Biology 611
Ethics of Big Data in the Life Sciences

Course Overview
This course will explore the ethics of big data’s applications, methods, and assumptions in the life sciences. We will focus our discussions on particular case studies in order to reflect on the social and ethical challenges which arise from concerns about big data, such as (1) how to uphold individual and group privacy, and their associated ethical principles; (2) what do to with knowledge about propensities, and its effects on predictive-policing and moral responsibility; (3) how to frame research ethics, especially research with human subjects; (4) and how to protect individual freedoms and ensure justice.

Learning Outcomes
In this course, students will learn how to identify the potential benefits and risks of particular uses of data in the life sciences, as well as analyze crosscutting themes in the ethics of big data science. These themes include: 1) the challenges of collecting, managing, storing, and sharing data, 2) issues concerning privacy and confidentiality, 3) issues in the governance of science and data, and 4) the challenges of maintaining public trust in science. Students will be encouraged to incorporate different levels of analyses, critical perspectives, ethical principles, and competing values into a rigorous ethical analysis of big data in the life sciences.

Requirements
The assignments are readings, short response papers, and a case or book review. Natural science and engineering graduate students typically prepare a case, while graduate students in the humanities or social sciences typically prepare a book review. In week one or two of class, we will decide which formal writing assignment you will complete.

This material is based upon work supported by the National Science Foundation under Award No. 1355547, Karin Ellison and Joseph Herkert, Arizona State University sub-award Co-PIs. Any opinions, findings, and conclusions or recommendations expressed in this material are those of the author(s) and do not necessarily reflect the views of the National Science Foundation.
Readings

The Course Schedule gives the reading assignments. Students must complete readings before each class so that discussion can draw on knowledge of the readings. The reading materials will be posted on Black Board.

Response Papers

Each session students will write brief (1-page) response papers on the assigned readings. These informal essays should state the argument of each piece assigned and raise two issues for discussion. At least one point should be positive – i.e. discuss some fashion in which a reading for the week might serve as a model for scholarship. The response papers are due at each class session on paper.

Cases

Students are required to write a 1-page narrative, which can be a summary of an actual event or a hypothetical scenario, and four pages of ethical analysis. The analysis will follow a format that we will discuss during week one.

Drafts are due via Blackboard AND in hard copy in class. Students will present their cases for class discussion. During the discussion, we will workshop the draft case. Final cases and case analyses, incorporating comments from class discussion, are due via Blackboard one week after the last class meeting.

Book Review

Students preparing reviews will write a four to five page book or article review of humanistic or social science scholarship on the unit topic. The idea is for students to explore the literature beyond that assigned for class. The review should be modeled on those in *Science and Engineering Ethics, American Journal of Bioethics, Technology and Culture, ISIS*, or another ethics or history journal. The work(s) you wish to review must be approved. If you don’t know how to locate this kind of scholarship, I can give you tips. Students will also submit draft reviews for comments.

Evaluation

Grades will generally be calculated as follows:

- Attendance, demonstrated knowledge of assigned readings, and thoughtful contributions to discussion: 20%
- 6 response papers: 30%
- Draft case or book review: 20%
- Final case or book review: 30%

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I reserve the right to assign any student a final grade that is higher than merited by strict calculation based on academic criteria, such as improvement in grades over the semester or atypical and explainable poor performance on a single assignment.

I only accept late assignments in rare circumstances. These include professional conflicts, traveling with a sports team, major and documented illnesses, personal or family crises, etc. Should any of these arise, you are responsible for discussing the circumstances with me ASAP, before the deadline is missed if possible.

Likewise, incompletes will only be given in extraordinary circumstances. To receive an incomplete, you would work with me to prepare a written agreement specifying how and when all work for the course would be completed. This agreement would have to be signed before I submit grades at the end of term.

Student Conduct and Academic Integrity

Academic honesty is expected of all students in all examinations, papers, laboratory work, academic transactions, and records. The possible penalties include, but are not limited to, appropriate grade penalties, course failure indicated on the transcript as a grade of E, course failure due to academic dishonesty indicated on the transcript as a grade of XE, loss of registration privileges, disqualification, and dismissal. For more information, see http://provost.asu.edu/academicintegrity. Additionally, required behavior standards are listed in the Student Code of Conduct and Student Disciplinary Procedures, Computer, Internet, and Electronic Communications policy, and outlined by the Office of Student Rights and Responsibilities. Anyone in violation of these policies is subject to sanctions.

It would be especially pathetic to fail an ethics course for cheating!

Students are entitled to receive instruction free from interference by other members of the class. An instructor may withdraw a student from the course when the student’s behavior disrupts the educational process per Instructor Withdrawal of a Student for Disruptive Classroom Behavior.

Appropriate online behavior, also known as netiquette, is expected. This includes keeping course discussion posts focused on the assigned topics. Students must maintain a cordial atmosphere and use tact in expressing differences of opinion. The instructor may delete inappropriate discussion board posts.

The Office of Student Rights and Responsibilities accepts incident reports from students, faculty, staff, or other persons who believe that a student or a student organization may have violated the Student Code of Conduct.

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Accessibility Statement

In compliance with the Rehabilitation Act of 1973, Section 504, and the Americans with Disabilities Act as amended (ADAAA) of 2008, professional disability specialists and support staff at the Disability Resource Center (DRC) facilitate a comprehensive range of academic support services and accommodations for qualified students with disabilities.

Qualified students with disabilities may be eligible to receive academic support services and accommodations. Eligibility is based on qualifying disability documentation and assessment of individual need. Students who believe they have a current and essential need for disability accommodations are responsible for requesting accommodations and providing qualifying documentation to the DRC. Every effort is made to provide reasonable accommodations for qualified students with disabilities.

Qualified students who wish to request an accommodation for a disability should contact the DRC by going to https://eoss.asu.edu/drc, calling (480) 965-1234 or emailing DRC@asu.edu.

Course Schedule

Class 1: Introduction to the Ethics of Big Data in the Life Sciences

ASSIGNED:


RECOMMENDED:


Website: http://bdes.datasociety.net

Class 2: Big Data in Genetics/Genomics 1

ASSIGNED:

Case Study - Big Data & Genetic Privacy: Re-Identification of Anonymized Data


RECOMMENDED:


**Class 3: Big Data in Genetics/Genomics 2**

**ASSIGNED:**


Seife, Charles. “23andMe is terrifying, but not for the reasons the FDA thinks: the genetic-testing company’s real goal is to hoard your personal data.” *Scientific American* 27 (2013).


**RECOMMENDED:**


**Class 4: Big Data in Neuroscience**

**ASSIGNED:**

Case Study - *Big Data & Neuroscience: Brain-Wave Technology and Neuromarketing*


Class 5: Big Data in Conservation Biology

*ASSIGNED:*

Case Study - *Big Data & Conservation Biology: eBird and Citizen Science*


*RECOMMENDED:*


Class 6: Big Data in Public Health

*ASSIGNED:*

Case Study - *Big Data & PublicHealth: Predicting & Tracking Pandemics*


*RECOMMENDED:*


Class 7: Big Data & Codes of Ethics

*ASSIGNED:*