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

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



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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

IRB review of clinical trial websites

- 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 identifiable 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

➤ “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!

Sources

- Elizabeth Buchanan: “Internet Research Ethics: Past, Present, and Future” (2011)
- The Intersection of Social Media and Human Subjects Research: a webinar produced by Laura Odwazny, HHS General Counsel



➤ **Lay of the Land**

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➤ **Social Media in Research: The IRB Perspective**

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➤ **Information Security and Research**

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