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

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CONFERENCE ON THE GOVERNANCE OF EMERGING TECHNOLOGIES: LAW, POLICY, & ETHICS
Information Gleaned from Social Networking Sites

Individual Attributes

Personal Networks

Social Networks

Alden S. Klovdahl, Social network research and human subjects protection: Towards more effective infectious disease control, Social Networks, Volume 27, Issue 2, May 2005, Pages 119-137, ISSN 0378-8733, 10.1016/j.socnet.2005.01.00
Opening Communication Channels

Government/Public Health Authorities

Health Providers/Emergency Personnel

Patients/Community
Social Network Analysis Tools

- Radian6 (Salesforce.com)
- Wisewindow
- Weka
- Synerscope
- UCINET
1) Communicable: Cholera Outbreak in Haiti

2) Chronic: Diabetes

3) Behavioral Risk Factors: Adolescent Drug Use

4) Social Science: Tastes, Ties, and Time (T3)
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 precise placed to an exact latitude and longitude, and could also be generalized to the administrative areas it falls within.

Chanura, et. al.
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

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

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 Considerations

- Autonomy
  - Informed Consent, Privacy, Dignity

- Beneficence
  - Who is Benefiting?, Misinformation, Data Quality

- Nonmaleficence
  - Public Fear, Privacy Violations

- Justice
  - Stigmatization, Discrimination, Access to Technology, Equity
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
(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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