; Spot On Sciences, Inc, Austin, TX), collection materials (alcohol prep pads, lancets, gauze pad, and adhesive bandages), an instruction card, and a return envelope with postage. Men read the instruction card or viewed a video that demonstrated how to collect their blood and mail their DBS specimen to the International STD Research Laboratory at Johns Hopkins University.

After self-collecting a DBS specimen, men completed a brief Web-based survey (herein referred to as the *M-Spot survey*), which inquired about the blood collection process; experience using the kit (ie, attempts to use the kit, experience using the lancet, etc); experience with the study materials (ie, did they watch the video, did they understand the instruction card); willingness to use a DBS kit in the future; and engagement in HIV care since the parent study's 12-month follow-up survey. After collecting their blood specimen and completing the M-Spot survey, men mailed their DBS specimen to the research laboratory.

HemaSpot-HF was developed to address technical issues associated with using traditional filter cards for DBS collection [19]. A protective plastic cartridge minimizes the risk of contamination and contains a desiccant ring to keep the sample free from moisture. Immediately after blood collection, the desiccant allows the kit to be closed for shipment. Upon receipt at the laboratory, DBS specimens were stored for up to 4 months at 4°C before testing. If a DBS kit was half-filled with blood or not filled at all, the sample was deemed untestable. Acceptable

samples were tested in batches corresponding to laboratory receipt date.

DBS specimens were placed in an Abbott Master Mix Tube (Abbott Molecular Inc, Des Plaines, IL) containing 1.3 mL of Abbott mSample Preparation system DBS Buffer (a research-use-only assay) incubated for 30 min at 55°C with gentle mixing and placed on the Abbott m2000sp instrument for sample extraction. The Abbott m2000sp/rt system used an open-mode protocol for DBS samples [20]. VL results were reported as "not detected," if no HIV-1 RNA was detected in the sample. A qualitative result of "≤832 copies/mL (≤2.92 log copies)" was reported when fewer than or equal to 832 copies/mL of HIV-1 RNA were detected. Quantitative VL results were reported when HIV-1 RNA was detectable above 832 copies/mL (2.93 log copies to 7.00 log copies). A lower limit of quantification was not reported by the manufacturer as there is a low probability of reproducibility when samples have viremia ≤2.92 log copies (832 copies/mL). On the completion of DBS specimen analysis, aggregate results from the study were emailed to all consenting participants. We did not have IRB approval to provide individual results to participants.

Survey Measures

The M-Spot survey was designed to assess the feasibility of collecting a DBS specimen for VL and also to capture HIV care information that may have occurred between the end of the parent study and enrollment in the M-Spot study. To reduce participant's burden, HIV care questions were only asked if the participant reported seeing an HIV care provider after completing the 12-month survey (see Self-Reported Viral Load Status subsection). M-Spot survey data were merged with data from the parent study's screener (herein referred to as *screener*) and the parent study's 12-month follow-up survey (herein referred to as the *parent survey*). Demographic measures were primarily collected from the screener, HIV care and adherence measures for this analysis were collected from the parent survey, and DBS feasibility questions were collected from the M-Spot survey. Median time between the completion of the screener and the M-Spot survey was 405 days (range: 367-617 days), and median time between the completion of the parent survey and the M-Spot survey was 36 days (range: 6-257 days). All survey data were collected online.

Participant Characteristics

The screener included questions on participant's age, race and ethnicity, gender identity, and sex at birth. Recruitment source was also identified from the screener, based on the recruitment URL used by the participant. Participants indicated on the parent survey whether they were diagnosed with HIV in the past year. The parent survey also obtained updated level of education, annual income, employment status, and insurance information.

Sexual History

Participants reported number of male anal insertive and receptive sex partners in the last 3 months on the parent survey. Pull-down menus listed 0 through 100 partners, 101+ partners, I don't know, and prefer not to answer.

HIV Care

To assess engagement in HIV care, men were asked on the parent survey whether they had a doctor, nurse, or other medical provider whom they considered to be in charge of their overall HIV health care. Response options included no, yes, and prefer not to answer. Participants were also asked on the parent survey when was the last time they had a health care appointment with their HIV care provider (last 3 months, 3-6 months ago, 6-9 months ago, 9-12 months ago, more than a year ago, I don't know, and prefer not to answer).

Antiretroviral Medication Adherence

Participants were asked on the parent survey about their current use of antiretroviral medications (yes, no). Among participants on treatment, past 30-day adherence to ART was assessed using a 3-item scale [18]. Participants were asked: "In the last 30 days, on how many days did you miss at least one dose of any of your HIV medicines?" (0-30 days); "In the last 30 days, how good a job did you do at taking your HIV medicines in the way you were supposed to?" (never, rarely, sometimes, usually, almost always, always); and "In the last 30 days, how often did you take your HIV medicines in the way you were supposed to?" (never, rarely, sometimes, usually, almost always, always). Responses to each question were linearly transformed to a 0 to 100 scale and averaged across all 3 items.

Self-Reported Viral Load Status

The M-Spot survey included items to measure self-reported VL status at the time of blood collection. Participants indicating an HIV care visit since the parent survey were asked whether they had a VL test. Men who reported having a VL test were asked to estimate the date of their last VL test and to select their most recent results from the following: My viral load was undetectable; My viral load was detectable; I don't know—but I think I was detectable; and I don't know—but I think I was undetectable. Participants reporting My viral load was detectable or I don't know—but I think I was detectable were categorized as having a self-reported detectable VL status. Participants reporting My viral load was undetectable or I don't know—but I think I was undetectable were categorized as having a self-reported undetectable VL status.

Data on self-reported VL status from participants who did not report an HIV care visit between the parent survey and the M-Spot study were obtained from the parent survey; men who reported a VL test in the past 6 months on the parent survey were asked to select their most recent results from the following: My viral load was undetectable, or <200 copies/mL; My viral load was detectable, or >200 copies/mL; I don't know—but I think I was undetectable; and I don't know—but I think I was detectable. Using the same strategy as in the M-spot survey, responses were dichotomized (detectable, undetectable). The date of the last VL test was not collected on the parent survey.

Time Between Self-Reported Viral Load and Dried Blood Spot Specimen Collection

The difference between the date of DBS specimen collection and date of self-reported VL status on the M-Spot or parent survey was used to estimate the time between a self-reported VL from a plasma sample (collected during an HIV care visit)

and a VL laboratory result from a DBS specimen. The calendar date reported for last VL test in the M-Spot survey was used as the participant's self-reported VL date. The parent survey did not ask participants to report the date of their last VL test. Thus, for participants who did not visit their HIV care provider in between the parent study and the M-Spot study, the day they finished the parent survey was used as a proxy for the participant's self-reported VL test date. If participants did not self-report a VL status on either the M-Spot survey or parent survey, their self-reported VL status was treated as missing.

Experience Using Dried Blood Spot Kit

Experience using the DBS kit at home was measured through several questions on the M-Spot survey. Men were asked if they felt comfortable collecting their own blood sample (yes, no, prefer not to answer), and they were asked to rate their overall experience using the HemaSpot-HF device (very easy, easy, hard, very hard, prefer not to answer). Participants were also asked to rate their willingness to use a DBS kit in a future study (very willing, willing, not willing, extremely not willing, prefer not to answer).

Statistical Methods

We assessed study feasibility by the proportion of participants who successfully completed various stages: enrollment, collecting a blood sample, mailing the kit to the laboratory, laboratory receipt of DBS specimens, and providing a testable blood sample. Pearson chi-square tests, Fisher exact tests, independent-sample *t*-tests, and Mann-Whitney *U* tests were used to identify group differences between participants who enrolled and did not enroll in the study and between participants who returned a DBS sample with detectable and undetectable viremia. Data analyses were performed using SAS version 9.4 (SAS Institute, Cary, NC).

Results

Participant Characteristics

From September 2016 to February 2017, an invitation link to participate in the M-Spot study was sent to 766 men living with HIV within a week of completing the parent survey (Figure 1, box A). Of note, 112 men had completed the parent survey before we received IRB approval and thus were not eligible to participate in the study. Among recruited men, 86.6% (663/766) opened the email and clicked on the screener link (Figure 1, box B). Men who clicked the link were more likely to have health insurance (93.6% [617/659] vs 88.1% [89/101], *P*=.04) and a past 6-month HIV health care visit (92.4% [549/594] vs 83.0% [78/94], *P*<.01) than men who did not click the link. In total, 568 men were eligible to participate, 562 consented (Figure 1, box C), and 554 (72.3% [554/766] of those recruited) enrolled in the study (Figure 1, box D). To enroll, participants had to provide a mailing address to receive the DBS kit by mail.

Most enrolled participants were white (68.8%, 381/554), college-educated (61.7%, 341/553), and had a yearly income of less than US $40,000 (54.9%, 304/554; see Table 1). Median age was 39 years (range: 19-72 years). Most men (56.1%, 332/542) enrolled in M-Spot had been recruited for the parent study from a website for men interested in condomless anal sex with a male partner. Over half (57.8%, 320/554) were employed full time, and 94.0% (516/549) were insured—half through public health insurance. Participants self-reported a median of 2 male sexual partners (range: 0-101) in the past 3 months. A minority of men (19.1%, 105/551) were diagnosed with HIV in the 12 months before they enrolled in the parent study. On the basis of participants' self-report, 91.1% (499/548) were engaged in HIV care; 93.0% (463/498) had visited their HIV care provider in the past 6 months; and 93.3% (516/553) were currently on ART, with a median Wilson adherence score of 88.9% (range: 0%-100%); and 90.8% (456/502) self-reported an undetectable VL (≤200 copies/mL) from their last clinical laboratory test. Compared with men who did not enroll in the M-Spot study, men who enrolled were more likely to have seen their HIV care provider in the past 6 months (93.0% [463/498] vs 86.3% [164/190], *P*=.02) and more likely to report ART use (93.3% [516/553] vs 89.1% [188/211], *P*=.05; see Table 1).

Feasibility and Acceptability

Of the 554 men enrolled in M-Spot, 79.2% (439/554) reported attempting to collect their blood (Figure 1, box E). Some participants (n=49) requested a second DBS kit; reasons included difficulties collecting their blood or losing the kit. Of these men, 11 had issues drawing blood with the lancet and attributed this to callused fingertips. The initial lancet used for this study had an 18-gauge blade with a 2.3-mm penetration depth. In response to lancet-related issues, we sent the 11 participants, and all subsequently enrolled participants, lancets that had a 21-gauge needle and 2.8-mm penetration depth.

A high proportion (75.5%, 418/554) mailed a DBS specimen to the laboratory (Figure 1, box F). The laboratory received and evaluated 413 kits (Figure 1, box G). The median time between sample collection and specimen receipt was 4 days (range: 1-69 days). Among the kits received, 76 were not analyzed: 65 had an inadequate amount of blood and were deemed untestable, an instrument error occurred when processing 7 specimens, and an internal control error occurred when processing 4 specimens. In total, 337 kits had a sufficient amount of blood and were tested (Figure 1, box H).

Among men who returned a DBS specimen to the laboratory and completed the study survey, 89.8% (326/363) reported feeling comfortable collecting their blood; 83.6% (306/366) rated their experience using the DBS kit as "very easy" or "easy," and 98.1% (357/364) reported willingness to use an at-home DBS kit in the future.

Among 115 participants who did not attempt to use the DBS kit, 105 men received the kit but did not participate (ie, were lost to follow-up), 7 men withdrew from the study, 2 men never received the kit, and 1 participant decided not to use the kit after opening the package. The men who were lost to follow-up or withdrew were predominantly white (69.6%, 80/115), college-educated (58.3%, 67/115), earned less than US $40,000 (57.1%, 64/112), and had a lower Wilson ART adherence score (81% vs 85%; *P*=.04) than men participating in study activities. Finally, 15 participants were unable to collect their blood and did not mail their kit.

Figure 1. M-Spot study recruitment and participation. M-Spot: Mailed-Spot.

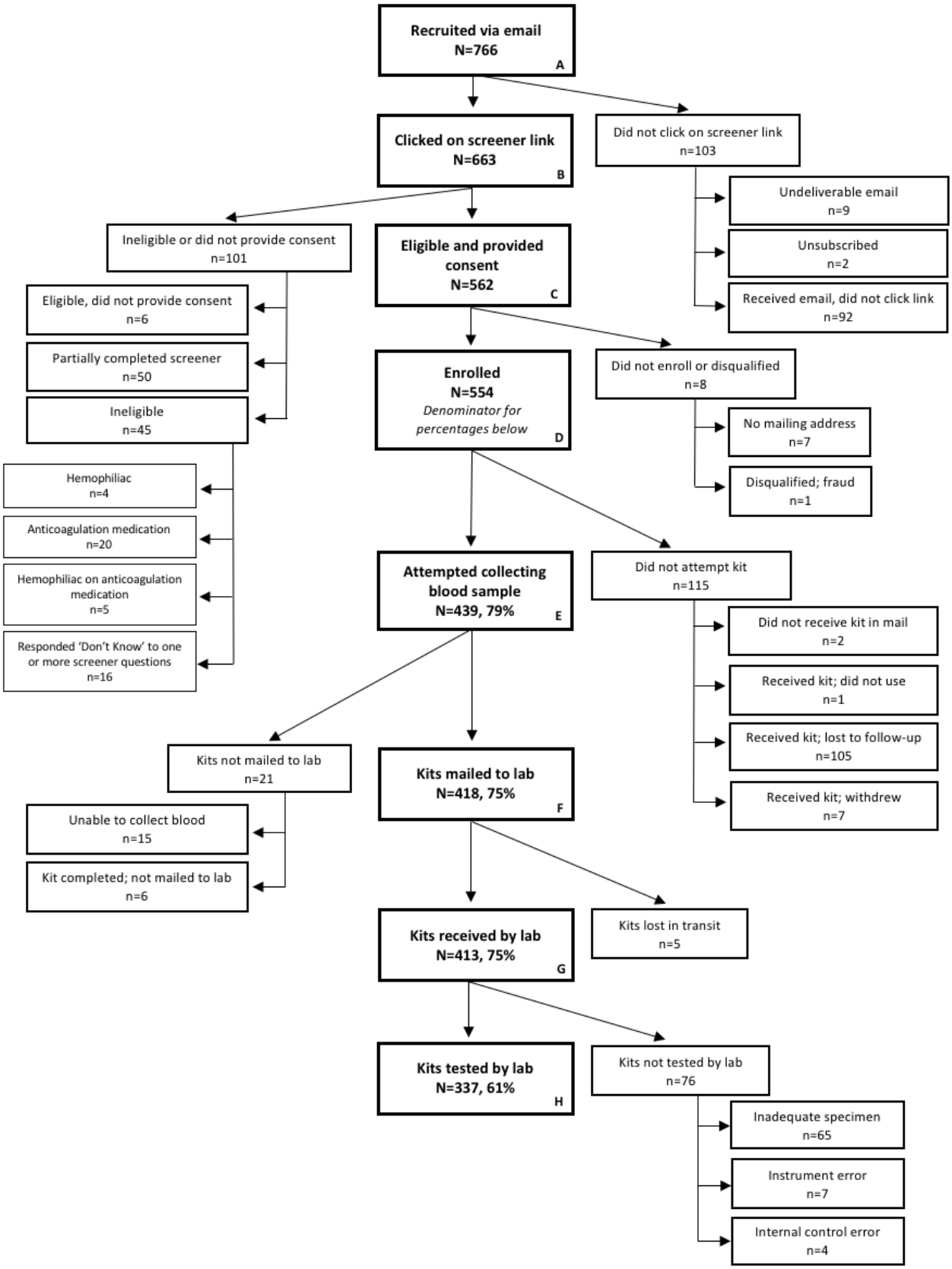


Table 1. Sociodemographic and behavioral characteristics of recruited participants, by enrollment status (N=766).

Characteristics	Total (N=766)	Enrolled (n=554)	Ineligible or not enrolled (n=212)	*P* value
Age in years (n=765)[a], n (%)				.10[b]
18-29	155 (20.3)	111 (20.1)	44 (20.8)	
30-39	233 (30.5)	181 (32.7)	52 (24.5)	
40-49	221 (28.9)	159 (28.8)	62 (29.3)	
50-59	126 (16.5)	84 (15.2)	42 (19.8)	
≥ 60	30 (3.9)	18 (3.3)	12 (5.7)	
Race (n=766), n (%)				.31[b]
Black	124 (16.2)	83 (15.0)	41 (19.3)	
Hispanic	120 (15.7)	90 (16.3)	30 (14.2)	
White	522 (68.2)	381 (68.8)	141 (66.5)	
Education (n=763)[a], n (%)				.55[b]
High school diploma or less	68 (8.9)	53 (9.6)	15 (7.1)	
Some college	224 (29.4)	159 (28.8)	65 (31.0)	
College graduate	309 (40.5)	228 (41.2)	81 (38.6)	
Professional or graduate degree	162 (21.2)	113 (20.4)	49 (23.3)	
Income (n=743)[a], n (%)				.21[b]
<$20,000	225 (30.3)	173 (31.9)	52 (25.9)	
$20,000-$39,999	182 (24.5)	131 (24.2)	51 (25.4)	
$40,000-$59,999	137 (18.4)	102 (18.8)	35 (17.4)	
$60,000-$99,999	111 (14.9)	80 (14.8)	31 (15.4)	
≥$100,000	88 (11.8)	56 (10.3)	32 (15.9)	
Insured (n=757)[a], n (%)				.41[b]
Yes, private health insurance	349 (46.1)	257 (46.8)	92 (44.2)	
Yes, public health insurance	357 (47.2)	259 (47.2)	98 (47.1)	
No	51 (6.7)	33 (6.0)	18 (8.7)	
Employed full time (n=766), n (%)	443 (57.8)	320 (57.8)	123 (58.0)	.95[b]
Recruitment source (n=764)[a], n (%)				.44[b]
Mobile phone app	234 (30.6)	170 (30.7)	64 (30.3)	
Bareback website	453 (53.3)	332 (60.0)	121 (57.4)	
Other sites	77 (10.1)	51 (9.2)	26 (12.3)	
Engaged in HIV care (n=758)[a], n (%)	689 (90.9)	499 (91.1)	190 (90.5)	.80[b]
Currently on antiretroviral therapy (n=764)[a], n (%)	704 (92.2)	516 (93.3)	188 (89.1)	.05[c]
Past year HIV diagnosis (n=762)[a], n (%)	151 (19.8)	105 (19.1)	46 (21.8)	.39[a]
Last HIV care visit (n=688)[a], n (%)				.02[b,c]
<6 months	627 (91.1)	463 (93.0)	164 (86.3)	
6-12 months	51 (7.4)	29 (5.8)	22 (11.6)	
>12 months	10 (1.5)	6 (1.2)	4 (2.1)	
Self-reported HIV viral load status (n=673)[a], n (%)				.18[b]
Undetectable	617 (91.7)	456 (90.8)	161 (94.5)	
Detectable	56 (8.3)	46 (9.2)	10 (5.9)	

Characteristics	Total (N=766)	Enrolled (n=554)	Ineligible or not enrolled (n=212)	*P* value
Antiretroviral therapy adherence score, mean (n=703)[a]	84.5	84.6	84.3	.88[d]
Number of male anal sex partners, last 3 months, mean (n=766)	18.3	21.2	10.5	.56[e]

[a]Denominators vary because of missing data.

[b]Pearson chi-square test.

[c]Statistical significance at level $P \leq .05$.

[d]Independent-sample *t* test.

[e]Mann-Whitney *U* test.

Viral Load Results

Of the 337 specimens tested for VL by the laboratory, over half (52.5%, 177/337) had detectable VL, whereas 47.5% (160/337) of participants returned a sample with no detectable HIV-1 RNA (Figure 2). Of the DBS specimens classified as having a detectable VL, a total of 99 DBS specimens from participants had a qualitative result of "≤832 copies/mL (≤2.92 log copies)," and 78 DBS specimens had a quantitative result of >832 copies/mL. Among the DBS specimens with a quantitative VL (n=78), the overall median VL was 3508 copies/mL (interquartile range, IQR: 1349-21,754 copies/mL). When stratified into different levels of viremia, 9 specimens had detectable viremia between 833 and 999 copies/mL (median: 891 copies/mL; IQR: 870-955 copies/mL), 43 specimens were between 1000 and 9999 copies/mL (median: 1995 copies/mL; IQR: 1349-4542 copies/mL), and 26 specimens had viremia ≥10,000 copies/mL (median: 46,823 copies/mL; IQR: 22,264-144,865 copies/mL; see Figure 2). Compared with participants who returned a DBS specimen with detectable viremia, men who returned a DBS specimen with undetectable viremia were significantly more likely to be employed full-time (63.1% [101/160] vs 52.5% [93/177], *P*=.05), report a recent HIV diagnosis (<1 year; 23.1% [37/160] vs 12.5% [22/176], *P*=.01), be engaged in HIV care (96.9% [155/160] vs 86.4% [152/176], *P*<.01), and be currently on ART (98.8% [158/160] vs 88.6% [156/176], *P*<.01; see Table 2).

Figure 2. Participant laboratory HIV-1 RNA results, n=337.

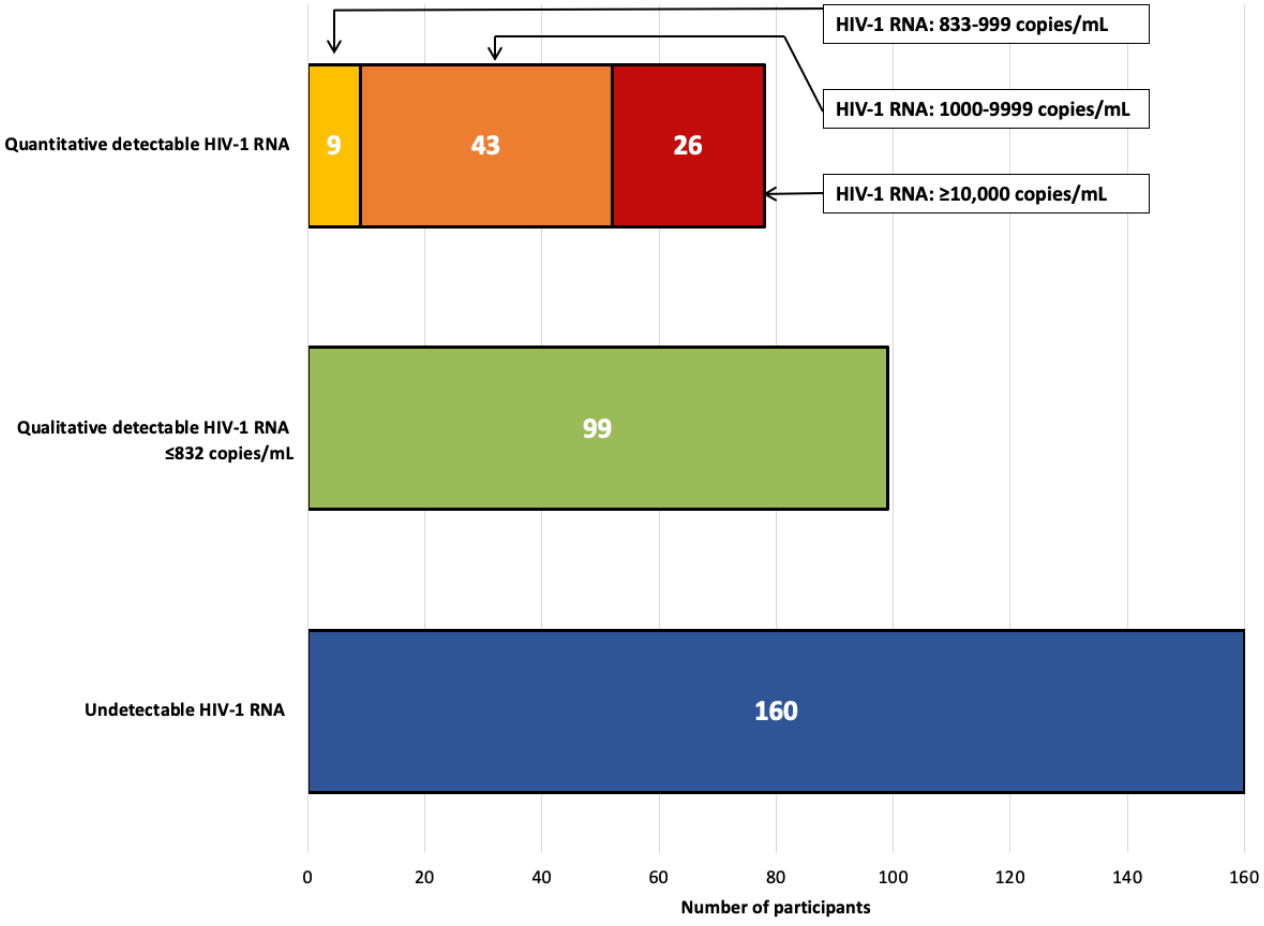


Table 2. Characteristics of participants who provided a testable dried blood spot specimen, by HIV-1 RNA viral load status (n=337).

Characteristics	Total (n=337)	Detectable HIV-1 RNA[a], (n=177)	Undetectable HIV-1 RNA[a], (n=160)	*P* value
Age in years (n=337), n (%)				.28[b]
18-29	69 (20.5)	34 (19.2)	35 (21.9)	
30-39	116 (34.4)	55 (31.1)	61 (38.1)	
40-49	91 (27.0)	55 (31.1)	36 (22.5)	
≥ 50	61 (18.1)	33 (18.6)	28 (17.5)	
Race (n=337), n (%)				.99[b]
Black	41 (12.2)	22 (12.4)	19 (11.9)	
Hispanic	57 (16.9)	30 (17.0)	27 (16.9)	
White	239 (70.9)	125 (70.6)	114 (71.3)	
Employed full-time (n=337), n (%)	194 (54.6)	93 (52.5)	101 (63.1)	.05[b,c]
Insured (n=333)[d], n (%)				.60[b]
Yes, private health insurance	158 (47.5)	79 (44.9)	79 (50.3)	
Yes, public health insurance	154 (46.3)	85 (48.3)	69 (44.0)	
No	21 (6.3)	12 (6.8)	9 (5.7)	
Past year HIV diagnosis (n=335)[d], n (%)	59 (17.6)	22 (12.5)	37 (23.3)	.01[b,c]
Engaged in HIV care (n=336)[d], n (%)	307 (91.4)	152 (86.4)	155 (96.9)	.001[b,c]
Last HIV care visit (n=307)[d], n (%)				.60[e]
<6 months	286 (93.2)	140 (92.1)	146 (94.2)	
6-12 months	17 (5.5)	9 (5.9)	8 (5.2)	
>12 months	4 (1.3)	3 (2.0)	1 (0.7)	
Self-reported HIV viral load status (n=316)[d], n (%)				<.001[b,c]
Undetectable	284 (89.9)	135 (83.9)	149 (96.1)	
Detectable	32 (10.1)	26 (16.2)	6 (3.9)	
Currently on ART[f] (n=336)[d], n (%)	314 (93.5)	156 (88.6)	158 (98.8)	<.001[b,c]
ART adherence score, mean (n=313)[d]	85.5	84.4	86.5	.33[g]
Number of male anal sex partners (mean), last 3 months (n=337)	26.5	29.8	22.9	.63[h]

[a]Individuals categorized as having a detectable HIV-1 RNA include participants with a quantitative result >832 copies/mL or qualitative result ≤832 copies/mL.

[b]Pearson chi-square test.

[c]Statistical significance at level $P \leq .05$.

[d]Denominators vary because of missing data.

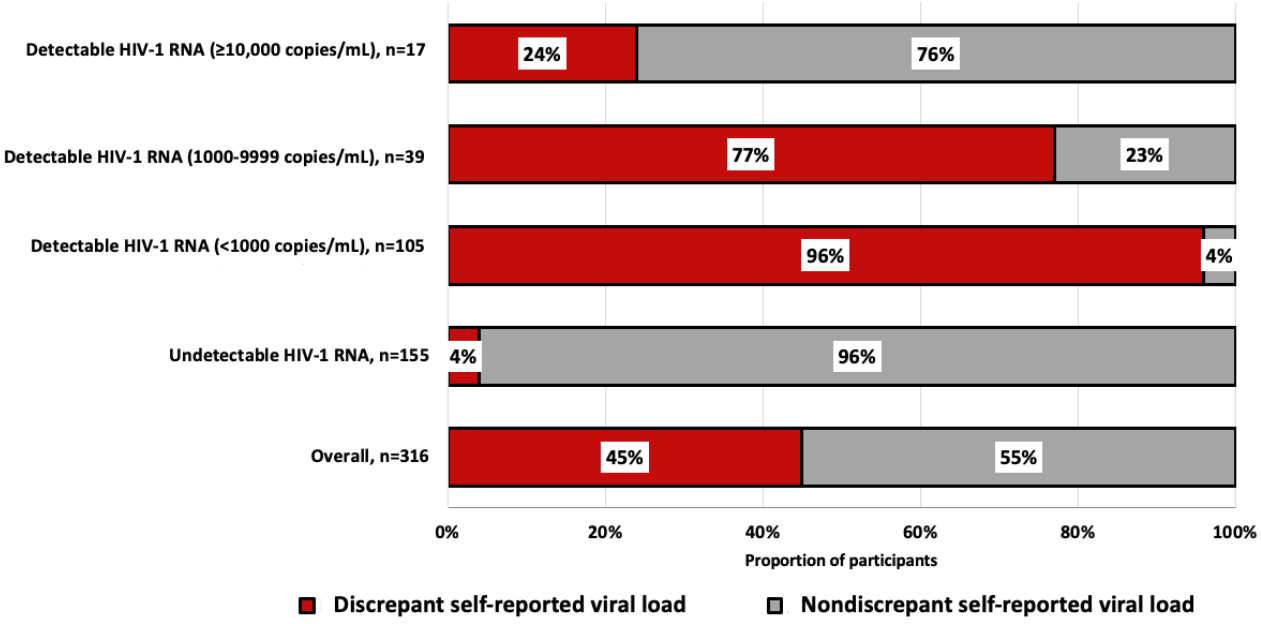
[e]Fisher exact test.

[f]ART: antiretroviral therapy.

[g]Independent-sample *t* test.

[h]Mann-Whitney *U* test.

Figure 3. Participant self-reported viral load status, by laboratory HIV-1 RNA result, n=316.



We compared participants' laboratory HIV-1 RNA result with their most recent self-reported VL. Among participants who returned a testable DBS specimen, 93.8% (316/337) also self-reported their VL in the M-Spot survey or the parent survey. Among the 316 DBS samples, 284 self-reported having an undetectable VL and 32 self-reported having a detectable VL. Among men with both laboratory and self-reported VL data, 44.6% (141/316) had a discrepant laboratory HIV-1 RNA result and self-reported VL status (Figure 3).

Of note, 83.9% (135/161) of the men who returned a DBS specimen with a detectable HIV-1 RNA result self-reported that they had an undetectable VL at their last clinical visit (Table 2). Among men self-reporting an undetectable VL, those living with HIV for >1 year at the start of the parent study were more likely to have a discrepant self-reported VL and a laboratory-quantified VL (88.2% [119/135] vs 77.0% [114/148]; *P*=.01). However, those who self-reported being engaged in care were less likely to have discrepancies between their self-reported VL and laboratory-quantified VL compared with those who self-reported not being engaged in care (91.1% [123/135] vs 97.3% [145/149]; *P*=.02).

Median time between a discrepant self-reported VL and a laboratory-quantified VL was 22 days. Median time between concordant self-reported VL and a laboratory-quantified VL was 25 days. Different proportions of discrepant self-reported VL were observed when the HIV-1 RNA results from the DBS specimens were disaggregated: 96.2% (101/105) of men with a laboratory HIV-1 RNA result <1000 copies/mL, 76.9% (30/39) of men with a laboratory HIV-1 RNA result <10,000, and 23.5% (4/17) of men with a laboratory HIV-1 RNA result ≥10,000 copies/mL had a discrepant self-reported VL (Figure 3—indicated in red). Finally, an additional 21 participants returned a testable DBS specimen but did not self-report their VL in the survey. Of these men, 16 returned a sample with detectable viremia; of these, 13 men had a VL >1000 copies/mL (median: 20,893 copies/mL; range: 3467-154,881 copies/mL).

Discussion

Principal Findings

This study assessed the feasibility and acceptability of an at-home DBS collection kit for laboratory VL quantification from US MSM living with HIV who had previously reported suboptimal ART adherence or a detectable VL. To our knowledge, this is the first DBS home collection study from a Web-based sample of MSM living with HIV who mailed a DBS specimen to a laboratory for VL quantification. Feasibility was demonstrated at multiple study stages: 72.3% (554/766) of recruited men enrolled; 79.2% (439/554) of enrolled men attempted to collect a blood sample; 75.5% (418/554) mailed their DBS specimen to the laboratory and were received by the laboratory; and 60.8% (337/554) provided a testable blood sample. Among participants who returned a kit with a testable

blood sample, 52.5% (177/337) had a detectable VL. Of significance, 83.9% (135/161) of DBS specimens with a detectable VL were from men who self-reported that they had an undetectable VL at their last clinical visit. These results suggest that at-home DBS collection for laboratory-quantified VL is both feasible and acceptable and may serve as a VL monitoring platform for MSM.

Our results support the findings of other studies with respect to the acceptability of self-collecting biologic specimens[21-23] and the willingness of MSM to self-collect blood samples for HIV testing [24-28]. The traditional DBS sampling using Guthrie cards or filter paper disks has been used for more than 40 years [29-31] and is now common in epidemiologic studies [32,33]. DBS sampling has been used in nonclinical settings for quantifying VL to identify acute and undiagnosed HIV infections [34,35]. However, DBS collection in nonclinical settings for VL quantification in known HIV-positive cohorts has largely been unexplored until now.

Results from 3 recent studies [36-38] prompted the Centers for Disease Control and Prevention and the National Institute of Allergy and Infectious Diseases to declare that people on ART who have an undetectable VL have no risk of transmitting the virus to HIV-negative partners [39,40]. To prevent further HIV transmission, individuals diagnosed with HIV must be engaged in care, take ART as prescribed, and achieve and maintain viral suppression [36,41]. The "Undetectable=Untransmittable" campaign has the potential to promote the benefits of HIV treatment, help alleviate stigma, and prevent further HIV transmission [42]. However, for the campaign to be effective, an individual's perceived undetectable VL status must accurately match their actual VL status. The high proportion of individuals with a discrepant laboratory HIV-1 RNA result and self-reported VL status reported in this study indicates that men either incorrectly perceived or falsely reported their actual VL status. A recent study of young MSM and transgender women living with HIV [43] similarly reports discrepant self-reported VL survey data with laboratory-based and electronic medical record VL measurements; approximately a third of participants had discrepant laboratory-measured VL and a self-reported VL status. Our study reports a much higher proportion (84% vs 34%) of men with discrepant VL data with differences likely because of 2 disparate study populations with different age and racial and ethnic distributions and recruitment methodologies. We echo the authors' concerns that discrepancies between self-reported and laboratory VL data have significant ramifications for continued HIV transmission, validity of epidemiological studies (eg, data misclassification), and the success of public health campaigns. Furthermore, inaccurate perception of one's VL status may have potential consequences for partner-seeking behaviors among HIV-positive MSM who believe that they are undetectable when they are not.

Although most men returned a DBS specimen with a testable blood sample, some participants experienced issues collecting their blood at home. We estimate that about 15% to 20% of participants had difficulties with the lancets provided with the DBS kit based on our email and phone communication with the participants. In addition, some reported difficulties depositing blood drops into the middle of the application surface, which prevented them from getting enough blood on the absorbent paper. Participants experiencing issues often requested a second kit (where we provided a different lancet with a deeper penetration depth), did not return their kit to the laboratory, or returned a kit to the laboratory with little or no blood. Future studies should anticipate possible specimen self-collection issues or issues with study materials such as lancets. Addressing these issues will likely increase the feasibility of at-home specimen collection.

Novel interventions, devices (eg, Food and Drug Administration–approved home VL test), and service delivery options (eg, sharing DBS VL laboratory results with a patient's provider) must be developed to increase the number of individuals who are retained in care and who achieve and accurately perceive their current VL status. An individual's VL is dynamic and viral "blips" can occur throughout the long-term treatment of HIV because of fluctuations in ART adherence or concurrent illnesses [44-47]. Individuals with a history of intermittent HIV care or detectable viremia may be more inclined to reengage in care or improve ART adherence, if they know they have a detectable (laboratory-quantified) VL from an at-home self-collected specimen; future studies should assess this, as well as whether there are clinical benefits with more frequent VL monitoring in between clinical visits from samples collected outside of clinical settings.

Limitations

A few study limitations should be acknowledged. First, with respect to our email recruitment approach, it is possible that some participants never saw the email in their inbox or spam folder. Second, 20.8% (115/554) of enrollees did not complete study activities; participants who withdrew or were lost to follow-up had a lower Wilson ART adherence score than those who attempted or completed study activities. It is possible that these participants chose not to collect their blood sample after reading the instructions, or they never opened the DBS package with study materials. It is also possible that participants who reported suboptimal ART adherence did not want to provide a blood sample that would show a detectable VL. Third, the study population was recruited from a sample of men who successfully completed a 12-month Web-based intervention. Perhaps these participants are more likely to complete a study such as M-Spot compared with other populations. Different study participation rates may be observed when collecting DBS specimens from other populations. Fourth, we did not collect a calendar date for the most recent VL test on the parent survey, limiting our ability to accurately estimate the time between an individual's plasma VL test result and DBS VL test result.

As with most DBS studies, there is concern about the correlation between a DBS specimen and laboratory result from a VL test from a plasma sample collected in a clinical setting. Several studies [48-50] have documented the high correlation between VL measurements obtained from DBS samples and those obtained from plasma, as well as the stability of samples stored under different conditions and for different time frames. In addition, stability of HIV serological markers in samples collected using the HemaSpot device has been reported and compared with DBS samples collected using the traditional

Whatman 903 cards [51]. Similarly, studies assessing the performance of the Abbott Real-Time HIV-1 assay, used for this study, have also reported a high correlation between VL measurements from DBS and plasma samples, with 99.4% of cases differing by <1.0 log copies in one study [52], and a mean difference of 0.29 log copies in another [53]. The Abbott assay and extraction method have been updated and improved frequently; this study used the most up-to-date open mode protocol available from the manufacturer. Dize et al performed validation of DBS specimens collected using HemaSpot devices compared with plasma samples [54]. Concordance analysis showed 100% agreement between samples with VL ≥1000 copies/mL and 86% agreement between samples with VL <1000 copies/mL. Finally, we acknowledge the possibility that intracellular nucleic acid contribution at low levels of viremia may explain our DBS specimen laboratory results and the discordance between self-reported VL status and DBS specimen VL results. Other studies have reported false-positive rates ranging from 6% to 13% in which DBS samples yielded detectable VL, whereas the plasma sample had undetectable VL, with the discrepancy attributed to a possible contribution of intracellular RNA that might be present in white blood cells in whole blood [55-58]. However, it is unlikely that intracellular nucleic acid led to misclassification of VL results for participants who had high HIV VL results from their DBS specimen. Further research is needed to identify the extent to which intracellular nucleic acid influences VL results from DBS specimens collected using the HemaSpot-HF device, especially in those with low detectable HIV VL levels.

Conclusions

Despite these limitations, findings from this study highlight the feasibility and acceptability of HIV-1 RNA quantification of home-collected DBS samples from MSM living with HIV. Individuals with a history of suboptimal ART adherence and/or detectable viremia, such as those in this study, may benefit from at-home VL monitoring as a tool to augment engagement in HIV care. Home collection of DBS for VL could be utilized as a monitoring tool in between clinical visits for patients who struggle with adherence. Research on complementary systems of clinical care should be expanded and further studied, especially in the era of treatment as prevention.

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Conflicts of Interest

None declared.

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Abbreviations

ART: antiretroviral therapy
DBS: dried blood spot
DBS kit: HemaSpot-HF device
IRB: institutional review board
IQR: interquartile range
M-Spot: Mailed-Spot
MSM: men who have sex with men
VL: HIV-1 RNA viral load

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Original Paper

Viral Loads Within 6 Weeks After Diagnosis of HIV Infection in Early and Later Stages: Observational Study Using National Surveillance Data

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Abstract

Background: Early (including acute) HIV infection is associated with viral loads higher than those in later stages.

Objective: This study aimed to examine the association between acute infection and viral loads near the time of diagnosis using data reported to the US National HIV Surveillance System.

Methods: We analyzed data on infections diagnosed in 2012-2016 and reported through December 2017. Diagnosis and staging were based on the 2014 US surveillance case definition for HIV infection. We divided early HIV-1 infection (stage 0) into two subcategories. Subcategory 0α: a negative or indeterminate HIV-1 antibody test was ≤60 days after the first confirmed positive HIV-1 test or a negative or indeterminate antibody test or qualitative HIV-1 nucleic acid test (NAT) was ≤180 days before the first positive test, the latter being a NAT or detectable viral load. Subcategory 0β: a negative or indeterminate antibody or qualitative NAT was ≤180 days before the first positive test, the latter being an HIV antibody or antigen/antibody test. We compared median earliest viral loads for each stage and subcategory in each of the first 6 weeks after diagnosis using only the earliest viral load for each individual.

Results: Of 203,392 infections, 56.69% (115,297/203,392) were reported with a quantified earliest viral load within 6 weeks after diagnosis and criteria sufficient to determine the stage at diagnosis. Among 5081 infections at stage 0, the median earliest viral load fell from 694,000 copies/mL in week 1 to 125,022 in week 2 and 43,473 by week 6. Among 30,910 infections in stage 1, the median earliest viral load ranged 15,412-17,495. Among 42,784 infections in stage 2, the median viral load declined from 44,973 in week 1 to 38,497 in week 6. Among 36,522 infections in stage 3 (AIDS), the median viral load dropped from 205,862 in week 1 to 119,000 in week 6. The median earliest viral load in stage 0 subcategory 0α fell from 1,344,590 copies/mL in week 1 to 362,467 in week 2 and 47,320 in week 6, while that in subcategory 0β was 70,114 copies/mL in week 1 and then 32,033 to 44,067 in weeks 2-6. The median viral load in subcategory 0α was higher than that in subcategory 0β in each of the first 6 weeks after diagnosis (P<.001).

Conclusions: In the 1st week after diagnosis, viral loads in early infections are generally several times higher than those in later stages at diagnosis. By the 3rd week, however, most are lower than those in stage 3. High viral loads in early infection are much more common in subcategory 0α than in subcategory 0β, consistent with 0α comprising mostly acute infections and 0β comprising mostly postacute early infections. These findings may inform the prioritization of interventions for prevention.

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KEYWORDS

acute HIV infection; early HIV infection; primary HIV infection; HIV testing; viral load

Introduction

The 2014 revision of the US surveillance case definition for HIV infection added "stage 0" to its staging system to represent early infection (assumed to last about 6 months after the start of infection). HIV infections are classified in stage 0 if they have evidence of being early—negative or indeterminate HIV test results near the time of diagnosis. Otherwise, they are classified in the later stages—1, 2, or 3 (acquired immunodeficiency syndrome [AIDS]) [1]. Prompt recognition of infections in stage 0 can provide a critical opportunity to prevent transmission of HIV infection during acute (or primary) infection (part of stage 0). Acute infection is often associated with very high viral loads [2-7], which increase the risk of transmission [8]. Intervention would include antiretroviral treatment to suppress the viral load and the provision of "partner services," in which public health workers interview the patient to identify sex or needle-sharing partners in the past 12 months; locate the partners; and offer them HIV testing, counseling, and linkage to care, as appropriate [9,10]. If infected, such partners may also have early infection.

This analysis was intended to document the high viral loads that justify giving priority to stage 0 infections for intervention to prevent transmission. For that purpose, we compared median earliest viral loads by week in the first 6 weeks after diagnosis for each stage (0, 1, 2, or 3). Another objective was to demonstrate how HIV surveillance data could be used to distinguish between acute infections and other early HIV infections in stage 0, as the highest priority for intervention should be given to acute infections (expected to have the highest viral loads) rather than given equally to postacute early infections (with lower viral loads). To do that, we defined subcategories of stage 0 that approximate acute infection and postacute early infection and compared median viral loads among these two subcategories.

Methods

Data

We used data for the 203,392 HIV infections diagnosed during 2012-2016 and reported to the National HIV Surveillance System (NHSS) of the Centers for Disease Control and Prevention through December 2017 from the 50 US states, the District of Columbia, Puerto Rico, and the US Virgin Islands. In the software of the NHSS database, the stage at diagnosis can be automatically classified as stage 0 only for HIV infections diagnosed in or after 2014, when the definition of stage 0 was published [1]. For this analysis, however, we retroactively extended the application of the definition of stage 0 to infections diagnosed in 2012 and 2013 to increase the number of stage 0 diagnoses available for analysis.

We excluded the 24.03% (48,880/203,392) of infections for which the stage at diagnosis could not be determined. Their reported data did not include the negative or indeterminate HIV test results required to meet the criteria for stage 0 nor a CD4 T-lymphocyte test result or opportunistic illness diagnosis required to meet the criteria for stage 1, 2, or 3 within 3 months after diagnosis.

We assumed that specimens for earliest viral loads would generally have been collected before starting antiretroviral therapy to enable physicians to assess the effect of therapy by comparing subsequent viral loads with the baseline viral load. Therefore, to reveal the natural trend of viral loads before their suppression by antiretroviral drugs, we restricted our analysis to the viral load with the earliest specimen collection date within 6 weeks after diagnosis for each infection. This restriction removed another 32,047 infections from the analysis because they had no viral load within 6 weeks after diagnosis. The date when antiretroviral drugs were first received was reported for only 17.27% (21,157/122,465) of the remaining infections, but it preceded the date of the first viral load for 10.04% (2,125/21,157) of them. Therefore, we also excluded those cases in which the drug was known to have preceded the viral load to minimize the effects of antiretroviral drugs on the viral loads.

To try to avoid erroneous data on earliest viral loads, we excluded another 4711 cases in which the first viral load was reported to be undetectable or 0-19 copies/mL. Such low values would be unlikely in the absence of antiretroviral prophylaxis or therapy started on the basis of a diagnosis earlier than the date of the reported first positive HIV test. In addition, viral loads reported as 0-9 copies/mL may actually have been logarithmically transformed values that could not be compared with the untransformed values on which our analysis was based. Enumerated viral loads reported to be undetectable probably represented the lower limit of the test's ability to quantify the viral load rather than its actual value. We also excluded another 167 cases with viral loads for which no numerical value was reported. To calculate the number of days between the diagnosis date and viral load date accurately, we also excluded 165 cases in which data for one or both of these dates were incomplete (eg, missing the day component). The final analytic file had data on 115,297 HIV infections (each corresponding to the first viral load within 6 weeks after a diagnosis), representing 56.68% (115,297/203,392) of the total reported cases diagnosed in 2012-2017.

Definitions

Stage 0

The HIV surveillance case definition published in 2014 says that stage 0 may be recognized based on either testing history—"a negative or indeterminate HIV test…result within 180 days before the first confirmed positive HIV test result"—or a testing algorithm—"a sequence of tests performed as part of a laboratory testing algorithm that demonstrate the presence of HIV-specific viral markers such as…nucleic acid (RNA or DNA) 0-180 days before or after an antibody test that had a negative or indeterminate result" [1]. Unfortunately, this definition is impractical to apply strictly to NHSS data because

our data do not state whether multiple reported tests belong to the same diagnostic algorithm or are from unrelated testing events. Therefore, the definition of stage 0 used for our analysis of NHSS data is based only on the sequence of HIV test results, and not on whether they were intended to constitute a diagnostic algorithm. We classified the stage of disease at diagnosis as stage 0 based on any of the following possible sequences of positive (or reactive) and negative (or nonreactive) or indeterminate HIV test results (as shown in Figure 1):

A. (1) The first positive HIV test result was from an antibody or antigen/antibody test; (2) it was accompanied (on the same date) or followed within ≤60 days by a negative or indeterminate result from an HIV antibody test or the antibody component of a combination antigen/antibody test; and (3) a positive HIV-1 nucleic acid test (NAT, qualitative or viral load) result was within ≤180 days after (or on the same date as) the negative or indeterminate test.
B. (1) The first positive HIV test result was an HIV-1 NAT (and there was no positive antibody test on the same date) and (2) the NAT was accompanied or followed within ≤60 days by a negative or indeterminate result from an HIV antibody test or the antibody component of a combination antigen/antibody test (regardless of whether there was a later positive antibody test).
C. (1) The first positive HIV test result was from an antibody or antigen/antibody test; (2) it was accompanied or followed by a positive NAT; and (3) both positive tests were followed by (were not on the same date as) a negative or indeterminate result from an HIV antibody test or the antibody component of a combination antigen/antibody test that was within ≤60 days after the first positive test.
D. (1) The first positive HIV test result was from an HIV-1 NAT; (2) it was followed by (was not on the same date as) a positive result from an HIV antibody or antigen/antibody test; and (3) both positive tests were followed by a negative or indeterminate result from an HIV antibody test or the antibody component of a combination antigen/antibody test that was within ≤60 days after (not on the same date as) the first positive test (NAT) but that could have been on the same date as the second positive test (the antibody or antigen/antibody test).
E. (1) A negative result from an HIV-1 qualitative NAT or a negative or indeterminate result from an HIV antibody or antigen/antibody test was followed within ≤180 days by, and was not on the same date as, (2) the first positive HIV test result, which was from an HIV-1 NAT.
F. (1) A negative result from an HIV-1 qualitative NAT or a negative or indeterminate result from an HIV antibody or antigen/antibody test was followed within ≤180 days by, and was not on the same date as, (2) the first positive HIV test result, which was from an HIV antibody or antigen test that was confirmed by (3) a positive result from a second (supplemental) HIV test of a different (orthogonal) type.

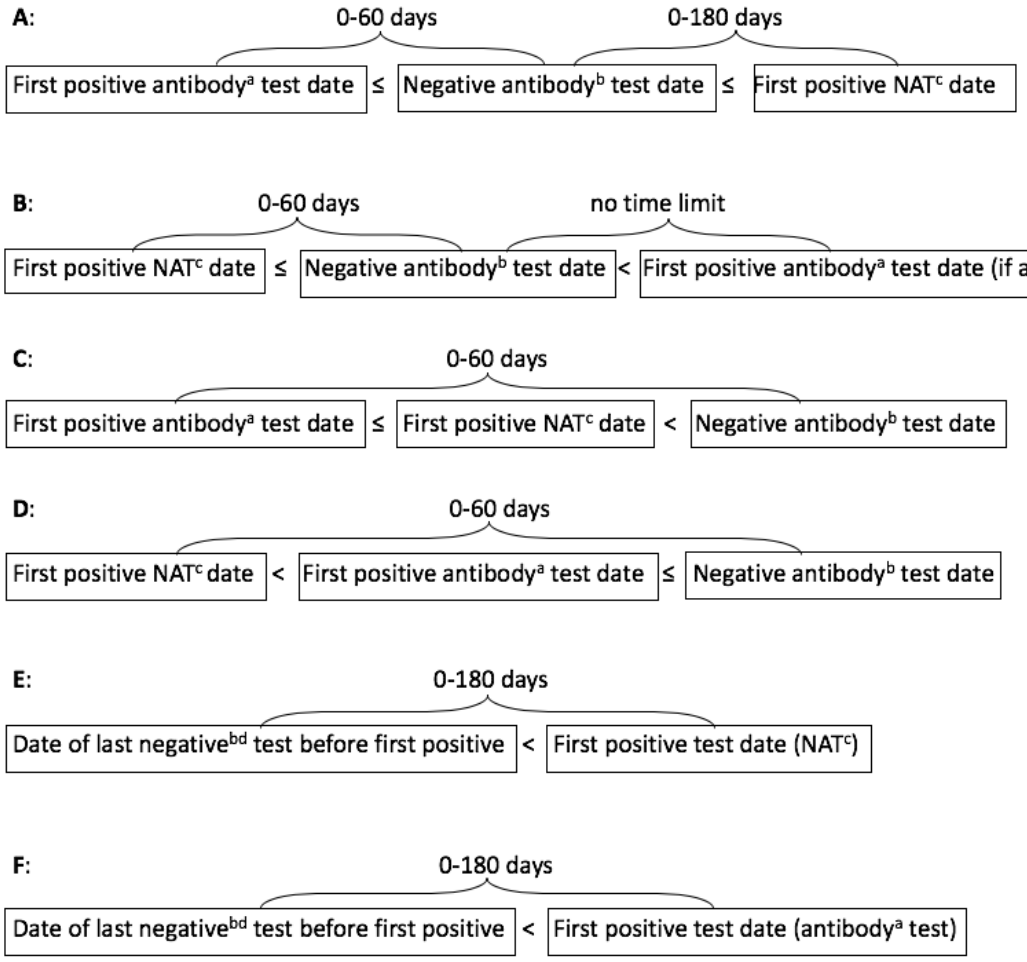
We defined preliminary subcategories of stage 0 (0A through 0F) based on each of the above sequences (A through F). Subcategory 0A includes infections recognized as acute based on results from a testing algorithm recommended by the Association of Public Health Laboratories and the US Centers for Disease Control and Prevention [11]. However, it also includes a small proportion of sequences that did not conform exactly to recommendations. For example, in a small percentage of those, the first positive result was from an antibody test that could detect only immunoglobulin G antibody, which would have been more appropriate as a supplemental test rather than the initial test. In others, the negative test result was from an antigen/antibody test that could detect both immunoglobulin M and immunoglobulin G antibodies, which would have been more appropriate as an initial test. Subcategory 0B includes infections recognized as acute based on results from a testing algorithm recommended for populations with a high incidence of HIV infection, in which a specimen for a pooled NAT is collected on the same date as the specimen for an initial HIV antibody immunoassay that had a negative result [12].

Subcategories 0C and 0D would have been the same as 0A and 0B, respectively, except that the negative or indeterminate antibody or antigen/antibody test follows both the positive NAT and the positive antibody or antigen/antibody test rather than preceding or being between them (Figure 1). Subcategories 0C and 0D seem not to fit the criteria for stage 0 in the published case definition [1] because their test sequences do not conform to any recommended algorithm and they do not fit a testing history of a negative result within 180 days before the first positive result. We included them in stage 0 for this analysis because we found them to be associated with high viral loads characteristic of acute infection.

Subcategories 0A through 0D are mutually exclusive, but their test sequences could overlap those of subcategories 0E or 0F in some cases. If there was such an overlap, we classified the cases in subcategories 0A through 0D rather than in 0E or 0F because the former are based on a more recent negative test result than the latter and therefore are more likely to represent acute infection. Subcategories 0E and 0F differ only by the fact that the first positive test in 0E was a NAT, while the first positive test in 0F was an antibody or antigen/antibody test. Since the interval between the negative or indeterminate test and the first positive test in 0E or 0F could be up to 180 days, these two tests would generally not belong to the same testing algorithm and most likely represent two separate testing events, of which the first received the interpretation that HIV infection was absent and the second that HIV was present.

We considered subcategories 0A through 0F as “preliminary” because, after our preliminary analysis showed that subcategories 0A through 0E were associated with high viral loads soon after diagnosis (Tables 3-5), we combined subcategories 0A through 0E into a larger subcategory named “0α” (assumed to approximate acute infection) and named the remainder (subcategory 0F) “0β” (assumed to consist mostly of postacute early infection).

Figure 1. Test sequences defining stage 0 preliminary subgroups. Superscripts are as follows: a) Positive "antibody" test results include positive results from the antigen component or the antibody component of combination antigen or antibody tests. b) "Negative antibody" test results include indeterminate results from supplemental immunoglobulin G–only supplemental antibody tests and negative results from antigen or antibody tests in which only the antibody component is negative or in which both the antigen and antibody components are negative. c) Positive nucleic acid tests (NATs) include qualitative and quantitative (viral load) tests. d) Negative NATs include only qualitative NATs.



For our analysis, an undetectable viral load before the first positive test result was not accepted as the negative HIV test result indicative of the earliness of the infection in subcategories 0E or 0F. An unpublished investigation (personal communication from Galang RR and Peters PJ, December 2014) found that such undetectable viral loads were not reliable evidence of early infection but were instead often due to therapy for established infections diagnosed on the basis of earlier test results that had not been reported to the surveillance system.

We did not classify the stage at diagnosis as stage 0 if a reported test result contradicted the first positive HIV test result or the negative or indeterminate HIV test result that would have been the indicator of earliness (ie, the contradictory test and the test that it contradicted were on same date and of the same type but had opposite results) because such contradictory results imply that one of them was erroneous. This happened in 10.4% (844/8077) of infections that would otherwise have met the criteria for stage 0 (including some that were excluded from our analysis for other reasons, eg, not having a reported viral load within 6 weeks after diagnosis); these were instead classified in other stages (1, 2, or 3) and kept in the analysis unless removed for other reasons described above.

The criteria for stage 0 took precedence over criteria for more advanced stages. If the criteria for stage 0 were not met, the stage at diagnosis was defined by the earliest criteria for stage 1, 2, or 3 met within 3 months after diagnosis of HIV infection. These criteria were based on a CD4 T-lymphocyte count or percentage indicative of stage 1, 2, or 3, or diagnosis of an opportunistic illness indicative of stage 3 [1]. If earliest criteria were met for different stages (other than stage 0) in the same month, the stage at diagnosis was selected as the most advanced of those stages.

Test Date

We defined a test date as the date on which the test specimen was collected. This could pertain to the dates of the positive and negative tests used for diagnosis of stage 0 or the date of the earliest viral load after or on the same date as the diagnostic tests. In some cases, the first viral load could function as a diagnostic test.

Diagnosis Date for HIV Infection

We defined the "diagnosis date" as the earliest date of objective evidence of HIV infection, selected from the earliest of the following 4 possible events: (1) the first positive HIV test (this was the earliest objective evidence for 96% of diagnoses; rarely

was it several days earlier than the confirmatory test date in a multitest algorithm); (2) the first diagnosis of an opportunistic illness indicative of stage 3; (3) the first CD4 T-lymphocyte count or percentage low enough to indicate stage 3; or (4) the first "clinical" diagnosis of HIV infection documented in a medical record but for which a prior positive HIV test result on which the diagnosis was based could not be found by surveillance staff (accounting for <1% of diagnoses). It should be borne in mind that, for infections not diagnosed in stage 0, the diagnosis date may be years after infection began, particularly for infections diagnosed in stage 3. Among all infections diagnosed in 2015, the estimated median interval from infection to diagnosis was 3 years [13].

Statistical Methods

Viral load data for each patient were unavailable for each week after diagnosis, as each individual was observed at only one point in time (the date of his earliest viral load) in whichever week it occurred. In aggregate, however, grouped by week after diagnosis, we assumed that these data would simulate a longitudinal series of weekly viral loads representative of what would have occurred in the average person in the study population if that individual had been followed over time. We calculated the median, 25th percentile, and 75th percentile for the earliest viral loads by week after diagnosis for each stage of disease at diagnosis and for each subcategory of stage 0. To assess the possible effect of unreported antiretroviral drugs on the speed of the decline in the viral load by week after diagnosis among all infections diagnosed in stage 0, we compared results for viral loads that had missing information on when antiretroviral drugs were started with results for viral loads reported to have been on or before the date when antiretroviral drugs were started (assumed not to have been affected by such drugs).

To test the statistical significance of differences between median viral loads in two different stages, we did pairwise two-sample Wilcoxon comparisons using PROC NPAR1WAY in SAS software, version 9.4 for Windows (SAS Institute, Inc, Cary, NC, USA). We used the Dwass, Steel, Critchlow-Fligner option to generate multiple comparisons (eg, 6 combinations of pairs from 4 categories [stages 0, 1, 2, and 3], or 10 combinations of pairs from 5 categories [stage-0 subcategories 0α and 0β and stages 1, 2, and 3]) for each family of comparisons (one family per week) [14]. We used Holm's method for stepwise adjustment of the significance threshold for each comparison to account for the number of comparisons in each family [15,16]. This adjustment was needed only if the *P* value was <.05 but ≥.001.

This analysis did not require approval by an institutional review board because it used only data reported to the NHSS by state or local public agencies as part of routine public health notifiable disease surveillance of HIV infection. The Centers for Disease Control and Prevention has determined that the collection of these data is not research as it is intended primarily for the purpose of disease control. In addition, the dissemination of the results of this analysis could not have any adverse effect on the subjects to whom the data pertain because the tabulations do not identify individuals.

Results

Among the 115,297 infections that remained in our analysis after we applied the exclusion criteria described above, the stage of disease at diagnosis was stage 0 for 4.40% (5081/115,297), stage 1 for 26.80% (30,910/115,297), stage 2 for 37.10% (42,784/115,297), and stage 3 for 31.70% (36,522/115,297). Among the infections in stage 0, the median earliest viral load fell from 694,000 copies/mL in week 1 to 125,022 in week 2 and 43,473 by week 6 (Table 1; Figure 2). In stage 1, the median earliest viral load alternated weekly between increasing and decreasing, ranging from a high of 17,495 copies/mL in week 2 to a low of 15,412 in week 5 (Table 1). In stage 2, the viral load declined from 44,973 copies/mL in week 1 to 38,497 in week 6 (Table 2). In stage 3, the viral load dropped from 205,862 copies/mL in week 1 to 167,297 in week 2 and 119,000 by week 6 (Table 2). In week 1, the median earliest viral load for diagnoses in stage 0 was much higher than that for diagnoses in stages 1, 2, or 3 (*P*<.001 for comparison of each pair of results), but by week 2, it did not differ significantly from that for diagnoses in stage 3 (*P*=.05), and by week 3, it had fallen below that for diagnoses in stage 3 (*P*<.001). The median viral load for diagnoses in stage 0 was higher than that for diagnoses in stage 2 in weeks 1-4 (*P*<.001) but did not differ from it in week 5 or 6 (*P*>.58).

Table 1. Median earliest viral load (in copies/mL) by week after diagnosis and stage of disease at diagnosis of HIV infection, for stages 0 and 1. (See Table 2 to compare with stages 2 and 3.)

Week	Stage 0			Stage 1		
	N	Median	25th-75th percentiles	N	Median	25th-75th percentiles
1st	2635	694,000	82,510-5,177,075	12,214	16,219	2,235-67,608
2nd	934	125,022	26,920-857,030	6476	17,495	3,335-55,845
3rd	629	70,886	16,113-289,407	4694	15,694	3,310-48,100
4th	408	55,734	16,898-210,577	3363	16,500	3,690-50,734
5th	277	52,067	10,500-168,526	2418	15,412	3,100-45,774
6th	198	43,473	11,890-119,960	1745	16,649	3,347-46,236

Figure 2. Median earliest viral load (in copies/mL) by week after diagnosis and stage of disease at diagnosis of HIV infection, comparing stages 0, 1, 2, and 3 and stage 0 subcategories 0α (0A+0B+0C+0D+0E) and 0β (0F).

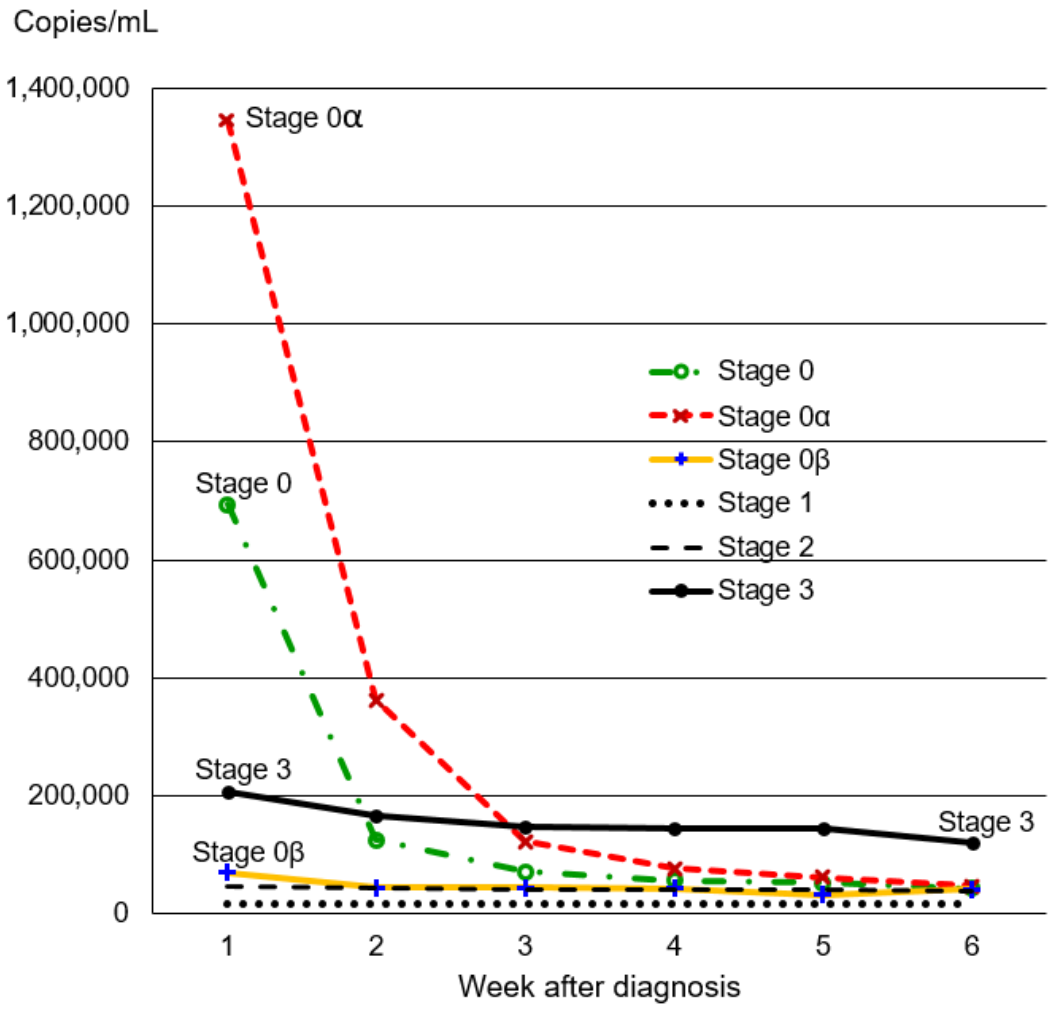


Table 2. Median earliest viral load (in copies/mL) by week after diagnosis and stage of disease at diagnosis of HIV infection, for stages 2 and 3. See Table 1 to compare with stages 0 and 1.

Week	Stage 2			Stage 3		
	N	Median	25th-75th percentiles	N	Median	25th-75th percentiles
1st	17,098	44,973	13,200-137,765	20,094	205,862	75,700-537,471
2nd	8968	42,892	14,400-107,936	6234	167,297	63,386-456,000
3rd	6357	39,800	13,994-99,185	4091	146,700	55,150-393,724
4th	4523	40,045	13,670-96,817	2726	144,840	53,085-405,503
5th	3326	41,549	14,544-101,780	1932	143,560	49,038-386,008
6th	2512	38,497	14,370-86,818	1445	119,000	44,620-359,040

Table 3. Median earliest viral load (in copies/mL) by week after diagnosis and stage of disease at diagnosis of HIV infection, for stage 0 preliminary subcategories 0A and 0B.

Week	Subcategory 0A			Subcategory 0B		
	N	Median	25^{th}-75^{th} percentiles	N	Median	25^{th}-75^{th} percentiles
1^{st}	1,083	1,258,925	238,487-7,413,102	408	1,307,793	210,000-9,768,809
2^{nd}	426	338,888	46,539-1,610,000	68	350,482	55,646-2,184,015
3^{rd}-6^{th}	715	77,380	16,847-299,330	89	104,500	32,451-347,555

Table 4. Median earliest viral load (in copies/mL) by week after diagnosis and stage of disease at diagnosis of HIV infection, for stage 0 preliminary subcategories 0C and 0D.

Week	Subcategory 0C			Subcategory 0D		
	N	Median	25th-75th percentiles	N	Median	25th-75th percentiles
1^{st}	187	1,780,000	456,000-7,500,000	125	2,160,000	106,000-8,426,138
2^{nd}	76	635,690	77,402-4,393,963	11	1,778,279	155,054-4,579,249
3^{rd}-6^{th}	71	75,300	11,000-550,398	24	64,294	22,292-237,806

Table 5. Median earliest viral load (in copies/mL) by week after diagnosis and stage of disease at diagnosis of HIV infection, for stage 0 preliminary subcategories 0E and 0F.

Week	Subcategory 0E			Subcategory 0F		
	N	Median	25th-75th percentiles	N	Median	25^{th}-75^{th} percentiles
1st	224	1,346,776	139,122-5,934,603	608	70,114	11,233-271,000
2nd	17	294,798	60,656-756,500	336	44,467	8,456-125,087
3rd-6th	16	135,540	46,915-530,205	597	42,000	11,040-114,000

In the first week after diagnosis, infections in stage 0 preliminary subcategories 0A, 0B, 0C, 0D, and 0E had median viral loads exceeding 1.2 million copies/mL compared with only 70,114 copies/mL for infections in subcategory 0F (Tables 3-5). In week 2, median viral loads for subcategories 0A through 0E remained higher (>290,000 copies/mL) than the 44,467 copies/mL for subcategory 0F, as well as higher than the median viral loads for stages 1 (17,495), 2 (42,892), and 3 (167,297; P<.001 for each of these comparisons). Subcategories 0E and 0F were both defined by a negative or indeterminate test result within 180 days before the first positive test result (a positive NAT for 0E and a positive antibody test for 0F), but their earliest viral loads in the first 2 weeks after diagnosis differed greatly (Table 5). This difference may be explained in part by the interval between the first positive test result and the preceding negative or indeterminate test result being short (1 or 2 weeks) for a much greater proportion of infections in subcategory 0E (130/257, 51%) than in subcategory 0F (139/1541, 9.0%) and by the median value for this interval being only 9 days for subcategory 0E while being 98 days for subcategory 0F. Due to the small number of observations per week after week 2 for subcategories 0D and 0E, we combined weeks 3 through 6 into a single time period in Tables 3-5. Because of the similarity of findings for preliminary subcategories 0A through 0E evident in Tables 3-5, we combined them into a larger subcategory named "0α" for further analysis by week and renamed subcategory 0F as "0β" (Table 6).

Median viral loads in stage 0 subcategory 0α were higher than those in subcategory 0β in each of the first 4 weeks after diagnosis (P<.001 for weeks 1, 2, and 3 and P=.008 for week 4, significant compared to a Holm-adjusted threshold of P=.02) but did not differ significantly from them in weeks 5 or 6 (P>.39; Table 6). The median viral load for stage 0 subcategory 0α was also much higher than that for stage 3 in weeks 1 and 2 (P<.001) but did not differ from it in week 3 (P=.09) and was lower than that for stage 3 in weeks 4-6 (P<.001; Figure 2). Median viral loads for subcategory 0α were higher than those for stage 2 in weeks 1 through 4 (P<.001) but did not differ from them in weeks 5 or 6 (P>.14). The median viral load for subcategory 0β was greater than that for stage 2 in week 1 (P<.001) but did not differ from it in later weeks (P>.88). In every week, the median viral load for stage 0 subcategory 0β was greater than that for stage 1, and the median viral loads for stages 1, 2, and 3 differed significantly from one another in the same direction as the order of their names (ie, 1<2<3; P<.001).

Table 6. Median earliest viral load (in copies/mL) by week after diagnosis and stage of disease at diagnosis of HIV infection, comparing stage 0 subcategory 0α with subcategory 0β.

Week	Subcategory 0α (0A+0B+0C+0D+0E)			Subcategory 0β (0F)		
	N	Median	25th-75th percentiles	N	Median	25th-75th percentiles
1st	2027	1,344,590	228,000-7,630,000	608	70,114	11,233-271,000
2nd	598	362,467	50,721-1,905,461	336	44,467	8,456-125,087
3rd	375	122,970	21,600-413,431	254	43,729	9,460-122,825
4th	243	77,100	19,570-301,190	165	42,300	13,900-131,377
5th	177	61,414	12,600-201,000	100	32,033	7,084-112,520
6th	120	47,320	8,628-171,652	78	41,606	19,120-87,670

Although high viral loads were much more common among infections diagnosed in subcategory 0α than in subcategory 0β or stages 1, 2, or 3, a small percentage of infections in subcategory 0β and other stages did have high viral loads. Earliest viral loads exceeding 500,000 copies/mL occurred in 11.6% (179/1541) of the infections in subcategory 0β, 4.20% (1310/30,910) of those in stage 1, 7.10% (3039/42,784) of those in stage 2, and 24.17% (8831/36,522) of those in stage 3 compared with 50.0% (1754/3540) of those in subcategory 0α. Among infections in subcategory 0β having a viral load of >500,000 copies/mL, the interval between the first positive test and the last prior negative test ranged from 1 to 176 days (with a median of 66 days); it could have been up to 180 days by the definition of 0β.

Among the 3540 infections diagnosed in subcategory 0α, the decline in the median earliest viral loads in the subgroup of 2834 cases with missing information on when antiretroviral drugs were started was similar to that in the subgroup of 706 cases in which antiretroviral drugs were started no earlier than the date on which the viral load specimen was collected. In each of these subgroups, the median earliest viral load decreased by more than half from week 1 to week 2 and did so again from week 2 to week 3. By week 4, the median viral load in each subgroup had decreased by >95% compared with its value for week 1 (from 1,298,413 to 41,687 copies/mL among the 2834 cases with missing antiretroviral information and from 1,485,669 to 73,809 copies/mL among the 706 cases reported to have started antiretroviral drugs no earlier than the viral load date).

Discussion

Principal Findings

Our findings confirmed that early HIV infection, represented by stage 0, is associated with viral loads higher than those in infections diagnosed in later stages of the disease. However, this was true mainly in the first week after diagnosis, when the median viral load among infections diagnosed in stage 0 was more than three times than that among infections diagnosed in stage 3.

We also found that stage 0 preliminary subcategories 0A, 0B, 0C, 0D, and 0E, which we combined as subcategory 0α, were associated with viral loads higher than those in preliminary subcategory 0F, which we renamed as subcategory 0β (stage 0 = 0α + 0β). This difference should be expected because most of 0α (preliminary subcategories 0A, 0B, 0C, and 0D) is limited to diagnoses in which a negative or indeterminate antibody test result indicative of the earliness of infection was either on the same date as or ≤60 days after the first positive HIV test date, and the median interval between the first positive HIV test and the last prior negative test was much shorter for infections in preliminary subcategory 0E (9 days) than for those in subcategory 0F (98 days). Thus, a negative or indeterminate test result was closer in time to viral loads in the first week after diagnosis for most infections in subcategory 0α than it was for most infections in subcategory 0β. This allowed most infections in subcategory 0β to have enough time for complete seroconversion and a decline in the viral load before it was first measured. This difference between subcategories 0α and 0β could justify more urgent intervention to suppress the viral load and to provide partner services to prevent transmission if infections are diagnosed in subcategory 0α rather than in subcategory 0β. If so, the NHSS software should be upgraded to distinguish automatically between stage 0 subcategories 0α and 0β to help health departments to account for this difference when they prioritize prevention efforts.

On the other hand, 11.6% (179/1541) of infections in subcategory 0β had viral loads >500,000 copies/mL, suggesting that they might be acute infections. This happened despite an interval of as long as 176 days between the first positive HIV test and the last prior negative test because the infection could have started long after that last negative test and much nearer to the first positive test date. In addition, a small percentage of infections in stages 1 and 2 had viral loads exceeding 500,000 copies/mL. These might actually have been acute infections that were misclassified in stages 1 or 2 because they were missing negative or indeterminate HIV test results required to be classified in stage 0. Therefore, when deciding which infections should receive the highest priority for prevention of transmission, consideration should be given not only to whether the criteria are met for stage 0 subcategory 0α but also to whether other evidence, such as a high viral load near the time of diagnosis, suggests acute infection.

If the restriction of our analysis to each patient's earliest detectable viral load succeeded in excluding viral loads influenced by antiretroviral drugs, then our findings may accurately reflect the natural trend of viral loads before

suppression by drugs. Our success in excluding the influence of antiretroviral drugs is suggested by the similarity of the decline in median earliest viral loads in the subgroup of subcategory 0α in which antiretroviral therapy was reported to have started no earlier than the viral load specimen collection date (when the earliest viral load was assumed not to have been affected by antiretroviral drugs) and those in the larger subgroup with missing information about antiretroviral drugs. It is also consistent with the similarity of the median viral loads we found for subcategory 0α and those found in a cohort of 19 untreated high-risk persons in Thailand [17]. In that cohort, the median viral load peaked at about 2,500,000 copies/mL in week 3 after the diagnosis of acute infection, dropped to 63,000 copies/mL in week 6, and remained at about the same level up to 144 weeks later in the absence of treatment. Similarly, in our study, the median earliest viral loads for subcategory 0α dropped from about 1,250,000 copies/mL in week 1 to about 40,000 copies/mL in week 6 after diagnosis. In contrast, our findings for subcategory 0α differed from the lower viral loads found in a cohort of 71 persons who received antiretroviral therapy promptly after the diagnosis of acute infection, in which the median viral load peaked at about 500,000 copies/mL in week 2 and dropped to about 2,500 copies/mL in week 4 and to <100 copies/mL after week 12 [17]. If our findings reflect viral loads in the absence of antiretroviral therapy, then they imply that the interval after diagnosis of acute HIV infection in which most viral loads exceed 500,000 copies/mL lasts <2 weeks. Thus, antiretroviral therapy to suppress the high viral loads of acute infection may be too late to make much difference if not started very shortly after diagnosis. By the third week after diagnosis, the viral load would probably have spontaneously declined to a level similar to that found in stage 2.

Our analysis was intended to assess the extent to which early infections have extremely high viral loads, as had been reported among acute infections because such high viral loads demand urgent intervention to prevent transmission. However, such intervention in early infection should perhaps receive high priority even after the acute phase, when the viral load has declined to a more stable lower level, as some studies suggest that the viruses in early infections may be more infectious than those in later infections with similar viral loads. This may be due to a partial immune response that develops in older infections, which might favor viruses having mutations that resist the immune response but at the expense of reducing their transmissibility [18-20]. In addition, even if an infection is no longer acute by the time of diagnosis, a diagnosis in stage 0 implies that the infection was recently acute and the viral load was therefore probably very high (even if only briefly), so transmission to recent sex partners would be more likely than if the infection had been diagnosed in a later stage. Therefore, such postacute early infections should also receive high priority for partner services. Another reason to give priority to intervention in stage 0, even after viral loads have declined, is that treatment of HIV infection within 6 months after the start of infection (approximately the time frame of stage 0) could reduce the patient's risk of morbidity and mortality. Such early treatment is associated with a smaller HIV reservoir size, lower levels of immune activation, and a higher probability of restoration of CD4 T-lymphocyte counts to normal levels [17,21-25].

Limitations

Our analysis was limited by its dependence on the negative or indeterminate HIV test results needed to meet criteria for stage 0 being reported by health departments to the NHSS database at the Centers for Disease Control and Prevention. Health departments may be unable to report these results to the NHSS if laboratories and health care providers do not report them to health departments. It may also be impossible for health care providers to recognize most early HIV infections because most HIV-infected patients may not present themselves for diagnostic evaluation until after complete seroconversion (when HIV tests would no longer have negative or indeterminate results) and because even patients who arrive during acute HIV infection may not be tested for it until after seroconversion if physicians do not suspect it as its symptoms are nonspecific. Early infections may then be misclassified as later infections, including some as stage 3 (AIDS) because low CD4 T-lymphocyte counts and opportunistic illnesses meeting criteria for stage 3 sometimes occur transiently in acute infection [26,27].

The stage of HIV disease at diagnosis found in our analysis depended on the frequency with which persons were tested for HIV infection, which can be estimated from the interval between HIV tests before diagnosis, based on data collected after diagnosis. Among the 6.94% (14,128/203,392) of all persons reported with HIV infection who had at least one reported negative HIV test result >28 days before diagnosis (implying it was from a prior testing event rather than part of a multitest algorithm on which a diagnosis of acute infection was based), the median interval between successive tests (calculated from the last 1-6 negative tests before diagnosis or between the diagnosis date and the last prior negative test) increased as the stage at diagnosis became more advanced. It rose from 121 days for stage 0, to 406 days for stage 1, to 533 days for stage 2, and to 1,098 days for stage 3 (P<.001 Wilcoxon test for each pair of stages compared). The longer intertest intervals, leading to diagnostic delays, may reflect less access to and use of the health care system.

The wide range between the 25th and 75th percentiles of the earliest viral loads for each stage and week after diagnosis (Tables 1 and 2) to some extent may be due to misclassification of the stage of disease "at diagnosis." Classification in stages 1, 2, or 3 could have been based on a CD4 count specimen obtained up to 3 months (16 weeks if just under 4 months) after diagnosis, during which time the CD4 count level could have changed greatly from what it was on the exact date of diagnosis or the earliest viral load. Among infections diagnosed in stage 0, the wide range of earliest viral loads could have been due in part to differences in the interval between the start of infection and the diagnosis date, during which viral loads could have risen from low to high levels and then fallen back.

Our analysis was also limited by the fact that data from the NHSS are incomplete (eg, missing the day component of some dates, some test results, information about antiretroviral drugs) and sometimes of questionable quality (eg, contradictory test results). We compensated for these limitations in NHSS data

by cleaning them in various ways, such as by excluding observations with incomplete dates or supposedly earliest viral loads that were reported to be undetectable or extremely low (0-19 copies/mL) and excluding those cases from stage 0 that had contradictory results (positive and negative) from apparently the same type of test on the same date. Even after the exclusion of these observations, our use of NHSS data brought the advantage of a much larger number of observations than could have been obtained from a study limited to patients receiving care from a small number of providers.

The final study population of 115,297 persons, which accounted for 56.7% of the 203,392 US residents reported with HIV infection diagnosed during 2012-2016, may not have been representative of all US residents because its demographic and other distributions differed significantly ($P<.001$, chi-square test) from those of the 88,095 persons excluded from the study population. In the study population, non-Hispanic whites were more common (32,447/115,297, 28.14% versus 20,534/88,095, 23.30%), non-Hispanic blacks were less common (46,821/115,297, 40.60% versus 41,214/88,095, 46.78%), persons aged >35 years at diagnosis were more common (52,334/115,297, 45.40% versus 36,550/88,095, 41.48%), the proportion residing in the Southern US region was lower (54,419/115,297, 47.19% versus 46,917/88,095, 53.25%), the proportion for which the transmission category was "men who had sex with men" was higher (66,009/115,297, 57.25% versus 46,411/88,095, 52.68%), the proportion reported with no identified HIV risk factor was lower (22,908/115,297, 19.86% versus 20,684/88,095, 23.47%), and the proportion whose infection was diagnosed after 2014 was higher (48,298/115,297, 41.89% versus 32,114/88,095, 36.45%). However, these differences between the included and excluded populations do not mean that our findings about stage-specific trends in viral loads in the first 6 weeks after diagnosis were invalid or that we would not have found similar trends among excluded persons if the missing data on test results and test dates that was the reason for excluding them had been available.

We interpreted the decreasing trends in earliest viral loads by week after diagnosis as if they represented results for individuals followed weekly in the absence of therapy, but actually each individual was observed at only one point in time (the date of his earliest viral load). Longitudinal data on weekly viral loads for individuals who were not receiving antiretroviral drugs would have provided a scientifically sounder basis for analyzing viral load trends during the first several weeks after diagnosis, but such a study would not have been practical or ethically feasible, as current treatment guidelines recommend starting therapy soon after diagnosis [28].

Conclusions

In summary, we confirmed that viral loads among infections in early infection (stage 0) are generally several times higher than those in later stages at diagnosis, particularly during the first week after diagnosis. By the 4th week, however, they are generally lower than those in stage 3. Viral loads are also higher for subcategory 0α of stage 0 than for subcategory 0β in the first 4 weeks after diagnosis. These findings may be useful in allocating prevention resources by indicating which infections should receive the highest priority for urgent intervention. Where health departments do not have the resources to intervene immediately for all persons with a new diagnosis of HIV infection to ensure linkage to care, counseling to prevent transmission, and partner services, they should give higher priority to those with infections diagnosed in stage 0, especially those in subcategory 0α or known to have recently had a high viral load, and should try to do so within the first 2 weeks after diagnosis.

Conflicts of Interest

None declared.

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Abbreviations

HIV: human immunodeficiency virus
NAT: nucleic acid test
NHSS: National HIV Surveillance System

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Original Paper

An Online Support Group Intervention for Adolescents Living with HIV in Nigeria: A Pre-Post Test Study

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Abstract

Background: Adolescents living with HIV (ALHIVs) enrolled in HIV treatment services experience greater loss to follow-up and suboptimal adherence than other age groups. HIV-related stigma, disclosure-related issues, lack of social support, and limited HIV knowledge impede adherence to antiretroviral therapy (ART) and retention in HIV services. The 90-90-90 goals for ALHIVs will only be met through strategies targeted to meet their specific needs.

Objectives: We aimed to evaluate the feasibility of implementing a social media-based intervention to improve HIV knowledge, social support, ART adherence, and retention among ALHIV aged 15-19 years on ART in Nigeria.

Methods: We conducted a single-group pre-post test study from June 2017 to January 2018. We adapted an existing support group curriculum and delivered it through trained facilitators in 5 support groups by using Facebook groups. This pilot intervention included five 1-week sessions. We conducted structured interviews with participants before and after the intervention, extracted clinical data, and documented intervention implementation and participation. In-depth interviews were conducted with a subset of participants at study completion. Quantitative data from structured interviews and group participation data were summarized descriptively, and qualitative data were coded and summarized.

Results: A total of 41 ALHIV enrolled in the study. At baseline, 93% of participants reported existing phone access; 65% used the internet, and 64% were Facebook users. In addition, 37 participants completed the 5-session intervention, 32 actively posted comments in at least one session online, and at least half commented in each of the 5 sessions. Facilitators delivered most sessions as intended and on-time. Participants were enthusiastic about the intervention. Aspects of the intervention liked most by participants included interacting with other ALHIVs; learning about HIV; and sharing questions, experiences, and fears. The key recommendations were to include larger support groups and encourage more group interaction. Specific recommendations on various intervention components were made to improve the intervention.

Conclusions: This novel intervention was feasible to implement in a predominantly suburban and rural Nigerian setting. Social media may be leveraged to provide much-needed information and social support on platforms accessible and familiar to many people, even in resource-constrained communities. Our findings have been incorporated into the intervention, and an outcome study is underway.

Trial Registration: ClinicalTrials.gov NCT03076996; https://clinicaltrials.gov/ct2/show/NCT03076996 (Archived by WebCite at http://www.webcitation.org/73oCCEBBC).

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KEYWORDS

adolescents; digital health intervention; HIV care continuum; social support

Introduction

Despite important gaps in our understanding of the HIV epidemic among adolescents (age, 10-19 years), available data indicate that this age group experiences high rates of new HIV infection, has less access to treatment, and is more likely to discontinue treatment and die from HIV-related causes than other age groups [1,2]. More than 80% of adolescents living with HIV (ALHIVs) are in sub-Saharan Africa, where, despite considerable progress, treatment coverage remains challenging: By 2016, less than 50% of ALHIVs received treatment [1-3]. Between 2010 and 2016, HIV-related mortality among adolescents decreased by 5% globally and 14% in Eastern and Southern Africa; however, in Western and Central Africa, the related mortality increased by 15% [2].

In 2016, nearly 50% of HIV-related deaths among adolescents in Western and Central Africa occurred in Nigeria [2]. One contributing factor to the high mortality may be poor treatment retention among ALHIVs. A 2016 study of youth (age, 14-24 years) initiating antiretroviral therapy (ART) in Nigeria found that they were less likely to remain in treatment at 12 months (46% vs 53%) and more likely to experience treatment disruptions (>3 months between clinic visits) in their first year on ART than older adults (relative risk=1.15, *P*=.008) [4].

Fear of stigma or disclosure, lack of social support, and limited knowledge about the disease, compounded by the physical, social, and psychological changes of adolescence, create numerous challenges to successful treatment [5-10]. For example, adolescence is a time when relationships outside of the immediate family, such as those with peers, become very important [11]; however, because of HIV-related stigma and discrimination, ALHIVs rarely disclose their status to their peers for fear of losing them, which can negatively impact their psychosocial well-being and treatment [12-13].

Evidence of effective interventions to improve treatment outcomes among ALHIVs, particularly in low- and middle-income countries, is limited [14-15]. ALHIVs are also less likely than adults or younger children to be targeted with interventions to improve health outcomes [14,15]; however, some intervention strategies designed for adults may be effective for ALHIVs. Emerging evidence supports group counseling and structured support groups as effective ways to improve adherence and retention among adults [16-21]. Digital health interventions such as mobile phone reminders improved adherence among adults in some low- and middle-income countries [22-27]. Two recent studies targeting youth in South Africa and the United States demonstrated that online social network interventions could be acceptable and feasible in this population [28-29].

According to a 2014 survey, 89% of Nigerians aged ≥ 18 years owned a mobile phone [30]. A 2012 study in Nigeria found that more than half of the females aged 12-30 years owned a phone, and almost all who did not own a mobile phone had access to one [31]. The rapid increase in mobile phone use in Nigeria indicates the potential of digital health strategies to help meet the support needs of ALHIVs.

In this study, we aimed to develop and test the feasibility and acceptability of a structured support group intervention—SMART (Social Media to promote Adherence and Retention in Treatment) Connections—which is delivered through a social media platform to improve retention in HIV health services and ART adherence among ALHIVs aged 15-19 years in periurban southern Nigeria.

Methods

Design

We conducted a mixed-methods, single-group, pre-post test study from June 2017 to January 2018. Participants were recruited from 3 health facilities in Akwa Ibom State and enrolled to receive 5 intervention sessions [32]. Data were collected through face-to-face interviews using a structured questionnaire at baseline and endpoint. In-depth interviews (IDIs) with a subset of purposively selected participants were conducted at endpoint and stratified by participation level. Participation data were collected using a Facebook group analytics tool [33]. The FHI 360 Protection of Human Subjects Committee, Durham, North Carolina, and the University of Uyo Teaching Hospital Ethics Committee Uyo, Akwa Ibom State, Nigeria, approved this study. Written informed consent was obtained from adult participants aged ≥18 years. Written parental permission and adolescent assent were obtained from participants aged 15-17 years.

SMART Connections: Development and Description

SMART Connections was designed to promote ART adherence and retention in HIV services by leveraging informational, emotional, and network dimensions of social support. Content was adapted from sessions of the Positive Connections: Leading Information and Support Groups for Adolescents Living with HIV guide, to be delivered online through “secret” Facebook groups [34]. Secret Facebook groups limit membership and access to those invited and added by a group administrator. Content in secret Facebook groups can be seen only by members. These groups cannot be found through online search engines and do not appear on Facebook users’ timelines; therefore, others who are not part of the group cannot determine whether a person is a member of a secret group [35].

Intervention components included informational messages and moderated group discussions, and 5 of 14 Positive Connections sessions were included in this study: Understanding HIV; Disclosure and Developing Trust in Relationships; Treatment and Adherence; Nutrition and Health; and Sex and Relationships. Sessions included activities for the facilitators

to post and subsequently lead discussions. Within each session, the activities included the following: At a glance, to introduce the topic of the week (Figure 1); word of the week, to define one key concept for the topic (Figure 2); cartoons, to tell a story related to the topic (Figure 3); key messages, to deliver important information; quizzes, to assess participants' knowledge and stimulate discussion; and group discussions moderated by facilitators. Four facilitators, recruited from existing community-based organizations and previously trained to lead in-person support groups for people living with HIV, received a 1-week training on the intervention.

Study support groups began with an initial, in-person meeting during which participants met each other and the facilitator. The facilitator described the intervention and the group agreed upon ground rules for interactions, emphasizing the need to maintain confidentiality for group interactions. All participants received a basic mobile phone (also known as a feature phone) that could access Facebook, regardless of current phone ownership, because our primary interest was to determine whether the intervention could be implemented as designed and if participants would engage in it, given the opportunity. Participants selected the cellular network on which the phone was registered and were allowed to keep the phones at the end of the study. Each participant received 1000 Naira (USD 3.33) of data each month to facilitate participation, corresponding to 1.5-2 gigabytes of data monthly, depending on the network provider. This amount of data translates roughly to 300-400 social media posts with photos [36].

Sample Size and Sampling Design

We aimed to enroll 40-50 ALHIVs to form 5 support groups of 8-10 individuals. Eligibility criteria for ALHIVs for inclusion in the study were age, 15-19 years; on ART for >6 months; and basic literacy to participate in online chats. Literacy was assessed by data collectors during eligibility screening by asking the participant to read aloud three short sentences from the intervention content. If the data collector determined that the participant could read all or most of the sentences, the person was deemed eligible. Participants who could not read at all or struggled with all three sentences were deemed ineligible. ALHIVs who planned to move from the area before the end of the study, were enrolled in an in-person support group, were enrolled in another HIV-related research study, or were critically or severely ill at enrollment were excluded from the study.

Eligible participants were sequentially recruited during clinic visits. Additionally, participants were identified from medical records by a clinic staff and contacted by telephone to tell them about the study and, if interested, to come to the facility to learn more about the study. IDIs were conducted for 8 participants with moderate to high active participation and 8 participants with no to low active participation at the study endpoint.

Measures

We collected demographic information of participants (sex, age, relationship status, education, occupation, and religion) and their HIV infection (date of diagnosis, date of start of ART, disclosure to others, viral load, and CD4 [cluster of differentiation 4] results). We also collected data on preintervention access to mobile phones, the internet, and experience with social media.

We measured intervention implementation and participation using Grytics software [33]. To measure fidelity, we determined if intervention activities occurred within 1 week of when they were scheduled and the proportion of scheduled activities completed. In addition, we measured if and how participants participated in each scheduled activity. Group members could participate in several ways: commenting on a scheduled post, "liking" or "reacting" to a post or comment, making a new post, or commenting on or reacting to others' posts. IDIs explored participants' experiences with the intervention.

Data Analysis

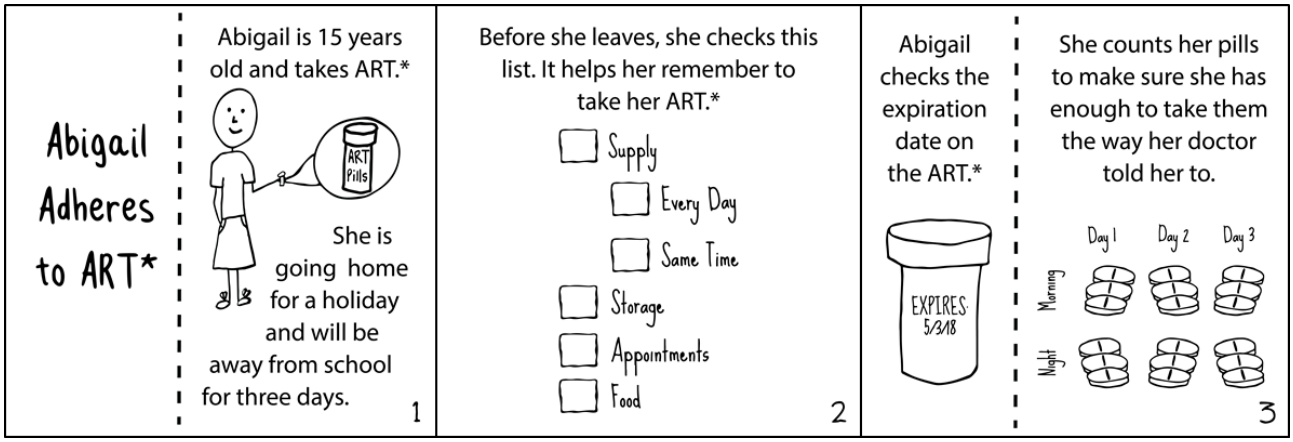
Quantitative data were analyzed descriptively and independently verified by a second analyst. For participation data, posts (original message) and comments (replies to a post) were equally weighted and each assigned a value of 1. Participation was categorized into approximate quartiles of total posts over the 5 sessions: none to very low (0-5 total posts), low (6-20 posts), moderate (21-50 posts), and high (≥51 posts).

IDIs were audio recorded and transcribed into English. Some IDIs were conducted in local languages and then simultaneously transcribed and translated. Qualitative data were analyzed by an applied thematic approach using NVivo 11 [37,38]. A codebook was created on the basis of the interview guide, and emergent thematic codes were added during analysis. Two analysts coded the transcripts and checked 12% of the transcripts for intercoder reliability. Summary memos documented overall themes related to the study objectives.

Figure 1. At a glance. *ART: antiretroviral therapy.

Figure 2. Word of the week.

Figure 3. Sample cartoon. *ART: antiretroviral therapy.



Results

A total of 41 adolescents enrolled in the study and completed a baseline interview, of whom 38 started the intervention and 35 completed the endpoint questionnaire. A flow chart describing the identification, enrollment, and follow-up of participants is presented in Figure 4.

Several individuals initially deemed eligible according to clinical records were later found to be ineligible due to incorrect age information in their medical records. Of those confirmed to meet eligibility criteria, 13 parents or guardians refused to allow their child to participate, 5 of whom stated they had not yet disclosed their child's HIV status to him or her.

Participants were nearly equally divided by sex (Table 1). About half of the participants were enrolled in school, mostly in secondary school, and one-quarter were employed. All participants had a home or primary residence. Most participants had been on ART for >4 years; 90% (37 of 41) had at least one CD4 cell count test recorded in their medical record, but only 73% (30 of 41) had a viral load test recorded in their medical record (Table 1). Among those with a recorded viral load, half were virally suppressed (Table 1). All participants who were not virally suppressed had viral loads >5000 copies/mL (data not shown).

Figure 4. Study flow chart. *ALHIV: adolescent living with HIV. **In 5 cases, the guardians refused to let the child participate because they had not yet disclosed their child's HIV status to him or her. ***One participant did not complete the endpoint structured interview, but completed the in-depth interview.

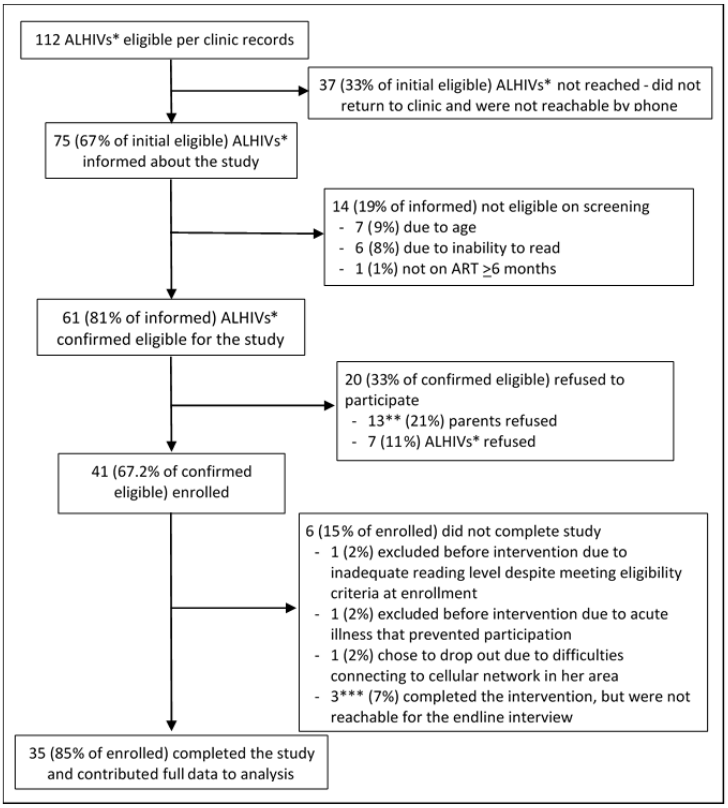


Table 1. Participant characteristics at baseline.

Characteristic (N=41)	Value
Sex, n (%)	
Female	22 (53)
Male	19 (46)
Age (years), median (range)	17 (15-19)
Currently employed, n (%)	11 (26)
Education, n (%)	
Currently enrolled in secondary school	18 (43)
Currently enrolled in postsecondary school	2 (4)
Not currently enrolled, completed secondary school	15 (36)
Not currently enrolled, completed some secondary school	6 (14)
Among those in school, location of residence during school (n=20), n (%)	
Live at home	19 (95)
Boarding school	0 (0)
With a friend's family	1 (5)
Has a primary household, n (%)	41 (100)
Religion, n (%)	
Christian denomination	41 (100)
Time on antiretroviral therapy[a] (years), median (range)	4.0 (0.5-11.0)
CD4[b] cell count at last test (cells/μl)[c], median (range)	414 (16-957)
Viral load at last test[d], n (%)	
Suppressed viral load (<1000 copies/mL)	15 (50)
Unsuppressed (≥1000 copies/mL)	15 (50)
Viral load (copies/mL), median (range)	31,210 (5338-936,973)

[a]Data for 6 participants missing.

[b]CD4: cluster of differentiation 4.

[c]Data for 4 participants missing.

[d]Data for 11 participants missing.

Three-quarters of all participants lived with one or both parents, and the rest lived with other family members, including one participant who was married and lived with the spouse (Table 2). The majority (68%) reported that at least one parent knew of their HIV status; fewer participants had other family members who knew their status, and only 3 (7%) reported that a close friend knew their status. Six participants stated they were in romantic relationships, and all but one participant reported that their partner knew their HIV status; 5 of the 6 participants knew their partner's HIV status.

Feasibility

At baseline, nearly all participants (93%) had existing access to a phone, and most (66%) ever used the internet (Table 3). Nearly all participants (96%) who used the internet had used Facebook. Among those who had phone access before this study, most reported difficulty charging phones (79%) or running out of airtime or phone credit (97%) sometimes or often.

Nearly all participants (92%) who completed the endpoint structured interview reported that connecting to Facebook was somewhat or very easy, and 97% stated that they wrote comments or asked questions during sessions (Table 4).

Participant Engagement

Most participants who completed the endpoint questionnaire (34 of 35) participated in the intervention sessions (Table 5). The majority of intervention participants took part in all sessions and reported actively commenting or asking questions at some point.

Participation varied widely by session and group (Figure 5). Within groups, participation varied considerably (Figure 6). Each group had 1-3 members who were considerably more active than the others. Two participants made >100 posts (327 and 155 posts; Figure 6).

Table 2. Relationships and disclosure status at baseline.

Characteristic (N=41)	n (%)
Lives with	
Both parents	14 (34)
Mother only	12 (29)
Father only	5 (12)
Spouse or partner	1 (2)
Other relative (sister, grandparents, cousin, aunt, or uncle)	9 (21)
Others who know the participant's HIV status[a]	
Parent(s)	28 (68)
Sibling(s)	12 (29)
Other family member(s)	14 (34)
Close friend(s)	3 (7)
Religious leader	3 (7)
No one	3 (7)
Relationship status[b]	
Married	1 (2)
Unmarried, in a relationship	5 (12)
Single	34 (85)
Spouse, girlfriend, or boyfriend knows the participant's HIV status (n=6)[c]	5 (83)
Spouse, girlfriend, or boyfriend has HIV (n=6)	
Yes	2 (33)
No	3 (50)
Don't know	1 (16)

[a]More than one response possible.

[b]Data for one participant missing.

[c]One person reported that no one knew her status besides the health providers, but then reported that her partner knew her status.

Table 3. Mobile phone and internet use from the baseline questionnaire.

Characteristic (N=41)	n (%)
Mobile phone access	
None	3 (7)
Has own basic phone	16 (39)
Has own smart phone	3 (7)
No personal phone but has access to phone in household	19 (46)
Among those who own or have access to phone (n=38)	
Ways of typically using the phone[a]	
Make voice calls	38 (100)
Send texts or SMS[b]	34 (91)
Send group texts or MMS	12 (31)
Access internet	21 (55)
Access social media	22 (57)
Frequency of running out of airtime or credit	
Rarely	1 (2)
Sometimes	27 (71)
Often	10 (26)
Frequency of facing difficulty charging phone	
Never or Rarely	8 (21)
Sometimes	25 (65)
Often	5 (13)
Ever used the internet	27 (65)
Among those who ever used the internet (n=27)	
Source of internet access[a]	
Own computer or laptop	0 (0)
Computer or laptop in household	2 (7)
Computer or laptop at friend's house	5 (18)
Cyber cafe	2 (7)
Own phone or tablet	9 (33)
Phone or tablet in household	21 (77)
Friend's phone	1 (3)
Ever used social media sites[a]	
Facebook	26 (96)
WhatsApp	12 (44)
Instagram	3 (11)
Other (Twitter, Palmchat, IMO)	7 (25)

[a]More than one response possible.

[b]Data for one participant missing.

Table 4. Intervention access reported in the endpoint questionnaire.

Parameter (N=35)	n (%)
Used the study phone to connect to Facebook	34 (97)
Status of the study phone at endpoint	
In participant's possession	33 (94)
Stolen	2 (5)
Participated in the intervention at least once	34 (97)
Among those who participated at least once (n=34), level of ease connecting to Facebook with the phone	
Very difficult	2 (5)
Somewhat easy	11 (32)
Very easy	21 (61)

Table 5. Intervention engagement in the endpoint questionnaire.

Parameter (N=34)[a]	n (%)
Logged in at least once for a session	
Session 1—Understanding	29 (85)
Session 2—Disclosure and trust[b]	20 (65)
Session 3—Treatment and adherence[c]	25 (76)
Session 4—Nutrition and health	29 (85)
Session 5—Sex and relationships	30 (88)
Ways engaged	
Read what the facilitator posted[c]	33 (100)
Read comments posted by others	34 (100)
"Liked" comments by others[d]	26 (87)
Wrote comments or asked questions	33 (97)
Engagement level during scheduled intervention (by number of posts or comments, n=38)[e]	
Very low (0-5)	11 (29)
Low (6-20)	11 (29)
High (21-50)	9 (24)
Very high (51-327)	7 (18)

[a]One participant did not participate in the online group in the endpoint questionnaire and was not asked the questions in this table.

[b]Data for 3 participants missing.

[c]Data for 1 participants missing.

[d]Data for 4 participants missing.

[e]All participants who started the intervention.

One group (Group 5) was the most active group overall, and the group's facilitator was the most active among all facilitators (Figure 7). Similarly, the group with the lowest member participation had a facilitator with the lowest activity.

Challenges to Participation

Through the IDIs, we explored the challenges faced during implementation that might affect participation. Just over half of the 16 IDI respondents mentioned occasional problems with charging their phone or running out of data. About one-third of IDI respondents mentioned issues with cellular networks, including poor connectivity or slow data speed, of whom 2 participants lacked network coverage when they traveled and 3 had persistent network problems at home. One of them commented the following:

> *Whenever I don't have data I can't use the internet...when you are chatting online, like you are chatting somehow it can cut off.* [low engager, 15-year-old male]

Figure 5. Group posts per session.

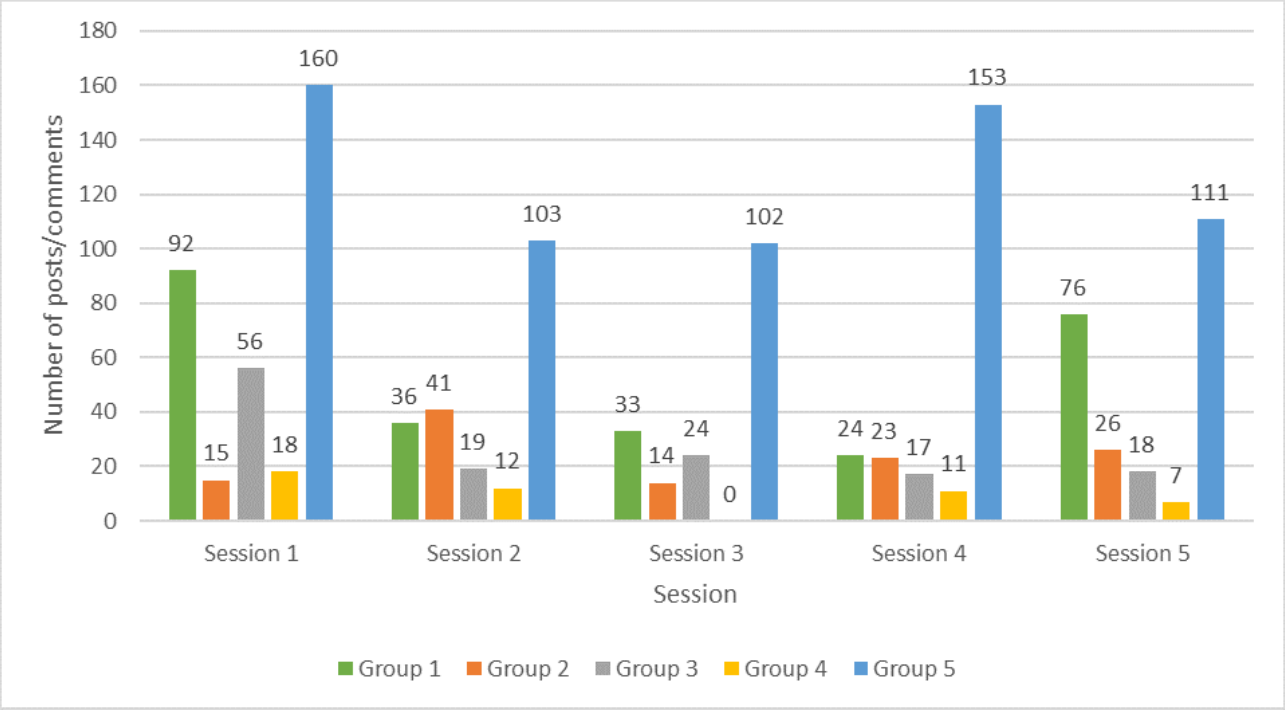


Figure 6. Individual posts per group.

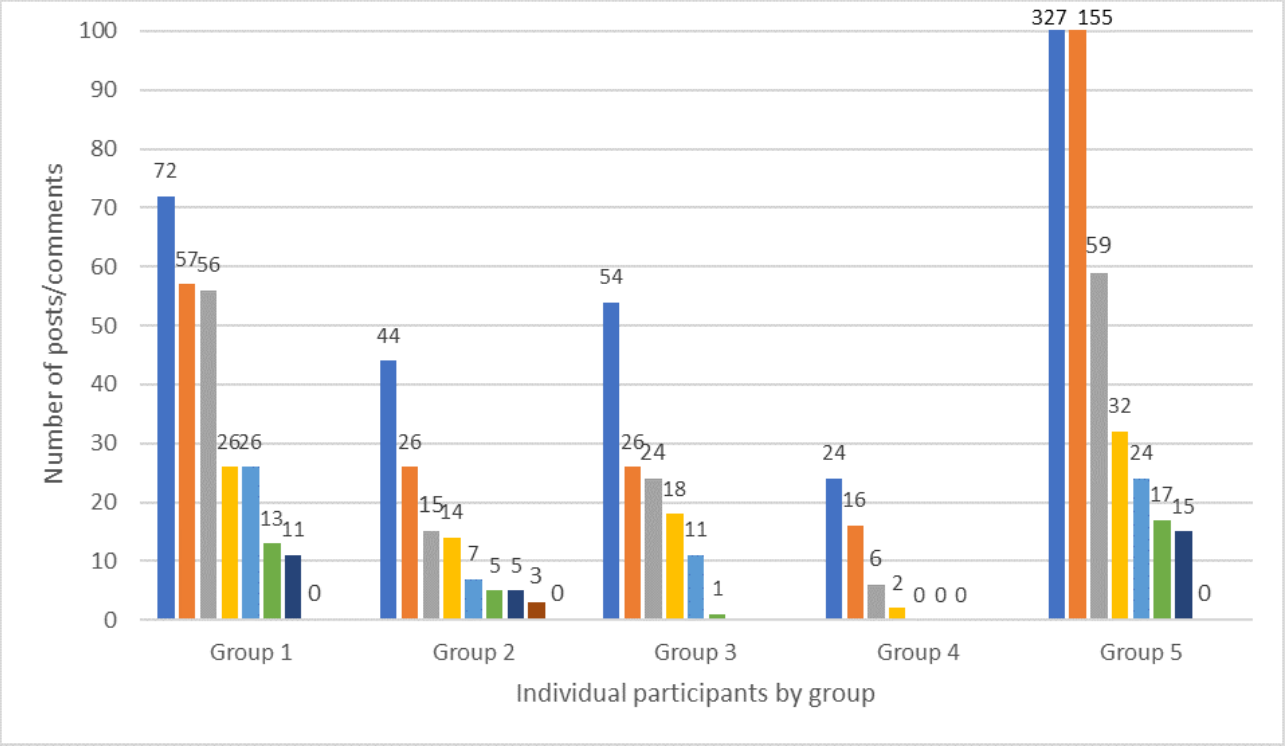
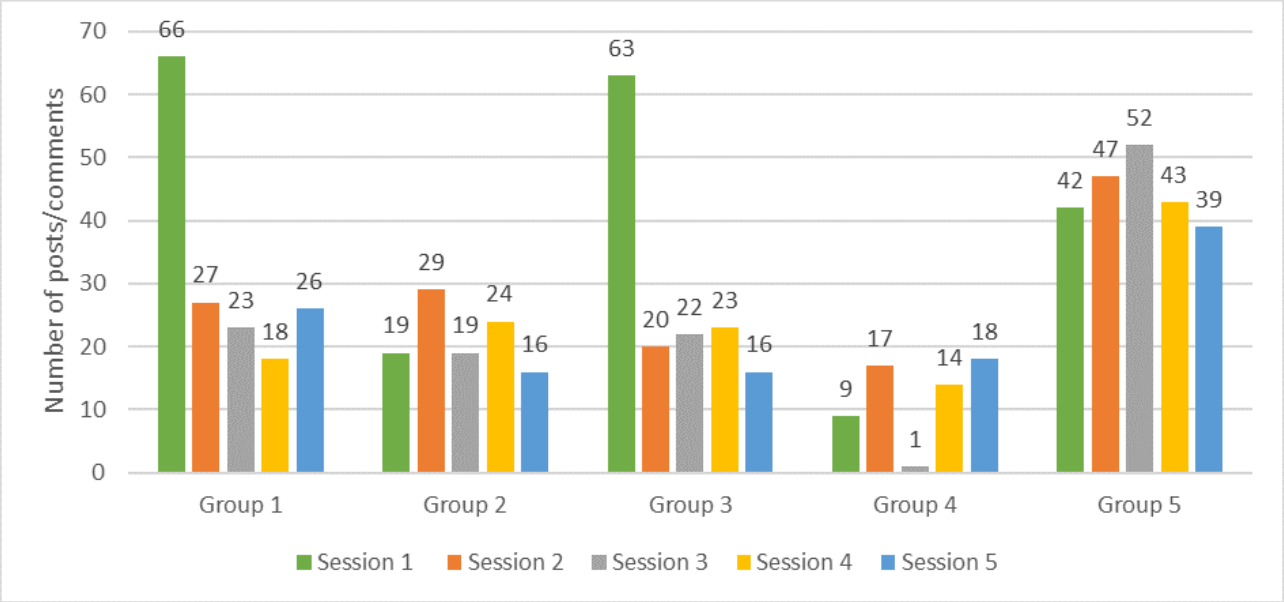


Figure 7. Number of posts or comments by group facilitators per session.



During the session on adherence, participants were asked to upload a photo of an adherence plan; however, none of the participants did so. Several IDI respondents described difficulties with photo uploads as the reason for not uploading an adherence plan photo. One other IDI respondent noted that the pictures did not always display correctly on his phone.

One IDI respondent said he thought another group member was sharing information publicly from the Facebook group, although he did not state that his HIV status or that of others was compromised:

> *Some of our members...will just pick what supposed to be post in [group name] to public Facebook and everybody will see it. I used to see some of them, some people who are in the public group start asking questions, are you, where, who are, where are from...So sometimes I used to sit them down in the Facebook and warn them.* [high engager, 18-year-old male]

Fidelity to Design

Overall, each of the facilitators for the 5 groups posted most of the scheduled activities and did so on time (Table 6). Quizzes (polls) aimed to assess knowledge and stimulate discussion proved problematic. IDI respondents noted that quizzes did not appear correctly formatted on their phones. In response, facilitators posted quiz questions and response options as comments.

Table 6. Proportion of activities posted and posted on time per session.

Parameter	Session 1 (6 activities), %	Session 2 (7 activities), %	Session 3 (7 activities), %	Session 4 (7 activities), %	Session 5 (7 activities), %	All sessions, %
Proportion of all activities posted (regardless of timing)						
Group 1	100	100	100	71	100	94
Group 2	100	100	86	100	100	97
Group 3	100	100	100	100	86	97
Group 4	83	86	14	43	71	60
Group 5	100	100	100	100	85	97
All groups	97	97	80	83	88	
Proportion of scheduled activities posted on time (within 1 week of schedule)						
Group 1	100	100	100	71	100	94
Group 2	100	100	86	100	100	97
Group 3	100	100	100	100	86	97
Group 4	83	57	0	43	71	51
Group 5	100	100	100	43	0	69
All groups	97	91	77	71	71	N/A[a]

[a]N/A: not applicable.

Intervention Acceptability

All participants who completed the endpoint questionnaire agreed that the intervention was useful: They enjoyed taking part in the Facebook group, felt comfortable with the facilitator and other group members, and wanted to continue to participate in the group (Table 7). In addition, participants unanimously felt that the Facebook group intervention was a good way for ALHIVs to interact and would recommend the group to other ALHIVs.

When asked to describe what they liked about the intervention, IDI respondents, both low and high engagers, most commonly reported that they enjoyed the intervention because it was educational or informative. They enjoyed "chatting," sharing experiences, and communicating with other ALHIVs; it helped them take care of themselves and their health (eg, most commonly, taking drugs on time) and felt supported or encouraged:

> *I am a very timid and shy person. But the intervention helped me. There are certain things I was able to overcome. I felt so miserable when I found out that I'm positive but after interacting with people, I find out that I don't have to kill myself or die or feel miserable...I have decided to open up and feel good about myself.* [low engager, 18-year-old female]

> *It has affected my life in a way that, I don't have anything like stigmatization in me I don't and I don't feel someone can discriminate me then I will start looking down on myself. I feel comfortable, I feel I have confidence in myself. Like disclosure, I'm not afraid, am not shame, I'm not shy to expose everything to my partner when is time to get married. So, I really like it has really done a lot of things in my life.* [high engager, 18-year-old male]

A few participants mentioned that they liked the confidentiality of the online forum and learning how to use Facebook:

> *I feel safe from exposing my status to other people. It was very good, I like it…Well, what I feel about having a Facebook group is very, very secured.* [high engager, 18-year-old male]

One participant was concerned about people learning of her HIV status by looking at the phone, but now feels comfortable:

> *At first, I was very scared. I was like what if someone should just carry my phone and see and say ha! what is this? But I was scared,…later on I became used to it, I wasn't afraid if someone should pick up my phone and see it.* [high engager, 18-year-old female]

A few participants said they did not like low participation from other group members:

> *There's something I didn't like because we were 8 in number in that group and anytime or sometimes when I go online, I will only see only one chat or sometimes I won't see anybody.* [high engager, 16-year-old male]

Future Directions

Participants had few specific recommendations to change the intervention. Recommendations from the endpoint questionnaires (Table 7, n=34) included the following: encourage group members to be more active (23%); increase the size of the group (14%); provide better instructions for Facebook (8%); and use of other social media, specifically WhatsApp (5%). Two participants thought some group members may require more explanation on using Facebook in terms of etiquette for posting comments. When asked whether both sexes should be included in future groups, 94% of endpoint questionnaire respondents said yes (Table 7). Just over half the participants (55%) favored inclusion of older youths, but several wanted to cap the age at 19 years. Participants who wanted to include older youths said younger participants could learn from older participants; those who preferred the current age range said younger ALHIVs may be afraid or less open to interacting with older youths. When asked whether they would prefer to be part of an online support group, in-person support group, or both, 58% of participants preferred an online group only and 41% preferred both groups. None of the participants preferred an in-person support group without the online group.

Table 7. Participants' perspectives on the intervention in the endpoint questionnaire.

Characteristic (N=34)[a]	n (%)
Agree with the following	
Enjoyed being a member of the online support group	34 (100)
Received useful information	34 (100)
Participating in the group improved understanding of HIV	34 (100)
Felt comfortable interacting with other HIV-positive young people in the group	34 (100)
Felt comfortable interacting with the group facilitator	34 (100)
Made new friends in the group	30 (88)
Would like to continue to be part of the group	34 (100)
Thinks Facebook groups are a good way for ALHIV[b] to interact	34 (100)
Thinks Facebook groups are a good way for support group leaders to get information to ALHIVs	34 (100)
Would recommend this group to other young people living with HIV	34 (100)
Ways to improve the intervention	
Encourage participation	8 (23)
Increase group size	5 (14)
Improve participant knowledge on Facebook use	3 (8)
Include WhatsApp texting	2 (5)
Specify a time to log in and be active	1 (2)
More encouragement for participants to ask questions	1 (2)
Encourage phone calls between participants	1 (2)
Have a monthly group meeting	1 (2)
Introduce the intervention elsewhere so others can benefit	1 (2)
Recommendations for future group structure	
Groups should remain mixed sex	32 (94)
Groups should include older youths (aged up to 21 or 22 years)	19 (55)
Would prefer support group that met	
Online only	20 (58)
In-person only	0 (0)
Combined online and in-person	14 (41)

[a]In the endpoint questionnaire, one participant said they did not participate in the online group and was not asked the questions in this table.

[b]ALHIV: adolescents living with HIV

Discussion

This online support-group intervention was feasible to implement and highly acceptable among the ALHIVs who participated in the study. We obtained important information on specific challenges and ways to improve the intervention in order to enhance delivery and participation.

The level of active participation varied, within and across groups, which is similar to in-person support groups [21]. Group participation appeared to correlate with facilitator activity, although other factors such as logistic issues also played a role in individual participation within groups. Notably, the facilitator with the lowest overall participation performed the worst on timely and complete posting of sessions. In the future, experienced, dynamic facilitators with adequate mastery of intervention delivery should be recruited; however, even participants with low active participation reported high levels of satisfaction and appear to have benefitted from the intervention. With social media, the ability to follow conversations may allow those who are not comfortable commenting, to learn from others in the group [39,40]. Basic literacy was an important factor to the success of the intervention. Education levels are relatively high in southern Nigeria; 75.9% of women aged 15-49 years have completed some secondary school or higher education [41]. As such, implementing this intervention for individuals with low education levels could prove more difficult.

The time taken for identification and enrolment of adolescents through health facilities was longer than anticipated. Although

Nigeria bears the second-highest burden of HIV on the continent in terms of absolute numbers of people infected [42], its prevalence is relatively low, with higher pockets of concentration in certain geographic areas [43]. According to the recently conducted AIDS Indicator Survey in Akwa Ibom State (2017), HIV prevalence among adolescents aged 15-19 years is 1.5% [44]. Facility staff attempted, without success, to reach several patients through their recorded contact information, which highlights the challenge of poor retention in health care services among this age group. Although inclusion of fewer eligible participants than anticipated complicated study enrollment, it supports the potential role of an online intervention that does not require individuals to live near each other or travel to a designated location and could connect people across a broader geographic area.

We also faced a few challenges during implementation of the study. Considering the limitations of the study phones, future interventions should use smartphones, which are increasingly popular and affordable, even in low- and middle-income countries [45]. Network coverage problems also limited use of the intervention among some participants. Despite these challenges, most subjects participated in most sessions.

Surprisingly, all participants who voiced an opinion preferred online support groups, either alone or in combination with an in-person group, but none of them preferred in-person groups alone. The global trend toward use of and comfort with social media among young people seems to have reached youths in periurban and rural southern Nigeria [46].

This study had a few limitations. The nonprobability sample prevents generalization of the results beyond the study sample. Social desirability bias may play a role in participants' responses to questions about the intervention. In addition, we adapted only 5 of 14 sessions from Positive Connections; therefore, we do not know if participation may change with a longer curriculum. Moreover, we could not determine if facilitators drove participation or group member participation drove facilitator engagement.

In conclusion, this feasibility study demonstrated that an online support group intervention was both feasible and acceptable among ALHIVs in southern Nigeria. Our results provide guidance on changes required to enhance participation. Based on these findings, we have adapted the intervention and expanded it to include the remaining Positive Connections topics. A subsequent randomized controlled trial will test the cost-effectiveness of this revised intervention to improve HIV treatment outcomes.

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Conflicts of Interest

None declared.

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Abbreviations

ALHIV: Adolescents living with HIV
ART: antiretroviral therapy
CD4: cluster of differentiation 4
IDI: In-depth interview

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Original Paper

Factors Related to Prostate-Specific Antigen–Based Prostate Cancer Screening in Primary Care: Retrospective Cohort Study of 120,587 French Men Over the Age of 50 Years

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Abstract

Background: International guidelines recommend avoiding prostate-specific antigen (PSA)-based prostate cancer screening in the elderly when life expectancy is less than 10 years. For younger men, most recommendations encourage a shared decision-making process taking into account patient comorbidities.

Objective: The objective was to assess the performance of PSA-based prostate cancer screening in men older than 74 years and assess whether the presence (vs absence) of comorbidities was related to the performance of PSA testing in younger men aged 50 to 74 years who were eligible for screening.

Methods: We analyzed data from the French national health care database (Loire-Atlantique geographic area). We reported the follow-up of two cohorts of men from April 1, 2014, to March 31, 2016: 22,480 men aged over 74 years and 98,107 men aged 50 to 74 years. We analyzed whether these patients underwent PSA testing after 2 years of follow-up and whether PSA testing performance was related to the following patient-related variables: age, low income, proxy measures indicative of major comorbidities (repeated ambulance transportation, having one of 30 chronic diseases, taking 5 or more drugs per day), or proxy measures indicative of specific comorbidities (cancer diseases, cardiovascular diseases, or psychiatric disorders). Statistical analysis was based on a multivariate mixed-effects logistic regression.

Results: The proportion of patients who underwent a PSA-based screening test was 41.35% (9296/22,480) among men older than 74 years versus 41.05% (40,275/98,107) among men aged 50 to 74 years. The following factors were associated with less frequent PSA testing in men older than 74 years—age (odds ratio [OR] 0.89, 95% CI 0.88-0.89), low income (OR 0.18, 95% CI 0.05-0.69), suffering from a chronic disease (OR 0.82, 95% CI 0.76-0.88), repeated ambulance transportation (OR 0.37, 95% CI 0.31-0.44), diabetes requiring insulin (OR 0.51, 95% CI 0.43-0.60), dementia (OR 0.68, 95% CI 0.55-0.84), and antipsychotic treatment (OR 0.62, 95% CI 0.51-0.75)—whereas cardiovascular drug treatment was associated with more frequent PSA testing (OR 1.6, 95% CI 1.53-1.84). The following factors were associated with less frequent PSA testing in men aged 50 to 74 years—low income (OR 0.61, 95% CI 0.55-0.68); nonspecific conditions related to frailty: suffering from a chronic disease (OR 0.80, 95% CI 0.76-0.83), repeated ambulance transportation (OR 0.29, 95% CI 0.23-0.38), or chronic treatment with 5 or more drugs (OR 0.89, 95% CI 0.83-0.96); and various specific comorbidities: anticancer drug treatment (OR 0.67, 95% CI 0.55-0.83), diabetes requiring insulin (OR 0.55, 95% CI 0.49-0.61), and antiaggregant treatment (OR 0.91, 95% CI 0.86-0.96)—whereas older age

(OR 1.07, 95% CI 1.07-1.08) and treatment with other cardiovascular drugs (OR 2.23, 95% CI 2.15-2.32) were associated with more frequent PSA testing.

Conclusions: In this study, 41.35% (9296/22,480) of French men older than 74 years had a PSA-based screening test. Although it depends on patient comorbidities, PSA testing remains inappropriate in certain populations.

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KEYWORDS

prostate cancer; screening; prostate-specific antigen testing; general practice; primary care

Introduction

Prostate-specific antigen (PSA)-based screening for prostate cancer is challenging for both clinicians and policy makers [1-2]. Based on the most recent evidence [3-6], the US Preventive Services Task Force modified its recommendation in 2017 [7-8]. While the previous 2012 version recommended against screening regardless of patient age, the latest draft is consistent with previous French and Canadian guidelines published in 2014 and 2015 [8-11].

These guidelines recommend avoiding screening in the elderly. The evidence shows that prostate cancer is slow growing, the 10-year survival rate is higher than 95%, and rates of overdiagnosis are elevated in older men [12]. In total, there is a consensus that screening may result in more harm than benefit in the elderly [8-11,13-14], and French guidelines recommend avoiding screening in men older than 74 years because they have a life expectancy shorter than 10 years [9-10].

Most recommendations encourage an individual approach for men aged 50 to 69 years [8-11,13-14] based on a shared decision-making process [15-16]. Thresholds provided by the US Preventive Services Task Force define a narrower group, limiting eligibility for screening to men aged 55 to 69 years, while French guidelines consider men aged 50 to 74 years [8-10]. However, the philosophy of these recommendations is similar, reporting that clinicians should inform eligible men about the potential benefits and harms of PSA-based screening. Screening probably offers a small benefit of reducing the probability of dying of prostate cancer, but many men will experience harms from screening, including false-positive results that require additional testing, possible prostate biopsy, overdiagnosis, overtreatment, and possible treatment complications such as incontinence and impotence [7-8,17-18].

In France, as in various other countries, general practitioners (GPs) prescribe the majority of PSA tests [19]. Various tools and decision aids have been developed to help GPs share and personalize the screening decision with their patients, integrating eligible men's values and medical characteristics [20-22]. From a medical perspective, based on scientific evidence, patients with an expected survival of less than 10 years should remain unscreened. To our knowledge, there is no algorithm allowing a robust assessment of survival for an individual, but screening decisions should at a minimum be related to patients' comorbidities [8-14,18]. Implementation of a shared decision-making process is difficult, and previous authors reported that 41% of French men underwent prostate cancer screening based on PSA between 2008 and 2010 [23-24]. Screening decisions might mainly depend on GPs' primary goals [2]. It is unclear whether a shared decision-making process would lead to decisions based on scientific evidence or whether the patient might make a decision without any consideration of medical factors, such as comorbidities or life expectancy.

The first objective of this study was to assess the inappropriate performance of PSA testing in men older than 74 years. The secondary objective was to assess whether the presence (vs absence) of comorbidities was related to the performance of PSA testing in younger men aged 50 to 74 years who were eligible for screening.

Methods

Design, Setting, and Patients

We used the French national health care system's administrative database to collect longitudinal follow-up data from two cohorts of male patients. Access to the anonymized data was provided by the national health care insurance services, which participated in the study after receiving permission from the health care insurance authorities.

All patients eligible for the study lived on the west coast of France in the Loire-Atlantique geographical area (1,346,592 inhabitants), were over the age of 50 years, and were affiliated with one of the 1183 GPs who practiced in the geographical area at the beginning of the study (April 1, 2014). Patients who changed their GP during the study period were excluded from the analysis regardless of the reason (ie, retirement, death, or career move). Patients were excluded if (1) they were currently being treated for prostate cancer using any of the following drugs: abiraterone, bicalutamide, cyproterone, degarelix, diethylstilbestrol, enzalutamide, flutamide, goserelin, leuprorelin, nilutamide, or triptorelin; (2) PSA testing was prescribed by a urologist (to avoid the inclusion of patients with prostate cancer); or (3) the patient died during the study period.

Patients were grouped into 2 cohorts: (1) 50- to 74-year-old patients eligible for prostate cancer screening and (2) patients older than 74 years for whom screening should be avoided.

Main Outcome Measure

We analyzed whether the patients had undergone PSA testing during the 2-year follow-up period using the French Classification of Medical Acts (code 7318), and the rate of patients screened during the study period was calculated for the 2 cohorts.

Data Extraction From National Health Care Insurance Records

Patient characteristics were collected as follows: age, whether the patient had a low income (defined as an annual income less than 8593 € [US $9992] for an individual or less than 12889 € [US $14,925] for a couple), and proxy measures indicative of major comorbidities. Frail individuals were first identified using the following nonspecific proxy measures: whether the patient required repeated ambulance transportation during the study period (6 times or more), whether he had one of 30 chronic diseases leading to reimbursements for facilities, and whether his chronic treatment included 5 or more drugs per day. Frail individuals were also identified by the following specific comorbidities (the related proxy measures are provided in parentheses):

Cancer diseases (31 anticancer drugs and tumor-related factors such as carcinoembryonic antigen, CA-19-9 antigen, and squamous cell carcinoma–related antigen)

- Cardiovascular diseases (number of cardiovascular drugs used for chronic treatment and chronic insulin use)
- Psychiatric disorders such as dementia (anticholinesterasic treatment or memantine) or major psychiatric disorders (chronic treatment with either antipsychotics or more than 3 psychiatric drugs)
- Variables indicative of other comorbidities (oxygen at home, more than 8 serum urea and creatinine tests during the 2-year study period, or more than 4 alpha-fetoprotein tests during the study period)

Patients with clinical symptoms of benign prostate hyperplasia (dysuria or prostatism) were identified using a proxy measure—treatment with one of the following drugs: alfuzosin, doxazosin, dutasteride, finasteride, prazosin, Pygeum africanum, Serenoa repens, silodosin, tamsulosin, and terazosin.

Statistical Analysis

We first reported the patient and GP characteristics. All analyses were then performed using R version 3.3.1 statistical software (R Foundation for Statistical Computing) and SAS version 9.4 (SAS Institute Inc). For all statistical analyses, the patient was considered the statistical unit. Descriptive statistics were reported using means, standard deviations, and frequency distributions. A first analysis focused on patients older than 74 years, for whom screening should be avoided. A second analysis was performed for patients aged 50 to 74 years, for whom screening should be based on a shared decision-making process. Bivariate analysis was used to compare men who had a PSA test to men who did not using a chi-square test or Student *t* test. Variables with a $P<.20$ were entered into the logistic regression model. A backward procedure based on Akaike information criterion minimization was then performed on these data in order to select the discriminant patients' characteristics. Finally, we adjusted the previous selected model on the general practitioner factor as a random effect in a mixed model. An alpha level of .05 was chosen to assess statistical significance.

Ethics Statement

Ethics approval and specific written informed consent from the participants were not required for this retrospective cohort study performed in France.

Results

Retrospective Cohort Constitution

In total, 129,392 men aged over 50 years were affiliated with GPs practicing in the Loire-Atlantique geographical area at the beginning of the study. However, 8805 of these patients were excluded for the following reasons: 774 individuals died during the study period, 6829 patients' GP stopped practicing during the study period, and 1202 men underwent prostate cancer–related treatment. In total, the study reported the 2-year follow-up of 120,587 men who were affiliated with 968 GPs: 98,107 were aged 50 to 74 years and 22,480 were older than 74 years.

Patient and General Practitioner Characteristics

The mean age of the GPs was 53.1 (SD 9.3) years, and 591 (61.1%) were men. Among the GPs, 56.2% (544/968) had an urban practice, 36.5% (353/968) had a semirural practice, and 7.3% (71/968) had a rural practice in cities with fewer than 2000 inhabitants. The mean number of male patients older than 50 years who visited the physicians during the study period was 124.6 (SD 72.3). Figure 1 shows that the probability of undergoing a PSA screening test, both in the cohort of men aged 50 to 74 years and in the cohort of men older than 74 years, varied depending on which physician a patient consulted.

The mean patient age was 64.6 (SD 10.5) years. A low income was identified in 1.96% (2367/120,587) of all patients. A total of 36.21% (43,663/120,587) of all patients suffered from one of 30 severe chronic diseases related to reimbursement of facilities. Other characteristics provided insights into frailty and comorbidities (Table 1).

Proportion of Patients Who Underwent Prostate-Specific Antigen Testing During the 2-Year Study Period

The proportion of patients who received a PSA test during the 2-year study period was not lower in the cohort of men older than 74 years than in the cohort of men aged 50 to 74 years: 41.35% (9296/22,480, 95% CI 40.7-42.0) vs 41.05% (40,275/98,107, 95% CI 40.7-41.4).

Factors Associated With Prostate-Specific Antigen Testing in the Cohort of Men Aged Older Than 74 Years

In the cohort of men older than 74 years, the following factors were associated with PSA testing: (1) age (odds ratio [OR] 0.89, 95% CI 0.88-0.89; (2) low income (OR 0.18, 95% CI 0.05-0.60); (3) nonspecific conditions related to frailty: chronic disease (OR 0.82, 95% CI 0.76-0.88) and repeated ambulance transportation (OR 0.37, 95% CI 0.31-0.44); and (4) various specific comorbidities: diabetes requiring insulin (OR 0.51, 95% CI 0.43-0.60), dementia (OR 0.68, 95% CI 0.55-0.84), and antipsychotic treatment (OR 0.62, 95% CI 0.51-0.75; Table 2).

Higher screening rates were observed in patients treated for cardiovascular diseases (compared to no cardiovascular treatment), and these rates remained high regardless of the number of drugs taken: 1 or 2 cardiovascular drugs (OR 1.6, 95% CI 1.53-1.84), 3 or 4 cardiovascular drugs (OR 1.73, 95% CI 1.57-1.91), or 5 or more cardiovascular drugs (OR 1.64, 95% CI 1.46-1.84). The following patient characteristics were not significantly correlated with lower PSA testing: having oxygen at home, more than 8 urea/creatinine tests during the study period, and more than 4 alpha-fetoprotein tests during the study period.

Figure 1. Distribution of prostate-specific antigen (PSA) testing performance rates according to general practitioner (GP; defined as the proportion of patients who underwent PSA testing in each GP's patient panel).

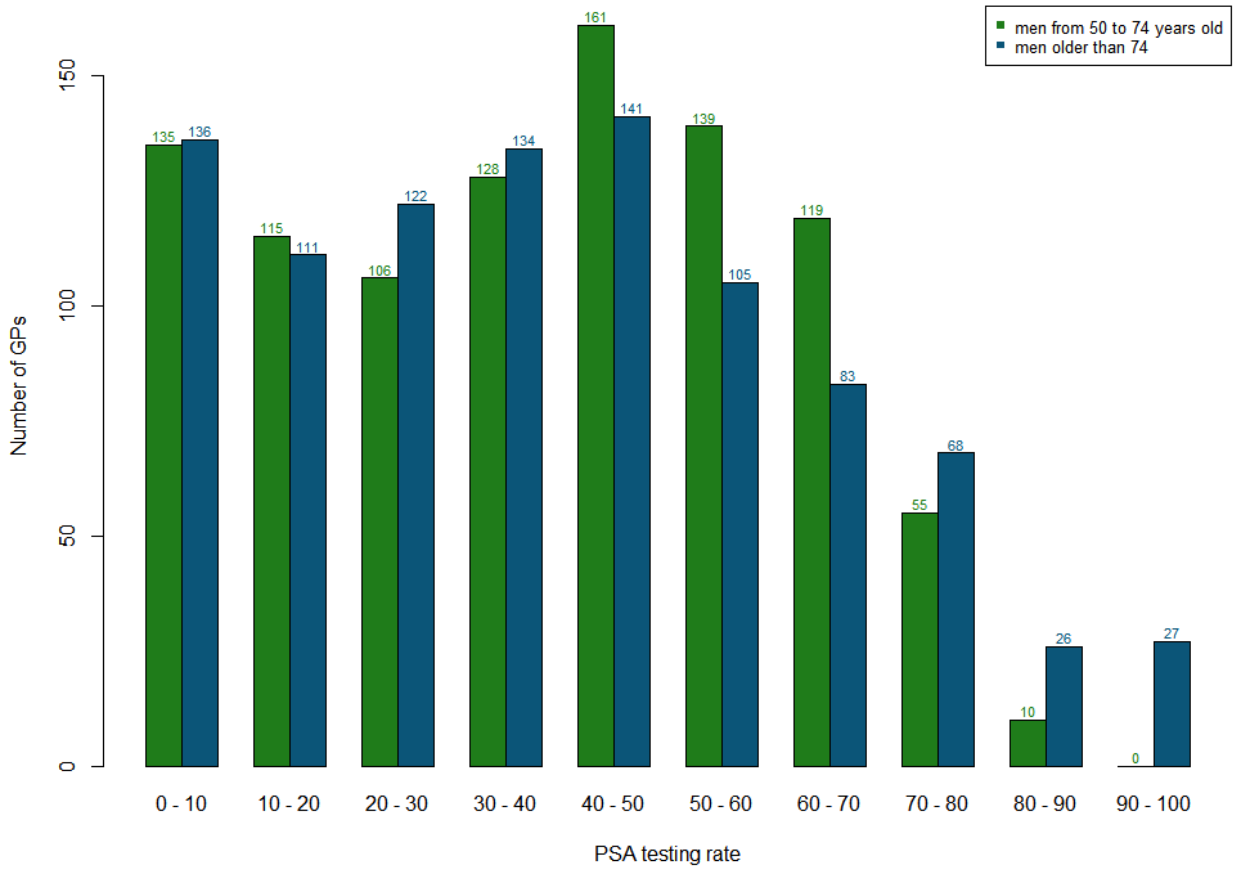

Table 1. Patient characteristics in 2 age-based cohorts of patients: 50 to 74 years and older than 74 years.

Characteristics	Total patients (N=120,587)	Patients aged 50 to 74 years (n=98,107)	Patients older than 74 years (n=22,480)
Age in years, mean (SD)	64.6 (10.5)	60.7 (6.9)	81.6 (5.1)
Low socioeconomic status[a], n (%)	2367 (1.96)	2344 (2.39)	23 (0.10)
Frail individual, n (%)			
Chronic disease status	43,663 (36.21)	29,875 (30.45)	13,788(61.33)
Repeated ambulance transportation	929 (0.77)	391 (0.40)	538 (2.39)
Chronic treatment with ≥5 drugs	19,212 (15.93)	12,277 (12.51)	6935 (30.85)
Cancer disease (treated with anticancer drug), n (%)	780 (0.65)	515 (0.52)	265 (1.18)
Cardiovascular disease, n (%)			
Number of cardiovascular drugs			
0	54,844 (45.48)	50,678 (51.66)	4166 (18.53)
1-2	32,497 (26.95)	25,180 (25.67)	7317 (32.55)
3-4	20,235 (16.78)	13,540 (13.80)	6695 (29.78)
5 or more	1301 (10.79)	8709 (8.88)	4302 (19.14)
Treated with insulin	3116 (2.58)	2194 (2.24)	922 (4.10)
Treated with antiaggregant	27,836 (23.08)	18,089 (18.44)	9747 (43.36)
Dementia (treated with anticholinesterase therapy), n (%)	699 (0.58)	126 (0.13)	573 (2.55)
Psychiatric disorder (treated with antipsychotic therapy), n (%)	3237 (2.68)	2541 (2.59)	696 (3.10)
Urology (treatment for benign prostate hyperplasia), n (%)	14,849 (12.31)	8863 (9.03)	5986 (26.63)
Other variables indicative of comorbidities, n (%)			
Oxygen at home	4932 (4.09)	3999 (4.08)	933 (4.15)
>8 urea/creatinine tests during the study period	1281 (1.06)	1042 (1.06)	239 (1.06)
>4 alpha-fetoprotein tests during the study period	255 (0.21)	199 (0.20)	56 (0.25)

[a]Defined as an annual income less than 8593 € (US $9992) for an individual or less than 12889 € (US $14,925) for a couple.

Table 2. Factors related to the performance of prostate-specific antigen testing in a cohort of French men older than 74 years (mixed-effects multivariate logistic regression with general practitioner as a random effect).

Characteristics	Proportion of patients screened using PSA[a,b] (%)	Crude odds ratio (95% CI)[c]	*P* value[d]	Adjusted odds ratio (95% CI)[e]	*P* value[f]
Age in years	N/A[g]	0.89 (0.89-0.90)	<.001	0.89 (0.88-0.89)	<.001
Low socioeconomic status[h]	13.04	0.25 (0.07-0.89)	.03	0.18 (0.05-0.69)	.01
Frail individual					
Chronic disease status	39.61	0.80 (0.75-0.85)	<.001	0.82 (0.76-0.88)	<.001
Repeated ambulance transportation	18.77	0.28 (0.22-0.36)	<.001	0.42 (0.33-0.54)	<.001
Chronic treatment with ≥5 drugs	41.50	0.98 (0.92-1.05)	.57	N/A	N/A
Cancer disease (treated with anticancer drug)	39.62	0.88 (0.67-1.16)	.36	N/A	N/A
Cardiovascular disease					
Number of cardiovascular drugs					
0	35.93	Reference	N/A	Reference	N/A
1-2	43.53	1.44 (1.32-1.57)	<.001	1.68 (1.53-1.84)	<.001
3-4	42.63	1.37 (1.25-1.49)	<.001	1.73 (1.57-1.91)	<.001
5 or more	40.91	1.24 (1.13-1.37)	<.001	1.64 (1.46-1.84)	<.001
Treated with insulin	27.22	0.49 (0.42-0.58)	<.001	0.62 (0.51-0.75)	<.001
Treated with antiaggregant	41.43	0.99 (0.93-1.05)	.80	N/A	N/A
Dementia (treated with anticholinesterase therapy)	25.83	0.44 (0.36-0.54)	<.001	0.68 (0.55-0.84)	<.001
Psychiatric disorder (treated with antipsychotic therapy)	29.02	0.49 (0.40-0.58)	<.001	0.62 (0.51-0.75)	<.001
Other variables indicative of comorbidities				N/A	N/A
Oxygen at home	43.30	1.12 (0.96-1.29)	.14		
>8 urea/creatinine tests during the study period	43.93	1.25 (0.94-1.66)	.12		
>4 alpha-fetoprotein tests during the study period	41.07	1.06 (0.58-1.91)	.85		

[a]Prostate-specific antigen.

[b]n=22,480.

[c]General practitioner as a random effect; bivariate analysis.

[d]*P* value for crude odds ratio.

[e]General practitioner as a random effect; multivariate analysis; adjusted on the variable "treatment for benign prostate hyperplasia."

[f]*P* value for adjusted odds ratio.

[g]N/A: not applicable.

[h]Defined as an annual income less than 8593 € (US $9992) for an individual or less than 12889 € (US $14,925) for a couple.

Factors Associated With Prostate-Specific Antigen Testing in the Cohort of Men Aged 50 to 74 Years

In the cohort of men aged 50 to 74 years, the following factors were associated with less frequent PSA testing: (1) low income (OR 0.61, 95% CI 0.55-0.68); (2) nonspecific conditions related to frailty: chronic disease (OR 0.80, 95% CI 0.76-0.83), repeated ambulance transportation (OR 0.29, 95% CI 0.23-0.38), or chronic treatment with more than 5 drugs (OR 0.89, 95% CI 0.83-0.96); and (3) various specific comorbidities: anticancer drug treatment (OR 0.67, 95% CI 0.55-0.83), diabetes requiring insulin (OR 0.55, 95% CI 0.49-0.61), and antiaggregant treatment (OR 0.91, 95% CI 0.86-0.96; Table 3). Higher screening rates were observed in patients treated for cardiovascular diseases (compared to no cardiovascular treatment), and these rates remained high regardless of the number of drugs taken: 1 or 2 cardiovascular drugs (OR 2.23, 95% CI 2.15-2.32), 3 or 4 cardiovascular drugs (OR 2.61, 95% CI 2.46-2.77), or 5 or more cardiovascular drugs (OR 2.64, 95% CI 2.40-2.91). Older age was also associated with more frequent PSA testing (OR 1.07, 95% CI 1.07-1.08). The following patient characteristics were not significantly correlated with lower PSA testing: having oxygen at home, having more than 8 urea/creatinine tests during the study period, having more than 4 alpha-fetoprotein tests during the study period, and treatment with psychotropic drugs.

Table 3. Factors related to the performance of prostate-specific antigen testing in a cohort of French men aged 50 to 74 years (mixed-effects multivariate logistic regression with general practitioner as a random effect).

Characteristics	Proportion of patients screened using PSA[a,b] (%)	Crude odds ratio (95% CI)[c]	*P* value[d]	Adjusted odds ratio (95% CI)[e]	*P* value[f]
Age in years	N/A[g]	1.09 (1.09-1.10)	<.001	1.07 (1.07-1.07)	<.001
Low socioeconomic status[h]	23.55	0.43 (0.39-0.48)	<.001	0.61 (0.55-0.68)	<.001
Frail individual					
Chronic disease status	46.28	1.42 (1.37-1.46)	<.001	0.79 (0.76-0.83)	<.001
Repeated ambulance transportation	24.55	0.42 (0.33-0.53)	<.001	0.29 (0.23-0.38)	<.001
Chronic treatment with ≥5 drugs	50.46	1.66 (1.59-1.73)	<.001	0.89 (0.83-0.96)	.002
Cancer disease (treated with anticancer drug)	37.48	0.83 (0.70-1.01)	.06	0.67 (0.55-0.83)	<.001
Cardiovascular disease					
Number of cardiovascular drugs					
0	31.11	Reference	N/A	Reference	N/A
1-2	51.31	2.66 (2.56-2.75)	<.001	2.23 (2.15-2.32)	<.001
3-4	53.69	2.98 (2.86-3.12)	<.001	2.61 (2.46-2.77)	<.001
5 or more	49.59	2.46 (2.34-2.59)	<.001	2.64 (2.40-2.91)	<.001
Treated with insulin	38.51	0.87 (0.79-0.96)	.005	0.55 (0.49-0.61)	<.001
Treated with antiaggregant	51.17	1.80 (1.73-1.86)	<.001	0.91 (0.86-0.96)	.001
Dementia (treated with anticholinesterase therapy)	53.17	1.46 (0.99-2.17)	.06	N/A	N/A
Psychiatric disorder (treated with antipsychotic therapy)	35.73	0.79 (0.72-0.86)	<.001	N/A	N/A
Other variables indicative of comorbidities				N/A	N/A
Oxygen at home	41.79	1.02 (0.95-1.10)	.51		
>8 urea/creatinine tests during the study period	40.50	0.98 (0.85-1.12)	.72		
>4 alpha-fetoprotein tests during the study period	41.71	1.02 (0.75-1.38)	.92		

[a]Prostate-specific antigen.

[b] n=98,107.

[c]General practitioner as a random effect; bivariate analysis.

[d]*P* value for crude odds ratio.

[e]General practitioner as a random effect; multivariate analysis; adjusted on the variable "treatment for benign prostate hyperplasia."

[f]*P* value for adjusted odds ratio.

[g]N/A: not applicable.

[h]Defined as an annual income less than 8593 € (US $9992) for an individual or less than 12889 € (US $14,925) for a couple.

Discussion

Principal Findings

In our study, the proportion of patients who underwent PSA testing during the 2-year study period was not lower in the cohort of men older than 74 years than in the cohort of men aged 50 to 74 years: 41.35% (95% CI 40.7-42.0) vs 41.05% (95% CI 40.7-41.4). The following factors associated with less frequent PSA testing were similar in men older than 74 years and in men aged 50 to 74 years—chronic disease, repeated ambulance transportation, diabetes, psychiatric disorders, and low income—whereas being treated with cardiovascular drugs was associated with more frequent PSA testing. Although PSA testing depends on patients' comorbidities, test performance remains inappropriate in certain populations: elderly patients should not be screened, particularly when they have dementia or major comorbidities. The reasons why lower screening rates are observed among patients with insulin or among patients with a low income are unclear.

The proportion of patients who underwent PSA screening in our study conducted in France is comparable to previous evaluations provided by other French authors [23-24] but is much higher than the proportions reported by authors from other countries [25-32]. Among men aged 50 to 74 years, the observed 41.05% rate of French patients who had undergone PSA screening is comparable to the rates of participation in systematic screenings for colorectal cancer or breast cancer. In France, participation in colorectal cancer screening is lower than 30% [33], and participation in breast cancer screening is 51.5% [34]. Although prostate cancer screening is not recommended in the elderly, the PSA blood test was performed

as frequently in patients older than 74 years as in younger men. A possible reason is that this test is highly acceptable to patients [35]. Other reasons may include positive attitudes toward screening, such as considering it a favorable option, or physicians' fear of legal consequences related to diagnostic delay [28,36]. Another reason might be that prescribing PSA screening might be easier than explaining the reason why this test should not be performed. As French GPs practice in a pay-per-act system, prescribing PSA testing might decrease the time spent on a consultation compared with a shared decision-making process leading to abstention. Finally, various other factors probably limit shared decision-making implementation in primary care practices in France: deficiencies in initial medical education and law medical demography as well as the lack of an interactive decision-making aid to support GPs and patients when making prostate cancer screening decisions.

PSA testing occurred less frequently in frail patients and patients with major comorbidities. This finding is consistent with international guidelines and recommendations suggesting that life expectancy should be considered before recommending screening [8,17]. Surprisingly, more than 30% of patients treated with anticholinesterase therapies and 20% of patients with 6 or more ambulance transportations during the study period underwent PSA-based prostate screening. While all guidelines recommend avoiding screening in patients with a life expectancy of less than 10 years [8,17,36-37], previous authors have also reported inappropriate screening practices in vulnerable patients [38-40]. These results emphasize that integrating life expectancy into medical decisions remains a challenge for primary care physicians [41-42].

Three populations were screened less frequently, although they had no clear link with a shorter life expectancy: patients treated with insulin, patients treated with antipsychotic medications, and patients with low incomes. Various authors have reported low participation in preventive procedures in patients treated with antipsychotic medications and patients with low incomes [43-44]. Lower PSA testing in deprived patients has been reported in other countries [30-45] and might be related to lower access to health care in these populations. We assume, however, that this result might paradoxically be appropriate for prostate cancer screening; physicians might concentrate their time and energy on other health problems in patients suffering from various diseases.

Patients treated for cardiovascular diseases underwent PSA screening more frequently than other patients. It is notable that this result is consistent with previous international findings, although the reasons remain unclear. One reason for this finding might be that these patients consult their physicians more frequently [46], at least for prescription refills, and may have more frequent blood analyses [30,47]. Another possible reason is that these patients might have experienced the positive impact of medical interventions, which might favor positive attitudes toward screening proposals.

Strengths and Limitations

This database study had many strengths. First, the study design allowed for the inclusion of a large number of patients and GPs; thus, our results should be representative of PSA performance in the general population and have high generalizability. Second, the data were extracted from the national health care insurance system database. We did not collect reported data from surveys, avoiding any related bias (eg, response bias or social desirability bias). Finally, the inclusion of a large number of patients permitted the analysis of specific conditions corresponding to a low proportion of patients.

This study also had limitations. First, the database did not contain clinical information allowing a determination of whether the PSA blood analysis had been prescribed as a result of clinical symptoms or as part of a screening practice. Second, we focused on PSA tests prescribed by GPs. Although they are a minority in the French health care system, asymptomatic patients might also consult urologists and be prescribed a PSA test for prostate cancer screening. Third, another weakness of the study was the use of proxy measures (comorbidities deduced from the types of drugs administered during the study period); although the use of proxy measures is common, the proxy measures used to assess frailty in this study had not been validated in previous studies.

Conclusion

This study provided insight into the wide variations in prostate cancer screening using PSA. This study demonstrated that PSA testing is much more frequent in France than in other countries. Although there is a consensus that screening should be avoided in patients with a life expectancy less than 10 years, PSA testing remained very frequent in patients older than 74 years. This study also demonstrated that physicians considered patient conditions but PSA testing remained inappropriate in certain populations such as patients with dementia.

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Conflicts of Interest

None declared.

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Abbreviations

GP: general practitioner
OR: odds ratio
PSA: prostate-specific antigen

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Review

Research Ethics in the European Influenzanet Consortium: Scoping Review

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Abstract

Background: Influenzanet was launched in several European countries to monitor influenza-like illness during flu seasons with the help of volunteering participants and Web-based technologies. As in the case of developing fields, ethical approaches are not well developed in the collection, processing, and analysis of participants' information. Existing controversies and varying national ethical regulations can, thus, hamper efficient cross-border research collaboration to the detriment of quality disease surveillance.

Objective: This scoping review characterizes current practices on how ethical, legal, and social issues (ELSIs) pertinent to research ethics are handled by different Influenzanet country groups to analyze similarities and identify the need for further harmonization of ethical approaches.

Methods: A literature search was carried out on PubMed, Web of Science, Global Digital Library on Ethics, and Bioethics Literature Database to identify ELSIs for Influenzanet country platforms. Only English-language papers were included with publication dates from 2003 to 2017. Publications were screened for the application of bioethics principles in the implementation of country platforms. Additional publications gathered from the Influenzanet Consortium website, reference screening, and conference proceeding were screened for ELSIs.

Results: We gathered 96 papers from our search methodology. In total, 28 papers that mentioned ELSIs were identified and included in this study. The Research Ethics Committee (REC) approvals were sought for recruiting participants and collecting their data in 8 of 11 country platforms and informed e-consent was sought from participants in 9 of 11 country platforms. Furthermore, personal data protection was ensured throughout the Consortium using data anonymization before processing and analysis and using aggregated data.

Conclusions: Epidemics forecasting activities, such as Influenzanet, are beneficial; however, its benefits could be further increased through the harmonization of data gathering and ethical requirements. This objective is achievable by the Consortium. More transparency should be promoted concerning REC-approved research for Influenzanet-like systems. The validity of informed e-consent could also be increased through the provision of a user friendly and standard information sheet across the Consortium where participants agree to its terms, conditions, and privacy policies before being able to fill in the questionnaire. This will help to build trust in the general public while preventing any decline in participation.

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KEYWORDS

communicable diseases; influenza, human; public health surveillance; research ethics; web-based technologies; mobile phones; smartphone; participatory surveillance

Introduction

Web-based technologies have become an integral part of public health surveillance over the last 2 decades [1]. It is estimated that 4.3 billion people globally will have mobile broadband subscriptions by the end of 2017 [2]. Their ubiquitous availability allows volunteer citizens to engage in disease detection through digital means [3]. Real-time granular health data are, thus, collected from volunteering participants (eg, via mobile phones with global positioning), supplementing the big data collected by public health authorities and laboratories [3,4]. Combining these different data sources allows earlier and finer spatial detection of public health threats than traditional surveillance systems, permitting more appropriate preventive and mitigating measures to be deployed [4]. A successful example of such disease digital detection is the European Influenzanet Consortium.

Every year in Europe, seasonal flu brings its share of morbidity and mortality among vulnerable groups (eg, the elderly) and a rise in associated medical costs [5]. Infection with influenza virus is hard to diagnose without virological confirmation, and public health authorities usually rely on influenza-like illness (ILI) as a surveillance indicator for outbreaks [6]. This surveillance program is carried out by the European Influenza Surveillance Network (EISN), which is coordinated by the European Centre for Disease Control [7]. Since 2008, EISN has relied on ILI reports by general practitioners from national sentinels in its 30 European Union and European Economic Area countries [8]. However, this traditional surveillance system is biased by the use of nonuniform case definitions for ILI by the Member States and depends on the rate at which patients seek medical care from general practitioners, thereby reflecting only medically attended ILI incidence rates [9-11]. The general practitioner consultation rate is itself dependent on several factors that include the time delay between the onset of symptoms and health complications, the need of certificates from general practitioners for prolonged work absenteeism owing to illness, types of health insurance, and health care systems [12]. Thus, there is a non negligible underestimation of the real disease burden of influenza outbreaks [13]. The current limitations of EISN led to the development of Influenzanet, an innovative ILI surveillance network based on the active participation of public volunteers and the use of Web-based technologies to report cases of ILI, complementing data gathered by EISN [12,14].

The Influenzanet Consortium was launched in 2003 in the Netherlands and the Flemish part of Belgium [6]. Denmark, France, Ireland, Italy, Portugal, Spain, Sweden, Switzerland, and the United Kingdom have also joined this surveillance network [15]. However, very recently in 2017, the Netherlands-Belgium platforms have ceased their activities because of lack of funding, which undermines the excellent work done by these platforms in promoting the ILI surveillance for 15 years in their countries. The platforms will resume their activities if funding is made available by May 2018. Otherwise, the platforms will terminate their activities permanently [16]. Public volunteers are usually recruited via mass media, and there are no exclusion criteria for registration (except for Sweden) [17-19]. At registration, volunteers fill in an intake questionnaire and afterwards, receive a weekly reminder by email to fill in an ILI-related symptom questionnaire [6]. Importantly, the absence of symptoms is also declared. In addition, participants are allowed to indicate symptoms of ILI for other household members in an attempt to increase the data collection for children and elderly individuals [17].

Influenzanet offers numerous advantages over EISN, including the following: ILI incidence rates are extrapolated from both medically attended and unattended patients, real-time disease-monitoring capability through the citizen participation, flexibility to changes without disturbance of the overall system functionality, uniform data collection allowing direct comparisons between countries, comparatively lower running costs, easier to increase scalability, and participant empowerment through information on prevention strategies and disease activity at local and national levels [11,13,17,20].

Nonetheless, Influenzanet also has some disadvantages, including the self-selection bias of participants (eg, underrepresentation of younger and older age groups), absence of virological confirmation of influenza cases, recruitment and motivation of participants to continuously donate their data for surveillance are problematic (eg, limited sample sizes in some countries), and limited amount and complexity of data that can be collected to ensure the continued use of platforms by participants [11,13,17].

This approach for monitoring disease involves the collection of information about users that affects their risks of influenza or complication from influenza; this information includes the demographic data, vaccination status, presence of certain medical conditions (eg, diabetes mellitus), use of food complements, daily activities, and household composition (eg, presence of children) [21]. Moreover, some national platforms have developed mobile apps as additional data collection tools; for instance, the Swiss mobile app gathers useful supplementary data through smartphone sensors (eg, inbuilt movement sensors to test for an association between the physical activity level of participants and the risk of ILI) or smartphone features (eg, test for an association between the psychological profile of participants, inferred via the list of apps installed, and attitude toward vaccination; Grippenet Switzerland, email communication, November 29, 2017). This complements the data gathered from questionnaires, allowing to answer innovative research questions and implement rational public health strategies while maintaining high privacy protection measures; for example, only highly aggregated and summarized versions of the data are transmitted for analysis, whereas the bulk of data is stored locally on participants' smartphones. Moreover, mobile app data will not be shared with the rest of

the Consortium until a framework for data sharing is set up. Nonetheless, Influenzanet data can be valuable and sensitive information. Thus, collecting such information poses ethical, legal, and social issues (ELSIs), in particular, if the collected data could be used for secondary research purposes or in the event of a cyber attack leading to data leakage.

As it is commonly the case for developing fields, ethical approaches are not yet well developed in the collection (here through Web-based technologies), processing, and analysis of participants' information. Existing controversies can, thus, be the cause of additional barriers to efficient collaboration. Furthermore, although research collaboration and comparability of data are important because epidemics do not stop at national borders, varying ethical regulations at national levels can hamper collaboration between countries. Additionally, a number of new ethical issues raised by Influenzanet-like activities do not or only partially fit traditional evaluation categories used by Research Ethics Committees (RECs) for clinical trials or data-based research. This scoping review aims to discuss ELSIs of these participatory surveillance systems. First, we characterized the current practices using findings from the literature search where we compared how issues related to research ethics are being handled by different Influenzanet country groups to analyze similarities and identify the need for further harmonization of ethical approaches. Thereafter, we carried out an ELSI analysis to suggest ways to strengthen them to lay the ground for expanding the capacity and positive impact of such systems in the future.

Methods

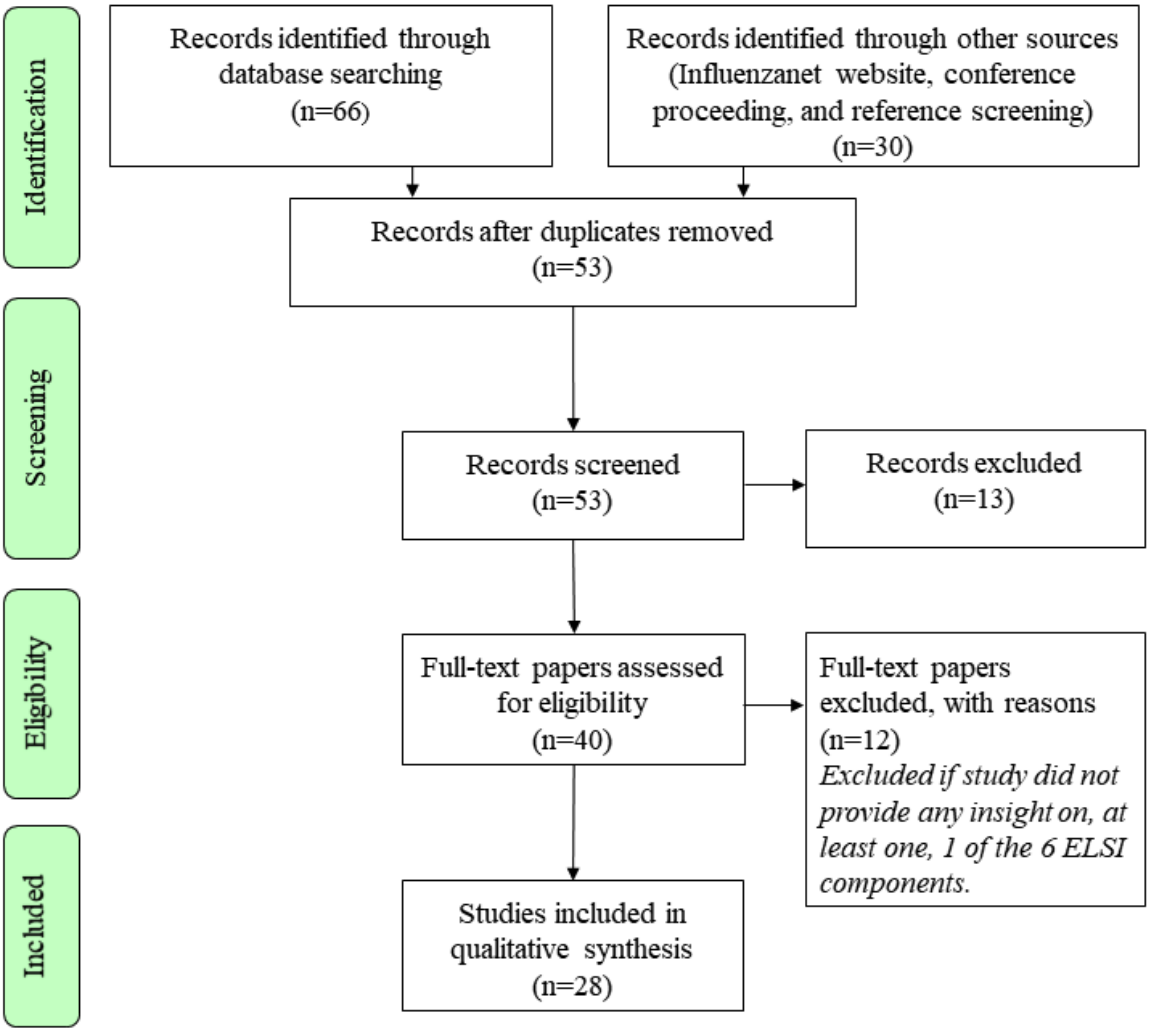
For this review, we followed the methodological guidance provided for conducting a scoping review [22]. Four databases, namely, PubMed, Web of Science (all databases), Global Digital Library on Ethics, and BELIT (Bioethics Literature Database) were searched to identify ELSIs for the national platforms of the Influenzanet Consortium.

We used the following key terms: *Influenzanet*, *De Grote Griepmeting*, *Flusurvey*, *Gripenet*, *Grippenet*, *Hälsorapport*, *Influmeter*, and *Influweb*. Only English-language papers with publication dates from the last 15 years (2003-2017) were included. The search started from 2003 because the first Influenzanet national platform, *De Grote Griepmeting*, was launched in this year.

In line with the conception of modern research ethics, we searched publications related to Influenzanet for the use and application of ethical principles [23,24] in the implementation of these national platforms; these principles are as follows: respect for autonomy (respect the decision-making capacity of Influenzanet participants through the provision of a: an informed consent and b: opt-out option); beneficence (direct and indirect benefits provided to Influenzanet participants via Web-based information on the study); nonmaleficence (prevention of informational harm to Influenzanet participants such as personal data protection measures, for example, anonymization of personal data); and justice (ensuring open and nondiscriminative participation of users to the Influenzanet network to ensure fairness in the distribution of benefits and risks) [25]. In addition, we evaluated the presence of ethical approval by an ethics committee to balance the benefits and risks to participants, future patients, or society. Additional publications found on the Influenzanet Consortium website [15] were gathered and screened for ELSIs as well. Furthermore, reference lists of included publications were searched for additional studies. Only publications mentioning at least one of these 6 ELSI components were included.

The included full-text papers were screened and analyzed independently by 2 review authors (LDG and TW) to ensure that they met the inclusion criteria of having information on the desired ELSI components previously described. Discrepancies between the 2 review authors were solved through discussion. Figure 1 illustrates the methodological process behind the selection and inclusion of publications for this review based on the PRISMA framework for systematic reviews and meta-analyses [26]. When the gathered literature did not provide sufficient information on some national platforms, country members of the Influenzanet Consortium were contacted either through email or the coordinator of the Consortium to provide additional details and to assess the veracity of the information gathered on their respective platforms.

Figure 1. The PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) flowchart of study selection. ELSI: ethical, legal, and social issues.



Results

The original literature search, carried out on September 11 and repeated on October 10 2017 in the databases mentioned above, identified a total of 66 potentially relevant papers (Table 1) on the Influenzanet Consortium and its national platforms (eg, *De Grote Griepmeting* for the Netherlands and Belgium, *Flusurvey* for the United Kingdom and Ireland, *Gripenet* for Portugal and Spain, *Grippenet* for France and Switzerland, *Hälsorapport* for Sweden, *Influmeter* for Denmark, and *Influweb* for Italy). No papers on Influenzanet were found on the Global Digital Library on Ethics and BELIT.

After the removal of duplicates (n=29), 37 papers were considered for this study. Among these 37, 4 were datasets, 5 included supporting information to other papers in the list (eg, tables and figures), 2 papers were in other languages (French and Swedish), and 2 were meeting abstracts; these 13 papers were excluded. The remaining 24 full-text papers were then screened for 6 ELSI components (informed e-consent obtained from participants; ability of participants to opt out from the study at any time; Web-based information on national platform and influenza; personal data protection measures, for example, anonymization and abiding to the national regulations on privacy, data collection, and treatment; open and nondiscriminative participation; and ethical approval by an REC or other competent entity). Only 16 of the 24 papers addressed some ethical, legal, and social components (eg, ethical approval by RECs, informed consent, etc).

Our search of the Influenzanet Consortium website [15] resulted in an additional 28 publications. After the removal of duplicates (n=14), 14 publications were considered for a detailed review of their ELSI components. Notably, 10 of the 14 papers addressed some ethical, legal, and social components.

Table 1. Initial search results (date of search: September 11, 2017 and October 10, 2017).

Search terms used	Results found in PubMed (n=22), n	Results found in all Web of Science databases (n=44), n
European network: Influenzanet	10	16
National platforms		
De Grote Griepmeting	0	0
Flusurvey	3	7
Gripenet	1	1
Grippenet	6	12
Hälsorapport	0	2
Influmeter	1	1
Influweb	1	5

Overall, 2 additional publications (retrieved from reference screening and a conference proceeding) were included, leading to a total of 28 papers included in our analysis, as seen in Figure 1. Table 2 reports on these 28 papers and summarizes the presence or absence of the ELSI components for each paper reviewed. However, Table 2 should be interpreted cautiously because the presence of some ELSI components does not automatically apply to all country platforms in noncountry-specific publications.

The Influenzanet country-specific information in Table 3 was collated from publications gathered in the literature search (Table 2) and additional information provided by country representatives. The information in Table 3 was subsequently double checked, updated, and corrected by country representatives (in many cases, authors of papers themselves) through the help of the supervisor of the Consortium who communicated our findings. This verification step was important to prevent inaccuracies resulting from the misinterpretation of the literature because the absence of an ELSI component in a publication does not automatically imply that it was not addressed by the platform(s) and temporal evolution of these platforms, where ELSI components might change over time.

Only 3 of 11 national platforms (Belgium-the Netherlands and Denmark) did not seek ethical approval by REC before the launch of their platforms. The Swiss national platform [45] has obtained ethical approval for the launch of its mobile app before the start of the flu season 2017/2018. Registration and participation to the national platforms were open and nondiscriminative to all residents of the respective countries [12,14], except for the Swedish platform, where participation is through invitations only [17,18]. The Web-based information on the study was provided to all Influenzanet participants and informed electronic consents were obtained from participants in 9 of 11 national Influenzanet platforms. The electronic consent or so-called “e-consent” commonly used in studies without face-to-face contact, but where communication is entirely taking place via Web-based technologies, is another exception to, or adaptation of, traditional informed consent. Influenzanet uses this type of e-consent, where participants through a few clicks on a screen agree to the terms, conditions, and privacy policies of the research project.

The Belgium-Dutch and Danish platforms were the only exceptions where an informed e-consent was not legally required for participation (Influmeter, email communication, August 10, 2017) [6,20,21]. All Influenzanet users were allowed to withdraw from the research at any time. Participant identifiers used in Influenzanet (eg, pseudonyms and email addresses) were stored separately from the questionnaire data and not used during the data processing and analysis phases. Personal data from participants were, thus, anonymized before processing or analysis, which were performed at the aggregate level in all national platforms [14].

Table 2. A list of included studies (n=28) with ethical, legal, and social issue components (with ethical approval of study). All platforms listed by each paper do not satisfy the ethical, legal, and social issue components equally.

Author (year)	Platform(s) concerned	Ethical, legal, and social issue components					
		Research ethics committee	Open and non-discriminative participation	Web-based information sheet	Informed e-consent	Opt out from study	Personal data protection measures
Adler et al (2014) [27]	UK[a]	✓	✓				✓
Bajardi et al (2014) [28]	BE[b], FR[c], IT[d], NL[e], PT[f], SE[g], UK	✓	✓	✓	✓		✓
Bajardi et al (2014) [29]	BE, FR, IT, NL, PT, SE, UK	✓	✓		✓		✓
Brooks-Pollock et al (2011) [19]	UK	✓	✓	✓	✓		✓
Cantarelli et al (2014) [14]	BE, FR, IT, NL, PT, SE, UK	✓	✓	✓	✓		✓
Debin et al (2013) [30]	FR	✓		✓			✓
Debin et al (2014) [10]	FR	✓			✓		
Eames et al (2012) [31]	UK		✓				✓
Eames et al (2012) [32]	UK	✓	✓			✓	✓
Friesma et al (2009) [5]	BE, NL		✓	✓			
Guerrisi et al (2016) [33]	BE, FR, IT, NL, PT, UK		✓	✓			✓
Kjelso et al (2016) [20]	DK[h]		✓			✓	
Koppeschaar et al (2017) [17]	BE, DK, FR, IE[i], IT, NL, PT, SE, ES[j], UK	✓	✓	✓	✓		✓
Land-Zandstra et al (2016) [34]	BE, NL		✓	✓			
Loubet et al (2016) [35]	FR	✓		✓	✓	✓	✓
Loubet et al (2016) [36]	FR	✓		✓	✓	✓	✓
Marquet et al (2006) [21]	NL		✓	✓			✓
Paolotti et al (2010) [37]	IT		✓	✓			
Peppa et al (2017) [38]	UK	✓	✓		✓		
Perrotta et al (2017) [39]	IT		✓				✓
Perrotta et al (2017) [40]	IT		✓				✓
Pini et al (2017) [18]	SE					✓	✓
Smolderen et al (2007) [41]	NL		✓				✓
Tilston et al. (2010) [42]	UK	✓	✓	✓			
van Noort et al (2007) [11]	BE, NL, PT		✓	✓			
van Noort and Stollenwerk (2008) [43]	BE, IT, NL, PT		✓			✓	
van Noort et al (2015) [9]	BE, IT, NL, PT	✓		✓			
Vandendijck et al (2013) [6]	BE		✓			✓	✓

[a]UK: United Kingdom.
[b]BE: Belgium.
[c]FR: France.
[d]IT: Italy.
[e]NL: the Netherlands.
[f]PT: Portugal.
[g]SE: Sweden.
[h]DK: Denmark.
[i]IE: Ireland.
[j]ES: Spain.

Table 3. The ethical, legal, and social dimensions of Influenzanet national platforms (with research ethics approval of study).

National platform	Date of creation	Research ethics approval of study	Open and non-discriminative participation	Web-based information sheet	Informed e-consent	Ability to opt out from the study	Personal data protection[a]
Belgium (Flanders)	2003	—[b]	✓	✓	—	✓	✓
Denmark	2013	—[c]	✓	✓	✓[c]	✓	✓
France	2012	✓	✓	✓	✓	✓	✓
Ireland	2013	✓	✓	✓	✓	✓	✓
Italy	2008	✓	✓	✓	✓	✓	✓
Portugal	2005	✓	✓	✓	✓	✓	✓
Spain	2012	✓[d]	✓	✓	✓[d]	✓	✓[e]
Sweden	2011	✓	—	✓	✓	✓	✓
Switzerland[f]	2016	✓	✓	✓	✓	✓	✓
The Netherlands	2003	—	✓	✓	—[g]	✓	✓
United Kingdom	2009	✓	✓	✓	✓	✓	✓

[a]Data anonymization before processing and analysis.

[b]Not applicable.

[c]Influmeter, email communication, August 10, 2017-September 07, 2017.

[d]GripeNet Spain, email communication, August 10, 2017.

[e]Information obtained from the Spanish national platform [44].

[f]Swiss Influenzanet platform [45]. Grippenet Switzerland, email communication, September 12, 2017.

[g]De Grote Griepmeting The Netherlands, email communication, January 10, 2018.

Discussion

Principal Findings

To the best of our knowledge, this is the first scoping review examining the similarities and differences in the implementation of research ethics for the country platforms of Influenzanet. Our comparative tables highlight the need for further clarification and harmonization of these ethical issues pertinent to citizens engaging in the digital disease surveillance across the Consortium. A number of ELSIs are similarly organized in the Consortium, for instance, participation is open and nondiscriminative to all residents of these countries (except for Sweden for representativeness and comparison purposes [17]), study information is provided to all participants, and they are free to opt out from the study. However, a number of ELSIs are also addressed differently; for instance, REC approvals and informed e-consent were sought for recruiting participants and collecting their data in 8 of 11 and 9 of 11 platforms, respectively. The following sections of the discussion will highlight the discrepancies seen in the implementation of research ethics for different country platforms.

Overall, 8 platforms of the Consortium obtained REC approval before the start of their studies. However, it is not known how national RECs judged and approved their respective studies; for instance, they could have considered the gathered personal health-related data from participants to be fully anonymized for which no informed consent is required or considered studies to be human subject research. In the latter case, RECs would need to evaluate if the balance between potential benefits and risks for study participants is favorable and ensure that participants received adequate information on these risks and benefits. Our comparative table shows that all country platforms where REC approvals had been sought obtained informed e-consents from participants; this seems to indicate that these national RECs consider this type of citizen participatory research as human subject research and that e-consent is considered a valid form of consent in this context. The regional REC in Geneva approved the implementation of the Swiss platform and the launch of its mobile app as a data collecting tool. Considered as human subject research in Switzerland, a reader friendly informed e-consent is requested from potential participants. Because we did not have access to additional REC evaluations, further studies are needed to determine how RECs from different countries debated the ethical issues. It is also well known that national RECs, as well as RECs within the same country, may assess and balance risk-benefit ratios differently. These divergences concerning the evaluation of similar Influenzanet projects in different countries could interfere with the harmonization of ethical approaches. Thus, we suggest more transparency in terms of ethical issues related to this type of technology-driven public health research. For instance, project leaders of national Influenzanet platforms could publish a summary of how RECs evaluated and debated the ethical issues of their respective studies (eg, if their studies fall under the category of human subject research and, thereby, need informed consent procedures, etc). Such transparency could help to harmonize the ethical approaches to be adopted by the country platforms even further.

REC approvals were not sought for the Belgian-Dutch (*De Grote Griepmeting*) and Danish (*Influmeter*) platforms (Influmeter, email communication, August 10, 2017) [6,20,21]. However, their studies abided by their national legislation on privacy and personal data protection (Influmeter, email communication, August 10, 2017) [6,20,21,46]; for instance, the *De Grote Griepmeting* privacy regulation was approved by the Dutch Data Protection Authority [21]. According to the Belgian and Dutch legislations, these are observational studies because no physical or psychological intervention is intended on participants [6,21,47]. Concerning *Influmeter*, the Danish platform is exempted from the REC approval for the following reasons: the Danish Data Protection Agency does not consider emails exchanged between study participants and *Influmeter* to be sensitive personal information; there is an automatic implicit consent from study participants because of its voluntary nature even if sensitive information is gathered (eg, health and coarse-grained geographical data); and the data manager of *Influmeter*, *Statens Serum Institute* that hosts a large proportion of Danish health data [48] received a broad permission from the Danish Data Protection Agency (record number: 2008-54-0474), which covers the surveillance of infectious diseases and identifiable sensitive information gathered by *Influmeter* (Influmeter, email communication, September 7, 2017) [20].

Another ethical issue arises in Influenzanet owing to the ability of participants to record personal data on other household members (eg, the elderly persons and children). Gathering data on underrepresented age groups is important, specifically, when they are the ones most vulnerable to influenza in terms of morbidity and mortality [5]. However, it is difficult to verify whether these family members, in particular, are legally competent and could provide consent themselves, having expressed their will for their personal information to be recorded by the participating family member. It would be interesting to evaluate through future research whether RECs have considered this issue or have simply considered the data collected from other family members to be anonymous and, thus, not identifiable.

Informed e-consent was gathered from study participants from all platforms with the only exceptions being the Belgian and Dutch platforms, which are mirror websites of each other (*De Grote Griepmeting*, email communication, January 10, 2018). It can be argued that there is an automatic implicit consent for Belgian and Dutch participants because registration to the study is voluntary. The Belgium-Dutch platforms [16] might consider providing an informed e-consent option to their participants in an attempt to harmonize consent practices across the Consortium if ever they resume their activities in the future. However, we noted that it is not clear whether informed consent was legally necessary in Belgium ("Law on experiments involving the human subject" of May 2004) and the Netherlands because of the observational natures of their studies (*De Grote Griepmeting*, the Netherlands, email communication, January 10, 2018) [6,21,47]. Indeed, the Belgian and Dutch legislations acknowledge the need for informed consent for interventional studies because of the potential physical or psychological harm to participants [6,21,47], but the legislations do not clearly define how broad the category of observational studies is; for instance, a detailed questionnaire revealing some very personal information can be seen as an intervention in the Netherlands [49]. Nonetheless, it is important to understand the shift from typical physical or psychological harm seen in medical research to informational harm in public health research involving Web-based communities of volunteer citizens or big data (eg, data discrimination) with the latter having potential repercussions on the physical and mental states of study participants (eg, stigmatization and discrimination for health insurance coverage) [50,51].

Critics might say that e-consent gathered from Influenzanet participants does not represent valid informed consent because researchers cannot control that participants read and understood the information. Although information on studies is available on their respective websites, participants usually have to look at different sections of the website to gather pertinent information on the study (eg, its goals, privacy policies, etc), which is tedious and unlikely to be read in detail. The Swiss legislation requires researchers to ensure that participants have understood all the information (provided in the written information form) through personal contact. According to the *Ethics Guidelines for Internet-Mediated Research* by the British Psychological Society, a valid consent can be assumed if there is an information sheet defining the study objectives and exact nature of questions before filling in the questionnaire, including a check box at its beginning and end where participants can tick in to give their explicit consent [52]. In addition, the Society recommends using a proper wording for "I agree" statements to encourage participants to read the information sheet, which should also include their rights to withdraw from the study at any time in a user friendly manner [52]. The Consortium could follow these guidelines to enhance its e-consent procedures. It is important to ensure that participants agreed (by clicking on an "I agree" checkbox) to the terms, conditions, and privacy policies listed on the informed consent sheet before being allowed to fill in the questionnaire. Such measures should be taken to ensure the validity of the informed consent from participants and for harmonization purposes, a standard information sheet could be used throughout the Consortium.

Personal data protection was ensured throughout the Consortium because participant data are pseudonymized, that is, participants' personal identifiers are replaced with pseudonyms. Furthermore, any data that are shared with the public through the Web portal are fully anonymized and highly aggregated [14]. As to the anonymized data shared with members of the Consortium, it can be aggregated or not depending on whether the national partner who owns the data agrees to the request. It is also worth noting that sharing of Influenzanet data with internal and external researchers should not pose *a priori* any legal barriers because the General Data Protection Regulation of the European Parliament and the Council will not apply to data being rendered anonymous, that is, the information is not linked to an identified or identifiable natural person (Recital 26) and shared for research and statistical purposes [53]. From information gathered on some Influenzanet platforms (ie, France and Switzerland), it appears that linked anonymization [54] is involved in ensuring data protection, whereby participants' email addresses and

pseudonyms are stripped from the gathered health-related data before analysis and stored separately. It will be difficult to conclude how challenging or easy it could be to reidentify participants directly or indirectly from specific combination of variables (which are anonymous if considered in isolation but permit the identification if several of them are combined), in particular for vulnerable groups where privacy risks are higher [48] or groups with rare variable entries, for instance, large household compositions with >6 persons (that only account for 2% of households in the European Union [55]).

Our results show that there is a need to harmonize consent requirements and practice throughout the Consortium because differences in the abovementioned national consent requirements could be the source of obstacles for the next generation of data collection, which may include collection and sharing of more sensitive data on a larger scale. Thus, these differences could hinder future productive cross-national collaboration, which will be detrimental to research and quality disease surveillance. The consent requirements and practice could be harmonized through international or European Union regulations. However, this could take some time; for instance, General Data Protection Regulation aims to harmonize data protection laws within the 28 European Union Member States to ensure an equivalent level of protection and freedoms of individuals within the European Union. At the same time, it will protect cross-border flows of personal data on European Union citizens to international organizations or third countries [56,57]. A quicker harmonization alternative would be for all national platforms of Influenzanet to use the strictest consent requirements and practice currently used by one of their platforms to find common ground.This particular platform would then be used as a benchmark for other country platforms to harmonize their practices.

Limitations

Only English-language papers were screened for this study for practical reasons. It is, thus, possible that pertinent papers in other languages were omitted but they could have provided better insight into how issues related to research ethics are being handled by the Influenzanet Consortium. In addition, most of our conclusions are based on the gathered literature, and our interpretations might be biased by the incomplete reporting of all ELSI components in some publications as a matter of space or pertinance to their study objectives. Consequently, despite our collaboration with the Consortium to verify our claims, we cannot guarantee that our interpretations are error free. Another limitation is that we do not have access to projects' evaluation reports from RECs (except for Switzerland) to understand how they judge and approve such research projects. This would have been beneficial to the understanding of national differences in project evaluation by RECs, which could then serve as the basis for further harmonization of these ethical approaches.

Conclusions

Epidemics forecasting activities such as Influenzanet are beneficial. Harmonized criteria for dealing with ethical issues are urgently needed internationally to ensure comparability of data and maximize participants' trust. Approaches used in handling issues related to research ethics by different Influenzanet platforms seem to be similar in many, although not all, ELSIs at present. Thus, harmonizing ethical requirements across the Consortium is feasible and could be achieved through the adoption of the strictest ethical requirements and practice currently used by one platform across the Consortium. Nonetheless, despite being similar, it does not automatically mean that these ethical approaches are adequately regulated. We recommend more transparency in terms of ethical issues related to this type of technology-driven public health research. These transparency modifications related to the current ELSIs of Influenzanet will help to build trust among the members of the general public, in particular, if they are properly informed about the expected benefits and potential risks their participation entails; this will prevent any decline in participation, which might be triggered by mediatization, including exaggeration, of the risks of public health surveillance using Web-based communities of volunteer citizens.

Moreover, this type of research has the potential to save many lives in the future because it has proven through its flexibility, easy implementation, and adaptability to different countries' requirements for data collection to serve as a potentially effective and relatively low-cost surveillance tool for other diseases of public health importance (eg, Middle East respiratory syndrome or Ebola) [12,17]. These characteristics could allow Influenzanet to be deployed in low- and middle-income countries to monitor emerging and reemerging infectious diseases [17].

Our suggested harmonization measures and approach for data gathering and ethical requirements for Influenzanet apply to other Influenzanet-like systems. Moreover, we also suggest that such systems increase the validity of their informed e-consent procedures by following the excellent ethical guidelines provided by the British Psychological Society. Such measures will further increase the benefits Influenzanet and Influenzanet-like systems could bring to society by promoting the comparability of data and safeguarding participants' trust on which they rely almost completely for data collection. These will ensure that Influenzanet-like systems are making even greater substantial contributions to global public health and reduce the health inequalities in societies worldwide through better targeting of public health interventions in line with the concept of *precision global health* in the digital age [58].

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Authors' Contributions

All 6 authors contributed to the conception of this paper. LDG undertook the initial scoping literature search and was assisted by TW and BSE. TW and BSE supported LDG on the synthesis of the methodology and results sections. All authors contributed to the writing, editing, and critical evaluation of the manuscript. They approved the submission of the final version of the manuscript.

Conflicts of Interest

AF is one of the project leaders, and OW-M and DD are project coordinators of the Swiss Influenzanet platform.

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Abbreviations

BELIT: Bioethics Literature Database
EISN: European Influenza Surveillance Network
ELSI: ethical, legal, and social issues
ILI: influenza-like illness
REC: Research Ethics Committee

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Viewpoint

Approaches to Improve the Surveillance, Monitoring, and Management of Noncommunicable Diseases in HIV-Infected Persons: Viewpoint

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Abstract

Low-income and middle-income countries (LMICs) are undergoing an epidemiological transition, in which the burden of noncommunicable diseases (NCDs) is rising and mortality will shift from infectious diseases to NCDs. Specifically, cardiovascular disease, diabetes, renal diseases, chronic respiratory diseases, and cancer are becoming more prevalent. In some regions, particularly sub-Saharan Africa, the dual HIV and NCD epidemics will pose challenges because their joint burden will have adverse effects on the quality of life and will likely increase global inequities. Given the austere clinical infrastructure in many LMICs, innovative models of care delivery are needed to provide comprehensive care in resource-limited settings. Improved data collection and surveillance of NCDs among HIV-infected persons in LMICs are necessary to inform integrated NCD-HIV prevention, care, and treatment models that are effective across a range of geographic settings. These efforts will preserve the considerable investments that have been made to prevent the number of lives lost to HIV, promote healthy aging of persons living with HIV, and contribute to meeting United Nations Sustainable Development Goals.

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KEYWORDS

HIV; noncommunicable diseases; systems integration; epidemiologic surveillance

The HIV and NCD Syndemic

In high-income countries, antiretroviral therapy (ART) has improved the survival of persons living with HIV (PLHIV), resulting in declines in morbidity and mortality and a shift in the natural history of HIV disease [1-3]. With ART scale-up in the low-income and middle-income countries (LMICs), similar epidemiologic transitions are expected, resulting in an expanding and aging HIV population [4,5]. Since 2004, the US President's Emergency Plan for AIDS Relief (PEPFAR), in collaboration with local governments, has established HIV prevention, care, and treatment programs in over 30 countries worldwide [6], and the Global Fund to Fight HIV, Tuberculosis and Malaria has funded programs in more than 100 countries, including some PEPFAR-funded countries [7]. Globally, the provision of ART accelerated dramatically over the past decade, supporting 19 million PLHIV on ART through June 2016. When the Joint United Nations Programme on AIDS (UNAIDS) [8] 90-90-90 goals (90% of people with HIV diagnosed, 90% of them on ART, and 90% of them virally suppressed by 2020) are realized, AIDS-related opportunistic infections will become rare [9], and noncommunicable diseases (NCDs) will become increasingly prevalent among PLHIV [10-16].

The natural history of HIV for persons who are stable on ART is that HIV becomes a chronic disease with an increased risk of chronic comorbidities. These chronic conditions include, but are not limited to, cardiovascular disease [17], depression [18-20], cancers [21,22], and metabolic abnormalities, including insulin resistance with consequent dyslipidemia, type 2 diabetes, and lipodystrophy [23-25]. The increased prevalence of NCDs

among HIV-infected adults reflects a combination of factors, including aging, a greater prevalence of traditional risk factors, infection with oncogenic viruses, direct consequences of HIV (eg, inflammation), and exposure to specific antiretrovirals [26-36]. A recent systematic review examined the prevalences of the following 4 NCDs (and their risk factors) in LMICs that are known to commonly occur among PLHIV: cardiovascular disease, cervical cancer, mental health, and type 2 diabetes [37]. However, data were sparse for some diseases entities.

Increasing patient awareness of the effects of long-term HIV infection and effective levels of antiretroviral treatment, that is, viral suppression, particularly the shift to a predominance of chronic diseases, is important because this improved awareness may prompt patients to report symptoms and request screening for related conditions. Therefore, patient education can improve our ability to detect NCDs as they become more prevalent. An effective public health response to HIV, now that the epidemic is maturing, requires treatment and prevention of NCDs among PLHIV in LMICs. It is imperative to understand the predominant risk factors, the consequent symptoms and complications, and the available appropriate treatments and preventative interventions for each NCD.

If left unaddressed, NCDs may undermine the gains in healthy life-years realized by global health investments in HIV prevention and treatment [38]. The emerging NCD epidemic presents a unique opportunity to leverage the tremendous investments made in the existing HIV health platforms so that these enhanced health systems can deliver improved HIV care, which includes the prevention and treatment of chronic comorbidities to achieve further reductions in preventable deaths. Additionally, lessons learned from the public health approach in response to the HIV epidemic could be applied to the care and treatment of NCDs, given the chronic nature of both conditions. To understand this emerging syndemic, improved surveillance and clinical monitoring of NCDs among PLHIV are necessary to estimate the burden of and risk factors for NCDs among HIV-infected persons.

HIV surveillance has been shifting with the epidemic response over the past 2 decades. Reliance on sentinel surveys and AIDS case reporting was augmented with household surveys, community-based surveys, and HIV case reporting. The current trend is to move toward more routine data collection activities. Patient monitoring systems that capture a variety of health conditions, such as routine perinatal mother-to-child transmission surveillance, are becoming more important as increasing numbers of PLHIV are accessing care and treatment. Some comorbidities are already recognized as important to monitor, though these are primarily infectious, such as tuberculosis, hepatitis B, and hepatitis C. As effective ART continues to be scaled up across LMICs, chronic conditions will become more important to monitor because more PLHIV will achieve virologic suppression.

National HIV program responses would benefit from the integration of screening for NCDs known to be associated with or closely linked to HIV, for example, human papillomavirus-related cancers, such as cervical cancer, and cardiovascular disease [37]. As indicated by a recent systematic review, current efforts are limited to clinical cohorts or studies [37]. Routine screening is not presently being conducted in many clinical settings in sub-Saharan Africa (SSA) that offer HIV care; however, some efforts do exist [39]. General screening could include blood pressure measurement, height and weight assessment, lifestyle counseling including smoking cessation and physical activity promotion, tests for liver and kidney function, and cervical cancer screening. Given the similarities between HIV and NCD care and management, a coordinated approach to address both seems feasible and warranted [40]. Additionally, the resultant health systems' strengthening will facilitate improvements in health care coverage worldwide.

Benefits of Noncommunicable Diseases-HIV Integration

The PEPFAR HIV program has been criticized as a vertical disease-specific health system with regards to funding, supply chain, and clinician staffing [41-43]. Horizontal integration avoids these issues by taking a multi-disease approach to care [43,44]. Models such as chronic disease clinics have proven effective in treating diabetes, hypertension, and HIV and allow caregivers to take a patient-centered approach in responding to the health needs of PLHIV [45]. By preventing late-stage NCD presentation, horizontally-integrated care models minimize NCD-related mortality and may thus maximize cost-effectiveness if cost-prudent integration is employed [38]. Integrated models of care have also shown increased retention of patients with comorbid disease, thereby conferring improvements in adherence to treatment and continuity of care [41,43]. Lastly, integration of HIV and NCD monitoring and evaluation (M&E) systems allows for improved data collection and analysis pertaining to NCDs, which could then be used to support large-scale health policy change [46].

Barriers to Integration

The integration of NCD and HIV health care can lead to improvements in the quality of care and treatment; however, this enhancement of service provision can be costly. Initial overhead costs needed for service integration include training of clinical staff, procurement and distribution of laboratory reagents and medications, and greater supply chain needs. These costs can often be daunting for policy makers in resource-limited settings [47]. In integrated care systems, deficits in human resources for health, such as limited numbers of health care workers, can become problematic owing to the need for increased requirements for clinical services. Deficits here can lead to bottlenecking because of high patient loads and increased responsibilities for few clinicians [48,49]. Task-shifting can alleviate this bottleneck, but the cost of additional staff and training may be prohibitive.

Economically, integrating NCD care into LMIC HIV systems is only viable with buy-in from the government, external donors, and national constituents. As with PEPFAR for HIV care, countries may require infrastructural capacity building before they become capable of supporting these larger health care

systems on their own [50]. Although not universally feasible, an ideal solution would entail HIV programs providing the necessary infrastructure for NCD programs with multi-sectoral support and coordination, thus minimizing cost [51]. As countries transition from low-income to middle-income, an additional challenge is finding resources to support HIV programs as donor resources diminish in the face of competing health care demands. These demands include the need for additional financial and human resources in constrained situations. Finally, the integration of separate health systems creates a need for improved management practices. Standards to address selection biases, validity, and reliability of data sources are needed to ensure that robust data are collected. This will ensure that data from a variety of sources (eg, clinical systems, research, and M&E) are standardized to some extent and will limit missing and unreliable data. M&E systems must be expanded to include NCD screening and treatment services, and quality of care must be ensured through continued monitoring, evaluation, and medical education [43,49,52].

As NCDs become more prevalent, resource allocation needs to be informed by knowledge of the burden of disease and evidence-based interventions. Cost-effective models of comprehensive care of HIV, a chronic disease when viral suppression is achieved and maintained, that integrates management of NCDs associated with HIV are needed. The first step is leveraging surveillance systems to enhance our knowledge of the NCD burden among PLHIV by collecting information on risk factors and related morbidity. Several strategies to improve knowledge of disease burden exist, allowing public health officials to design or enhance interventions to reduce years of life lost. Among these are case-based surveillance and population-level monitoring systems; registries, which use medical records data for clinical surveillance; cohort monitoring in LMICs; and population-based surveys.

Case-Based Reporting and Population-Level Patient Monitoring Systems

HIV case reporting has been a part of second generation surveillance, as proposed by the World Health Organization (WHO) and UNAIDS, since 2000 [53]. Case-based reporting systems remain unevenly developed across LMICs [54,55]. The rapid expansion of ART and the promulgation of the 90-90-90 treatment targets have renewed the focus on case reporting, linked to patient monitoring systems, by WHO and UNAIDS. In settings where unique identifiers are available, HIV case report systems can be crossed with registries where they exist to link associated conditions; currently, cancer registries are the most prevalent [56]. Every effort should be made to protect patient privacy and ensure confidentiality as individual systems grow to collect more data elements and are linked to other systems. To strengthen overall patient care, the population-level HIV patient monitoring system, which is designed to track ART adherence and HIV viral suppression, can monitor conditions associated with both HIV infection and long-term exposure to ART. Population-level patient monitoring systems can capture risk factors such as hypertension and hyperlipidemia as well as outcomes such as cardiovascular disease and cancer [57]. Specific conditions that have a demonstrated link to HIV infection or long-term use of ART should be collected and reported, and appropriate responses should be developed for the patient and the population.

Registries

Registries collect clinical information of all patients diagnosed with a certain condition within a particular catchment area over a period of time and are particularly useful for patient care, especially in areas that lack population-level patient monitoring systems. Patients' information from participating clinics is entered into the registry after diagnosis of a particular NCD or identification of a person with previously diagnosed NCD(s) of interest; this registry contains all patients under the same participating health care provider or in the same facility who have the same NCD. The clinic data collected at each visit is entered into the registry or, ideally, automatically flows from the patients' medical records into the registry without additional resources required for data entry[58]. These data can then be aggregated at the regional or national level and can be used for cohort monitoring; program evaluation; tracking indicators for accountability to funders, policy makers, and stakeholders; and for performance reporting. Furthermore, at the patient level, registries can be used to track adherence, provide reminders for follow-up and preventative services as well as track health changes over time [59].

Registries range from a low-tech paper-based format to a higher-tech electronic format. An electronic medical records (EMRs) system is ideal because it allows for the data to be collected in real-time from a linked EMRs system, and individual or cohort outcomes can be more easily monitored. However, an EMR is not necessary [60]. As the number of cases grows, as expected for an NCD of interest, paper-based registries cannot work efficiently or accurately. Collecting patient data and manually creating a registry is time-consuming and takes health care staff away from patient care [61]. However, it is still a useful modality, and the lack of EMRs systems should not preclude the development of registries, at least in part, for improving patient care.

The creation of registries is important and prudent because the current management of NCDs is, in many places, unstructured and unmonitored. Through the creation of registries, health care systems can gain the ability to collect data on NCDs [62]. Reliable patient data at all levels are necessary for surveillance, forecasting drug and commodity procurement, human resource needs, and logistics required to keep the program on track [63]. However, it is important to ensure that any new data collection requirements render useful information and do not create an additional burden for the health care staff. Registries can also be structured to give feedback on performance, which serves as a benchmark to determine the quality of care and quality improvement at the level of individual providers, health care teams, or clinics. Registries can also be used to support clinical decision making; to allow providers to be proactive rather than reactive, for example, by setting up patient reminders about

needed services or follow-up visits; and to share data throughout a practice, among practices, and potentially throughout an entire health care system.

Ethical considerations may prevent the inclusion of name-based HIV status in a registry, requiring unique identifiers. However, even with unique identifiers, confidentiality may be lost if systems are not created with checks to ensure privacy. Therefore, precautions to protect the identity of individuals in both name-based HIV case report databases as well as databases that use unique identifiers must be taken, particularly in contexts where stigma and discrimination against PLHIV are strong.

Cohort Monitoring

An important use of registries is cohort monitoring [64], which is inspired by directly observed treatment, short-course for tuberculosis and provides a useful way of assessing whether interventions, as specified in the country guidelines for NCDs, are being performed as well as to track performance and progress of the intervention. This allows the country to review the progressive scale-up of those alive and on treatment and see where these patients are being treated (hospital, urban health center, rural health center, or private clinic). Furthermore, individual patient data can be deidentified and aggregated to determine morbidity and mortality levels for NCDs generally, generate incidence and prevalence rates of complications, and assess performance at local and national levels [59]. Successful application of the directly observed treatment, short-course monitoring system to patients with diabetes in Malawi [58] and those with hypertension in Jordan [61] has been reported.

Population-Based Surveys

The WHO-UNAIDS Technical Working Group on HIV Surveillance has advocated the use of population-based surveys to understand the risk factors for HIV and to determine HIV incidence and prevalence. As the HIV epidemic matures in SSA, these surveys should include questions about NCDs and related risk factors. Basic screening for diseases such as hypertension would be easy to employ as well [65]. Household surveys such as the Demographic and Health Surveys (DHS) collect data on screening for NCDs and HIV. Some DHS include testing for NCDs and HIV [66,67]; however, it is uncommon for DHS to routinely report on any associations. These data are publicly available and can be examined for associations, but this should become part of routine public health reporting. Additionally, the WHO STEPwise approach to surveillance should consider an HIV module for high-burden countries. This would allow for both general population and HIV-specific estimates of NCD burden, which would inform national policies and plans to address the growing NCD burden.

The PEPFAR-funded Population-based HIV Impact Assessment surveys are nationally representative, household-based HIV surveys that are used to provide subnational estimates for HIV prevalence and viral load suppression and national estimates for HIV incidence to measure the status of the HIV epidemic and impact of HIV prevention and treatment programs [68]. Data on demographic characteristics, risk behaviors, and testing and treatment history are collected through household and individual questionnaires. These surveys can also be leveraged to collect data about NCDs by including questions about NCD risk factors and diagnosed NCDs. Additionally, HIV testing is routinely performed with laboratory capacity to test blood samples, which provides an opportunity for screening for NCDs as well.

Mathematical Modeling

Given the limited data currently available concerning the NCD burden among PLHIV in LMICs, mathematical modeling could provide useful information about prevalence. The granularity of the prevalence rates may be limited based on available country-specific data for the models. However, with concerted efforts to collect meaningful data to inform these models, relevant figures could be generated. Currently, the Global Burden of Disease Study generates estimates for the prevalence of various diseases and has a Web-based tool that generates visualizations of these data [69]. As a next step, it may be imperative to develop a tool to generate the estimates of coburden of certain diseases such as HIV and tuberculosis or HIV and cardiovascular disease. Data of coburden can help us to identify syndemics and thus better focus our efforts and resources to prevent and treat these diseases.

Conclusions

With the success of the global effort to scale up ART access, LMICs, particularly those in SSA, in which mortality has been dominated by HIV over the past decades, will start to experience syndemics. Increasingly, mortality attributable to NCDs will be greater than communicable diseases as it is in the rest of the world. Improved data collection and surveillance of NCDs among HIV-infected persons in LMICs are necessary to inform integrated NCD-HIV prevention, care, and treatment models that are effective across a range of geographic settings. Implementation of integrated care will strengthen current health systems and facilitate a platform for more comprehensive and less fragmented health care delivery as well as M&E systems. These efforts will preserve the considerable investments that have been made to prevent lives lost to HIV, promote healthy aging of PLHIV, and contribute to meeting United Nations Sustainable Development Goals [70]. Additional incremental investments in NCD management among PLHIV could broaden health care coverage and support a research agenda, which would benefit both PLHIV and the general population. Furthermore, as countries start to achieve HIV epidemic control, the integration of HIV and NCD management will provide a transition plan for extending the comprehensive care provided to PLHIV to the general population; this will facilitate the goal of improved overall access to health care.

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Conflicts of Interest

None declared.

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Abbreviations

ART: antiretroviral therapy
DHS: Demographic and Health Surveys
EMR: electronic medical record
LMIC: low-income and middle-income countries
M&E: monitoring and evaluation
NCD: noncommunicable diseases
PEPFAR: President's Emergency Plan for AIDS Relief
PLHIV: persons living with HIV
SSA: sub-Saharan Africa
UNAIDS: Joint United Nations Programme on AIDS
WHO: World Health Organization

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Original Paper

Where No Universal Health Care Identifier Exists: Comparison and Determination of the Utility of Score-Based Persons Matching Algorithms Using Demographic Data

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Abstract

Background: A universal health care identifier (UHID) facilitates the development of longitudinal medical records in health care settings where follow up and tracking of persons across health care sectors are needed. HIV case-based surveillance (CBS) entails longitudinal follow up of HIV cases from diagnosis, linkage to care and treatment, and is recommended for second generation HIV surveillance. In the absence of a UHID, records matching, linking, and deduplication may be done using score-based persons matching algorithms. We present a stepwise process of score-based persons matching algorithms based on demographic data to improve HIV CBS and other longitudinal data systems.

Objective: The aim of this study is to compare deterministic and score-based persons matching algorithms in records linkage and matching using demographic data in settings without a UHID.

Methods: We used HIV CBS pilot data from 124 facilities in 2 high HIV-burden counties (Siaya and Kisumu) in western Kenya. For efficient processing, data were grouped into 3 scenarios within (1) HIV testing services (HTS), (2) HTS-care, and (3) within care. In deterministic matching, we directly compared identifiers and pseudo-identifiers from medical records to determine matches. We used R stringdist package for Jaro, Jaro-Winkler score-based matching and Levenshtein, and Damerau-Levenshtein string edit distance calculation methods. For the Jaro-Winkler method, we used a penalty (p)=0.1 and applied 4 weights (ω) to Levenshtein and Damerau-Levenshtein: deletion ω=0.8, insertion ω=0.8, substitutions ω=1, and transposition ω=0.5.

Results: We abstracted 12,157 cases of which 4073/12,157 (33.5%) were from HTS, 1091/12,157 (9.0%) from HTS-care, and 6993/12,157 (57.5%) within care. Using the deterministic process 435/12,157 (3.6%) duplicate records were identified, yielding 96.4% (11,722/12,157) unique cases. Overall, of the score-based methods, Jaro-Winkler yielded the most duplicate records (686/12,157, 5.6%) while Jaro yielded the least duplicates (546/12,157, 4.5%), and Levenshtein and Damerau-Levenshtein yielded 4.6% (563/12,157) duplicates. Specifically, duplicate records yielded by method were: (1) Jaro 5.7% (234/4073) within HTS, 0.4% (4/1091) in HTS-care, and 4.4% (308/6993) within care, (2) Jaro-Winkler 7.4% (302/4073) within HTS, 0.5% (6/1091) in HTS-care, and 5.4% (378/6993) within care, (3) Levenshtein 6.4% (262/4073) within HTS, 0.4% (4/1091) in HTS-care, and 4.2% (297/6993) within care, and (4) Damerau-Levenshtein 6.4% (262/4073) within HTS, 0.4% (4/1091) in HTS-care, and 4.2% (297/6993) within care.

Conclusions: Without deduplication, over reporting occurs across the care and treatment cascade. Jaro-Winkler score-based matching performed the best in identifying matches. A pragmatic estimate of duplicates in health care settings can provide a corrective factor for modeled estimates, for targeting and program planning. We propose that even without a UHID, standard national deduplication and persons-matching algorithm that utilizes demographic data would improve accuracy in monitoring HIV care clinical cascades.

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KEYWORDS

deterministic matching; score-based matching; HIV case-based surveillance; unique case identification; universal health care identifier

Introduction

In Sub-Saharan Africa, HIV case-based surveillance (CBS) has not yet been implemented to its full potential yet it is one of the recommended methods for second generation HIV surveillance [1,2]. Second generation surveillance systems advanced beyond initial epidemic monitoring approaches that focused on aggregate numbers to use of individual-level clinical data. Within CBS, individual patient demographic attributes can be linked to key clinical events over time allowing for individual tracking. Hence, HIV cases are tracked from (1) diagnosis, (2) linkage to care, (3) antiretroviral treatment (ART), (4) viral suppression, and (5) other outcomes such as retention in care, transfer-out, and loss to follow up or death. This level of follow up is useful for developing epidemiological profiles at the smallest geographical units [3], monitoring of the HIV care and treatment clinical cascades, and measuring achievement of the Joint United Nations Program on HIV and AIDS (UNAIDS) Fast-Track 90-90-90 targets [4].

Case-based surveillance has advantages over aggregate data reporting systems since it uses individual-level data, allowing for better tracking of treatment course and outcomes. Case-based surveillance can also more accurately show trends and event sequences in the HIV epidemic, for example, trends of time to linkage to treatment from HIV testing or even changes in the clinical cascade over time [5]. Though CBS has been shown to be feasible in low resource settings [6], accuracy in CBS is contingent upon unique patient identification and correct record linkage from HIV diagnosis through the treatment course, due to the longitudinal nature of HIV care and multiplicity of data sources and care settings. Moreover, record linkage is useful for attaching records to a residence and geographic locality for example, in demographic and health surveillance systems where individuals are tracked routinely in their households [7], for data aggregation, and to facilitate correct assessment of program coverage.

There are 2 broad approaches to matching and records linking by using personally identifiable information (demographic data matching) and using a universal health care identifier (UHID) assigned to uniquely identify persons within a health care setting. Some of the earlier use cases for persons matching include immunization programs [8,9], and in other settings where unique identification is important such as a national census [10,11]. Though less common in settings such as HIV care and treatment programs, unique patient identification has recently and increasingly become important as patient volume grows in these settings. In HIV care and treatment, patient volume continually increases and so does the need for electronic medical records (EMRs). There are commensurate benefits of EMRs over paper records such as improved patient care coordination and clinical decision support [12]. Electronic medical records improve the capture of patient identifiers including UHIDs needed for longitudinal patient follow up. The utility of UHID for longitudinal follow up of patients has been demonstrated through correcting misclassification of the final patient outcomes such as loss to follow up in highly mobile populations. For example, in South Africa, a study among postpartum women found that a third may be misclassified as having been lost to care [13]. As a chronic condition, HIV care entails the use of HIV services by patients at multiple locations over a lifetime. Additionally, individuals may get an HIV diagnosis at one facility and choose to engage in HIV care at another location, they may receive a diagnosis in more than one care setting, and patients may move HIV care locations with or without notifying health care staff.

While UNAIDS recommends patient-centered colocation and integration of services across care settings such as antenatal care, tuberculosis, and HIV [4], colocation is not always feasible and hence tracking patients across the cascade of treatment can be difficult without a UHID and reliable EMR. Even when a government identification document is issued at adulthood, use of its unique number for reproductive and health care services is limited by acceptance and excludes younger populations. Additionally, name and location matching may be used where patient details such as names and locator information exist [14], but have limited utility in mobile populations. In the absence of a UHID, biometrics such as fingerprints are recommended [15] and may be used among HIV infected patients receiving care [16]. Other forms of patient identification, for example, the HIV comprehensive care clinic (CCC) medical record number used in Kenya suffers from low portability since they may not be permanent when a patient reinitiates care in a different facility. Program-identifiers have limited potential for a national surveillance system since they are unique to issuing facility. Hence, patients may acquire a new identifier when they transfer to a different facility resulting in unlinked data [17].

Given the chronic nature of HIV infection, integrating care across multiple service providers is essential. Nonetheless, unique patient identification in HIV programs, especially in Sub-Saharan Africa is rarely harmonized across service providers [18]. Without a unique patient identifier, if name and location data are available, they may be used to link medical

records [14]. Therefore, demographic data have utility in records linkage. There are 2 types of algorithms for records matching, allowing for subsequent linkage and deduplication. The first is deterministic matching—a stepwise procedure in which sets of rules are used to pair up records based on actual or pseudo-identifiers identifying them as either a match or belonging to different persons. The second is score-based matching which refers to arithmetical models used to classify record pairs based on calculating a string distance measure quantifying how dissimilar 2 strings or words are to 1 another and applying a decision rule such as a score. The score is then used to determine whether duplicate records belong to the same individual.

Persons matching using score-based demographic data matching algorithms may be feasible for patient clinical encounter data and surveillance where demographic data is documented. However, there is a lack of data on the utility of score-based demographic data matching methods and how they compare with deterministic matching in low-resource settings including Sub-Saharan Africa. We used data from a pilot of HIV case-based surveillance in Siaya and Kisumu—two high HIV-burden counties in western Kenya to (1) compare deterministic and score-based patient matching algorithms and (2) propose an efficient algorithm for deduplicating and uniquely identifying HIV cases in CBS data collection and reporting in Kenya and similar settings.

Methods

Study Setting

This HIV case-based surveillance pilot was conducted between July 2015 and December 2015 in 124 facilities in Kisumu and Siaya counties. The facilities were selected to represent a variety of settings such as levels of care (dispensary, health center, subcounty, and county referral), use of an EMR versus paper records, and size of the patient population. Data were collected retrospectively to allow for at least four months of follow-up time from initial diagnosis, entry into care, or ART initiation within the study period. Data were collected by subcounty AIDS and sexually transmitted infections (STI) coordinators and Kenya Medical Research Institute (KEMRI) surveillance officers, and in some cases, facility staff. Data were entered from paper medical records and registers into the customized data entry platform for cases newly diagnosed or newly enrolled in HIV care from January through June 2015 using Android-based tablets and a standardized HIV case report form. Surveillance officers were trained in data collection using tablets and provided with login credentials. All surveillance officers signed a data confidentiality statement. As collected data contained patient names and other patient identifiers they were encrypted before transmission via a dedicated virtual private network in real-time to a server hosted on the Amazon cloud computing service. The staff at the National AIDS and STI Control Program (NASCOP) managed the data [19].

A case was defined minimally to include the date of diagnosis, age at diagnosis, gender, first name, and surname. Cases originated from the following 3 scenarios and analytical frameworks relating to the HIV care cascade. The first scenario is within HIV testing services (HTS). This scenario accommodates cases found within the same facility (cases that were tested at the facility and retested at the same facility hence having different dates of diagnosis). It also included cases that moved to a different facility (cases that tested at one facility and retested at a different facility). The second scenario is HTS-care. This accommodated HTS-to-care scenario in which cases were tested and linked within the same facility. It also included HTS-to-care cases that would be tested at one facility and then linked to care in a different facility. These 2 scenarios accounted for movement of persons diagnosed with HIV and accessing care within the same facility and clients that may test at one facility and access care in a different facility. The third scenario is within care scenarios. This included referrals and linkages from one facility to another. Similar to HTS-to-care linkage scenarios some cases had enrolled into care in one facility and throughout care transferred to another facility. However, HTS was not a source of data for the diagnosis information, and hence we did not have any testing location information for these cases.

Data Collection

Methods for data collection are described in the HIV case-based surveillance pilot report [19]. Briefly, data were extracted prospectively for everyone newly diagnosed or enrolled in care in a given 6-month period in the participating facilities and subsequent updating of sentinel events for those individuals. At the end of the pilot, we had 12,260 records but excluded 100 which had a missing date of diagnosis and 3 which had a missing date of birth before matching (Figure 1).

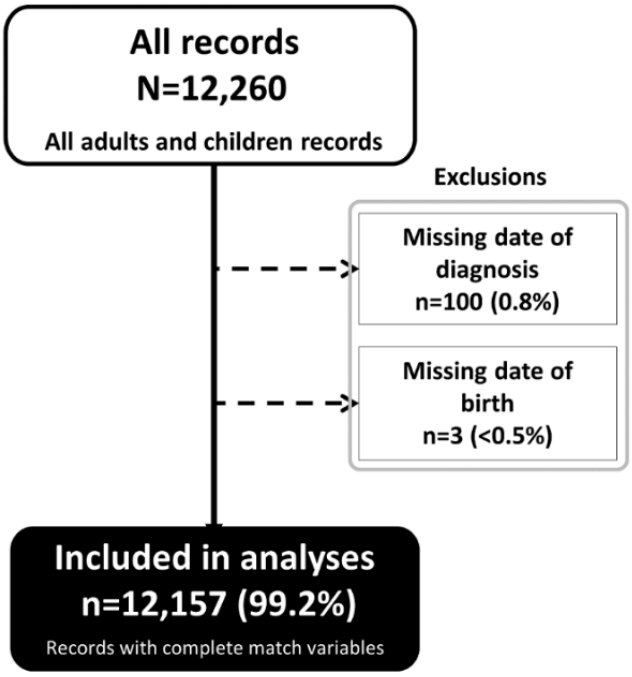
Data Preparation and Standardization

We created analytical groups—also called “blocking” according to the scenarios described in the study setting before carrying out matching analyses to allow for comparability and faster processing,

Before carrying out matching processes, we standardized patient identifying fields used in matching. First, all blank spaces, commas, apostrophes, and dashes were stripped from first names middle names and surnames. Second, all string fields were converted to lower case. A Soundex [20] was created for the first names in all records since the first names are mostly of English origin. Third, we created double metaphone for middle names and surnames. Fourth, the year of birth was standardized to a four-digit number.

A potential patient identifier for the deduplication process is CCC number which is a unique patient number assigned at first clinical encounter once an HIV-infected patient has gone through triage and is ready for enrolment into a facility-managed HIV program. The CCC number is an 11-character code comprising a 5-digit unique facility code followed by a separator and a 5-digit sequentially facility-assigned unique number. We standardized CCC numbers to consider variations in recording (eg, use of spaces, slashes, dashes, adding leading zeros, and commas).

Figure 1. Number of records used for deterministic and probabilistic matching, HIV case-based surveillance in Kenya (2015).



Deterministic Matching

We used the following fields in deterministic matching (1) the first name, (2) surname, (3) gender, and (4) year of birth. To reduce mismatching due to variation in spellings of English first names, we used Soundex. We then created a "pseudo-unique key" combining the resulting Soundex values as well as gender, surname, and year of birth. The CCC numbers were used to match care records that were missed by using the "pseudo-unique key."

Score-Based Matching

We separated the data according to the "blocking" scenarios described in the deterministic process. These blocking scenarios are necessary so that comparisons are made among potentially related records. We used R (an open-source software) in our study since it provided programming flexibility to implement the matching string preparation and matching process. We created a matching key field by including the data elements (1) first character of gender at birth, (2) Soundex of the first name, (3) secondary double metaphone of middle name, (4) secondary double metaphone of surname, and (5) year of birth. This produced strings such as "fF465aknannk1983," "fI650aknkannk1990" (where middle name secondary double metaphone was available), and "fG620ans1994" (where secondary double metaphone of the middle name was unavailable). We then implemented Jaro and Jaro-Winkler string matching and Levenshtein and Damerau-Levenshtein string edit distance algorithms in the R stringdist package [21,22]. String score-based matching was conducted using ratios of matching strings, and a penalty was applied for the first 4 characters when Jaro-Winkler algorithm is used as in the formula (Figure 2) where d_j is the Jaro-Winkler distance score, m is the number of matching characters, $|s_1|$ is length of string 1, $|s_2|$ is length of string 2 and t is half the total transpositions or the number of matching (but different sequence order) characters divided by 2. String edit distance calculations, on the other hand, quantify how different 2 strings or words are to one another by counting the minimum number of deletions, insertions, substitutions and transposition operations required to transform 1 string into the other. Score-based methodologies are based on the Fellegi-Sunter linkage rule that classifies a record pair as matching or nonmatching [11]. The score level to determine a match is determined a priori or based on experience by the user and dependent on the setting. For our case, a score of 98% and above was considered sufficient to determine a match. When we implemented the Jaro and Jaro-Winkler methods, we set a standard penalty factor to 0.1. This penalizes matches based on similarity at the beginning of the string to give favorable ratings to strings that match from the beginning for a set prefix length of up to 4 characters according to Winkler and Cohen [11,23]. The penalty factor is added to discount matches that are found based on up to a maximum of first 4 characters since in string writing, the person recording is more likely to make an error after the first 4 characters. We considered the 4 weights (ω) applicable to the Levenshtein and Damerau-Levenshtein methods (1) deletion (ω=0.8), (2) insertion (ω=0.8), (3) substitutions (ω=1), and (4) transposition (ω=0.5). For the Levenshtein method, the penalty for substitution is ignored [22].

Due to possibilities of age variations for the same person accessing HTS and care services at differing periods, the numeric comparator age, with a variation of not more than 12 months within identified matches was considered sufficiently close for confirming a match. We compared deterministic and score-based processes for unique case identification regarding the number of matches yielded and the deduplication extent achieved within the scenarios. We also assessed match yield when HTS and HTS-care records were treated as mutually exclusive versus as a combined set. Regardless of approach, total yield was a sum of duplicates from all scenarios.

Figure 2. The Jaro-Winkler equation.

$$d_j = \frac{1}{3}\left(\frac{m}{|s_1|} + \frac{m}{|s_2|} + \frac{m-t}{m}\right)$$

Postmatch Processing

Based on the date of HIV diagnosis, we carried out extra steps to determine how to retain unique records after the matching process. If the retained and duplicate records had conflicting dates of diagnosis, we retained the records with the earliest date of diagnosis. For retained records, we maximized completeness of data for all fields by comparing with the duplicate records. Whenever a retained record had missing data that was in duplicate record, an append merge was carried out to overwrite missing values with the nonmissing value from the matched record.

Ethical Considerations

Ethical approval was obtained from the KEMRI (SSC #2827) and the Office of the Associate Director for Science, Centers for Disease Control and Prevention (CDC) with tracking #2014-136. Access to data used in these analyses was password protected, and all study coordinators, data abstractors, and analysts signed a confidentiality form.

Results

HIV Case Records and Demographic Data Variables

A total of 12,260 records were collected. We excluded 100 (0.8%) records due to missing dates of diagnosis, and 3 (0%) missing the date of birth (Figure 1). The final data set used for the matching exercise included 12,157 records representing adult and pediatric cases. From these records and before data deduplication, 33.5% (4073/12,157), 9.0% (1091/12,157), and 57.5% (6,993/12,157) corresponded to HTS, HTS-care and within care scenarios respectively. In Table 1, completeness and uniqueness of variables used to construct score-based matching string are presented. In the entire data set, gender, year of birth, first name and surname were 100% complete while the middle name was missing for 38% of the records. First names were less unique than surnames: 8.2% (1002/12,157) versus 19.1% (2321/12,157). When Soundex was applied to standardize the English first names, 273/12,157 (2.2%) remained unique compared to 1002/12,157 (8.2%) of the original unstandardized format. When secondary double metaphone was applied to standardize the middle and surnames, 2.6% (316/8772) and 3.1% (373/12,157) respectively remained unique compared to 13.1% (1150/8,772) and 19.1% (2321/12,157) of the original unstandardized format. The similarity of names varied by setting (Table 1).

Matches Identified

Out of the 12,260 records, 12,157 (99.2%) were used in the analyses. Using the deterministic method, 67/12,157 (1.6%) records were matches in HTS, 164/12,157 (15.0%) in HTS-care, and 204/12,157 (2.9%) in the care-only scenario. This yielded a total of 435/12,157 (3.6%) matches and 11,722 unique cases across the testing and, care and treatment cascade (Table 2).

Overall, of the score-based methods, Jaro-Winkler yielded the most duplicate records (686/12,157, 5.6%), Jaro yielded the fewest (546/12,157, 4.5%), and both Levenshtein and Damerau-Levenshtein yielded the same number (563/12,157, 4.6%). Specifically, duplicate records yielded by method were: (1) Jaro 5.7% (234/4073) within HTS, 0.4% (4/1,091) in HTS-care, and 4.4% (308/6993) within care, (2) Jaro-Winkler 7.4% (302/4073) within HTS, 0.5% (6/1091) in HTS-care, and 5.4% (378/6993) within care, (3) Levenshtein 6.4% (262/4073) within HTS, 0.4% (4/1091) in HTS-care, 4.2% (297/6993) within care, and (4) Damerau-Levenshtein 6.4% (262/4073) within HTS, 0.4% (4/1091) in HTS-care, and 4.2% (297/6993) within care.

Table 1. Completeness and uniqueness of demographic fields used in the matching process for HIV case-based surveillance in Kenya 2015 (N=12,157).

Fields	Completeness (%)	Unique[a] (n)	Out of n (%)
Gender[b]	100	2	12,157 (0)
Year of birth	100	6	12,157 (0)
First name	100	1002	12,157 (8.2)
Soundex of first name	100	273	12,157 (2.2)
Middle name	72	1150	8772 (13.1)
Phonetic middle name[c]	72	316	8772 (3.6)
Surname	100	2321	12,157 (19.1)
Phonetic surname[c]	100	373	12,157 (3.1)

[a]Unique refers to similar occurrences of the field (eg, only two types of gender).

[b]Two statuses possible (male or female).

[c]Secondary double metaphones for standardizing Kenyan native names.

Table 2. Scenarios in HIV diagnosis, care and treatment cascade, and deduplication yield for HIV case-based surveillance in Kenya 2015.

Scenarios	Deterministic matching method, n (%)	Matches identified for each score-based matching algorithm, n (%)			
		Jaro	Jaro-Winkler	Levenshtein	Damerau-Levenshtein
All[a] (N=12,157)	435 (3.6)	546 (4.5)	686 (5.6)	563 (4.6)	563 (4.6)
HTS[b] (n=4037)	67 (1.6)	234 (5.7)	302 (7.4)	262 (6.4)	262 (6.4)
HTS-care[c] (n=1091)	164 (15.0)	4 (0.4)	6 (0.5)	4 (0.4)	4 (0.4)
Care only[d] (n=6993)	204 (2.9)	308 (4.4)	378 (5.4)	297 (4.2)	297 (4.2)
Unique[e]	11,722 (96.4)	11,611 (95.5)	11,471 (94.4)	11,594 (95.4)	11,594 (95.4)

[a]Summed up for all the scenarios.

[b]HTS: HIV testing services (records where data were primarily from the HTS setting and the records contained HIV diagnosis data only).

[c]HTS-care (records that contained both HTS and HIV care information).

[d]Care only (records from primarily HIV care with no additional HTS records).

[e]Unique records after deduplication.

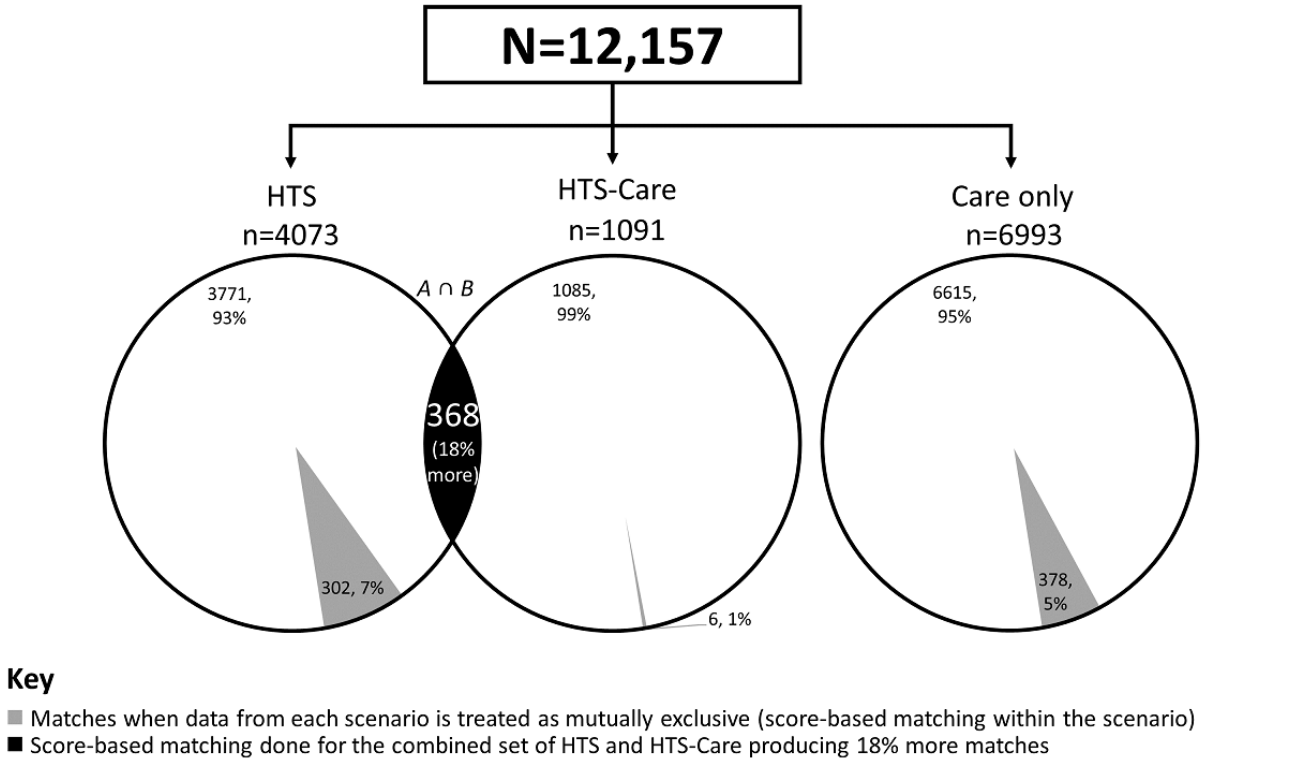
Jaro-Winkler Yield for Mutually Exclusive and Combined Data Sets

A comparison of Jaro-Winkler yield for mutually exclusive and data sets that were combined across the scenarios is presented in Figure 3. When scenarios were treated as mutually exclusive, Jaro-Winkler score-based matching algorithm yielded 7.0% (302/4073) matches in the HTS scenario, 1% (6/4073) in the HTS-care scenario compared to a higher yield of 7.1 % (368/5164) when the 2 scenarios were treated as 1 block.

Steps for Score-Based Matching and Considerations

Based on the outcomes of the score-based matching process, we propose a procedure comprising of 7-steps that is easy to apply to quickly match and link unique cases across HIV care settings (Textbox 1). To decide whether or not to use demographic data matching, we propose a decision model (Figure 4).

Figure 3. Percent match yield by blocking scenarios using Jaro-Winkler score-based matching, HIV case-based surveillance in Kenya (2015). HTS: HIV testing services; HTS-Care: records from HTS-care scenarios; Care only: records from care scenarios only. A ∩ B indicates that the intersection of HTS and HTS-case records yields 386 matches (18% more matches than in mutually exclusive matching).



Textbox 1. Expandable simplified steps used in the demographic data matching process.

Step 1: Select data sources

- Select data sources with common fields
- If additional sources are available, add to the list

Step 2: Prepare the data

- Cleaning and coding
- Standardizing fields

Step 3: Create a match-string

- Ensure mutually exclusive blocks
- Test internal validity

Step 4: Create blocks

- Ensure mutually exclusive blocks
- Test internal validity

Step 5: Run the matching algorithm

- Apply a match rate of ≥98%
- Test in a small identified data set and adjust the match rate

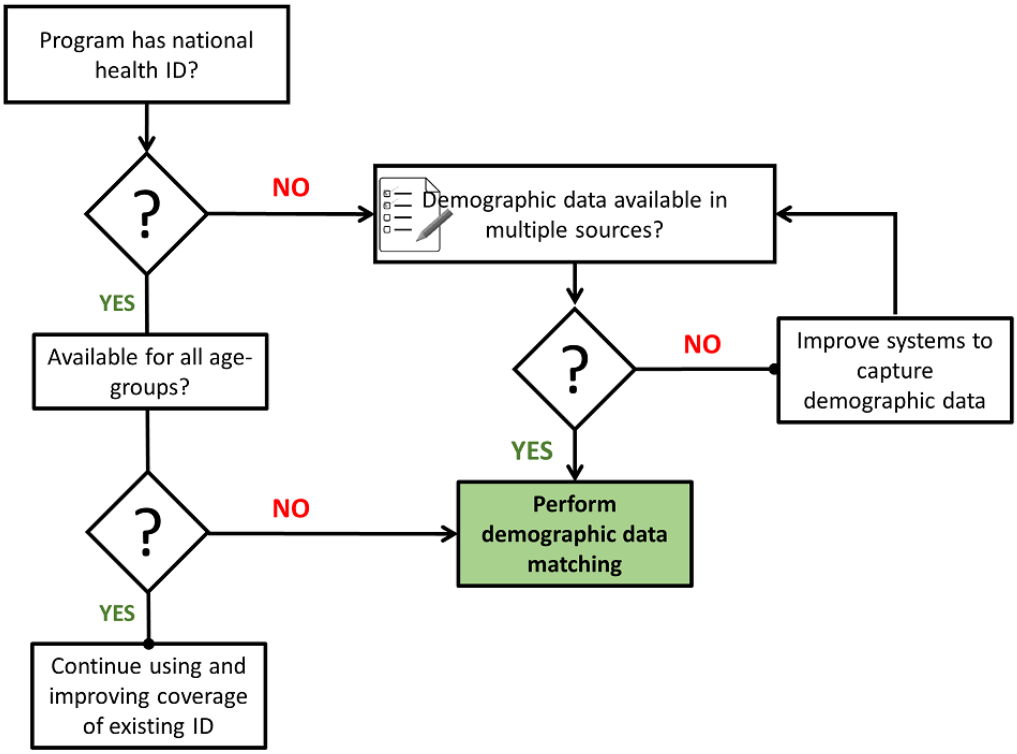
Step 6: Merge the data

- Update records that need an update
- Create a master patient index

Step 7: Adjudication, quality checks, and use cases

- For care coordination, recheck that the matches are correct
- For surveillance and indicator reporting, use a combination of the matched but deduplicated records and the unmatched records

Figure 4. Decision model for when to use score-based matching.



Discussion

Principal Findings

Universal health care identifiers are recommended and ideal for patient-centered monitoring and CBS [24,25]. However, in low resource settings, their use is limited. In the interim, demographic data score-based matching algorithms can play an important role in improving the quality of CBS data as well as patient-centered care. We have demonstrated that score-based methods succeeded in patients matching and identifying more matches compared to the deterministic process. It is possible to match cases, merge sentinel events, and enhance the completeness of individual deduplicated data using this process. Consequently, this improves accuracy in CBS and other longitudinal encounter data. The process also has a dual utility of allowing better care coordination and patient management at the facility level and improved HIV surveillance at a higher subnational or national level. The matching process can be inbuilt in EMRs and at patient registries to allow for lookup of already registered patients at the facility level. This may improve processes, patient flow and avoid unnecessary double entry. We also demonstrate that we can do enough matching in the absence of a UHID to move ahead with CBS implementation in low-resource settings such as Kenya. As such, lack of a UHID should not stifle movement towards the use of CBS.

Score-Based Matching Yield

Our study compared 4 variants of score-based string-distance matching methods. The Jaro-Winkler distance method was found to perform better in score-based matching since it gave the best yield while considering common spelling mistakes and logical combination of demographic fields. In developed countries, it has been shown that about 5% to 10% of medical records may be duplicate [26], which compares well with our results. Jaro-Winkler has been proposed as a method over other string-matching algorithms since it was designed with relatively short strings in mind [21], hence may be best suited to our setting. In addition, it works well when the name beginnings are the same [27]. For that reason, we standardized beginning of the match strings by using a Soundex of the English names and using secondary double metaphone of middle and surnames. Further, a decision was made to add the first character of gender at birth to the beginning of the string to improve the accuracy of the matching score.

Application Considerations

Although we used R in our analyses and matching process, open source software such as CDC Registry Plus Linkplus [28], which was originally developed for cancer registries has been explored in low-resource HIV care settings for example in Haiti [29]. Other Web-based applications that have utility for fuzzy matching and record cleaning, for example, Freely Extensible Biomedical Record Linkage [6], may have potential. However, post-match processing is necessary to achieve a high degree of true matches. A certain degree of human adjudication may be necessary especially when testing the algorithms. Users of off-the-shelf solutions such as Linkplus should take caution since many mismatches may be likely to be true matches [29]. The use of current English name-based Soundex algorithms is not appropriate for Kenyan names. In creating unique identifiers that contain a Soundex component, variations of the first name can yield a different Soundex since the first character is always part of the Soundex [20]. A visual inspection of matches based solely on Soundex of first and surname showed a high false-positive rate. Research on how to construct a Soundex algorithm for Kenyan names may be useful as has been

successfully done in Japan, India, and South Africa [30-32]. We determined that using a double metaphone had discriminatory power for Kenyan names and hence we used it for middle and surnames.

Limitations

Our study has several limitations. First, the choice of a combination of several fields for a concatenated "pseudo-unique key" may not be optimal. However, we developed the matching string taking advantage of existing identifiers in our data. First names in Kenya are usually English baptismal or anglicized names. We took advantage of this to standardize names that are misspelled using Soundex. Other challenges include manual transcription errors during patient transfers and assigning of new numbers for transfer-in patients. Despite these limitations, we were able to merge the cases based on the names, gender, date of birth and CCC number in the within care scenario and hence identify potential matches in the deterministic process. Finally, many studies have applied common measures of validity such as positive predictive value, sensitivity, and specificity [33]. Unlike those studies, we did not have a gold standard for comparison in the pilot.

The choice of which string distance score-based algorithm to use largely depends on the nature of the match strings and the nature of typographic errors [21]. Choice of the matching string is therefore important. For example, deterministic matching yielded more duplicates for the HTS to care scenario (15%) compared to 4.6% to 7.1% across the score-based methods. This may be because a rigorous manual assessment of possible matches was done using the CCC numbers such that matches within the HTS to care scenario were more efficiently captured. Minimalistic demographic fields were used in score-based matching across all scenarios, and the CCC number was not included in the process.

Conclusions and Recommendations

There has been an ongoing discussion and suggested approaches for countries to consider in developing UHIDs [17,34]. If, and when implemented, UHIDs would have the highest potential to mitigate challenges with a unique identification and record linkage for an expanded national CBS system. This benefit extends to other health sectors as countries move towards universal health care. The recent World Health Organization guidelines for patient-centered monitoring advocate for using unique patient identifiers instead of names [25]. However, where there is no UHID, a unique patients' deduplication algorithm based on available demographic data is necessary and feasible. Such an algorithm would improve monitoring of the HIV epidemic including the UNAIDS Fast-Track 90-90-90 targets.

We propose a stepwise process that builds up from first identifying data sources and blocking scenarios. This should be followed by an examination of the data quality using completeness as a measure coupled with quality improvement measures through routine data quality audits. The next step involves developing a matching key, lower-level deduplication and finally cross-examination, validation and sending of CBS data to the national level for surveillance. Although validation of the score-based approach is a necessary extra step, this may be best done with data sets from settings where a gold standard is available such as those utilizing biometric finger vein technologies for patient identification. Given that these settings are rare, we suggest that programs identify a percentage that best suits their setting and resources for validation purposes. A decision model such as the one presented in Figure 4 may help programs to decide whether or not to use demographic data matching. Comparing score-based matches to gold standard data in Kenya and similar settings offer an opportunity for future work in search of alternatives for patient matching. In the meantime, score-based demographic data matching has utility for improving the quality of data in monitoring the 90-90-90 cascade and in other health care settings where patients are longitudinally followed.

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Authors' Contributions

AW conceived the idea for this manuscript and prepared the concept, data analyses and wrote the first and subsequent drafts of the manuscript. AN, helped with data analyses. PWY, AN, TAK, WW, KM, and EZG provided extensive comments on the concept and manuscript drafts. LMN, JO, PWY, and EJM provided insights on policy implications and recommendations. RH and KM supervised the data abstraction process. All authors read the manuscript, provided feedback, and approved the final version.

Conflicts of Interest

None declared.

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Abbreviations

ART: antiretroviral treatment
CBS: case-based surveillance
CCC: comprehensive care clinic
CDC: Centers for Disease Control and Prevention
EMR: electronic medical record
HTS: HIV testing services
KEMRI: Kenya Medical Research Institute
NASCOP: National AIDS and STI Control Program
STI: sexually transmitted infection
UHID: universal health care identifier
UNAIDS: Joint United Nations Program on HIV and AIDS

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Review

Assessing the Concepts and Designs of 58 Mobile Apps for the Management of the 2014-2015 West Africa Ebola Outbreak: Systematic Review

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Abstract

Background: The use of mobile phone information technology (IT) in the health sector has received much attention especially during the 2014-2015 Ebola virus disease (EVD) outbreak. mHealth can be attributed to a major improvement in EVD control, but there lacks an overview of what kinds of tools were available and used based on the functionalities they offer.

Objective: We aimed to conduct a systematic review of mHealth tools in the context of the recent EVD outbreak to identify the most promising approaches and guide further mHealth developments for infectious disease control.

Methods: Following the Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines, we searched for all reports on mHealth tools developed in the context of the 2014-2015 EVD outbreak published between January 1, 2014 and December 31, 2015 on Google Scholar, MEDLINE, CAB Abstracts (Global Health), POPLINE, and Web of Science in any language using the search strategy: (“outbreak” OR “epidemic”) AND (“mobile phone” OR “smartphone” OR “smart phone” OR “mobile phone” OR “tablet” OR “mHealth”) AND (“Ebola” OR ”EVD” OR “VHF” OR “Ebola virus disease” OR “viral hemorrhagic fever”) AND (“2014” OR “2015”). The relevant publications were selected by 2 independent reviewers who applied a standardized data extraction form on the tools’ functionalities.

Results: We identified 1220 publications through the search strategy, of which 6.31% (77/1220) were original publications reporting on 58 specific mHealth tools in the context of the EVD outbreak. Of these, 62% (34/55) offered functionalities for surveillance, 22% (10/45) for case management, 18% (7/38) for contact tracing, and 6% (3/51) for laboratory data management. Only 3 tools, namely Community Care, Sense Ebola Followup, and Surveillance and Outbreak Response Management and Analysis System supported all four of these functionalities.

Conclusions: Among the 58 identified tools related to EVD management in 2014 and 2015, only 3 appeared to contain all 4 key functionalities relevant for the response to EVD outbreaks and may be most promising for further development.

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KEYWORDS

case management; contact tracing; Ebola virus disease; eHealth; mHealth; systematic review; West Africa

Introduction

Background

The 2014-2015 Ebola virus disease (EVD) outbreak caused almost 11,000 deaths and tragically demonstrated the need for effective surveillance and outbreak management [1]. In the absence of established vaccines and specific pharmaceutical treatment, the main measure of containment for epidemics caused by emerging pathogens like Ebola virus is a rapid and efficient interruption of human-to-human transmission. Even for diseases for which vaccines or specific treatments are available, the epidemiological, nonpharmaceutical control measures are indispensable [2]. A particular challenge for EVD control is contact tracing, which assures that all persons who had contact with an EVD case are identified and monitored for the potential appearance of symptoms for 21 days after exposure to a patient with EVD [3].

Containment Strategy

Dhillon et al (2014) stated that for an epidemic such as Ebola virus to be controlled, complementary interventions are required, namely (1) community engagement; (2) identification of contacts; (3) contact monitoring for symptoms; (4) rapid lab confirmation of cases; (5) isolation and treatment of new cases; and (6) safe and dignified burials. Each activity is fundamentally complex, yet all need to be harmonized to stop transmission and control the outbreak [4]. Because of the dynamically changing nature of epidemics, it is important to have real-time data for action, strategy, and coordination of multiple efforts or interventions to ensure efficient execution of tasks and protocols and also a management platform that aligns, coordinates, and monitors all these measures and information resulting from them.

Integrated Disease and Surveillance Response

In 1998, the World Health Organization (WHO) African Regional Office established the resolution of the 48th assembly endorsing Integrated Disease Surveillance and Response (IDSR) for all member countries to adopt as the core strategy to strengthen national disease surveillance systems. The objective of the IDSR is to strengthen district-level surveillance and response for epidemic-prone diseases, integrating laboratory support for reference laboratories, reducing the duplication of reporting, and sharing resources among disease control programs, which in turn translates surveillance and laboratory data into timely public health actions [5]. The major setback with the IDSR since 1998 is that in practice, it remains majorly a paper-based system, collecting information from the periphery and transporting it in an aggregated manner, which results in considerable delay to the national level without implementing the notion of bidirectional information flow and even less that of integrated response [6].

mHealth Technology

The use of mobile phone information technology (IT) in the health sector (mobile health, mHealth) has received much attention, especially during the EVD outbreak and could in principle help implement the basic fundamentals of IDSR [7]. mHealth promises to overcome many of the communication and management hurdles and delays commonly experienced in countries with limited infrastructure in communication and transportation [8]. A study conducted in 2009 by WHO confirmed that majority of the WHO member states offer health call centers and toll-free emergency services using mobile communications, but these programs rarely used mHealth in surveillance, raising public awareness, and decision support systems [9]. These require enhanced capabilities and infrastructure to implement and therefore may not be a health priority in affiliate states with financial constraints. Evaluation is important to determine cost-effectiveness and involves educating the community about the benefits of mHealth, which leads to government policy. Despite the need for evaluation, the survey found that results-based evaluation of mHealth implementations is not routinely conducted, and only 12% of member states reported evaluating mHealth services [9].

Study Objective

The main objective of this study was to generate an overview of mHealth tools that were developed from 2014 to 2015 to identify tools with the most promising portfolio of functionalities, which might build the basis for further mHealth developments for infectious disease surveillance and control.

Methods

Identification Criteria

We conducted a systematic search for all articles published in any language indexed in Google Scholar, MEDLINE, CAB Abstracts (Global Health), POPLINE, and Web of Science with publication dates from January 1, 2014 to December 31, 2015 using the Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines [10].

Systematic Search and Selection

We used the following search strategy: (“Outbreak” OR “Epidemic”) AND (“mobile phone” OR “smartphone” OR “smart phone” OR “mobile phone” OR “tablet” OR “mHealth”) AND (“Ebola” OR ”EVD” OR “VHF” OR “Ebola Virus Disease” OR “viral hemorrhagic fever”) AND (“2014” OR “2015”).

The publications that were original, addressed mHealth in the context of the EVD outbreak, and reported on specific mHealth tools were independently selected by 2 coauthors (DTA and CCA). In case of discrepancy in assessment, both authors revised the findings and agreed on a joint assessment.

The first step was to screen titles and abstracts and discard any publication that was not original such as editorials, summaries, videos, and commentaries. The second step was to select those publications that, based on title or abstract, covered or dealt with an actual mHealth tool that runs on mobile phones and tablets and dealt with the management of EVD or other hemorrhagic fever outbreaks. The third step was to select those publications that, based on the full article, reported on or described ≥1 specific mHealth tool within the context defined above.

Categorization and Extraction

Each publication finally selected for review was categorized as one of the following: book chapter, scientific peer-reviewed journal article, or nonpeer-reviewed Web article. To extract the content of these publications, we used a standardized extraction form assessing key functionalities, technical characteristics, and epidemiological capabilities of the respective mHealth tools.

Key Functionalities

The key functionalities included (1) surveillance capability (ability of the tool to cover surveillance tasks); (2) contact tracing (capacity of the tool to conduct contact interviews, take temperature, follow-up contacts for a certain number of days, and display results); (3) case management (ability of the tool to handle case management issues such as alert response for immediate suspect case evacuation, disinfection, and isolation as well as provide feedback for contact tracing and follow-up) [8]; and (4) laboratory data management (ability to integrate and update laboratory findings, an essential component of case verification).

Technical Characteristics

The technical characteristics included the following:

1. Offline capabilities: the ability of the tool to still function if there is no internet or data network and to send automatically stored data to the server once it connects again to a network.
2. Type of system: whether the tool was developed on an open or closed source platform.
3. Server characteristics: the ability of the tool to function as a cloud network or client side network, installation criteria regarding automatic updates, and user-friendly installation process.
4. Integrated data analytics: the capacity of the tool to analyze and generate reports for immediate action automatically.
5. Data migration: the capability of the tool to import and export data and its elements from 1 platform to the other.
6. Data security system: the security of the data system with respect to disaster recovery, data protection, and backups.
7. Bidirectional information flow: the data flow from the lowest level of data entry to the highest level of decision making and analysis with a standardized feedback mechanism back to the lowest level.

Epidemiological Characteristics

The epidemiological characteristics included the following:

1. Outbreak management unspecified, referring to tools that state the offering of functionalities but do not specify which ones and how.
2. Rumor management capability to capture rumors from the community via a hotline and real-time situational awareness to track the detection of diseases and spread.
3. National response management functionality to coordinate response measures at national level.
4. Regional response management functionality to coordinate response measures at regional or state level.
5. District response management functionality to coordinate response measures at the district level.
6. Performance of a systematic evaluation to evaluate the usefulness of the tool.
7. Piloted or deployed for use in the field via tool implementation in the field with real patients, at least for piloting.
8. Design based on IDSR concepts and strategy used for health surveillance in Africa.
9. Design based on preexisting data models such as Centers for Disease Control and Prevention viral hemorrhagic fever case investigation form integration or Epi Info Viral Hemorrhagic Fever App [11].
10. Health facility notification, referring to health facilities using the tool to notify cases digitally.

Data Analysis

Data variable responses were categorized into yes (function available), no (function not available), or unknown (publication does not clearly reveal whether the tool offers the respective function or not). For computation of percentages, we used the sum of yes and no answers for each of the respective outcomes as the denominator.

Results

Identified Publications

We identified 1220 publications from the automatic search in Google Scholar. PubMed found 8 publications that were duplicates of those in Google Scholar, 4 of which were relevant to the topic. We did not find any publications in CAB Abstracts (Global Health), POPLINE, or and Web of Science using the same search string across the search engines. After manual selection, we identified 79.10% (965/1220) original publications of which 15.0% (145/965) addressed mHealth and EVD outbreak response. Among these 145 publications, 53.1% (77/145) reported on 58 specific mHealth tools. Figure 1 shows the flowchart of the number of publications initially retrieved and the proportion selected for extraction following the Preferred Reporting Items for Systematic Reviews and Meta-Analyses approach.

Key Functionalities

With respect to the 4 key functionalities, 62% (34/55) out of the 55 tools offered functionalities for surveillance, 22% (10/45) for case management, 18% (7/38) for contact tracing, and 6% (3/51) for laboratory data management. Only 3 tools, namely Community Care (CommCare) [12], Sense Ebola Followup [13], and Surveillance and Outbreak Response Management and Analysis System (SORMAS) [14] supported all 4 of these functionalities (3/58, 5%). The detailed profile of key functionalities is displayed in Table 1.

Technical Characteristics

Table 2 displays the technical characteristics of the 58 identified tools. For 3% (2/58) of the tools, namely CommCare and Sense Ebola Followup, the publications indicated that they displayed all 7 technical characteristics.

Figure 1. Preferred Reporting Items for Systematic Reviews and Meta-Analyses approach for the selection of publications on mHealth tools for the 2014-2015 Ebola virus disease outbreak. EVD: Ebola virus disease.

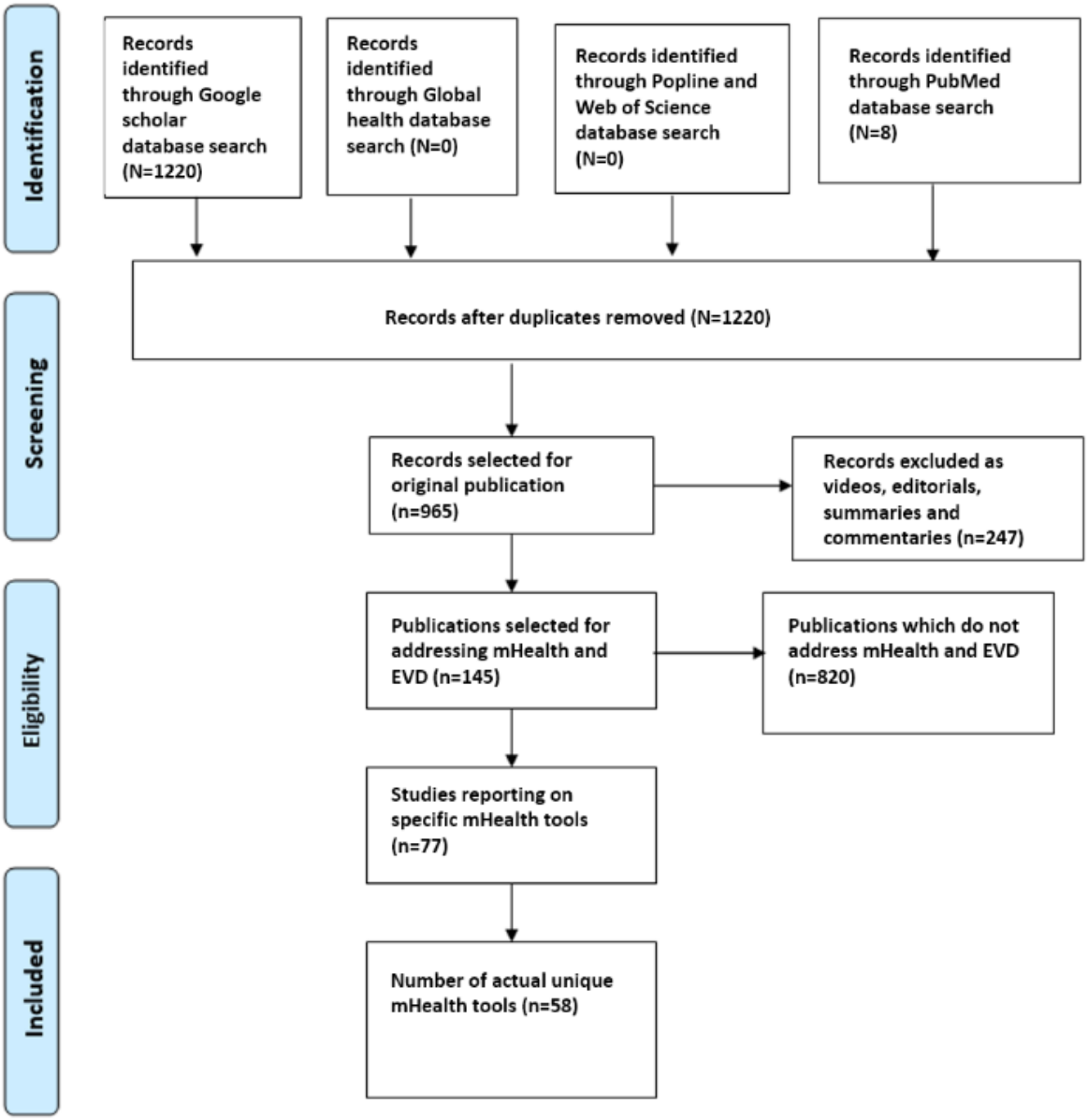

Table 1. Key functionalities for 58 mHealth Ebola virus disease tools, 2014-2015.

Key functionalities	Yes, n	No, n	Unknown, n	Yes[a], %
Surveillance capability	34	21	3	62
Contact tracing	7	31	1	18
Case management	10	35	13	22
Laboratory data management	3	48	7	6

[a]The sum of yes and no answers for each of the respective functionalities was used as the denominator.

Table 2. Technical characteristics for 58 mHealth Ebola virus disease tools, 2014-2015.

Technical characteristics	Yes, n	No, n	Unknown, n	Yes[a], %
Offline capabilities	9	24	25	27
Type of system (open source)	36	21	1	63
Server characteristics	43	15	0	74
Integrated data analytics	22	11	25	67
Data migration	40	18	0	69
Data security system	33	6	19	85
Bidirectional information flow	7	40	11	15

[a]The sum of yes and no answers for each of the respective characteristics was used as the denominator.

Table 3. Epidemiological characteristics for 58 mHealth Ebola virus disease tools, 2014-2015.

Epidemiological characteristics	Yes, n	No, n	Unknown, n	Yes[a], %
Outbreak management unspecified	5	50	3	9
Rumor management	7	31	20	18
National response management	6	43	9	12
Regional response management	8	42	8	16
District response management	8	42	8	16
Systematic evaluation	24	16	18	60
Piloted or deployed	26	16	16	62
Design based on Integrated Disease and Surveillance Response concepts and strategy used for health surveillance in Africa	3	52	3	5
Design based on preexisting data models such as Center for Disease Control and Prevention viral hemorrhagic fever case investigation form integrated or Epi Info Viral Hemorrhagic Fever Application	2	53	3	4
Health facility notification	27	23	8	54

[a]The sum of yes and no answers for each of the respective outcomes was used as the denominator.

Epidemiological Characteristics

Table 3 contains the results of the epidemiological characteristics. All 10 epidemiological characteristics were present for 2% (1/58) of the tools, namely SORMAS.

None of the 58 tools covered all 4 key functionalities, all 7 technical characteristics, and all 10 epidemiological characteristics. SORMAS covered 20 functionalities and characteristics, the highest within 1 tool, 1 of its missing characteristics being open source. Table 4 shows a breakdown of the 58 identified mHealth tools according to the key functionalities for EVD outbreak management.

Table 4. Characteristics of the 58 mHealth tools showing the key functionalities for Ebola virus disease outbreak management.

Name of mHealth tool	Surveillance	Contact tracing	Case management	Laboratory data management
BioCaster Portal	Yes	Unknown	Yes	No
Bio-Sense 2.0	Yes	Unknown	Yes	No
BSVE	Yes	Unknown	Unknown	No
CDRs Simulator	Unknown	Unknown	Unknown	Unknown
Cell phone messaging technology	No	No	No	No
CKAN	No	No	No	No
CliniPAK	Unknown	Unknown	Unknown	Unknown
Collaborative Overarching Multi-feed Biosurveillance System (COMBS)	Yes	Unknown	Yes	No
CommCare Contact Tracing	Yes	Yes	Yes	Yes
Data De-Identification Toolkit	Yes	Unknown	Unknown	No
DHIS 2	Yes	No	No	No
Doctor App	No	No	No	No
Early Warning systems (EWS)	Yes	No	No	No
Sense Ebola Followup	Yes	Yes	Yes	Yes
Ebola Spatial Care Path (POCT)	Unknown	Unknown	Unknown	Unknown
Ebola Tracks	Yes	Yes	No	
EbolaAlert	Yes	Unknown	No	No
EIDSS	Yes	Unknown	Unknown	No
EpiRobot	No	No	No	No
Esoko SMS app/WhatsApp	No	No	No	No
ESSENCE-FL	Yes	Unknown	Unknown	No
Facebook	No	No	No	No
Flu Caster	Yes	No	No	No
Google Analytics	No	No	No	No
GPHIN	Yes	No	No	No
GSMS	No	No	No	Unknown
Hadoop	No	No	No	No
Health 2.0	No	No	No	No
Healthmap	Yes	No	No	No
HIT	No	No	No	No
iPhone app	No	No	No	No
LEEDS	Yes	Unknown	Unknown	No
mHealth real-time infectious disease interface (contact tracing app)	Yes	Yes	No	Unknown
NNDSS	Yes	Unknown	Yes	No
Open Data Kit	Yes	Yes	No	No
OpenESSENCE	Yes	Unknown	Unknown	No
OpenMRS	Yes	Unknown	Unknown	No
OpenStreetMap (maapJack)	No	No	No	No
PHIN-MS	Yes	Unknown	Unknown	No
Polly	No	No	No	No
POP (Practice-Oriented Project) on Crowdmap	No	No	No	No

Name of mHealth tool	Surveillance	Contact tracing	Case management	Laboratory data management
QGIS	No	No	Yes	No
R	Yes	Unknown	Unknown	No
RapidSMS	No	No	No	No
Response Call Center app	Yes	No	No	Unknown
SAGES	Yes	Unknown	Unknown	No
Screening expert system (SES)	Yes	No	No	No
Sentinel surveillance system (SSS)	Yes	Unknown	Yes	No
SMARTech	Yes	Unknown	No	No
Smartphone-based contact tracing system	Yes	Yes	No	No
SORMAS	Yes	Yes	Yes	Yes
SoundCloud	No	No	No	No
SWAP (surveillance window app)	Yes	Unknown	Unknown	No
Telefónica	No	No	No	No
Telemedicine	Yes	No	Yes	No
The Minnesota African Task Force Against Ebola (MATFAE)	No	No	No	No
Twitter	No	No	No	No
WBDS	Yes	Unknown	Unknown	No

Discussion

Principal Findings

It is surprising that as many as 58 mHealth tools identified in our search addressed management of EVD (hemorrhagic fever) during the 2014-2015 outbreak. The vast difference in functionality indicates that during the wake of the tragic outbreak and the urgency to stop the outbreak, many initiatives were started, which aimed and claimed to provide support for EVD outbreak response. However, only a few appear to have contained sufficient medical and public health expertise to actually address the procedural and technical needs. It is, therefore, needful to carefully assess the respective specifications and functionalities via a quality control system before deciding on one tool or another for deployment in such a situation. Only 3 tools have the overall capability for the key functionalities of surveillance and outbreak management (surveillance capability, contact tracing, and case management) and contain embedded functional requirements for data reporting and analytics through an integrated implementation of the surveillance guidelines and standards regarding functionality. Some tools, such as District Health Information System 2, had the advantage of being widespread in West Africa as a health management information system [15], yet it was not designed to manage interventions as needed for infection control and outbreak response by itself. Such a tool should feed information into every task related to a particular officer and improve each task assigned to the officer [16]. Ideally, it can be used as a real-time rumor management system, contact-tracing management system, case management system, and a surveillance system. The tool should include disease control management functionalities [17].

The tools CommCare, Sense Ebola Followup, and SORMAS supported all tasks and functions involving surveillance, contact tracing, and case management. CommCare and Sense Ebola Followup were used during the EVD outbreak. SORMAS was piloted in the field during the EVD outbreak after the epidemic in Nigeria and is therefore based on a practical EVD outbreak scenario. Additionally, it contains a function for rumor management, which was particularly important during the 2014-2015 Ebola outbreak [18]. Sense Ebola Followup was deployed during the EVD outbreak in Nigeria [19]. Since outbreaks only occur sporadically, and the information processed during an outbreak is comparable to that handled for surveillance purposes, it appears necessary to aim for a system that can function as a monitoring tool as well as an outbreak management tool [20]. Another factor that is likely to affect the acceptability of an mHealth tool is the independence from a specific provider. Tools based on open source platforms are more sustainable in this aspect and can potentially build a dynamic broader programming community for further developments and improvements. CommCare and Sense Ebola Followup were developed on an open source platform [21]. SORMAS was originally programmed in platforms proprietary to Systems Applications and Products [22] but has now been developed on an open source platform (SORMAS-open) [23].

CommCare Ebola Contact Tracking

The cloud server open source Android app for contact tracking developed in 2014 was based on the CommCare development platform, which was designed to support Community Health Extension Workers acting in Guinea, and it has been promoted by the United Nations Population Fund, other United Nations agencies, and the actors involved in the fight against Ebola in Guinea [21]. CommCare technology was chosen to support the

implementation of the Government Response Plan against EVD in order to obtain timely and reliable information as well as facilitate contact tracing. The Earth Institute at Columbia University (USA), United Nations Population Fund, and the Monitoring Cell of the National Coordination Against the Ebola Virus have promoted the idea. It requires a CommCare account and the Open Data Kit for Android to be deployed on an Android phone or tablet [24].

Sense Ebola Followup App

The contact-tracing follow-up electronic health (eHealth) Sense app was developed in 2014 during the EVD outbreak in Nigeria. It is a mobile phone app for real-time data capture. The major technologies used were 2 Android-based apps, the Open Data Kit and Formhub [24]. Supporting technologies were dashboard technology and ArcGIS mapping. The contact listing form, contact follow-up form, laboratory investigation request, and case investigation forms were created using extensible markup language and the eHealth Sense Ebola Android app [19] developed for 21-day follow-up. It has an automatic alert system for temperature readings ≥38°C for contacts that were under follow-up.

Surveillance and Outbreak Response Management and Analysis System

SORMAS is an open source Android and Web app, which was developed for case management, contact tracing, and surveillance with an equipped laboratory module for management of laboratory samples and tests [25]. SORMAS enables surveillance officers and epidemiologists to detect diseases based on real-time health facility data. Automatic notification validates rumors and notifications, and SORMAS enables decision makers to respond immediately to incoming information and to take adequate measures via the public health officers. Information about cases and contacts are made readily available for action, data quality assurance is performed for decontamination, and isolation tasks can be conducted.

Limitations

Only a fraction of the identified publications was found in conventional scientific literature databases, such as Medline and PubMed, all of which were duplicates, but 99% of the publications were found in Google Scholar. This may indicate a major limitation of our approach. The methodology of systematic reviews, being well established in evidence-based medicine, may be of limited value for health informatics because it may not be as common practice in the IT field to publish developments and findings in scientific journals, even less so in peer-reviewed ones. The urgency by which tools were developed in response to the EVD outbreak may even have accentuated this effect. Search criteria imputed to PubMed displayed only 8 results compared with 965 results in Google Scholar. An explanation might be that mHealth initiatives born out of urgent public health needs may not be accompanied by a systematic process of planning and evaluation and are thus not likely to be transferred into sustainable continuous implementation and even less likely to be published in scientific publications once the urgency of the need has diminished.

While it would have been valuable to conduct this review beyond the application of EVD and hemorrhagic fevers and beyond 2015, removing these selection criteria from the search strategy would have resulted in an unmanageably large output with an extremely low positive predictive value. Hence, we covered mHealth tools developed between 2014 and 2015. Taking into consideration the fact that we stopped data collection on December 31, 2015 on a topic that became relevant shortly before that, the delay in publication may have led to some tools not being captured in our analysis. There was a limited appearance of publications in established databases such as Medline, although Google Scholar will generate a very comprehensive, but also unspecified, output of search strategies that are not defined in a highly-targeted way, especially if the period is increased beyond 2015.

Conclusion

Among a large number of reported tools developed in the context of the EVD outbreak response, it appears that only 3 of these tools contain the 3 key functionalities of outbreak management for EVD (surveillance capability, contact tracing, and case management) supported by tools developed from January 2014 to December 2015. These 3 tools, namely CommCare, Sense Ebola Followup, and SORMAS may serve as an orientation and reference for further developments of mHealth tools for infectious disease surveillance and outbreak management.

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Authors' Contributions

DTA and CCA searched, selected, and extracted data based on criteria; DTA and GK conceptualized the study design and analyzed and interpreted the results of the data; GK initiated the study approach and supervised all steps of the study; PMN contributed to the manuscript confirming events and outcomes of software applications. All authors read and approved the final manuscript.

Conflicts of Interest

None declared.

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Abbreviations

CommCare: Community Care open source mobile platform
EVD: Ebola virus disease
IDSR: Integrated Disease Surveillance and Response
IT: information technology
SORMAS: Surveillance and Outbreak Response Management and Analysis System
WHO: World Health Organization

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