

Setting the Stage: IRE Then and Now

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Disclosures

- I have no conflicts of interest related to this educational activity.
- Any opinions or recommendations expressed in this presentation are mine and do not necessarily reflect the views of MCRI/MCHS.

Unofficial Disclosures and Context



IRE—Buchanan and Zimmer (2012, 2016, 2021)

“Conceptually and historically, Internet research ethics is most related to computer and information ethics and includes such ethical issues as participant knowledge and consent, data privacy, security, anonymity and confidentiality, and integrity of data, intellectual property issues, and community, disciplinary, and professional standards or norms.”

So. Many. Questions.

- What ethical obligations do researchers have to protect the privacy of subjects engaging in activities in “public” Internet spaces?
- What are such public spaces?
- Is there any reasonable expectation of privacy in an era of pervasive and ubiquitous surveillance and data tracking?
- How is confidentiality or anonymity assured online?
- How is and should informed consent be obtained online? How should research on minors be conducted, and how do you prove a subject is not a minor?
- Is deception (pretending to be someone you are not, withholding identifiable information, etc.) an acceptable online norm or a harm?
- How is “harm” possible to someone existing in an online space?
- How identifiable are individuals in large data sets?
- Do human subjects protections apply to big data?
- As more industry-sponsored research takes place, what ethical protections exist outside of current regulatory structures?
- As laws, such as the EU’s General Data Protection Regulation (GDPR 2016) are enacted, what are the global implications for data privacy and individual rights?

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Values and Norms

The Belmont Report

- **Respect for Persons:** Individuals should be treated as autonomous agents, and second, that persons with diminished autonomy are entitled to protection.
- **Beneficence:** (1) do not harm and (2) maximize possible benefits and minimize possible harms.
- **Justice.** Who ought to receive the benefits of research and bear its burdens?

On Being a Scientist

- To honor the trust that their colleagues place in them.
- To honor an obligation to themselves to do the best work possible and embrace productive and honest work.
- To uphold an obligation to act in ways that serve the public.

INFORMATION

Misinformation

- *Misinformation is false or inaccurate information that is communicated regardless of an intention to deceive*

Disinformation

- *Disinformation is a species of misinformation that is deliberately deceptive, e. g. malicious hoaxes, spear phishing, and computational propaganda; “deliberately misleading or biased information; manipulated narrative or facts; propaganda.*

Buchanan, 2017

- “The shifting research landscape is complex; data come from a myriad of sources, some intentional and some unintentional. We see more research bystanders, or collateral subjects, in these complex streams of data. One’s connections in a social media landscape matter, even those distant and impersonal. Human subjects research, as broadly understood, is fundamentally different in the age of data science. Methods such as IVCC rely on continuous data streams and analytics. Many of these data mining and analytic studies are considered “secondary analysis.” The degree to which a researcher has access to identifiable data, or the ability to ascertain information about the individual through, for example, reidentification techniques, are used as determinants of the level of risk and benefit in the current US regulatory model of the Common Rule.”



**THE NEW
COMMON RULE**

Thank you!

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