Internet Research, Social Media, and the IRB

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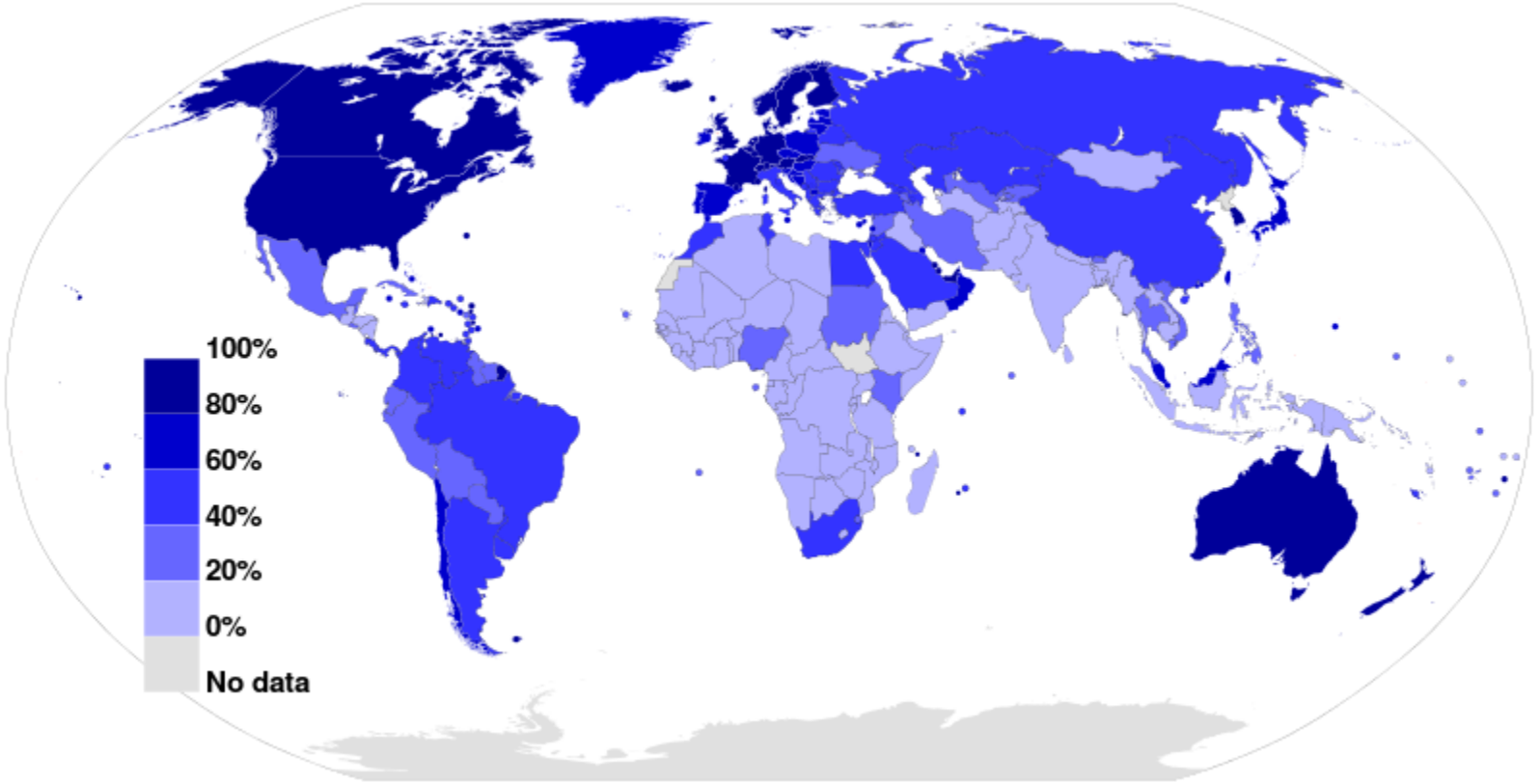
Disclaimer

This presentation does not constitute legal advice. The views expressed are the presenter's own and do not bind the U.S. Department of Health and Human Services or its operational components.

Outline

- How is social media used by researchers
- How specific requirements of the HHS protection of human subjects regulations apply to research involving the use of social media
- Challenges in managing ethical issues and regulatory considerations, including assessing privacy and identifiability of subject information, subject recruitment and retention through social media, and maintaining confidentiality
- Recent events: the Facebook study! And, as of this week, OkCupid too
- Possibly upcoming on the Federal horizon…

With increasing INTERNET saturation…



Internet penetration world map, updated June 28, 2013, Wikimedia Commons: http://en.wikipedia.org/wiki/File:InternetPenetrationWorldMap.svg

…and Widespread Social Media Use…

Social media – Internet-based applications that allow creation and exchange of user-generated content

Provide mechanisms for users to interact:

--chat, instant messaging, email, video, file sharing, blogging, discussion groups

= Increasing Use of Internet and Social Media for Research Purposes

NOTE:

- The HHS protection of human subjects regulations do not specifically reference Internet research
- OHRP has no formal written guidance specifically on Internet research

Setting the Stage: What is Internet Research?

- Internet research
  - Internet used as a tool for conducting research
    - Examples: online survey, subject recruitment, email or chat interviews
  - Internet as a location or site for conducting research
    - Examples: Collecting data about or observing online environments such as chatrooms, gaming sites, virtual worlds
  - Internet as a source of information
    - Examples: data mining from social media site; collecting data from online datasets, databases, repositories

"Recommendation Concerning Internet Research and Human Subjects Research" SACHRP, approved March 13, 2013, Att. B, p1-2.

How is Social Media Used by Researchers?

- Locale for observational research (e.g., examining social networks of Facebook users)
- Locale for interventional research (e.g., asking Facebook users to rate the attractiveness of headshots posted on a fictitious FB profile)
- Platform for survey/interview research
- Resource for data scraping/data mining
- Subject recruitment and retention
  - Ancillary to F2F research

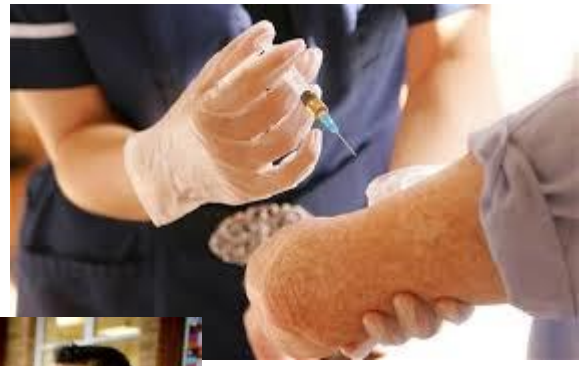
In the Absence of Specific Internet Regulations/Guidance…

Apply the existing regulations and OHRP guidance!

Question for contemplation: How different is Internet research from other types of research?

Is it special?

vs.



Big Regulatory Issues Related to Internet Research Using Social Media

- What is “private”?
- What is “identifiable”?
- How to protect subjects’ privacy and confidentiality interests?
- Minimizing risk when using sensitive online data
  - Current sensitivity vs. future sensitivity

Some of the Related Regulatory Decision Points

- Is the activity research?
- Does the research involve human subjects?
- Does the human subjects research qualify for exemption from the regulatory requirements?
- Does the research present no more than minimal risk such that it may be reviewed via expedited review?
- Informed consent –how to describe confidentiality protections?

Research

What is Research?

- Research: systematic investigation designed to develop or contribute to generalizable knowledge (45 CFR 46.102)
- Studying social media sites or using social media as a research tool
  - Studying dynamics of online social networks
  - Social media as ethnographic field site
  - Data mining/scraping from social media sites
  - Web-based surveys
  - Web-based interviews

Human Subjects

Human Subjects – identifiable private information

45 CFR 46.102(f): "a living individual about whom an investigator conducting research obtains (1) data through intervention or interaction with the individual, or (2) identifiable private information

- Private information: "information about behavior that occurs in a context in which an individual can reasonably expect that no observation or recording is taking place, and information which has been provided for specific purposes by an individual and which the individual can reasonably expect will not be made public (for example, a medical record)."

Privacy on the Internet?

How to interpret “reasonably expect that no observation or recording is taking place” or “reasonably expect will not be made public”

- IM, tweet, email, Facebook profile, chatroom discussion, listserve posting – what is reasonable expectation of privacy in each?
- Or is everything on the Internet that I can see public?

or

?

When is an expectation of privacy "reasonable"?

- People in online environments that are presumptively public often act as if they are in private space
  - Caused by online feelings of anonymity, norms of the Internet space, reduced inhibitions, separation of people from text
- Expectations of privacy may not equate with reality of privacy (or lack thereof)

Asa Rosenberg, "Virtual world research ethics and the private-public distinction," International Journal of Internet Research Ethics, v.3, December 2010:

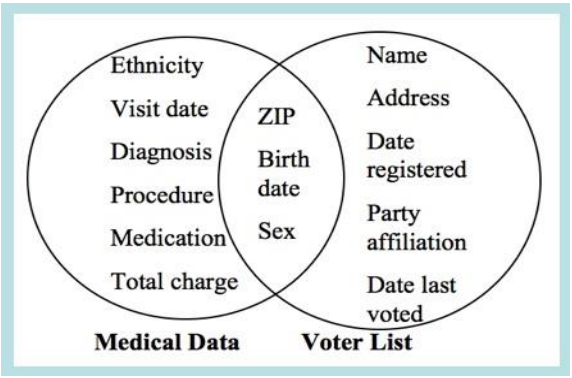
http://ijire.net/issue_3.1/3_rosenberg.pdf

How may the IRB assess whether information obtained via the Internet should be considered private?

- Regulatory standard of “reasonable” does not depend on individual subject’s own expectation of privacy
- How to consider what expectations of privacy in the information are “reasonable”
  - Get information about the social media site
  - Get information about the users/members
  - Review Terms of Service, site policy

Human Subjects – Identifiable Private Information (2)

- Identifiable
  - Individually identifiable = subject's identity readily ascertainable by the investigator or associated with the information
  - Structure of social network, search terms, purchase habits, movie ratings on Netflix may uniquely identify individual
    - Zip code + sex + DOB enough for Professor Latanya Sweeney to uniquely identify 87% of U.S. population (de-identified medical data linked to voter registration information re-identified patients by name)



  - Question for contemplation: given demonstrated ability to reidentify individuals from anonymized or aggregated data, is this a meaningful decision point?

How Can the IRB Assess Identifiability?

- When will the subject's identity be "readily" ascertainable by the investigator or associated with the information?
  - Consider the investigator, e.g. Professor Latanya Sweeney vs. Professor Laura Odwazny
  - Consider the potential identifiers or partial identifiers
    - Direct quotes easily traceable to Twitter account even if handle is removed
  - Consider likelihood of reidentification with triangulation, not just whether it is theoretically possible

Relevant Exemptions

Relevant Exemptions – Online Education

- 45 CFR 46.101(b)(1): Research conducted in established or commonly accepted educational settings, involving normal educational practices, such as (i) research on regular and special education instructional strategies, or (ii) research on the effectiveness of or the comparison among instructional techniques, curricula, or classroom management methods.
- Internet locale could be an "established or commonly accepted educational setting" and online education could be a "normal educational practice"
- Examples:
  - Evaluating the conduct of a web-based class
  - Assessing the efficacy of the use of social media site to disseminate class information
  - Comparison of virtual simulation training to traditional training – ex/ online dentistry procedures conducted in Second Life

Relevant exemptions – Educational Tests, Survey and Interview research, Observation of Public Behavior

- 45 CFR 46.102(b)(2), unless: information is recorded in a manner whereby subjects can be identified AND disclosure of the responses could reasonably place them at risk of criminal or civil liability or be damaging to the subjects' financial standing, employability, or reputation.
- What is "recorded in a manner whereby subjects can be identified" when the Internet is used?
- What is "observation of public behavior" online?

Relevant exemptions – data mining

- 45 CFR 46.101(b)(4) -- collection or study of existing data/specimens, if sources are publicly available or if information is recorded by investigator in such a manner that subjects cannot be identified
  - 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 social media site?
    - What if data are restricted -- available only to ‘friends’, listserve members?

Exemption 4 continued: "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?
  - Note: For HIPAA, OCR has stated position (below); OHRP has no formal guidance

The second is the "Safe Harbor" method:

(2)(i) The following identifiers of the individual or of relatives, employers, or household members of the individual, are removed:	
(E) Fax numbers	(M) Device identifiers and serial numbers
(F) Email addresses	(N) Web Universal Resource Locators (URLs)
(G) Social security numbers	(O) Internet Protocol (IP) addresses

If not exempt… IRB review

Challenges in IRB review of research using social media:

- Requirement that risks be minimized
  - Two main sources of risk in Internet research:
    - Participation --No direct contact with subjects; more difficult to deal with individual reactions (intervention, debriefing, follow-up)
    - Breach of confidentiality
- Eligible for expedited review?
  - Must be minimal risk and fall within expeditable research category

Minimal risk

- Probability and magnitude of harm/discomfort in the research not greater than ordinarily encountered in daily life or during routine physical or psychological examinations/tests (46.102(i))
  - Gateway to expedited review; waiver of consent and documentation; no need to explain compensation or any treatments for research-related injury in consent; Subparts B, C, D categories of permissible research
- Risks associated with data security breach, likelihood of access by 3rd parties alter conception of minimal risk in Internet research?
  - Less privacy, more observation in general in daily life

Subject Recruitment

Internet-Based Subject Recruitment

- Facebook page
- YouTube video
- Matching algorithm on social media sites (e.g., PatientsLikeMe)
- “Push” method (e.g., Inspire.com)

OHRP Guidance on Subject Recruitment

- OHRP considers subject recruitment part of informed consent
  - Recruitment plan must receive IRB review/approval prior to initiation
- 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)
  - how to contact the study site for further information

OHRP Guidance (continued)

- IRB review needed if additional information 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
    - But screen shots may be helpful to the IRB

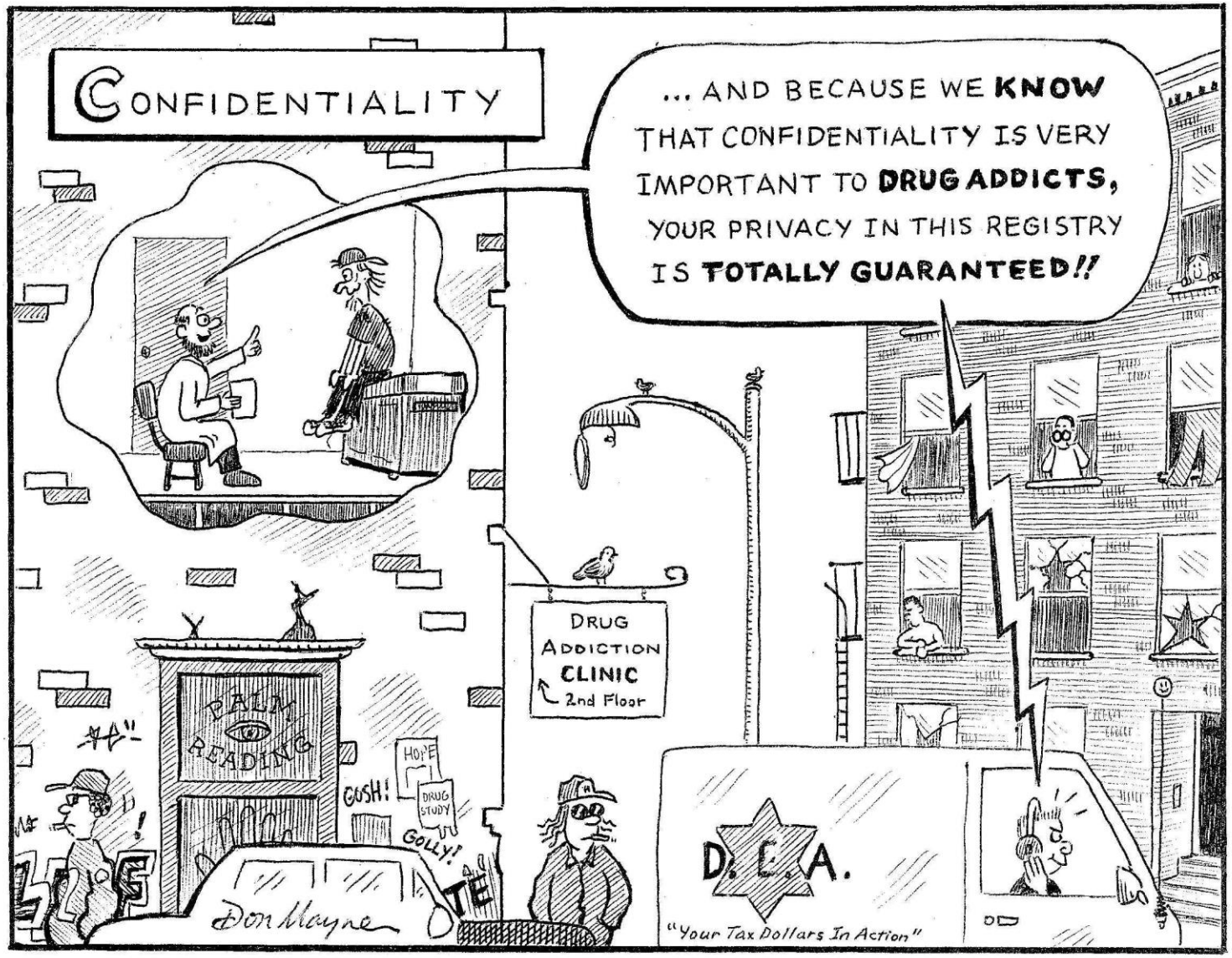
Considerations with Use of Social Media for Recruitment

- Uncontrolled following discussion among viewers/bloggers: interactive, not static
  - Subsequent posts in effect add to posted information from user perspective?
- Must PI/IRB actively monitor social media sites used for recruitment for accuracy of information posted in comments, information about possible unanticipated problems?

Obtaining Informed Consent– Confidentiality Protections

Informed Consent in Internet Research

CONFIDENTIALITY



Challenge: Protecting Confidentiality while Utilizing Social Media for Research

- Sometimes no direct researcher – subject interaction
  - Interaction could be through avatar, profile, survey tool
- Not always clear who subjects are
  - Fluidity of social media site membership, identity assumed online may differ from actual identity
- Subjects may be surveilled unknowingly to them or the researcher (spyware)
- Unknown/uncertain risks: possibility of hackers or other cyberattack


Hacker group Anonymous targets Children's Hospital

By Michael B. Farrell and Patricia Wen | GLOBE STAFF APRIL 24, 2014

ARTICLE GRAPHIC VIDEO COMMENTS (51)

Description of Confidentiality Protections in Informed Consent

- 45 CFR 46.116(a)(1)(5) – informed consent must include statement describing the extent, if any, to which confidentiality of records identifying the subject will be maintained
- “Locked file cabinet in locked room” description not sufficient for Internet research!
- Regulatory requirement pertains to “identifying” records: consider potential identifiability of research data obtained through social media

Consider When Describing Confidentiality Protections Including…

- **How subject information is transmitted via the Internet**
  - Survey host (e.g., Zoomerang, Survey Monkey) used? Will host retain identifiable information? Will the transmission be encrypted?
- **How information is maintained**
  - Individually identifiable form, de-identified aggregate form?
  - Cloud storage?
- **Circumstances in which subject information might be disclosed outside the research team**
  - Data sharing and data use agreements increasingly being required by funding agencies (NIH, NSF mandates)
  - Remember funding agency access rights and possible mandatory disclosure to OHRP, FDA, ORI, other oversight agency
  - Patriot Act allows access to cloud

Consider When Describing Confidentiality Protections (2)

- **Data security plan**
  - Explain the efforts to protect the data, e.g., secure servers, computers not connected to university network
- **Do not absolutely guarantee confidentiality of subject information**
  - Unrealistic and likely inaccurate
- **If aggregated de-identified data will be made publicly available, consider the likelihood of re-identification of individual subjects whether this should be described**

A New Trend? Language in Consent Documents Limiting Social Media Discussions of the Research

- Glickman, et al, 2012: “If you participate in this clinical study, you should feel free to discuss the study with your family and with other people who are close to you. You should also tell any health care providers who treat you that you are in the study. However, to help make sure that the data from the study is as accurate and reliable as possible, please do not discuss information about the study in public places while the study is in progress. Public places may be situations like support groups, or may be places like internet message boards. If you have questions about side effects, please talk to your study nurse or study doctor.”

Why Attempt to Limit Subject's Social Media Discussions? WSJ addresses this 7/29/14…

THE WALL STREET JOURNAL. | U.S.

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3 of 12

Holder Takes Voting Rights Battle to Oh...

U.S. NEWS

Researchers Fret as Social Media Lift Veil on Drug Trials

Online Chatter Could Unravel Carefully Built Construct of 'Blind' Clinical Trials

A A

By AMY DOCKSER MARCUS CONNECT

July 29, 2014 10:30 p.m. ET

On her first day in a clinical trial for an experimental multiple sclerosis drug, Jeri Burtchell was convinced she was getting the new drug, not the standard therapy that some patients were randomly assigned to receive.

Subject Retention

Social Media -- Communications During the Study

- Online or mobile diaries, questionnaires
- Reminders through texts, email, Facebook messages
- Information about study progress

- IRB review required of research procedures
- Subjects should be informed of method of communication
  - May be costs to subjects (e.g. text messaging fees)
  - Privacy concerns? Consider subject population: do multiple family members share 1 cell phone?

Promoting Subject Networking

- A PI for a longitudinal study of a chronic disease wants to create a Facebook page for study subjects to facilitate communications between participating families
  - Confidentiality of participation?
  - Privacy settings for Facebook?
  - IRB understanding of Facebook operations?
  - Impact on subject retention or validity of data?

Subjects Lost to Follow-Up

- Should research staff/investigators be allowed to use social media to search for, and contact, subjects lost to follow-up?

Return of Results

Return of study results

- Return of study results to subjects through social media vs. through publishing data analysis in peer-reviewed journal
  - Appropriate re validity of conclusions? Eliminates extra layer of protection peer review provides
  - If planned, IRB should review and subject should be informed in consent
  - If combined with request for additional research participation, IRB must review as recruitment materials

Care and Feeding of the IRB

Investigator and IRB Responsibilities:

- Investigators are going to have to provide technical information on how they will deal with considerations particular to the use of social media
- IRBs need to have sufficient expertise on the technical aspects of social media in order to ask the right questions and appropriately evaluate the information provided
  - Regulations allow IRBs to get expert help to assist in review (45 CFR 46.107(f))
- More information = greater comfort!

Recent Events! The Facebook Study and OKCupid

The Facts – The Facebook Study

- June 17, 2014: "Experimental Evidence of Massive-Scale Emotional Contagion Through Social Networks" published in *Proceedings of the National Academy of Sciences*
- Facebook intentionally manipulated the feeds of 689,003 English-speaking Facebook users between January 11th-18th, 2012 in order to determine whether showing more positive/negative posts in a user's Facebook feed was an "emotional contagion" that would inspire the user to post more positive/negative posts
- Public outcry!

The Questions

- Was this research subject to the Federal protection of human subjects regulations?
  - Funded by FB
  - But 2 authors are from Cornell and UCSF, FWA-holding institutions
- If the regulations did apply:
  - Was this “research” involving “human subjects”?
  - Could an IRB have approved this study under the regulatory requirements?
  - Would this study have qualified for a waiver or alteration of informed consent?

More Questions

- Was this research unethical to conduct? *Should* an IRB have been required to review it? Consider the population of FB users and the likely involvement of children.
- Was this research ethical to conduct? The FB data use policy state that FB asserts its right to use your personal data **"for internal operations, including troubleshooting, data analysis, testing, research and service improvement."** Given this language, did FB users provide a general consent to such research?

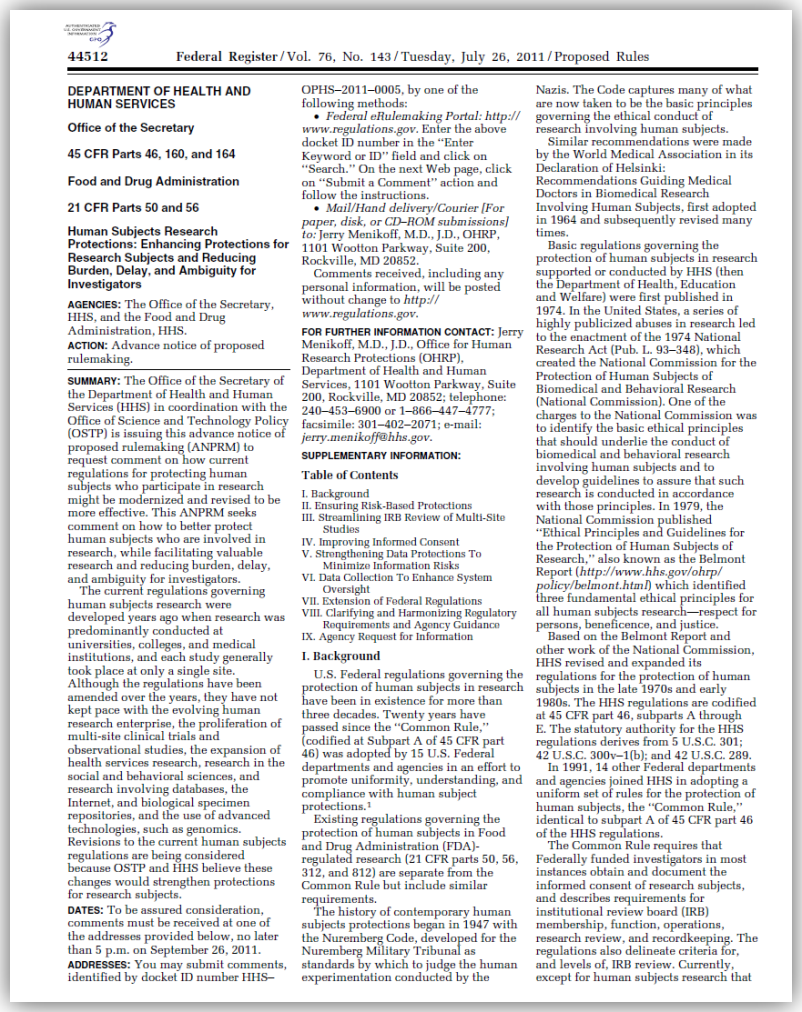
And now OKCupid

- July 28, 2014: OKCupid states that the dating service conducted experiments on users to test their algorithms for matching couples, including telling couples who were a bad match that they were a good match and vice versa; removing profile photos and text
- “If you use the Internet, you’re the subject of hundreds of experiments at any given time, on every site,” Christian Rudder, president of OKCupid, wrote on the company’s blog. “That’s how websites work.”
- How is this different from FB study (or is it)?

On The Horizon…

The ANPRM!

ANPRM seeking comment on possible areas of change to the Common Rule



44512 Federal Register / Vol. 76, No. 143 / Tuesday, July 26, 2011 / Proposed Rules

DEPARTMENT OF HEALTH AND HUMAN SERVICES

Office of the Secretary

45 CFR Parts 46, 160, and 164

Food and Drug Administration

21 CFR Parts 50 and 56

Human Subjects Research Protections: Enhancing Protections for Research Subjects and Reducing Burden, Delay, and Ambiguity for Investigators

AGENCIES: The Office of the Secretary, HHS, and the Food and Drug Administration, HHS.

ACTION: Advance notice of proposed rulemaking.

SUMMARY: The Office of the Secretary of the Department of Health and Human Services (HHS) in coordination with the Office of Science and Technology Policy (OSTP) is issuing this advance notice of proposed rulemaking (ANPRM) to request comment on how current regulations for protecting human subjects who participate in research might be modernized and revised to be more effective. This ANPRM seeks comment on how to better protect human subjects who are involved in research, while facilitating valuable research and reducing burden, delay, and ambiguity for investigators.

The current regulations governing human subjects research were developed years ago when research was predominantly conducted at universities, colleges, and medical institutions, and each study generally took place at only a single site. Although the regulations have been amended over the years, they have not kept pace with the evolving human research enterprise, the proliferation of multi-site clinical trials and observational studies, the expansion of health services research, research in the social and behavioral sciences, and research involving databases, the Internet, and biological specimen repositories, and the use of advanced technologies, such as genomics. Revisions to the current human subjects regulations are being considered because OSTP and HHS believe these changes would strengthen protections for research subjects.

DATES: To be assured consideration, comments must be received at one of the addresses provided below, no later than 5 p.m. on September 26, 2011.

ADDRESSES: You may submit comments, identified by docket ID number HHS–OPHS–2011–0005, by one of the following methods:

- *Federal eRulemaking Portal: http://www.regulations.gov.* Enter the above docket ID number in the "Enter Keyword or ID" field and click on "Search." On the next Web page, click on "Submit a Comment" action and follow the instructions.
- *Mail/Hand delivery/Courier [For paper, disk, or CD–ROM submissions] to:* Jerry Menikoff, M.D., J.D., OHRP, 1101 Wootton Parkway, Suite 200, Rockville, MD 20852.

Comments received, including any personal information, will be posted without change to *http://www.regulations.gov.*

FOR FURTHER INFORMATION CONTACT: Jerry Menikoff, M.D., J.D., Office for Human Research Protections (OHRP), Department of Health and Human Services, 1101 Wootton Parkway, Suite 200, Rockville, MD 20852; telephone: 240–453–6900 or 1–866–447–4777; facsimile: 301–402–2071; e-mail: *jerry.menikoff@hhs.gov.*

SUPPLEMENTARY INFORMATION:

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I. Background
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IX. Agency Request for Information

I. Background

U.S. Federal regulations governing the protection of human subjects in research have been in existence for more than three decades. Twenty years have passed since the "Common Rule," (codified at Subpart A of 45 CFR part 46) was adopted by 15 U.S. Federal departments and agencies in an effort to promote uniformity, understanding, and compliance with human subject protections.[1]

Existing regulations governing the protection of human subjects in Food and Drug Administration (FDA)-regulated research (21 CFR parts 50, 56, 312, and 812) are separate from the Common Rule but include similar requirements.

The history of contemporary human subjects protections began in 1947 with the Nuremberg Code, developed for the Nuremberg Military Tribunal as standards by which to judge the human experimentation conducted by the Nazis. The Code captures many of what are now taken to be the basic principles governing the ethical conduct of research involving human subjects.

Similar recommendations were made by the World Medical Association in its Declaration of Helsinki: Recommendations Guiding Medical Doctors in Biomedical Research Involving Human Subjects, first adopted in 1964 and subsequently revised many times.

Basic regulations governing the protection of human subjects in research supported or conducted by HHS (then the Department of Health, Education and Welfare) were first published in 1974. In the United States, a series of highly publicized abuses in research led to the enactment of the 1974 National Research Act (Pub. L. 93–348), which created the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research (National Commission). One of the charges to the National Commission was to identify the basic ethical principles that should underlie the conduct of biomedical and behavioral research involving human subjects and to develop guidelines to assure that such research is conducted in accordance with those principles. In 1979, the National Commission published "Ethical Principles and Guidelines for the Protection of Human Subjects of Research," also known as the Belmont Report (*http://www.hhs.gov/ohrp/policy/belmont.html*) which identified three fundamental ethical principles for all human subjects research—respect for persons, beneficence, and justice.

Based on the Belmont Report and other work of the National Commission, HHS revised and expanded its regulations for the protection of human subjects in the late 1970s and early 1980s. The HHS regulations are codified at 45 CFR part 46, subparts A through E. The statutory authority for the HHS regulations derives from 5 U.S.C. 301; 42 U.S.C. 300v–1(b); and 42 U.S.C. 289.

In 1991, 14 other Federal departments and agencies joined HHS in adopting a uniform set of rules for the protection of human subjects, the "Common Rule," identical to subpart A of 45 CFR part 46 of the HHS regulations.

The Common Rule requires that Federally funded investigators in most instances obtain and document the informed consent of research subjects, and describes requirements for institutional review board (IRB) membership, function, operations, research review, and recordkeeping. The regulations also delineate criteria for, and levels of, IRB review. Currently, except for human subjects research that

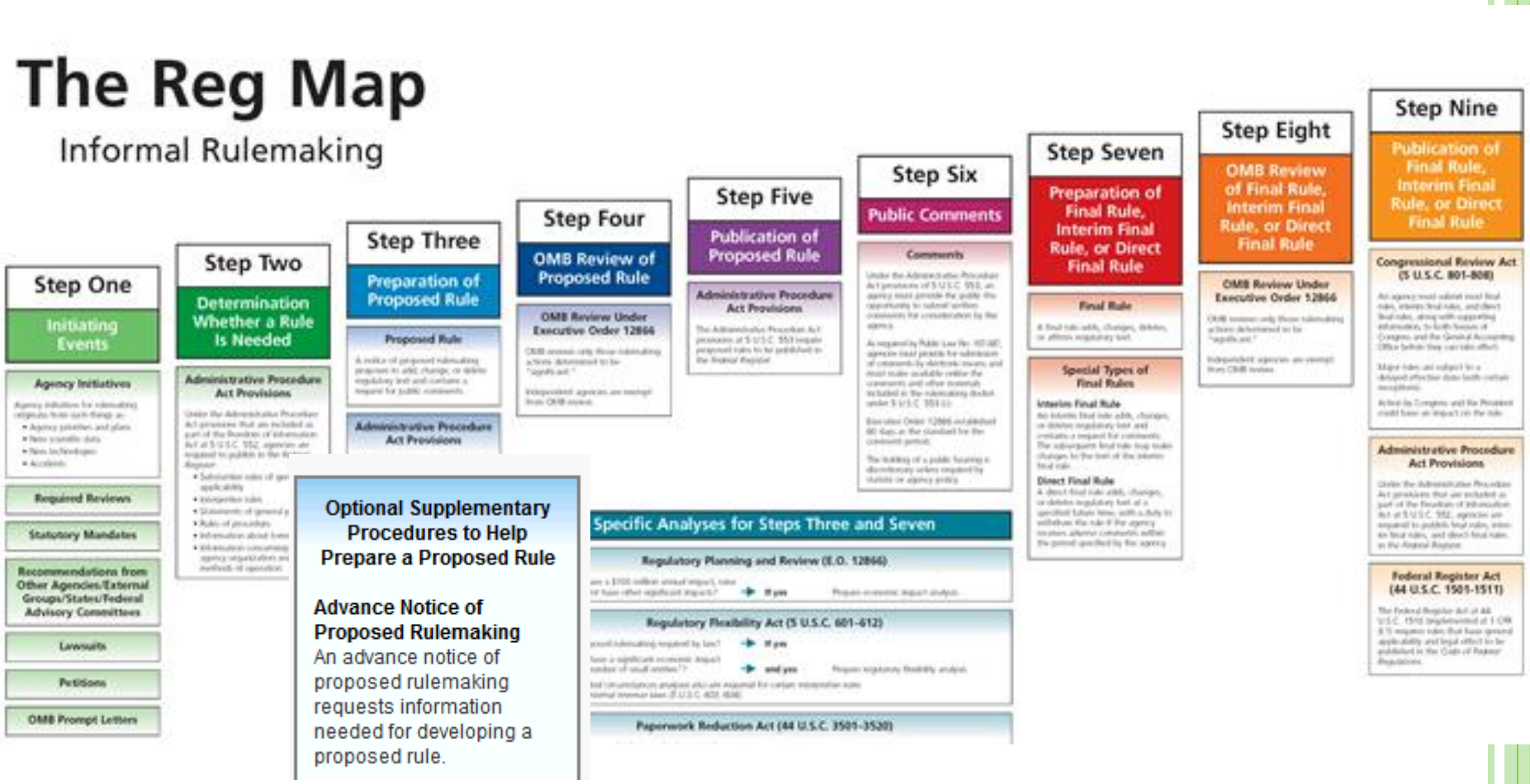
- Published July 26, 2011 by HHS "in coordination with the Office of Science and Technology Policy":

  "Human Subjects Research Protections: Enhancing Protections for Research Subjects and Reducing Burden, Delay and Ambiguity for Investigators"

1000+ comments received

Federal Rulemaking Process

http://www.reginfo.gov/public/reginfo/Regmap/index.jsp



↑ OHRP is in Step 3

ANPRM– Implications for Research using Social Media

- Base concept of identifiability under Common Rule on HIPAA Privacy Rule standards of identifiability?
- Tor protect from informational risks (inappropriate use/disclosure of information), mandatory data security measures “modeled on” HIPAA?
- Apply Common Rule to all institutions receiving support from CR agency?
- No continuing review for most minimal risk research?

ANPRM – Proposals for "Excused" Research

- Add a new category of minimal risk SBR involving competent adults?
- Additional requirements for "excused" (formerly exempt) research?
  - Consent, oral or written, depending, with waiver contemplated
    - Oral w/o documentation for educational tests, surveys, focus groups, interviews
  - Data security standards

TIMEFRAME FOR NPRM? AS OF JULY 2014, SPRING 2014 REGULATORY PLAN INCLUDES…

OFFICE of INFORMATION and REGULATORY AFFAIRS
OFFICE of MANAGEMENT and BUDGET
EXECUTIVE OFFICE OF THE PRESIDENT

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HHS/OASH **RIN:** 0937-AA02 **Publication ID:** Spring 2014

Title: Human Subjects Research Protections: Enhancing Protections for Research Subjects and Reducing Burden, Delay, and Ambiguity for Investigators

Abstract: The Department is considering revisions to the current human subjects regulations in order to strengthen protections for research subjects.

Agency: Department of Health and Human Services(HHS)

Priority: Other Significant

RIN Status: Previously published in the Unified Agenda

Agenda Stage of Rulemaking: Proposed Rule Stage

Major: No

Unfunded Mandates: No

CFR Citation: 45 CFR 160; 45 CFR 164; 21 CFR 56; 21 CFR 50

Legal Authority: 21 USC 321p; 21 USC 331; 21 USC 351 to 353; 21 USC 355; 21 USC 360; 21 USC 371

Legal Deadline: None

Timetable:

Action	Date	FR Cite
ANPRM	07/26/2011	76 FR 44512
ANPRM Comment Period End	10/26/2011	
NPRM	09/00/2014	

SACHRP Recommendations

March 13, 2013: SACHRP voted to provide recommendations re internet research

- SACHRP= Secretary's Advisory Committee on Human Research Protections
- SAS and SOH subcommittees developed recommendations for SACHRP to make to Secretary of HHS and Assistant Secretary of Health re Internet research
- Available on OHRP website: http://www.hhs.gov/ohrp/sachrp/mtgings/2013%20March%20Mtg/internet_research.pdf
- **Recommendations are not official OHRP guidance**, as not yet adopted by HHS or OHRP

Thank You!

Questions for OHRP?
Toll-Free : (866) 447-4777
E-mail: OHRP@hhs.gov