Direct-to-Consumer Genetic Testing in the College Classroom: Knowledge, Attitudes, and Concerns of Introductory Biology Students

Nicanor Pier Giorgio Austriaco, O.P.[*]

Department of Biology
Providence College
1 Cunningham Square
Providence, Rhode Island 02918, U.S.A.

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[*] Corresponding Author: Rev. Nicanor Pier Giorgio Austriaco, O.P., Ph.D., Department of Biology, Providence College, Providence, RI 02918, U.S.A. Telephone: 401-865-1823; Fax: 401-865-2959; E-mail: naustria@providence.edu.

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ABSTRACT

Pioneered by companies like 23andMe.com, deCODEme.com, and Navigenics.com, direct-to-consumer genetic testing refers to genetic tests that are marketed directly to consumers via television, print media, or the Internet. This kind of testing provides access to a customer's genetic information without necessarily involving either a medical health care professional or a genetic counselor in the process. In recent years, a course offered to medical and graduate students at Stanford University has included an option for students to undergo personal genotyping, raising the possibility that direct-to-consumer genetic testing could also be incorporated into undergraduate biology courses to enhance student learning. In this study, I assess the attitudes and concerns of college students enrolled in the first semester of an introductory majors course in biology, before and after they had completed the course, regarding the availability of this technology and its possible use in the college classroom. The pre-course survey revealed that these students were open to the possibility of using this technology in their courses, but that they had concerns about the confidentiality and the accuracy of their genetic results. Strikingly, however, completing the genetics, molecular and cellular biology semester-long portion of the yearlong introductory sequence in biology appeared to boost student confidence in this technology and its use in the undergraduate classroom.

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INTRODUCTION

Pioneered by companies like 23andMe.com, deCODEme.com, and Navigenics.com, direct-to-consumer genetic testing refers to genetic tests that are marketed directly to consumers via television, print media, or the Internet (Borry, Cornel, & Howard, 2010; Offit, 2008; Singleton, Erby, Foisie, & Kaphingst, 2012). Significantly, most of the personal genome testing companies screen for risks associated with serious diseases such as heart disease, cancer, and diabetes. This kind of testing provides access to a customer's genetic information without necessarily involving either a medical health care professional or a genetic counselor in the process. Customers are asked to mail either a saliva sample or a cheek scraping to the company for DNA analysis. Several weeks later, personal genomic results are made available – usually anonymously – to the customer via an Internet account. Based on whole genome scans that screen for single nucleotide polymorphisms (SNPs) that have been correlated with either an increased or a decreased risk for a specific disease or trait within the general population, these results are usually reported to the customer as one's lifetime risk for a particular medical condition or disease.

The advent of this technology has generated much debate both in the academy and in the public square (Bloss, Darst, Topol, & Schork, 2011; Callier, 2012; Hogarth, Javitt, & Melzer, 2008; Mangin, Hudson, & Toop, 2012; Singleton et al., 2012; Valles, 2012). Three categories of concerns are often raised. First, and most important, some commentators are concerned about the clinical validity and reliability of genetic tests that are marketed directly to consumers (Burke & Evans, 2011; Hunter, Khoury, & Drazen, 2008; Kuehn, 2010; Wallace, 2008). Disturbingly, a systematic review of the evidence supporting the association between a particular gene and a particular disease from seven direct-to-consumer genetic testing companies revealed that only 38% of those reviewed in meta-analyses (57% of the total genetic associations) were found to be statistically significant (Janssens et al., 2008). Moreover, the findings of a United States Government Accountability Office (GAO) investigation revealed that the results for identical DNA samples from four prominent direct-to-consumer personal genomics companies were inconsistent and in some cases, conflicted with the medical status or family history of the individual who had supplied the DNA (Kuehn, 2010). As such, there have been calls to regulate genetic testing to ensure a minimum level of efficacy and of safety (Caulfield, 2011; Hogarth et al., 2008; Kaye, 2008; McGuire, Evans, Caulfield, & Burke, 2010; Valles, 2012; Wright & Gregory-Jones, 2010; Wright, Hall, & Zimmern, 2011).

Next, other commentators are worried that without proper explanation and counseling, lay consumers will misunderstand their test results and experience unnecessary anxiety (Gollust, Wilfond, & Hull, 2003; Ransohoff & Khoury, 2010). They will not realize that most of the genetic risk factors uncovered by personal genome testing are not deterministic but are only probabilistic in nature, because most human diseases are complex traits whose genesis is influenced not only by numerous genes but also by the environment. While there are companies that hire in-house genetic counselors to speak to their customers about the results of their genome scan, a majority of websites send their customers back to their personal physician for a medical consultation. However, many of these primary care physicians may have neither the expertise nor the time to accurately interpret personalized genomics test results (Baars, Henneman, & Ten Kate, 2005; Caulfield & Wertz, 2001; Greendale & Pyeritz, 2001; McGuire & Burke, 2008).

Finally, some commentators have argued that the proliferation of direct-to-consumer genetic testing will unnecessarily increase the cost of healthcare with little actual health gain (Caulfield, 2009; McGuire & Burke, 2008). Armed with genetic test results of questionable clinical value, consumers would seek further medical consultation and unnecessary care that would only overburden an already overtaxed health care system (Deyo, 2002). Significantly, it is striking that there is little evidence to suggest that genetic risk information would motivate consumers to alter their unhealthy behaviors, even in the face of health information that tells them that change is a good idea (Bloss, Schork, & Topol, 2011; Hall & Gartner, 2009; McBride, Koehly, Sanderson, & Kaphingst, 2010). Indeed, Caulfield has even suggested that personalized genome testing may provide individuals with either a justification for fatalistic inaction or a false sense of security because of the presence of a "protective" gene (Caulfield, 2009). If so, personalized genomic tests could, counter intuitively, lead to less healthy behavior among consumers.

Despite these concerns, however, both Stanford University and Tufts University have considered incorporating personalized genetics testing into their medical school curriculum (Ormond et al., 2011; Walt et al., 2011). Stanford has actually begun offering a course that has included an option for enrolled medical and graduate students to undergo personal genotyping (Ipaktchian, 2010). Tufts piloted a learning module in their medical curriculum that used data from anonymous gene profiles rather than from students’ personal gene profiles to introduce students to personalized genomic medicine (Walt et al., 2011). Beth Israel Deaconess Hospital in Boston has also established a first-in-the-nation resident curriculum in genomic and personalized medicine (Haspel et al., 2010), and Temple University and the Ohio State University have incorporated genetic testing into their graduate pharmacy curriculums (Knoell, Johnston, Bao, & Kelley, 2009; Krynetskiy & Lee Calligaro, 2009).

These pedagogical innovations raise the possibility that personalized genetic testing could be incorporated into undergraduate biology courses to enhance student learning. However, before this can be done, the pros and cons of such a curricular novelty would have to be considered by faculty and administrators with broad multidisciplinary representation. To date, there are no published studies examining the views of college students toward personalized genetic testing and the possible use of this technology in the college classroom. This data will be important for any informed discussion involving the use of direct-to-consumer genetic testing in the undergraduate biology classroom.

In this study, I assess the knowledge, attitudes, and concerns of college students enrolled in the first semester of an introductory majors course in biology, before and after they had completed the course, regarding the availability of this technology and its possible use in the college classroom. This protocol allowed me to determine the impact, if any, of completing an introductory course in genetics and molecular and cellular biology on the students' survey responses. The pre-course survey revealed that these students were open to the possibility of using this technology in their courses, but they had concerns about the confidentiality and the accuracy of their genetic results. Strikingly, however, completing the genetics, molecular and cellular biology semester-long portion of the yearlong introductory sequence in biology appeared to boost student confidence in this technology and its use in the undergraduate classroom.

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MATERIALS AND METHODS

Participants

Students registered to take BIO103: General Biology I, in the fall semester of the 2011-2012 academic year at Providence College were recruited to participate in this study. This course is the first semester component of a yearlong introductory majors sequence in biology that is required for all students majoring either in biology or in biochemistry. It introduces students to the fundamental principles of genetics and molecular and cellular biology.

At the beginning of this study, during the summer preceding the start of the course, 183 students were signed up to enroll in the class. One hundred and eighteen students completed the pre-course survey during the summer preceding the first day of classes (64.5% response rate), and ninety-five completed the post-course survey in January after they had completed the final exam and received the final grades for the class (52% response rate). To maintain anonymity, no demographic information was collected from the survey respondents. However, aggregate demographic information for all the students registered for the course (*N*=183), most of whom were freshmen (79%), is as follows: Mean age, 18.2 years (range, 17-21 years); 28% male; and 17% from underrepresented minority groups (student-reported ethnic self-descriptions as African-American, Asian, Hispanic, or Puerto Rican). Academic major distributions were as follows: 55% biology, 8.2% chemistry or biochemistry, 7.7% psychology, 10% other, and 19% undeclared. Participation in this study was completely anonymous and voluntary and was not linked in any way to a student's completion of, or final grade in, the course.

Survey Instrument

The survey used in this study was constructed to assess the knowledge, attitudes, and concerns of introductory college students regarding direct-to-consumer genetic testing and its possible use in the college biology classroom. It was modeled after the questionnaire developed by Ormond et al., who had used their survey instrument to assess the attitudes of medical students at Stanford University regarding direct-to-consumer genetic testing and its possible incorporation into a medical school curriculum (Ormond et al., 2011). The Stanford survey itself was based on the instrument designed by McGuire et al. to explore the interests and attitudes of social networkers on Facebook towards personal genome testing (McGuire, Diaz, Wang, & Hilsenbeck, 2009). Modeling the survey instrument used for this study on these previously published questionnaires will allow the results of this study to be compared to the findings obtained with its predecessors that have been used to assess the attitudes and concerns of medical students (Ormond et al., 2011) and of Facebook social networkers regarding personal genome testing (McGuire et al., 2009).

Composed of 45 Likert-scale and multiple-choice questions, the survey was divided into three parts. Part I assessed the respondent's general views toward personal genotyping in general; Part II determined the respondent's views toward commercially available direct-to-consumer testing more specifically; and Part III queried the student's attitudes and concerns surrounding the possible use of direct-to-consumer genetic testing in the college biology classroom. The majority of the closed-ended questions were answered on a five-point Likert scale (e.g. strongly

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agree, agree, neutral, disagree, strongly disagree) or with multiple-choice answers where respondents could check all the choices that applied. A significant portion of the questions were taken from Ormond et al. (2011), with modifications in language to help the undergraduate respondents better understand the scientific jargon that had been used in the Stanford survey instrument. For example, the term "genome wide association studies" was explained and replaced with the simpler "genetic studies" that are more commonly found in high school biology textbooks.

The survey was distributed through SurveyMonkey.com, a commercial online site for survey administration and data collection. An initial pre-course email containing the survey link was sent out to all the students enrolled in the course in early July, prior to the beginning of the course in September, with follow up reminder emails sent out once a week for a three-week period. Each survey took between 10-20 minutes to complete. To assess the impact, if any, of completing the introductory semester in genetics, and molecular and cellular biology, a follow-up post-course email containing the survey link was sent out to all students in January, with follow up reminder emails sent out once a week for a three-week period.

The Institutional Review Board of Providence College (Federal Assurance No. FWA00014558) approved this study. The survey instrument was prefaced with a short description of the research project to fulfill the requirements of informed consent. It included a statement that described the purpose of the survey, the expected length of the survey participant’s participation, and a description of the survey, including expected benefits from the research project. It explained that completion of the survey was completely voluntary, that it would not result in compensation, or in the advent of non-participation, would not result in penalty, and that it would remain completely anonymous. It also reassured survey participants that the principal investigator, an instructor for one of the sections of the course, would not know either the identities of the survey participants or the names of the students who had not completed the survey.

Data Analysis

To ensure the anonymity of the respondents, responses were not paired. Therefore, pre-course and post-course paired data analysis was not possible. Instead data for each of the Likert-style questions was compared between the pre-course and post-course surveys using the Chi-squared test to discern changes in the beliefs, attitudes, and knowledge about direct-to-consumer genetic testing in the college classroom. Differences were deemed statistically significant at a threshold level of $p<0.05$.

RESULTS

Knowledge, Attitudes, and Concerns Regarding Personalized Genomics

Table 1 summarizes the survey responses that highlight the knowledge, attitudes, and concerns of the participating introductory biology students regarding personalized genomics. A significant majority of respondents knew that human genes had been linked to complex physical and health related traits (91% knew this) and to complex behavioral traits (58% knew this). A majority of the respondents also thought that this information would be helpful for both themselves and their physicians. Of note, a substantial number of the respondents (89%) thought that knowledge of their personalized genome and how it is associated with different health related traits would be indispensable or very useful information for their physicians to have. A small majority of just over 50% admitted that knowing something about their own genetic makeup would actually prompt them to change their behavior.

Knowledge, Attitudes, and Concerns Regarding Direct to Consumer Genetic Testing

Table 1 also includes the survey responses that highlight the knowledge, attitudes, and concerns of the participating students regarding direct-to-consumer genetic testing. As summarized in the introduction, commentators have raised concerns regarding the popularization and spread of direct to consumer genetic testing services that can be put into three broad categories: the ineffectiveness of these tests, the inability of consumers to understand their results, and the unnecessary burden these tests would place on our health care system.

With regards to the efficacy of these personalized tests, a majority (56% Neutral) of the undergraduate respondents who responded to the survey were not sure if the test results that they would receive from a direct-to-consumer testing service would be accurate and reliable. Moreover, not many (29% Strongly agree or agree) thought that the information could be used to diagnose a medical condition or disease. However, a majority (66%) still thought that the tests would be useful for consumers. This is comparable to the number (67%) who thought that the tests would be useful for themselves.

With regards to the ability of consumers to interpret their results accurately, a large number (66% strongly disagree or disagree) did not think that they knew enough to understand the results they would receive from a personal genome testing service. An even larger number (84% strongly disagree or disagree) thought that consumers in general would not be able to interpret their own personalized genomics results. Thus, it is not surprising, that nearly all (96% strongly agree or agree) intend to ask a physician to help them interpret the results of their personal genome test, and a similar number (92% strongly agree or agree) wanted personal genome companies to have a medical expert to help them to interpret their results. These attitudes were echoed in the number of respondents (73% strongly agree or agree) who believe that physicians have a professional responsibility to help consumers to interpret their test results even if the physicians had not ordered the testing themselves. Strikingly, however, only a minority (46% strongly agree or agree) thought that their physicians would have the prerequisite knowledge to help them interpret their results. Nonetheless, nearly half (49% strongly agree or agree)

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believed that they themselves knew of the risks and benefits of personalized genetic testing. A near majority (47% Strongly agree or agree) thought that the federal government should regulate personal genome companies.

Finally, with regards to the concern that personalized genomics testing would place an unnecessary burden on the health care system, it is noteworthy that a significant majority of the survey respondents (96% Strongly agree or agree) reported that they would seek out additional help from a physician – most likely their primary care physician – to help them interpret their results.

Reasons Given For or Against Taking a Direct to Consumer Personalized Genomics Test

Significantly, a large number of the college student respondents (71%) were unaware that direct-to-consumer personalized genetic tests were already available to the public. A small majority of them (53%) would not use such a personal genomics test for themselves, though a larger majority (66%) thought that such a test would be helpful for consumers in general.

Table 2 lists the reasons given by the study participants for or against their using a direct to consumer genetic testing service. Of the 47% of the students who thought that they would take a personal genomics test, significant majorities of them would take the test either to satisfy their general curiosity regarding their genetic make up (82%) or to determine if a specific disease runs in their family (87%). A majority (56%) would also want to take the personalized genomics test to learn about the basics of human genetics. It is striking that a significant number of respondents (85%) thought that consumers in general would take the test to obtain

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a family member's risk for a particular disease, though a smaller number (49%) would themselves take the test for that reason.

In contrast, for those students who would not take a personalized genomics test, the two most popular reasons given for their choice are that the results are not reliable (46%) and that the results may reveal unwanted information (43%). Respondents who did not think that personal genomic testing would be helpful for consumers explained their reasoning by affirming that doctors should be involved in ordering and interpreting results (78%) and that individual consumers would be unable to interpret their test results accurately (78%).

What about cost? A not insignificant number of the respondents (41%) who would not take a personalized genomics test raised the issue of the test costing too much, though fewer (22%) believed that this would be a burden on the average consumer. Finally, when the survey respondents were asked how much money they would be willing to pay for a personalized genomics test, nearly half (48%; N=56/116) would pay up to USD100.00 for the service. Nearly 70% (N=81/116) would pay USD25.00, while only 15% (N=17/116) would pay USD200.00 for the test. As for the remainder of the survey results, 6% (N=7/116) and 1.7% (N=2/116) were willing to pay up to USD400.00 and USD1000.00 respectively for a personal genomic test.

Knowledge, Attitudes, and Concerns Regarding Direct to Consumer Genetic Testing in the College Classroom

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Table 3 summarizes the survey responses that highlight the knowledge, attitudes, and concerns of the participating students regarding the use of personalized genomics in the college classroom. Significantly, a majority of students who responded to the survey (52% Strongly agree or agree) believed that they did not know enough about personal genetic testing to make a decision one way or another regarding their participation in an in-class personal genetics testing opportunity. Strikingly, the respondents were evenly divided (45% Strongly agree or agree; 42% Strongly disagree or disagree) about consulting their parents about their decision to participate in an in-class personalized genomics testing service. Again, the group was evenly divided (34% Strongly agree or agree; 30% Neutral, 36% Strongly disagree or disagree) about consenting to take the in-class personalized genomics test only if their parents agreed to their participation.

Despite their concern that they may get genetic results that may be disturbing for themselves (55% Strongly agree or agree), a near majority of the students (47% Neutral) were ambivalent about the need for a genetic counselor to help them decide if they should participate in the in-class testing *before* actually taking the test. However, a sizeable number (40% Strongly agree or agree) thought that they would want genetic counseling *after* receiving the results of the test in order to consent to the test.

With regards to the logistics of using personalized genetic tests in the college classroom, a majority (62% Strongly agree or agree) believed that having their own genetic test results would be better than having someone else's genetic results. At the same time, the respondents were evenly divided (42% Strongly agree or agree;

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32% Strongly disagree or disagree) when they were asked if they would feel at a disadvantage compared to their classmates if they themselves did not undergo the genetic testing themselves.

With regards to their reasons for their taking the genetic test as part of a college biology course, a significant majority of the respondents (72% Strongly agree or agree) would see this as an opportunity to get a service for less than its original price, and a majority would also see this as opportunities to get information about their own health (65% Strongly agree or agree) or a family member's health (67% Strongly agree or agree).

Of note, in response to questions dealing with possible concerns regarding direct to consumer testing in the college classroom, a majority of students (55% Strongly agree or agree) were concerned that they may get genetic results that may be disturbing for themselves or for their families. However, slightly less were concerned that their professors would know who or who did not take up the offer for testing (48% Strongly agree or agree) or that their classmates would know if they did or did not take up the test as well (51% Strongly agree or agree). Only a small number (19% Strongly agree or agree) were concerned that other persons would find out genetic or health information about them. Of this small number, for the most common responses, students were concerned that health insurance companies (15%; N=3/20), professors, classmates or friends (45%; N=9/20), scientists (10%; N=2/20), or the government (5%; N=1/20) would find out about their personalized genome-related information.

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Finally, a significant majority (64% Strongly agree or agree) would permit a personal genome testing company to include their de-identified sample in scientific research though most of them (82% NO) would not want to be involved in social networks built on personal genomic information.

Impact of an Introductory Majors Course in Biology on Knowledge, Attitudes, and Concerns Regarding Personalized Genomic Testing

To determine the impact of the first semester of a yearlong introductory majors course that covered the basic topics in genetics, molecular, and cellular biology, on the students' attitudes towards personalized genetic testing and the possible use of this technology in the college classroom, the survey instrument was re-administered to students after the completion of the course. Significantly, I should stress that the course did not specifically discuss either personalized genetic testing as a technological innovation or its strengths or weaknesses as a diagnostic tool.

Not surprisingly, the post-course survey revealed that the students thought that they knew more about human genetics to understand the results of a personal genome test (p=0.001 as compared to the pre-course survey). They also were more aware of the existence of commercial genetic testing services for the ordinary consumer (p<0.001). Next, the respondents thought that after the course, they better understood the risks and benefits of using personal genomic testing (p=0.027). However, they were also more likely to ask a physician for help in interpreting the results of a personal genome test (p<0.001), probably because they were more likely to think that physicians are knowledgeable to help individuals interpret results of personal genome tests (p=0.016). The survey respondents were also less likely to think that personal genome companies should be regulated by the federal government (p=0.001).

More strikingly, however, the survey responses also suggest that the students' participation in the course boosted their confidence in personalized genomics testing. As summarized in Table 1, the post-course survey revealed that students thought that personalized genetic testing is more useful for consumers (p=0.002), that the results of this testing is more likely to change their behavior (p=0.019), that especially information regarding behavioral genetics is more useful both for patients (p=0.019) and for physicians (p=0.005), and that the results of personal genomic testing would influence their future healthcare decisions (p=0.03).

Though the post-course survey revealed that there was no significant increase in the percentage of respondents who would avail themselves of personal genomic testing services, the students still thought that these tests were more accurate and reliable (p<0.001), and that they were more likely to be diagnostic of medical conditions or diseases (p<0.001).

With regards to the use of personalized genomics testing in the college classroom, the post-course survey revealed that the respondents were less likely to think that their own genetic results mattered more than the genetic results of someone else (p<0.018). However, they were more concerned both that they would receive disturbing genetic results for themselves and for their families (p<0.001), and that other people would discover genetic or health information about them (p<0.001). Not surprisingly, therefore, the post-course respondents were more likely to take up the offer of genetic counseling before availing themselves of genetic testing services (p<0.001).

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DISCUSSION

Simple genetic experiments that involve student testing of their own DNA have already been included in the undergraduate curriculum to enhance learning in the genetics classroom. For instance, Carolina Biological Supply Company sells a kit that allows students to use PCR on their own DNA to predict their bitter tasting ability (Catalog Item #211376). These laboratory exercises -- which highlight the pedagogical first principle that the best way for students of all ages to learn science is for them to actually do hands-on experiments (Cartier & Stewart, 2000; Dalton, Morocco, Tivnan, & Mead, 1997) -- have sometimes raised some ethical concerns but are not usually considered problematic (Rogers & Taylor, 2011; Taylor & Rogers, 2011). Incorporating direct-to-consumer genetic testing into the college classroom will not be as straightforward.

What are the ethical concerns raised by use of this technology in the undergraduate curriculum? When the University of California at Berkeley decided to ask its approximately 5,500 incoming freshman and transfer students to submit a DNA sample for personalized genetic testing as part of its annual new-student orientation program in 2010, the proposal generated a heated debate surrounding three ethical issues: obtaining informed consent without coercion, protecting student privacy, and preparing students to properly interpret the results of their genetic tests (Jabr, 2011). Similar concerns could also be levied against proposals to incorporate direct-to-consumer genetic testing in the college classroom.

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Concerns Surrounding Informed Consent

First, commentators were concerned that the incoming UC Berkeley students could not give proper informed consent because they lacked the knowledge that they would need to adequately assess the benefits and burdens associated with direct-to-consumer genetic testing (Sanders, 2010). Significantly, the organizers of the UC Berkeley orientation program asked their students to attend a lecture that would help them understand genetic testing *after* and not before they had consented to taking the genetic test. Moreover, the consent form given to the students listed the benefits, but not any of the risks, of genetic testing.

It is clear that the introductory biology students who participated in my study had limited knowledge about direct-to-consumer genetic testing. A large number of the college student respondents (71%) were unaware that direct-to-consumer personalized genetic tests were already available to the public. This is not surprising since surveys of the general public have revealed that a majority of respondents were similarly not aware of this technology. (Goddard et al., 2007; Goddard et al., 2009; Kolor, Liu, St Pierre, & Khoury, 2009). To address this lacuna, a proposal to incorporate direct-to-consumer genetic testing in the undergraduate classroom will have to include ways to introduce prospective student participants to this technology prior to their giving or withholding of consent. This information needs to be provided not only to students but also to their parents -- it is striking that a not insignificant number of students (34%) acknowledged that they would seek out parental guidance and permission before deciding to participate in an in-class genetic test -- either the semester before or during the summer prior to the beginning of the course. It should include descriptions of the benefits, the risks, and the inherent technical limitations associated with personalized genetic testing.

Next, commentators were also worried that the incoming students at UC Berkeley could have experienced some coercion when they were asked to participate in the direct-to-consumer orientation activity. This would have impaired their ability to give consent freely. The coercion could have been experienced in at least three ways. First, the new students could have experienced pressure to participate in the genetic testing program because they were aware that their participation would impress or influence their professors (Duster, 2010). Next, the freshmen could have experienced peer pressure to participate because they may not have wanted to be left out of any of their orientation activities (Jabr, 2011). Finally, the opportunity to take a test that normally involves significant costs without payment -- the genetic tests were made available at no cost to the Berkeley students -- could have unduly pressured students to take the test despite concerns about their participation.

The results of my survey revealed that about half of the undergraduate study participants who responded to the questionnaire were not concerned about whether or not their professors (48% Strongly agree or agree) or their peers (51% Strongly agree or agree) would know about their involvement in the genetic testing. Despite this, it is clear that the remainder of the potential participants would still be worried to some degree that their professors and their peers would know if they chose to participate or to forego the genetic testing. These students could then experience some coercion that could impair their ability to give consent freely.

It is not clear how one could set up an undergraduate course so that neither the professor nor the class would know the identities of those students who chose to take the test. Nonetheless, no effort should be spared to minimize any and all external pressures that prospective participants could experience. For instance, participation in the classroom-based personalized genome testing should be completely voluntary and should have no impact on a student's grade in any way. This should be made clear to all students not only when consent is requested prior to the beginning of the course, but also when the syllabus is distributed to the class on the first day of the semester.

As for financial coercion, this study also revealed that a significant majority of the respondents (72% Strongly agree or agree) would see their participation in the personal genomic testing as an opportunity to get a service for less than its original price. This suggests that any efforts to incorporate direct-to-consumer genetic testing in the college classroom should include a fee for participants to mitigate any undue pressure they may experience from financial exigencies. Though UC Berkeley offered the genetic testing to its students without a fee, Stanford University asked its medical and graduate students to pay ninety-nine dollars to have their genotypes analyzed by the personalized genomics company (Jabr, 2011). The residency program in genomics and personalized medicine at Beth Israel Deaconess Hospital in Boston does the same (Haspel et al., 2010).

Finally, one potential solution to the complex problems associated with obtaining proper informed consent in a personalized genomics course at the undergraduate level is to limit genomic testing to the instructors of the course.

Presumably, the faculty instructors would understand enough of the scientific and ethical issues raised by personalized genomics to give proper informed consent. This was done at Tufts University where several of the faculty involved in the personalized genomics course accepted an offer to get their genomes profiled without cost (Walt et al., 2011). However, their experience revealed some of the unexpected consequences of this approach. One of the faculty instructors discovered that he was at increased risk for developing glaucoma, while another received results that showed that he was a carrier for two clinically significant disease genes. Both genetic discoveries had an immediate and unexpected impact on the lives of these faculty members and their families. Moreover, the instructor with the heightened risk for glaucoma sought medical advice from an ophthalmologist who did not know how to incorporate the results from the genetic test into his patient's care plan. This case illustrated two potential dilemmas of providing personalized genetic testing to students: the need to involve family members who may not have wanted to be informed about their risk for having disease genes, and the heightened chance of referral to physicians who lack the education to evaluate genetic test results. Besides, students who engage in self-testing may be more interested in the lesson itself and more likely to learn from it (Salari, Pizzo, & Prober, 2011).

Concerns Surrounding Student Privacy

Next, several commentators were concerned that the privacy of the incoming UC Berkeley students would not be respected by the personalized genomics testing companies (Jabr, 2011). In response, the university's administrators argued that the personalized DNA samples provided by the students would be incinerated as soon as testing was completed. However, it is clear that the results of the tests would have been preserved electronically on computer servers at the personal genomics companies. Indeed, one specific concern is that direct-to-consumer genetic testing companies generally define their privacy policies in terms of "appropriate" use of genetic information where it is unclear as to what does and what does not qualify as “appropriate” use of personal genetic results (Fraker & Mazza, 2011). There is always some risk that a customer's personalized genomics information could be inadvertently divulged (Rothstein, 2010). Significantly, two scholars have performed landmark studies demonstrating the re-identification of stored anonymous health data (Malin & Sweeney, 2000, 2001).

Of note, a large majority (64% Strongly agree or agree) of the undergraduate survey respondents would permit a personal genome testing company to include their de-identified sample in scientific research. However, it is not clear if this permission is based upon an informed decision since many of them do not appear to understand the potential benefits or drawbacks of their involvement in research with this -- for many of them, still unfamiliar -- technology. Thus, any proposal to incorporate direct-to-consumer genetic testing in the college classroom should include efforts to inform potential participants about all the foreseeable consequences and possible risks arising from their participation in long-term research programs conducted by a personal genome testing company.

Concerns Surrounding Student Interpretation of their Genetic Test Results

Finally, commentators were worried that the UC Berkeley students would not know enough about personal genomics to properly interpret the results of their genetic testing (Jabr, 2011). This concern arose despite the limited scope of the testing: The Berkeley orientation project would have only involved genetic testing for three nutritional genes involving in the body's ability to metabolize alcohol, lactose, and folates (Schlissel, 2010). In contrast, direct-to-consumer tests screen a battery of genes, many involved in human disease, some of which do not have a known cure or remedy. Will undergraduate students be able to properly interpret the probabilitistic data linking numerous disease genes to their future health prospects?

Strikingly, the results of my survey suggest that the inability of college students to understand their test results is indeed a legitimate concern. A large number of the undergraduate respondents (66% strongly disagree or disagree) did not think that they knew enough to understand the results they would receive from a personal genome testing service. Coupled with this, a majority of students (55% Strongly agree or agree) were concerned that they may get genetic results that may be disturbing for themselves or for their families. Thus, it is not surprising, that nearly all (96% strongly agree or agree) intend to ask a physician to help them interpret the results of their personal genome test, and a similar number (92% strongly agree or agree) wanted personal genome companies to have a medical expert to help them to interpret their results. However, as numerous studies have discovered, many of these primary care physicians have neither the expertise nor

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the time to accurately interpret personalized genomics test results (Baars et al., 2005; Caulfield & Wertz, 2001; Greendale & Pyeritz, 2001; McGuire & Burke, 2008).

One possible response is to provide participants, and in certain cases, participants and their families, with the option of one-on-one genetic counseling to discuss the impact of their test results on their lives. However, this can be financial burdensome. One potentially cheaper option suggested by colleagues at my home institution is to invite our college alumni who had gone on to become genetic counselors to return to campus not only to provide this one-on-one counseling opportunity but also to make an in-class presentation on their work and career choice. This homecoming could be hosted in conjunction with the university's career services and placement office to highlight genetic counseling as a career.

Conclusion

Direct-to-consumer genetic testing could potentially enhance student learning in the undergraduate classroom by having students learn science by doing hands-on experiments. My survey revealed that the college students who participated in the study are willing to use this technology, but they also had concerns about the reliability, the confidentiality, and the interpretation of their genetic test results. However, the pros and cons of such a curricular novelty would have to be considered by faculty and administrators with broad multidisciplinary representation. They should especially consider the findings of a United States Government Accountability Office (GAO) investigation, already discussed above, that revealed that the personalized genetic tests used by several companies are not reliable.

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REFERENCES

Baars, M. J., Henneman, L., & Ten Kate, L. P. (2005). Deficiency of knowledge of genetics and genetic tests among general practitioners, gynecologists, and pediatricians: a global problem. *Genet Med, 7*(9), 605-610.

Bloss, C. S., Darst, B. F., Topol, E. J., & Schork, N. J. (2011). Direct-to-Consumer Personalized Genomic Testing. *Hum Mol Genet*. doi: 10.1093/hmg/ddr349

Bloss, C. S., Schork, N. J., & Topol, E. J. (2011). Effect of direct-to-consumer genomewide profiling to assess disease risk. *N Engl J Med, 364*(6), 524-534. doi: 10.1056/NEJMoa1011893

Borry, P., Cornel, M. C., & Howard, H. C. (2010). Where are you going, where have you been: a recent history of the direct-to-consumer genetic testing market. *J Community Genet, 1*(3), 101-106. doi: 10.1007/s12687-010-0023-z

Burke, W., & Evans, J. P. (2011). Teaching with single nucleotide polymorphisms: learning the right lessons. *Genet Med, 13*(1), 17-18. doi: 10.1097/GIM.0b013e3182049618

Callier, S. L. (2012). Swabbing students: should universities be allowed to facilitate educational DNA testing? *Am J Bioeth, 12*(4), 32-40. doi: 10.1080/15265161.2012.656803

Cartier, J., & Stewart, J. (2000). Teaching the Nature of Inquiry: Further Developments in a High School Genetics Curriculum. *Science Education, 9*(3), 247-267.

Caulfield, T. (2009). Direct-to-consumer genetics and health policy: a worst-case scenario? *Am J Bioeth, 9*(6-7), 48-50. doi: 10.1080/15265160902918770

Caulfield, T. (2011). Direct-to-consumer testing: if consumers are not anxious, why are policymakers? *Hum Genet, 130*(1), 23-25. doi: 10.1007/s00439-011-0987-8

Caulfield, T., & Wertz, D. (2001). Creating needs? A review of survey data and concerns relevant to the commercialization of genetic testing. *Community Genet, 4*(2), 68-76. doi: 10.1159/000051160

Dalton, B., Morocco, C., Tivnan, T., & Mead, P. R. (1997). Supported Inquiry Science: Teaching for Conceptual Change in Urban and Suburban Science Classrooms. *Journal of Learning Disabilities, 30*(6), 670-684.

Deyo, R. A. (2002). Cascade effects of medical technology. *Annu Rev Public Health, 23*, 23-44. doi: 10.1146/annurev.publhealth.23.092101.134534

Duster, T. (2010, May 28, 2010). Welcome Freshmen, DNA Swabs Please. The Chron. of Higher Educ. *The Chron. of Higher Educ.* Retrieved August 22, 2011, from http://chronicle.com/article/Welcome-Freshmen-DNA-Swabs/65729/

Fraker, M., & Mazza, A. (Eds.). (2011). *Direct-to-Consumer Genetic Testing: Summary of a Workshop*. Washington, DC: The National Academies Press.

Goddard, K. A., Moore, C., Ottman, D., Szegda, K. L., Bradley, L., & Khoury, M. J. (2007). Awareness and use of direct-to-consumer nutrigenomic tests, United States, 2006. *Genet Med, 9*(8), 510-517. doi: 10.1097/GIM.0b013e31812e6ac3

Goddard, K. A., Robitaille, J., Dowling, N. F., Parrado, A. R., Fishman, J., Bradley, L. A., . . . Khoury, M. J. (2009). Health-related direct-to-consumer genetic tests: a public health assessment and analysis of practices related to Internet-based

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tests for risk of thrombosis. *Public Health Genomics, 12*(2), 92-104. doi: 10.1159/000176794

Gollust, S. E., Wilfond, B. S., & Hull, S. C. (2003). Direct-to-consumer sales of genetic services on the Internet. *Genet Med, 5*(4), 332-337. doi: 10.1097/01.gim.0000076972.83711.48

Greendale, K., & Pyeritz, R. E. (2001). Empowering primary care health professionals in medical genetics: how soon? How fast? How far? *Am J Med Genet, 106*(3), 223-232. doi: 10.1002/ajmg.10010

Hall, W., & Gartner, C. (2009). Direct-to-consumer genome-wide scans: astrologicogenomics or simple scams? *Am J Bioeth, 9*(6-7), 54-56. doi: 10.1080/15265160902894021

Haspel, R. L., Arnaout, R., Briere, L., Kantarci, S., Marchand, K., Tonellato, P., . . . Saffitz, J. E. (2010). A call to action: training pathology residents in genomics and personalized medicine. *Am J Clin Pathol, 133*(6), 832-834. doi: 10.1309/ajcpn6q1qkclykxm

Hogarth, S., Javitt, G., & Melzer, D. (2008). The current landscape for direct-to-consumer genetic testing: legal, ethical, and policy issues. *Annu Rev Genomics Hum Genet, 9*, 161-182. doi: 10.1146/annurev.genom.9.081307.164319

Hunter, D. J., Khoury, M. J., & Drazen, J. M. (2008). Letting the genome out of the bottle--will we get our wish? *N Engl J Med, 358*(2), 105-107. doi: 10.1056/NEJMp0708162

Ipaktchian, S. (2010, June 7, 2010). Medical School to Offer Course that Gives Students Option of Studying their own Genotype Data. Stanford School of

Medicine News. *Stanford School of Medicine News.* Retrieved August 2, 2011, from http://med.stanford.edu/ism/2010/june/genotype.html

Jabr, F. (2011, July 6, 2010). Exposing the Student Body: Stanford Joins U.C. Berkeley in Controversial Genetic Testing of Students. Scientific American. *Scientific American.* Retrieved August 22, 2011, from http://www.scientificamerican.com/article.cfm?id=exposing-the-student-body

Janssens, A. C., Gwinn, M., Bradley, L. A., Oostra, B. A., van Duijn, C. M., & Khoury, M. J. (2008). A critical appraisal of the scientific basis of commercial genomic profiles used to assess health risks and personalize health interventions. *Am J Hum Genet, 82*(3), 593-599. doi: 10.1016/j.ajhg.2007.12.020

Kaye, J. (2008). The regulation of direct-to-consumer genetic tests. *Hum Mol Genet, 17*(R2), R180-183. doi: 10.1093/hmg/ddn253

Knoell, D. L., Johnston, J. S., Bao, S., & Kelley, K. A. (2009). A genotyping exercise for pharmacogenetics in pharmacy practice. *Am J Pharm Educ, 73*(3), 43.

Kolor, K., Liu, T., St Pierre, J., & Khoury, M. J. (2009). Health care provider and consumer awareness, perceptions, and use of direct-to-consumer personal genomic tests, United States, 2008. *Genet Med, 11*(8), 595. doi: 10.1097/GIM.0b013e3181b1cc2c

Krynetskiy, E., & Lee Calligaro, I. (2009). Introducing pharmacy students to pharmacogenomic analysis. *Am J Pharm Educ, 73*(4), 71.

Kuehn, B. M. (2010). Inconsistent results, inaccurate claims plague direct-to-consumer gene tests. *JAMA, 304*(12), 1313-1315. doi: 10.1001/jama.2010.1328

Malin, B., & Sweeney, L. (2000). Determining the identifiability of DNA database entries. *Proc AMIA Symp*, 537-541.

Malin, B., & Sweeney, L. (2001). Re-identification of DNA through an automated linkage process. *Proc AMIA Symp*, 423-427.

Mangin, D., Hudson, B., & Toop, L. (2012). Direct-to-consumer genetic testing: letting the genie out of the bottle? *N Z Med J, 125*(1364), 7-10.

McBride, C. M., Koehly, L. M., Sanderson, S. C., & Kaphingst, K. A. (2010). The behavioral response to personalized genetic information: will genetic risk profiles motivate individuals and families to choose more healthful behaviors? *Annu Rev Public Health, 31*, 89-103. doi: 10.1146/annurev.publhealth.012809.103532

McGuire, A. L., & Burke, W. (2008). An unwelcome side effect of direct-to-consumer personal genome testing: raiding the medical commons. *JAMA, 300*(22), 2669-2671. doi: 10.1001/jama.2008.803

McGuire, A. L., Diaz, C. M., Wang, T., & Hilsenbeck, S. G. (2009). Social networkers' attitudes toward direct-to-consumer personal genome testing. *Am J Bioeth, 9*(6-7), 3-10. doi: 10.1080/15265160902928209

McGuire, A. L., Evans, B. J., Caulfield, T., & Burke, W. (2010). Science and regulation. Regulating direct-to-consumer personal genome testing. *Science, 330*(6001), 181-182. doi: 10.1126/science.1194006

Offit, K. (2008). Genomic profiles for disease risk: predictive or premature? *JAMA, 299*(11), 1353-1355. doi: 10.1001/jama.299.11.1353

Ormond, K. E., Hudgins, L., Ladd, J. M., Magnus, D. M., Greely, H. T., & Cho, M. K. (2011). Medical and graduate students' attitudes toward personal genomics. *Genet Med, 13*(5), 400-408. doi: 10.1097/GIM.0b013e31820562f6

Powell, K. P., Cogswell, W. A., Christianson, C. A., Dave, G., Verma, A., Eubanks, S., & Henrich, V. C. (2011). Primary Care Physicians' Awareness, Experience and Opinions of Direct-to-Consumer Genetic Testing. *J Genet Couns*. doi: 10.1007/s10897-011-9390-9

Ransohoff, D. F., & Khoury, M. J. (2010). Personal genomics: information can be harmful. *Eur J Clin Invest, 40*(1), 64-68. doi: 10.1111/j.1365-2362.2009.02232.x

Rogers, J. C., & Taylor, A. T. (2011). Teaching about genetic testing issues in the undergraduate classroom: a case study. *J Genet Couns, 20*(3), 231-240. doi: 10.1007/s10897-011-9352-2

Rothstein, M. A. (2010). Is deidentification sufficient to protect health privacy in research? *Am J Bioeth, 10*(9), 3-11. doi: 10.1080/15265161.2010.494215

Salari, K., Pizzo, P. A., & Prober, C. G. (2011). Commentary: to genotype or not to genotype? Addressing the debate through the development of a genomics and personalized medicine curriculum. *Acad Med, 86*(8), 925-927. doi: 10.1097/ACM.0b013e3182223acf

Sanders, R. (2010, September 10, 2010). Tempest in a Spit Cup. UC Berkeley News. *UC Berkeley News.* from http://berkeley.edu/news/media/releases/2010/09/10_tempest_over_DNA_testing.shtml

Schlissel, M. (Producer). (2010, August 22, 2011). Bring Your Genes to Cal Video Version of Consent Form. Retrieved from http://webcast.berkeley.edu/media/common/media/one_off/pa_20100708_ls_h264fs.mov

Singleton, A., Erby, L. H., Foisie, K. V., & Kaphingst, K. A. (2012). Informed choice in direct-to-consumer genetic testing (DTCGT) websites: a content analysis of benefits, risks, and limitations. *J Genet Couns, 21*(3), 433-439. doi: 10.1007/s10897-011-9474-6

Taylor, A. T., & Rogers, J. C. (2011). The ethical implications of genetic testing in the classroom. *Biochem Mol Biol Educ, 39*(4), 253-260. doi: 10.1002/bmb.20521

Valles, S. A. (2012). Should direct-to-consumer personalized genomic medicine remain unregulated?: a rebuttal of the defenses. *Perspect Biol Med, 55*(2), 250-265. doi: 10.1353/pbm.2012.0019

Wallace, H. (2008). Most gene test sales are misleading. *Nat Biotechnol, 26*(11), 1221. doi: 10.1038/nbt1108-1221

Walt, D. R., Kuhlik, A., Epstein, S. K., Demmer, L. A., Knight, M., Chelmow, D., . . . Bianchi, D. W. (2011). Lessons learned from the introduction of personalized genotyping into a medical school curriculum. *Genet Med, 13*(1), 63-66. doi: 10.1097/GIM.0b013e3181f872ac

Wright, C. F., & Gregory-Jones, S. (2010). Size of the direct-to-consumer genomic testing market. *Genet Med, 12*(9), 594. doi: 10.1097/GIM.0b013e3181ead743

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Wright, C. F., Hall, A., & Zimmern, R. L. (2011). Regulating direct-to-consumer genetic tests: what is all the fuss about? *Genet Med, 13*(4), 295-300. doi: 10.1097/GIM.0b013e3181f69dd2

TABLE 1: GENERAL ATTITUDES AND BELIEFS ABOUT PERSONAL GENOME TESTING SERVICES

QUESTION	PRE-COURSE SURVEY		POST-COURSE SURVEY (Asterisk Indicates p<0.05)	
	%	N	%	N
Recent genetic studies, called genome wide association studies (GWAS), have successfully identified a number of genes that contribute to common complex genetic traits and diseases including height, baldness, Type II diabetes, schizophrenia, cancer, and heart disease, among others. Before participating in this survey, did you know that scientists have been able to link particular human genes to common complex physical and health related traits?	91% YES	107/118	95% YES	90/95
In your opinion as a college student, how useful would this genetic information be for a physician?	89% indispensable or very useful	105/118	89% indispensable or very useful	85/95
In your opinion as a college student, how useful would this genetic information be for patients to have for themselves?	67% indispensable or very useful	79/118	73% indispensable or very useful	69/95
In your opinion as a college student, how likely is it that knowing this genetic information about yourself would lead to changes in your own behavior?	52% almost certainly or very likely	61/118	62% almost certainly or very likely* (p=0.019)	59/95
In addition to medical and physical traits, these genetic studies have produced a number of well-validated associations that link genes to complex behavioral traits such as risk taking and sexual promiscuity. Before participating in this survey, did you know that scientists have linked specific human genes to complex behavioral traits?	58% YES	68/118	65% YES	62/95
In your opinion as a college student, how useful would this genetic information about a person's behavioral genetics be for a physician?	55% indispensable or very useful	65/118	66% indispensable or very useful* (p=0.005)	63/95
In your opinion as a college student, how useful would this genetic information about a person's behavioral genetics be for patients to have for themselves?	57% indispensable or very useful	67/118	71% indispensable or very useful* (p=0.0185)	67/95
In your opinion as a college student, how likely is it that knowing information about your particular behavioral genetics would lead to changes in your own behavior?	51% almost certainly or very likely	60/118	62% almost certainly or very likely* (p=0.050)	59/95
Before participating in this survey, did you know that these commercial genetic testing services were available for the ordinary consumer?	71% NO	82/116	52% YES* (p<0.001)	49/94

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Given what you know as a college student at this moment in time, would you use a personal genomics testing service for yourself now?	53% NO	62/116	52% YES	49/94
The test results provided by personal genome testing companies are accurate and reliable.	28% Strongly agree or agree 56% Neutral	33/116 65/116	58% Strongly agree or agree 35% Neutral* (p<0.001)	53/91 32/91
Physicians have a professional responsibility to help individuals understand the results they receive from a personal genome test, even if the physician had not ordered the test.	73% Strongly agree or agree	85/116	72% Strongly agree or agree	66/92
Physicians have enough knowledge to help individuals interpret results of personal genome tests.	46% Strongly agree or agree 38% Neutral	53/116 44/116	53% Strongly agree or agree 35% Neutral* (p=0.016)	49/92 32/92
Most people can accurately interpret their own personal genome results.	84% Strongly disagree or disagree	97/116	83% Strongly disagree or disagree	76/92
Personal genome companies should tell their customers everything they need to know to make informed decisions about using their services.	97% Strongly agree or agree	113/116	89% Strongly agree or agree	82/92
I consider information obtained from personal genomic testing to be diagnostic of medical conditions or diseases.	29% Strongly agree or agree 35% Neutral	34/116 41/116	44% Strongly agree or agree 26% Neutral* (p<0.001)	40/92 24/92
If I underwent personal genome testing, I would ask a physician for help in interpreting the results of a personal genome test.	96% Strongly agree or agree	111/116	86% Strongly agree or agree* (p<0.001)	79/92
I know enough about human genetics to understand the results of a personal genome test.	66% Strongly disagree or disagree	77/116	47% Strongly disagree or disagree* (p=0.001)	43/92
Results of personal genome testing would influence my future healthcare decisions.	67% Strongly agree or agree	78/116	78% Strongly agree or agree* (p=0.03)	72/92
I understand the risks and benefits of using personal genome testing services.	49% Strongly agree or agree 28% Neutral	57/116 32/116	63% Strongly agree or agree 20% Neutral* (p=0.027)	58/92 18/92
Personal genome companies should have a medical expert to help customers interpret their results.	92% Strongly agree or agree	107/116	90% Strongly agree or agree	83/92
Personal genome companies should be regulated by the federal government.	47% Strongly agree or agree 37% Neutral	53/116 43/116	41% Strongly agree or agree 37%	38/92 34/92

			Neutral* (p=0.001)	
In your opinion as a college student, do you think that personal genomic testing services are useful for consumers.	66% YES	77/116	82% YES* (p=0.002)	75/92

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TABLE 2: PRE-COURSE REASONS FOR USING OR NOT USING A PERSONAL GENOME SERVICE FOR ONESELF OR FOR A TYPICAL CONSUMER

QUESTION	PERCENTAGE SELF	N	PERCENTAGE CONSUMER	N
Given what you know as a college student at this moment in time, would you use a personal genomics testing service for yourself now?	53% NO	62/116		
In your opinion as a college student, do you think that personal genomic testing services are useful for consumers.			66% YES	77/116
If you answered YES, why? (Check all that apply)				
To satisfy my general curiosity about my genetic make-up.	82%	45/55	69%	52/75
To see if a specific disease runs in my family or is in my DNA.	87%	48/55	93%	70/75
To learn about my genetic makeup without going through a physician.	29%	16/55	43%	32/75
To obtain information about a family member's health risk.	49%	27/55	85%	64/75
To help me understand what patients may learn and experience.	40%	22/55	65%	49/75
To help me understand the basic principles of human genetics.	56%	31/55		
If you answered NO, why? (Check all that apply)				
I do not think that the results are reliable.	46%	28/61	29%	12/41
I am concerned about my privacy.	30%	18/61	44%	18/41
I do not think that the information would be medically useful.	18%	11/61	22%	9/41
I do not think that the information would help me learn about human genetics	11%	7/61		

I am worried that I will learn something about my DNA that is troubling.	25%	15/61		
I am concerned that it would give me unwanted information.	43%	26/61		
It would cost too much.	41%	25/61	22%	9/41
A medical doctor should be involved in ordering and interpreting medical results.			78%	32/41
Individuals have a limited ability to understand and interpret their test results.			78%	32/41

TABLE 3: POST-COURSE REASONS FOR USING OR NOT USING A PERSONAL GENOME SERVICE FOR ONESELF OR FOR A TYPICAL CONSUMER

QUESTION	PERCENTAGE SELF	N	PERCENTAGE CONSUMER	N
Given what you know as a college student at this moment in time, would you use a personal genomics testing service for yourself now?	52% NO	49/94		
In your opinion as a college student, do you think that personal genomic testing services are useful for consumers.			82% YES	75/92
If you answered YES, why? (Check all that apply)				
To satisfy my general curiosity about my genetic make-up.	88%	43/49	75%	56/75
To see if a specific disease runs in my family or is in my DNA.	90%	44/49	95%	71/75
To learn about my genetic makeup without going through a physician.	27%	13/49	37%	28/75
To obtain information about a family member's health risk.	61%	30/49	71%	53/75
To help me understand what patients may learn and experience.	47%	23/49	56%	42/75
To help me understand the basic principles of human genetics.	47%	23/49		
If you answered NO, why? (Check all that apply)				
I do not think that the results are reliable.	21%	9/44	29%	5/17
I am concerned about my privacy.	36%	16/44	47%	8/17
I do not think that the information would be medically useful.	11%	5/44	18%	3/17
I do not think that the information would help me learn about human genetics	5%	2/44		

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I am worried that I will learn something about my DNA that is troubling.	59%	26/44		
I am concerned that it would give me unwanted information.	68%	30/44		
It would cost too much.	54%	23/44	71%	12/17
A medical doctor should be involved in ordering and interpreting medical results.			82%	14/17
Individuals have a limited ability to understand and interpret their test results.			88%	15/17

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TABLE 4: GENERAL ATTITUDES AND BELIEFS ABOUT PERSONAL GENOME TESTING SERVICES IN THE COLLEGE CLASSROOM

QUESTION	PRE-COURSE SURVEY		POST-COURSE SURVEY (Asterisk Indicates $p<0.05$)	
	%	N	%	N
At this point in time, I do not know enough about personal genetic testing to make a decision one way or another regarding my participation in an in-class personal genetics testing opportunity.	52% Strongly agree or agree	60/116	42% Strongly agree or agree	38/90
At this point in time, I think that I would need to speak to my parents before I could make my decision to participate in or to refuse an in-class personal genetics testing opportunity.	45% Strongly agree or agree 42% Strongly disagree or disagree	52/116 49/116	54% Strongly agree or agree 24% Strongly disagree or disagree	49/90 22/90
Having my own genetic results for my use in a course would help me to understand genetics concepts better than having someone else's genetic results.	62% Strongly agree or agree	72/116	52% Strongly agree or agree* ($p<0.018$)	47/90
I would feel that I would be at a disadvantage compared to my classmates if I did not undergo the genetic testing.	42% Strongly agree or agree 32% Strongly disagree or disagree	49/116 37/116	44% Strongly agree or agree 37% Strongly disagree or disagree	40/90 42/90
I would see this course-related offer for genetic testing as an opportunity to get a service that I would not ordinarily get if I had to pay full price.	72% Strongly agree or agree	83/116	67% Strongly agree or disagree	59/90
I would be concerned that my professors would know who took up the offer of testing and who didn't.	48% Strongly disagree or disagree	56/116	51% Strongly disagree or disagree	46/90
I would be concerned that my classmates would know who took up the offer of testing and who didn't.	51% Strongly disagree or disagree	59/116	52% Strongly disagree or disagree	47/90
I would see this course-related offer for genetic testing as an opportunity to get information that help me improve my health.	65% Strongly agree or agree	75/116	63% Strongly agree or agree	57/90
I would see this course-related offer for genetic testing as an opportunity to get information that would help other members of my family to improve their health.	67% Strongly agree or agree	78/116	64% Strongly agree or agree	58/90
I would be concerned that I might get some genetic results back that would be disturbing for myself or for my family.	55% Strongly agree or agree	64/116	78% Strongly agree or agree* ($p<0.001$)	70/90
I would only take up the offer of genetic testing if I could get genetic counseling before I sent my sample in to the company to be tested.	17% Agree 47% Neutral	20/116 54/116	26% Agree 42% Neutral* ($p<0.001$)	23/90 38/90

I would only take up the offer of testing if I could get genetic counseling after I got my results back from the company.	40% Strongly agree or agree 41% Neutral	46/116 47/116	50% Strongly agree or agree 33% Neutral	45/90 30/90
I would only take up the offer of genetic testing in the course if my parents agreed that I could get tested.	34% Strongly agree or agree 30% Neutral 36% Strongly disagree or disagree	39/116 35/116 42/116	44% Strongly agree or agree 27% Neutral 29% Strongly disagree or disagree	40/90 24/90 26/90
I would be concerned that people would find out genetic or health information about me.	40% Strongly disagree or disagree 41% Neutral	46/116 47/116	35% Strongly disagree or disagree 42% Neutral* (p<0.001)	32/90 38/90
I would permit a personal genome testing company to include my de-identified sample in scientific research.	64% Strongly agree or agree	74/116	62% Strongly agree or agree	56/90

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