GENETICS AND PERSONALIZED MEDICINE: A COMPARISON OF COLLEGE STUDENTS' PERSPECTIVES

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CERTIFICATION OF APPROVAL

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ABSTRACT

Personalized medicine is an emerging practice in health care that promises improvements in disease treatment and prevention. The future of personalized medicine, however, depends on consumers and providers of medicine understanding its worth and becoming interested in it as a new form of health care. In 2010, the University of California, Berkeley recognized this need and implemented the *On the Same Page Project*. The project gave incoming freshmen and transfer students the opportunity to have genetic testing, participate in personalized medicine-focused seminars, and take a survey related to their experience. This current follow-up study assessed the perspectives of those same students four years later and compared their perspectives to a control population of students at San Francisco State University. The purpose of the study was to assess what impact exposure to genetic testing had on the interest and understanding of genetics and personalized medicine. The student populations differed significantly in their knowledge of and interest in personalized medicine and genetic testing even after adjusting for covariates. The results indicate that previous exposure to genetic testing could have an impact on genetics knowledge but does not necessarily increase awareness of or interest in genetic testing. This study contributes to the expanding literature on the public's knowledge of genetic testing by providing a better understanding of the factors that influence interest in genetic

testing and the perspectives of educated young adults on the emerging field of personalized medicine.

INTRODUCTION

Personalized medicine, sometimes referred to as precision medicine, is an emerging practice of medicine that uses an individual's genetic profile to guide decisions made in regard to the prevention, diagnosis, and treatment of disease (NIH, 2015). The success of personalized medicine relies on the accurate sequencing and interpretation of the human genome or exome. With the goal of acquiring an accurate sequence of the human genome, the Human Genome Project (HGP) began in 1990 and was finished slightly over a decade later (Consortium, I. H. G. S., 2004). It has been determined that the human genome is comprised of ~3 X 10^9 bases, 1% of which are protein coding sequences (Rabbani, Tekin, & Mahdieh, 2014). Since the completion of the HGP, advances in sequencing technology have led to an exponential decrease in sequencing costs and time (PMC, 2014). When the HGP began the cost to generate a human genome sequence was $1 billion and it took 10 years to complete. Now, more than two decades since the beginning of the HGP, the cost to generate a human genome sequence is around $1,000 and takes 1-2 days (PMC, 2014). This exponential decrease in sequencing time and cost has allowed for the sequencing of thousands of different human genomes. Sequencing has generated data on variations in the human genetic code revealing that each human has approximately 3 million genetic differences from other humans (Tishkoff & Kidd, 2004). Many of these genetic differences affect the protein coding regions of genes in

such a way as to produce defective proteins, which can lead to disease or a predisposition to certain diseases depending on the protein affected.

Rapid developments and demand for improved medical care has lead to the discovery of thousands of disease causing genetic changes and it is becoming increasingly important for consumers and providers to understand the science of genetics and the technology behind genetic testing (Goh et al., 2007). When the HGP began over two decades ago, there were 53 genes with known disease causing mutations and phenotypes. Now there are nearly 3000 (PMC, 2014). A similar increase in use of genetic information for cancer treatment and pharmacological prescription has occurred during the same time frame. Using genetic information to understand how a person responds to drugs is a relatively new field called pharmacogenentics. Pharmacogenetics combines pharmacology and genetics to develop effective, safe medications and doses tailored to a person's genetic makeup (NIH, 2015). At the start of the HGP, only 4 drugs had pharmacogenetic information on their labels and now over 100 drugs have pharmacogenetic information on their labels (PMC, 2014). With continued discoveries, more individuals will have the potential to benefit from their genetic information being included in their medical care and it is imperative that providers and patients are able to utilize genetic information appropriately to improve health.

Proper interpretation and utilization of genetic testing including genome sequencing results requires communication to consumers by trained medical professionals but also requires that consumers understand genetics and genetic

testing. Research on U.S. public opinion about personalized medicine indicates that most people have not heard of personalized medicine and even fewer people feel very informed about what personalized medicine is (Nash, 2014). A study conducted by Haga et al. in 2012 found that individuals vary greatly in their genetics knowledge. This study asked 300 individuals from the general public of Durham, North Carolina with relatively high education levels factual genetics knowledge questions. The range of scores was from 50% to 100% exemplifying the variety in public knowledge about scientific and medical concepts related to genetics. The participants' perceived knowledge of the social consequences of genetic testing was significantly lower than their perceived knowledge of the medical uses of testing. The authors state that their findings suggest, "that more effort is needed to present the benefits, risks, and limitations of genetic testing, particularly at the social and personal levels, to ensure informed decision making" (Haga et al., 2013).

Understanding the scientific concepts behind genetics and genetic testing is important for the adoption of personalized medicine. Research indicates that there is a positive association between knowledge about genetics and attitudes towards gene tests. In a study in Finland researchers found that those with a low level of genetics knowledge were less able to state their attitude towards genetic testing than those with a high level of genetics knowledge (Jallinoja, & Aro, 2000).

Currently, in order to have most types of genetic testing individuals need a clinician to order the testing and to return the test results. Although direct-to-consumer genetic testing services previously offered genetic tests and results directly

to patients without requiring a clinician to order the testing, currently a clinician is required to be involved in the ordering and results disclosure process. Whether this changes or not, it is essential for clinicians to understand what personalized medicine is and specifically how the results of diagnostic tests can aid in prevention and treatment of disease. Therefore, for personalized medicine to reach its full potential, clinicians must be comfortable ordering, interpreting, and utilizing diagnostic tests. In a 2013 U.S. public opinion study, only 11% of people in a study conducted by the Personalized Medicine Coalition reported that their doctor has discussed or recommended personalized medicine to them (Nash, 2014). A study by Grey et al. found that many physicians are not confident in their knowledge of genomics (22%), ability to explain genomic concepts to patients (14%), and ability to make treatment recommendations based on genomic data (26%) (Gray, Hicks-Courant, Cronin, Rollins, & Weeks, 2014). Furthermore, less than 50% of physicians in the same study reported being very confident in their knowledge about genomics, ability to explain genomic concepts to patients, and ability to make treatment recommendations on the basis of genomic information. The success of personalized medicine as a valid component of clinical care relies upon providers' confidence in their knowledge of genomics and ability to appropriately order genetic testing and explain the results.

Current college students in particular are at a critical sector of the general population who need to be well informed on personalized medicine, as they will become the primary consumers and professionals who will help shape the future of the new age of personalized medicine. Accompanying this new age of personal

genome sequencing is a heightened hope of fulfilling the promises of personalized medicine and an acute awareness of the need for an educated populace to take full advantage of it. This is further exemplified by President Obama's recent announcement regarding his proposed Precision Medicine Initiative, which plans to launch a new research effort to revolutionize how we improve health and treat disease. The long–term goal of the initiative is to build a comprehensive scientific knowledge base to enable the wide spread practice of precision medicine. In order to achieve this goal the initiative plans to study a national cohort of a million or more Americans. The volunteers for this project will share genetic data, biological samples, and diet/lifestyle information in order to increase our understanding of health and disease (Collins & Varmus, 2015).

To begin addressing the gaps in understanding of genetic testing and personalized medicine, University of California, Berkeley (UCB) embarked on a personalized medicine focused project in 2010 called "*On the Same Page Project: Bring your Genes to Cal"*. The On the Same Page Project (OTSP) is a yearly program that unifies the new students and all others on campus around one project, typically a summer reading book, that gives the university population something to talk about with one another. The goal of the research in 2010 was to collect a DNA sample (using saliva kits) from as many incoming class members as possible and with informed consent, to test, through genotyping, three genes encoding enzymes (LCT encoding lactase, ALDH2 encoding aldehyde dehydrogenase, and MTHFR encoding methylene tetrahydrofolate reductase) in each person, for the presence of genetic

variants that are known to affect the function of these genes. Variants in these genes are common in the human population and affect enzyme function. The overall goal of the project was to help prepare a new generation of healthcare providers and consumers to become familiar with personalized medicine and genetic testing.

This study represents a continuation of the 2010 project, adding data to the original goal by capturing the same UCB student's opinions and understanding of genetic testing and personalized medicine four years after their exposure to those concepts as incoming students. The additional data provides insight into how this exposure impacted their understanding of genetics and interest in genetic testing options. In order to increase the comprehensiveness of the study, San Francisco State University (SFSU) seniors were also invited to participate as a comparative sample group. SFSU students did not participate in the 2010 OTSP project and therefore were not given the opportunity to submit a DNA sample for genotyping and to attend seminars and discussions on genetic testing and personalized medicine that the UCB students were given. Thus, their participation in this study presented an important opportunity to better understand the factors that impact interest in genetic testing and personalized medicine through comparing the responses of two cohorts of college students that differ in many way including their previous exposure to genetic testing and personalized medicine.

It is of vital importance to the success of personalized medicine that the new generation of consumers and providers of medicine understand and are interested in genetic testing and personalized medicine. There is need for more literature related to

how individuals understand genetics, genetic testing, and personalized medicine. This study aimed to address this gap in literature by providing information regarding knowledge and opinions of young adults, with and without previous exposure to genetic testing, on genetics and personalized medicine. It is the hope of the researchers that this information can inform future research on the best practices for educating students and the general public on genetic testing and personalized medicine while also contributing information regarding consumer's desires for the delivery of genetics services.

METHODS

A survey was developed to assess college students' interest in personalized medicine and genetic testing. This survey also intended to determine how college students would like to receive genetic test results and what information they would like to receive based on a wide range of options. Furthermore, the survey utilized a published genetics knowledge scale to better assess the participant's understanding of genetics concepts. The genetics knowledge scale was broken into two categories each containing several questions. The first section included basic science questions related to genetics to test the participant's factual knowledge; all questions were in true/false format. The second section asked participants to state how much they felt they knew about the social or personal impact of genetics and genetic testing with response options to statements being "a lot", "a little", and "none".

The survey was developed by a group of researchers at the University of California, Berkeley (UCB), California State University, Stanislaus (CSUS) and University of California, San Francisco (UCSF). The survey was a revised version of the original survey sent out to UCB students in 2010. It included some of the exact questions from the original survey, some new questions and a validated genetics knowledge scale. It collected both quantitative and qualitative data. The University of California, Berkeley Committee for the Protection of Human Subjects (CPHS) approved the continuation of the 2010 project # 2014-03-6076 on April 8th 2014. The San Francisco State University approved the project #X14-10 on March 18th, 2014.

The CSU Stanislaus University Institutional Review Board (IRB) approved the project #1314-130 on April 14th, 2014. The study invited all students who started at the University of California, Berkeley or San Francisco State University in 2010 to take the online survey. Inclusion criteria for this study required that participants be 4th year students at either institution and at least 18 years old.

Appointed UCB and SFSU faculty emailed messages to the students and invited them to participate in the web-based survey. Approximately 5,500 students at UCB and 2,000 students at SFSU were invited to participate. The email message included a link to the survey, which was facilitated via the Survey Monkey platform. In order to optimize participation rate, the students were reminded multiple times over the course of 6 weeks to participate in the survey. The survey required 10-15 minutes for completion. All survey data was anonymous and participation was voluntary.

Separate surveys and survey links were sent to the UCB students and the SFSU students. The SFSU population was included in this study in order to provide an additional set of data, which could be used for comparison to the UCB data set or used to control for factors to better understand predictors of interest in genetic testing. San Francisco State University students were selected as the comparative group for this survey for several reasons. The population also presented an opportunity to acquire the perspective of individuals who shared similarities with the UCB participants including environment (California Bay Area), life-stage (students), age (18-26), education level (pursuing bachelor's degrees), and educational institution

(public university). There are also several differences between the two student populations including the academic standing of the two institutions and the demographic information of the students admitted to the two institutions, which also contribute to the richness of the study created by analyzing responses from both cohorts. The two surveys sent were exactly the same with the exception of one additional section of questions, which were only sent to the UCB students. The survey sent to UCB students included six sections and 70 questions. Sections one through five asked questions about demographic information, interest in personalized medicine, health history information, genetics knowledge and opinions on whole genome sequencing. The sixth section asked questions related to the 2010 On the Same Page Project and was only sent to the UCB students. The data generated from the sixth section of the UCB survey was not used for this paper and will be incorporated into a separate paper. The survey sent to SFSU students included sections one through five, for a total of 60 questions, but did not include section six, as they were not apart of the 2010 project. The fifth section asked situational questions about whole genome sequencing to better understand what type of information participants would want from whole genome sequencing and how much they would be willing to pay. The data generated from this section was not used in this study and will be included in a separate publication.

As an incentive to participate in the study, participants were invited to fill out a separate section of the survey after completion where they had the option of

entering a drawing for an iPad. The participants at UCB were also given the opportunity to enter a drawing for a dinner with UCB professors.

Once the survey was closed in June 2014 and all responses had been collected data were cleaned and downloaded to SPSS version 22.0.0.0 for statistical analyses. Analysis for this study included only questions that were included on both the UCB and SFSU surveys. Descriptive statistics figures were determined using SPSS for both UCB and SFSU responses. Chi-squared tests were performed to compare the relationship between categorical variables for responses to the same questions between the UCB data and SFSU data. Regression analysis was performed using STATA to determine differences in responses between participants from UCB and SFSU after controlling for covariates. The survey contained opportunities for free response to a few questions, however these responses were not used in the analysis for this study. A p-value of less than 0.05 was used to establish statistical significance.

RESULTS

The main goals of this study were to assess college students' interest in genetic testing and personalized medicine, understanding of genetics, opinions on whole genome sequencing, and opinions on return of genetic testing results. Furthermore, this study hoped to compare responses of a population that was previously exposed to genetic testing and personalized medicine to a similar population that was not exposed to genetic testing.

Demographics

A total of approximately 5,500 students at UCB and 2,000 students at SFSU were invited to participate in the study. A total of 701 students (12.7%) at UCB responded to the survey. However 10 respondents did not fit the inclusion criteria and 87 respondents clicked "Accept" to begin the survey but did not answer any of the questions. Therefore, a total of 604 UCB (11%) students' responses were analyzed. A total of 381 students (19%) at SFSU responded to the survey, however 5 students clicked "Accept" to begin the survey but did not answer any questions. Therefore, a total of 376 SFSU (18.8%) students' responses were analyzed. A total of 980 participants' responses were analyzed, which equates to a 13% response rate (980/7500).

Comparing the demographic information from the study participants to the demographic information from the general university student population for each respective institution showed that the respondent population had similarities and differences from the general student population at each institution. A review of

reported ethnicity between UCB study participants and the general UCB population showed similarities and differences. For instance, while 4% of the general UCB population is African American/Black, only 1% of the respondent population identified themselves at African American/Black. There was also a difference between the percentage of participants who identify as Chicano/Mexican American (n= 54, 9%) and the percentage of the general UCB population who is Chicano/Mexican American (15%). Contrastingly, the percentage of individuals who identify as White was similar in the participant population (n= 223, 37%) and the general UCB population (32%). With regards to gender, 33% (n=198) of the participant population was male compared to 48% of the general UCB population and 65% (n= 391) of the participant population was female compared to 52% of the general population indicating that a greater proportion of females participated in the survey. Reported ethnicity was similar between the SFSU study participants and general SFSU population. For example, 6.6% (n= 25) of the SFSU respondents stated their race and ethnicity as African American/Black and 5.9% of the general SFSU student population state their race and ethnicity as African American/Black. There was a slight difference in the reported gender of those who participated in the study from SFSU relative to the enrollment profile of the school with slightly more females participating in the study than males relative to the enrollment information. Thirty-one percent of the participants from SFSU were male and 68% were female whereas the enrollment statistics state that 43.4% of students were male and 56.6% of students were female.

A wide variety of majors were represented in the participant populations for both UCB and SFSU. At both UCB and SFSU the most represented majors included a biology or health focus (Figure 1). The second most represented major was Business Administration (17%, n= 65) for SFSU participants and "Other" (18.9%, n= 114) for UCB participants.

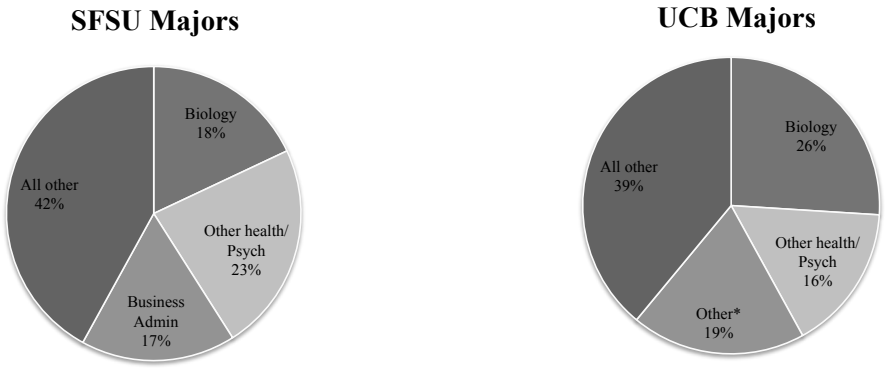

Figure 1: Participant major by college

Table 1 presents frequencies of responses for both UCB and SFSU students to questions about demographic information including but not limited to age, gender, ethnicity, major, religious affiliation, primary language, family income, and parental education. The majority of respondents at both UCB and SFSU were either 21 (UCB 48% N= 287, SFSU 46%, N= 174) or 22-24 (UCB 49% n= 292, SFSU 154 n= 41). On average, SFSU participants were slightly older than UCB participants with more SFSU students reporting their age range as 25-29 or 30 or older than UCB students ($p<0.001$). For the UCB survey, 33% (n= 198) of the participants were male and 65% (n= 391) were female. Similarly, 31% (n= 115) of the SFSU participants were male

and 68% (n= 256) were female. There was also no statistically significant difference between the two populations in terms of when the students learned to speak English.

Table 1: Demographics of respondents by college

When you started at UCB/SFSU in 2010 were you a freshman or a transfer student?	Freshman	586	97.3	319	84.6	**<0.001**
	Transfer	15	2.5	57	15.1	
	Other	1	0.2	1	0.3	
What is your current age?	18	2	0.3	1	0.3	**<0.001**
	19	1	0.2	0	0	
	20	8	1.3	2	0.5	
	21	287	47.7	174	46.2	
	22-24	292	48.5	154	40.8	
	25-29	3	5	22	5.8	
	30 or older	1	0.2	22	5.8	
What is your gender?	Male	198	32.9	115	30.5	0.539
	Female	391	65	256	67.9	
	Other	3	0.5	3	0.8	
What is your race and ethnicity? (please choose all that apply)	I am an international student	29	4.8	3	0.8	
	African American/Black	8	1.3	25	6.6	
	American Indian or Alaska Native	5	0.8	5	1.3	
	Chicano/Mexican American	54	9	55	14.6	
	Other Latino	24	4	35	9.3	
	Chinese	173	28.7	76	20.2	
	Filipino	12	2	35	9.3	
	Japanese	15	2.5	7	1.9	

	Korean	45	7.5	3	0.8	
	South Asian	35	5.8	6	1.6	
	Vietnamese	23	3.8	26	6.9	
	Other Asian	23	3.8	6	1.6	
	Native Hawaiian or other Pacific Islander	4	0.7	4	1.1	
	Eastern European Immigrant	4	0.7	1	0.3	
	Middle Eastern	24	4	6	1.6	
	White	223	37	149	39.5	
	Other	21	3.5	12	3.2	
	Refuse	9	1.5	11	2.9	
What is your religion?	Spiritual but not associated with a major religion	76	12.6	69	18.3	
	Not particularly spiritual	112	18.6	65	17.2	
	Agnostic	78	13	31	8.2	
	Atheist	89	14.8	34	9	
	Buddhist	12	2	20	5.3	
	Hindu	9	1.5	1	0.3	
	Jewish	18	3	13	3.4	
	Muslim	11	1.8	3	0.8	
	Roman Catholic	61	10.1	72	19.1	
	Other Chrisitan	105	17.4	49	13	
	Other religion	12	2	10	2.7	

When did you come to the United States	Born in the United States	449	74.6	315	83.6	**0.016**
	Before the age of 13	94	15.6	33	8.8	
	Age 13 or older	46	7.6	22	5.8	
Which of the following is true, to the best of your knowledge, regarding your parents?	Both of my parents were born in the United States	171	28.4	141	37.4	**0.004**
	Only my mother was born in the United States	24	4	23	6.1	
	Only my father was born in the United States	32	5.3	26	6.9	
	Neither of my parents were born in the United States	354	60.5	176	46.7	
	Don't know	0	0	3	0.8	
When did you learn to speak English	English is my first language	329	54.7	242	64.2	**0.032**
	Before I was 5 years old	152	25.2	72	19.1	

	When I was 6 to 10 years old	94	15.6	41	10.9	
	After turning 11 years old	17	2.8	17	4.5	
What is the highest education level of your parent(s) or guardian?	Less than a high school degree	43	7.1	41	10.9	**<0.001**
	High school degree (or GED)	76	12.6	92	24.4	
	Associate's degree or post-secondary certificate	32	5.3	58	15.4	
	Bachelor's degree or post-baccalaureate certificate	131	21.8	95	25.2	
	Master's degree	151	25.1	54	14.3	
	Professional degree	64	10.6	5	1.3	
	Doctorate	89	14.8	16	4.2	
	Don't know	7	1.2	11	2.9	
To the best of your knowledge, what was your immediate family's annual income in 2013?	Under $20,000	38	6.3	37	9.8	**<0.001**
	$20,000-34,999	55	9.1	52	13.8	
	$35,000-64,999	73	12.1	68	18	
	$65,000-99,999	89	14.8	63	16.7	

	$100,000-149,999	126	20.9	63	16.7	
	$150,000 or more	164	27.2	31	8.2	
	Don't know	45	7.5	59	15.6	

The two student populations differed from each other on several questions about demographic information. There was a statistically significant difference between whether participants from each school started their undergraduate education as freshmen or transfer students in 2010. SFSU participants were more likely to report starting as transfer students compared to UCB students ($p<0.001$) (Table 1). Participants at UCB reported a higher level of education for their parents or guardians than participants at SFSU ($p<0.001$) (Table 1). For example, 15% (n= 89) of participants from UCB reported their parents/guardians highest level of education to be a doctorate whereas 4% (n= 16) of SFSU participants reported that their parent's highest level of education to be a doctorate. There was also a statistically significant difference between reported immediate family income for 2013 between UCB and SFSU participants with 27% (n= 164) of UCB participants and 8% (n= 31) of SFSU participants reporting a family income of $150,000 or more ($p<0.001$) (Table 1). Another statistically significant difference between the two schools was whether student's parents were born in the United States or not, with fewer SFSU students reporting that neither of their parents were born in the United States ($p<0.05$) (Table 1).

Genetics Knowledge Scale

A validated genetics knowledge scale was included in both the UCB and SFSU survey to measure differences in genetics knowledge between the two schools. Pearson's Chi-squared test was performed to determine whether there was a difference in accuracy of responses between the UCB participants and the SFSU participants. When analyzing average percentage of correct answers per question, UCB had a statistically significant higher percentage of correct answers than SFSU participants for several questions (Table 2). The average genetic knowledge scores also differed between UCB participants (n= 540, M= 86.33, SD= 8.95) and SFSU participants (n= 346, M= 81.67, SD= 10.04) with UCB students having a statistically significant higher mean score ($p< 0.05$) (Table 3). Additionally, UCB students correctly answered a statistically significant higher mean number of genetics knowledge questions correctly compared to SFSU students ($p< 0.05$) (Table 4). Of note, a larger percentage of SFSU students that UCB students answered the questions "a gene is a molecule that controls hereditary characteristics" correctly (UCB M= 74.3, SFSU M= 89.86, $p<0.001$)

Table 2: Percentage of participants answering genetics knowledge questions correctly by college

	UCB		**SFSU**		**p-value**
	(n=604)		**(n=376)**		
	(N) Correct	**% Correct**	**(N) Correct**	**% Correct**	
1. One can see a gene with a naked eye.	526	97.59	314	91.01	<0.001

2. A gene is a disease.	539	100	340	98.55	0.009
3. A gene is a molecule that controls hereditary characteristics.	396	74.3	310	89.86	<0.001
4. Genes are inside cells.	491	91.43	299	86.67	0.032
5. A gene is a piece of DNA.	493	91.47	320	92.75	0.575
6. A gene is a cell.	515	95.72	290	83.82	<0.001
7. A gene is part of a chromosome.	479	89.2	309	89.31	1
8. Different body parts include different genes.	412	77.01	194	56.56	<0.001
9. Genes are bigger than chromosomes.	496	92.54	281	81.45	<0.001
10. The genotype is not susceptible to human intervention.	113	21.04	72	20.93	1
11. It has been estimated that a person has 22,000 genes.	383	71.86	227	66.57	0.113

12. Healthy parents can have a child with a hereditary disease.	525	97.4	329	95.64	0.215
13. The onset of certain diseases is due to genes, environment, and lifestyle.	526	97.95	329	95.64	0.076
14. The carrier of a disease gene may be completely healthy.	529	98.14	335	97.1	0.432
15. All serious diseases are hereditary.	531	98.52	316	91.59	<0.001
16. The child of a disease gene carrier is always also a carrier of the same disease gene.	463	86.38	237	69.1	<0.001
Overall average score	--	86.33	--	81.67	--

Table 3: Comparison of average genetic knowledge scores by college

	UCB	**SFSU**
# of Observations	540	346
Minimum	43.75	41.67

Maximum	100	100
Mean	86.33	81.67
Standard Deviation	8.95	10.04
Median	87.5	81.25

Table 4: Frequency of correct answers in the genetic knowledge quiz by college

	UCB		**SFSU**	
# of Correct Answers	Frequency	Percent (%)	Frequency	Percent (%)
3	1	0.19	0	0
5	0	0	1	0.29
7	3	0.56	1	0.29
8	2	0.37	3	0.87
9	2	0.37	4	1.16
10	12	2.22	13	3.76
11	24	4.44	35	10.12
12	37	6.85	57	16.47
13	100	18.52	83	23.99
14	187	34.63	91	26.3
15	139	25.74	50	14.45
16	33	6.11	8	2.31
Total Participants	540	--	346	--
Mean	13.74		13.01	
Standard Deviation	1.54		1.63	
Median	14		13	

Participants were also asked to rate their perceived personal knowledge about the implications of genetic testing. Of the 11 questions asked, seven questions indicated that SFSU students were significantly more likely to state they knew nothing or very little about a specific genetics topic than UCB students ($p<0.05$) (Table 5) (Figure 2).

Table 5: Questions about personal knowledge of genetics

Personal Knowledge of Genetics Questions
1. The significance of genetic (DNA) testing for my offspring.

2. The possibilities and risks of gene therapy.
3. My right to refuse genetic (DNA) testing.
4. The consequences of genetic (DNA) testing for my daily life.
5. The consequences of genetic (DNA) testing for affecting health insurance.
6. The rights of third parties to inquire about the results of a genetic (DNA) test.
7. Your own possibilities to participate in genetic (DNA) testing.

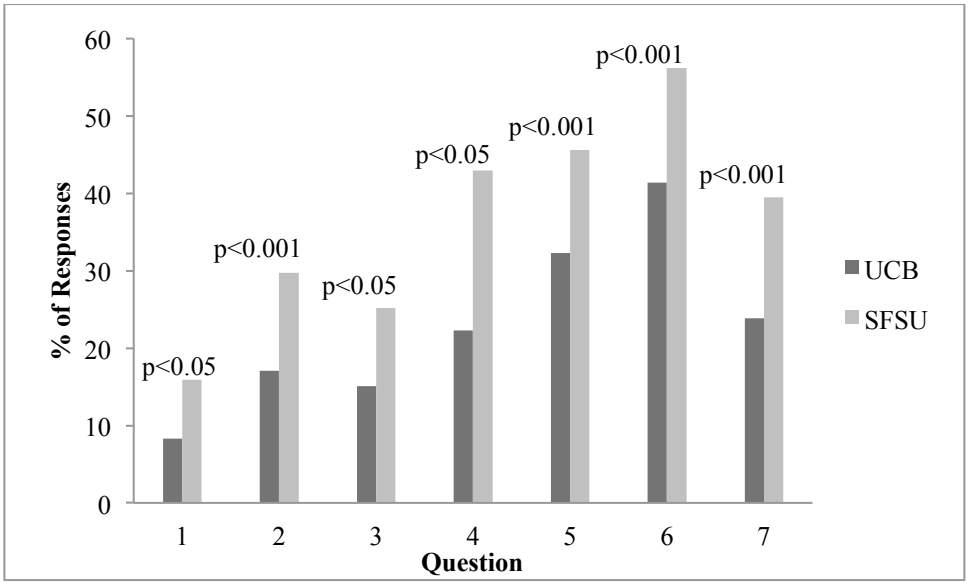

Figure 2: Responses to perceived personal knowledge about implications of genetic testing by college.

Perspectives on Genetic Testing

Several questions in the survey aimed to assess exposure to and interest in personalized medicine and genetic testing. Some of the questions were taken from the original OTSP survey in 2010 and others were new questions. Many of the questions that assessed participants' perspectives on genetic testing and personalized medicine are included in the "controlled comparison of responses" section. The questions that were not analyzed using regression analysis are described in this section.

Questions related to personal health information did not elucidate any statistically significant differences between the two participant populations. However, questions related to previous experience with genetic testing for a personal medical condition for themselves, a family member and/or a friend, indicated that more SFSU participants reported having genetic testing themselves for a personal medical condition (5.8%) or knowing a family member (29.4%) who had genetic testing for a personal medical decision than UCB participants (self: 2.7%, family: 16.8%) ($p<0.001$). SFSU participants were also more likely to have a friend or family member who previously had paternity testing (friend: 8.8%, family: 5.8%) than UCB participants (friend: 4.7%, family 1.8%) ($p<0.05$) (Table 6). Other questions regarding exposure to genetic testing personally or for a friend of family member had no statistically significant difference in response rate between the two schools. Other types of genetic testing inquired about included: carrier screening, prenatal screening, direct to consumer testing and ancestry testing. In addition to questions regarding exposure to genetic testing, participants were also asked to indicate their preferred process for genetic testing if there were going to pursue it. Options included pursuing genetic testing themselves in a direct to consumer manner, utilizing a genetics specialist pre- and post-testing, utilizing a genetics specialist post-testing, and not interested in pursuing genetic testing. Of note, an equal proportion of SFSU and UCB students stated they were not interested in genetic testing (13.5%). Additionally, SFSU students were less likely to select the option “I would order a test for myself and directly receive my results through email or mail” than UCB students and more

likely to select the option "I would discuss my concerns/interests prior to testing with a genetic specialist (physician, genetic counselor, nurse) for advice and then discuss my results with this specialist after receiving them", but the differences were not statistically significant.

Table 6: Frequency of responses to questions about previous genetic testing

		UCB		**SFSU**		p-value
Question	Response	Number	%	Number	%	
Personal medical condition (for example: breast cancer, hemophilia, muscular dystrophy, cystic fibrosis, developmental delay, other)	**Self**	**16**	**2.7**	**22**	**5.8**	**0.042**
	Family	**101**	**16.8**	**111**	**29.4**	**<0.001**
	Friend	47	7.8	47	12.5	0.052
	None	403	66.9	225	59.7	0.053
Paternity testing	Self	1	0.2	3	0.8	0.322
	Family	**11**	**1.8**	**22**	**5.8**	**0.003**
	Friend	**28**	**4.7**	**33**	**8.8**	**0.034**
	None	496	82.4	301	79.8	0.542

Controlled Comparison of Responses

In order to assess the differences and similarities between the participants responses based on university, regression analysis was performed to control for several covariates (Table 6). The analysis focused on determining statistically significant differences, or lack thereof, between respondent populations (UCB vs. SFSU) on genetics knowledge questions, awareness of genetic testing, exposure to genetic testing, and interest in genetic testing after controlling for confounding factors including several demographic factors. The variables controlled for when performing the analysis included: age, parental education, family income, when participants' parents moved to the US and admission type. Regression analysis reviewing the

percent of genetic knowledge questions correct while controlling for the previously stated variables showed that SFSU students scored lower than UCB students. Contrastingly, after adjusting for covariates, SFSU students were more aware of genetic testing options than UCB students were. Ordered logistic regression analysis was performed on the responses to the question "I have heard about and/or discussed genetic testing and personalized medicine through the following sources: school, internet, newspaper, television, work, home, doctor, friends, religious congregation, other". After adjusting for covariates, there was a statistically significant difference in responses between the two school populations in the "school", "newspaper" and "friends" categories where SFSU students were found to be less likely to hear about genetic testing from those sources than UCB students. With regards to other exposure related questions in the survey, SFSU students were found to have lower odds of reading, listening to, and/or watching mass media reports on genetic testing and personalized medicine than UCB students after controlling for covariates. Similarly, SFSU students were found to have lower odds of reading scientific literature related to research and discoveries in human genetics and personalized medicine than UCB students after controlling for covariates. Despite SFSU students having less exposure to genetic testing and personalized medicine by their own omission, they had an increase in the log odds of being in a higher level of "interest in testing", after adjusting for covariates, meaning they are more interested in genetic testing than UCB students after adjustment.

Table 7: Regression analysis results for study outcomes based on college

Topic	**LR**	**p-**	**95% CI**

	Coef.	value		
Genetics knowledge score	-4.3	<0.001	-5.62	-2.97
Awareness of genetic testing	0.71	<0.001	0.46	0.97
Exposure to genetic testing				
School	0.53	<0.001	0.27	0.79
Internet	0.33	0.012	0.07	0.6
Newspaper	0.66	<0.001	0.4	0.92
Television	-0.1	0.445	-0.36	0.15
Work	0.21	0.13	-0.06	0.49
Home	0.1	0.49	-0.18	0.37
Doctor	-0.02	0.9	-0.3	0.26
Friends	0.49	<0.001	0.22	0.76
Religious Congregation	0.41	0.076	-0.04	0.86
Other	0.17	0.61	-0.48	0.81
Interest in genetic testing	0.66	<0.001	0.39	0.93
Topic	**OR**	**p-value**	**95% CI**	
Mass media exposure to genetic testing	0.4	<0.001	0.28	0.59
Read scientific literature on personalized medicine	0.52	<0.001	0.36	0.74

DISCUSSION

This survey elucidated significant differences in awareness of and interest in genetic testing and personalized medicine between two different participating college student populations. The student populations shared some demographic similarities including gender profile, average age, life stage, and average personal education level. However, a few demographic factors were significantly different between the participant populations including family income and parental education level. Most importantly for the focus of this study, the two populations differed in their prior exposure to genetic testing and personalized medicine. Specifically, UCB students were exposed to genetic testing and personalize medicine at the start of their undergraduate education through the OTSP whereas SFSU students were not exposed to genetic testing and personalized medicine through the OTSP. In order to better understand the similarities and differences between the students' interest in genetic testing, the responses to demographic, genetics knowledge questions, and perceptions of genetic testing questions were analyzed by comparing the responses of the two student populations. Most importantly, the responses were compared after adjusting for covariates that were found to differentiate the two groups in order to understand the true differences between the cohorts.

The genetics knowledge scale asked participants to answer basic factual questions about genetics in order to assess similarities and differences between the two cohorts in their knowledge about genetics. After adjusting for factors that

differed between the two groups, UCB students scored 4.30% higher on average than the SFSU students. This indicates that despite accounting for differences such as age, parental education, family income, whether they started university as a freshmen or transfer student, and when the participants' parents came to the United States, UCB students still scored significantly higher on the genetics knowledge score than SFSU students. There are several reasons that could explain why UCB students scored higher on the genetics knowledge scale even after accounting for differences between the two populations.

One possible explanation is that UCB students are more knowledgeable about genetics because they have greater exposure to genetics and genetic testing because of the 2010 OTSP. However, a study by Jallinoja et al. in 1999 utilizing this knowledge scale found that previous exposure to genetic illness and testing did not increase participant's genetics knowledge score (Jallinoja & Aro, 1999). A study addressing knowledge of genetics two-years after exposure to genetic testing also found that exposure to genetic testing did not increase performance on the genetics knowledge scale (Calsbeek, Morren, Bensing, & Rijken, 2007). Several studies utilizing a genetics knowledge scale found that the most common factors associated with increased genetics knowledge were higher education, age (~20's-40's), and high socioeconomic status (Fitzgerald-Butt, Klima, Kelleher, Chisolm, & McBride, 2014; Henneman, Timmermans, & van der Wal, 2004; Molster, Charles, Samanek, & Leary, 2009; Morren, Rijken, Baanders, & Bensing, 2007). These findings do not explain the differences found in this study because this study surveyed students with

approximately the same level of education and the social status was taken into consideration when adjusting for covariates.

Analysis showed that after adjusting for covariates, UCB students were more likely to read, listen to, and/or watch mass media on genetic testing, read scientific literature on genetic testing, discuss genetic testing with friends and discuss genetic testing at school. Many studies have found that reading about or discussing genetic testing was associated with an increase in genetics knowledge (Henneman et al., 2004; Molster et al., 2009). Therefore, the fact that UCB students are more likely to read about and discuss genetic testing could be contributing to their increased performance on the genetics knowledge scale. An additional explanation for why UCB students performed better on the genetics knowledge scale than SFSU students after accounting for demographic differences could be that UCB is a more academically rigorous school and therefore the student body at UCB is, on average, stronger academically than SFSU students (US News, 2015). It is possible that increased exposure through the OTSP, reading and watching mass media on genetics and personalized medicine, reading scientific literature, and higher academic standards could all have attributed to UCB participants' better performance on the knowledge scale than SFSU students. Thus it is not possible to conclude exactly which factor or which combination of factors is contributing to UCB participants' better performance on the knowledge scale.

After adjusting for covariates, UCB students were less interested in genetic testing than SFSU students and in a lower category of perceived awareness than

SFSU students. Of note, prior to adjusting for covariates, chi-square analysis indicated that UCB students were significantly more interested in genetic testing and significantly more aware of genetic testing options than SFSU students. Thus factors such as age, parental education, family income, admission status, and when participants' parents came to the U.S. had an impact on the results of the interest and awareness questions.

There are several possible explanations for the finding that UCB students were less interested in genetic testing than SFSU students. Firstly, SFSU students increased interest could be related to their increased self-reported awareness of genetic testing options. Prior to adjusting for covariates, chi-square analysis indicated that UCB students were more interested in genetic testing than SFSU students. Thus factors such as age, parental education, family income, admission status, and when participants' parents came to the U.S. had an impact on the results of the interest questions. A study at Mt. Sinai School of Medicine in 2013 found that after students took a course about clinical whole genome sequencing and clinical genetic testing, their interest in having genetic testing increased (Sanderson et al., 2013). The researchers concluded that teaching students about the technical aspects of genetic testing as well as the clinical testing options allowed them to make a more informed decision and increased their interest in having testing. A similar study at Stanford University concluded that education on genotyping options did not lead to a significant change in students' interest in genetic testing (Ormond et al., 2011*)*. Bosompra et al. concluded that awareness of genetic testing options increased the

likelihood that an individual was ready to undergo genetic testing thus indicating that increased awareness of testing options increases interest in having genetic testing (Bosompra et al., 2000). This is an important finding in the context of genetic counseling as it demonstrates the importance discussing various options with patients as part of the decision making process. The finding that awareness of options increases interest in testing in this study is similar to the findings by Sanderson, et al. and Bosompra et al., thus further exemplifying the importance of educating consumers and patients on genetic testing options as part of the genetic testing decision making process.

Another possible explanation for the finding that UCB students were less interested in genetic testing than SFSU students could be that because UCB students have an increased understanding of genetics they are more critical of the benefits and implications of genetic testing. A study by Jallinoja and Aro found that higher levels of genetics knowledge led to more enthusiasm and more skepticism about genetic testing (Jallinoja & Aro, 2000). Several additional studies support the idea that positive attitudes about genetic testing may be inversely related to knowledge about genetic testing (Rose, Peters, Shea, & Armstrong, 2005). Contrastingly, a study analyzing the association between knowledge and attitudes about genetic testing for cancer risk in the general public found that greater knowledge is correlated with more positive attitudes about the benefits of genetic testing (Rose et al., 2005). There are mixed results regarding the relationship between knowledge of genetics and attitudes towards genetic testing, the results in this study imply an inverse relationship between

knowledge of genetics and interest in testing. However, it is important to consider that because there is mixed data on how genetics knowledge impacts interest in testing it could be that genetics knowledge is not the best predictor of interest, or lack thereof, in general.

A major goal of this study was to understand whether previous exposure to genetic testing and personalized medicine increased students' interest in genetic testing. In the literature, there is only limited information on this topic. After adjusting for covariates, it was determined that SFSU students were more interested in genetic testing than UCB students. This indicates that those with previous exposure to genetic testing and personalized medicine will not necessarily be more interested, on average, than those without previous exposure to genetic testing. Based on the analysis done in this study it is not possible to determine what impact exposure, or lack thereof, had on interest in genetic testing specifically. It is possible that awareness of genetic testing options is associated with an increased interest in genetic testing. There is limited data looking at how exposure to genetic testing impacts future interest in genetic testing. Many studies have analyzed what factors contribute to interest in genetic testing. Based on previous research significant predictors of interest in genetic testing include perceived risk of genetic illness, perceived barriers to testing, and beliefs about the clinical utility and benefits of results (Bosompra et al., 2000; Condit, 2001; Durfy, Bowen, McTiernan, Sporleder, & Burke, 1999; Etchegary, et al., 2010). To add to this list, the results of our current study suggest

that awareness of genetic testing options may be associated with increased interest in genetic testing.

In general several studies have determined that there are many factors impacting interest in genetic testing and that the issue is quite complex (Etchegary, 2014). This study confirms those findings while also adding an additional layer of understanding of the factors that influence knowledge of genetics and interest in testing by comparing the responses of two populations.

CONCLUSION

The current study compared knowledge of genetics, awareness of genetic testing options, exposure to mass media and scientific literature on genetic testing and personalized medicine, and interest in genetic testing between two 4th year college student populations (UCB and SFSU). Analysis found several similarities and differences between the two populations and elucidated some potential reasons for the differences in the responses. Of particular interest and importance are the results of the comparison of the genetics knowledge scores and interest in genetic testing after adjusting for covariates. The results indicate that previous exposure to genetic testing could have an impact on genetics knowledge but does not necessarily increase awareness of or interest in genetic testing. This study adds to the current literature on perceptions of personalized medicine and genetic testing while contributing more information on how educated young-adults understand the field of personalized medicine. Importantly, this study found that awareness of genetic testing options was correlated with an increased interest in genetic testing. This finding demonstrates the importance of the public being informed of the genetic testing options for utilization of direct access testing and/or for informed decision making during a clinical visit with a genetics expert. As noted in numerous other studies, there are many factors impacting interest in genetic testing, and the issues are quite complex. Further studies focusing on more detailed analysis of these various factors are clearly needed in light of the rapidly expanding utilization of genetic testing in comprehensive healthcare.

LIMITATIONS

Though this study contributed to the body of knowledge and research regarding awareness of and attitudes towards personalized medicine and genetic testing, there are some limitations to the study.

Several of the study's limitations are related to the respondent population and the generalizability of the study. There were not an equal number of participants from both school populations. Although the number of eligible SFSU student population was smaller than the eligible UCB student population, a greater proportion of SFSU students actually participated in the survey than UCB students. The differences between the numbers of participants in each population could have skewed the data to reflect more similarities and/or differences between the populations than truly exist. It is also possible that some students completed the survey more than once, as it is not possible in an anonymous survey to ensure that each person only completes the survey once. An additional limitation is that there was a limited ability to compare the respondent populations at each school to the general student population at each school. Therefore, it is hard to know whether the data is generalizable to the entire school populations. It was determined that there was a gender bias in the study populations from both schools, with more females participating in the study than males. It was also determined that there was an ethnic bias in participation that could have impacted the results of this study. Additionally, the overall response rate was 13% (11% at UCB and 19% at SFSU). The results of this study would be more generalizable if the response rate was higher. Another limitation is that the population

studied was very specific (fourth year college students) and therefore this study may not reflect the opinions of the general public. Lastly, there may be participation bias occurring in the sample population whereby those who are more interested in genetic testing and personalized medicine may be more likely to participate in the survey than those who are not interested in the topic or those who do not know what personalized medicine is. It would have been possible to control for this bias between the population by performing a regression analysis comparing the responses between the two student populations after adjusting for major in addition to the other variables controlled for.

The current study was able to analyze many factors and found several similarities and differences between the two school populations. Statistical significance was established for several of these differences but it is not possible to completely understand the reasons for these differences. Although the study included several different types of questions ranging from demographic information to genetics knowledge to awareness of and interest in genetic testing, the study could have contained additional questions to further evaluate similarities and differences between the populations. This could have allowed for a more robust analysis of what factors do or do not influence interest in genetic testing.

The study analysis and results are also limited by the inherent differences between the two student populations that cannot be accounted for. Most importantly, the two schools differ in their academic standing and the type of students they admit. It is possible that academic caliber of student admitted to and attending each

institution impacted the results related to understanding of genetic testing, exposure to genetics and personalized medicine and interest in genetic testing and personalized medicine. This difference cannot be analytically accounted for based on the information obtained through the study so this is a limitation in analysis and interpretation of the results.

A main focus of this study was to understand the impact of exposure to genetic testing and personalized medicine on interest in genetic testing. Comparing the UCB student's responses to the SFSU student's responses helped contribute to that understanding. However, to more fully understand the impact it is important to appreciate the difference in the UCB student's interest before and after exposure, which was not analyzed in this study.

FUTURE RESEARCH

Future research is needed to further explore factors that contribute to the general public's awareness of and interest in genetic testing and personalized medicine. A similar study focusing on the impact of genetics knowledge, demographic information, and awareness of genetic testing and personalized on interest with a different study population, such as the general public, would provide more generalizable information. Qualitative research on the general public or specific groups such as college students, including focus groups and semi-structured interviews, could provide deeper insight into individual's enthusiasms and reservations about personalized medicine and genetic testing.

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APPENDIX

APPENDIX A

STUDY SURVEY

Genetics and Personalized Medicine Survey				
1. If you agree to take part in the research, please print a copy of this page if you want to keep for future reference, then click on the "Accept" button below.				
2. What is your major? Check all that apply. Do not include minors.				
Answer Options				
Africana Studies				
American Indian Studies				
American Studies				
Anthropology				
Apparel Design and Merchandising				
Applied Mathematics				
Atmospheric and Oceanic Sciences				
Art				
Art, History of				
Art, Education				
Art, Studio				
Art, Studio and History of				
Asian American Studies				
Bachelor of Music				
Biochemistry				
Biology				
Biology- Botany				
Biology- Cell and Molecular Biology				
Biology- Ecology				
Biology- Marine Biology				
Biology- Microbiology				
Biology- Physiology				
Biology- Zoology				

Broadcast and Electronic Communication Arts				
Business Administration				
Chemistry				
Child and Adolescent Development				
Chinese				
Cinema				
Classics				
Communication Studies				
Communicative Disorders				
Comparative Literature				
Comparative Literature				
Computer Science				
Criminal Justice Studies				
Dance				
Dietetics				
Drama				
Earth Sciences				
Economics				
Engineering, Civil				
Engineering, Computer				
Engineering, Electrical				
Engineering, Mechanical				
English				
Environmental Sciences				
Environmental Studies				
Family and Consumer Sciences				
French				
Geography				
Geology				
German				
Health Education				
Hospitality and Tourism Management				
History				
Humanities				
Industrial Arts				
Industrial Design				
Interior Design				
International Relations				
Italian				

Japanese				
Journalism				
Kinesiology				
Labor and Employment Studies				
Latina/Latino Studies				
Liberal Studies				
Mathematics				
Modern Jewish Studies				
Music				
Nursing				
Philosophy				
Philosophy and Religion				
Physics				
Political Science				
Psychology				
Recreation, Parks, and Tourism Administration				
Social Work				
Sociology				
Spanish				
Special Major				
Statistics				
Technical and Professional Writing				
Urban Studies and Planning				
Visual Communications Design				
Women and Gender Studies				
If Other, please specify				
3. When you started at SFSU in 2010 were you a freshman or a transfer student?				
Freshman				
Transfer Student				
Other (please specify)				
4. What is your current age?				
Answer Options				
18				
19				
20				

21				
22-24				
25-29				
30 or older				
5. What is your gender?				
M				
F				
Other				
6. What is your race and ethnicity? (please choose all that apply)				
Answer Options				
I am an international student				
African American/Black				
American Indian or Alaska Native				
Chicano/Mexican American				
Other Latino				
Chinese				
Filipino				
Japanese				
Korean				
South Asian				
Vietnamese				
Other Asian				
Native Hawaiian or other Pacific Islander				
Eastern European Immigrant				
Middle Eastern				
White				
Other				
Refuse				
If Other, please specify				
7. What is your religion?				
Answer Options				
Spiritual but not associated with a major religion				
Not particularly spiritual				

Agnostic				
Atheist				
Buddhist				
Hindu				
Jewish				
Muslim				
Roman Catholic				
Other Christian				
Other religion				
If Other religion, please specify)				
8. When did you come to the United States?				
Answer Options				
Born in the United States				
Before the age of 13				
Age 13 or older				
9. Which of the following is true, to the best of your knowledge, regarding your parents?				
Answer Options				
Both of my parents were born in the United States				
Only my mother was born in the United States				
Only my father was born in the United States				
Neither of my parents were born in the United States				
Don't know				
Other (please specify)				
10. When did you learn to speak English?				
Answer Options				
English is my first language				
Before I was 5 years old				
When I was 6 to 10 years old				
After turning 11 years old				

11. What is the highest education level of your parent(s) or guardian(s)?					
Answer Options					
Less than a high school degree					
High school degree (or GED)					
Associate's degree or post-secondary certificate					
Bachelor's degree or post-baccalaureate certificate					
Master's degree					
Professional degree					
Doctorate					
Don't know					
12. To the best of your knowledge, what was your immediate family's annual income in 2013?					
Answer Options					
Under $20,000					
$20,000 – 34,999					
$35,000 - 64,999					
$65,000 – 99,999					
$100,000 - 149,999					
$150,000 or more					
Don't Know					
13. I have heard about and/or discussed genetic testing and personalized medicine through the following sources:					
Answer Options	Often (4+ times/month)	Sometimes (1+ time/month)	Rarely (1-2 times/year)	Never	
Class/at school					
Internet					
Newspaper or magazine					
Television					
At work/through co-workers					
At home/from family					
From my doctor or health care					

provider				
Friends				
Church/Mosque/Synagogue/Temple or other religious congregations				
Other				
If Other, please specify				
14. Check all that apply:				
Answer Options				
I have read, listened to, and/or watched mass media reports on genetic testing and personalized medicine such as Angelina Jolie having BRCA testing for breast and ovarian cancer				
I have read scientific literature related to research and discoveries in human genetics and personalized medicine				
I have not read, listened to, or watched any mass media reports on genetic testing and personalized medicine				
I have not read any scientific literature related to research and discoveries in human genetics and personalized medicine				
15. I am currently interested in having genetic testing related to health and personalized medicine				
Answer Options				
Strongly Agree				
Agree				
Neutral				
Disagree				
Strongly Disagree				
Refuse				

16. I am aware of available genetic testing options for health and personalized medicine such as Whole Genome Sequencing, Exome Sequencing, Direct to Consumer Genetic Testing, or Carrier Screening.				
Answer Options				
Strongly Agree				
Agree				
Neutral				
Disagree				
Strongly Disagree				
Refuse				
17. If I wanted to pursue genetic testing for myself related to health and personalized medicine...(choose ONE answer option that BEST describes what you would do).				
Answer Options				
I would order a test for myself and directly receive my results through email or mail				
I would discuss my concerns/interests prior to testing with a genetic specialist (physician, genetic counselor, nurse) for advice and then discuss my results with this specialist after receiving them				
I would order a test for myself and review results with a genetic specialist only after I had seen my results				
I am not interested in pursuing genetic testing				
Other (please specify)				

18. In general, my personal health is:				
Answer Options				
Excellent				
Very good				
Good				
Fair				
Poor				
19. I have a chronic disease or disability.				
Answer Options				
Yes				
No				
20. I am aware of medical condition(s) in my immediate family (my parents, sibling, child) that may be inherited or influenced at least in part by genes.				
Answer Options				
Yes				
No				
21. I am aware of medical condition(s) in my extended family (grandparents, aunts, uncles, first cousins) that may be inherited or influenced at least in part by genes.				
Answer Options				
Yes				
No				
22. To the best of my knowledge, I, myself, or an immediate family member (parent, sibling, child) or friend has had genetic testing for any of the following reasons. (Check all that apply)				
Answer Options	Self	Family	Friend	None
Personal medical condition (for				

example: breast cancer, hemophilia, muscular dystrophy, cystic fibrosis, developmental delay, other)				
Carrier screening where the person being tested does not have symptoms of the condition (for example: sickle cell, cystic fibrosis, Tay Sachs, other)				
Prenatal screening (for example: to detect changes in a fetus's genes or chromosomes before birth. This type of testing is offered during pregnancy if there is an increased risk that the baby will have a genetic or chromosomal disorder				
Paternity testing				
Direct to Consumer Testing for a potential future medical condition or for more knowledge of personal health (for example: 23 & Me)				
Testing to determine genetic ancestry (continental origin of ancestors and related information)				
Testing to find unknown relatives, family members				
Other*				
*Please specify other reason				
23. One can see a gene with a naked eye.				
Answer Options				
True				
False				
24. A gene is a disease.				
Answer Options				
True				
False				

25. A gene is a molecule that controls hereditary characteristics.				
Answer Options				
True				
False				
26. Genes are inside cells.				
Answer Options				
True				
False				
27. A gene is a piece of DNA.				
Answer Options				
True				
False				
28. A gene is a cell.				
Answer Options				
True				
False				
29. A gene is a part of a chromosome.				
Answer Options				
True				
False				
30. Different body parts include different genes.				
Answer Options				
True				
False				

31. Genes are bigger than chromosomes.				
Answer Options				
True				
False				
32. The genotype is NOT susceptible to human intervention.				
Answer Options				
True				
False				
33. It has been estimated that a person has 22,000 genes.				
Answer Options				
True				
False				
34. Healthy parents can have a child with a hereditary disease.				
Answer Options				
True				
False				
35. The onset of certain diseases is due to genes, environment, and lifestyle.				
Answer Options				
True				
False				
36. The carrier of a disease gene may be completely healthy.				
Answer Options				
True				
False				

37. All serious diseases are hereditary.					
Answer Options					
True					
False					
38. The child of a disease gene carrier is always also a carrier of the same disease gene.					
Answer Options					
True					
False					
39. The possibility of early detection of certain disorders using genetic (DNA) testing.					
Answer Options					
A lot					
A little					
None					
40. The significance of genetic (DNA) testing for my relatives.					
Answer Options					
A lot					
A little					
None					
41. The significance of genetic (DNA) testing for my offspring.					
Answer Options					
A lot					
A little					
None					
42. The possibility to use genetic knowledge to prevent or treat a					

disorder.				
Answer Options				
A lot				
A little				
None				
43. The possibilities and risks of gene therapy.				
Answer Options				
A lot				
A little				
None				
44. My right to refuse genetic (DNA) testing.				
Answer Options				
A lot				
A little				
None				
45. The consequences of genetic (DNA) testing for my daily life.				
Answer Options				
A lot				
A little				
None				
46. The consequences of genetic (DNA) testing for affecting health insurance.				
Answer Options				
A lot				
A little				
None				
47. My possibilities to apply for a genetic (DNA) test.				

Answer Options				
A lot				
A little				
None				
48. The rights of third parties to inquire about the results of a genetic (DNA) test.				
Answer Options				
A lot				
A little				
None				
49. Your own possibilities to participate in genetic (DNA) testing.				
Answer Options				
A lot				
A little				
None				
50. I am protected under Federal Law against genetic discrimination that could affect employment or eligibility for health insurance.				
Answer Options				
True				
False				
51. Based on the information provided above, how likely are you to have your whole genome sequenced?				
Answer Options				
Very Likely				
Likely				
Neutral				

Unlikely				
Very Unlikely				
Refuse				
Comments:				
52. Based on the information provided above, how much would you be willing to pay out of pocket for whole genome sequencing?				
Answer Options				
$0-$200				
$200-$500				
$500-$1000				
$1000-$3000				
>$3000				
Refuse				
53. The potential to receive extra results pertaining to my genetic and health information, such as a predisposition for heart problems, which are unrelated to my initial reason for testing, would impact my decision to have my DNA sequenced.				
Answer Options				
Yes				
No				
Not Sure				
Refuse				
54. Given the option to 'opt out' of receiving results pertaining to my genetic and health information, which are unrelated to my initial reason for testing, I would ____. (Please choose one)				
Answer Options				
Opt out of receiving the unrelated results. I would only receive				

results related to my initial reason for testing.				
Not opt out of receiving unrelated results. I would receive results for my initial reason for testing as well as other medical and health relevant results found through whole genome sequencing.				
I am unsure whether I would choose to receive the unrelated results or whether I would opt out of receiving the unrelated results.				
I would not have whole genome sequencing.				
Refuse				
Comments:				
55. Based on the information provided above, how likely are you to get your whole genome sequenced?				
Answer Options				
Very Likely				
Likely				
Neutral				
Unlikely				
Very Unlikely				
Refuse				
Comments:				
56. Based on the information provided above, how much would you be willing to pay out of pocket for sequencing?				
Answer Options				
$0-$200				
$200-$500				
$500-$1000				
$1000-$3000				
>$3000				
Refuse				

57. Based on the information provided above, how likely are you to get your whole genome sequenced?					
Answer Options					
Very Likely					
Likely					
Neutral					
Unlikely					
Very Unlikely					
Refuse					
Comments:					
58. Based on the information provided above, how much would you be willing to pay out of pocket for sequencing?					
Answer Options					
$0-$200					
$200-$500					
$500-$1000					
$1000-$3000					
>$3000					
Refuse					
59. Based on the information provided above, how likely are you to get your whole genome sequenced?					
Answer Options					
Very Likely					
Likely					
Neutral					
Unlikely					
Very Unlikely					
Refuse					
Comments:					

60. Based on the information provided above, how much would you be willing to pay out of pocket for sequencing?				
Answer Options				
$0-$200				
$200-$500				
$500-$1000				
$1000-$3000				
>$3000				
Refuse				