Consent and Research Involving Online Health Information

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The growth of research in the online environment

- Personal health data online has grown exponentially
  - much "created" or at least added by individuals themselves
- Evolving functionality and applications of web, mobile and social media have created a new research environment
  - Research designs are increasingly different than researcher-participant interactions

Health-related data gathered from the Web

- Information “actively” supplied by individual users
  - medical histories, genomic data, web posts
- Personal information collected while users interact with websites
  - IP and e-mail addresses, searches, location data
- Both types are often required for use of sites
- Disclosures to users of the potential uses of personal data vary dramatically from site to site

Consent practices in this evolving area

- Research participation as a condition of the use of the site
  - Web sites state in their terms of use, terms of service, or privacy statements that they maintain the right to use the data they collect for research, among other uses
  - This is like a "browsewrap" agreement (eg, the "I agree" button)
  - Three concerns
    - General consent rather than consent to specific research use
    - Disclosure is boilerplate, which calls into question meaningfulness or even awareness
    - Based on consumer agreement rather than informed consent to research
- Opt-in to research
  - Link that leads to research description
  - Requires agreement to specific participation
  - Also carried over from consumer context, borrowing the "clickwrap" agreement (eg, the "I agree" checkbox)
  - Seems closest to satisfying conventional criteria of informed consent
- Opt-out of research
  - Sometimes obvious, other times buried
  - Not clear how consistent these approaches are with informed consent for research
- These are all carryovers from more consumer-oriented web environment

Recommendations

- Goal: ". . . protecting individual rights and respecting autonomy while enabling a dynamic research environment for the advancement of clinical medicine and public health."
- One size will not fit all
  - Appropriate consent models will depend on
    - Mission of the site, sensitivity and identifiability of the data collected, purpose of the research, and risks and benefits of participation
  - An interactive process is better suited to meeting the criteria of informed consent
    - At a minimum, transparent disclosure of the research uses of online personal data are required.
- Portable Legal Consent and its goals
  - Some shortcomings for web environment
- Collaborative and context-specifc consent
  - employ the communicative and real-time features of the Web to facilitate a more dynamic approach to informed consent