Nexus Learning Grant Final Report
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Project Overview: What We Did

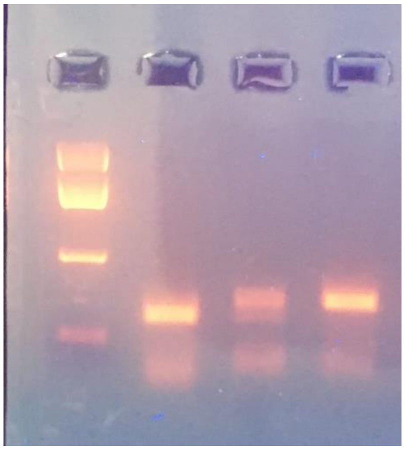
Summary:

1. Developed an exercise blending all aspects of Nexus Learning (active, collaborative, real world, liberal arts-infused)
2. Wrote and administered questionnaire to gauge student attitudes and preconceptions related to ethical questions surrounding genetic information privacy
3. Guided students through an experimental exercise to measure their individual genetic information
4. Optimized an in-house protocol making the exercise more cost effective

The Nexus grants enable development of new learning strategies for our students. Many students at the university have an interest in health-related careers. Genetic information is recognized as an important predictor for patient outcomes. Access to this information by numerous parties is considered to be essential for public health management. However, ethical dimensions of access to this information must be evaluated so that benefits to individuals and to society come to light with minimal harm done to members of the community. Thus, we sought to develop an exercise to engage students in ethical reasoning about this information. Further, we sought to determine if an exercise whereby students determine previously-unknown information about themselves would alter their attitudes toward privacy. The funded proposal was successful in this regard.

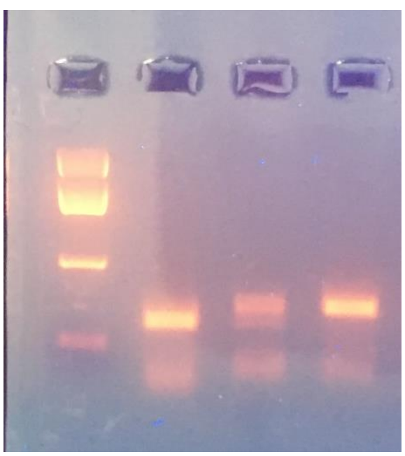
Ethical considerations regarding privacy of genetic information are numerous. An early effort of the project was to categorize realms of privacy concerns. In the spirit of the liberal-professional university, we broadly identified personal, professional, and societal concerns. Within each of these realms, we posed statements and asked students to respond to the extent that they agreed or disagreed. Student responses were anonymous and quantified using a Likert scale. (6: strongly agree; 5, agree; 4 mildly agree; 3, mildly disagree; 2, disagree; 1, strongly disagree). The mean responses for each question are discussed in the section below (see Project Assessment: What We Learned). Thus were have an early measure of our students' attitudes toward ethical consideration of genetic information privacy.

To underscore the mandate for ethical consideration of genetic privacy, we used a commercial experimental exercise that allows students to learn their own genetic information. This exercise can be used to illustrate how access to genetic information permits *predictions* about individuals. The experiment takes advantage of a genetic link between a particular gene for a taste receptor (TAS2R38) and the ability to taste a chemical reagent, phenylthiocarbamide (PTC). The PTC tasting ability is commonly measured in high school biology labs as an illustration of simple inheritance. People can be broadly categorized as those who can taste and those who cannot. Inheritance of a certain form of the TAS2R38 gene is associated with tasting ability. Since two forms of TAS2R38 can be distinguished (designated T and t), and each person has two copies of the gene, a total of 3 distinct genetic combinations are possible (i.e. a TT taster, a Tt taster, or a tt nontaster). Since it is known that at least one copy of the T form of TAS2R38 is necessary to confer tasting ability, then those individuals can be predicted to taste PTC (similarly tt individuals are predicted to be non-tasters). Even those students who have never attempted to taste the PTC can be predicted to have tasting ability or not by examination of their genotype at the end of the experiment. Thus the door is opened to challenge students to ask questions about how such information should be used.



TT | Tt | tt

The value of this exercise will be manifest by its continued implementation. Our plan is to continue to run the exercise for students in Bioethics and Principles of Genetics (currently 4-5 sections per year). To make the experiment more cost effective, we developed a protocol that can be used with individual reagents rather than the packaged reagents from the commercial supplier. Other changes to the experiment were found to improve the quality of the output (compare the panels below for clarity noting the improved resolution of the orange DNA “bands” for a TT and a Tt individual).



TT | Tt

Commercial kit visualization protocol

TT | Tt

In-house modified protocol

Project Assessment: What We Learned

Secondly, explain what the lessons learned were with regard to teaching and teaching methods within a "Project Assessment: What We Learned" section.

We learned much about our students, though not quite in the way we expected. The table below lists each of the questions and mean Likert score for all sections. Scores are shown for those PRE and POST exercise, values are mean ± standard deviation. A global analysis reveals that students largely "agreed" with the question though standard deviation values indicate that this ranged considerably between mild and strong agreement. There is also a high degree of semester-to-semester consistency.

The column of p values in the table show the likelihood of differences comparing PRE to POST responses of the same cohort (we were not interested in cohort-cohort variation). P values less than 0.05 were considered significant. For those responses with p less than 0.05, those shaded green indicate that the Likert response increased (more agree) and those shaded in red indicate Likert response decreased (more disagree). It can be observed that most questions did not show statistically significant changes in response to the exercise.

"Personal" question set.

Question	15FL PRE	15FL POST	p	16SP PRE	16FL POST	p
1A. Determination of a person's genetic information has become routine laboratory procedure.	4.4±1.1	4.6±1.0	0.128	4.3±1.0	4.5±0.8	0.175
1B. Genetic information can be determined in just a few hours in many laboratories.	4.0±1.2	4.6±1.0	0.011	4.4±0.9	4.6±1.0	0.122
1C. A hospital has the necessary tools to get genetic information of a patient.	4.9±0.9	4.7±1.0	0.203	4.8±0.8	4.9±0.9	0.331
2A. Genetic information can be used to a person's benefit (diagnosis, heritage, etc.)	5.5±0.7	5.5±0.7	0.317	5.5±0.5	5.2±0.7	0.006
2B. Making genetic information publically available will benefit people if it remains anonymous.	4.1±1.4	4.5±1.1	0.066	4.2±1.1	4.2±1.1	0.487
2C. If pharmaceutical companies can study genetic diversity in the human population, they can develop better medicines.	4.9±1.1	5.1±0.9	0.264	4.9±0.7	5.1±0.8	0.154
3A. A person can be harmed by knowledge of their own genetic information.	4.1±1.2	3.8±1.3	0.227	4.0±1.1	4.5±1.0	0.027
3B. A person's quality of life can be lowered by knowledge of their genetic information.	4.0±1.4	3.8±1.3	0.315	3.8±1.2	4.4±1.2	0.005
3C. Knowledge of your genetic information always has a medical benefit.	4.1±1.2	4.3±1.2	0.309	4.2±1.0	4.2±0.9	0.455
3D. A third party can use knowledge of your genetic information against you.	4.1±1.2	4.2±1.3	0.363	4.2±1.3	4.3±1.1	0.435
4A. Release of genetic information to an	4.7±1.1	4.9±0.9	0.155	4.9±0.9	4.8±0.8	0.425

unsecure location can cause harm to a person.						
4B. Release of your anonymized genetic information cannot harm you.	3.3±1.3	3.2±1.3	0.460	3.5±1.1	3.6±1.0	0.451
4C. A database of genetic information that is anonymous is sufficient to ensure confidentiality.	3.8±1.2	4.0±1.0	0.193	3.9±1.2	4.0±1.0	0.209
4D. Anonymized genetic information will protect those who provide the information to the database.	4.1±1.1	4.3±1.0	0.193	4.0±1.2	4.1±0.9	0.274
5A. People should have access to their genetic information meaning it should not be withheld from them.	5.2±0.8	5.1±1.0	0.315	5.3±0.5	5.2±0.8	0.386
5B. People have a right to access their personal genetic information.	5.6±0.6	5.3±1.0	0.025	5.5±0.6	5.4±0.8	0.209
5C. It is always in one's interest to have more personal genetic information.	4.1±1.3	4.3±1.4	0.268	4.0±1.1	4.0±1.0	0.386

"Professional" question set.

Question	15FL PRE	15FL POST	p	16SP PRE	16FL POST	P
1. My profession can gain access to genetic information as part of routine practice.	4.3±1.6	4.6±1.2	0.133	4.1±1.1	4.4±1.0	0.118
2. My profession can use genetic information to the benefit of a person.	4.2±1.0	4.3±0.9	0.293	4.8±0.9	4.8±0.9	0.427
3. My profession has policies and procedures to maintain genetic confidentiality.	4.3±0.9	4.0±0.9	0.089	4.7±0.9	4.6±1.1	0.293
4. It is possible for people in my profession to misuse a person's genetic information.	4.0±1.0	3.6±1.0	0.073	4.0±1.3	4.5±1.1	0.047
5. The benefits of my profession's access to genetic information are greater that the harm it could cause.	3.9±0.8	3.8±1.0	0.270	4.6±1.0	4.5±1.1	0.289

"Societal" question set.

Question	15FL PRE	15FL POST	p	16SP PRE	16FL POST	P
1. Our society should maintain confidentiality of genetic information.	5.2±1.0	4.9±1.2	0.103	5.0±0.9	4.9±1.0	0.407
2. The government has established legal codes to maintain confidentiality of genetic information.	4.2±1.2	4.2±0.8	0.463	4.2±0.8	4.6±0.8	0.007
3. The benefits of using anonymized genetic information outweigh the risks.	4.2±1.0	4.6±1.0	0.046	4.5±1.0	4.4±0.9	0.410

4. An individual should not be able to withhold access to their genetic information from the medical and/or research communities.	2.9±1.4	3.6±1.6	0.016	3.2±1.4	3.3±1.5	0.412
5. A person who provides genetic information for the benefit of society should be individually compensated.	3.7±1.5	4.1±1.4	0.144	4.0±1.0	4.1±0.9	0.419

The level of statistical significance between PRE and POST survey responses was not as predicted. Our expectation was that we would see larger, statistically-verified shifts in attitudes. We have considered that this outcome may reflect the population uniformity of our sample. Most students in the sessions were in health-focused programs. Given that these students may have gained background knowledge of the techniques and/or issues, the "disruptive" dimension of the exercise may have been attenuated. So, as one exercise within a 4-5 year educational context, the modest shifts observed here may just reflect sustained, incremental, learning by the students. Alternatively, we considered that our methods may not be evaluating the attitudes and preconceptions as we have hoped. Both principle investigators have little prior experience in designing questionnaires. We have adjustments planned and are willing to consider strategies and additional suggestions from the university community.

Planning for future iterations.

Student population. We will seek additional, non-health focused populations of students to participate as volunteers in the exercise. This approach will provide an "outgroup" representing the population that will experience the exercise as a "disruptive" and show statistically-significant changes in attitudes in the PRE/POST survey. We can approach this population by drawing on students from K-DEC and CABE programs.

Document individual learning. We would like to document evidence of individual learning. This effort can be integrated with Hallmarks learning goals (such as ethical reflection) assigned to ETHIC-200-Bioethics and BIOL-207-Principles of Genetics. Students can prepare a short reflective essay about one of the questions and reveal how their experience with class discussion and/or the experiment caused them to reevaluate their position.

Document class-based discussion. The exercise sections included lively class discussions about newsworthy topics related to genetic information privacy. Notable topics included FDA intervention to halt a genetic information screening activity implemented by the University of California and an artist who recovers DNA from discarded items then uses the genetic information to compose a sculpture of the persons features. No record exists of student attitudes and opinions about these uses of genetic information. We may also include discussions of DNA collection and use by the criminal justice system and biobanks. Documentation of these discussions can be used programmatically to demonstrate individual learning and to gauge changes in attitudes on a larger scale over time.

Guide students to debate these issues. As a more focused discussion, students can be tasked to debate a particular issue in more depth. In 2015-16, the most sustained discussion usually occurred after the lab and POST survey. We plan to integrate the discussion into specific points of the lab exercise to provide more structure and to have the POST survey give a more holistic picture of the impact of the whole activity rather than mostly measuring the impact of the lab exercise.

Discussion and debate as transformative experiences. We want to use the discussion and debate segments as a driver for student to reflect on their own positions. We intent to implement the POST survey following the class discussion and debate segments. If reflection leads to more transformative experiences for the students, we may observe larger, more statistically significant, shifts in attitudes as measured by the responses.

Increase sophistication of statistical analysis. We will use a new survey system that can track individuals throughout the exercise so we can then perform a paired t-test.

Deliverables and Dissemination: Getting the Word Out

Presentation to the university community (February 17, 2016 and Fall 2016 Knowledge Exchange)

Poster presentations at College of Science, Health, and Liberal Arts Research Expo (April 2016)

Manuscript to be prepared and submitted to peer-reviewed pedagogy journal pending additional data and statistical analysis