Social Media, Research, and Ethics: Challenges and Strategies

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Presentation for The Department of Energy and the University of Southern California Community IRB Members
Objectives

• To define types of Internet and social media
• To review examples of research intersecting with the Internet and social media
• To describe the types of ethical and regulatory issues that these interactions raise
• To discuss how IRBs are reviewing novel forms of research recruitment, data collection, dissemination, and storage of data
• To provide strategies for successful research and review of research in social media/Internet-based research
Internet Research
Internet Research

Internet-based research, broadly defined, is research which utilizes the Internet to collect information through an online tool, such as an online survey; studies about how people use the Internet, e.g., through collecting data and/or examining activities in or on any online environments; and/or, uses of online datasets, databases, databanks, repositories.

- Internet as a **TOOL FOR** research or...
- Internet as a **MEDIUM/LOCALE OF** research

- TOOL = search engines, databases, catalogs, etc...
- MEDIUM/LOCALE = chat rooms, MUDs, MOOs, newsgroups, web sites, MMORPGs, blogs, skype, social media, tweets, online course software, etc

- Increasingly, the line between tool and locale is blurring in the face of social media
Key Ethical and Regulatory Issues

• Recruitment
• Consent
  – Age verification
  – Documentation
• Privacy/Anonymity/Confidentiality
• Data Sharing
• Data Storage
• TOS/EULA—bind the user/subject to other terms?
What is Ethically Unique to E-Data?

• Greased
• Malleable
• Trackbackable/Mineable
• “Mashable”
• Travels across platforms (collapse of “internet” and cell/mobile/grid)
Forms of Research Venues

• Email, listserves, archives, chat rooms, SMS, IM, social network sites, blogs, home pages, media sharing sites, virtual worlds, online marketplaces, online gaming, databanks, repositories

• “Non-place” based sites such as mobile data collection and dissemination
Forms of Research: Exploring Where Human Subjects Fit

• Consider Methodologies, Venues, Types of Data Generated through:
  • Quantitative Research
    – Data Aggregation, Scraping, Transaction Log Analysis, Network Analysis, Statistical Analysis, Surveys, etc
  • Qualitative Research
    – Ethnography, Focus Groups, Observation, Surveys, Content/Discourse Analysis, etc
    – Emerging use of *synchronous* data collection/sharing across methodologies
    – Emerging use of mixed venues leads to “greased and malleable” data flow
For Example

California Clinical Trials
CA Clinical Trials
@cttresearch Glendale, CA
California Clinical Trials (CCT) was founded in 1986 and has conducted hundreds of clinical research studies involving thousands of patients.
http://facebook.com/CCTrails

Follow

Tweet to @cttresearch

Alzheimer's Everyday Health
Alzheimer's cases could double with new guidelines: oly/BJ63D
13 hours ago
Retweeted by cttresearch

@cttresearch CA Clinical Trials
Thanks for the mention! @Homburg
27 Jan

@cttresearch CA Clinical Trials
ppl w/disorders such as #Parkinson's and #A1z at higher risk of suffering phys or mental abuse bit.ly/wBcnAy via @digitaljournal
27 Jan

@cttresearch CA Clinical Trials
Depression has many faces. Actor Brad Pitt opens up about his struggles - ind.pn/wF8lg via @TheIndyNews
27 Jan

@cttresearch CA Clinical Trials
The difference between dementia and Alzheimer's via demeniatoday.net bit.ly/A0a2AF
27 Jan
CA Clinical Trials has 120 followers
Here's more about them.

People

All · Followers you follow

teaminspire
Our online patient support communities are safe, secure & moderated. Connect with others who know what you're going through. Tweets by John Novack. #patient

Bloafs

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REEMA SINGH

ParkinsonsAssoc
The Parkinson's Association of San Diego supports people with PD and their families with information, educational programs and family services.

DeepBrainMedia
Just a guy with PD, trying to raise money to fight it and fix the world at the same time.

ycpd1
Young Onset Person with Parkinson's who has two young kids, one with special needs. Software engineer during the day.

borderlinesblog
Struggling with bpd. Just trying to make sense of everything.

SpinaBifidaAssn
Working to promote the prevention of Spina Bifida and enhance the lives of all those affected. http://www.facebook.com/spina.bifida.lear
Subject recruitment

• OHRP considers subject recruitment part of informed consent
  – Recruitment plan must receive IRB review/approval prior to initiation

• Online recruitment methods
  – YouTube
  – Twitter streams
  – Blog postings
  – “Push” methods
Subject recruitment (2)

• OHRP guidance on IRB review of clinical trial websites
  http://www.hhs.gov/ohrp/policy/clinicaltrials.html

• No IRB review needed for descriptive information:
  – study title
  – purpose of the study
  – protocol summary
  – basic eligibility criteria
  – study site location(s), and
  – how to contact the study site for further information.
Subject recruitment (3)

• IRB review needed if additional information is provided
  – Description of research risks/potential benefits
  – Solicitation of identifiable private information (e.g. eligibility survey)
  – Incentives – monetary and non-monetary

• What needs to be reviewed:
  – Recruitment plan, not the actual webpage
Social media vs. Traditional Recruitment

• Uncontrolled following discussion among viewers/participants (and others, possibly)
• Interactive, not static
• Subsequent posts may modify already posted information
  – Must PI/IRB actively monitor social media sites used for recruitment?
  -FDA watch for reporting
Privacy....
“Recorded in a manner whereby subjects may be identified...”

• Is an email address an identifier?
• Do tweets contain identifiers?
• Does the inclusion of IP address make information identifiable?

• Possibility of reidentification – how meaningful is this decision point?
Public and Private Spaces

• Is a particular forum, listserv, chat room, bulletin board, etc considered *by its members* to be a public space or a private space? What expectations of privacy exist?
• What role does the researcher play in the space? (Observer, participant, member, other?)
• What is the content of the data? (Sensitive/non-sensitive?)
• Sveningsson’s continuum:

<table>
<thead>
<tr>
<th>Private</th>
<th>Non-Sensitive Information</th>
<th>Public</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>?</td>
<td>?</td>
</tr>
<tr>
<td>Sensitive Information</td>
<td>?</td>
<td></td>
</tr>
</tbody>
</table>
IRB Review

• Risks--Two main sources of harm:
  – Participation in the research
    • No direct contact with subjects; can’t deal with individual reactions (intervention or debriefing)
  – Breach of confidentiality
• Reliability and validity of the data
  – skewed subject populations
  – ease with which subjects can mislead investigators
  – difficulty in preventing multiple submissions
• Invalid research can have no benefit
  – inappropriate when there is risk to subjects
Minimal Risk

• Probability and magnitude of harm or discomfort in the research not greater than ordinarily encountered in daily life or during performance of routine physical or psychological examinations/tests (.102(i))

• Gateway to expedited review (.110); waiver of consent (.116(d)) and documentation (.117(c)(2)); no need to explain compensation or any treatments for research-related injury in consent (.116(a)(6)); Subparts B, C, D categories of permissible research

• Have the risks associated with breaches of data security or the likelihood of access by 3rd parties altered the conception of minimal risk in internet research?
  – Less privacy, more observation in general in daily life activities
Consent
Informed consent

• Consider waiver of consent and/or documentation, if appropriate
• Where consent required but documentation is waived, a “portal” can be used to provide consent information.
  – e.g., subjects must click on consent page to get to next page.
• Virtual worlds—consent rooms and tokens
• Where documentation required – consider alternatives to traditional documentation
  --e.g., electronic signature
Welcome to the Columbia University Sharing Survey

This survey is designed to measure people’s privacy concerns with Facebook. It should take less than 20 minutes to complete. 5 people will be randomly selected to receive a $100 Amazon gift card!

Read the consent form below and click the button to continue to install the application and take the survey.

Questions

If you have any questions while taking part in this research study, you should contact Maritza Johnson (maritza@cs.columbia.edu) or Steve Bellovin (smb@cs.columbia.edu, 212-939-7149).

If you have any questions about your rights as a research subject, you should contact the Institutional Review Board by phone at (212) 851-7040 or by email at askirb@columbia.edu. More information about taking part in a research study can be found on Columbia’s IRB website.

Continue to the survey, I have read and agree to the terms above.

Download a PDF of the consent form for your records.
Research with Minors/Vulnerable Populations

• Points to consider in “screening out” children:
  – use internet monitoring software or adult check systems
  – none of these is foolproof.
• Since it may be difficult to guarantee that children won’t access research, some research may not be appropriate in the online context
• Importance of using “chunked” consent documents
Welcome

You are invited to be in a study examining the sexual behavior, attitudes, and beliefs of Internet-using, Latino, Men who have Sex with Men (MSM) who live in the United States. This includes men who may consider themselves gay, bisexual, or straight (heterosexual).

WHAT IS THE PURPOSE OF THE STUDY?

The purpose of the study is to better understand the risk behaviors of Latino men who use the Internet and how meeting other men for sex on the Internet influences our safer sex decisions. The information we get from this study will help us to design a new HIV prevention program for this population.

WILL I BE PAID?

Yes, participants will receive $20 for completing the on-line survey.

WHO IS CONDUCTING THE STUDY?

This study is being conducted by Dr. Simon Rosser, Ph.D., M.P.H., and a team of investigators at the Center for HIV/STI Intervention and Prevention Studies (HIPS) at the Program in Human Sexuality, Department of Family Practice and Community Health, University of Minnesota Medical School. Your decision about whether or not to participate will not influence your future relations with the University of Minnesota or any other organization or agency connected with this research project. For more about the study investigators see who we are.

CHECK TO SEE IF YOU ARE ELIGIBLE TO PARTICIPATE:

☐ Yes  ☐ No  I am male. This includes all biological males and anyone currently identifying as male.
We brought our eligibility criteria forward so we did not waste non-eligible persons’ time.

CHECK TO SEE IF YOU ARE ELIGIBLE TO PARTICIPATE:

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
<th>I am male. This includes all biological males and anyone currently identifying as male.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>No</td>
<td>I am Latino. This includes men who identify as Hispanic Chicano, Mexican-American, Caribbean, or Latino. The definition we are using is a person of Mexican, Puerto Rican, Cuban, Central or South American, or other Spanish culture or origin, regardless of race.</td>
</tr>
<tr>
<td>Yes</td>
<td>No</td>
<td>I am 18 or more years old. This is an adults-only website. If you are not 18 years old, you must leave this site now.</td>
</tr>
<tr>
<td>Yes</td>
<td>No</td>
<td>I have had sex, meaning any kind of sexual contact, with at least one other man. All men who have sex with men, not just gay and bisexual men, are welcome to participate.</td>
</tr>
<tr>
<td>Yes</td>
<td>No</td>
<td>I currently live in the United States, including Puerto Rico and Hawaii, regardless of legal status.</td>
</tr>
<tr>
<td>Yes</td>
<td>No</td>
<td>I understand that I will be asked some questions about sex and sex with other men.</td>
</tr>
<tr>
<td>Yes</td>
<td>No</td>
<td>I have not filled in the study before. It is very important that you only complete the study once. (If you are returning to complete the study, please click here.)</td>
</tr>
</tbody>
</table>

I click to affirm I am eligible to enter this study

← Exit the study
Welcome to the *Drugs on Forums* project website.

This website provides information for online forum users and moderators interested in participating in the *Drugs on Forums* project, as well as other students and researchers with an interest in this topic. It includes: a [project summary](#), the [participant information sheet](#) and the [encryption guide](#) for participants interested in learning more about secure online interviewing.

The *Drugs on Forums* project is an independent university-based project conducted through the [National Drug Research Institute, Curtin University](#). Monica's PhD scholarship is provided by the [Australian Government Department of Health and Ageing](#). This study has been approved by the [Curtin University Human Research Ethics Committee](#) (Approval Number 102/2006).

Media representatives who would like to report on this research are invited to contact [NDRI's media officers](#).
Encryption Guide?

• Thanks for your interest in participating in an online interview with me as part of the Drugs on Forums project. I use instant messaging as a means of conducting the online interview. This webpage explains how this process can be conducted with the same kind of confidentiality that applies to face-to-face or telephone interviews.

• As you may already be aware, emails and instant messages are insecure when sent in plain text. Firstly, they can be intercepted (read by others or altered by others), and secondly, the reader cannot be certain that the sender is who they claim to be.

• The most effective way of ensuring that what we write will only be read by each other is to use encryption. All the program options I recommend below are free and you will be able to use them with anyone once you show them how. Some are packaged as portable software, which means you can run them from a USB flash drive on any computer.

• If you are unable or unwilling to use these programs, using an instant messaging account that is not linked to your full name (eg. someguy@hotmail.com) will also provide a degree of confidentiality. If we communicate without encryption, it is possible that third parties could intercept and read our conversation without our consent. However as long as your identity cannot be easily worked out, any risk to you will be reduced.

• Many people who are concerned about online privacy may already have an email account that has never been associated with their full name. It is easy to start a free webmail account completely for this purpose.
Cutting.

Stress

By There Is Hope on Tue, 01-19-10, 18:08
Posted in Group: Stress

Hello, i am norma. im fifteen. i've been cutting for 3 years. i want to share my story all over the world because i believe in a thing called hope. online support groups are amazing to me, i wish more people would join in them. i've tried to stop cutting but nothing has worked but i can tell you that my friends are a big support. cutting is not a way out, its a bad habit. i'm a big supporter of twloha. i believe that recovery is possible and so is treatment. taking the first step to recovering is the hardest but it gets better i promise. if you feel the need to cut, talk or text me. message me for my number. i will always be here wheather i know you or not. i love helping people, and i will try my best to help you in any way possible.

Support Points: 145  Offline  Login or register to post comments

By tiggy on Tue, 02-09-10, 01:45

i haven't cut since 08 but i REALY struggle at times.im 30 but i started cutting when i was about ur age.can i have ur number,email and if u r on facebook will u add me?? shanna host,shannatiger@hotmail.com if u email me i will give u my number if u want it.i am also a BIG texter also.

Support Points: 115  Support Badges Offline  Login or register to post comments
Data Aggregation/Scraping
Regulatory Considerations

• Human subjects
  – Private
    • How to interpret “reasonably expect that no observation or
      recording is taking place” or “reasonably expect will not be
      made public”
  – Identifiability, again
    • Zip code + sex + DOB enough for Latanya Sweeney to
      identify
    • Structure of social network, search terms, purchase habits,
      movie ratings on Netflix may uniquely identify individual
    • IP address
Regulatory Considerations

• Exemption 4
  – When is information “recorded in an identifiable manner”
  – When are data, documents, or records publicly available on the internet?
    • Does “publicly available” include large datasets purchased/obtained from Google or Facebook?
    • What if data are semi-restricted -- available only to ‘friends’, listserve members?
    • What if data are available through Wikileaks or other source where provenance is questionable?
Key Considerations for Review

- What type of venue
- Expectations of privacy
- Consent procedures
- Sensitivity of data
- Harm/Risk
- Age verification
- Authentication of participants
- Identification of participants
- Use of encryption
- Storage/transmission of data
Example Guidelines

- http://irb.uconn.edu/internet_research.html
- http://inside.bard.edu/irb/guidelines/
- http://www.luc.edu/irb/irbonlinesurveys2.shtml
- http://www.research.psu.edu/policies/research-protections/irb/irb-guideline-10
Resources

• Internet Terminology@internetresearchethics.org
• Expert consultation@interentresearchethics.org
• New Internet research section in JERHRE