Teaching Data Ethics in the Introductory Statistics Course

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The ethical use of data is a prime topic to introduce the subject of research in Introductory Statistics.

This presentation will include conversations about confidentiality, informed consent, special populations, and the history of Institutional Review/Research Boards.

Participants will see available resources and hear how these topics can be incorporated in the classroom.

Considerations:

What type of course do you teach? Quantitative (data), Research, Qualitative/Social?

These are often foundation courses for students. From our foundation course or along side, they are doing research — often needing IRB approval.

It is helpful for our students to have an understanding of this process and why it's needed as they learn about the design of experiments, sampling methods, collection, analysis, and interpretation of results.

What resources are available for faculty and your students at your college?

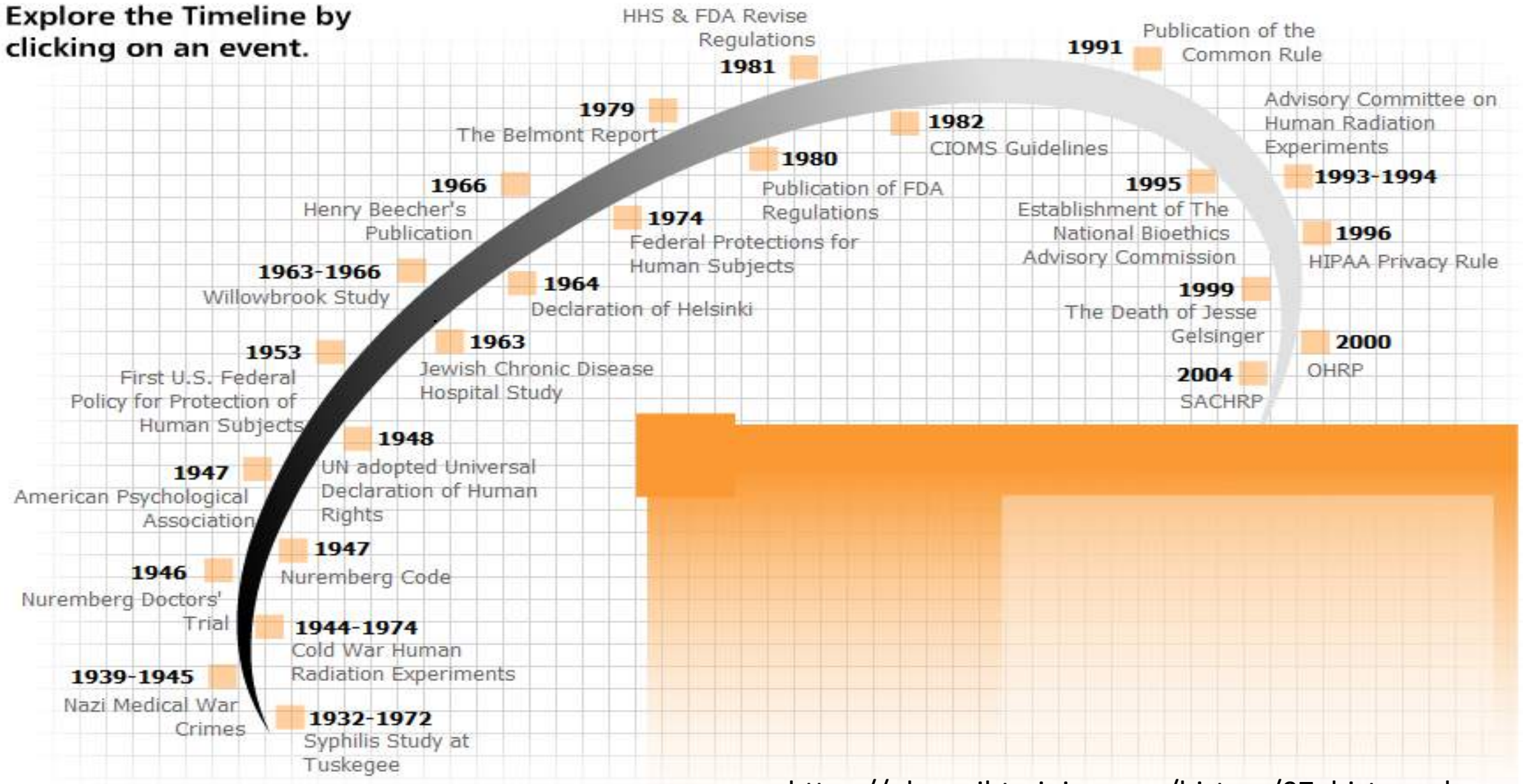
What is Data Ethics?

Data ethics is a branch of ethics that studies and evaluates moral problems related to data.

- including collecting, recording, processing, dissemination, sharing and use of data, along with the related practices, to formulate and support *morally* good solutions.

Floridi, L., & Taddeo, M. (2016). What is data ethics? *Philosophical Transactions. Series A, Mathematical, Physical, and Engineering Sciences*, *374*(2083), 20160360. http://doi.org/10.1098/rsta.2016.0360

Timeline of Events



https://phrp.nihtraining.com/history/07_history.php

The Belmont Report

On July 12, 1974, the National Research Act (Pub. L. 93-348) was signed into law, creating the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research.

The Belmont Report attempts to summarize the basic ethical principles identified by the commission in the course of its deliberations. It has become a seminal document in establishing principles for research with human subjects. Belmont Report

https://www.hhs.gov/ohrp/regulations-and-policy/belmont-report/index.html

The Importance of Teaching Ethics in Statistical Consulting Courses
AMSTATNEWS 9/1/2017

An important component in any statistical consulting course is the topic of ethics. The three main reasons to include a study of ethics within your introductory statistics course:

- As a first/introductory statistics course/social science/research, this is the first impression about data – the experimental design, collection, analysis, human subjects – that students often see.
- Many universities require ethics as part of a degree requirement or research requirement.
- Anyone conducting research should be aware of ethical guidelines involving human subjects.

http://magazine.amstat.org/blog/2017/09/01/ethics-2/

Institutional Review Board (IRB)

An **Institutional Review Board** provides ethical and regulatory oversight of research that involves human subjects. The IRB has the authority to review, approve, modify or disapprove research protocols submitted by faculty, staff and student investigators. In particular, if the study is intended for publication or presentation, it needs to have IRB approval.

The US Department of Health and Human Services provides resources for Human Research Protections, including the *official* registering of college/university IRB's.

This agency offers mini-tutorials, videos, and additional resources to the public.

https://www.hhs.gov/ohrp/education-and-outreach/index.html

Office for Human Research Protections (OHRP) Webinars

A series of educational webinars were developed by OHRP's Division of Education and Development and are intended to provide information regarding the requirements of the Department of Health and Human Services (HHS) regulations for the protection of human subjects at 45 CFR part 46.

Archived Webinars on YouTube:
https://www.youtube.com/view_play_list?p=5965CB14C2506914

Interactive Training Video

The Office of Research Integrity (ORI) and the Office for Human Research Protections (OHRP) have created The Research Clinic, an interactive training video to educate clinical and social researchers on the importance of appropriately protecting research subjects and avoiding research misconduct.

Training modules: https://ori.hhs.gov/TheResearchClinic

Research and Protecting Human Participants

Responsible Conduct of Research (RCR): RCR covers core norms, principles, regulations, and rules governing the practice of research. The National Institutes of Health (NIH), National Science Foundation (NSF), and U.S. Department of Agriculture (USDA) require certain categories of researchers to receive this training. RCR is increasingly viewed as an essential component of training, regardless of a researcher's source of funding. (https://about.citiprogram.org/en/course/responsible-conduct-of-research-basic/)

Human Subjects Research (HSR): HSR training is intended for anyone involved in research studies with human subjects, or who have responsibilities for setting policies and procedures with respect to such research, including Institutional Review Boards (IRBs). (https://about.citiprogram.org/en/series/human-subjects-research-hsr/)

Ethical Guidelines for Statistical Practice

Prepared by the Committee on Professional Ethics of the American Statistical Association, Approved by the ASA Board in April 2016

Purpose of the Guidelines

The American Statistical Association's Ethical Guidelines for Statistical Practice are intended to help statistics practitioners make decisions ethically.

Additionally, the Ethical Guidelines aim to promote accountability by informing those who rely on statistical analysis of the standards that they should expect.

The discipline of statistics links the capacity to observe with the ability to gather evidence and make decisions, providing a foundation for building a more informed society.

Because society depends on informed judgments supported by statistical methods, all practitioners of statistics, regardless of training and occupation or job title, have an obligation to work in a professional, competent, and ethical manner and to discourage any type of professional and scientific misconduct.

The principles expressed in this article are a guide to both those whose primary occupation is statistics and those in all other disciplines who use statistical methods in their professional work.

http://www.amstat.org/ASA/Your-Career/Ethical-Guidelines-for-Statistical-Practice.aspx

8 Ethical Guidelines for Statistical Practice ASA

The following guidelines are meant to focus ethical discussion and thought surrounding research:

1. Professional Integrity and Accountability
2. Integrity of Data and Methods
3. Responsibilities to Science, Public, and Client
4. Responsibilities to Research Subjects
5. Responsibilities to Research Team Colleagues
6. Responsibilities to Other Statisticians
7. Responsibilities Regarding Allegations of Misconduct
8. Responsibilities of Employers

http://www.amstat.org/ASA/Your-Career/Ethical-Guidelines-for-Statistical-Practice.aspx

The Forum Guide to Data Ethics

The National Forum on Education Statistics prepared a 50 page guide to "best practices" for those involved with educational data and research. The Forum *Guide to Data Ethics* is written for a broad range of stakeholders in the education data community. It addresses ethical issues related to the management and use of education data. https://nces.ed.gov/pubs2010/2010801.pdf

Integrity

1. Demonstrate honesty, integrity, and professionalism at all times.
2. Appreciate that, while data may represent attributes of real people, they do not describe the whole person.
3. Be aware of applicable statutes, regulations, practices, and ethical standards governing data collection and reporting.
4. Report information accurately and without bias.
5. Be accountable, and hold others accountable, for ethical use of data.

Data Quality

6. Promote data quality by adhering to best practices and operating standards.
7. Provide all relevant data, definitions, and documentation to promote comprehensive understanding and accurate analysis when releasing information.

Security

8. Treat data systems as valuable organizational assets.
9. Safeguard sensitive data to guarantee privacy and confidentiality.

How to Incorporate Data Ethics

- Have students complete the free NIH training and submit their certificate(s) of completion. https://phrp.nihtraining.com/users/login.php?l=2

  There is a virtual module and pdf version available. https://phrp.nihtraining.com/users/PHRP.pdf

  Your college may also be participating with other organizations to provide training to faculty, staff, and students. **Many institutions accept the NIH training for IRB applicants - FREE.**

  Some colleges utilize the CITI training modules, fee for use content/certifications.

- Make a module or quiz in your learning management system.

  Many colleges offer information about the IRB process including quizzes, decision flowcharts/trees, and types of research requiring approval on their website.

- Have someone from your IRB/Institutional Research department talk to your class.

IRB Review Types

- Exempt
- Expedited
- Full Board

Every IRB has their **own criteria** on the review types, including the timeframe and process for review. Currently, TCC is in the process of defining our process which includes a decision tree for applicants.

https://www.hhs.gov/ohrp/regulations-and-policy/regulations/45-cfr-46/index.html#46.101%28b%29

Exempt

A research activity may be declared exempt if it is considered low-risk and the only involvement of human subjects will be in the categories outlined in federal law 45 CFR 46.101(b). Briefly described, these categories are:

- Research conducted in established or commonly accepted educational settings, involving normal educational practices.
- Research using anonymous or no-risk tests, surveys, interviews, or observations. (Note that *anonymous* is not the same as *confidential*. Most research involving public officials.
- Research involving the collection or study of existing data if it is publically available or if subjects cannot be identified.
- Research examining public benefit or service programs.
- Taste and food quality evaluation and consumer acceptance studies.

Expedited

A research design plan may qualify for expedited review if it is judged to involve only minimal risk, does not include intentional deception, does not employ sensitive populations or topics, and includes appropriate informed consent procedures. The most common types of studies considered for expedited review include the following:

- Collection of data from voice, video, digital, or image recordings made for research purposes.
- Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior), or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.
- The collection of physical data through non-invasive procedures such as height and weight; MRI, ECG, ultrasound; moderate exercise; collection of blood samples by heel stick or finger stick. See a full list of procedures at 45 CFR 46.110.

Full Board

Research that is judged to involve more than minimal risk, or involves protected populations such as children, prisoners, or disabled individuals, must undergo a full board review. Individuals intending to conduct research that requires a full board review should allow ample time to complete the review process as this review type may take longer than the prior review processes. The following categories of research require full IRB approval:

- Projects for which the level of risk is determined by the IRB to be greater than minimal.
- Projects that involve the intentional deception of subjects, such that misleading or untruthful information will be provided to participants.
- Projects that involve sensitive or protected populations (such as children or cognitively disabled individuals).
- Projects that plan to use procedures that are personally intrusive, stressful, or potentially traumatic (stress can be physical, psychological, social, financial, or legal).

Informed Consent

Informed consent refers to:

A legally-effective, **voluntary** agreement to participate in research, by a **competent** individual who has received and understood the necessary information.

Who can give consent?

What are Protected populations?

Vulnerable Populations

Research in which pregnant women, human fetuses and neonates, prisoners,
or children respectively may be involved.

Other vulnerable populations include, but are not limited to, mentally disabled persons
and economically and/or educationally disadvantaged persons.

While the regulations do not specify what additional protections are necessary for these groups,
the HHS regulations (45 CFR 46.111) do require that investigators include additional
safeguards
in the study to protect the rights and welfare of these individuals
"when some or all of the subjects are likely to be vulnerable to coercion or undue influence."

(http://www.hhs.gov/ohrp/humansubjects/guidance/45cfr46.html#46.111)

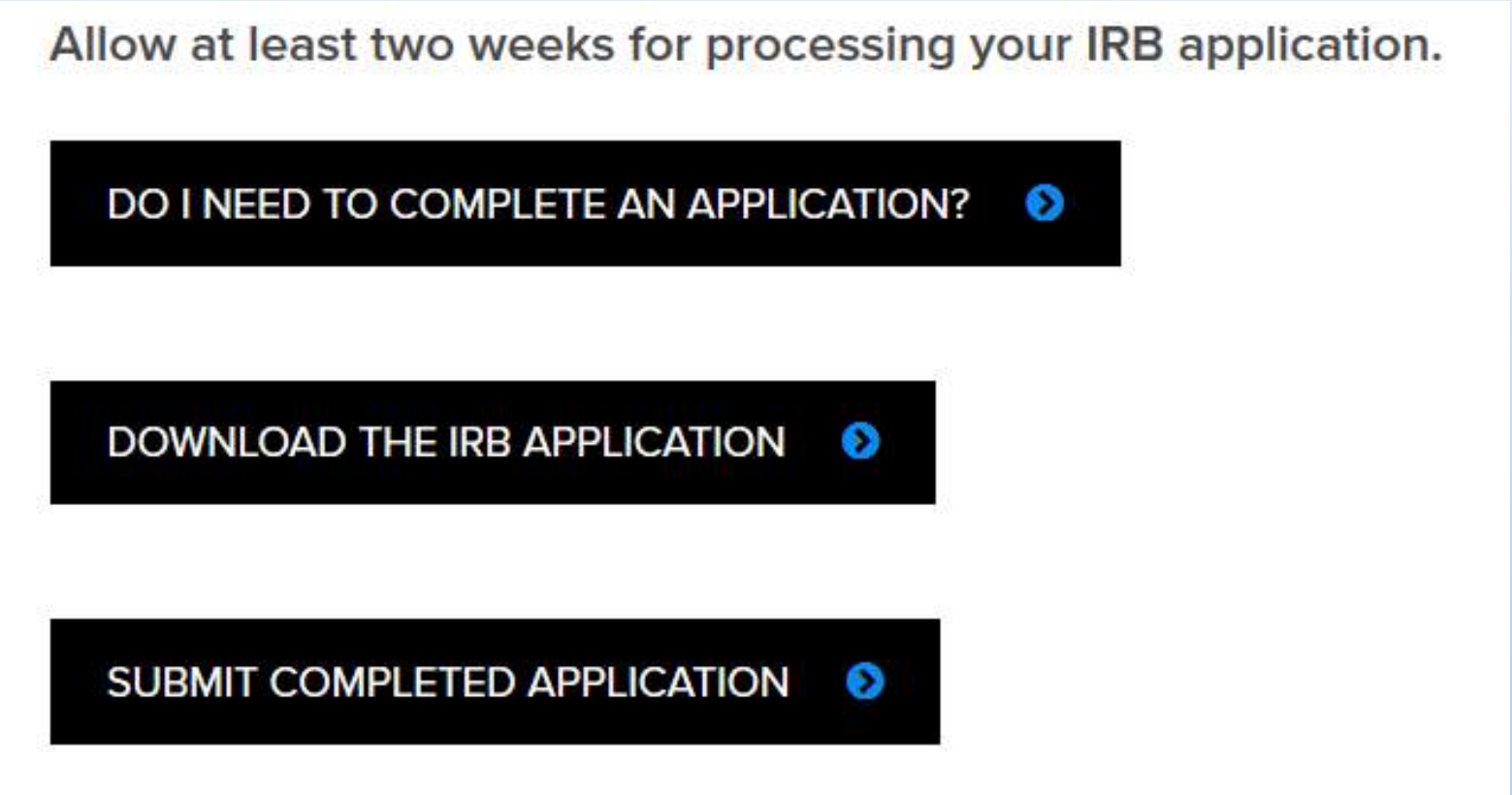
Considerations for the need of IRB approval:

- ❑ Do you plan on presenting or publishing?
- ❑ Does the research include the collection of data needs to have ethical considerations made?
- ❑ Does the research involve children (concurrent students or students under 18)?
- ❑ Is the research systematically biased, is the collection of data accurate & trustworthy, was those surveyed or the archived data from those in a protected population?
- ❑ Is it anonymous? Confidential? Who potentially sees the names? The researcher, the public, just the person that pulled/collected the data?
- ❑ Are the limitations of the study given? Implications? Negative and positive implications addressed?
- ❑ Was the analysis reported accurately?

Tulsa Community College example

https://tulsacc.edu/IRB

On this website you will find a decision tree to help determine if you need IRB approval:



http://www.tulsacc.edu/about-us/administration/offices/academic-affairs/institutional-review-board-irb/irb-application

Other Resources:

There are numerous books and articles about research ethics/data ethics, Sage has recently published a book as part of their Q&A Sage 100 Questions and Answers Series, Volume 5 (2018)

100 Questions (and Answers) About Research Ethics by Emily Anderson & Amy Corneli

Thoughts, Comments, Feedback…

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