**January 2019**

**Ethics – excerpts from a review of the literature**

#### Ethics and data governance

Conceptualizing and implementing the data science framework as an ecosystem moves the framework from a set of isolated steps to set of seamless activities (Berman et al. 2018).[[1]](#footnote-1) Underlying the framework is an environment of ethics, policies, rules, and stewardship that guide the implementation of the data science framework. The digital age imposes additional challenges on researchers, journals, and businesses.

##### Ethical Challenges for Researchers in the Digital Age

Social science research in the digital age is different because researchers can now observe behavior without consent or awareness by those providing the data (Salganik 2018). **An analogy is the panopticon prison, a circular building that allows an observer in the watchtower (the most inner circle) to observe the behavior of all the people in their cells without being seen.** There is concern that that companies and governments are constantly observing and recording our data (Salganik 2018) similar to the observer in the watchtower.

Three examples of ethical challenges in the digital age are the Emotional Contagion experiments conducted by Facebook in 2012; the merging of Facebook and university records by researchers at Harvard University in 2006 and then sharing deidentified data with other researchers; and Encore, a code used to measure Internet censorship, implemented with good intentions but others raised concern that people in some countries would be exposed to risk if their computer tried to visit certain websites (Salganik 2018)

**One challenge is that social scientists and data scientists may think about ethics differently** (Salganik 2018). Social scientists follow a rules-based approach and data scientists use ad hoc approaches. Instead, Salganik (2018) advocates a **principles-based approach**, which allows researchers to make decisions and communicate their decision process for cases where rules do not yet exist. The approach emphasizes responsibility and methods expected to produce results that will benefit society.

These principles are rooted in the rules that were developed after ethical failures by researchers (e.g., the Tuskegee Syphilis Study conducted from 1932-1972). University research and others already follow these rules with approval and monitoring by their Institutional Review Boards. These existing principles are (Salganik 2018):

* Respect for persons – treating people as autonomous and honoring their wishes
* Beneficence – understanding the risks and benefits of the study and weighing the balance between (1) do no harm and (2) maximize possible benefits and minimize possible harms.
* Justice – deciding if the risks and benefits of research are distributed fairly
* Respect for Law and Public Interest – extends principle of beneficence to include all relevant stakeholders

These rules are based on two ethical frameworks (1) deontologists focus on means and (2) consequentialists focus on ends. These two frameworks help to explain current thinking about challenges with respect to digital data. The principles allow researchers (with approval of their IRBs) to weigh tradeoffs. For example, there are some circumstances that obtaining informed consent could increase risks for participants, change behavior and thus jeopardize the scientific findings of the study, or is not possible, given the breadth and scope of the study, or because the participants are anonymous. **Therefore, the rule is adapted to be “some form of consent for most things” (Salganik 2018, page 306), which is also consistent with IRB rules.**

**Thus, taking a binary approach to ethics polarizes discussions and stalls research. Instead, continuous thinking about ethics in the context of a research project using digital data encourages difficult discussions and proposes directions for the research that are made conscientiously to benefit society** (Salganik 2018, Erickson et al. 2018, Fritzler 2018).

Salganik (2018) suggests that the **IRB is a floor not a ceiling** (page 32) in that researchers are required to follow the IRB rules and complete their protocols. However IRB approval is not sufficient for addressing a researcher’s ethical responsibility in his/her research. **A recommendation is to write an ethical appendix to a research paper at the beginning of the research to be transparent in what they think is right or wrong, they conduct their research based on what they have decided, and they are transparent in sharing the plan publicly.**

An **ethical checklist** for data science is a series of questions that researchers ask themselves throughout the project (Fritzler 2018).[[2]](#footnote-2) These questions cover topics such as

Create ethical checklist for each stage of research

* Project selection and scoping, e.g., is the choice of this project a good use of resources?
* Building a team, e.g., does the team engage members from the target community? Are they given a voice to express their needs and culture?
* Data acquisition, e.g., does collecting or acquiring data protect privacy? Are the data anonymized? Are they maintained securely to ensure privacy and confidentiality?
* Analysis, e.g. what biases do the researchers have? Are biases introduced in the study through the choice of variable selection, such as including male/female, but not other options? Are the right tools being used? Are methods and outputs transparent?
* Implementation, e.g., are limitations of the research clearly presented? What are potential effects of false negatives? What are benefits and costs when implementing options that result from a predictive model or incomplete information?

**Courses are also beginning to address ethical issues of using non-traditional data sources in research.** Margo Boenig-Liptsin, co-instructor of UC Berkeley’s Human Contexts and Ethics of Data[[3]](#footnote-3) course, notes “In this time of rapid social and technological change, concepts like **‘privacy,’ ‘fairness,’ and ‘representation’** are reconstituted.”[[4]](#footnote-4) **One example of bias** is that current Artificial Intelligence algorithms and systems significantly do not correctly identify women and darker skinned individuals. MITresearcher Joy Buolamwini systematically investigated AI technology and found that some systems did not detect her face and some labeled her face as male.[[5]](#footnote-5) Buolamwini analyzed results on 1270 unique faces and uncovered gender and skin-type bias in how AI systems classify faces. Professional societies are also creating and refining their code of ethics in the context of the availability of massive amounts of new data sources.[[6]](#footnote-6)

T**he results of these ethical frameworks and principals are rules,** the most common followed in the United States is **the Common Rule** (the set of regulations for most government funded research in the US). The Common Rule was updated in 2017 to reflect changes in how research is conducted.[[7]](#footnote-7) The Federal Register Notice notes that “Evolving technologies—including imaging, mobile technologies, and the growth in computing power—have changed the scale and nature of information collected in many disciplines” (page 7151). The revisions, originally planned for implementation in January 2018, were implemented in January 2019.

Another ethical framework is the European Union’s General Data Protection Regulation (GDPR).[[8]](#footnote-8) Regulation (EU) 2016/679 regulates the processing by an individual, a company or an organization of personal data relating to individuals in the EU. Passed in 2016 and implemented in May 2018, the regulation is expected to have worldwide impact. The goals for the GDPR is to harmonize data privacy laws across Europe, to protect data privacy and provide choices to EU citizens, and to change the way organizations manage data privacy.[[9]](#footnote-9)

##### Creating Ethical Standards for Researchers and Journals

Several groups are defining **principles, standards, and norms** around the uses of data, analysis, and interpretation, that is around the steps associated with implementing a data science framework. For example, the Community Principles on Ethical Data Sharing, formulated at a Bloomberg conference in 2017, is based on four principles – fairness, benefit, openness, and reliability. Each are defined on their website (CPED 2017):[[10]](#footnote-10)

**Fairness** - Understand, mitigate and communicate the presence of bias in both data practice and consumption.

**Benefit -** Set people before data and be responsible for maximizing social benefit and minimizing harm.

**Openness -** Practice humility and openness. Transparent practices, community engagement, and responsible communications are an integral part of data ethics.

**Reliability -** Ensure that every effort is made to glean a complete understanding of what is contained within data, where it came from, and how it was created. Extend this effort for future users of all data and derivative data.

To implement these four principals, CPED recommends obtaining consent; maintaining data securely; ensuring anonymity of the data; providing sufficient documentation of practices to be transparent through the data lifecycle; acknowledging and addressing bias or potential bias; demonstrating an understanding of tensions across stakeholders (if they exist); and taking care to communicate carefully; all while “exercising ethical imagination in their work, including considering the implication of what came before and what may come after, and actively working to increase benefit and prevent harm to others.” (CPED 2017).

**One area of confusion can be the issue of consent. From an ethical perspective, for surveys, obtaining consent is almost always required**. An ongoing discussion is needed to address such questions as whether consent is needed if collecting data through Amazon Mechanical Turk? What about using publicly available data that can link local property records, with permit data, and other data that may (or may not) give the perception of identifying individuals. Are statements by researchers sufficient, for example, that all data are deidentified and no attempt to identify individuals will be made?

##### Ethical Challenges and Alignment of Incentives

Ethical challenges arise when incentives focus on quantity and innovation rather than quality and reproducibility of science, and researchers are encouraged to ‘warehouse any negative findings’ (Nosek et al. 2012[[11]](#footnote-11) in Alberts et al. 2015[[12]](#footnote-12)). Some authors propose that **open science that values transparency, openness, and reproducibility** should include reporting on ‘null results’ as well as statistically significant results (Nosek et al. 2015)[[13]](#footnote-13)

Science has many norms that most often ensure critique and correction of findings, but the process is not foolproof, and incentives can distort norms. A group, organized by the National Academy of Sciences and the Annenberg Retreat met to discuss how to remove the disincentives to high quality science (Alberts et al. 2015), although this may be easier said than done. Their proposed actions are to:

* Reward scholars for “publishing well rather than often;”
* Increase mentoring younger reviewers during the peer review process;
* Ensuring clarity and quality of editorial responses;
* Uncovering reviewer biases for or against an article or other output.

A proposed way to do this is to allow reviewers to share their comments with each other and to collaborate on a response to the author. *eLife*,[[14]](#footnote-14) an open access life and biomedical online journal and *Science* both follow this practice.

Underlying these principles for reporting on science and science findings are ethical practices in the laboratory ensuring that research is conducted ethically from the start, including **documentation, privacy, confidentiality, and transparency**. Constructive criticism and questioning is an integral part of science; overcoming one’s own biases and others through ongoing discussion is an integral part of the scientific process.

**The Transparency and Openness Promotion (TOP) committee** also propose guidelines for procedures and publication policies in social and behavioral sciences journals with the goal to drive towards more openness. To do this, they propose modular standards across three levels, each level designed to allow for increasing adoption of the standards. The guidelines recognize challenges with implementing the first four standards (citation standards, data transparency, analysis methods (code) transparency, and research materials transparency) allowing exceptions to sharing for ethical reasons, intellectual property concerns, or availability of necessary resources. The next four standards (design and analysis transparency, preregistration of studies, preregistration of analysis plans, and replication) define openness across the scientific process.

At the time of the article publication, 86 social and behavioral journals had agreed to follow the standards. The Center for Open Science[[15]](#footnote-15) at the University of Virginia provides an “information commons” and support to support journals in adopting the standards (Nosek et al. 2015). The Center also tracks adoption across journals.

##### Creating Ethical Standards for Businesses

An ethical framework that insists that businesses play an active role in ensuring privacy is the European Union’s General Data Protection Regulation (GDPR).[[16]](#footnote-16) Regulation (EU) 2016/679 regulates the processing by an individual, a company or an organization of personal data relating to individuals in the EU. Passed in 2016 and implemented in May 2018, the regulation is expected to have worldwide impact.

The GDPR applies to all companies processing personal data of people living in the European Union, regardless of the company’s location. Non-EU businesses that process data about EU citizens also have to appoint a representative in the EU. Organizations that do not meet GDPR requirements can be fined, for example, for not having customer consent to process data or violating the *privacy-by-design* concepts. All companies involved in processing data about EU citizens are subject to fines.

The GDPR requires clearly written consent guidelines and ease to give or withdraw consent by citizens. *Data breach notifications* are required within 72 hours of the incident. EU citizens have the *right to access* their data without charge and also the *right to be forgotton*. *Privacy by design* requires the inclusion of data protection as an integral part of building systems, not as an add on.

Article 23 requires companies to process only the data necessary for completing their work (data minimization). Finally there are requirements related to Data Protection Officers, which are “mandatory only for those controllers and processors whose core activities consist of processing operations which require regular and systematic monitoring of data subjects on a large scale or of special categories of data or data relating to criminal convictions and offences.”

##### Privacy (Maybe should come before ethics or could be a Text Box as part of the ethics discussion)

**Privacy** is intimately integrated in the discussion of ethics. Privacy is defined as the amount of personal information individuals allow others to access about themselves (NRC 2007). The EU GDPR explicitly allows individuals to explicitly determine the amount of information they are willing companies to keep.

**Confidentiality** is the process that data producers and researchers follow to keep data about individuals private (NRC 2007). The availability of massive amounts of data and the ability to find associations across many data sources may make it impossible to achieve complete assurances of confidentiality if the data are to still be useful for research.

The digital age is changing the focus of the privacy discussion from camouflaging and suppressing data for maintaining confidentiality, to trust, policy, and governance (Keller et al. 2016). A trust-but-verify approach, balancing trade-offs of privacy with societal gains from the use of the data, will require not only cultural changes but legislative changes (Keller et al. 2016[[17]](#footnote-17), Erlich et al. 2014[[18]](#footnote-18)). ***This will be challenging as the existing U.S. legislation and practice is premised on the unacceptability of any potential disclosure risk.***

**Food for thought**

**Does the Census Bureau need to address inferential harm? (Vince’s Barabba’s 2005 PDU report)**

“Inferential harm occurs when an individual is identified with a group of other individuals (either by type or within a specific geography) and someone or some organization takes action against that group which is seen as harmful by both the group and the individuals within the group. The Census Bureau uses every possible means to ensure that no single individual is identified, although the aggregate information could result in harm to groups (and hence the individuals in those groups). Alternatively, the same practices are used when actions are taken that are beneficial to the same individuals that make up the specific group.”

What are the questions that I should ask myself? Stage of research

Context of research is critical to level of data literacy, ethics, etc.

Does it satisfy those 4 criteria? Crosse by stages of research or VV.

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