



# A How to Guide: The Use of Social Media in Research

**Brenda Curtis, PhD, MsPH**  
**Chief Technology and Translational Research Unit**  
**4/13/2023**

# Objectives

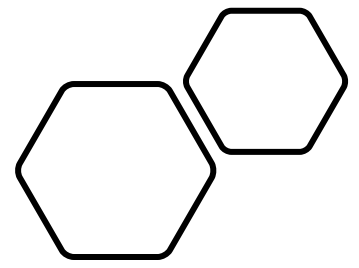
1. Understand the current landscape of social media research and the different human subjects protections issues each raise
2. Develop a comprehensive understanding of the ethical considerations for social media recruitment techniques
3. Identify what IRBs will consider when reviewing studies that involve the use of social media
4. Explore what the use of social media data in research means for the future





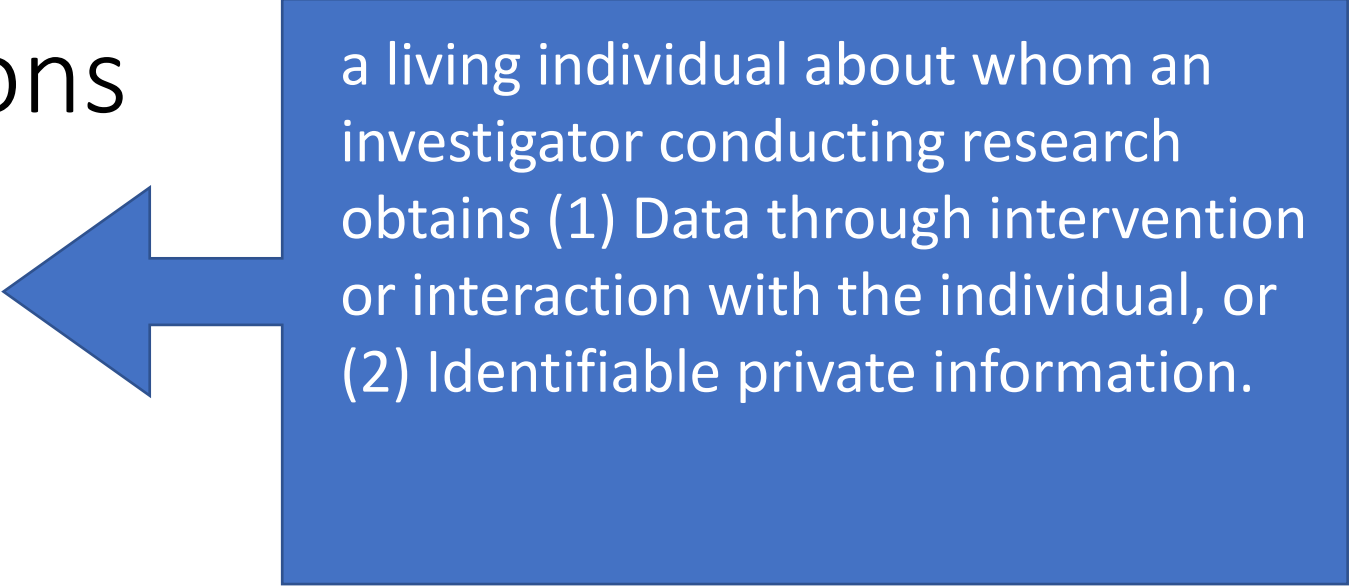
Urging users to **build personal profiles** and **connect** with people from various locations by **sharing personal** details through posting updates, **photos, videos,** and **comments**





# Definitions

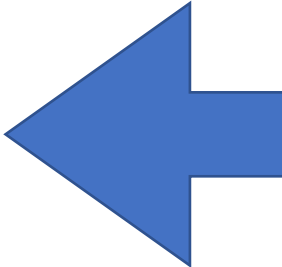
- Human subject



a living individual about whom an investigator conducting research obtains (1) Data through intervention or interaction with the individual, or (2) Identifiable private information.

# Definitions

- Human subject
- Private Information



Information about behavior that occurs in a context in which an individual can reasonably expect that observation or recording is not taking place, or **information which an individual has provided for specific purposes and which the individual can reasonably expect will not be made public.**

<https://www.hhs.gov/ohrp/sachrp-committee/recommendations/2013-may-20-letter-attachment-b/index.html>

<https://www.hhs.gov/ohrp/sachrp-committee/index.html>



## Search Results for social media

### [Use of Social Media](#)

SACHRP Committee International Breadcrumb HHS OHRP SACHRP Committee SACHRP Recommendations Use of **Social Media** by Research Subjects Ethical and Regulatory Text Resize A A A Print Share Left Nav ohrp sachrp...Materials Use of **Social Media** by Research Subjects Ethical and Regulatory Considerations for the Protection of Human Research Subjects Approved October 19 2022 The use of **social media** by research subjects...drawn increasing attention as a result of the steady growth of the use of **social media** platforms The availability of **social media** has made it much easier for research subjects to find one another and communicate...

<https://www.hhs.gov/ohrp/sachrp-committee/recommendations/use-social-media-research-subjects-ethical-regulatory-considerations/index.html> - 49KB- Invalid date

### [A New Interpretation of the "Engaged in Research" Standard | ...](#)

study aims and design The organization after the study is approved helps in its meetings and its **media** presence to publicize the study so that enrollment is completed in a timely way and it encourages...biostatistician would be more clearly not engaged without need for a defined exception What about independent **social** workers who are paid to conduct in depth interviews of incest survivors for a study They too are...

<https://www.hhs.gov/ohrp/sachrp-committee/recommendations/attachment-d-july-25-2022-letter/index.html> - 75KB- Invalid date

### [October 13, 2011 SACHRP Letter to the HHS Secretary: SACHRP ...](#)

currently available flexibility a guidance that may be of particular utility to those involved in **social** and behavioral research 4 Strengthening Data Protections to Minimize Information Risk This section...rulemaking process Moreover this change could be particularly burdensome to investigators in the **social** and behavioral sciences and those conducting educational research There is debate in some quarters...extending it further to non clinical

## Use of Social Media by Research Subjects: Ethical and Regulatory Considerations for the Protection of Human Research Subjects

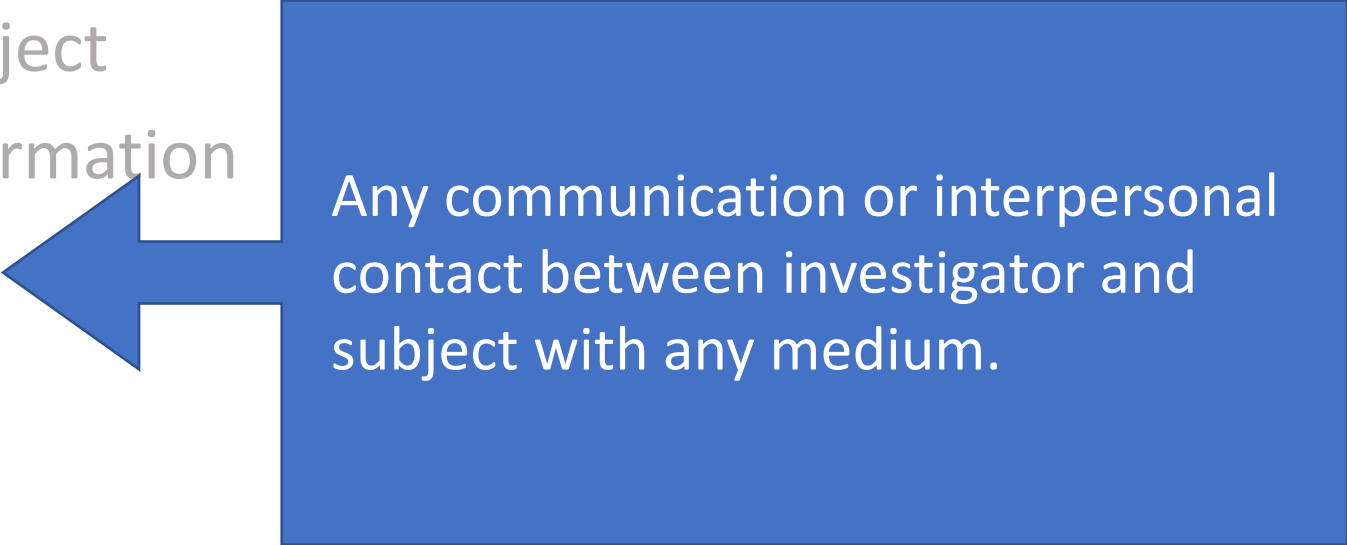
Approved October 19, 2022

## Attachment B: Considerations and Recommendations concerning Internet Research and Human Subjects Research Regulations, with Revisions



# Definitions

- Human subject
- Private Information
- **Interaction**

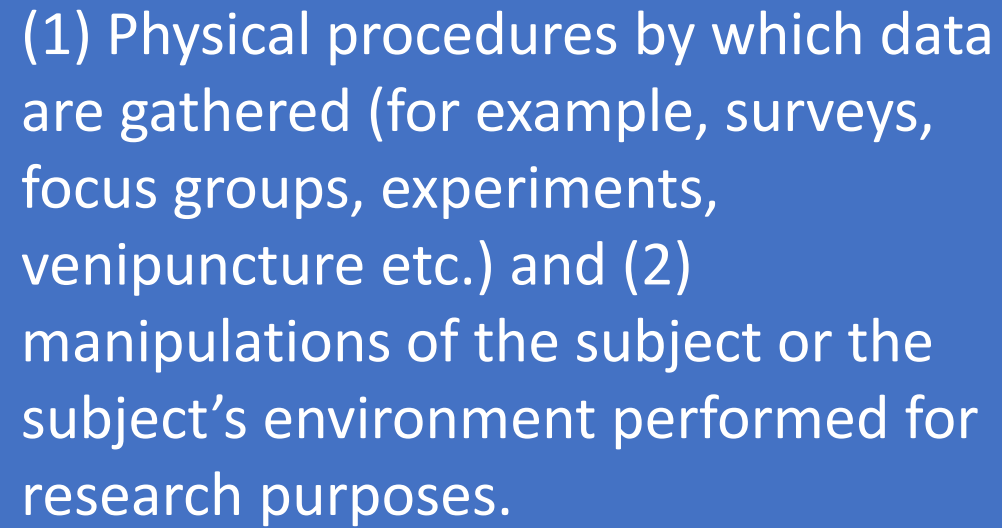


Any communication or interpersonal contact between investigator and subject with any medium.

Surveys presented online should be considered "interaction" with subjects.

# Definitions

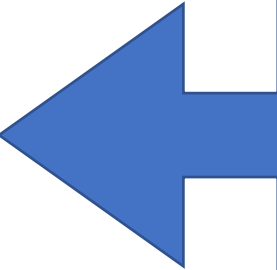
- Human subject
- Private Information
- Interaction
- **Intervention**



(1) Physical procedures by which data are gathered (for example, surveys, focus groups, experiments, venipuncture etc.) and (2) manipulations of the subject or the subject's environment performed for research purposes.

# Definitions

- Human subject
- Private Information
- Interaction
- Intervention
- **Social Media/networking sites**



Web and mobile device-based services that provide a collection of ways for users to interact, such as social networking sites, blogs, discussion groups, or other information sharing or communication services that support messaging, email, video, posting comments, etc.

# “reasonable” expectation of privacy on social media?

Numerous courts have found that the inherent purpose of a social networking site undercuts any subjective or objective expectation of privacy.

- U.S. v. Lifshitz
- Guest v. Leis
- Moreno v. Hanford Sentinel, Inc
- Romano v. Steelcase Inc
- Dexter v. Dexter



“reasonable”  
expectation of  
privacy on social  
media?

---

Since the sharing of personal information “is the very nature and purpose of these social networking sites else they would cease to exist”, **users of those platforms could not have a reasonable expectation of privacy for shared content.** Romano, 907 N.Y.S.2d at 657, n.16.

## ROMANO v. STEELCASE INC (2010)

Print

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Kathleen ROMANO, Plaintiff, v. STEELCASE INC. and Educational & Institutional Cooperative Services Inc., Defendants.

No. 2006-2233.

Decided: September 21, 2010

Kelner & Kelner, Esqs, New York City. Gallagher Gosseen Faller & Crowley, Esqs, Garden City. John T. Ryan & Associates, Riverhead City. Orrick Herrington & Sutcliffe LLP, New York City.

ORDERED, that Defendant STEELCASE's motion is hereby granted as set forth herein below.

Defendant STEELCASE moves this Court for an Order granting said Defendant access to Plaintiff's current and historical Facebook and MySpace pages and accounts, including all deleted pages and related information upon the grounds that Plaintiff has placed certain information on these social networking sites which are believed to be inconsistent with her claims in this action concerning the extent and nature of her injuries, especially her claims for loss of enjoyment of life.

The present application was brought on by Order to Show Cause. The Court has reviewed the submissions both in favor of and in opposition to the relief sought, as well as the applicable federal statutory law, specifically the Stored Communications Act, 18 U.S.C. ¶ 2701 et seq., which prohibits an entity, such as **Facebook and MySpace** from disclosing such information without the consent of the owner of the account (see, 18 U.S.C. ¶ 2702(b)(3); Flaqq v. City of Detroit, 252 FRD 352 [ED. Mich.2008] ).

Really...no  
“reasonable”  
expectation of  
privacy on  
social media?



**reasonable expectation of  
privacy**

## What Does the Fourth Amendment Mean?

*The Constitution, through the Fourth Amendment, protects people from unreasonable searches and seizures by the government. The Fourth Amendment, however, is not a guarantee against all searches and seizures, but only those that are deemed unreasonable under the law.*



**No reasonable expectation of privacy when sent to 3<sup>rd</sup>  
parties**

## Attachment B: Considerations and Recommendations concerning Internet Research and Human Subjects Research Regulations, with Revisions

Final document, approved at

### Introduction


The purpose of this document is to Consider regarding the co regulations originally written

### **Q7: What is *observation of public behavior* online?**

If an activity (textual, visual, auditory) is legally available to any Internet user without specific permission or authorization from the individual being observed, or from the entity controlling access to the information, the activity should be considered "public behavior." Examples include "comment" postings on news sites; posting on publicly available hosting sites such as YouTube® or Flickr®; postings on classified sites such as Craigslist®; and postings on unrestricted blog or wiki sites. Information posted on social networking sites such as Facebook®, LinkedIn®, Myspace®, or similar fora, and available without restriction to any authorized user of the site, should also be considered "public behavior," even though access to the website itself may be restricted to individuals who have established an account to use the site.[\[18\]](#) Note that the mere fact of an activity being considered "public behavior" does not mean that observation of the activity should automatically be considered exempt from the requirement of IRB review. Per 45 CFR 46.101(b)(2), if the information is recorded in a way that permits identification of subjects, and if disclosure of the identifiable information could "reasonably place the subjects at risk of criminal or civil liability or be damaging to the subjects' financial standing, employability, or reputation," then the research would not be exempt from IRB review.[\[19\]](#)



[SACHRP Recommendations](#) > Attachment B: Considerations and Recommendations concerning

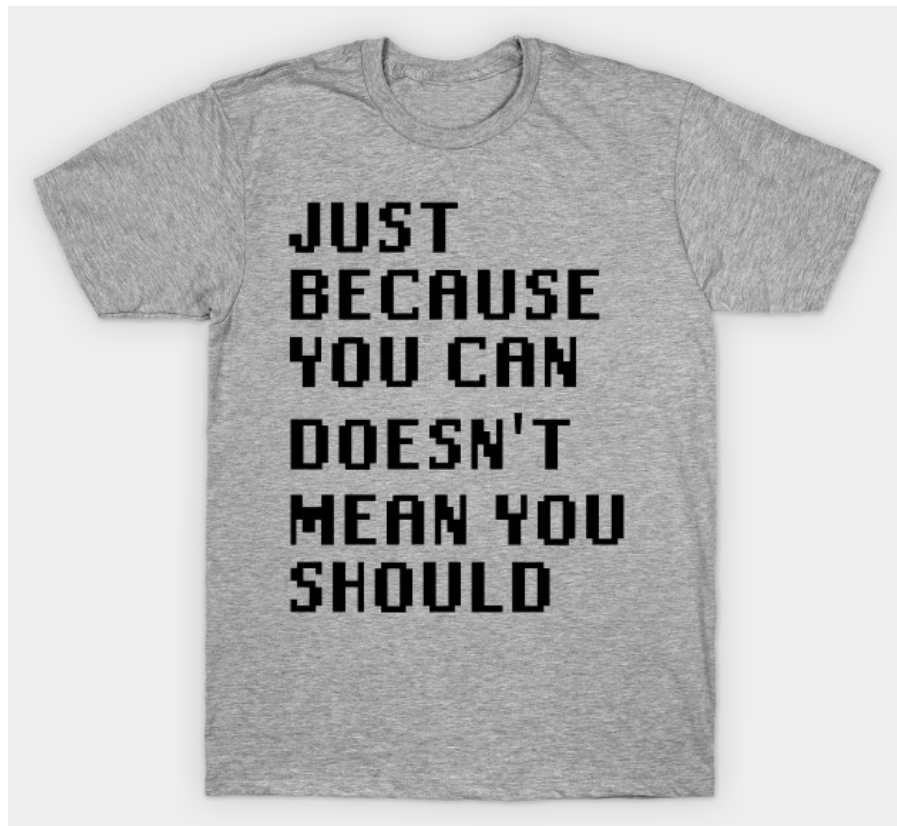
Text Resize **A A A** | Print  | Share   

## Attachment B: Considerations and Recommendations concerning Internet Research and Human Subjects Research Regulations, with Revisions

Final document, approved at SACHRP meeting March 12-13, 2013

### Introduction

The purpose of this document is to provide a starting point for the development of FAQs and/or Points to Consider regarding the conduct and review of Internet research. Current human subjects regulations, originally written over thirty years ago, do not address many issues raised by the unique



- One suggestion is to follow the published privacy/confidentiality policy of the site; if there is no policy the site could be considered public.
- Investigators should be aware of and respect the shared expectations of members of groups.

<https://www.hhs.gov/ohrp/sachrp-committee/recommendations/2013-may-20-letter-attachment-b/index.html>



# Types of Social Media Research



COMMUNICATE



SURVEILLANCE



DATA SOURCE



RECRUIT



INTERVENE



# COMMUNICATE

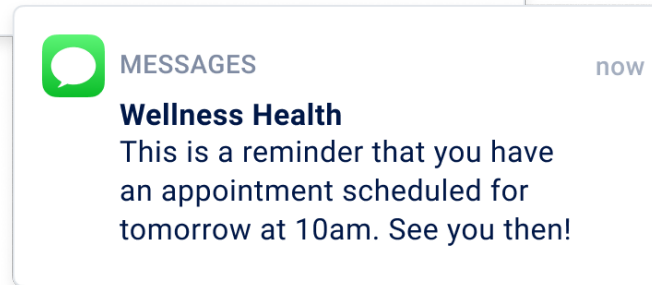
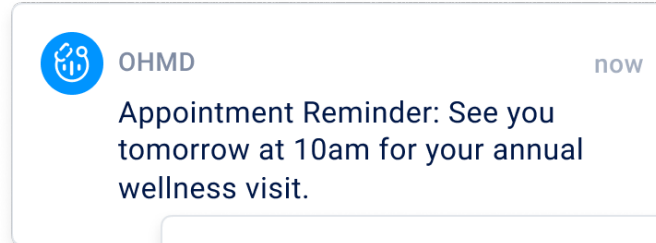
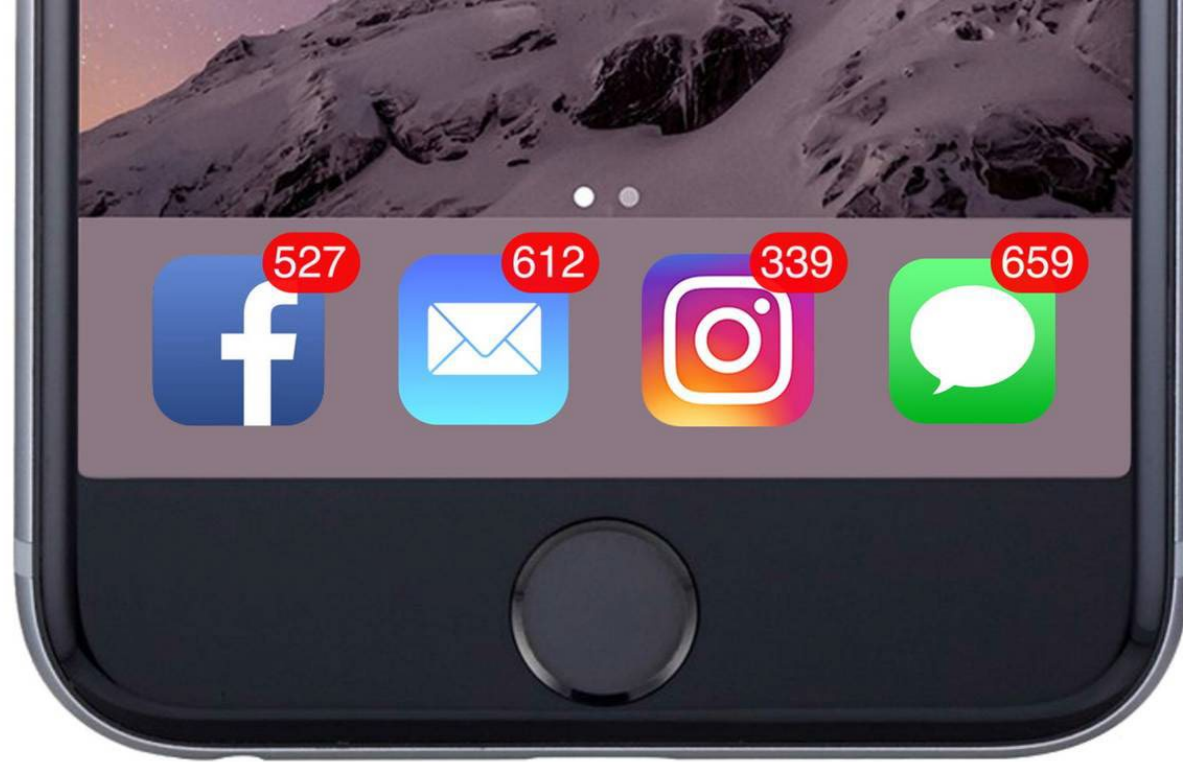
- Messaging





## COMMUNICATE

- Notifications





COMMUNICATE

• Groups

facebook



## Anxiety, Depression & Mental Health Support Group

Private group · 68.5K members

Join group

About

Discussion

### About this group

1. Be kind and courteous. Negative behavior on a post or towards someone will not be tolerated. Repeat offenders will be banned. We are not here... [See more](#)



#### Private

Only members can see who's in the group and what they post.



#### Visible

Anyone can find this group.



#### History

Group created on August 31, 2017. Name last changed on March 25, 2018.

[See more](#)





## COMMUNICATE

- Live Sessions

facebook [Sign Up](#) Email or phone

 **In The Rooms**  
October 26, 2015 · 🌐

LIVE AA/NA ONLINE VIDEO MEETINGS @InTheRooms.com Worlds Largest Recovery Social Network



WWW.INTHEROOMS.COM

**AA/NA Online Meetings NOW** [Sign up](#)

For those in Recovery or Seeking Help! 12 Step & Social Network Featuring 114+ LIVE...



# scientific reports

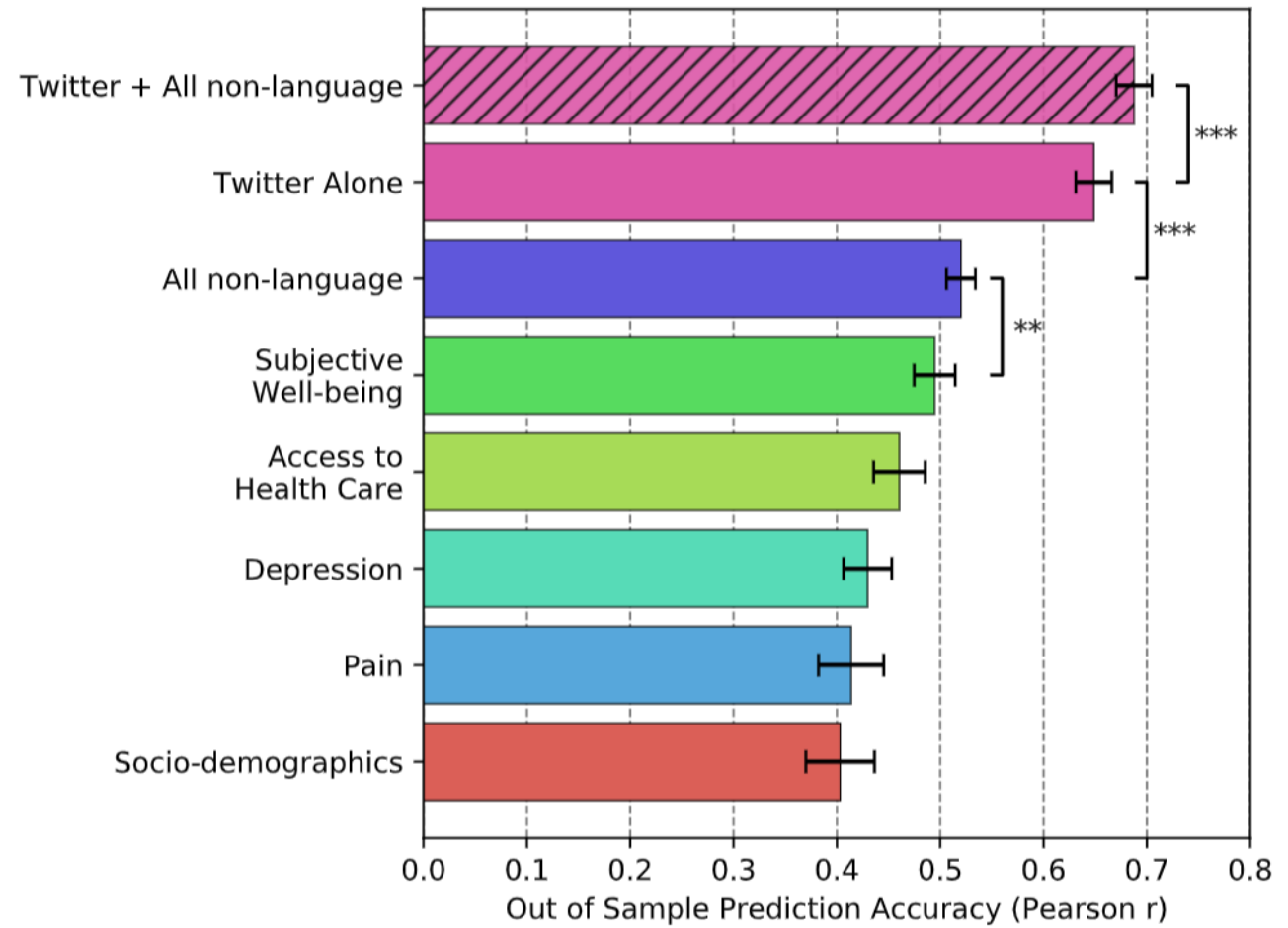
## Predicting U.S. County Opioid Poisoning Mortality From Multi-Modal Social Media and Psychological Self-Report Data

Salvatore Giorgi<sup>1,2</sup>, David B. Yaden<sup>3</sup>, Johannes C. Eichstaedt<sup>4</sup>, Lyle H. Ungar<sup>2</sup>, H. Andrew Schwartz<sup>5</sup>, Amy Kwarteng<sup>1</sup>, and Brenda Curtis<sup>1,\*</sup>

<sup>1</sup>National Institute on Drug Abuse, Intramural Research Program, Baltimore, MD, USA

- Twitter Data (random sampling)
- Opioid Mortality (CDC)
- Gallup-Sharecare Well-Being Index
  - well-being, depression, and physical pain
- U.S. Census variables

Twitter model outperformed all other models and was statistically different from the “All non-language”











Surveillance research raises ethical concerns related to privacy and data security.

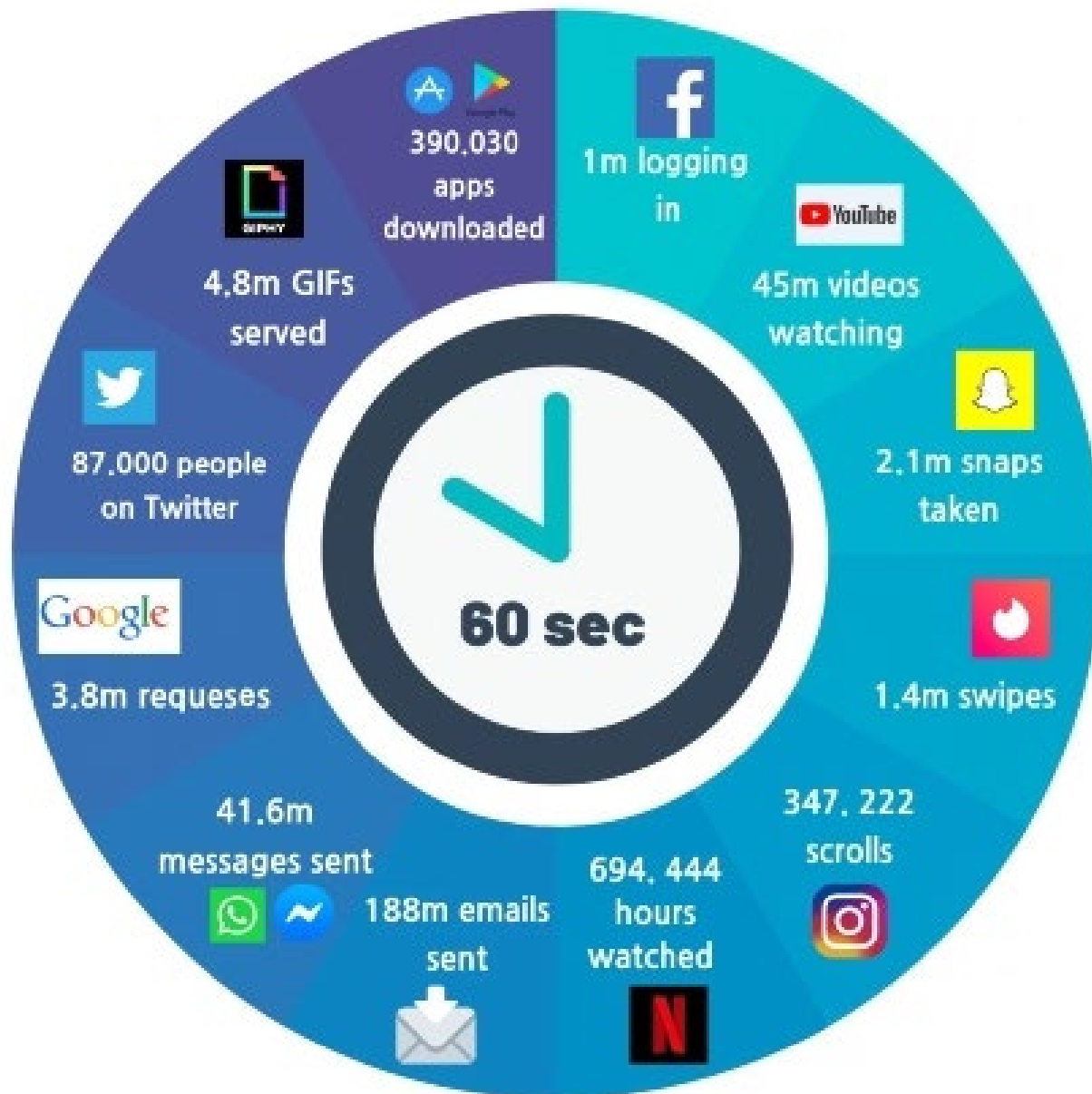
Data from Reddit (as well as Twitter, and various online message boards) is public and accessible to researchers. As such, this study was classified as not involving human subjects from the Institutional Review Board. However, there are still ethical concerns with using these data. At the forefront are issues of informed consent; while members of intimate communities like r/selfharm implicitly consent to have their experiences shared with other participants on the platform, they may not have consented to having their experiences analyzed in a research study.

Per recommendations from Proferes, Jones, Gilbert, Fiesler, and Zimmer (2021), we refrain from reporting usernames or illustrative quotes in this paper, as is often common in qualitative research, to prevent identification of specific r/selfharm users. While information associated with these users is often limited to their username, posts on other subreddits, and location, we wanted to afford our “participants” as much anonymity as possible.



# WHAT HAPPENS ON INTERNET IN 1 MINUTE

DATA SOURCE





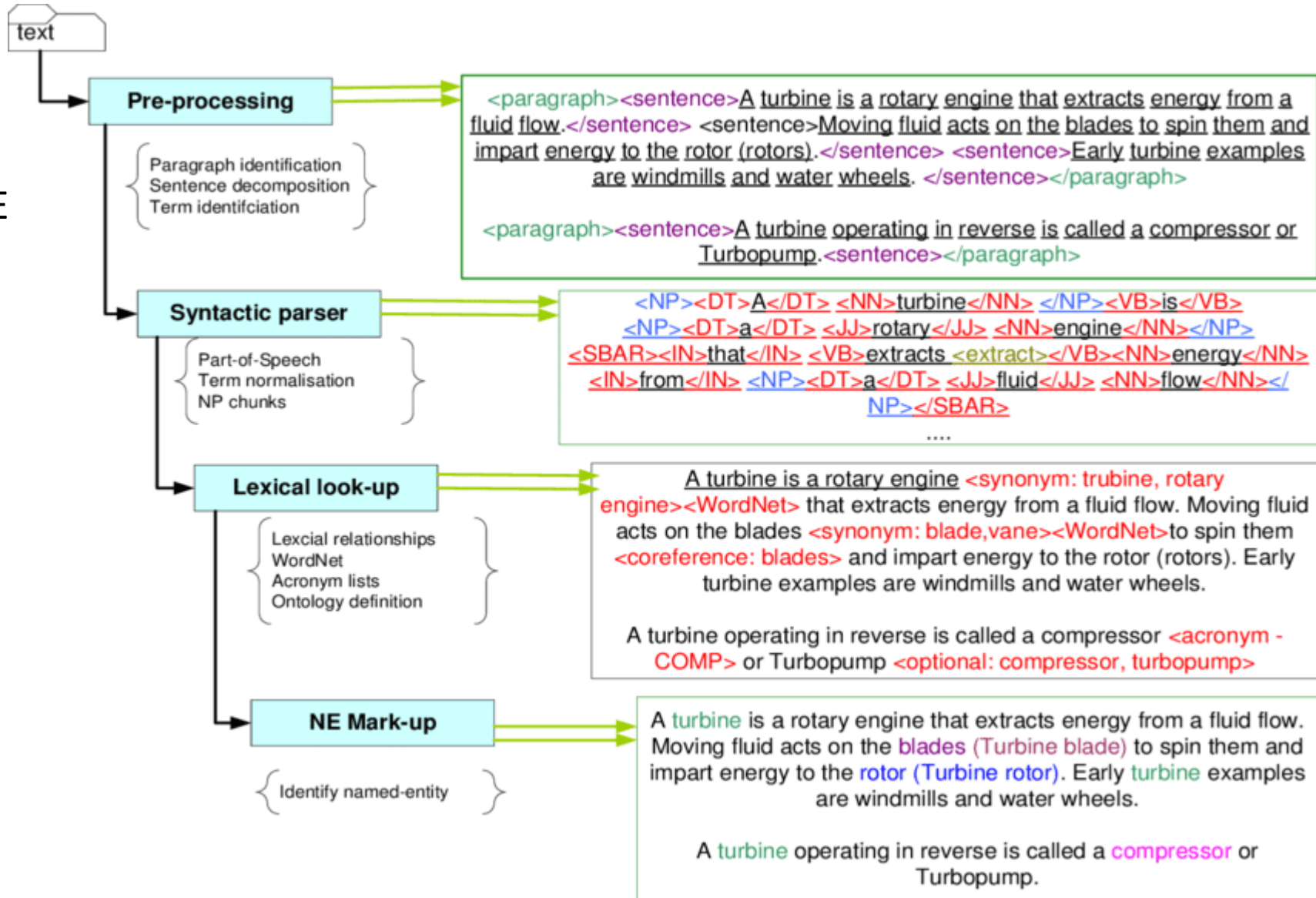


Real-time  
Naturalistic



# Text analysis


DATA SOURCE



# Sentiment analysis



DATA SOURCE

 **Deepinder S Rana** @DeepinderSRana · Dec 15, 2020

It's **frustrating** when the support team keeps saying, I have manually updated your campaign, it will reflect in couple of hours, with no avail! Just say it will take 24-48 hours, so one can plan accordingly!!

**Pathetic** customer support @ [redacted]  
# [redacted]

<b>Aspect:</b>	Campaign Update
<b>Topic:</b>	Customer Support
<b>Sentiment:</b>	Negative









## LIVED EXPERIENCE MATTERS: AUTOMATIC DETECTION OF STIGMA TOWARD PEOPLE WHO USE SUBSTANCES ON SOCIAL MEDIA

**Salvatore Giorgi**  
National Institute on Drug Abuse  
sal.giorgi@nih.gov

**Douglas Bellew**  
National Institute on Drug Abuse

**Daniel Roy Sadek Habib**  
National Institute on Drug Abuse

**João Sedoc**  
New York University

**Chase Smitterberg**  
National Institute on Drug Abuse

**Amanda Devoto**  
National Institute on Drug Abuse

**McKenzie Himelein-Wachowiak**  
National Institute on Drug Abuse

**Brenda Curtis**  
National Institute on Drug Abuse

npj | Schizophrenia

www.nature.com/npjshz

ARTICLE OPEN

## A machine learning approach to predicting psychosis using semantic density and latent content analysis

Neguine Rezaii<sup>1,2</sup>, Elaine Walker<sup>3</sup> and Phillip Wolff<sup>3</sup>

## Detecting Symptoms of Depression on Reddit

**Tingting Liu**  
National Institute on Drug Abuse  
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sharathg@cis.upenn.edu

Journal of Behavioral Addictions

Volume/Issue: Volume 11: Issue 1

Getting “clean” from nonsuicidal self-injury: Experiences of addiction on the subreddit r/selfharm



privacy



Control

Re-identification

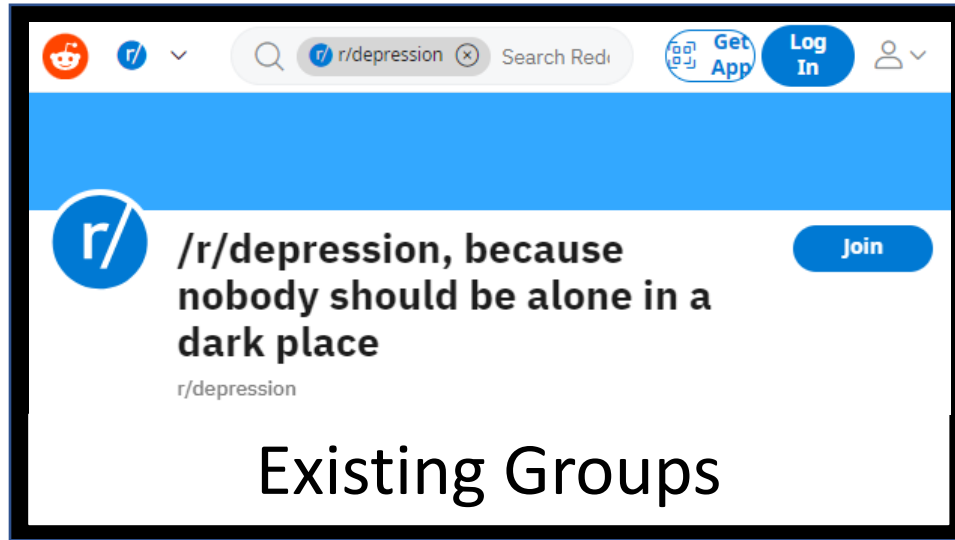
CONFIDENTIALITY

INFORMED CONSENT





## RECRUIT



## Existing Groups



## Social Media Ad



## Social Media Influencers



## RECRUIT

# Considerations

- Social media is very informal...research is formal
- ALWAYS clear with the IRB before interacting with potential (or actual) participants on social media.
  - When planning your protocol, discuss scenarios with the IRB team
- Unblinding on social media
- Follow all NIH social media policies
- All NIH clinical trial ethical policies apply
- Always work with your ICs communications team





# INTERVENE

JOURNAL ARTICLE

## Feasibility of pediatric obesity and prediabetes treatment support through Tess, the AI behavioral coaching chatbot

Taylor N Stephens ✉, Angela Joerin, Michiel Rauws, Lloyd N Werk

*Translational Behavioral Medicine*, Volume 9, Issue 3, June 2019, Pages 440–447,

<https://doi.org/10.1093/tbm/ibz043>

**Published:** 16 May 2019

*AIDS Education and Prevention*, 28(3), 216–230, 2016  
© 2016 The Guilford Press

## WECARE: A SOCIAL MEDIA–BASED INTERVENTION DESIGNED TO INCREASE HIV CARE LINKAGE, RETENTION, AND HEALTH OUTCOMES FOR RACIALLY AND ETHNICALLY DIVERSE YOUNG MSM

Amanda E. Tanner, Lilli Mann, Eunyoung Song, Jorge Alonzo, Katherine Schafer, Elías Arellano, Jesus M. Garcia, and Scott D. Rhodes

## Online Support Groups

  **Psycho-Oncology**  
Journal of the Psychological, Social and Behavioral Dimensions of Cancer WILEY

Paper |  Full Access

### Not all negative emotions are equal: the role of emotional expression in online support groups for women with breast cancer

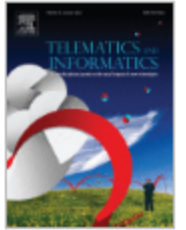
Morton A. Lieberman , Benjamin A. Goldstein

First published: 03 May 2005 | <https://doi.org/10.1002/pon.932> | Citations: 123





Telematics and Informatics

Volume 76, January 2023, 101918



Health Campaigns



# Do social media campaigns foster vaccination adherence? A systematic review of prior intervention-based campaigns on social media

Young Anna Argyris<sup>a</sup>  , Victoria R. Nelson<sup>b</sup>, Kaleigh Wiseley<sup>a</sup>, Ruoyu Shen<sup>a</sup>,  
Alexa Roscizewski<sup>c</sup>



Mobile health apps

# Digital recovery networks: Characterizing user participation, engagement, and outcomes of a novel recovery social network smartphone application

Robert D. Ashford<sup>a b</sup>  , Salvatore Giorgi<sup>c</sup>, Beau Mann<sup>d</sup>, Chris Pesce<sup>d</sup>, Lon Sherritt<sup>d</sup>,  
Lyle Ungar<sup>c</sup>, Brenda Curtis<sup>e</sup>



Healthcare



Volume 2, Issue 4, December 2014, Pages 220-224



Health education

The Leading Edge

# Using social media to engage adolescents and young adults with their health

Charlene A. Wong<sup>a b</sup>  , Raina M. Merchant<sup>a b</sup>, Megan A. Moreno<sup>c</sup>



# IRB Review of Studies Using Social Media

- What exactly are you doing?
- Identifiers to be collected
- Is the data public or private
- What technologies will be used to collect this data
- Once data is collected, where will it be transmitted, processed, and stored
- During lifecycle of data collection, processing and storage...who has access to the data—this includes third parties!

Overcoming Racial Bias In AI Systems And Startlingly Even In AI Self-Driving Cars

Racial bias in a medical algorithm favors white patients over sicker black patients

## AI expert calls for end to UK use of 'racially biased' algorithms

AI Bias Could Put Women's Lives At Risk - A Challenge For Regulators

## Gender bias in AI: building fairer algorithms

Bias in AI: A problem recognized but still unresolved

Amazon, Apple, Google, IBM, and Microsoft worse at transcribing black people's voices than white people's with AI voice recognition, study finds

## Millions of black people affected by racial bias in health-care algorithms

Study reveals rampant racism in decision-making software used by US hospitals – and highlights ways to correct it.

## When It Comes to Gorillas, Google Photos Remains Blind

Google promised a fix after its photo-categorization software labeled black people as gorillas in 2015. More than two years later, it hasn't found one.

Google 'fixed' its racist algorithm by removing gorillas from its image-labeling tech

## *The Week in Tech: Algorithmic Bias Is Bad. Uncovering It Is Good.*

Artificial Intelligence has a gender bias problem – just ask Siri

## The Best Algorithms Struggle to Recognize Black Faces Equally

US government tests find even top-performing facial recognition systems misidentify blacks at rates five to 10 times higher than they do whites.

# IRB Review of Studies Using Social Media

- With “big data” we are accustomed to collecting all the data that’s possible using it without the type of oversight seen in human subjects research reviewed by IRBs.
- In human subject research, only the minimal amount of data necessary to answer the research question is allowed and all data collection must be justified.

# IRB Review of Studies Using Social Media

- Policies and procedures:
  - In addition to standard HIPAA policies (if required) you should have policies in place for your studies that use social media that the IRB has reviewed
- Training
  - Make sure to train everyone on the team
    - Trainees, Staff, IT personnel
- Checklist / “cheat sheet”
  - Include common misconceptions
  - Develop new vendor checklists to make sure that new digital tools are validated and that data security requirements are known and agreed to

# Discussion: Case Study

- Recruiting adult participants who use drugs using ads on Facebook and Pro-Drug Sites
- Hired a company to collect their social media data from when they opened their account and following them for a year
  - Images, videos, post, private messages, etc
  - Content is timestamped and link to accounts of others on the social media platform
  - Able to merge data from all of their SM accounts and Browser searches
- Weekly Facebook private messages will ask participants if they used drugs and to provide information about which drugs they used and who they used the drugs with



# IRB Review of Studies Using Social Media

- Describe in tabular and graphical the data
- Provide a schematic (wireframe) of the underlying logic of the platform.
- Make a distinction between what's novel technology vs. what is using technology to do something that has been done before.
- Rethink the risks, including situational risks based on a reasonable prediction of how/when/where you will be using social media and other digital tools.

# IRB Review of Studies Using Social Media

	Who?	What?	Where?	When?	Why?	How?
Data Type	Entered by subject?  Auto-collected by device/platform?	PHI? Survey? GPS?  Interaction or usage of device/platform?	Under what circumstances or situation will it be entered?	By user action?  By device/platform?	Primary data for the study?  Data about the device/platform itself?	What is the detailed mechanism for collecting this?

**Investigators and developers** should map out all the data collection, and sharing points along with descriptions of the security measures and how it protects the privacy of the subjects

**This will go a very long way in terms of explaining to the IRB and IT the more complicated workings of the applications researchers develop and seek to use**

# Discussion

## Electronic Data Security

Data management of human subjects research data includes: data collection, data entry, and database repository oversight (controlling access, tracking use of analytic datasets). When reviewing electronic data collection, there are 4 important areas to examine:



### Identifiers

1

- What type of identifying information will be collected?



### Technologies

2

- What types of technologies will be used in the research study?



### Data

3

- Once data is collected, how will it be transmitted, processed, and stored?



### Security

4

- During data collection, how will it be transmitted, processed, and stored?

### 1. Identifiers

Anonymous data – at no time will any identifiers be collected including IP addresses?

If these identifiers are being collected, a data security review is recommended:

- Name
- Device identifiers/serial numbers
- Account numbers
- Electronic mail address
- Certificates / license numbers

## 1. Identifiers

Anonymous data – at no time will any identifiers be collected including IP addresses?

If these identifiers are being collected, a data security review is recommended:

- Name
- Electronic mail address
- Social security number
- Telephone number
- Fax number
- Internet protocol (IP) address
- Device identifiers/serial numbers
- Biometric identifiers
- Images (face)
- Health plan beneficiary numbers
- Account numbers
- Certificate/license numbers
- Vehicle identifiers and serial numbers
- Medical record number

## 2. Technologies

What types of technologies will be used in the research study?

Cellphone app, wearable device, text messaging, web-site, web-survey, electronic recording, and or video?

- Who developed the platform?
- How will it be accessed?
- How will the data be stored?
- How is the data coded?
- Where is the site/data hosted?
- Security features of the platform? (ex: password protected, encrypted during transmission)
- Will GPS data be collected?
- Can users turn GPS off?
- Is the communication one-way or two-way?

## 3. Data

Once data is collected, how will it be transmitted, processed, and stored?

- Who owns the server? Server operating system?
- Will cloud file storage be used?
- Will data live on a workstation? Laptop?
- Where will the data be housed?

## 4. Security

During data collection, how will it be transmitted, processed, and stored?

- Who will have access to the data?
- How will data access be managed?
- Who is responsible for maintaining the security of the data?



The Future



**Once a day**

everyone receives a  
**notification** at the same time



It's becoming all about  
"authenticity"

# Better Data + Better Models = Better Detection





JAMA Psychiatry | Original Investigation

## Real-time Mobile Monitoring of the Dynamic Associations Among Motor Activity, Energy, Mood, and Sleep in Adults With Bipolar Disorder

Kathleen Ries Merikangas, PhD; Joel Swendsen, PhD; Ian B. Hickie, MBBS; Lihong Cui, MSc; Haochang Shou, PhD; Alison K. Merikangas, MPH, PhD; Jihui Zhang, MD, PhD; Femke Lamers, PhD; Ciprian Crainiceanu, PhD; Nora D. Volkow, MD; Vadim Zipunnikov, PhD

RESEARCH-ARTICLE

## How Do You Feel Online: Exploiting Smartphone Sensors to Detect Transitory Emotions during Social Media Use

Authors:  [Mintra Ruensuk](#),  [Eunyong Cheon](#),  [Hwajung Hong](#),  [Ian Oakley](#) [Authors Info & Claims](#)

Proceedings of the ACM on Interactive, Mobile, Wearable and Ubiquitous Technologies, Volume 4, Issue 4 • Article No.: 150, pp 1-32 • <https://doi.org/10.1145/3432223>

ACS > Discover Chemistry > News Releases > 2018 > Implantable sensor relays real-time personal health data to a cell phone

FOR IMMEDIATE RELEASE | March 19, 2018

## Implantable sensor relays real-time personal health data to a cell phone

*Note to journalists: Please report that this research will be presented at a meeting of the American Chemical Society.*












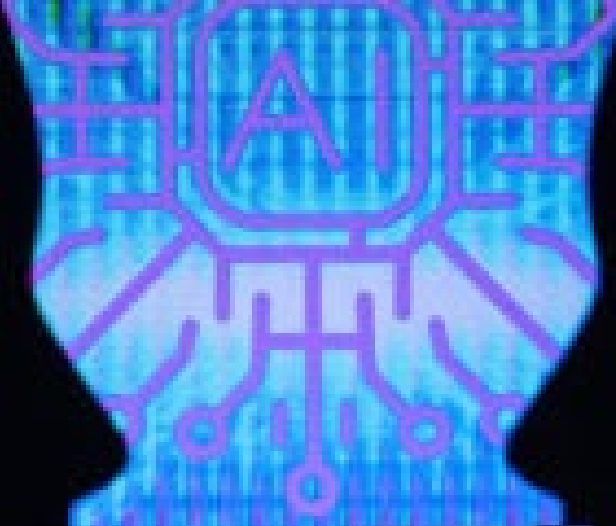
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## Wearable and mobile sensors connected to social media in human well-being applications

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