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Theme: Scientific Ethics

Ethical Considerations Regarding Classroom Use of Personal Genomic Information

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Rapidly decreasing costs of genetic technologies—especially next-generation sequencing—and intensifying need for a clinical workforce trained in genomic medicine have increased interest in having students use personal genomic information to motivate and enhance genomics education. Numerous ethical issues attend classroom/pedagogical use of students' personal genomic information, including their informed decision to participate, pressures to participate, privacy concerns, and psychosocial sequelae of learning genomic information. This paper addresses these issues, advocates explicit discussion of these issues to cultivate students' ethical reasoning skills, suggests ways to mitigate potential harms, and recommends collection of ethically relevant data regarding pedagogical use of personal genomic information.

Fulfillment of the promise of genomic medicine rests, in part, on the development of a trained workforce, including laboratory technicians and directors, genetic counselors, pharmacists, and clinicians, as well as increased scientific literacy among the public. Substantial need to identify effective methods to teach about genetic testing and genome sequencing has prompted interest in using "hands-on" testing/sequencing of students' own genomes in secondary-school classrooms, college courses, and professional schools (13, 25). Supporting employment of this hands-on approach are studies showing that college students are more likely to enroll in a course offering personal DNA testing and that they find the course more interesting and the material easier to grasp when personalized in this way (4). Seventy percent of Stanford medical students having personal genetic testing as part of their curriculum, for example, believed that it enhanced their understanding of human genetics (19). Undergoing testing and using personal data in class exercises were found to enhance self-reported and assessed learning. Given such reports of educational benefit, a growing interest in courses incorporating such testing (1), and the rapidly decreasing cost of genome sequencing (14), there is—and should be—increased attention to the ethical issues associated with incorporating personal genomic testing/sequencing into curricula (3, 17). This paper examines the types and technologies of testing and the particular issues raised by each; issues specific to the educational context; issues of privacy (including risks of discrimination and stigmatization); issues surrounding the right to know/not-know personal information; and subtle psychosocial sequelae of learning personal genomic information. In addition, the paper both proposes measures to mitigate ethical concerns associated with the curricular use of personal genomic testing/sequencing and suggests how classroom discussion of these ethical concerns can be used to prompt consideration of ethical issues related to research design and conduct.

ISSUES ASSOCIATED WITH PARTICULAR TECHNOLOGIES

Chromosomal analysis (karyotyping) of one's own blood is a long-standing classroom exercise. Students and teachers have long needed to be prepared to address the unexpected discovery of an abnormal karyotype; for example, a female student's rare discovery that she has a 46,XY karyotype indicating that she has complete androgen insensitivity syndrome, is sterile, and may need evaluation for cancer risk. Her discovery would explain her amenorrhea, but is a discovery better made under the care of a physician, not in high-school biology class. Similarly, chromosomal analysis may reveal a balanced translocation (with relevance for reproductive planning), chromosomal inversion (of potential relevance to fertility), or mosaicism of sex chromosomes (e.g., 46,XY/47,XXY mosaicism resulting in a rare, mild, and frequently undiagnosed form of Klinefelter syndrome). Educators asking students to karyotype their own chromosomes should be prepared to refer students to appropriate physicians or genetic counselors and should discuss the privacy of health-related information including karyotypes,

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as unthinking self-disclosure is a primary risk to the privacy of health-related information.

Genetic testing reveals variations in the DNA that are associated with a range of traits including eye color, (in)ability to taste bitterness, continental ancestry, alcohol tolerance, and disease risk. How genetic testing is actually performed for classroom use varies. Sending student samples for analysis by commercial direct-to-consumer companies fails to provide students with hands-on experience in laboratory techniques (e.g., DNA extraction and amplification) that they may gain by running polymerase chain reactions on their own DNA. In-class genotyping to identify polymorphisms may focus on DNA fingerprinting or identification exercises, or on analysis of genes associated with traits or disease conditions. The latter borders on—and may constitute—medical testing, which raises issues about quality control and the (likely) failure to conduct the test in a laboratory certified under the Clinical Laboratory Improvement Amendments (CLIA certification), as well as the ethical concerns arising with any medical test: e.g., informed consent, appropriate use of test results, and privacy protection. Attempting to avoid these concerns, educators may avoid testing exercises focused on disease-associated genes, particularly when students analyze their own genes and/or access their own test results. Educators may instead focus on obvious phenotypic traits (e.g., eye color) or non-deleterious variations like the PTC gene, TAS2R38, that codes for a taste receptor enabling or preventing people from tasting phenylthiocarbamide (PTC), a bitter-tasting compound. Nevertheless, it must be remembered that pleiotropy, whereby one gene can influence more than one phenotypic trait, can result in seemingly benign findings acquiring health-related import as knowledge of genetics grows.

Particularly if the class is large enough, another approach is to treat the class as a population with the students' individual test results forming an aggregate data set for further study. The students can test their own DNA; those who prefer not to can be supplied with alternate samples. With this approach, focusing on disease-related polymorphisms might be deemed less problematic if individual testing is done anonymously (i.e., with no results returnable to individuals). Commentators expressed concern about one classroom exercise employing anonymous testing (21), both that "several participants could potentially identify their results by examining the data, illustrating one disadvantage of working with a relatively small sample size," and that the educators did not indicate whether students could, in fact, opt out of personal testing and work with other samples (18). If the total number of participants is small or if there is limited diversity in the sample (e.g., only a few male students, or only a few of Asian continental ancestry), a trait that segregates with genotypes indicating the minority sex or the distinctive continental ancestry may be attributed to those few students in the class, raising question about the protection of their privacy even if only aggregate data are analyzed. Explicit classroom discussion of this concern may be used to introduce a broader discussion of how various types of research can affect community interests, as well as methods of protecting those interests, including community consultation or consent (26).

Whether or not disease-related polymorphisms are studied, classroom testing may raise some of the issues arising with clinical carrier testing. Knowing patterns of inheritance of particular genes, for example, enables prediction of the likelihood that the offspring of a genetic mother-father pair will inherit a particular gene. Similarly, in reverse, knowing inheritance patterns and an individual's genotype can enable estimation (with limited accuracy and barring spontaneous mutation) that persons with particular genotypes are the individual's genetic parents. Thus genetic testing of mother-father-child trios (unlikely in an educational context)—or in the case of some traits, knowledge of the parents' phenotypes (likely)—can indicate a student's misattributed parentage (frequently, misattributed paternity, but also previously undisclosed adoption or use of a gamete donor). Inheritance patterns can raise questions about familial relationships even in the case of presumptively neutral traits like bitter taste perception, as the ability to taste PTC is a dominant genetic trait (and thus at least one parent of a student who can taste PTC should also be able to taste it). When planning for and discussing the potential for such discoveries through classroom testing, instructors may explore the research ethics issue of managing incidental findings that arise in multiple research domains (28).

Next-generation sequencing technologies determine the order of nucleotides in a single gene, genetic region, or across the whole genome (in the case of whole genome sequencing, WGS). Less costly than WGS is sequencing of the protein-coding genes in the genome (the exome, approximately 1% of the genome) in which variations are more likely to have phenotypic relevance. Sequencing of single nucleotide polymorphisms (SNPs, a single base pair mutation at a specific locus) can reveal variations of relevance for both understanding disease risk and pharmacogenomics. Although the cost of both genome and exome sequencing is falling at a rate exceeding Moore's Law, access to even the $1,000 exome is not widely available and is out of reach for most classroom use (2). For educational exercises, genotyping of students' personal genomes typically involves collecting samples (typically saliva) and sending them to a commercial company (e.g., 23andMe), whose charges are within the budgets of many undergraduate and graduate students or their schools' course budgets. More rarely, samples may be run on university-owned sequencers, potentially affording students "hands-on experience of detecting, analyzing and interpreting DNA variants to determine, for example, whether or not they are of clinical significance" (20).

Currently, personal genomics companies are prohibited from returning health-related genetic information (24). They are thus generally limiting themselves to reporting genetic ancestry, though they had provided disease-risk information in the past and may once again if they satisfy

concerns raised by the Food and Drug Administration. Companies like 23andMe do return raw data—SNPs—to those who submit samples, and individuals can use web-based resources (e.g., Interpretome or Promethease) to analyze their own results at pharmacogenomic- or disease-relevant loci. Astute students can thus obtain disease-risk and pharmacogenomics information as a result of current classroom sequencing exercises (15). Of scientific, and thus ethical concern, is the accuracy of data returned by personal genomics companies. During the time that they were returning disease-risk results, when the Government Accounting Office investigated the accuracy of companies' reports, results for identical DNA samples sometimes varied between companies and sometimes conflicted with the medical status of the donor (16).

In addition to having obvious implications for students' reliance on test results, discussion of such conflicting and thus erroneous results can motivate classroom discussion of the ethical importance of reporting accurate information. Reporting individual or aggregate research results that fail to meet rigorous standards of validity risks undermining public confidence in scientific research. Discussion of the gravity of scientific misconduct, as well as the confidence-eroding effects of failing to acknowledge the limitations of one's study or of overstating the importance of research findings, can follow from initial discussion of what students' personal genomic information can (and cannot) tell them and with what degree of confidence.

INFORMATION-RELATED ETHICAL ISSUES

Accurate or not, information presents three sets of ethical issues attending genetic testing/genomic sequencing in any context. The first concerns privacy and the reasons that individuals want to keep their information private. So-called privacy absolutists simply want to control access to personal information about themselves, either in general or with regard to particular types of information or potential audiences for it. Students who share a lot about their dreams, worries, or weekend activities with friends in person or on Facebook, for example, may want to withhold such information from parents or others. Some privacy concerns relate not to control *per se*, but to the consequences of information's disclosure. Health-related information is regarded as private not only because it may be relevant to personal, even intimate states of affairs and decision-making, but also because its discovery by others presents risks of stigmatization or discrimination. While social responses (stigmatization) cannot be legislated against, in 2008 the Genetic Information Nondiscrimination Act did prohibit discrimination in the United States by employers and health insurers on the basis of genetic information. Using such information in underwriting life, long-term care, automobile, or other insurance, however, is not prohibited. Insurers, who fear the purchase of substantial insurance by those whose genetic testing suggests they are accident prone or at increased risk of late-life dementia, may wish to deny such insurance or charge higher premiums. Whether particular classroom exercises present students with such information about themselves or not, educators should "practice preventive ethics" (7): they should anticipate issues that may arise imminently or, more likely, in the future, and prepare students to address them. In particular, students who may not anticipate future uses of health information should be cautioned that current self-disclosure of personal genetic information may make that information permanently accessible, for example if it is shared within social media or within social or family circles. Moreover, discussion of the protection of their own health information provides a context to consider the short- and long-term risks to privacy of research participation.

The second constellation of ethical issues centers on the right to know personal information about oneself and the concomitant right not to know. It is hard to imagine students who would prefer to live in "blissful ignorance" of their PTC gene status; indeed, they likely already know whether they can taste bitterness in coffee or dark beer. Many health conditions and risks may be well-known to students based on their family or personal medical history. For some, however, learning genetic information would not be welcome. Even pharmacogenomic information—seemingly benign or almost unqualifiedly helpful—could be unwelcome or could exacerbate underlying problems: while one student, struggling to treat his depression, might find it comforting to learn that genomic variation may account for his difficulty finding an anti-depressant that "works," another student's depression may be worsened by learning that his genotype will make it especially difficult to find effective treatment.

Finally, information that individuals believe they want may have unexpected and subtle psychosocial sequelae (8). Some young women who sought clinical genetic testing for breast cancer risk were nevertheless surprised to find that a positive result altered the way they viewed themselves and their futures, as well as their relationships. In qualitative studies, they reported feeling like "damaged goods"; feeling pressure to speed up dating, marriage, and reproductive plans; altering career paths; and feeling "out of synch" with their peers, like one BRCA+ woman who experienced ambivalence about her breasts while her friends were focused on more frivolous things like how clothing flattered their bustline (9, 10, 11, 27). The ethical implication of these sequelae is that educators have an obligation to practice preventive ethics to anticipate and mitigate the negative impact of learning personal genomic information. Consideration of the possible impact of learning genetic information should be a part of informed decision making and/or informed consent. Moreover, explicit classroom discussion of such potential impact may be used to introduce discussion of researchers' obligations to identify, mitigate, and disclose risks of their research, including risks to human participants.

Even with regard to less weighty genetic information—specifically the sort of genetic ancestry information

currently available from personal genomics companies—upon receiving results, students have expressed surprise and not uniformly positive reactions. In 2005, Samuel Richards used genetic testing in his Pennsylvania State University sociology class to demonstrate "to students how complex race and ethnicity are" (5). His colleague in anthropology and genetics, Mark Shriver, took cheek swab samples from 100 class volunteers for a test Shriver developed with partners at DNAPrint Genomics to measure genetic admixture in populations (because of the relevance of continental ancestry and admixture for clinical drug trials). Richards believed that if DNA results indicated continental ancestry differing from students' initial beliefs about their race, they might be more open to differences and have deeper discussions about race. Instead the results seemed to reinforce racially constructed categories (12), with one student saying, for example, "I am 48 percent white—genetically … but not culturally. And the fact that I'm black is more important … It's who I'm comfortable with. … Just because I found out I'm white, I'm not going to act white. I'm very proud of my black side" (5). The *New York Times* headline reporting the study, "DNA Tells Students They Aren't Who They Thought," suggests how DNA findings can disrupt individual identity and familial understandings of ancestry, cultural origins, and relationships (5). For some, DNA evidence of ancestry admixture, for example between those of European and African descent, may raise previously unconfronted questions of sexual relations—consensual or not, recent or distant—between individuals of different culturally-defined races. Educators using genetic ancestry information need to recognize and prepare to address such intrafamilial or historical questions (e.g., the legacy of rape of African-American slaves by European-American slave owners, or miscegenation laws).

Moreover, some social benefits attach to having a particular ethnic or racial identity, e.g., eligibility for scholarships or organization membership, or entitlement to settlements from legal disputes or to particular revenue streams (e.g., receipt of revenues from businesses run by Native American nations or tribes). It remains to be seen how a scholarship committee (or students themselves) might interpret the eligibility of a student who has always self-identified as Black or African-American, but whose classroom DNA test reveals him to be, for example, 62 percent European. When tribal membership—usually established on the basis of tribal group relations, a tribal land-base, and cultural continuity—is contested, individuals or tribes may employ DNA analysis, though thus far its legal status is not established and genetic markers usually cannot identify tribal membership (6, 22). Both science and law, however, evolve.

Finally, it is instructive to note that the results of DNA-testing of Richards' students were stored in Shriver's research database. This arrangement raises the usual research ethics questions regarding informed consent, consent to subsequent research use of the results, whether and how individuals can withdraw their results, third-party access to results (with or without court order), and whether students will be informed of any findings (individual or aggregate) of future research employing their results.

TESTING IN THE CLASSROOM CONTEXT: EDUCATION, RESEARCH, AND THE ROLE OF INSTITUTIONAL REVIEW BOARDS

Testing/sequencing in the classroom presents a special set of issues because of the opportunity for students to feel pressured—by peers or faculty—to acquire genetic information about themselves that they do not want. While there is a dearth of empirical data regarding whether students actually feel such pressures (20), students have recognized that the opportunity to receive personal genome sequencing at no cost to them may constitute a substantial benefit. Whether receiving a ($100+) service that most admit they would not get if they were paying for it themselves (20) constitutes the equivalent of "excessive compensation" that would be prohibited by an institutional review board (IRB) in the research context is an open question that likely depends on contextual factors surrounding individual students and courses (e.g., whether it is required or elective). Classroom discussion of broader ethical questions of pressure to participate in research, informed autonomous decision making, and appropriate levels of compensation of research participants may be pursued when presenting opportunities for personal genome testing. "Empirical evidence addressing whether students are making independent, informed decisions about analyzing their own personal genomes and whether efforts to help students make informed decisions are successful would shed valuable light on a major ethical concern surrounding personal genomes in the classroom" (20). In the absence of such data, given the empirical data that are reported on student uptake of offers of personal genomic testing and their positive responses regarding its educational impact, it is reasonable to assume that while a substantial majority of students at all levels may be interested in personal testing, a minority may not. Care must be taken when incorporating personal genomic testing into course curricula, as some students may not only feel pressured to participate, but also worry that opting out, if permitted, may indicate that they know or suspect something about themselves that they do not want to confirm or enable others to learn.

Provision of alternate, non-personal samples for students to use for class exercises—particularly if fellow students and faculty members remain uninformed of a student's choice of the alternative—may maximally shield students from pressure. In the case of testing that yields raw SNP data, students may be invited to submit saliva samples on their own to a designated personal genomics company. The company should have its own consent process that explains privacy protection measures. Students may then submit their own data for inclusion in the class data set, or may pick up

one of the alternate non-personal samples or testing reports (depending on the nature of the planned exercises) to use for class exercises.

Even if it is not a research activity, educational use of personal testing/sequencing might be helpfully reviewed by an IRB or other body experienced in identifying and mitigating risks to privacy and pressure to participate. When research is conducted on the educational process employing personal genome information, it can be complicated to determine whether the activity constitutes research involving human subjects that should be reviewed by an IRB or whether it qualifies for exemption under 45 CFR 46.101(b)(1) because it is "conducted in established or commonly accepted educational settings, involving normal educational practices, such as (i) research on regular and special education instructional strategies, or (ii) research on the effectiveness of or the comparison among instructional techniques, curricula, or classroom management methods" (23). Particularly when the instructional technique under study involves genomic testing/sequencing, something that in a non-educational context would require the informed consent of the person tested, it seems wise to consult an IRB about the status of the activity. Especially if a commercial company employing its own consent process is not utilized but testing is done "in house" or classroom, consideration should be given to obtaining students' informed consent, and this process may be used as an opportunity to teach this fundamental doctrine of research ethics. Even if informed consent is not considered necessary, enabling students to make an informed decision about participating is ethically required.

The process of facilitating informed decision making has been studied by one group at the Icahn School of Medicine at Mount Sinai where instructors designed a 26-hour introductory course discussing ethical and psychosocial implications of genetic testing/sequencing, including familial and reproductive implications, as well as the scientific and technological foundation for analyzing and interpreting WGS results, and the limitations thereof. Students were also told that if they chose to work with their own WGS data later in the course sequence, they could exclude data they did not want to see. Following completion of the introductory course, there was a shift from 47% of students saying that they were able to make an informed choice about analyzing their own genomes to 84%. Those affirming that they "knew the risks" similarly rose from 47% to 90%, and fewer students were concerned about the consequences of others learning their genetic information and about their privacy. An increased number expressed belief that using their own genomic information would have educational benefits not afforded by using others' results (22). Despite its employing a small sample (n = 19) of self-selected, motivated, genetics-focused students, this study suggests that students' decision making about using their own genomic information can be enhanced. Further study would be required to determine whether a 26-hour course is necessary, or which components of it were most important to their enhanced decision-making ability.

Finally, the very idea of using personal genomic testing as a pedagogical tool may be usefully discussed with students as a way of introducing broader questions about the use of resources (in education and, by analogy, in research) and of agenda-setting in science. Despite substantial interest among educators in employing personal genomic testing to enhance learning, one study found that taking a core genetics course substantially reduced students' belief that working with their own genomic information would enhance their learning more than using others' (from 67% pre- to 45% post-course) and lowered their perceptions of the usefulness of genomic information for themselves, physicians, and patients (17). Nevertheless, roughly the same proportion (57% pre- and 55% post-) remained interested in learning their personal genomic information, with general curiosity being the primary reason given before and after the course (96% and 94%). In light of these findings, instructors and students might have productive discussions of the appropriateness of employing expensive genomic testing/sequencing technologies to satisfy curiosity or to compete for enrollment against other courses using "cutting-edge technology." Instructors may draw analogies to broader issues in research ethics such as the multiple influences on determination of which research questions are worth pursuing and investigators' responsibilities to help the public interpret and assign value to findings.

CONCLUSION

Careful consideration of how to enable students to make informed decisions about obtaining and using their personal genomic information in educational contexts is incumbent upon educators. In addition, instructors should anticipate and take measures to mitigate risks to privacy and potential negative psychosocial sequelae. Just as currently unknown pleiotropy can result in seemingly innocuous genetic information having health relevance in the future, what instructors do not know about their students' personal circumstances and preferences may render seemingly innocuous exercises or information problematic for some students. These risks should be neither overblown nor ignored. With thoughtful planning, many can be mitigated. Moreover, explicit discussion of these ethical considerations provides an opportunity to enhance students' research ethics skills by encouraging consideration of underlying ethical values and issues pertinent to multiple research contexts.

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