Social Technologies and Data in AI-Related HIV Research

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Conflict of Interest Statement

Funding to University

NCCIH
NINDS
NIAID
NIDA
NIMH
NCATS
NSF
University of California
Wholistic
IEEE
Intel
NIMHHD

Advising/Consulting

Health technology companies

Book Royalties

HarperCollins Publishers
Penguin Books
Cheers Publishing
Sextante
Toyo Keizai
MIF
Book21
Commonwealth Publishing Group

An Indiana town recovering from 190 HIV cases

Shari Rudavsky, shari.rudavsky@indystar.com 7:15 a.m. EDT April 11, 2016

The Scott County Health Department Needle Exchange Program was started in 2015 as a response to an HIV outbreak linked to intravenous drug use in Scott County. Austin, IN is the epicenter of the crisis. Kelly Wilkinson/IndyStar

(Photo: Matt Herp / Special to the Courier-Journal)

AUSTIN, Ind. — From the start of the HIV outbreak, health officials emphasized that nothing set Scott County apart from many other rural communities where opioid drug use had become an epidemic. This could happen anywhere, people were told.

Many people had viewed HIV as a big-city disease, something that might afflict people in San Francisco or New York. But not in Austin, a small city of about 4,000 people 80 miles south of Indianapolis.

Then, in February 2015, the first 30 cases of HIV were reported. By mid-March, the number had climbed to 55. State health officials, the governor and the federal Centers for Disease Control and Prevention were looking for answers. Few public

MORE STORIES

The Drop for May 26: Jungle Park Speedway, what we're Googling, and Cap's haps
May 26, 2016, 5:53 p.m.

Tully: Despite life's struggles, he's 'a happy-going guy'
May 26, 2016, 12:08 a.m.

Can Hale help Gregg with female voters?
May 25, 2016, 10:48 p.m.

Jacob Cox-Brown
2 hours ago

Drivin drunk... classsic ;) but to whoever's vehicle i hit i am sorry. :P

[redacted] @john_kendrick_ · 8h
Getting back into **meditation**. It helped with my **anxiety** and depression before, maybe it can help tame my rage.

7 1 36

The Pimp Juices @potatoshitface · 37m
I'm going to **buy cocaine**

3

ambiguous @YungMeese · 4m
Why **am I addicted to** marihuana?!

[redacted]

got the test results back from today's physical.

when i started my weight loss journey, my a1c was 6.5. it was just over the prediabetic range. diabetes runs in my family so i had to get it together.

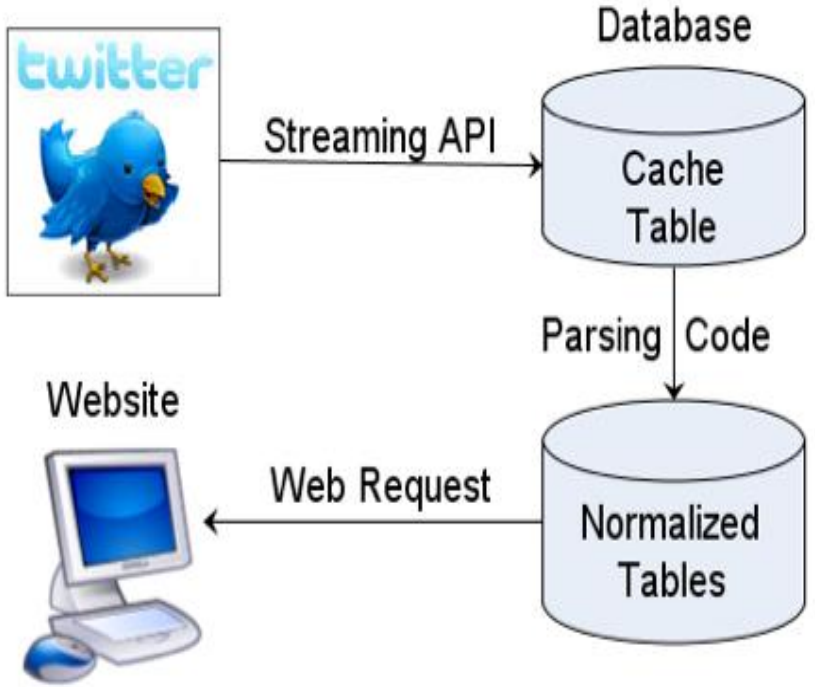
today, 50lbs later, it's 5.6, meaning i'm no longer in the prediabetic range.

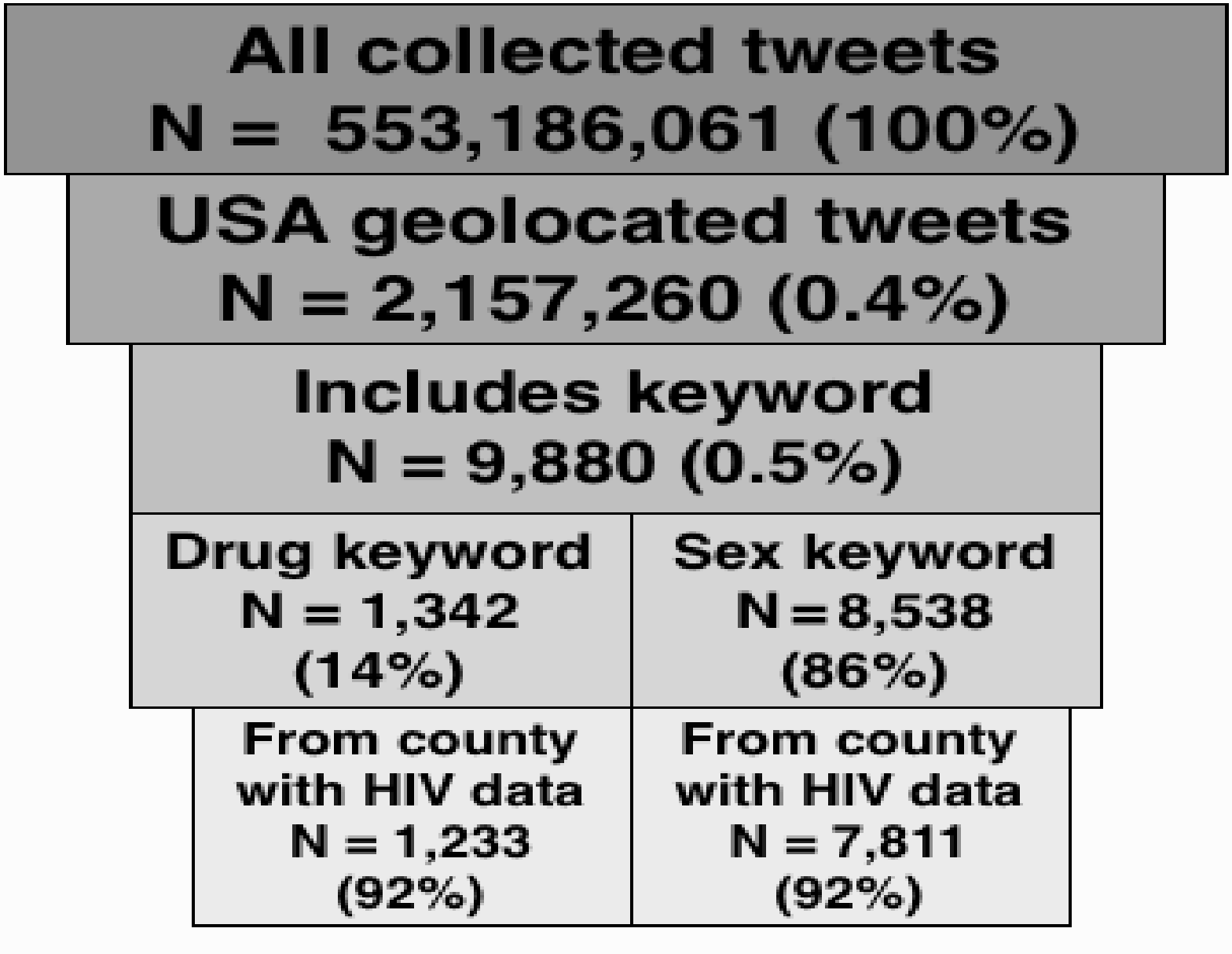
6:50 PM · May 21, 2021 · Twitter for iPhone

47 Likes

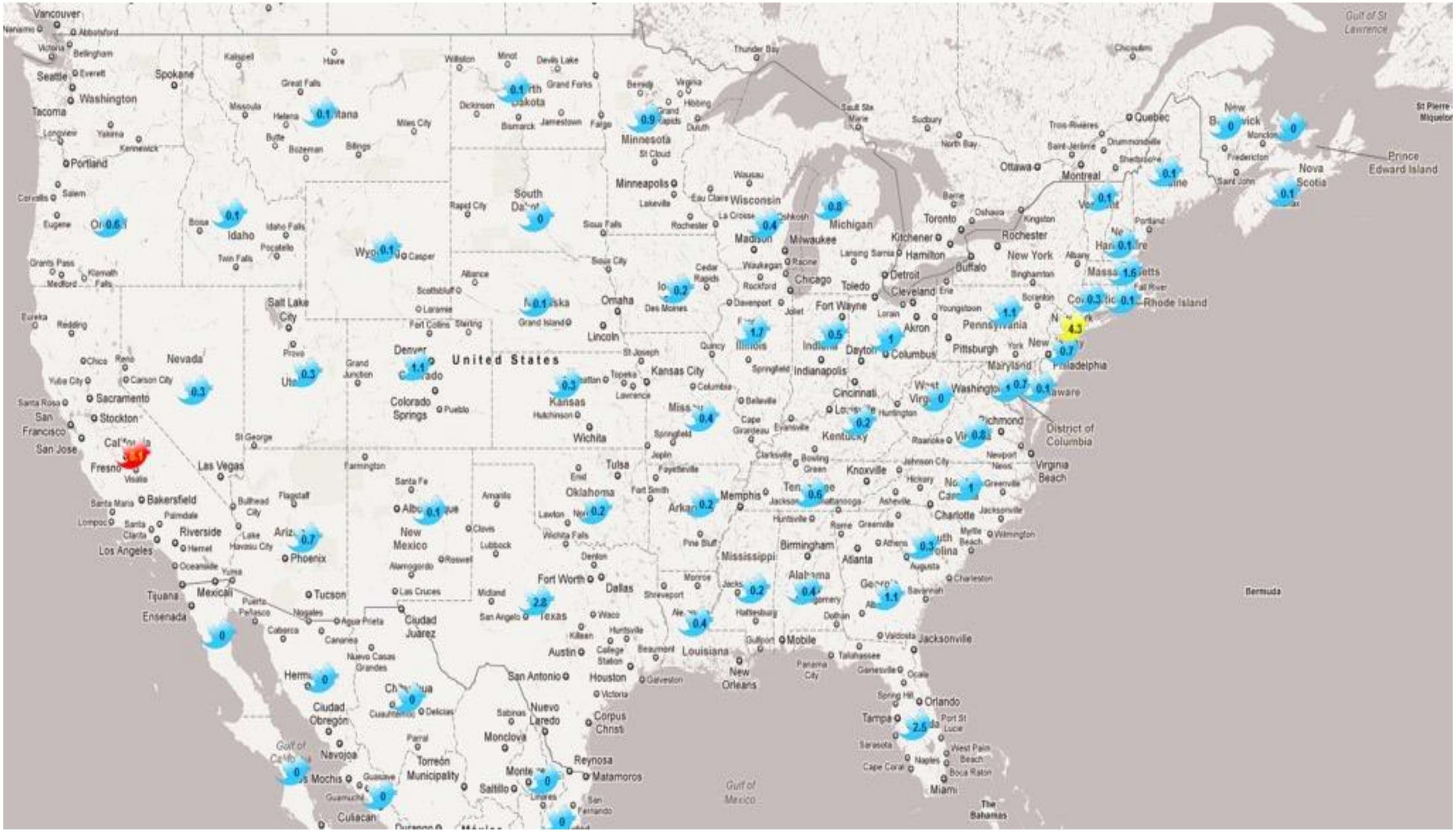
Bon @MiahMiah · 24h
You made me into a machine with drugs gave me **hiv** made me gay now why don't **I have** anything in my life? Why so desperate for everything?

Psychologically-Driven AI to Predict HIV?

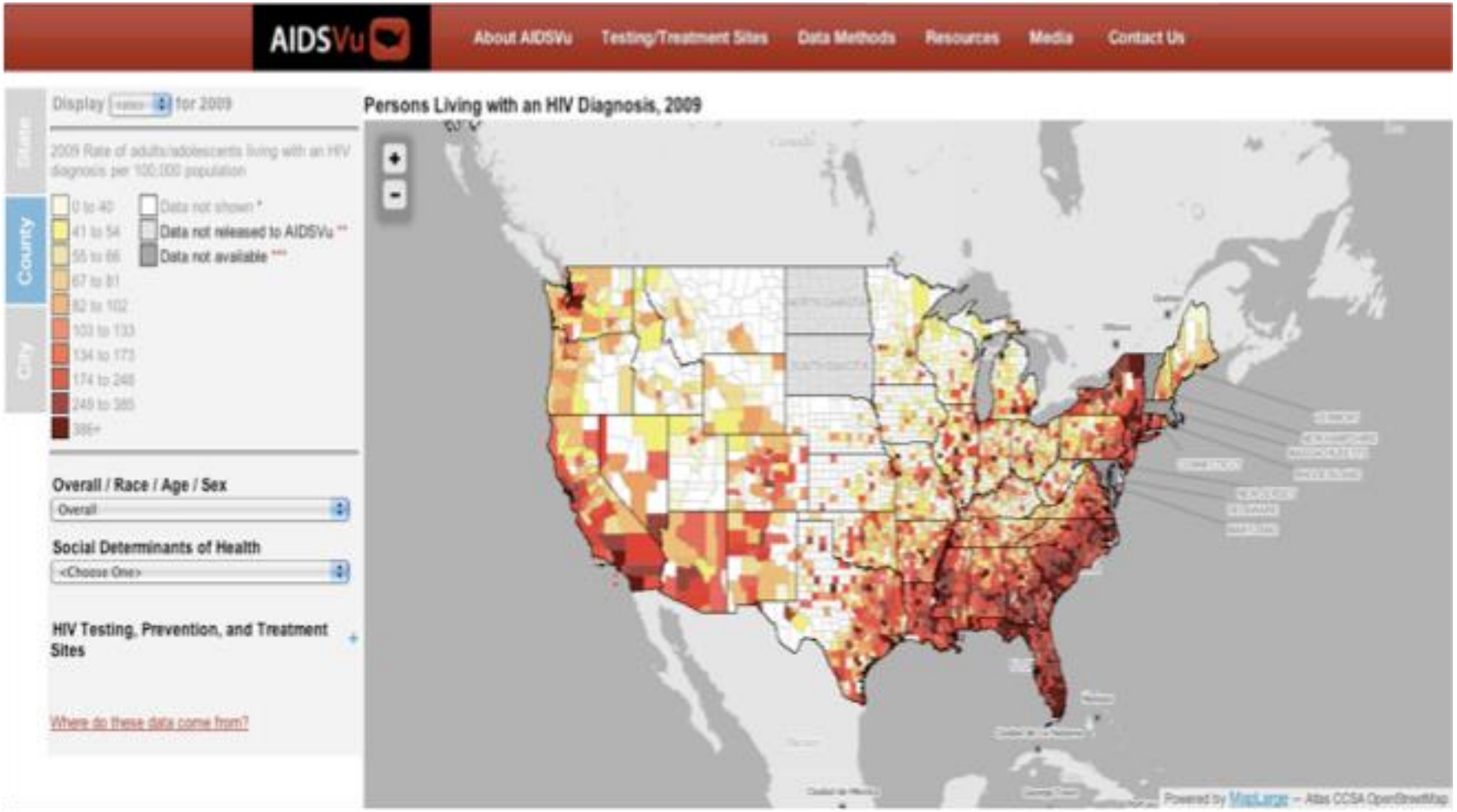



All collected tweets
N = 553,186,061 (100%)
USA geolocated tweets
N = 2,157,260 (0.4%)
Includes keyword
N = 9,880 (0.5%)
Drug keyword
N = 1,342
(14%)
Sex keyword
N = 8,538
(86%)
From county with HIV data
N = 1,233
(92%)
From county with HIV data
N = 7,811
(92%)

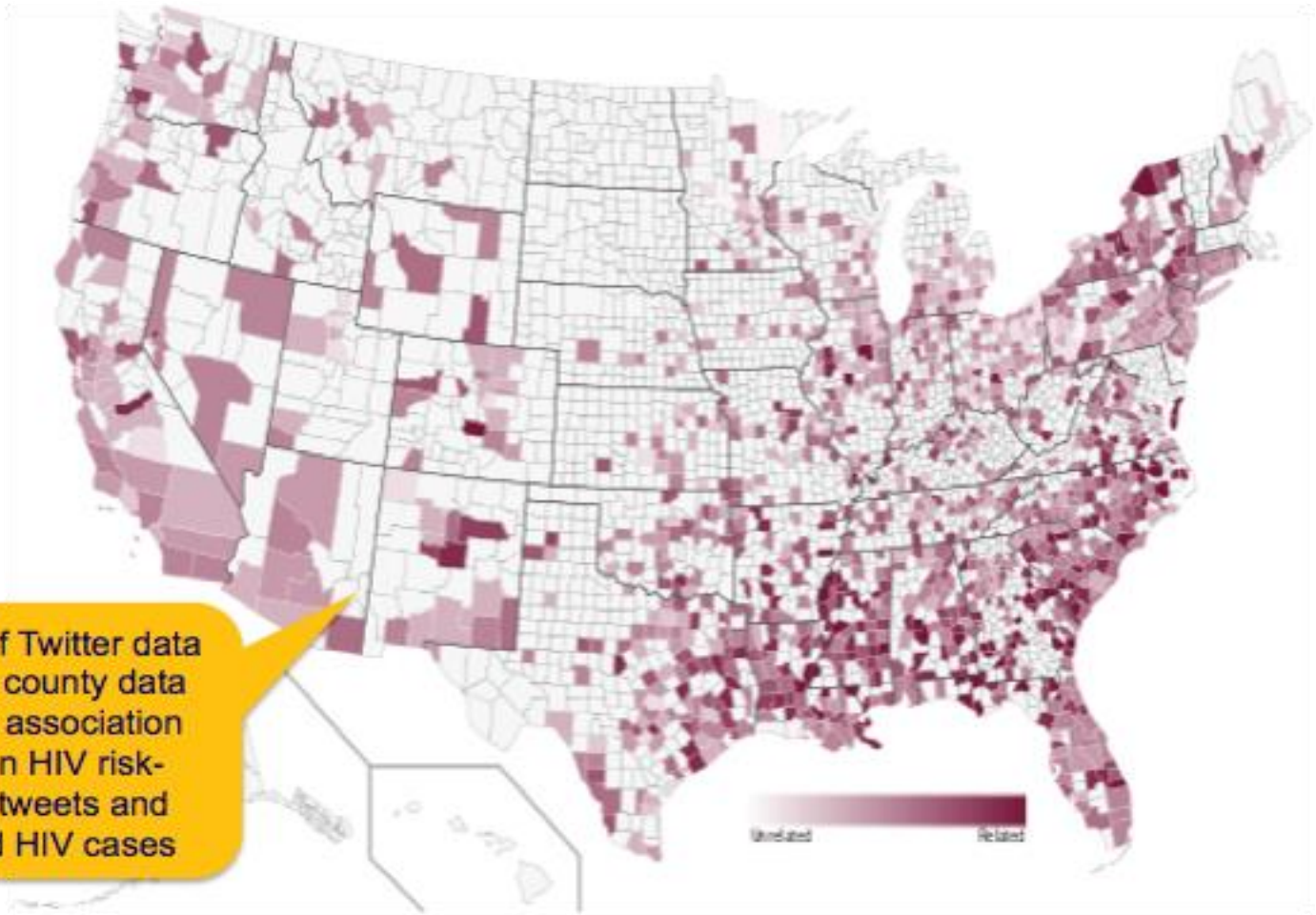
Category	*Sample 1*	*Sample 2*	*Sample 3*
Sex risk-related	I neeeeeeed sex now!	Sex ain't better than love	[@ another user] all about the sex
Substance use-related	Anybody wanna get high?	who got some drugs for tonight?	need an easier way to get drugs
General	This weather is crazy!	Watching the Celtics game.	headed to take my exam, wish me luck



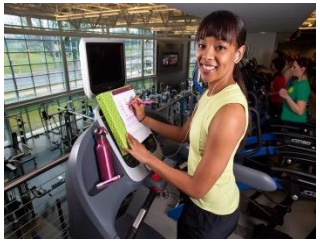
United States
Vancouver
Seattle
Washington
Portland
Spokane
Idaho
Nevada
Sacramento
Stockton
San Francisco
San Jose
Fresno
Bakersfield
Los Angeles
Riverside
Las Vegas
Phoenix
Tucson
Salt Lake City
Denver
Colorado Springs
Kansas
Wichita
Oklahoma
Tulsa
Dallas
Fort Worth
Texas
Austin
San Antonio
Houston
Minnesota
Minneapolis
Wisconsin
Michigan
Chicago
Detroit
Toronto
Ottawa
Montreal
Quebec
New York
Rochester
Pennsylvania
Pittsburgh
Philadelphia
Washington
Richmond
Kentucky
Knoxville
Memphis
Atlanta
Birmingham
Mississippi
Louisiana
New Orleans
Jacksonville
Orlando
Tampa
Miami
Rhode Island
Nova Scotia
Prince Edward Island
Gulf of Mexico
Bermuda


AIDSVu
About AIDSVu
Testing/Treatment Sites
Data Methods
Resources
Media
Contact Us
Display rates for 2009
2009 Rate of adults/adolescents living with an HIV diagnosis per 100,000 population
0 to 40
41 to 54
55 to 66
67 to 81
82 to 102
103 to 133
134 to 173
174 to 248
249 to 385
386+
Data not shown *
Data not released to AIDSVu **
Data not available ***
County
City
Overall / Race / Age / Sex
Overall
Social Determinants of Health
<Choose One>
HIV Testing, Prevention, and Treatment Sites
Where do these data come from?
Persons Living with an HIV Diagnosis, 2009
Powered by MapLarge – Atlas CCSA OpenStreetMap

AI: Social & Environmental Level



Partnerships with Industry (Intel)



Data and Approach: Freshmen 200

- 200 UCLA freshmen took weekly surveys on emotions, stress-levels, activities
- Followed them on Twitter
- Wore fitness/sleep trackers

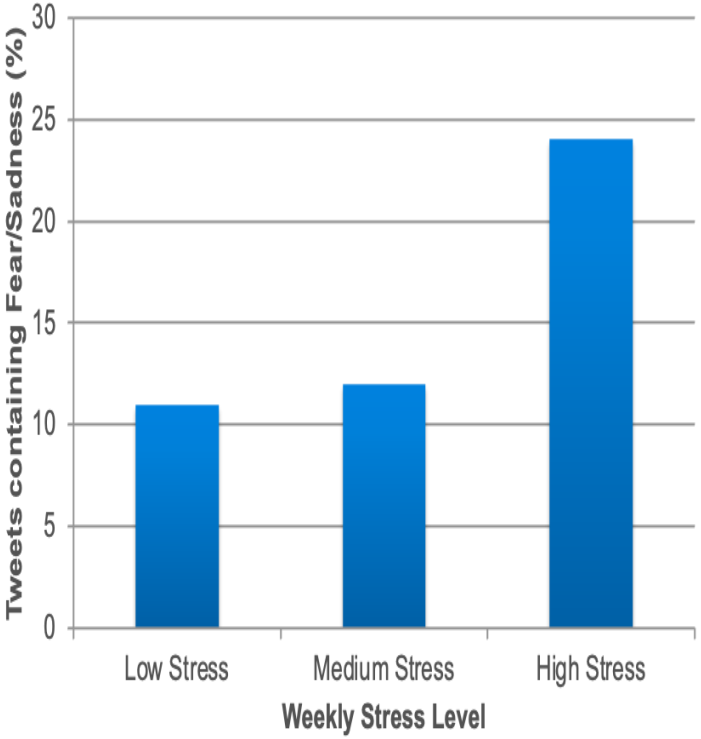
- We seek to use these social data to predict student health
- Can be used by administration and campus services

Study 1: Twitter Results

- Weekly stress was associated with
  - negative sentiment tweets
  - tweets containing sadness
  - tweets containing love and hope
    - (β±SE: 3.6±1.4; *p*=0.01).

- Anger was negatively associated with
  - positive sentiment (β±SE: -1.6±0.8; p=0.05)
  - tweets with joy (β±SE: -2.2±0.9; p=0.02).

- Fear was positively associated with
  - negative sentiment (β±SE: 1.67±0.7; *p*=0.01)
  - tweets related to sadness (β±SE: 2.4±0.8; p=0.01).



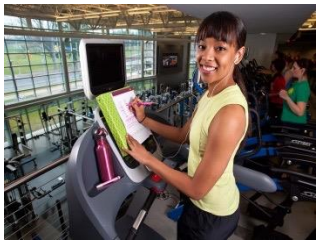
Liu, S., Zhu, M., Yu, D., Rasin, A., Young, S.D. (2013)
JMIR Mental Health

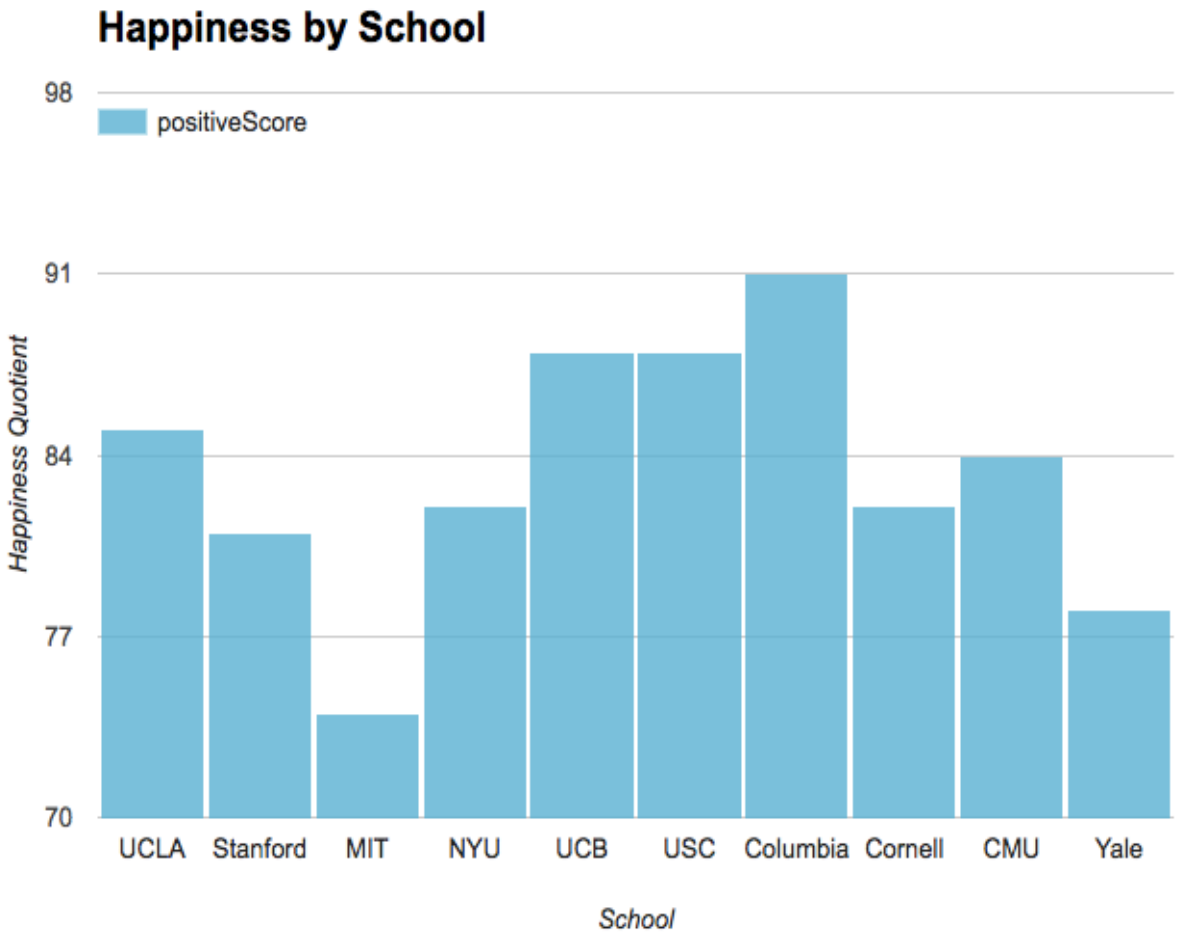
Create an Automated Tool

Sentiment Analysis: Classify each tweet into Positive, Neutral, or Negative

AI: Behavioral, Social & Environmental Levels

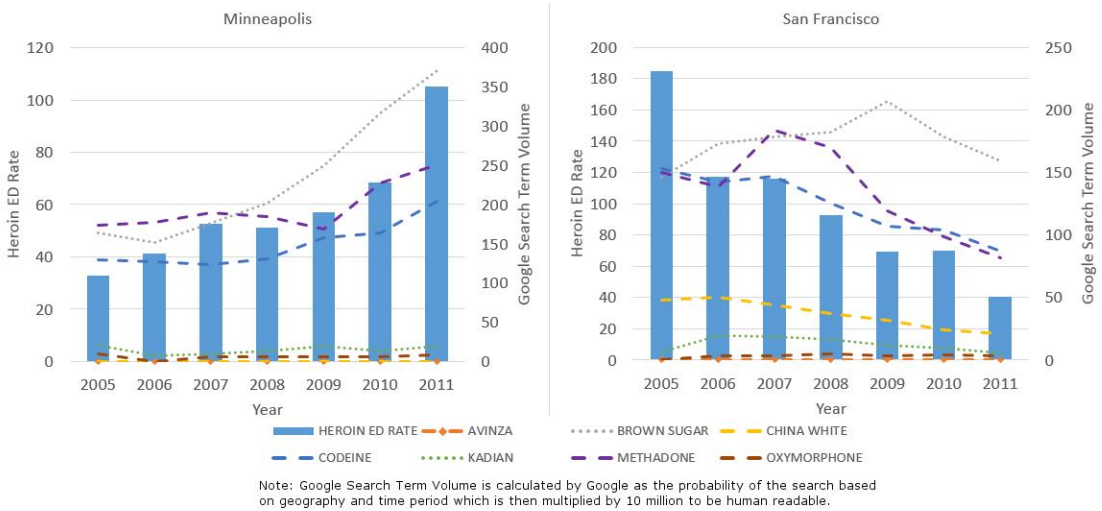
twitter





Jiang et al., 2019; *CIKM: ACM Conference*.

Predicting the Opioid Crisis



Young, S.D., Zhang, K., Chu, L., Humphries, K. 2018; *Drug and Alcohol Dependence.*

Young, S.D., Zheng, Q., Pacula, R.L. 2021; *Nature Digital Medicine.*

Monitoring/Predicting Misinformation

Research Letter | Public Health

February 1, 2021

Public Attitudes About COVID-19 in Response to President Trump's Social Media Posts

Dominic Arjuna Ugarte, MD[1]; William G. Cumberland, PhD[2]; Lidia Flores, BS[1]; Sean D. Young, PhD[1,3]

» Author Affiliations | Article Information

JAMA Netw Open. 2021;4(2):e210101. doi:10.1001/jamanetworkopen.2021.0101

COVID-19 Resource Center

Introduction

Misinformation has hampered health officials' ability to control the coronavirus disease 2019 (COVID-19) pandemic.[1-3] Public beliefs about COVID-19 are influenced by political ideology and media.[4] In particular, President Trump's tweets regarding his clinical status may have affected the beliefs of US individuals about the pandemic's severity. Surveys and interviews, typically used to gauge public perspectives, have collection lag times.[5] Accordingly, we sought to use near real-time social media data to capture the public's changing COVID-19–related attitudes during President Trump's recent infection.

Methods

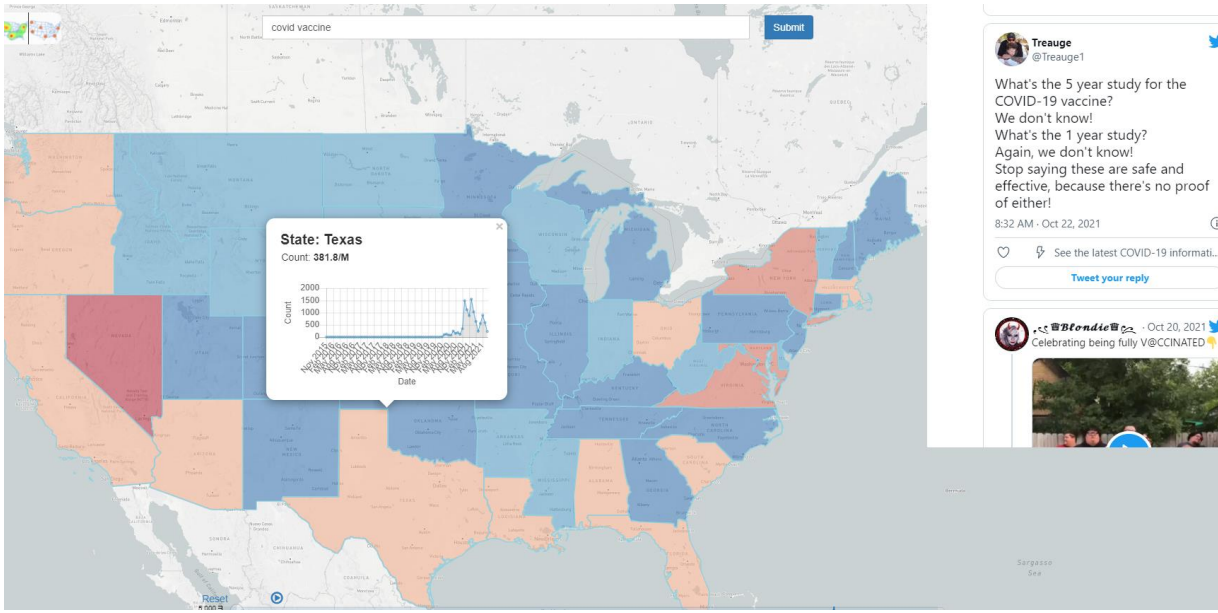
For this cross-sectional study, from September 23 to October 8, 2020, we collected 22 800 tweets regarding public views on COVID-19 using Twitter's free application programming interface. Search criteria included COVID-19–related keywords (eg, *COVID-19*, *coronavirus*) within 15 characters of a supporting (eg, *serious*, *real*) or contradicting (eg, *hoax*, *#CovidHoax*) adjective or hashtag. Tweets were collected from "swing states" (Florida, Michigan, Colorado, Iowa, Minnesota, Nevada, New Hampshire, North Carolina, Ohio, Pennsylvania, Virginia, and Wisconsin) (Box), were restricted to individual accounts, excluded retweets, and were obtained from 1 of 3 periods: (1) September 23 to October 1, 2020 (before President Trump's tweet that he had contracted COVID-19); (2) October 1 to October 5, 2020 (between his infection announcement and his tweet, "Don't be afraid of COVID"); and (3) October 5 to October 8, 2020 (after his "Don't be afraid" tweet). This study and

Table. COVID-19-Related Beliefs Over Time[a]

Table. COVID-19-Related Beliefs Over Time[a]

COVID-19 severity category	Tweets, No. (%) [95% CI]		
	Period 1 (n = 3800)	Period 2 (n = 13 800)	Period 3 (n = 5200)
Hoax	417 (19.5) [17.8-21.1]	66 (3.1) [2.3-3.8]	164 (10.0) [8.5-11.4]
Not serious	284 (13.3) [11.8-14.7]	30 (1.4) [0.9-1.9]	199 (12.0) [10.5-13.7]
Serious	1441 (67.3) [65.3-69.3]	2060 (95.6) [94.7-96.4]	1284 (78.0) [76.0-80.0]
Total	2142 (100)	2156 (100)	1647 (100)

AI on Social Data: Outcomes on All Levels of Health



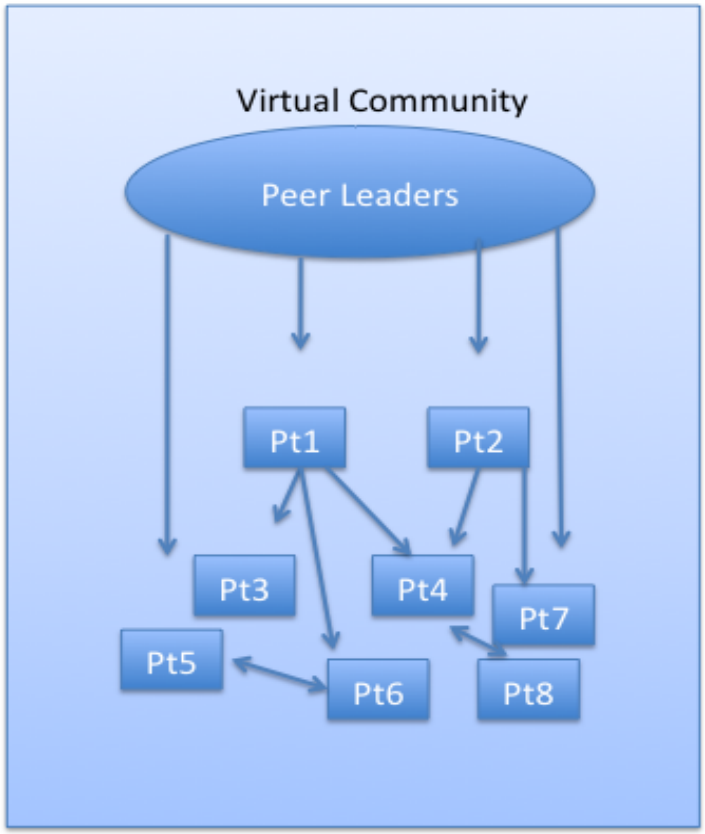
Young, S.D. (2014). Behavioral Insights on Big Data: Using Social Data for Predicting Biomedical Outcomes. *Cell: Trends in Microbiology*, 22 (*11),* P601-2.

Online Support & Behavior Change

HOPE: An Intervention at All Levels

Step 1: Establish community norms
Peer leaders reach out at community and individual level to promote HIV prevention norms

Step 2: Community norm diffusion
Participants communicate with each other about the importance of HIV prevention and testing. Vocal community members help to spread norms to other community members, and ultimately, to people outside of the virtual community.



ORIGINAL RESEARCH | Annals of Internal Medicine

Social Networking Technologies as an Emerging Tool for HIV Prevention

A Cluster Randomized Trial

Sean D. Young, PhD, MS; William G. Cumberland, PhD; Sung-Jae Lee, PhD; Devan Jaganath, MPH; Greg Szekeres, BA; and Thomas Coates, PhD

Background: Social networking technologies are an emerging tool for HIV prevention.

Objective: To determine whether social networking communities can increase HIV testing among African American and Latino men who have sex with men (MSM).

Design: Randomized, controlled trial with concealed allocation. (ClinicalTrials.gov: NCT01701206)

Setting: Online.

Patients: 112 MSM based in Los Angeles, more than 85% of whom were African American or Latino.

Intervention: Sixteen peer leaders were randomly assigned to deliver information about HIV or general health to participants via Facebook groups over 12 weeks. After participants accepted a request to join the group, participation was voluntary. Group participation and engagement were monitored. Participants could request a free, home-based HIV testing kit and completed questionnaires at baseline and 12-week follow-up.

Measurements: Participant acceptance of and engagement in the intervention and social network participation, rates of home-based HIV testing, and sexual risk behaviors.

Results: Almost 95% of intervention participants and 73% of control participants voluntarily communicated using the social platform. Twenty-five of 57 intervention participants (44%) requested home-based HIV testing kits compared with 11 of 55 control participants (20%) (difference, 24 percentage points [95% CI, 8 to 41 percentage points]). Nine of the 25 intervention participants (36%) who requested the test took it and mailed it back compared with 2 of the 11 control participants (18%) who requested the test. Retention at study follow-up was more than 93%.

Limitation: Only 2 Facebook communities were included for each group.

Conclusion: Social networking communities are acceptable and effective tools to increase home-based HIV testing among at-risk populations.

Primary Funding Source: National Institute of Mental Health.

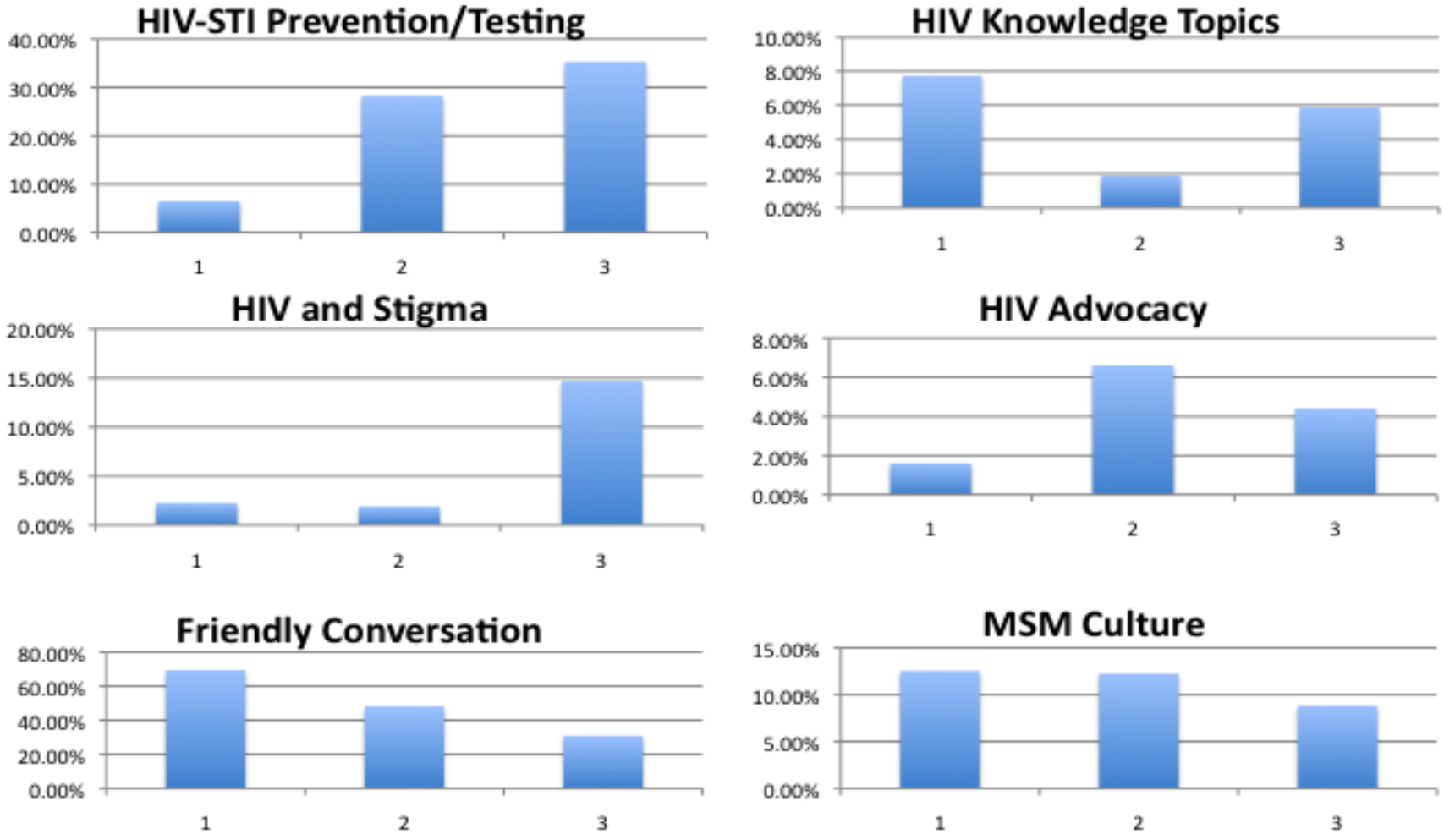
Ann Intern Med. 2013;159:318-324. www.annals.org
For author affiliations, see end of text.

African Americans and Latinos in Los Angeles, California, as in the rest of the United States, have high rates of incident cases of HIV and new diagnoses (1, 2). Since 1981, most of these cases have been attributable to men who have sex with men (MSM), a group that accounts for up to 82% of all infections (2). Researchers have proposed using novel strategies to increase HIV prevention

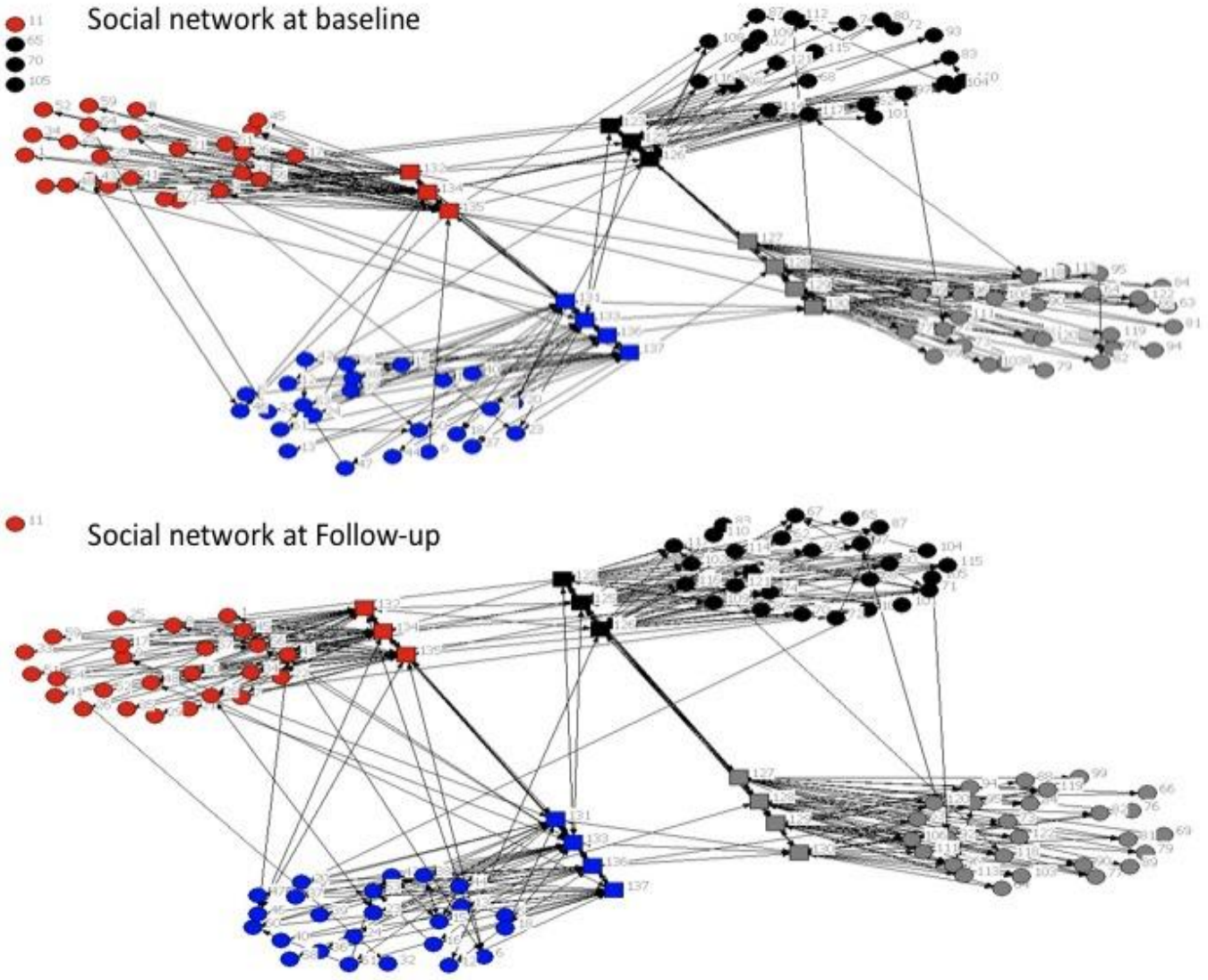
17). These networks are thus potentially useful platforms for delivering a peer-led intervention on HIV prevention (18, 19). However, this approach has not been systematically tested.

The HOPE (Harnessing Online Peer Education) study tested the feasibility, acceptability, and effectiveness of using social networking sites (specifically Facebook) to

Figure 1. Percent of total excerpts related to a given topic, by time period



Young, S.D. & Jaganath, D. (2013) *Sexually Transmitted Diseases, 40 (2), 162-7.*



Young, S.D., Jaganath, D., Westmoreland, D. Coates, T., (2014) *American Journal of Public Health, 104 (9), 1707-12.*

HOPE HIV (2021)

Odds of HIV test kits requested					
	Odds Ratio	Std. Err.	[95% Conf. Interval]		Proportion (Std. Err.)
Intervention	1.43	0.23	[1.04,	1.95]	0.06 (0.03)
Odds of having taken a home-based HIV test					
	Odds Ratio	Std. Err.	[95% Conf. Interval]		Proportion (Std. Err.)
Intervention	1.47	0.28	[1.01,	2.13]	0.05 (0.02)
Change in weekly alcohol consumption (3 month follow up compared to baseline)					
	Coefficient	Std. Err.	P-value	[95% Conf. Interval]	
Intervention	-0.80	0.30	0.008	[-1.39,	-0.21]

Young, S.D., Cumberland, W.G., Singh, P., Coates, T. (2021). *Journal of AIDS.*

Table 2 Effect of the HOPE social media intervention on requesting a test and getting tested among Peruvian men who have sex with men (n=498), Peru, 2012

	Intervention	Control	Unadjusted model 1		Adjusted			
			OR (95% CI)	p value	Model 2		Model 3	
					aOR (95% CI)	p value	aOR (95% CI)	p value
Requested HIV test	31% (77/252)	15% (36/246)	2·96 (1·62–5·41)	0·0003	2·69 (1·42–5·08)	0·001	2·79 (1·42–5·72)	0·003
Tested for HIV	17% (43/252)	7% (16/246)	2·61 (1·58–4·30)	<0·0001	2·83 (1·72–4·64)	<0·0001	2·61 (1·55–4·38)	0·003

Young, S.D., Cumberland, W.G., Nianogo, R., Menacho, L., Galea, J.T., Coates, T. (2014) *Lancet HIV.*

Social media communications by condition at baseline and follow-up (12 weeks).

Communicated about: n (%)	Baseline				12 weeks			
	Intervention Group (n = 20)	Control Group (n = 18)	Effect size[a]	p-value	Intervention Group (n = 20)	Control Group (n = 18)	Effect size[a]	p-value
Feelings of pain	16 (80%)	11 (61%)	0.21	0.19	19 (95%)	12 (67%)	0.36	0.02
Opioid use	10 (50%)	7 (39%)	0.11	0.49	16 (80%)	5 (28%)	0.52	0.001
Coping strategies	15 (75%)	10 (56%)	0.20	0.21	19 (95%)	11 (61%)	0.42	0.01
Places to seek help	12 (60%)	8 (44%)	0.16	0.34	17 (85%)	7 (39%)	0.48	0.003
Use of illegal drugs for pain	6 (30%)	4 (22%)	0.09	0.59	8 (40%)	3 (17%)	0.25	0.11
Use of alternative therapies	14 (70%)	11 (61%)	0.09	0.56	18 (90%)	10 (56%)	0.39	0.02

Young, S.D., Koussa, M., Lee, S., Perez, H., Gill, N., Gelberg, L., & Heinzerling, K. (2019). *Journal of Addictive Diseases, 37 (1), 96-101*

HOPE Chronic Pain Intervention

Intervention had decreased COMM & GAD-7 compared to control

Young et al., 2020

Compared to control group participants, intervention participants had almost 10 times higher posting engagement (*n* = 411 posts versus 45; 73% versus 52% of participants). Participants discussed coping, pain, medication and non-medication treatments, and other opioid and addiction-related topics.

Young et al., 2019

Participants thought that online support communities could decrease stigma associated with opioid use disorder

Young & Heinzerling, 2017

Implementation Considerations

1. Partnerships are critical for successful implementation of technological approaches
    - Academic-Industry collaborations are essential

2. Constant and rapidly changing ethical perspectives
    - Community key stakeholders are essential for guidance

3. Need better standards on how to deliver and measure interventions

4. Policymakers need to ensure long-term resources

5. Successful implementation of technology use in public health needs to involve end users at the start
    - Requires understanding the person

Table 3. Sample quotes about willingness to share data with researchers and for-profit organizations.

Themes	Participant quote
General willingness to share data with researchers	Well, anything that could help find treatment or cure for my diseases would be good. I would just be concerned with privacy. But I mean, if it's not direct messages, I don't see a problem with it really.
	As long as I am confident that the research, that I will be anonymous and it will not come back to me, I am pretty comfortable sharing information with researchers, because I think that they're trying to help and if I don't share it, how can they help me? So I want to be able to get that help just as long as I know that it's confidential.
	I think it's more data breaches and making sure my information stays safe. Besides that, I don't really have any more problems with sharing all that.
	I guess it depends on the records. If it was something like pathology reports for an endoscopy for (condition), that would be used to further research and development of medications to treat it, if it would be, yeah, I've taken the biopsies and the information that I'm using that to further treatments, I think I'd be okay with that. I think some other things, maybe not. I think it really just depends on the type of health data. It wouldn't be an all or nothing. It wouldn't be yes or no. It'd be this specifically yes, this no.
Lack of willingness to share with for profit organizations	I see researchers using it for a purpose to potentially benefit people; assuming you guys would be using this information to find something out. And I guess that would be like Amazon or Google or corporation like that to do it just for the purpose of making money and where's the data going? It's not necessarily confidential and I don't necessarily trust that.
	I would be a little hesitant sharing to Google just because, you don't know what they're doing with that information. As opposed to if it's for research then yeah, I would a hundred percent give my consent. But what is Facebook and Google and Amazon doing with my information. That's what I would want to know before I could give consent.
Willingness to share data for COVID-19 purposes	Yeah, I think the more narrow your scope is, the more willing I would be. I think just saying, let's have access to all your stuff, I'd be, no, thank you.

Romero, R., Young, S.D. (2021) *Ethics and Behavior*

BMJ Open

Exploring mobility data for enhancing HIV care engagement in Black/African American and Hispanic/Latinx individuals: a longitudinal observational study protocol

Maryam Hassani ,[1] Cristina De Haro,[2] Lidia Flores,[1] Mohamed Emish,[1] Seungjun Kim,[1] Zeyad Kelani,[1] Dominic Arjuna Ugarte,[3] Lisa Hightow-Weidman,[4] Amanda Castel,[5,6] Xiaoming Li,[7] Katherine P Theall,[8,9] Sean Young[1,3]

To cite: Hassani M, De Haro C, Flores L, *et al*. Exploring mobility data for enhancing HIV care engagement in Black/African American and Hispanic/Latinx individuals: a longitudinal observational study protocol. *BMJ Open* 2023;**13**:e079900. doi:10.1136/bmjopen-2023-079900

► Prepublication history for this paper is available online. To view these files, please visit the journal online (http://dx.doi.org/10.1136/bmjopen-2023-079900).

Received 14 September 2023
Accepted 05 December 2023

ABSTRACT

Introduction Increasing engagement in HIV care among people living with HIV, especially those from Black/African American and Hispanic/Latinx communities, is an urgent need. Mobility data that measure individuals' movements over time in combination with sociostructural data (eg, crime, census) can potentially identify barriers and facilitators to HIV care engagement and can enhance public health surveillance and inform interventions.

Methods and analysis The proposed work is a longitudinal observational cohort study aiming to enrol 400 Black/African American and Hispanic/Latinx individuals living with HIV in areas of the USA with high prevalence rates of HIV. Each participant will be asked to share at least 14 consecutive days of mobility data per month through the study app for 1 year and complete surveys at five time points (baseline, 3, 6, 9 and 12 months). The study app will collect Global Positioning System (GPS) data. These GPS data will be merged with other data sets containing information related to HIV care facilities, other healthcare, business and service locations, and sociostructural data. Machine learning and deep learning models will be used for data analysis to identify contextual predictors of HIV care engagement. The study includes interviews with stakeholders

STRENGTHS AND LIMITATIONS OF THIS STUDY

⇒ The study aims to include a large sample of Black/African American and Hispanic/Latinx (N=400) individuals ages 18 years and over, living with HIV, and with poor engagement in care residing within an Ending the HIV Epidemic county.
⇒ Quantitative and qualitative data and approaches (ie, machine learning models and qualitative interviews/analysis) will be used to explore barriers and facilitators of engagement in HIV care.
⇒ We focus on Black/African American and Hispanic/Latinx communities, which may limit the generalisability of the findings.
⇒ Ethical and privacy concerns surrounding individuals sharing their location might be a challenge in data collection.

respectively.[2] HIV prevalence was also found to be higher among Black or Hispanic populations in the USA, according to a study that constructed

Thank you!

Funders

NCCIH
NINDS
NIAID
NIMHHD
NIDA
NIMH
NCATS
NSF
UC

Team

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