

# **Evaluation of Change in Attitudes in Response to a Personal Genetic Information Exercise**

## **1. Project Abstract**

Genetic testing offers the possibility of tremendous benefits in medical risk assessment, diagnosis, treatment, basic biological research, and other areas. It also puts people at risk of harm. Knowledge of one's own genetic information may cause distress. When genetic information is not kept private, this exposes one to the risk of being harmed by third parties. Genetic testing therefore generates ethical, professional, and public policy problems. We intend to study how performing genetic self-tests and participating in classroom discussions on genetic testing impacts student attitudes on such issues. The project will be implemented simultaneously in Hallmarks core and Biology major courses in both the fall and spring.

## **2. The Project Advances Nexus Learning**

This project is essentially collaborative and interdisciplinary: it unites general education and the biology major, it deals with the intersection of ethics, biology, and pedagogy, and it allows a wide range of students enrolled in a humanities class the opportunity to do real lab work that they may otherwise lack. The ethical dimensions of the project are of pressing importance in our students' personal, professional, and civic lives. The prevalence and importance of genetic testing continues to grow, and students need to be equipped to form and defend coherent ethical stances on a range of related issues.

Studying the impact of genetic self-tests and related classroom discussions on student attitudes may provide us with valuable insight on how to:

- challenge students to reflect on transformative experiences
- do a better job equipping our students to meet these challenges
- develop future collaborative opportunities between general education and the majors-specific courses
- improve alignment of general education and majors learning outcomes

## **3. Project Goals and Project Learning Outcomes**

Goals:

- Identify the shared beliefs and preconceptions that students bring to our classes about genetic testing and its ethical, professional, and public policy implications.
- Improve students' ability to critically reflect on these problems and to articulate and defend a coherent view about the ethical and policy implications of genetic testing.

Outcomes:

- Measure how the experience of performing genetic self-tests and discussing genetic testing impacts those beliefs and preconceptions. This will be accomplished by collecting survey

data before and after the students perform the experiment and participate in the discussions.

- Evaluate how this classroom experience contributes to students' ability to reflectively evaluate and defend their ethical views on the topic of genetic testing. The investigators will assess student performance in discussion and the students will complete a short, reflective writing exercise on what they learned and how the experience influenced their ethical views.

#### **4. Activities and Time Frame**

The student exercise will consist of surveys and discussions conducted as part of normal class time and two sessions conducted in the common period for the experimental work. The timeline for completion is the entire 15FL-16SP academic year. Courses with the targeted student populations will be offered in the fall and spring. Sampling from all of these courses will contribute to statistical sample size expected of peer-review publication. The statistical analysis and evaluation of the results will be performed at the conclusion of the 16SP semester. Additional samples may be performed prior to publication in the subsequent academic year.

#### **Ethical Considerations of the Activities**

The investigators recognize the potential for harm that arises from knowledge of genetic information and the privacy concerns. The survey questionnaires are in the approval process of the IRB. Student participation in any or all activities will be voluntary. Those wishing to opt-out will be permitted to do so, free of inquiry from the course instructor or investigators, and with no negative impact on course standing. Personal information will be safeguarded from third parties by anonymizing the individual survey results and genetic information. Students will be assigned a random number and genetic information revealed only to the individual student upon request. The students' genetic information revealed during the activity will have no value for further analysis, thus it will be destroyed immediately after conclusion of the exercise.

Table of participating courses

Semester	Course	Curriculum placement	Expected Enrollment
15FL	BIOL 207 Genetics	Biology Major	15
15FL	ETHIC 200 Bioethics	Hallmarks Core	28
16SP	BIOL 207 Genetics	Biology Major	24
16SP	BIOL 207 Genetics	Biology Major	24
16SP	ETHIC 200 Bioethics	Hallmarks Core	28

The exercise is proposed to follow this schedule:

- Day 1 (in class): pre-experiment survey of attitudes using the questionnaire. Proposed questions are shown in appendix 1. The researchers will discuss the survey results with the students.
- Day 2 (common period meeting in Biology laboratory): experimental sampling of students guided by instructor and student workers. The experimental protocol is diagramed in Appendix 2 and the full kit manual from Carolina Biological Supply Inc. is provided in Appendix 3. Several sessions will be planned to accommodate participation in student clubs and other obligations (exam preparation, work, etc). This experimental protocol can be completed within a 50-minute block.
- Day 3 (common period meeting in Biology laboratory): continuation of experimental sampling of students. See Appendices 2 and 3 for protocol details. Several sessions will be planned to accommodate participation in student clubs and other obligations (exam preparation, work, etc). This experimental protocol can be completed within a 50-minute block with the assistance of a student worker.
- Day 4: (in class): response survey of attitudes using the questionnaire (see Appendix 1). The investigators will determine mean and standard deviations for the student responses. Statistical significance will be determined by using the T-test. These results will be made available to the class to stimulate discussion and reflection.
- Day 5: follow up survey of attitudes/personal reflection essay assignment (Hallmarks artifact) with classroom discussion of previous survey results.

## **5. Project Assessment**

Our preliminary assumptions are that students will enter these classes with a relatively low assessment of the risks of genetic testing, a limited awareness of the variety of harms posed by genetic testing, and a high level of confidence that merely making one's genetic information anonymous will protect one from harm. We also assume that these views will change significantly after the lab exercise and discussions. We will measure our results by collecting survey data and having students write a short reflective response to the experience addressing what they learned, how their views about potential harms changed, and whether their ethical views with regard to genetic testing changed.

We will assess our success by looking for a statistically significant change in student attitudes on the surveys. We will also examine the reflective writing exercises and look for evidence that they learned from the exercise and that they developed more critical and coherent ethical views as a result. If we do not see such results in the first semester we will experiment with variations in the classroom activities to hopefully generate stronger results.

In addition to those Nexus Learning goals, this exercise can be incorporated into the schedule of student exercises to evaluate learning outcomes in both the Hallmarks general education and Biology program curricula.

The learning outcomes for the Hallmarks ethical reflection category that can be satisfied with this exercise include:

Hallmarks Core Outcome	Learning outcome	Artifact essay reflection
<b>ETHICAL REFLECTION</b> Affirm an ethical compass to guide personal, civic and professional life	Recognize how the major world belief systems shape the values and behaviors of yourself and others	Student recognizes factors that shape privacy values and behaviors.
	Identify your own personal core beliefs and their origins	Student develops and defends their personal beliefs regarding privacy.
	Apply ethical reasoning appropriately to complex real-world situations	Student uses insight gained through reflection to evaluate privacy issues in medicine, employment, public policy, etc.
	Define your obligations and rights as a citizen in local, national and global communities	Student defines obligations and rights concerning privacy in local, national and global communities

The learning outcomes for the Biology major curriculum that can be assessed with this exercise include:

Biology Program Goal	Learning outcome	Measurable student competency
Explain information and observations using contemporary biological theories	Select and apply elementary and advanced biological principles to projects at multiple levels	Students will relate specific, measured, genetic information to differences in a trait
	Interpret and employ graphical and tabular presentations of data	Students will use the visual information presented at the conclusion of the experiment to determine the genetic information
	Prepare oral presentations based on laboratory work or literature review information	Students will prepare oral presentations to disseminate the experimental outcomes and relate the outcomes to genetic information

Perform effectively in the laboratory	Execute and perfect laboratory skills	Students will complete the experimental work
	Synthesize content and skills in planning a research project	Students will relate concepts with practices to achieve experimental success.
	Prepare comprehensive laboratory reports in manuscript format	Students will prepare lab reports documenting the experimental results
Access and critically review published biological literature	Identify, summarize and compare contrasting expert viewpoints on biological subjects	Students will compare differing viewpoints about genetic information privacy. Students will be challenged to compare the pre-experiment- and the response survey results.
	Integrate critical review of biological literature in support of a research project	Students will use library resources to locate and retrieve articles as preparation and follow-up analysis of the project

## **6. Documentation and Dissemination**

Preliminary results will be made available to the university community in the form of statistical analyses and summaries. These results can be used for assessment of general education and majors-specific program goals. These data will be available as material evidence used to assess the general education curriculum and the major curriculum. Additional documentation may be through publication in peer-reviewed pedagogical or professional journals.

Nexus learning will be advanced through two ways. It can be used for other faculty to design similar modules for both ethics and biology classes. The survey data will be available to other faculty to gauge student preconceptions and attitudes. The effects of an active learning/collaborative exercise on the students will indicate the degree of transformation. Future modules can be adjusted to meet the needs of the students. The general education-major integration of learning can be used to model subsequent proposals by other faculty. The reflective experiences submitted as Hallmarks artifacts for the students will indicate the extent of self-recognition of the changes in their attitudes. Again, future modules can be adjusted to meet the needs of the students.

## **7. Project Personnel**

- Ryan Long and Frank Wilkinson – Primary investigators
- Undergraduate Student worker - pre-lab set up, assist with the experimental part, cleanup
- Students in BIOL 207 Principles of Genetics and ETHIC 200 Bioethics courses

Frank Wilkinson will supervise the experimental section (days 2 and 3).

Ryan Long and Frank Wilkinson will develop the pre-experimental survey questionnaire, the response survey questionnaire, the follow-up survey questionnaire, and the reflective writing exercise. They will also guide in-class discussion of the ethical, professional, and public policy problems related to genetic testing.

Ryan Long and Frank Wilkinson will prepare the dissemination of the project to the university. If the outcomes are of sufficient quality, they will prepare the manuscript for publication in a peer-reviewed journal.

Students in BIOL 207 Principles of Genetics and ETHIC 200 Bioethics courses will be the participants on the genetic analysis exercise and the survey respondents.

## **8. Budget Narrative and Worksheet**

The budget includes requested funds for Principal Investigator (PI) stipends, a student worker to assist with the experimental protocol (8 hours expected in the fall semester, 8 hours expected in the spring semester) and 5 instructional kits (one kit is sufficient for 25 students) from Carolina Biological Supply (item 211377P, listed for \$215.00 ea.).

PI stipends are required because this project is in addition to our normal teaching and research loads. We will spend significant time integrating discussions, lab exercises, and other related activities across General Education and Biology courses. Since Bioethics is a new offering in Hallmarks, this is the perfect time to start this project. We will also do literature surveys on humanities-bioscience collaboration and on previous pedagogical work on genetic testing.

## **8. Attachments**

Appendix 1: Survey

Appendix 2: Bitter tasting ability flowchart

Appendix 3: Bitter tasting ability manual

Appendix 4: Ryan Long's final report from his 2013-2014 Nexus grant