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# Intro Course Helps Students Decide Whether to Analyze Their Own WGS Data, Mount Sinai Study Shows

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**A study by researchers** from Mount Sinai's Icahn School of Medicine has shown that enrolling students in a prerequisite introductory class helped insure they made informed decisions on whether to analyze their own whole genomes in a follow-on course on clinical interpretation of whole-genome sequencing data.

The study, published late last month in *Genome Research*, followed 19 students enrolled in a 26-hour introductory genomics course designed to help them make informed decisions about whether to receive free whole-genome sequencing and analyze their own data in a subsequent semester's advanced genomics course, or to use an anonymous genome.

According to the group, the results indicate that the intro course did affect students' decision making, and, in the small cohort, resulted in all 19 students opting to analyze their own genomic data.

"We want to make sure the students have a good understanding of the type of information that they might receive (and the limitations thereof) and [that they] have time to consider that information, consult family/partner/friends … and/or health professionals, such as a genetic counselor, prior to making a decision," Mount Sinai's Eric Schadt and Michael Linderman told *Clinical Sequencing News* in an email this week.

"Thus there is then both an educational and time motivation to the separate introductory course. And as a practical matter, we need 8+ weeks to complete the sequencing and so need to create time for that in the schedule as well," the two wrote.

Mount Sinai is not the first university to offer students the chance to analyze their own genetic data, nor is it the first to study how this affects them.

Stanford University has previously published data on its elective genomics and personalized medicine course in which students could obtain microarray-based genetic testing from a choice of personal genetics companies at a discounted rate, tracking students' feelings about the value of the results they received, and the impact on learning and retention of using ones own genetic data. According to the Mount Sinai team, these two studies were previously the only ones to have collected empirical data regarding students' actual experiences of obtaining personal genomic information in the educational setting, and neither dealt with issues and potential gains to be had by having students analyze their own entire complex WGS datasets rather than already interpreted genotyping-based results.

The Mount Sinai team hopes their new study will add to the empirical evidence informing an ongoing debate about whether individuals in an educational setting, or in everyday life, should have the option of accessing their own genomic data, especially whole-genome data, and what the potential risks and benefits of this access might be.

In the study, researchers assessed students' intentions, informed decision making, attitudes, and knowledge using questionnaires completed before and after the Mount Sinai introductory course, and then again before the advanced course.

Students had one and a half months after the intro course in which to consider their decision before having a blood sample drawn for WGS, and had "many support resources made available to them including genetic counselors both within and outside of the institution, and access to the student mental health services," the study authors wrote.

The group analyzed the questionnaires using a measure called O'Connor's Decisional Conflict Scale to mark changes in students' "decision uncertainty," under the premise that such changes may be viewed as indicators of the influence of informed choice interventions: in this case the introductory course.

At the start of the intro course, which took place in the summer of 2012, 17 of the 19 students reported that they intended to receive their personal WGS data in the subsequent course, "but many expressed conflict around this decision."

According to the study authors, the Mount Sinai course introduced students to scientific fundamentals required to assemble, analyze, and interpret WGS data, as well as to potential risks and benefits and ethical and psychological issues. Students were also informed that if taking part in the advanced course using their own data, they could exclude discrete categories of data they did not wish to see or analyze while including others.

According to the authors, at baseline, before the intro course, the mean overall decisional conflict scale score was 33.9 plus or minus 18.2, which is lower than the upper cutoff of 37.5, over which scores indicate clearly unsure feelings.

The baseline scores also exceeded the lower cutoff of 25, under which scores are associated with implementing decisions. Overall, this suggested that the students had some conflict around their decision of whether or not to have their genome sequenced.

This conflict decreased after the introductory course — for example, the proportion of students who reported making "an informed choice" increased from about half at baseline to 84 percent at the end of the introductory course — but did not change again before the advanced course, which took place in the fall of 2012, the researchers reported.

According to the authors, this suggests it was the introductory course content "rather than simply time passing," that caused this change in conflict. In the end, in the advanced course, all 19 of the students ended up opting to receive their personal WGS data.

The sequencing was performed in the Mount Sinai CLIA-certified sequencing core, Schadt and Linderman said in their email.

During the advanced course, instructors did not provide any direct interpretation to the students. "The students receive the raw data and proceed with the analysis themselves over the course of the semester guided by the course material/instructors [which cover] sequencing technology, short-read alignment and variant calling algorithms, ancestry, GWAS for physical traits and disease risk, genetically informed risk prediction, variant interpretation in clinical contexts, and the communication of genetic information," they wrote.

Of the 19 students enrolled, five were genetic counseling masters students, three were medical genetics residents, three were MD/PhDs, three were PhD students, two were medical students, two were junior faculty, and one was a genetics fellow.

Admittedly, this is a select, and self-selecting group, whose experiences with exposure to their whole-genome data, and to making decisions about receiving whole-genome data, can't be generalized to a larger population.

Additionally, the authors wrote that the finding is limited by "the fact that the students in our study were able to obtain and keep their personal genome sequence data at no financial cost to them," which "could clearly have been a significant incentive to them to participate and have their genomes sequenced, perhaps trumping even significant concerns or worries about risks that they might have been feeling."

According to Schadt and Linderman, the intro and advanced genomics courses are now ongoing at Mount Sinai — offered once every year. "The introductory course is steadily expanding to serve more of the institution [and] we had over 30 students last year," they wrote.

Informed by the results of the study of the 2012 class population, the two authors also said some changes have been made to the curriculum, including "additional content around the kinds of information [it] is possible to learn and the subset of that information that is "easy" to learn" from one's genome.

"We want to make sure students aren't 'surprised' by information, and that their expectations for the kinds of information they will encounter are well-calibrated," they wrote.

According to the two, the team also has another paper in the works on the program, which will deal more on how the introductory course may or may not have mitigated the possibility of students feeling coerced into viewing and interpreting their own genomic data.

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