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Ethics and Issues related to the use of emerging technologies in research

Kevin Hardcastle  
*Washington University School of Medicine in St. Louis*

Stephanie Solomon  
*Saint Louis University*

Jen Weinman  
*Washington University School of Medicine in St. Louis*

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Ethics and Issues Related to the Use of Emerging Technologies in Research

Kevin Hardcastle, CISSP CBCI, Information Security Officer, Washington University

Stephanie Solomon, PhD, Assistant Professor of Health Care Ethics, Saint Louis University

Emerging technologies

- Implications of new and moving target
  - Legally uncertain

- Examples: mobile technologies, websites, social media (Facebook), tablets, USB flash drives, GPS, the “cloud”; “deidentification”; electronic medical records, Skype, Text messaging, SurveyMonkey
Major areas of concern for IRBs nationally

1. Privacy
2. Data security
3. Appropriate models and modes of eliciting and maintaining consent
4. Sensitivity of data
5. Appropriate models for ensuring confidentiality and anonymity

-Buchanan & Ess (2009)
Using the internet as a research tool

- Advertisement tool
- Screening tool
- Recruitment tool
- Dissemination tool
- Follow-up tool
When Is IRB Review Required?

When information posted on a clinical trial website goes beyond “basic descriptive information.”

Basic descriptive information includes:
- 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.

Information exceeding such basic listing information includes descriptions of clinical trial risks and potential benefits, or solicitation of identifable information.
Using the Internet as a research locale

- Blogs
- Facebook groups
- Chats
- RPG’s
- Health forums
Internet data: Private or Public?

Why important? Could be **exempt** (46.101b2)

1. Exemption 2: “Research involving the use of educational tests. . .survey procedures, interview procedures or **observation of public behavior**” AND

2. Exemption 4: “Research involved the collection or study of existing data, documents, records. . . if these resources are **publicly available**, unless
   1. recorded in unidentifiable way
   2. disclosure could reasonably put subjects at risk
“Private information” =

1. information about behavior that occurs in a context in which an individual can reasonably expect that no observation or recording is taking place.

2. information which has been provided for specific purposes by an individual and which the individual can reasonably expect will not be made public.

3. Private information must be individually identifiable (by the investigator) --46.102(f)
Public/private physical space → Public/private virtual space

- Private vs. public spaces
- Identifiable vs. Deidentified data
- How do these apply?

Think about:
- Site policies
- Demonstrations of intent
- Implications for trust in research enterprise
- Accessible ≠ Available
Obligation vs. Decency

* Just because you can do it doesn’t mean you should do it!

The Intersection of Social Media and Human Subjects Research: a webinar produced by Laura Odwazny, HHS General Counsel
Lay of the Land
Stephanie Solomon, PhD, Assistant Professor of Health Care Ethics, Saint Louis University

Social Media in Research: The IRB Perspective

Information Security and Research
Kevin Hardcastle, CISSP CBCI, Information Security Officer, Washington University