EUROPEAN HEALTH FORUM GASTEIN 2015
Securing health in Europe. Balancing priorities, sharing responsibilities

Creating a better future for health in Europe

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Ethical issues in using social media for health and health care research

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McKee, Rebecca. "Ethical issues in using social media for health and health care research." Health Policy 110.2 (2013): 298-301
Social media as data in health and health care research

1. Introduction

2. Ethical challenges

3. Potential responses
Introduction:
Types of social media

• Social networking sites
  • Twitter, Facebook, Vine, Tumblr
• Blogs
• Discussion boards
  • Mumsnet
• Media sharing sites
• Virtual reality
Traditional uses of social media in health care

- Networking
- Education
- Health promotion
  - Public health programs/ Outreach programs
- Patient care
- Not always specifically designed for healthcare
Tweeting about Adderall, a commonly used stimulant among students

Hanson et al, 2013
Where are people tweeting about Adderall from?

Hanson et al, 2013
Public and Twitter attitudes towards health reforms in England

King et al. 2013
## MySpace profiles and health risk behaviors in adolescents

<table>
<thead>
<tr>
<th>Risk Behavior Referenced</th>
<th>Profiles With This Display, % (N=500)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sexual behavior</td>
<td></td>
</tr>
<tr>
<td>Profiles with any references to sex</td>
<td>24.0</td>
</tr>
<tr>
<td>Profiles with self-disclosure of sexual activity</td>
<td>3.6</td>
</tr>
<tr>
<td>Substance use</td>
<td></td>
</tr>
<tr>
<td>Profiles with references to alcohol use</td>
<td>37.0</td>
</tr>
<tr>
<td>Profiles with references to tobacco use</td>
<td>13.0</td>
</tr>
<tr>
<td>Profiles with references to drug use</td>
<td>10.2</td>
</tr>
<tr>
<td>Profiles with references to use of any substance</td>
<td>41.0</td>
</tr>
<tr>
<td>Profiles with references to use of &gt;1 substance</td>
<td>15.6</td>
</tr>
<tr>
<td>Profiles with references to use of all 3 substances</td>
<td>3.6</td>
</tr>
<tr>
<td>Violence</td>
<td></td>
</tr>
<tr>
<td>Profiles with references to violence</td>
<td>14.4</td>
</tr>
<tr>
<td>Profiles with references to any of these 3 risk behaviors</td>
<td>54.4</td>
</tr>
</tbody>
</table>
The Facebook experiment

• “We show, via a massive \((N = 689,003)\) experiment on Facebook, that emotional states can be transferred to others via emotional contagion, leading people to experience the same emotions without their awareness. We provide experimental evidence that emotional contagion occurs without direct interaction between people (exposure to a friend expressing an emotion is sufficient), and in the complete absence of nonverbal cues.”

• When positive expressions were reduced, people produced fewer positive posts and more negative posts; when negative expressions were reduced, the opposite pattern occurred.

Kramer et al. Experimental evidence of massive-scale emotional contagion through social networks. PNAS 2014
“one can decide to buy or sell according to the presence of a peak in the tweet volume and the level of polarity in the corresponding direction”
Ethical Considerations: Theoretical approaches

- Deontological
  - The Golden Rule
- Teleological
  - Utilitarianism
- Relativistic
  - Ethical cultural norms
Ethical Considerations: New Challenges

- The challenge is how to transfer traditional principles into the world of social media?
- Sensitive topics in health research
- Distance between the researcher and the subject
- Private Vs. Public space
- Anonymity
Ethical Considerations: New “new” social media

- Moved from internet discussion forums to mass social media such as Twitter
- Specific concerns about the speed, automation and volume of data collected in this way
- Can be collected by single researchers
- Increasingly relying on outsourcing data collection for example to computer science departments
Potential responses and measures

- Paraphrasing quotations
- Identifying variables
  - Suppress cells with only a few individuals
- Informed consent
  - Too simplistic?
@CaeruleanSea F ***ing stupid cretinous s*theaded dog-w*king c*t-brained murderous d*kless evidence-denying public health bastards.
Conclusions

• Be aware of the challenges
• Some measures we can take but be self-reflective
• Ethical considerations are shifting with new data
• There will have to be continual reviews as technology evolves
Thank you!

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