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Semester
Session, Dates
Day, Time
1 credit

Instructor
E-Mail
Phone
Office
Office Hours

Developed by Valerie Racine, Arizona
State University, Fall 2016

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.

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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%

	Percentage
A+	98-100%
A	93-97%
A-	90-92%

B+	87-89%
B	83-87%
B-	80-82%
C+	77-79%
C	70-76%
D	60-69%
E/F	0-59%

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.

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:

boyd, danah, and Kate Crawford. 2012. "Critical Questions for Big Data." *Information, Communication & Society* 15 (5):662-679.

Crawford, Kate, Mary L. Gray, and Kate Miltner. "Big Data Critiquing Big Data: Politics, Ethics, Epistemology| Special Section Introduction." *International Journal of Communication* 8 (2014): 1-11.

Steinmann, Michael, Julia Shuster, Jeff Collmann, Sorin Adam Matei, Rochelle E. Tractenberg, Kevin FitzGerald, Gregory J. Morgan, and Douglas Richardson. "Embedding Privacy and Ethical Values in Big Data Technology." In *Transparency in Social Media*, pp. 277-301. Springer International Publishing, 2015.

Zwitter, Andrej. "Big data ethics." *Big Data & Society* 1, no. 2 (2014): 1-6.

RECOMMENDED:

Nuffield Council on Bioethics - *The Collection, Linking and Use of Data in biomedical research and Healthcare: Ethical Issues* <http://nuffieldbioethics.org/project/biological-health-data/>

Web site: <http://bdes.datasociety.net>

Class 2: Big Data in Genetics/Genomics 1

ASSIGNED:

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

Mittelstadt, Brent Daniel, and Luciano Floridi. "The Ethics of Big Data: Current and Foreseeable Issues in Biomedical Contexts." *Science and engineering ethics* (2015): 1-39.

RECOMMENDED:

Gymrek, Melissa, Amy L. McGuire, David Golan, Eran Halperin, and Yaniv Erlich. "Identifying personal genomes by surname inference." *Science* 339, no. 6117 (2013): 321-324.

Rodriguez, Laura L., Lisa D. Brooks, Judith H. Greenberg, and Eric D. Green. "The complexities of genomic identifiability." *Science* 339, no. 6117 (2013): 275-276.

Lunshof, Jeantine E., Ruth Chadwick, Daniel B. Vorhaus, and George M. Church. "From genetic privacy to open consent." *Nature Reviews Genetics* 9, no. 5 (2008): 406-411.

Class 3: Big Data in Genetics/Genomics 2

ASSIGNED:

Allyse, Megan. "23 and Me, We, and You: direct-to-consumer genetics, intellectual property, and informed consent." *Trends in biotechnology* 31, no. 2 (2013): 68-69.

Saha, Krishanu, and J. Benjamin Hurlbut. "Research ethics: Treat donors as partners in biobank research." *Nature* 478, no. 7369 (2011): 312-313.

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).

<https://www.scientificamerican.com/article/23andme-is-terrifying-but-not-for-the-reasons-the-fda-thinks/> Accessed on December 12, 2016.

RECOMMENDED:

Alyass, Akram, Michelle Turcotte, and David Meyre. "From big data analysis to personalized medicine for all: challenges and opportunities." *BMC medical genomics* 8, no. 1 (2015): 33.

McGuire, Amy L., Timothy Caulfield, and Mildred K. Cho. "Research ethics and the challenge of whole-genome sequencing." *Nature Reviews Genetics* 9, no. 2 (2008): 152-156.

Robinson, Ann. "DNA-testing kit 23andme: patient powered healthcare or just confusing" *The Guardian*. January 12, 2016. <https://www.theguardian.com/sustainable-business/2016/jan/12/dna-testing-kit-23andme-patient-powered-healthcare-genetics>

Stoeklé, Henri-Corto, Marie-France Manzer-Bruneel, Guillaume Vogt, and Christian Hervé. "23andMe: a new two-sided data-banking market model." *BMC medical ethics* 17, no. 1 (2016): 1.

Schwartz, Peter H. "The value of information and the ethics of personal-genomic screening." *The American Journal of Bioethics* 9, no. 4 (2009): 26-27.

Wasson, Katherine. "Direct-to-consumer genomics and research ethics: should a more robust informed consent process be included?" *The American Journal of Bioethics* 9, no. 6-7 (2009): 56-58.

Class 4: Big Data in Neuroscience

ASSIGNED:

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

Choudhury, Suparna, Jennifer R. Fishman, Michelle L. McGowan, and Eric T. Juengst. "Big data, open science and the brain: lessons learned from genomics." *Frontiers in human neuroscience* 8 (2014): 239.

Illes, Judy, and Sofia Lomber. "Identifiable neuro ethics challenges to the banking of neuro data." *Minn. J. L. Sci. & Tech.* 10 (2008): 71-94.

Class 5: Big Data in Conservation Biology

ASSIGNED:

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

Bowser, Anne, Andrea Wiggins, Lea Shanley, Jennifer Preece, and Sandra Henderson. "Sharing data while protecting privacy in citizen science." *Interactions* 21, no. 1 (2014): 70-73.

Devictor, Vincent, and Bernadette Bensaude-Vincent. "From ecological records to big data: the invention of global biodiversity." *History and philosophy of the life sciences* 38, no. 4 (2016): 13.

RECOMMENDED:

Soranno, Patricia A., Kendra S. Cheruvilil, Kevin C. Elliott, and Georgina M. Montgomery. "It's good to share: why environmental scientists' ethics are out of date." *BioScience* 65, no. 1 (2015): 69-73.

Straka, Jason R., and Devin M. Turner. "What Those Who Seek Rare Birds Do For Ornithology." aba.org/birding. Accessed on October 27, 2016.

Class 6: Big Data in Public Health

ASSIGNED:

Case Study - *Big Data & Public Health: Predicting & Tracking Pandemics*

Vayena, Effy, Marcel Salathé, Lawrence C. Madoff, and John S. Brownstein. "Ethical challenges of big data in public health." *PLoS Comput Biol* 11, no. 2 (2015): e1003904.

RECOMMENDED:

Ives, Mike. "When Epidemics go Viral." *The Atlantic*. October 18, 2016.
<https://www.theatlantic.com/health/archive/2016/10/when-epidemics-go-viral/504503/>

Class 7: Big Data & Codes of Ethics

ASSIGNED:

Metcalf, Jacob. 2016. "Ethics Codes: History, Context, and Challenges." *Council for Big Data, Ethics, and Society*. Accessed November 29, 2016. <http://bdes.datasociety.net/council-output/ethics-codes-history-context-and-challenges/>