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Direct-to-consumer genetic testing in the college classroom: Knowledge, attitudes, and concerns of introductory biology students

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

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21 **ABSTRACT**

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

41 **INTRODUCTION**

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

58 The advent of this technology has generated much debate both in the
59 academy and in the public square (Bloss, Darst, Topol, & Schork, 2011; Callier, 2012;
60 Hogarth, Javitt, & Melzer, 2008; Mangin, Hudson, & Toop, 2012; Singleton et al.,
61 2012; Valles, 2012). Three categories of concerns are often raised. First, and most
62 important, some commentators are concerned about the clinical validity and
63 reliability of genetic tests that are marketed directly to consumers (Burke & Evans,

64 2011; Hunter, Khoury, & Drazen, 2008; Kuehn, 2010; Wallace, 2008). Disturbingly, a
65 systematic review of the evidence supporting the association between a particular
66 gene and a particular disease from seven direct-to-consumer genetic testing
67 companies revealed that only 38% of those reviewed in meta-analyses (57% of the
68 total genetic associations) were found to be statistically significant (Janssens et al.,
69 2008). Moreover, the findings of a United States Government Accountability Office
70 (GAO) investigation revealed that the results for identical DNA samples from four
71 prominent direct-to-consumer personal genomics companies were inconsistent and
72 in some cases, conflicted with the medical status or family history of the individual
73 who had supplied the DNA (Kuehn, 2010). As such, there have been calls to regulate
74 genetic testing to ensure a minimum level of efficacy and of safety (Caulfield, 2011;
75 Hogarth et al., 2008; Kaye, 2008; McGuire, Evans, Caulfield, & Burke, 2010; Valles,
76 2012; Wright & Gregory-Jones, 2010; Wright, Hall, & Zimmern, 2011).

77 Next, other commentators are worried that without proper explanation and
78 counseling, lay consumers will misunderstand their test results and experience
79 unnecessary anxiety (Gollust, Wilfond, & Hull, 2003; Ransohoff & Khoury, 2010).
80 They will not realize that most of the genetic risk factors uncovered by personal
81 genome testing are not deterministic but are only probabilistic in nature, because
82 most human diseases are complex traits whose genesis is influenced not only by
83 numerous genes but also by the environment. While there are companies that hire
84 in-house genetic counselors to speak to their customers about the results of their
85 genome scan, a majority of websites send their customers back to their personal
86 physician for a medical consultation. However, many of these primary care

87 physicians may have neither the expertise nor the time to accurately interpret
88 personalized genomics test results (Baars, Henneman, & Ten Kate, 2005; Caulfield &
89 Wertz, 2001; Greendale & Pyeritz, 2001; McGuire & Burke, 2008).

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

104 Despite these concerns, however, both Stanford University and Tufts
105 University have considered incorporating personalized genetics testing into their
106 medical school curriculum (Ormond et al., 2011; Walt et al., 2011). Stanford has
107 actually begun offering a course that has included an option for enrolled medical
108 and graduate students to undergo personal genotyping (Ipaktchian, 2010). Tufts
109 piloted a learning module in their medical curriculum that used data from

110 anonymous gene profiles rather than from students' personal gene profiles to
111 introduce students to personalized genomic medicine (Walt et al., 2011). Beth Israel
112 Deaconess Hospital in Boston has also established a first-in-the-nation resident
113 curriculum in genomic and personalized medicine (Haspel et al., 2010), and Temple
114 University and the Ohio State University have incorporated genetic testing into their
115 graduate pharmacy curriculums (Knoell, Johnston, Bao, & Kelley, 2009; Krynetskiy
116 & Lee Calligaro, 2009).

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

126 In this study, I assess the knowledge, attitudes, and concerns of college
127 students enrolled in the first semester of an introductory majors course in biology,
128 before and after they had completed the course, regarding the availability of this
129 technology and its possible use in the college classroom. This protocol allowed me
130 to determine the impact, if any, of completing an introductory course in genetics and
131 molecular and cellular biology on the students' survey responses. The pre-course
132 survey revealed that these students were open to the possibility of using this

133 technology in their courses, but they had concerns about the confidentiality and the
134 accuracy of their genetic results. Strikingly, however, completing the genetics,
135 molecular and cellular biology semester-long portion of the yearlong introductory
136 sequence in biology appeared to boost student confidence in this technology and its
137 use in the undergraduate classroom.

138 **MATERIALS AND METHODS**

139 *Participants*

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

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

161 *Survey Instrument*

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

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

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

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

200 The Institutional Review Board of Providence College (Federal Assurance No.
201 FWA00014558) approved this study. The survey instrument was prefaced with a
202 short description of the research project to fulfill the requirements of informed
203 consent. It included a statement that described the purpose of the survey, the
204 expected length of the survey participant's participation, and a description of the
205 survey, including expected benefits from the research project. It explained that
206 completion of the survey was completely voluntary, that it would not result in

207 compensation, or in the advent of non-participation, would not result in penalty, and
208 that it would remain completely anonymous. It also reassured survey participants
209 that the principal investigator, an instructor for one of the sections of the course,
210 would not know either the identities of the survey participants or the names of the
211 students who had not completed the survey.

212

213 *Data Analysis*

214 To ensure the anonymity of the respondents, responses were not paired. Therefore,
215 pre-course and post-course paired data analysis was not possible. Instead data for
216 each of the Likert-style questions was compared between the pre-course and post-
217 course surveys using the Chi-squared test to discern changes in the beliefs,
218 attitudes, and knowledge about direct-to-consumer genetic testing in the college
219 classroom. Differences were deemed statistically significant at a threshold level of
220 $p < 0.05$.

221 **RESULTS**

222 *Knowledge, Attitudes, and Concerns Regarding Personalized Genomics*

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

235

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

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

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

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

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

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

275

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

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

282 Table 2 lists the reasons given by the study participants for or against their
283 using a direct to consumer genetic testing service. Of the 47% of the students who
284 thought that they would take a personal genomics test, significant majorities of
285 them would take the test either to satisfy their general curiosity regarding their
286 genetic make up (82%) or to determine if a specific disease runs in their family
287 (87%). A majority (56%) would also want to take the personalized genomics test to
288 learn about the basics of human genetics. It is striking that a significant number of
289 respondents (85%) thought that consumers in general would take the test to obtain

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

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

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

309

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

312 Table 3 summarizes the survey responses that highlight the knowledge,
313 attitudes, and concerns of the participating students regarding the use of
314 personalized genomics in the college classroom. Significantly, a majority of students
315 who responded to the survey (52% Strongly agree or agree) believed that they did
316 not know enough about personal genetic testing to make a decision one way or
317 another regarding their participation in an in-class personal genetics testing
318 opportunity. Strikingly, the respondents were evenly divided (45% Strongly agree
319 or agree; 42% Strongly disagree or disagree) about consulting their parents about
320 their decision to participate in an in-class personalized genomics testing service.
321 Again, the group was evenly divided (34% Strongly agree or agree; 30% Neutral,
322 36% Strongly disagree or disagree) about consenting to take the in-class
323 personalized genomics test only if their parents agreed to their participation.

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

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

335 32% Strongly disagree or disagree) when they were asked if they would feel at a
336 disadvantage compared to their classmates if they themselves did not undergo the
337 genetic testing themselves.

338 With regards to their reasons for their taking the genetic test as part of a
339 college biology course, a significant majority of the respondents (72% Strongly
340 agree or agree) would see this as an opportunity to get a service for less than its
341 original price, and a majority would also see this as opportunities to get information
342 about their own health (65% Strongly agree or agree) or a family member's health
343 (67% Strongly agree or agree).

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

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

361

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

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

372 Not surprisingly, the post-course survey revealed that the students thought
373 that they knew more about human genetics to understand the results of a personal
374 genome test ($p=0.001$ as compared to the pre-course survey). They also were more
375 aware of the existence of commercial genetic testing services for the ordinary
376 consumer ($p<0.001$). Next, the respondents thought that after the course, they
377 better understood the risks and benefits of using personal genomic testing
378 ($p=0.027$). However, they were also more likely to ask a physician for help in
379 interpreting the results of a personal genome test ($p<0.001$), probably because they

380 were more likely to think that physicians are knowledgeable to help individuals
381 interpret results of personal genome tests ($p=0.016$). The survey respondents were
382 also less likely to think that personal genome companies should be regulated by the
383 federal government ($p=0.001$).

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

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

398 With regards to the use of personalized genomics testing in the college
399 classroom, the post-course survey revealed that the respondents were less likely to
400 think that their own genetic results mattered more than the genetic results of
401 someone else ($p<0.018$). However, they were more concerned both that they would
402 receive disturbing genetic results for themselves and for their families ($p<0.001$),

403 and that other people would discover genetic or health information about them
404 ($p < 0.001$). Not surprisingly, therefore, the post-course respondents were more
405 likely to take up the offer of genetic counseling before availing themselves of genetic
406 testing services ($p < 0.001$).

407 **DISCUSSION**

408 Simple genetic experiments that involve student testing of their own DNA
409 have already been included in the undergraduate curriculum to enhance learning in
410 the genetics classroom. For instance, Carolina Biological Supply Company sells a kit
411 that allows students to use PCR on their own DNA to predict their bitter tasting
412 ability (Catalog Item #211376). These laboratory exercises -- which highlight the
413 pedagogical first principle that the best way for students of all ages to learn science
414 is for them to actually do hands-on experiments (Cartier & Stewart, 2000; Dalton,
415 Morocco, Tivnan, & Mead, 1997) -- have sometimes raised some ethical concerns but
416 are not usually considered problematic (Rogers & Taylor, 2011; Taylor & Rogers,
417 2011). Incorporating direct-to-consumer genetic testing into the college classroom
418 will not be as straightforward.

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

428

429

430 *Concerns Surrounding Informed Consent*

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

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

453 beginning of the course. It should include descriptions of the benefits, the risks, and
454 the inherent technical limitations associated with personalized genetic testing.

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

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

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

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

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

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

517

518 *Concerns Surrounding Student Privacy*

519 Next, several commentators were concerned that the privacy of the incoming
520 UC Berkeley students would not be respected by the personalized genomics testing
521 companies (Jabr, 2011). In response, the university's administrators argued that the

522 personalized DNA samples provided by the students would be incinerated as soon
523 as testing was completed. However, it is clear that the results of the tests would
524 have been preserved electronically on computer servers at the personal genomics
525 companies. Indeed, one specific concern is that direct-to-consumer genetic testing
526 companies generally define their privacy policies in terms of "appropriate" use of
527 genetic information where it is unclear as to what does and what does not qualify as
528 "appropriate" use of personal genetic results (Fraker & Mazza, 2011). There is
529 always some risk that a customer's personalized genomics information could be
530 inadvertently divulged (Rothstein, 2010). Significantly, two scholars have
531 performed landmark studies demonstrating the re-identification of stored
532 anonymous health data (Malin & Sweeney, 2000, 2001).

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

543

544

545 *Concerns Surrounding Student Interpretation of their Genetic Test Results*

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

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

568 the time to accurately interpret personalized genomics test results (Baars et al.,
569 2005; Caulfield & Wertz, 2001; Greendale & Pyeritz, 2001; McGuire & Burke, 2008).

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

579

580 *Conclusion*

581 Direct-to-consumer genetic testing could potentially enhance student
582 learning in the undergraduate classroom by having students learn science by doing
583 hands-on experiments. My survey revealed that the college students who
584 participated in the study are willing to use this technology, but they also had
585 concerns about the reliability, the confidentiality, and the interpretation of their
586 genetic test results. However, the pros and cons of such a curricular novelty would
587 have to be considered by faculty and administrators with broad multidisciplinary
588 representation. They should especially consider the findings of a United States
589 Government Accountability Office (GAO) investigation, already discussed above, that

590 revealed that the personalized genetic tests used by several companies are not
591 reliable.

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762

763

**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

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

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		

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

**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 would 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