

Online Research, Social Media, and the IRB: Assessing Ethics, Norms, and Risks

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Welcome!

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In this webinar, we will review:

- The specificity of social media as it relates to online research
- Different types of social media used in human subjects research
- Tips for evaluating what qualifies as appropriate recruitment and data collection techniques in diverse online spaces
- Relevant issues and important considerations for IRBs regarding social media research
- Techniques for IRBs to address questions of social norms in online communities and social media for a
- Strategies for how IRBs can estimate baseline risks to subjects, and specifically, what constitutes risk and what constitutes more than minimal risk in online research.



Definitions: “internet research” as an umbrella term

- (a) Utilizes the internet to collect data or information, e.g., through online interviews, surveys, archiving, or automated means of data scraping
- (b) Studies how people use the internet, e.g., through collecting and observing activities or participating on social network sites, listservs, web sites, blogs, gaming, or other online environments or contexts
- (c) Utilizes or engages in data processing, analysis, or storage of datasets, databanks, and/or repositories available via the internet
- (d) Studies software, code, and internet technologies
- (e) Examines the design of systems, interfaces, pages, and elements
- (f) Analyzes visual and textual content of sites, including websites and Internet-facilitated images, writings, and media forms
- (g) Studies large scale production, use, and regulation of the Internet by governments, industries, corporations, and military forces. (AoIR, 2012)

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Social Media Landscape



FredCavazza.net

What is ethically unique to internet data and internet research?

- Greased
- Malleable
- Trackbackable/mineable
- “Mashable”
- Scale and access
- Interoperable: travels across platforms (collapse of “internet” and cell/mobile/grid)
- Interconnectedness: more readily collapsible boundaries between subjects/researchers (and third parties)



Myopic versus hyperopic perspectives

- Bleeding out of/from research frame
- Social space
 - Participants WILL discuss, interrogate, and sometimes flame the research
- Transiently populated—both researchers and subjects
 - Consider two examples from WoW: University of Denver versus Chen’s WoW research
- Explosion of perspectives and norms



New ethical issues or repackaged issues?

The Same Principles	New Problems?
Ethical research is that which seeks to do no harm.	Harm may be unforeseeable due to greased and malleable nature of Internet data. DOWNSTREAM HARMS.
The greater the vulnerability of the subject, the greater the obligation to protect.	Continuum of masked nature of vulnerabilities versus open vulnerabilities; ensuring of informed consent
Research integrity itself (good methods and ethics = good research)	Verifiability of subjects; crowdsourced research; "involvement" of subjects in methods may unblind or bias research results

"Investigators and IRBs should remember that the *Belmont* principles...are as applicable to internet research as they are to any other form of human subjects research. Regardless of how the regulations may be interpreted in individual studies, adherence to these fundamental principles is important to encouraging public trust in the ethical conduct of internet research" (SACHRP DRAFT 2013)



Remember: As CNN Tells Us...



The screenshot shows a CNN web page with the URL www.cnn.com/2013/02/15/tech/internet-rules/index.html?hp=hp_bn5. The main headline reads "ANYTHING you post will eventually become PUBLIC". Below it, a section titled "Our 12 Rules of the Internet" is displayed, with the number 3 highlighted in red. To the right, there's a sidebar titled "TECH: NEWSPULSE" featuring a list of popular tech stories. At the bottom, there's a "More from CNN Video" section with thumbnail images and titles.

This screenshot shows the same CNN page but with a different main headline: "However bizarre or obscure your interests, SOMEONE SHARES THEM.". The rest of the page content, including the sidebar and video section, remains the same as the first screenshot.

Poll

- What area of internet research brings the most concerns to your board?
 - Recruitment issues
 - Privacy issues
 - Data security issues
 - Considerations of public versus private data/information
 - Others?



Let's look at cases in three areas:

- Social media and recruitment
- Social media and data collection
- Social media and experimental research



Case 1: Recruitment in World of Warcraft

- A researcher would like to solicit WoW gamers for survey research. The researcher gets IRB approval and then proceeds to post to the guild discussion board.
 - What issues arise?
 - What should the IRB look for in the recruitment script and consent document?
- Three scenarios show the importance of context and knowing the norms of the site prior to recruiting:



Issues:

- Recruitment, part of informed consent considerations
- “Permissions” and norms
 - FAQs
 - Community input
- Risks
 - Informational risk: “Inappropriate and or unauthorized disclosure, misuse, transmission or appropriation of data”
 - Foreseeable? Everyday life?



Amendment 1. Posting Surveys

Survey posting by outside parties is allowed only for educational purposes. Commercial surveys, or surveys without an academic background are expressly prohibited and will be immediately removed.

Prior to posting any survey, you are required to contact one of the following Forum Administrators:

Kaolian@allakhazam.com
darqlflame@allakhazam.com

And to provide verified contact information and academic credentials, including a university associated e-mail address from which the request originates. A full, unaltered copy of the survey questions must also be provided.

All other survey posts will be removed and the originating account banned.

In-forum poll system exemption: This amendment specifically does not cover in forum polls generated by forum users. The intent is to prevent unnecessary spam by outside entities with no real investment in the forum system.

Section updated: 3/16/2010

Amendment 2. Forum user names

Any forum name found to contain offensive references that were not caught by the filter will be immediately changed to something of our choosing. At the Administrator's discretion, the account may be banned if the name is particularly offensive.

Section updated: 3/16/2010

Amendment 3. Posting torrent sites, illegal content, or copyrighted material

Legitimate torrent sites, such as those hosting legitimate game patches, are allowed, but should be cleared with an administrator prior to posting if there is any question. Sites hosting illegal downloads, "private" servers, or material that has been brought to our attention as being in violation U.S. law is not allowed and will be immediately removed. All copyrighted content, regardless of format, that is submitted to the forums will be removed at the request of the copyright holder.

Section updated: 3/16/2010

Amendment 4. Reporting Forum Images

Forum images that have objectionable content should be reported, however excessive and persistent reporting of images that are not objectionable is considered a form of harassment and will be dealt with as such. Currently the only way to prevent image reporting is a full ban.

Section updated: 3/16/2010

Amendment 5. Reporting Forum Posts

Forum posts that have objectionable content should be reported, however excessive and persistent reporting of posts that are not objectionable is considered a form of harassment and will be dealt with as such. Currently the only way to prevent post reporting is a full ban.

Poll

- Does your IRB consider or require the researcher to address the TOS or EULA or other site policies as part of your protocol review?
 - YES
 - NO
 - NOT SURE

Case 2: Recruitment on a dating site

- **The research question:**

Do men who go online to seek domination (by women) differ from baseline rates of sexually-transmitted disease and STD risk?

- **The strategy:**

Phony personal ad on fetish dating site for recruitment. Plan is to find the men, get contact information, then follow up to recruit for study. Will adopt persona to attempt to get contact info.



Traits:
Honest, Sensitive, Creative, Sexual, Dominant, Generous, Sarcastic, Quiet, Confident, Direct, Ethical, Self-conscious, Aggressive, Independent, Optimistic, Social, Strong Will-power, Selective

Into:
Domination, Bondage, Blindfolding someone, Dressing in latex, Dressing in leather, Role playing, Erotic chat, Cross-dressing, Administering discipline, Groups / Orgy, Foot worship, Pain (giving), Spanking, Whipping, Other

Tell about yourself - your personality, lifestyle, etc.
a young mistress brought up to this world to dominate men.. mistress love to train, humiliate men, hurt them and get pleased by them... well you can call me average mistress like the others but there's something about me that so unique.. even though am so young i discover my dominant side when i was in college, am a psychology major wen we tackle about the behavior of men, wen it said some men like to be dominated because its were they find pleasure and kinda like it.. am doing this to help slave and for my own pleasure to.. it like the saying "you rub my back ill rub yours" ... that's how i came into this life style.

What kind of person are you interested in meeting?
so slave if you want to inquire or to be my slave just ask, its free to ask am good to a good slave and please don't ever ask what i look like if my slave is bad.. because no live to tell the story... so interested try to look for the qualification.
can handle 2 or more of the following:
1. golden shower
2. willing to be my sex slave
3. can undergo chastity

Poll

- Mark your biggest concern ...
 - Deception in the personal ad
 - Deception in post-ad contact
 - Harming the trustworthiness of the site
 - Vulnerability of potential recruits
 - Handling recruits' personal information (privacy)
 - Just feel queasy about it / Other
 - No concerns, seems like an easy approval



A few issues ...

- Baseline exposure / risk
- Appropriateness of deception / misdirection
- Norms and terms of use of sites
- Privacy



Baseline exposure / risk

- What is everyday risk among the target population?
 - Does the fetish dating site already create a profile? With what information? Who can see it?
 - What is the risk-acceptance of the site user who responds to a non-research message?
 - What is the risk profile of site users overall?
- What new risks are associated with recruitment and participation?
 - Of course, this gets to the essence of the study



Deception and misdirection

- Contrast three versions of the fetish recruitment scenario:
 - v1. When the recruit contacts the “dominant,” “she” gets contact info, and then a researcher calls, identifies self, and attempts to recruit / provides informed consent (acknowledging fake ad)
 - v2. Just like v1., but never admits it was a fake ad
 - v3. Instead of getting contact info, the “dominant” asks him to share his profile; study consists of reviewing the private profile shared under deception.



Deception and informed consent

- Timing and context matter
 - Informed consent requires “informed”
 - Usual requirement to debrief, correct misinformation
 - For these to be waived, there has to be good justification
- Some special issues online
 - May lose contact with subject before able to debrief
 - Consider the worst-case point to lose contact
 - May have difficulty convincing subject of the real information



Norms and privacy considerations

- Norms
 - Expectations and consensus
 - Shifting terrains
 - Sensitivity of topic → risk levels
- Privacy
 - “Appropriate control and flow of information”
(Nissenbaum, 2011)
 - “If access to an online context is publicly available, do members/participants/authors perceive the context to be public? What considerations might be necessary to accommodate ‘perceived privacy’ or the notion that individuals might care more about the appropriate flow of information as defining it as public or private?”
(AoIR, 2013)



Case 3: Data collection and observation

▪ Example 1:

A research team wants to use “public” postings to analyze reports of adverse effects to a medication. The IRB is conflicted whether this is human subjects research or not, as there is no direct interaction or intervention with subjects. However, some of the postings have *identifiable* - and possibly *private* - information.

▪ Two scenarios:

- Collecting Twitter streams, message board postings, and blogs
- Facebook graph



www.ajicjournal.org
Vol. 38 No. 3

Scanfeld, Scanfeld, and Larson 185

Table 3. Antibiotic-related categories, definitions, examples, and frequencies from Twitter status updates

Category	Definition	Example	Frequency
General use	Commenting generally on taking antibiotics	"Got more antibiotics from doc. Hope these ones finally get rid of this cough"	289 Updates
Advice and information	Offering or seeking advice, information, or explanations regarding antibiotic use	"Absolutely, it could mess up your stomach. A good rule of thumb with antibiotics is to eat [sic] a yogurt every time you take your dose."	157 Updates
Side effects/negative reactions	Claiming or mentioning side effects from antibiotics, negative reactions, complaints	"The antibiotic I took a while ago is killing my stomach ... ugh!"	113 Updates
Diagnosis	Mentioning the reason for taking antibiotics	"A dying tooth. Painkillers. Antibiotics. Root canal scheduled. Ahhh . . . the sweet curves life throws."	102 Updates
Resistance	Discussing resistance, including reference to antibiotics in farm animals	"Dangers from overuse of antibiotic use in animal feed leading to MRSA outbreaks http://tinyurl.com/cqj638 "	92 Updates
Misunderstanding and/or misuse	Referencing viruses, cold, flu; attempts to access or sell antibiotics without a prescription; incorrect use; refusal to take antibiotics under any circumstances	"Go get a shot, babe. Or some Murine ear drops from Walgreens. I can also mail out my leftover antibiotics."	55 Updates
Positive reactions	Expressing a positive reaction to or result from taking antibiotics	"I promise this is my last sickness tweet (bored with me yet!) But I could literally FEEL the antibiotic start to work. Amazing."	48 Updates
Animals	Referencing an animal, not including antibiotics in farm animals	"Cat has antibiotics. Doesn't like traveling when it means there might be peroxide at the end. Is currently being bathed. Not happy. Is loud!"	46 Updates
Other	Miscellaneous mention of antibiotics that fails to fit into any other category	"From the pharmacy frontier: Does the world really need 20 flavor options to make medicine go down easier? Cotton-candy antibiotic, anyone?"	42 Updates
Wanting/needng	Expressing a desire for antibiotics but not having received them yet	"Needs antibiotics right now!"	19 Updates
Cost	Discussing cost or pricing	"Turns out I can still take my antibiotic if I take an anti-histamine for the reactions: Total bill for illness? \$165 thus far."	8 Updates

MRSA, methicillin-resistant *Staphylococcus aureus*.



186 Scanfeld, Scanfeld, and Larson

American Journal of Infection Control
April 2010

Table 4. Misuse and misunderstanding: categories, examples, frequencies, and reach of Twitter status updates

Category	Example	Frequency	Reach
Cold + antibiotics	"Finally over my cold. Summer colds suck. Thank-you Z-pack antibiotics."	302 Updates	Unique users: 277 No. followers: 1 to 759,127 Median followers: 66 Total followers: 850,375
Flu + antibiotics	"Starting to feel better from the terrible flu. One antibiotic to go."	345 Updates	Unique users: 317 No. followers: 0 to 34,721 Median followers: 78 Total followers: 172,571
Leftover + antibiotics	"Trying to find out how to get health care card for my uninsured urinary tract needing antibiotics. If you have any left over, ill pay u!"	23 Updates	Unique users: 21 No. followers: 6 to 2337 Median followers: 62 Total followers: 5860
Share + antibiotics	"Hella productive . . . haha! feel better homie. If I need to share my remaining antibiotics I will."	10 Updates	Unique users: 10 No. followers: 7 to 3574 Median followers: 164 Total followers: 6216
Extra + antibiotics	"Well, looks like I have strep throat. Anyone have some extra antibiotics I could snag?"	7 Updates	Unique users: 5 No. followers: 11 to 10,750 Median followers: 71 Total followers: 10,940

NOTE. "Unique users" refers to the number of people who posted a status update demonstrating evidence of misunderstanding or misuse. In some cases, status updates were associated with users that lacked data on number of followers. In those cases, the user was not included as a unique user, and their followers were not included in the follower count.

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Poll

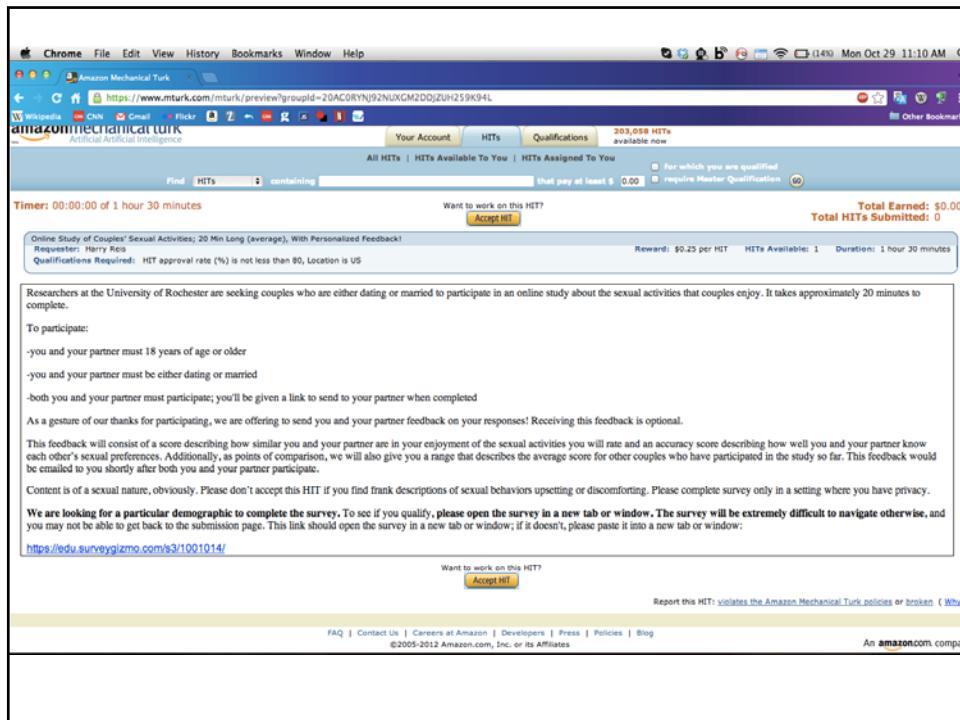
- Have you reviewed a crowd-sourced protocol?
 - A. Yes
 - B. No
 - C. Unsure



Case 4: Data collection and observation

- **Example 2:**
A research team would like to use crowd sourcing as a means to obtain data.
They will post their recruitment script to M-Turk.





Case 4: Data collection and observation

- **Example 3:**
Data from repositories
- Variety of types of data banks and repositories
 - Individual researcher data (NSF/NIH data sharing)
 - Crowd sourced datasets
- Most have terms of use/user agreements
- IRBs can be forward thinking and start including questions of reuse and banking on protocol forms

Crowd-sourced datasets/repositories



"There is zero privacy anyway, get over it

Although you can upload your data using a pseudonym, there is no way to anonymously submit data. Statistically speaking it is really unlikely that your medical and genetic information matches that of someone else. By uploading you do not only disclose information about yourself, but also about your next kinship (parents and siblings), that shares half of a genome with you. Before uploading any genetical data you should make sure that those people approve of you doing so." ([openSNP](#))



Issues with crowd-sourced data

- Principles of justice—maybe it can balance out the WEIRD problem?? (Henrich, 2010: undergrad research subjects are typically: “Western, Educated, Industrialized, Rich and Democratic”)
- Integrity of data
- Consent—community, family?
- Confidentiality—worker ID is correlated with other data
- Payment to subjects
- “What are the potential ethical consequences of stripping data of personally identifiable information?” (AoIR, 2013)

Case 5: Experimenting on Wikipedia

■ The challenge:

Wikipedia has trouble retaining new editors because their early edits are often reverted without explanation, often by people using mass-revert tools.

■ The research idea:

Build a tool to help educate/socialize Wikipedians into being nice to editors. It can semi-automate feedback to them saying “don’t bite the newbies” – with progressively more intense messages from helpful tips to severe rebukes.

■ Measure of success:

Retention of newbies



The screenshot shows the English Wikipedia page titled "Wikipedia:Please do not bite the newcomers". The page is a behavioral guideline. At the top, there are links for "Project page", "Talk", "Read", "Edit", "View history", and a search bar. Below the title, it says "From Wikipedia, the free encyclopedia". A note states that "WP:DNB" redirects here. The main content area contains two boxes: one about the guideline itself and another about the "nutshell". The sidebar on the left includes links for Main page, Contents, Featured content, Current events, Random article, Donate to Wikipedia, and various interaction and language options. The right sidebar lists "Wikipedia guidelines" such as Behavioral, Content, and Editing, along with specific topics like Assume good faith, Conflict of interest, and Notability.

User talk:Raywood

From Wikipedia, the free encyclopedia

Contents [hide]

- 1 Your edits to Comparison of file verification software
- 2 Speedy deletion nomination of Ray Woodcock
- 3 Your recent edits
- 4 Henry Fairlie
- 5 Linking personal blogs
- 6 Formal mediation has been requested
- 7 Request for mediation rejected

Your edits to Comparison of file verification software [edit]

Speedy deletion nomination of Ray Woodcock [edit]

! Thank you for experimenting with Wikipedia. Your test worked, and the page that you created has been or soon will be deleted. Please use the [sandbox](#) for any other tests you want to do. Take a look at the [welcome page](#) if you would like to learn more about contributing to our encyclopedia.

If you think that this notice was placed here in error, you may contest the deletion by adding `((hang on))` to the top of the page that has been nominated for deletion (just below the existing speedy deletion, or "db", tag; if no such tag exists, then the page is no longer a speedy delete candidate and adding a hang-on tag is unnecessary), coupled with adding a note on the [talk page](#) explaining your position, but be aware that once tagged for speedy deletion, if the page meets the criterion, it may be deleted without delay. Please do not remove the speedy deletion tag yourself, but don't hesitate to add information to the page that would render it more in conformance with Wikipedia's policies and guidelines. If the page is

If this is the first article that you have created, you may want to read the guide to [writing your first article](#). You may want to consider using the Article Wizard to help you create articles.

A few thoughts...

- The talk page, even though specific to the user, is public
- The user may be only identified by a self-chosen pseudonym
- There are already plenty of bots out there to automate or semi-automate reverts and feedback
- Does it matter who the messages appear to come from?
- The result being studies is about newbies, not the direct targets of the intervention

Poll

- Is this proposed research:
 - Not human subjects research
 - Exempt
 - Expedited
 - Full Review
 - Not appropriate at all
 - Don't know, Depends



Case 6: MovieLens: Building an online community for research

- True story
- Short-window opportunity to build an online community based on movie recommendations for tens of thousands of users
- Once the community is there, two types of activities
 - General improvements (add features, improve design, etc.)
 - Specific experiments and studies (field experiments, virtual lab experiments, recruit from site for surveys, etc.)



The screenshot shows the MovieLens website at www.movieLens.org/main. The top navigation bar includes links for Home, Find Movies, Q&A (new), Preferences, and Help. A welcome message for 'konstan@cs.umn.edu' indicates 59 movies rated and 10 visitors in the past hour. To the right, a legend defines rating stars: 5 = Must See, 4 = Will Enjoy, 3 = It's OK, 2 = Fairly Bad, 1 = Awful.

Shortcuts (Search is selected)

- Rate and Find Movies**
 - Top Picks For You
 - Newest Additions
 - Most Often Rated
 - Rate Random Movies
 - Browse Movies by Tags
- Your Movies**
 - Your Ratings
 - About Your Ratings
 - Your Wishlist
 - Your Tags
- Your Account**
 - Your Profile (edit)
 - Preferences
 - Manage Buddies
 - Manage RSS Feeds
- Help MovieLens**
 - Volunteer Center
 - Add a Title

(We've moved your saved searches to the [search tab](#))

New Movies

★★★★ Django Unchained (2012)	★★★★ Searching for Sugar Man (2012)
★★★★ Hobbit: An Unexpected Journey, The (2012)	★★★★ Imposter, The (2012)
★★★★ Zero Dark Thirty (2012)	★★★★ Holy Motors (2012)
★★★★ 56 Up (2012)	★★★★ Game Change (HBO) (2012)
★★★★ Miéralbe, Le (2012)	★★★★ Robot & Frank (2012)
★★★★ Love (Amour) (2012)	★★★★ Batman: The Dark Knight Returns, Part 2 (2013)
★★★★ Warm Bodies (2013)	★★★★ Ballad of Narayama, The (Narayama Bushiko) (1958)
★★★★ War Witch (Rebelle) (2012)	★★★★ Kid With a Bike, The (Le gamin au vélo) (2011)
★★★★ Fitzgerald Family Christmas, The (2012)	★★★★ Diana Vreeland: The Eye Has to Travel (2011)
★★★★ Impossible, The (Lo imposible) (2012)	★★★★ Chronicle of a Summer (Chronique d'un été) (1961)

135 new movies have been added since you last visited. See the [newest additions](#).

New DVDs

★★★★ Searching for Sugar Man (2012)	★★★★ Must See
★★★★ Imposter, The (2012)	★★★★ Will Enjoy
★★★★ Holy Motors (2012)	★★★★ It's OK
★★★★ Game Change (HBO) (2012)	★★★★ Fairly Bad
★★★★ Robot & Frank (2012)	★★★★ Awful

Movie Tuner Updated!

Search Criteria: Similar to *Pulp Fiction*, but [more action](#)

Kill Bill: Vol. 1 (2003)	★★★★
Kill Bill: Vol. 2 (2004)	★★★★
True Romance (1993)	★★★★
Sin City (2005)	★★★★
Grindhouse (2007)	★★★★

Want a movie like *Pulp Fiction* but less "violent"? Or a movie like *Mission: Impossible* but more "realistic"?

Movie Tuner lets you "tune" your movie selection along 1500 unique dimensions.

We recently updated Movie Tuner. We improved the list of default dimensions and added predictions to the results.

★'s are MovieLens predictions. ★'s are your ratings.

Look for Movie Tuner on the [Movie Details](#) and [Search Results](#) pages. [More info](#)

Latest Questions from MovieLens Q&A

Help other movieLens users by answering these questions. [Click here to see more](#)

Poll

- How should the IRB handle this?
 - Site needs one-time review before launch (including sign-up info for informed consent), also needs new review for every design change or experiment.
 - Site should get a comprehensive protocol review to cover design, maintenance, and a range of experiments.
 - Site development / maintenance isn't human subjects research; review specific studies as they arise.
 - This doesn't seem to need review at all.
 - Don't know, help!

Starting with the Wikipedia study ...

- Collateral damage
 - No risk to people being studied, but risk to the editors who were “biting the newbies”
 - If we studied them, we’d have to look at that risk
 - Can we conduct a Marx Brothers study to see whether hitting a bystander with a frying pan makes our subject feel better?
- Risks to the community vs. individual
 - Even if nobody is harmed, what if this damages the culture, community of Wikipedia?
 - Is this relevant to IRB review? Should it be?
- And what about the community/operator’s right to control research on their site??



The MovieLens example

- This isn’t just real, it is one of hundreds of such examples
- How we handled it:
 - System isn’t human subjects research
 - But worked with general counsel on member agreement
 - System upgrades also aren’t
 - But specific studies usually are ...
 - either separate IRB review (exemption)
 - or protocol review for a suite of related research
 - Different answers from different IRBs



Four closing thoughts ...

- Norms are different, and often evolve
 - Privacy expectations keep changing
- Nobody worried about the effect on “the park”
 - Recruitment and studies can have repercussions far beyond enrolled subjects
- Anonymity is all too impermanent
 - AOL, Netflix, Amazon mTurk
- Everything will change
 - No effective alternatives to education, interaction



Resources

1. AoIR, 2013, “Ethical Decision Making...”
2. 2013 Draft SACHRP Considerations
3. Sample IRB Internet Research Guidelines



Questions and comments

To submit a question,
simply click on the Q & A menu
at the top of the screen.

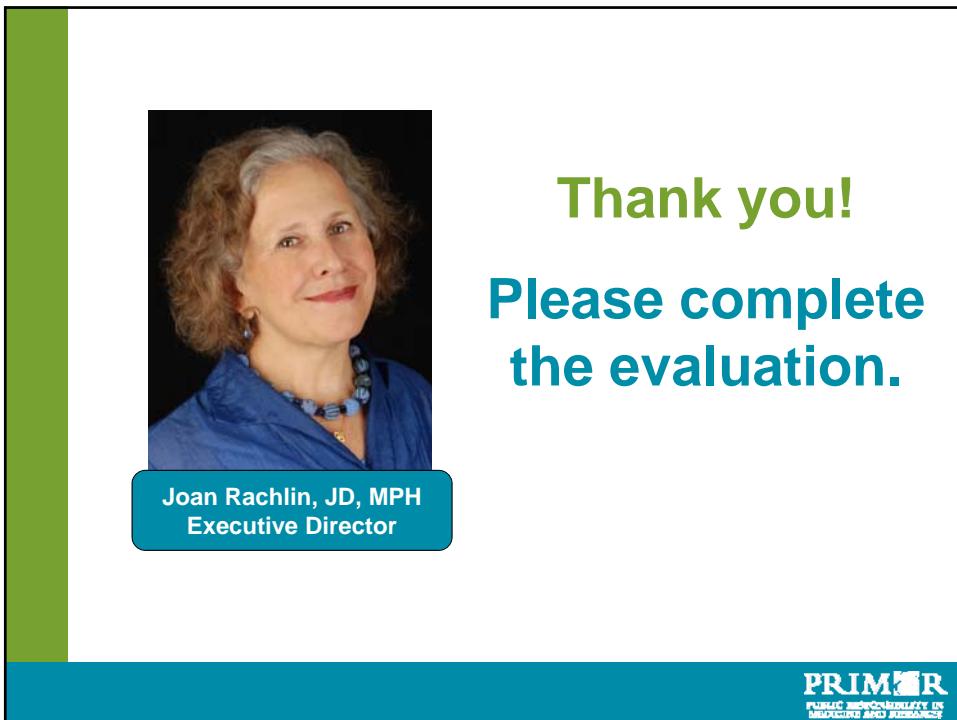
webinars@primr.org



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