

Regulations and the Secrets of Big Data: Public, Private, or What?

Ivor Pritchard, Ph.D.

Ivor.Pritchard@hhs.gov

June 1, 2023



OASH

Office for
Human Research
Protections

Disclosure and Disclaimer: Ivor Pritchard

I have a relevant professional relationship with respect to this educational activity with the following organization:

*The Office for Human Research Protections (OHRP)
U.S. Department of Health and Human Services
(Senior Advisor to the Director of OHRP)*

The opinions expressed are those of the presenter and do not necessarily reflect the policy of the U.S. Department of Health and Human Services.





"Remember when, on the Internet, nobody knew who you were?"

Data/Information in the Common Rule

“(e)(1) *Human subject* means a living individual about whom an investigator (whether professional or student) conducting research

(i) Obtains information or biospecimens through intervention or interaction with the individual, and uses, studies, or analyzes the information or biospecimens; or

(ii) Obtains, uses, studies, analyses, or generates identifiable **private** information or identifiable biospecimens” (.102(e)(1))



“Public” & “Private” in the Common Rule

“...**Private** information includes 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** (e.g., a medical record)....” (.102(e)(4))



“Privacy” and “Confidentiality” in the Common Rule

“When appropriate, there are adequate provisions to protect the **privacy** of subjects and to maintain the **confidentiality** of data.” (.111(a)(7))



Motivations to Intrude on Privacy

Privacy vs Academic/Scientific Inquiry
Freedom of Expression
Freedom of the Press
Public Welfare
The Free Market
Curiosity



The Challenges of Observing Privacy

- Privacy varies across cultures.
- The boundaries of privacy are moving over time.
- Privacy is a right, not an obligation.
- Privacy is shaped by technology.
- The boundaries of privacy are becoming easier to cross.



Legally Recognized Confidential Relationships in the Modern West

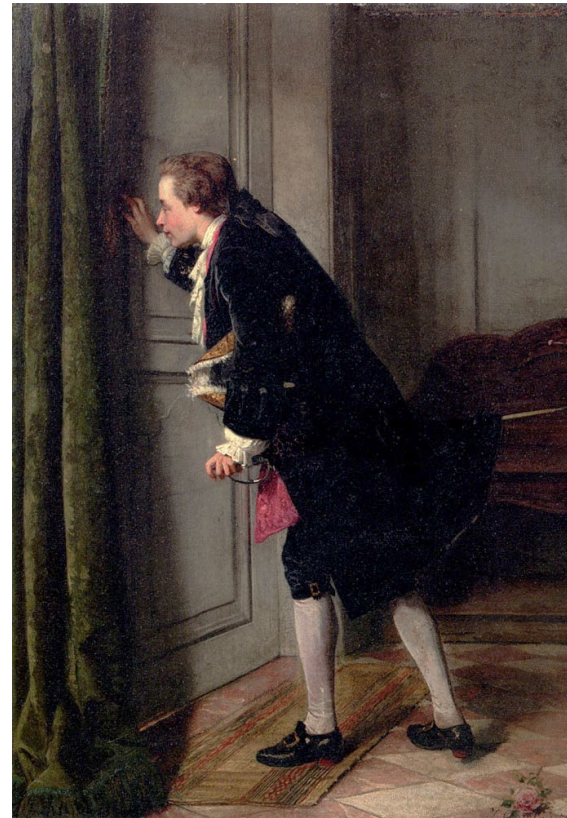
- Spousal Relationship
- Physician/Patient
- Attorney/Client
- Priest/Confessor



Lady Godiva



Peeping Tom



The 4th Amendment and Privacy

“The right of the people to be secure in their persons, houses, papers, and effects, against unreasonable searches and seizures, shall not be violated, and no warrants shall issue but upon probable cause supported by oath or affirmation, and particularly describing the place to be searched, and the persons or things to be seized.”

(U.S. Constitution, 1791)



Olmstead v. United States (1928)



Olmstead v. United States (1928)

“The makers of our Constitution undertook to secure conditions favorable to the pursuit of happiness. They recognized the significance of man’s spiritual nature, of his feelings, and of his intellect....They sought to protect Americans in their beliefs, their thoughts, their emotions and their sensations. They conferred as against the Government, the right to be let alone – the most comprehensive of rights, and the right most valued by civilized man.”

(Brandeis, 1928)



Why Was Brandeis Worried?



Katz v United States (1967)



Smith v. Maryland (1979)



- The person has a reasonable expectation of privacy.
- Society is prepared to recognize that the expectation is (objectively) reasonable.

United States v. Jones (2012)



- Physical intrusion
- Reasonable expectation of privacy
- 3rd party disclosure

Carpenter v. United States (2017)



Majority Opinion (**Roberts**): The 4th amendment was violated based on the Katz/Smith test. The volume of information (3 years of cell phone ping data) violated a reasonable expectation of Privacy.

Dissent #1 (**Kennedy**): Third Party records are not protected by the 4th Amendment. No search.

Carpenter v. United States (2)



Dissent #2 (**Thomas**): Carpenter's property not searched. No violation of the 4th Amendment. And the Katz Test has no Constitutional basis.

Dissent #3 (**Alito**): Majority Opinion ignores 3rd Party holding of the data. And a compulsory process is not the same as a search. No violation of the 4th Amendment.

Dissent #4 (**Gorsuch**): Persons may have a property interest in things they have given to a third party, but that is not a Katz reasonable expectation of privacy argument. No violation of the 4th Amendment.

What are the necessary conditions of a right to privacy?





Men's Restroom
Conference
Center
Montreal, Canada

**CES LIEUX SONT
SOUS SURVEILLANCE
ÉLECTRONIQUE**

**THIS AREA IS
UNDER ELECTRONIC
SURVEILLANCE**



OFFICE OF THE
ASSISTANT SECRETARY FOR HEALTH
Office for
Human Research
Protections

OHRP
Office for Human
Research Protections

Technology is Changing the World



The Technological Ease of Violent Behavior



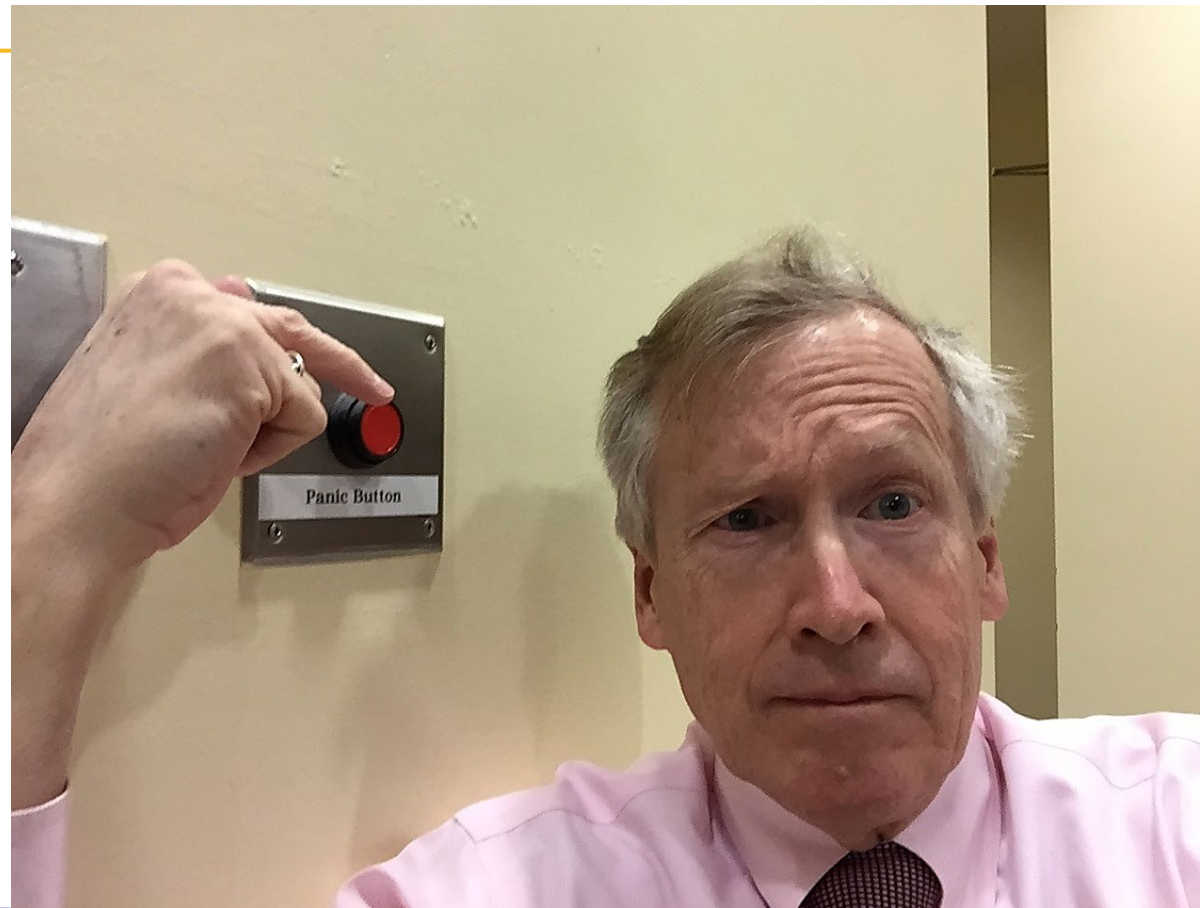
The changing technology of private communication



A Funny Story



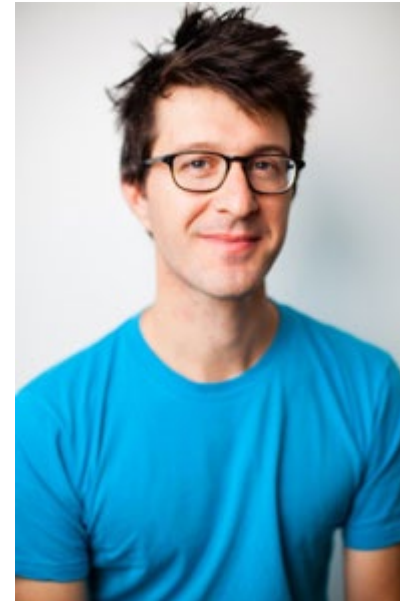
The technological ease of sharing images



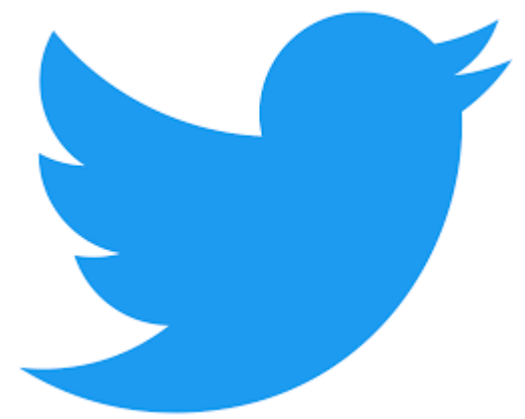
The technological ease of sharing information



Who Are Those Guys?



Caveat Emptor!



******WARNING****WARNING****WARNING******

**“THERE IS NO RIGHT OF PRIVACY
IN THIS SYSTEM”**

The End of Privacy?

“You have zero
privacy anyway.
Get over it.”

(attributed to Scott
McNealy, 1999)



The Technological Ease of Mining Data

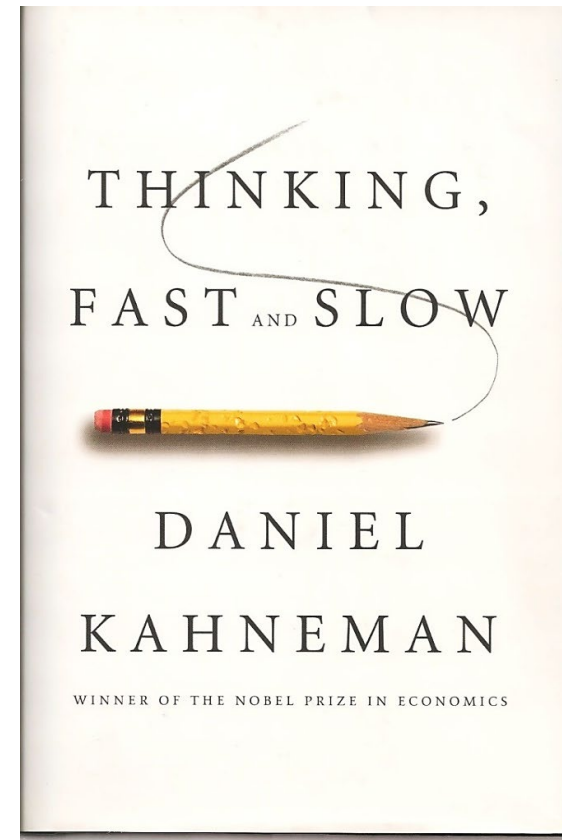
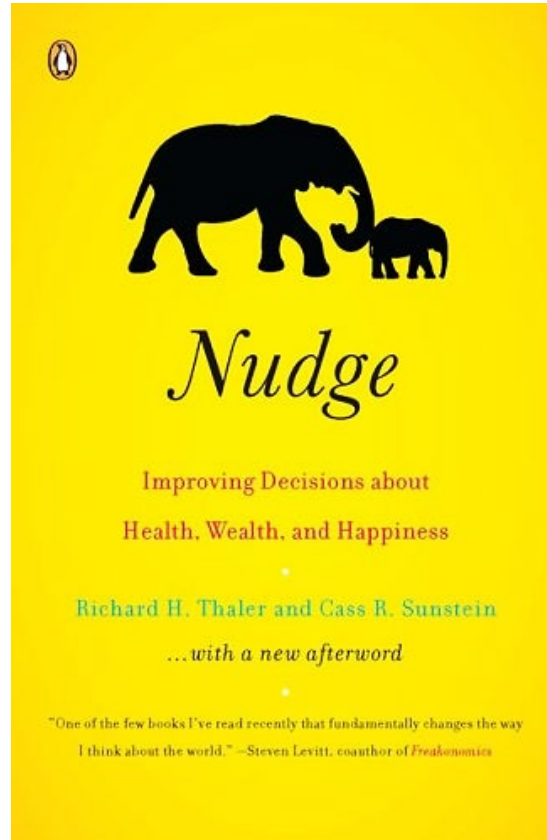


The Technological Ease of Accessing Information

“Computers, however, have nothing better to do; keeping track is their only job. They don’t lose the scrapbook, or travel, or get drunk, or grow senile, or even blink. They just sit and remember. The myriad phases of our lives, once gone but to memory and the occasional shoebox, are becoming permanent, and as daunting as that may be to everyone with a drunk selfie on Instagram, the opportunity for understanding, if handled carefully, is self-evident.”
(Rudder, *Dataclysm*, 2014)



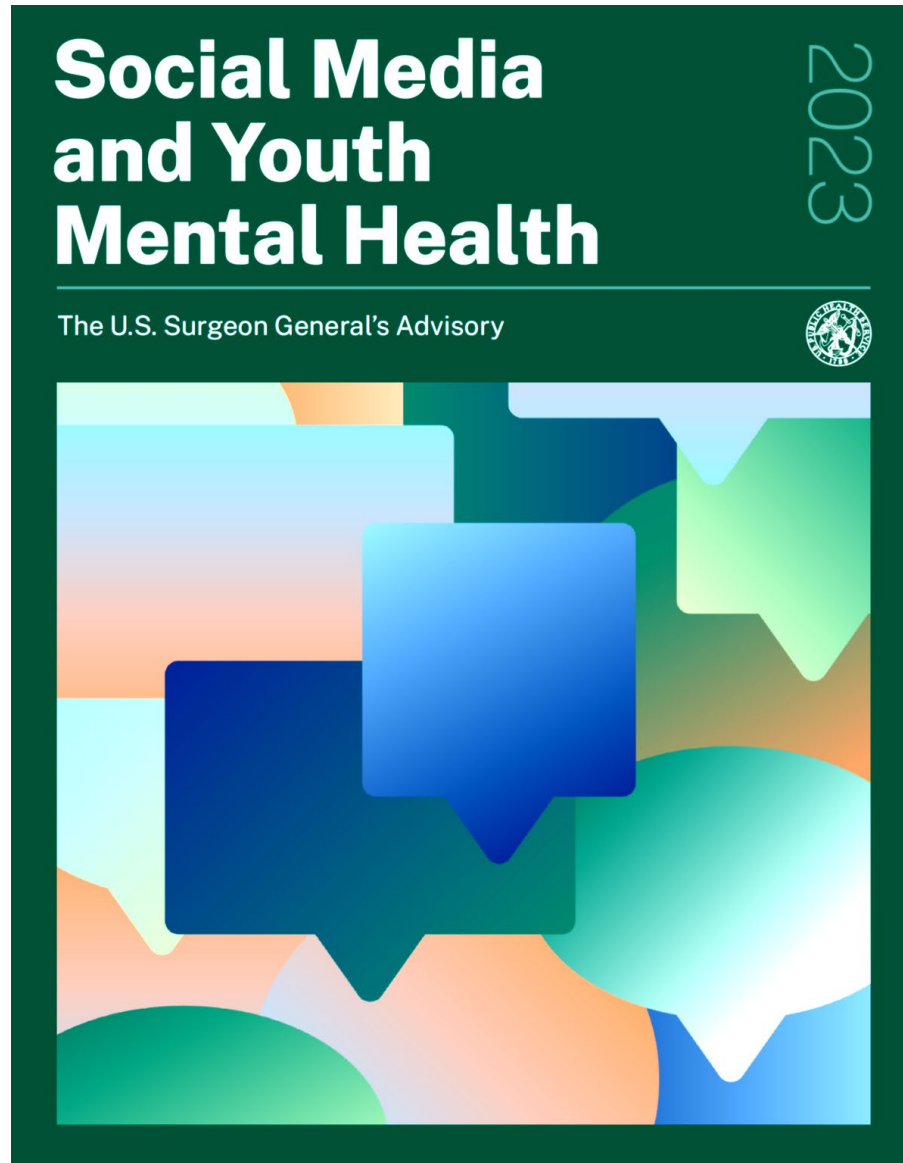
Advances in Scientific Knowledge About Human Decision-making



The CyberWorld Environment Alters Human Behavior

- “Controversial information spreads faster and further than non-controversial information in Reddit”, (2022) .
- “Tracing controversies in hacker communities: ethical considerations for internet research”, (2020) Richterich.
- “Studying ‘Friends’: The Ethics of Using Social Media as Research Platforms”, (2017) Lee.
- “The Danger of Lurking”: Different Conceptualizations of “User Awareness” in Social Media Research”, (2017) Samuel.
- “Sexually Explicit Cell Phone Messaging Associated with Sexual Risk Among Adolescents”, (2012) Rice et. al.
- “The Online Disinhibition Effect” (2004) Suler.
- “The Internet Regression”, (1996) Holland.

Surgeon General's Report on Social Media



“What Researchers Can Do:

Establish the impact of social media on youth mental health as a research priority and develop a shared research agenda” including:

- Social media’s impact
- Role of Age, Stage, Cohort processes, in-person environment
- Benefits and Risks of specific media
- Long-term effects.....

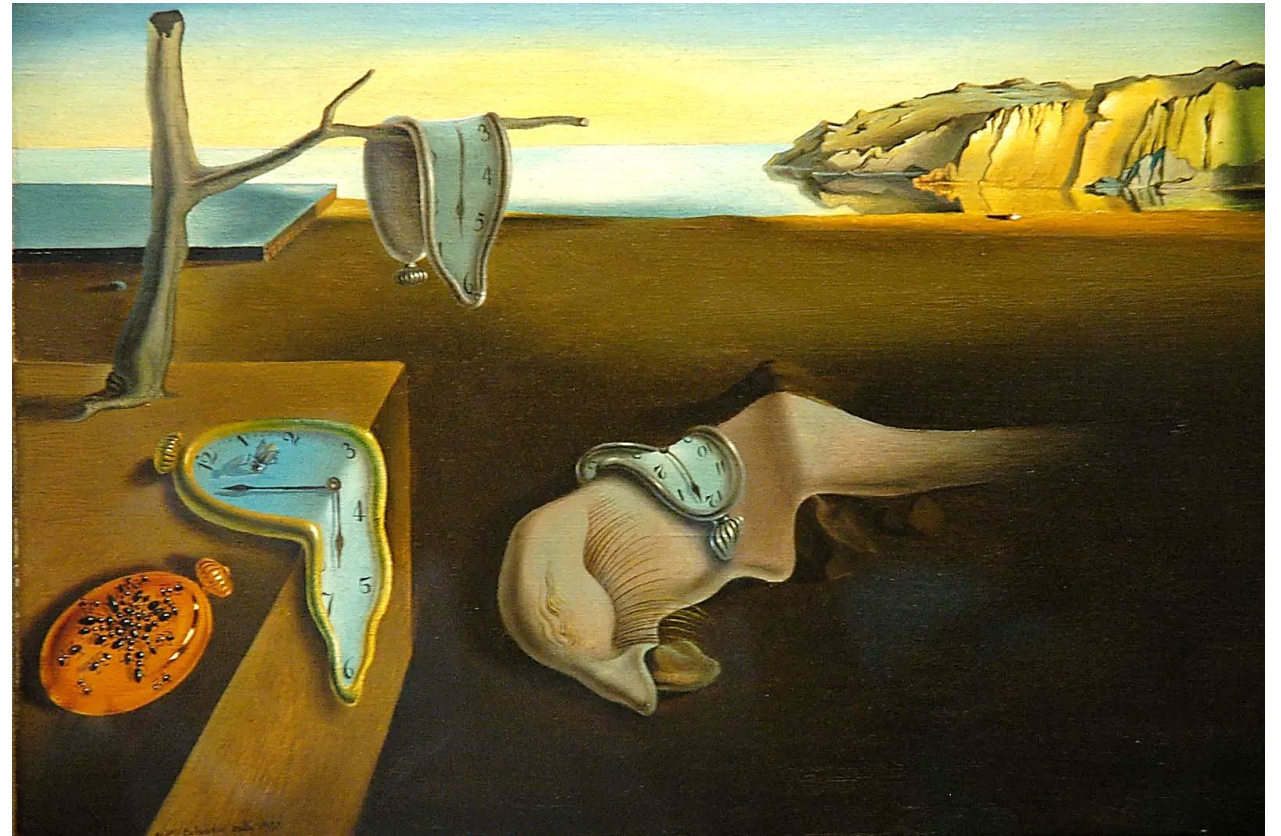
Notorious Internet Studies

- Facebook Study of Emotional Contagion
- OkCupid Study of Mis-matched Match-making
- Columbia/Penn Graduate School Faculty Appointment Request Temporal Discrimination Effect Study
- Koko's GPT-3 Therapist Experiment

And then there's AI and ChatGPT.....

“AI’s potential depends on how it’s used, Califf said. “It could be used for tremendous gain or it could be used for tremendous harm.” (5/31/23)

“Mitigating the risk of extinction from AI should be a global priority alongside other societal-scale risks such as pandemics and nuclear war.” (Center for AI Safety, 5/30/23)



Public/Private

“The most elementary meaning of the two realms [private and public] indicates that there are things that need to be hidden and others that need to be displayed publicly if they are to exist at all.” (Arendt, *The Human Condition*, 1958)



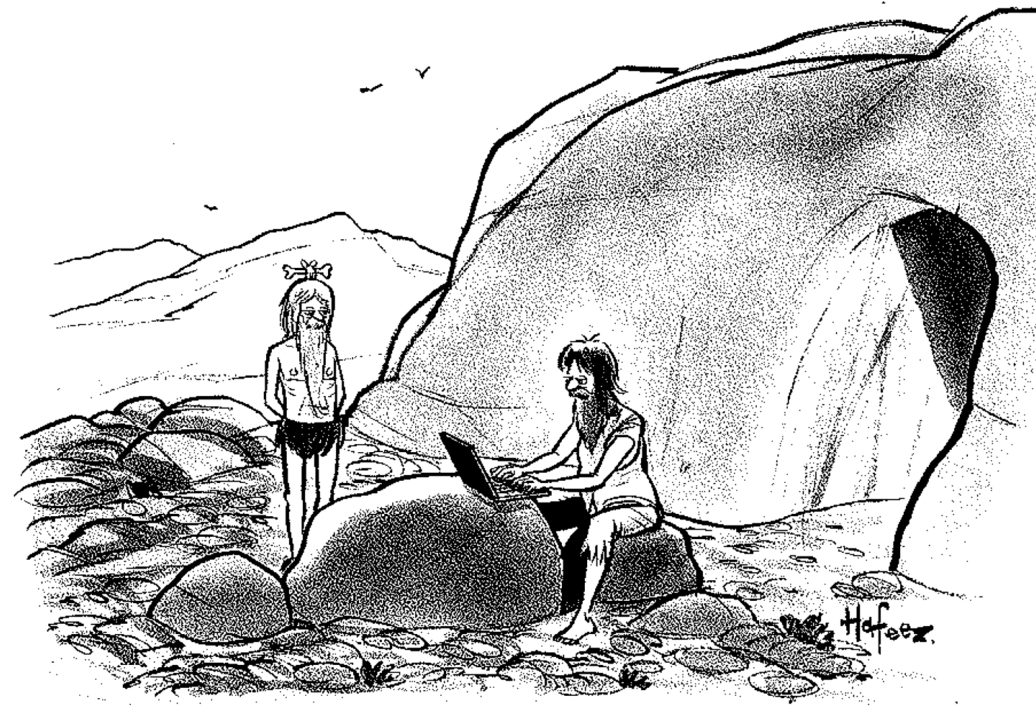
Public/ [Social?] /Private

“The emergence of *society* – the rise of housekeeping, its activities, problems, and organizational devices - from the shadowy interior of the household into the light of the public sphere, has not only blurred the borderline between private and political, it has also changed almost beyond recognition the meaning of the terms and their significance for the life of the individual and the citizen.” (Arendt)



Private/Social/Public Information

	Physical World	Records World	Cyber World
Private	Home	Diary	Notes App
Social	Classroom Workplace Shopping Mall Restaurant Party Venue Invitation only Conference Government	Health Education Personnel Commercial Criminal Classified Government-Controlled	Chatroom Email Online Shopping Sites with EULAs/TOS Facebook Friends IRB Forum
Public	The National Mall Nationals Park Lafayette Park	The National Enquirer Fox News The Washington Post	Twitter Instagram



“That’s what I love about social media. I can have connections with thousands of people and yet still be completely isolated and alone.”

For Social Media & Internet Research:

1. Is the research observation of private behavior or information warranted?
2. Will the subjects provide informed consent?
3. Does the research involve intervention or interaction with the subjects?
4. Will the obtained information be individually identifiable?
5. To what extent will the information be kept confidential?
6. Do the subjects reasonably expect that their information could be re-disclosed or re-purposed?

Who Should Control Secret Social Information?

What are the Parameters
of the Various Confidentiality Provisions
of Shared Nonprivate/Nonpublic Information?





OASH

Office for
Human Research
Protections

Public Discussion?
