

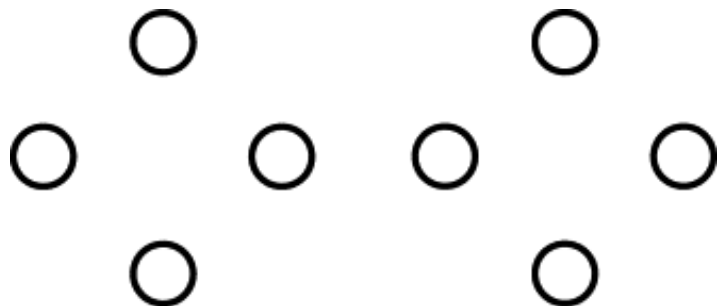
Ethical Considerations Surrounding the Use of Social Media in Public Health Surveillance and Epidemiological Research

CONFERENCE ON THE GOVERNANCE OF
EMERGING TECHNOLOGIES:
LAW, POLICY, & ETHICS

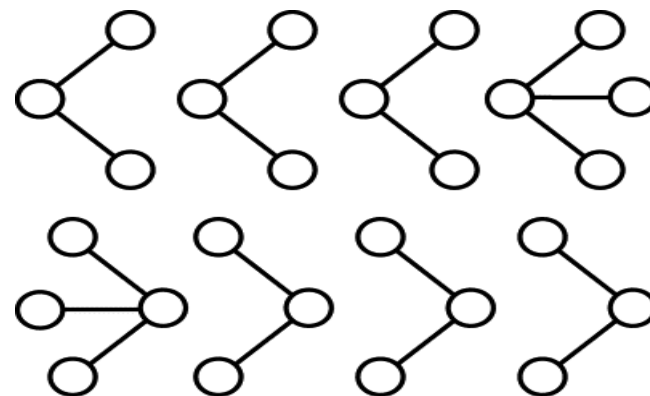
May 20, 2013

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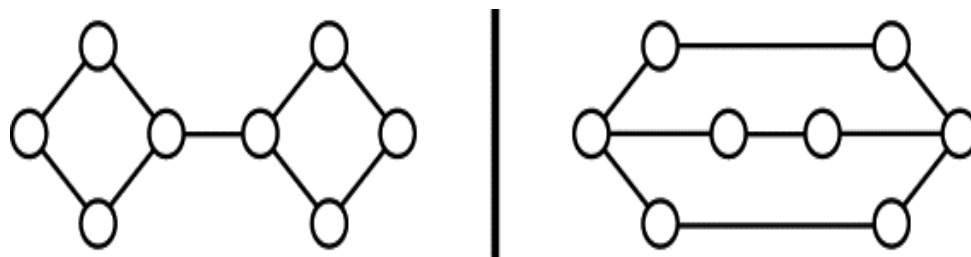
Information Gleaned from Social Networking Sites



Individual Attributes

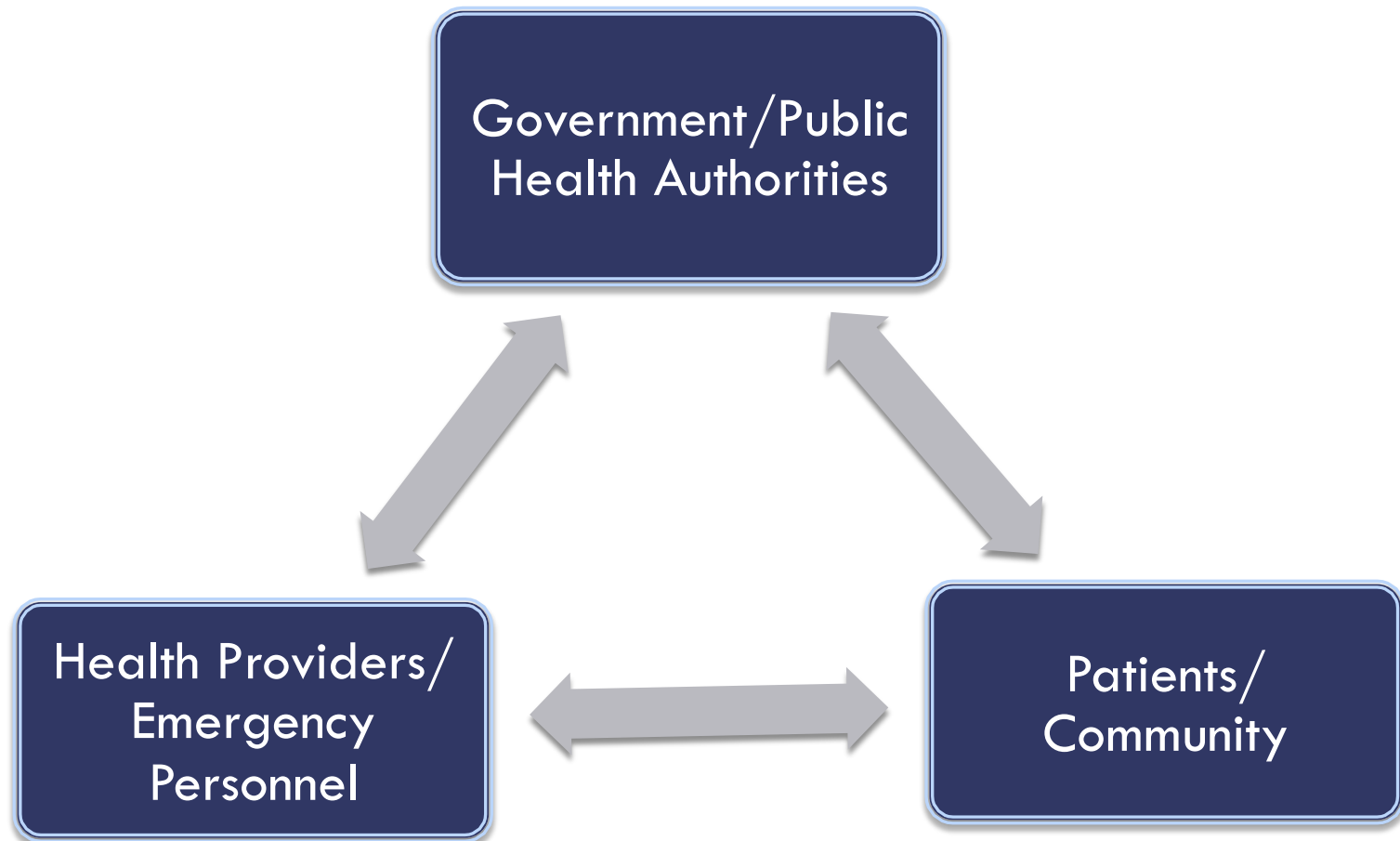


Personal Networks



Social Networks

Opening Communication Channels



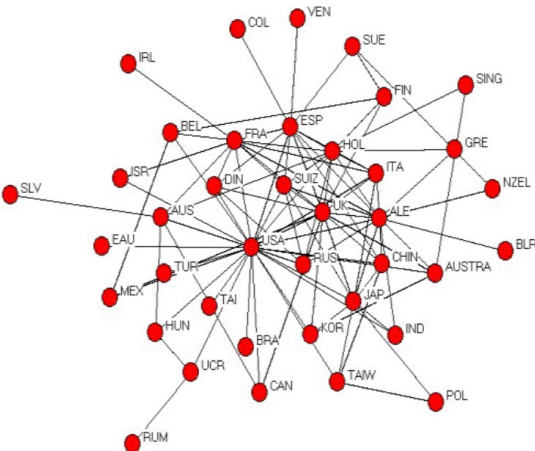
Social Network Analysis Tools

- Radian6 (Salesforce.com)
- Wisewindow
- Weka
- Synerscope
- UCINET

Radian6 Dashboard



Dashboard 2



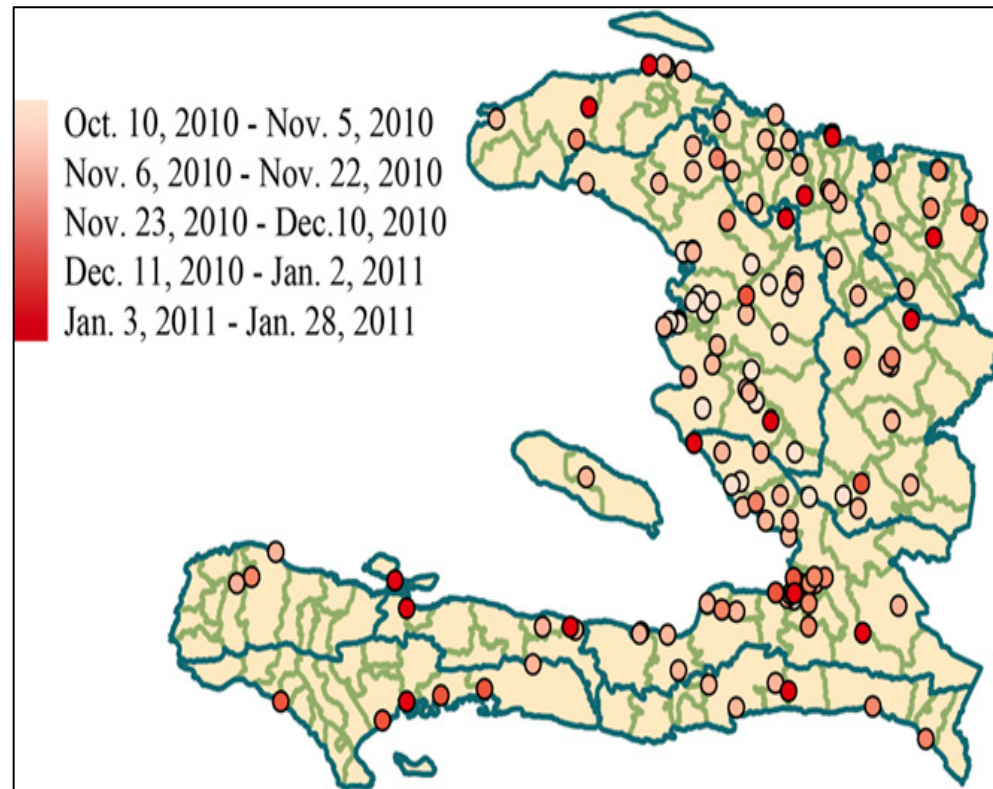
UCINET Cluster

Case Studies

- 1) Communicable: Cholera Outbreak in Haiti
- 2) Chronic: Diabetes
- 3) Behavioral Risk Factors: Adolescent Drug Use
- 4) Social Science: Tastes, Ties, and Time (T3)

Distribution of Twitter updates in the 100 days following the Haiti cholera outbreak

Harvard Medical School & McGill University researchers analyzed 188,819 tweets and 4,697 reports with the word *cholera* during the first 100 days of the cholera outbreak



Time and space distribution of HealthMap alerts for the first one hundred days of the Haiti cholera outbreak. Each HealthMap alert (marked by a circle colored corresponding to its date) is precisely placed to an exact latitude and longitude, and could also be generalized to the administrative areas it falls within.

Examples of Tweets Responding to Haiti's Cholera Outbreak in 2010



Ameliebaron Amélie Baron

La journée avait si bien commencé, collègues de [#RFI](#) primés... mais épidémie de choléra officialisée en [#Haiti](#).

21 Oct



wyclef Wyclef Jean

My visit to Sant Nicolas hospital in Saint Marc, As haiti is still fighting Cholera <http://plixi.com/p/53255834>

27 Oct

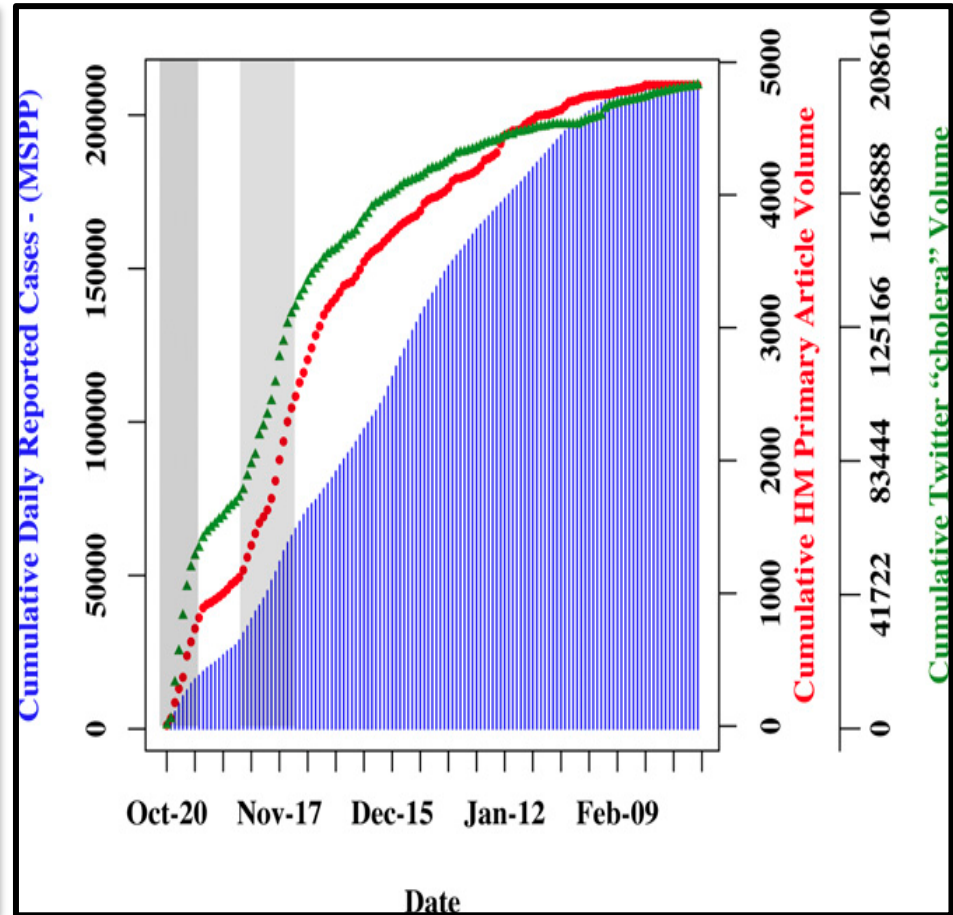
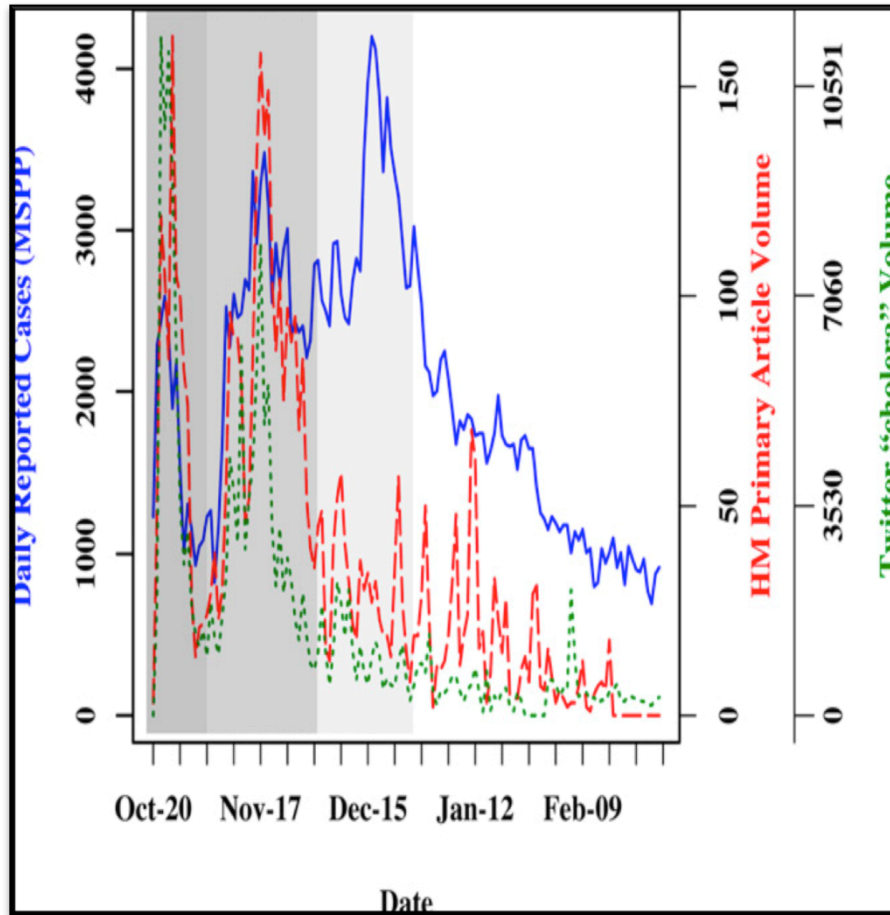


jacquiecharles Jacqueline Charles

Sitting w/a father who just lost his 7-year-old to cholera. Reality still has not hit

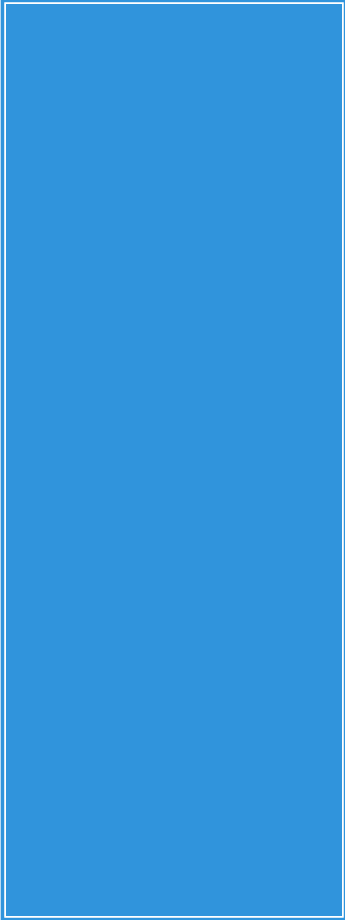
30 Oct

Informal Data Directly Correlates to Formal MOH Data



The first 100 days of the outbreak are shaded in light grey. (Chanura, et. al.)

Chronic Diseases

- 
- Associated with behavioral risk factors
 - ▣ Depression
 - ▣ Type II Diabetes
 - A randomized trial by Yu et al., demonstrated that self-management education programs online which incorporated self-efficacy have been shown to improve knowledge, health behavior, self-efficacy, HbA1c, weight.
 - ▣ Cardiovascular Diseases
 - ▣ Pulmonary Diseases

Diabetes-Specific Social Networks

Networking Site	No. of Members	Reviews All Content	Funding Source
http://www.tudiabetes.org	18,864	Administrator	Volunteer donations, foundation
http://www.diabetesmine.com	Confidential	Administrator	Pharmaceutical, manufacturer, device manufacturer, exercise/diet
http://www.diabeticrockstar.com	4334	Members	Volunteer donations
http://www.juvenation.org	11,785	None	Volunteer donations, foundation, pharmaceutical, manufacturer, device manufacturer
http://www.diabetescommunity.dlife.com	159,156	Members	Pharmaceutical manufacturer, device manufacturer, exercise/diet
http://www.presentdiabetes.com	Confidential	Administrator	Pharmaceutical manufacturer, device manufacturer, insurer
http://www.diabetes.org	18,451	None	Volunteer donations, foundation
http://www.diabetesdaily.com	48,227	Administrator, members	Pharmaceutical manufacturer, device manufacturer, not-for-profit, exercise/diet
http://www.thediabetesoc.com	30,930 ^a	Administrator, members	Web host
http://www.exchanges.webmd.com/diabetes-exchange	3,074	Administrator	Web host, pharmaceutical manufacturer, exercise/diet
http://www.healthcentral.com/diabetes	>160,000	Administrator, educator, physician	Device manufacturer, not-for-profit, insurer, exercise/diet
http://www.diabeticconnect.com	>300,000	Members	Pharmaceutical manufacturer
http://www.diabetessisters.org	5,000	Administrator, diabetes educator	Device manufacturer, not-for-profit, insurer, exercise/diet

Shrank WH, Choudhry NK, Swanton K, Jain S, Greene JA, Harlam B, Patel KP. Variations in structure and content of online social networks for patients with diabetes [Internet]. Arch Intern Med 2011;171:1589-91.

Behavioral Risk Factors

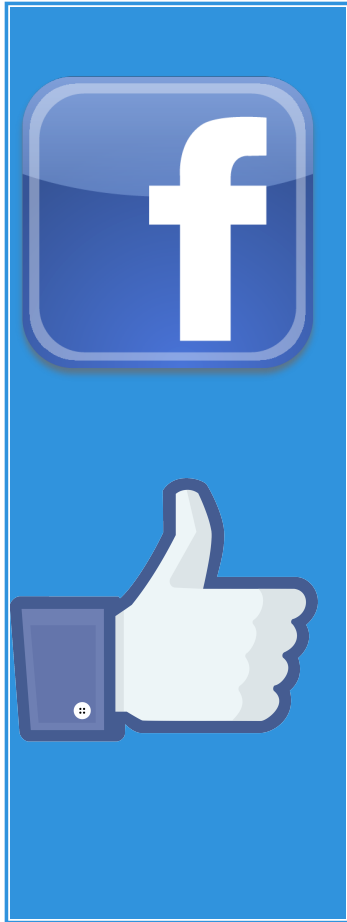


- Tweaking and Tweeting: Exploring Twitter for Nonmedical Use of a Psychostimulant Drug (Adderall) Among College Students, Hanson et al.
- 213,633 tweets from 132,099 unique user accounts mentioned “Adderall” from November 2011 to May 2012.
- The number of Adderall tweets peaked during traditional college and university final exam periods.
- Rates of Adderall tweeters were highest among college and university clusters in the northeast and south regions of the United States.
- 27,473 (12.9%) mentioned an alternative motive (eg, study aid) in the same tweet.
- The most common substances mentioned with Adderall were alcohol (4.8%) and stimulants (4.7%), and the most common side effects were sleep deprivation (5.0%) and loss of appetite (2.6%).

Benefits of Using Social Networking Sites in Adolescent Research

- Provide a database of adolescents that is vastly larger than traditional survey or ethnography
- Lower administrative burden than of traditional research methods
- Observational studies of adolescent behavior can be conducted with exemption from IRB oversight
- Opportunity to study and *modify* adolescent risk behaviors, a population largely outside of care

Tastes, Ties, and Time (T3)



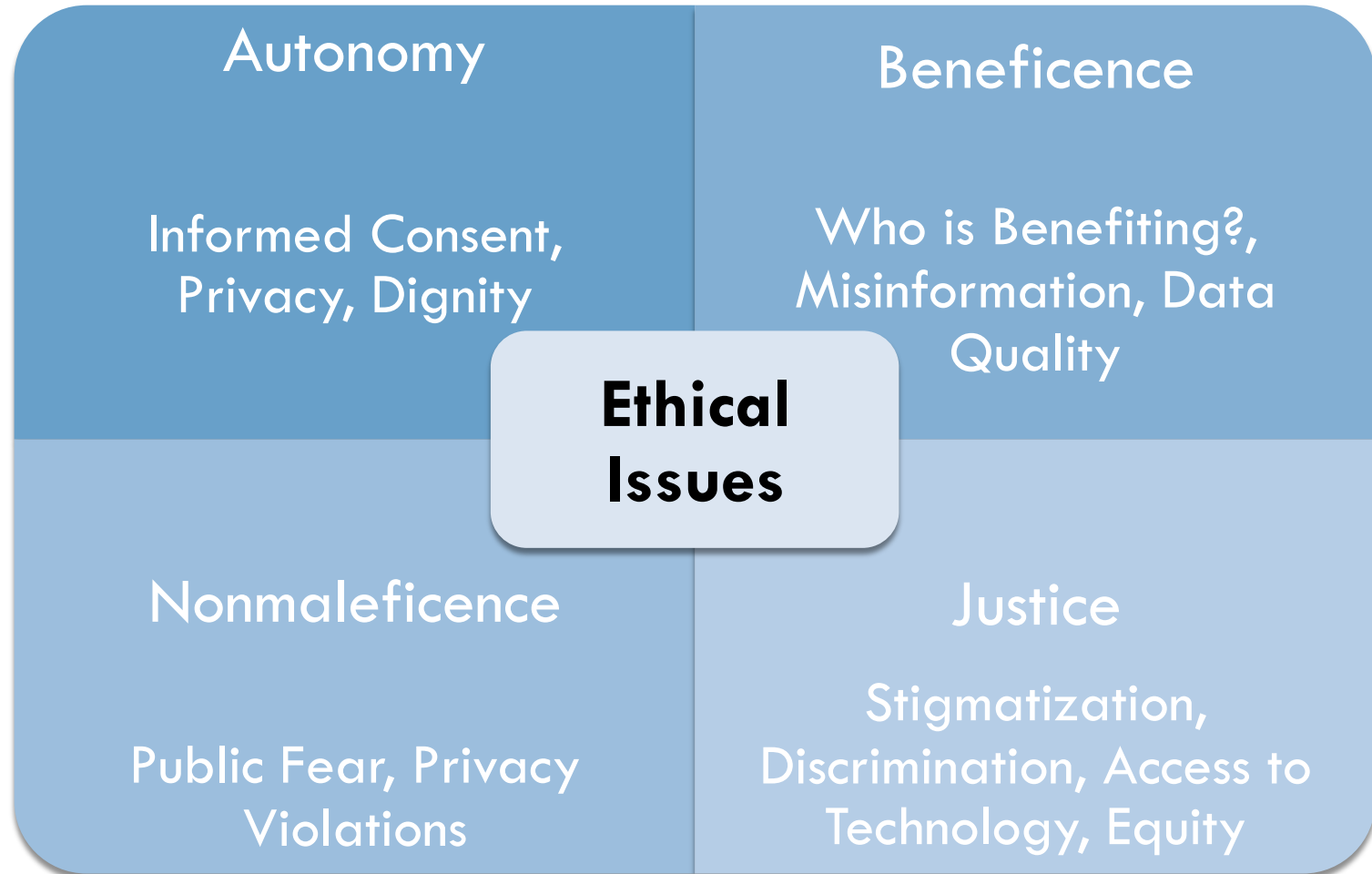
- Cultural fingerprint of an anonymous, Northeastern University
- Dataset of approximately 1,700 Facebook profiles
- Study by Jason Kaufman et al.
- Mapped lives throughout 4 years longitudinal to show changes in demographic, relational, and cultural information over time

T3: Efforts to Protect Privacy

- Only those assessable by default by each (in network) RA were collected
- No students were contacted for additional information
- All identifying information was deleted or encoded immediately after the data was downloaded
- Cultural taste labels released only after a “substantial delay”
- For access, researchers must agree to “terms and conditions for use” which prohibits efforts to re-identify
- IRB Approval

ETHICAL IMPLICATIONS

Ethical Considerations



Ethical Concerns

- Human subject protection: Research v Practice
- Privacy
- Autonomy
- Right to know v. Right to be let alone
- Stigmatization
- Decreased trust in public health authorities
- Autonomy
- Compromised Decision Making Capacity
 - ▣ Dementia
 - ▣ Children and Adolescents
- Digital Dignity
- Data Quality Concerns

Blurring the Lines Between Public Health Research and Practice

- Epidemiological Research

- Human subject research

- “A systematic investigation, including research development, testing, and evaluations, designed to develop or contribute to generalizable knowledge

- The Common Rule and HIPAA

- Public Health Surveillance

- “Intends primarily to prevent or control disease or injury in a given population”

- CDC

- “Interventions designed to enhance human well-being”

- Belmont Report

Council & Territorial Epidemiologists (CSTE) Proposal

- Distinguish “Practice” from “Research”
 - Legal Authority
 - Specific Intent
 - Participant benefits
 - Methodology
 - Proven Interventions v. Experimental Design

The Common Rule §46.102 Definitions

- ▣ (f) *Human subject* means a living individual, about whom an investigator (whether professional or student) conducting research obtains:

- data through intervention or interaction with the individual, or
- identifiable private information.

- ▣ **Waivers of consent**

- ▣ Minimal risk

- probability and magnitude of harm or discomfort anticipated in the research are not greater in and of themselves than those ordinarily encountered in daily life or during the performance of routine physical or psychological examinations or tests
 - Risks to subjects are reasonable in relation to anticipated benefits, if any, to subjects, and the importance of the knowledge may reasonably be expected to result

Personal Health Information (PHI)

▣ The Common Rule

- Consent
- IRB Review

▣ HIPAA Privacy Rule

- No more than minimal risk
- Research could not be practicably conducted without waiver
- Privacy risks are reasonable in relation to expected benefits
- Plan to destroy identifiers (unless justified)
- Written assurance the data will not be reused or discloses

▣ Certificates of Confidentiality

- Cannot be compelled to identify research subjects in civil, criminal, or legislative proceedings

US Model v. EU Model

- Personally identification (PII)

- United States

- Name; Social Security Number, Driver's License Number; Credit Card Number

- European Union:

- Includes physiological, mental, economic, cultural, or social identity

Privacy

“Privacy is an individual's right to determine what information they would like others to know about themselves; which people are permitted know that information; and the ability to determine when those people can access that information.”

- Elias Bizannes

Privacy

- Harm Based Privacy

- ▣ Data security

- ▣ Prevent harm from those wishing to gain access and do harm

- Dignity Based Privacy

- ▣ Recognizes that concerns about privacy extend beyond tangible harm

- ▣ Blouston 1964

Characteristics of Human-Computer Interface

- Online Disinhibition Effect
- Deindividuation
- Depersonalization of others
- Privacy Paradox
- Optimistic biases

Possible Biases in Observational Studies Using Self-Report Data

- Selection Bias
 - ▣ Ascertainment bias
 - ▣ Non-participation bias
 - ▣ Health volunteer bias

- Information Bias
 - ▣ Misclassification bias
 - ▣ Detection Bias
 - ▣ Recall bias
 - ▣ Hawthorne Effect

- Confounding
 - ▣ By Indication

Contact Tracing & Partner Notification

- Contact Tracing: Drug Resistant TB
- Partner Notification: HIV Ryan White Care Act provides grants to states to implement partner notification programs for HIV-infected people

Public Health Perspectives:

- Duty to Warn
- Right to know
- Right to be let alone

Policy Suggestions

- Code of Public Health Research Ethics
- Give subject opportunity to amend data
- IRB education on social media issues
- Innovate methods of informed consent
- Sharing information via Terms of Agreement
- Opt-out system
- Strive towards anonymity
- Common Rule (45 CFR part 46)
 - ▣ Amend to make public health surveillance more like research
- Companies to form data-sharing partnerships with health agencies/NGOs “data philanthropy”

Questions

- For further information

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