

Course Enhancement Grant: Living in the age of Personal Genomics -Your Privacy versus Personal or Societal Benefits (Case Study)

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Budget: \$500

Course affected: BIOL3450 Introductory Genetics (Sections 03/04, 60 students, writing enhanced, taught Fall and Spring)

Executive Summary:

This project will be to refine, execute and publish a case based lesson to facilitate student exploration of the world of personal genomics, personal genetic data and privacy. The goal is for students to be able to generate an informed opinion about the role of this data for the individual and for society and to engage the students in public communication/education surrounding these issues.

Project Narrative:

Some aspects of genetic data are protected under the current Genetic Information Nondiscrimination Act (GINA), while others exist in a gray area that is currently unregulated. In the last decade we have seen a proliferation of personal genomic services (e.g. 23&me, Ancestry, and others), as well as increased genetic testing within healthcare settings. Whole genome sequencing is now only a few hundred dollars, with an increasing number of providers offering the service to private individuals.

With the proliferation of these datasets, researchers have been able to conduct large genome wide association studies, speeding the discovery of new biomarkers for disease and disease susceptibility/resistance loci. Law enforcement have been able to use information in genealogy sites to track down elusive criminals, most famously the Golden State Killer. While these are arguably beneficial outcomes for society, the rights of the individual to control their data and to have it be private remain uncertain in this new landscape. Further, as the data is generated by private companies, whether this information is proprietary or exists in the public domain is unresolved. In the coming decade or two, real decisions will need to be made by the users of these services as well as lawmakers regarding accessibility and usage of these data sets.

This semester I piloted a research assignment to introduce students to these issues and help them to become informed citizens. This was broken up into two assignments. In the first assignment a set of common readings were assigned along with a reading comprehension short answer assignment to introduce the Genetic Information nondiscrimination act, the protections and limitations of protections associated with this legislation, and the view of the medical community regarding this legislation. In the second assignment students were asked to write a "data-driven opinion essay" related to one of four possible subtopics and writing prompts. I provided some starter resources and the writing prompts. Students were encouraged to engage with the provided sources as well as seek additional scholarly/professional resources to write

an evidence based succinct (<600 words) essay with citations to clearly take a position and defend it in response to the writing prompt. Current writing prompts are: 1) Anonymous data can be re-identified; 2) Federal policies on Genetic data collection at the borders; 3) Popular genomics...How do you control your data?; and 4) The impact of popular genomics on research and forensics...Who has the right?

Within the scope of the current project I would like to refine and expand on this lesson. Broadly my aims are to increase the ability of students to think critically and communicate effectively about science, to increase their ability to become lifelong learners, and to empower them to be ambassadors of science in the community.

To achieve these broad aims, the specific project goals are:

- 1) Refine the writing prompts and resource collection in reflection on this semester's essays.
- 2) Develop a technical writing instructional document to guide students through structuring the opinion paper. Student questions this semester indicated they were not prepared for this style of writing.
- 3) To facilitate increased student engagement I will implement a survey of which subtopic students will investigate and create "pods" of those students for a peer-review workshop. I will develop rubrics for the peer review/feedback session. Reviewing other's writing will improve the ability of students to recognize the components of and write an effective, evidence-based argument.
- 4) Develop a dissemination component in collaboration with the Academic Community Engagement office to help students educate peers/community/or policy makers on the issue. This may take a form of writing letters to policy makers regarding proposed legislation, or writing a letter to the editor for either the campus or local/regional newspapers, or an engagement via social media.
- 5) I want to write up the assignment for publication on CourseSource during Summer 2021. This case would be addressing content need under the CourseSource> Genetics>Genetics & Ethics>

Course Source, Subject: Genetics, Topic: Genetics and Ethics, Learning objectives addressed by this case:

- Compare the benefits and risks associated with the acquisition, ownership and storage of person genetic and genomic information.
- Contrast past and present views about how genetic information should be used by society, employers, and the government in support of public policies.
- Write about how obtaining personal genetic information could lead to negative consequences affecting others.

Budget justification: I am seeking salary support of \$500 for the preparation of the manuscript during Summer 2021.