

HELA'S ANCESTORS

Teaching about Race and Science

A guide to teaching with Rebecca Skloot's *The Immoral Life of Henrietta Lacks*

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Rebecca Skloot's masterpiece of science writing, *The Immoral Life of Henrietta Lacks* (2009), tells the story of how American science developed the ability to culture and grow cell lines in science laboratories—and how this development is intimately tied to the story of one woman, her family, and their unfortunate experiences with racial and health care inequality in the United States. My goal in this Teaching Guide is to explore some of the ways in which Henrietta Lacks's story emerges from a larger history in which people of color have been mistreated by the scientific establishment in so very many ways. While Skloot alludes to some of these issues, her book is better understood as a biography of the HeLa cell line—and thus, it is up to those of us who use the book in our classrooms to ensure that we teach the book not only as the story of one poor woman and her family's suffering or as the story of the casualties of scientific progress but instead as a chronicle of one incident in a litany of incidents that make up the history of racial science in our nation.

While there are many ways to approach these topics, this teaching guide will focus on three particular aspects of the history of race and science of relevance for teaching and learning in the context of *The Immortal Life of Henrietta Lacks*: (1) race, ethics, and experimentation in relation to the development of protections for human subjects in research; (2) the history of attempts to “scientize” racial inequality; and (3) race-based medical practice. In each case, this teaching guide will briefly review the relevant historical and contemporary issues and provide suggestions for in-class exercises or assignments designed to enhance student learning around these issues.

RACE, ETHICS, AND EXPERIMENTATION

The United States has a long history of experimenting on people—particularly people of color—without informed consent. Henrietta Lacks’s experiences comprise only one chapter in this history. Here, I will briefly review several significant episodes in this history and discuss the importance of these developments to the emergence of Institutional Review Boards (IRBs). While this history really begins with the Nazi medical experiments (discussed below), I will concentrate here on the Tuskegee Syphilis Study and on the revelations in 2011 about sexually-transmitted disease research conducted without consent on Guatemalans.

Despite the fact that the Tuskegee Syphilis Study is one of the best-known examples of unethical research in the United States, few undergraduates have heard of it. The study, which was conducted under the auspices of the U.S. Public Health Service, was concerned with documenting the progression of untreated syphilis. At the beginning of the study, in the 1930s, treatments for syphilis were generally ineffective or had intolerable side effects. For example, mercury was often used as a treatment, but caused severe ulcers in the mouth (and mercury poisoning itself can be fatal). Participants were offered medical care (except for syphilis treatment) and food, and their families received burial stipends when they died (Skloot 2009). So far, so good, right? But by the time the study ended, in the early 1970s, medical professionals had known that penicillin would cure syphilis for several decades, and yet researchers had not provided penicillin to participants in the Tuskegee study. Indeed, researchers had at times actively worked to prevent participants from receiving treatment. This story is so horrible that it hardly needs embellishment, and yet the myth of Tuskegee became even worse than reality in the minds of many Black Americans. As Skloot details on page 186, it became common belief that the Tuskegee study had involved the deliberate infection of Black men with syphilis.

While the U.S. Public Health Service did not inject Black American men with syphilis, it did inject the bacterium into Guatemalans in a separate study. That study, which only recently came to light, was conducted between 1946 and 1948 and involved approximately 5,500 individuals, at least 83 of whom died (McNeil 2011). During the study, prostitutes infected with syphilis were paid to have sex with prison inmates. Additionally, syphilis bacteria were purposely placed in wounds made for this purpose on subjects’ faces or genitals, and some were infected through punctures to the spine or the base of the skull (McNeil 2011; Presidential Commission for the Study of Bioethical Issues 2011). Subjects were not compensated for their suffering and not all received appropriate medical treatment. More details about the study can be found in a report issued by a White House commission established to investigate the matter (Presidential Commission for the Study of Bioethical Issues 2011) as well as in the John D. Cutler Records at the National Archives (<http://www.archives.gov/research/health/cdc-cutler-records/>).

It was episodes like these that lead to the development of the IRB as a body responsible for protecting the rights of human subjects in research. As the 1993 edition of the IRB Handbook states:

|| The modern story of human subjects protections begins with the Nuremberg Code, developed for the Nuremberg Military Tribunal as standards by which to

judge the human experimentation conducted by the Nazis. The Code captures many of what are now taken to be the basic principles governing the ethical conduct of research involving human subjects. The first provision of the Code states that “the voluntary consent of the human subject is absolutely essential.” Freely given consent to participation in research is thus the cornerstone of ethical experimentation involving human subjects. The Code goes on to provide the details implied by such a requirement: capacity to consent, freedom from coercion, and comprehension of the risks and benefits involved. Other provisions require the minimization of risk and harm, a favorable risk/benefit ratio, qualified investigators using appropriate research designs, and freedom for the subject to withdraw at any time.

Such regulations were formally adopted in the United States in 1974, just two years after the Tuskegee Syphilis Study came to an end.

CLASS EXERCISE SUGGESTION

One starting point for discussing these issues would be conducting a mock IRB session in class. Stephan Sweet first proposed this method for teaching research ethics (Sweet 1999); I have modified his suggestions to incorporate more current events and issues as well as real research scenarios. In preparation for using this exercise in class, instructors—especially those teaching in courses or programs in which students will collect original data—may wish to require their students to complete the student training module from the CITI program, which provides background on IRBs and other issues related to human subjects in research (see <http://www.ric.edu/IRB/training.php>).

At the beginning of class, instructors should distribute the Mock IRB handout (see Appendix) and provide students with a suitable period in which to read the four scenarios. Instructors should note on the chalkboard or whiteboard that one side of the room represents “Approve” and one side represents “Disapprove.” Then, instructors should review the rules of the Mock IRB and contrast them with the workings of a real IRB. I typically say something like this:

Institutional Review Boards typically contain faculty members from a variety of disciplines, including social sciences as well as natural and medical sciences. They typically contain fewer members than the number of people in this room. Their role is to ensure the ethical treatment of participants in research. The IRB typically does not concern itself with empirical or research design issues unless there is something particularly risky or faulty about the research. As we discuss each of the four research proposals, you should move to the side of the room (“approve or “disapprove”) that represents your opinion, or stay in the middle of the room if you are undecided. You are free to change positions at any time, and we will discuss each proposal in turn and then vote on it at the end of the discussion. I will serve as committee chair and my role will primarily be to answer questions about the research proposals; I will only vote if there is a strict tie. I will not act as teacher during this time.

Spend five to ten minutes discussing each proposal. Read the scenario aloud, then ask students to move to the side of the room that represents their views. After students have moved, begin by asking those students who are opposed to explain why and encourage discussion and debate from others. Encourage those who are undecided to explain why or

ask questions for further clarification. When it seems like several central issues have been raised, determine the final vote for approval or disapproval of the project.

After discussing all four scenarios, ask students to return to their seats and initiate a discussion of some of the issues these scenarios have raised. For example, when discussing the first scenario, I talk about the Milgram studies (Milgram 1965) as an example of the potential ethical issues around deception—as well as the scientific benefits of the Milgram studies in increasing our understanding of fascism and obedience to authority. I also play Dar Williams’s song *Buzzer*, which was inspired by the Milgram experiments (Williams 2008). As a class, we then discuss when deception might be acceptable and when it might not.

In discussing the second and third proposals, I focus on the issue of confidentiality and the differences between the protections given to the sources of journalists and those given to those who participate in social science research. Courts have ordered that materials do have to be turned over, as in the case of Rik Scarce, who studied animal rights activists accused of illegal activities, Scarce spent months in jail because of his refusal to comply with such an order. I suggest to students that the only way to avoid such outcomes when researching potentially illegal activities—and this is one that Scarce himself feels is an unethical copout (Scarce 2005)—is to keep notes without any identifying information and then testify only as to the content of the notes.

When discussing the fourth scenario, I think it is important to emphasize that this really happened, as well as to discuss the history of medical experimentation during the Holocaust (See, for instance, Benedict 2003; Misterlich and Mielke 1949) and the fact that while many such experiments were nothing more than sadistic torture, there were occasional exceptions that did result in findings which may have been useful to the development of biomedical science (such as those on hypothermia). You might want to discuss the debate between those who argue that the harm done by such research means it should be destroyed entirely and those who argue that those findings which are potentially useful should be preserved so that “at least some good” can come out of victims’ suffering. Another potential avenue of discussion is the proposal, in relation to the recent revelations about the Guatemalan experiments, that researchers who conduct potentially harmful research on human subjects be required to carry insurance that would compensate victims.

I then turn to presenting several other examples of research that contemporary scholars might see as unethical, such as the Stanford Prison Experiment (Zimbardo 2012) and the Tea Room Trade study (Humphreys 1975), and especially in this context, the Tuskegee Syphilis Study (see above). We discuss the ethical problems related to each study; instructors using this exercise in a class in which students have read some or all of Skloot’s book may then wish to return to the book to discuss the ethics of the medical experiment undergone by Lacks and her tissue, focusing on the text of the Afterword—as well as, perhaps, the prisoners Skloot discusses on p. 130-37. If this exercise is taking place in a research methods course, I recommend closing by developing a list of all the sorts of risks and harms human research subjects may experience (physical, medical, emotional, psychological, collective/stereotyping, legal, social/stigmatization, economic,

etc.), the issues faced by so-called special populations (those under 18, prisoners, pregnant women, and the cognitively impaired), and the ways in which we minimize these risks (the role of the IRB, the importance of properly-obtained informed consent, maintaining anonymity and confidentiality of research data, and potentially compensating participants for risks if appropriate to a given study).

RACE & RACIAL “SCIENCE”

While the research projects discussed below may be, in many ways, just as unethical as those discussed above, they are problematic for a number of other reasons as well—most importantly because they attempted to use science to justify racial inequality. Henrietta Lacks’s story can be seen as a part of this historical lineage as well—in Skloot’s book, she discusses how HeLa cells, coming from a Black woman, could be seen as a “contaminant” of other cell lines (pp. 154, 199), for example—but it is a much broader and more involved history. I will not detail all of this history here, instead providing a schematic outline with suggested sources as well as some suggestions particular issues, topics, and ideas that are particularly worthwhile in connection with a discussion of Skloot’s book.

Attempts to use the methods of science to demonstrate the relative inferiority or superiority of various racial groups (not only the Black, White, Asian, and Native American categories of contemporary U.S. Census usage but often dozens of discrete groupings like “Southern Europeans”) have a long history. As Stephen Jay Gould detailed in *The Mismeasure of Man*, such attempts included filling skulls with lead shot or mustard seeds, weighing brains, taking dozens of measures of skull dimensions, and devising all manner of intelligence tests (Gould 1996). Many of these endeavors produced the exact results that researchers expected—for instance, the skull capacity of Blacks was repeatedly demonstrated to be less than that of Whites (though, it turns out, the skulls used in such experiments were obtained from Egyptian tombs; their classification by race and gender was based on nothing more than guesses). When the results did not turn out as expected, researchers turned to other methods or sought explanations for the deviations. For example, the brain-weighing experiments often resulted in findings of particularly low brain weight for scientific luminaries, which caused racial scientists to look elsewhere for their evidence. This is because the brain loses weight with age or prolonged illness, both common features in the biographies of the deceased scientists whose brains were weighed.

We as contemporary observers tend to look back on this history as evidence of the pseudoscience of racists, who simply did whatever they could to prove their theories right. The astonishing thing, as Gould demonstrates, is that many of these scientists worked hard to practice what was then seen as state-of-the-art science: they kept careful records, performed and re-performed their experiments to ensure the reliability of the results, and published their methods openly so that experiments could be replicated. As just one example of the racial scientists’ attempts to do “good science,” consider Morton’s skull-capacity experiments. He began measuring skull capacities with mustard seed, but found the measurements to be highly variable. Gould says of Morton:

“[Morton] eventually became discouraged, fired all his assistants, and redid all his measurements personally, with lead shot...[which] never varied by more than

a cubic inch, and we may accept Morton’s judgment that measures by shot were objective, accurate, and repeatable...”

In other words, Morton’s procedures were good—it was his interpretations that were faulty.

Of course, not all racial science was based on such a rigorous methodology. One particularly noteworthy example of non-scientific racial “science” is the Hottentot Venus episode (Holmes 2007). The Hottentot Venus was the stage name of Saartjie Baartman, sometimes called Sarah Bartman, a young woman removed from her home country (Cape Colony, now part of South Africa) and brought to London to be publically exhibited due to the enlarged buttocks and labia common to her particular ethnic group. After her death in 1815, she was dissected and her body parts remained on public display; she was not buried until 2002. Baartman’s story, like Henrietta Lacks’s, is a reminder of how Black women’s bodies have long been treated by science as nothing more than curiosities to be poked and prodded. Instructors who are interested in a literary work to pair with Skloot’s non-fiction text may wish to consider the play *Venus*, an award-winning theatrical treatment of Baartman’s life (Parks 1997).

In the more modern era, racial scientists have turned to intelligence testing as their “scientific” tool of choice. It just so happens that this new tool continues to provide results that help racial scientists continue to defend their suppositions—almost all standardized tests result in test score gaps between Whites and Blacks. While the exact magnitude of these gaps vary, they are often large and significant, especially on tests that are designed to measure intelligence or aptitude (for example, the Black-White test score gap on the SATs averages roughly 200 points). Statistical analyses can reduce the size of this gap by controlling for various factors like poverty, educational quality, and test preparation, but they cannot eliminate it (Farkas 2004; Jencks and Phillips 1998).

This means that explanations must be sought elsewhere—and as in days of old, some seek them in arguments about the underlying intellectual inferiority. Such arguments ought to be easy to debunk (Fischer, Hout, Jankowski, Lucas, Swidler, and Vos 1996). Once they have been debunked, we can turn our attention to the real culprits—educational and economic inequality, as mentioned above, as well as two more complex concepts: stereotype threat (Steele and Aronson 1998; Steele 1999) and testing bias (Gould 1996; Jencks 1998).

Stereotype threat refers to the notion that stereotypes of Blacks’ inferior performance on standardized tests have become so powerful that they have taken on a life of their own—that they have become, in other words, a self-perpetuating and self-fulfilling prophecy. Proponents of stereotype threat as an explanation for continuing test score gaps have shown that these gaps are considerably larger when Black test-takers are told that the test they are about to take measures intelligence or aptitude than when they are told it measures achievement or learning; test score gaps are also larger when Black test-takers are primed to think about race before the test. Notably, Black test-takers with otherwise poor academic performance seem to be much less subject to stereotype threat. It seems that the mechanism here is that Black students who are academically strong are so worried about falling into the stereotypical category of “Black students who perform poorly on standardized tests” that they actually work *too hard* on the tests, second-guessing

themselves, changing their answers, and otherwise working themselves out of a good score. And stereotype threat is not limited to Black test-takers—researchers have observed it among Koreans in Japan (who are stereotypically seen as inferior there) as well as among women in the United States who are taking tests of complex mathematic or spatial reasoning skills (Wraga, Helt, Jacobs, and Sullivan 2007). Finally, we come to arguments about bias in standardized testing—the subject of the in-class exercise below.

In-Class Exercise: Bias and Standardized Tests

For this exercise, instructors will need to download several pages from the Army Group Examination tests used in the 1920s for army recruitment and selection purposes. These tests can be found at the Eugenics Archive (<http://www.eugenicsarchive.org>) a resource collecting documents and images from the history of eugenics (Dolan DNA Learning Center n.d.). Visit the website, click “enter the archive,” click “search the archive,” accept the terms of service, enter “Army Group Examination” in the search box, and click “search.” When the Topics page comes up, click on “Physical and Intellectual Measurement,” and you will be taken to a set of 25 images. While not all of these are relevant, a number are pages from actual Army intelligence tests from the 1920s; particularly recommended are Test 3 (image #2323) and Test 8 (image #2328), though you may wish to use other or additional tests. Download the images you want and print copies for each student.

In class, with as little introduction as possible, hand out the test pages and instruct students to complete the assessment. As the pages you are distributing already have answers marked (unless you choose to retype them without markings), instruct students to ignore the marked answers and consider what they themselves believe the right answer to be. After students have completed the test pages—or become sufficiently frustrated—go through the questions as a class. Discuss which ones seem like adequate measures of intelligence or general knowledge and which seem culturally specific or biased. Ask students whether they think a test of this nature would accurately estimate their own intelligence, academic skill, or capacity for military service. Do note that an alternative form of the test was available for illiterate recruits. Images from that test are also available on the Eugenics Archive site). You may also wish to note that when Alfred Binet developed the first IQ test in 1905, it was designed not as a test of innate intelligence but rather as screening tools designed to determine which young students might need extra attention in class (Lehmann 1999).

Next, tell students about some of the history of racial science as outlined above, and turn to a discussion of bias in standardized testing. As we all know, standardized testing companies have sought mightily to reduce biases like those observed on these 1920s army test. Research on methods of reducing biases, though, began not out of any great commitment to racial equality or educational progress. Rather, just like the racial scientists of old, standardized testing companies were concerned that the results of their tests did not line up with their theories about racial superiority. Indeed, northern urban Blacks outperformed southern rural Whites on early army tests (Gould 1996), due to the northern urban Blacks’ superior diet, economic resources, and educational backgrounds. Gradually, attempts to reduce bias in tests evolved; today, test makers pre-test all questions in experimental non-graded test sections before using them in real graded tests. Any test question in which a particular demographic group performs differently from its

average performance on the test in general is typically discarded—on some tests, this means that questions on which Blacks are disproportionately likely to do *well* may be discarded too!

Given this history, open the class discussion to a broader consideration of the potential for bias in standardized tests today. Ask students about their own experiences with standardized testing and whether they perceived any biases in the tests. Present several examples of potential topics for reading comprehension sections, analogy questions, or math word problems and ask students if they think these might have the potential to introduce bias into the testing process. For example, you might propose:

- ✿ A question on a test for young children asking test-takers to read a paragraph about Holsteins (but not specifying that a Holstein is a dairy cow) and then answer reading comprehension questions.
- ✿ The following math problem, based on New York City buses: “Susan gets on the M15 local bus at 125th Street at 2 pm. Assuming that the M15 bus travels at an average rate of speed of 4.9 miles per hour, will Susan reach the M23 bus in: 30 minutes, 1 hour, 1.5 hours, or 2 hours.”
- ✿ A section on a high school level reading comprehension test asking test-takers to read a two-page synopsis of a cricket game and answer questions about who won and how various players felt.
- ✿ “Quahog is to stuffie as _____ is to dolma” (the answer is grape leaf, but you have to know something about both Greek *and* Rhode Island food to do well on that one!).

As a final—and up-to-date—example, you might present the case of the racing pineapple (Collins 2012). In April of 2012, eight graders in New York public schools took their standardized English test. The test included a reading comprehension passage entitled “The Hare and the Pineapple,” (Pearson Publishing 2012) a take-off on “The Tortoise and the Hare,” except this time the pineapple challenges the rabbit to a race. All the other animals assume the pineapple must have some scheme for beating the rabbit, but it does not, and the story ends with the animals eating the fruit (see the entire reading passage, and the inscrutable reading comprehension questions that follow it). Gail Collins, a columnist for the *New York Times*, describes the reaction and fallout: “*Jeopardy!* champion Ken Jennings...concluded that ‘the plot details are so oddly chosen that the story seems to have been written during a peyote trip.’”

To make a strange story even stranger, we turn to the backstory (McGrath 2012). It seems that the author of the story, Daniel Pinkwater, had sold the rights to a testing company years ago. But the story he sold the rights to did not feature a pineapple—it featured an eggplant. The eggplant still ended up as dinner, and Pinkwater ended his story with the moral “Never bet on an eggplant.” The story had been part of a collection of rather nihilistic fables, and according to McGrath, the one featuring the race was one of the least suited to standardized test adaptation. In any case, how did the eggplant turn into a pineapple? The test’s authors thought eighth graders might not be familiar enough with eggplants and that pineapples were a less biased choice.

RACIALLY-SPECIFIC MEDICINE

Racial science is not limited to attempts to demonstrate racial superiority through skull measurements or intelligence testing. Today, racial scientists have turned to DNA and genomic medicine as the next and newest frontier. But just as in the examples discussed above, this is not exactly a new turn. Indeed, the history of racially-specific medicine is a long and colorful one, too long to detail here. Instead, I'll begin with one central historical example, and then turn to more contemporary issues.

In 1851, a graduate of the University of Pennsylvania Medical School and practicing physician by the name of Samuel Cartwright published an article in *The New Orleans Medical and Surgical Journal*—a respected scientific publication—entitled “Report on the Diseases and Physical Peculiarities of the Negro Race” (Cartwright 1851). This paper detailed several diseases unknown within the White population but supposedly prevalent within the Black population living in Alabama, Mississippi, and Louisiana. Among the purported diseases was “dysaesthesia aethiopica,” a condition marked by lack of worth ethic, lack of intellectual abilities, skin insensitivity, and lesions, and requiring care and supervision by Whites. Even more astounding is another of Cartwright’s conditions, “drapetomania,” a mental illness provoking its “sufferer” into fleeing from slavery. To prevent this condition, Cartwright instructed slave owners to treat their slaves kindly, like children, and if this failed, he recommended whipping.

While it may seem a big leap to travel from antebellum Cartwright to contemporary DNA, in fact the gulf is not so great. Today’s racial scientists look to DNA as a site for locating racial difference. Due to the work of the Human Genome Project, which spent thirteen years constructing a complete sequence of the genes that make up human DNA and released its work in 2003 (Biological and Environmental Research Information System 2012), we now have the capacity to engage in previously-unprecedented investigations into the meaning, nature, and prevalence of genetic markers. While much of this research focuses on how genetic markers for medical conditions can be used to improve treatment and detection, DNA is also being used to further the projects of racial science.

One of the more nefarious examples of such uses is a practice that has come to be known as “pharmacogenomics.” This term refers to the idea that pharmaceutical treatments can be customized to “match” individual patients’ DNA signatures. In some cases, this is actually what happens—for example, cancer researchers have been working to identify the genetic signatures of tumors so as to best match them to the types of chemotherapy drugs that they are most likely to respond to. However, in other cases, pharmacogenomics has become nothing more than a shorthand for a kind of racial science that allows pharmaceutical companies to profit off of purported racial difference (Lee 2003). For example, in the 1990s, a pharmaceutical company sought approval from the Food and Drug Administration to market a medication known as BilDil as a treatment for heart failure. BilDil is nothing more than a pill combining two previously available medications, and the combination does not work differently than the two separate medications would if taken together. The first time around, the company’s application was rejected because clinical trial data about BilDil’s efficacy were inconclusive (Krimsky 2012; Sankar and Kahn 2005). However, it occurred to those involved in the application process that the

company had data showing that BilDil was more effective among the 49 Black individuals who participated in a clinical trial—and thus, the company began an all-out effort to demonstrate that the drug should be approved as a treatment for heart failure *among Blacks*. The FDA was ultimately convinced to approve this marketing and treatment strategy, making the prescription of BilDil to non-Blacks an “off-label” treatment through the year 2020 (Sankar and Kahn 2005).

BilDil does, in fact, seem to be an effective drug—probably for people of all racial backgrounds. And while the company has traded on the idea of pharmacogenomics in explaining why it should retain exclusive marketing rights over this combination, there is nothing genomic about it—potential BilDil customers do not receive genetic testing, just an assumption about their genetics that is made based on their skin color (Duster 2005). Yet by approving this marketing method, the FDA has allowed a private pharmaceutical company to profit off of Americans’ suppositions about racial difference.

The same sorts of arguments and techniques have been used for non-medical purposes as well. On the more harmful side, the FBI has a DNA database; this database and other associated information have been used to make racial assumptions (Duster 2005) and as evidence to approve “DNA dragnets” involving genetic testing of all Black males in a particular area (personal conversation with Troy Duster). Yet most Americans who have come into contact with the new racial science of DNA have done so in an entertainment context. Today, dozens of companies offer at-home DNA tests that, when mailed back to the lab, will generate a profile that purports to document an individual’s “racial ancestry.” One of the oldest of these companies, Ancestry-by-DNA, has been actively providing and marketing these tests for about a decade. While consumers are told that they will receive a profile detailing what percentage of their genetic “admixture” comes from European, Sub-Saharan African, East Asian, and “Indigenous American” ancestry (DNAPrint Genomics 2012), this is not in fact what the company is doing.

Here’s the dirty little secret of racial science: there are no genetic markers for race (Duster 1994). Even skin color, the biological fact most Americans turn to first in making assumptions about individuals’ racial backgrounds—is controlled by a number of different genetic markers, not all of which are scientifically understood yet. So companies like Ancestry-by-DNA can’t simply do a test to see what race you are the way they could do a test to determine your sex, eye color, blood type, or susceptibility to certain cancers. Instead, they have amassed a vast database of DNA samples obtained from individuals who identify as European, Sub-Saharan African, East Asian, and Indigenous American, and who—given our understanding about human migration and reproduction—are unlikely to represent “pure” expressions of the genetic profiles that may be associated with such ancestry. When a customer sends in a sample of his or her DNA, companies like Ancestry-by-DNA then compare key portions of the customer’s genetic code to the samples in the company’s database. The resulting percentages are *not* percentages of ancestry, but rather figures indicating the probability that the customer’s DNA is sufficiently similar to the samples from that group already in the database. Even Ancestry-by-DNA itself admits that a figure like “4% Indigenous American Ancestry” might be nothing more than statistical noise (DNAPrint Genomics 2012, FAQ section).

Yet these tests have become so popular that their use has extended beyond the pool of individuals who would pay for a genetic test and into the entertainment industry. In 2010, PBS broadcast a television series called *Faces of America* in which 12 famous Americans explored their genealogy, and—unless they refused—their so-called genetic ancestry (WNET.org 2012). Hosted by Henry Louis Gates, Jr., the notable Harvard professor who became famous after the confrontation with the Cambridge, MA police department that earned him a “beer summit” with President Obama (Ogletree 2010), the series features individuals including Stephen Colbert, Mario Batali, and Eva Longoria; videos from the series are available on the website at <http://www.pbs.org/wnet/facesofamerica/>. So why include this “harmless” bit of entertainment and celebrity worship in a discussion of racial science? The issue here is that entertainment plays an important role in shaping our views about race. After watching *Faces of America*—and perhaps being motivated to order their own genetic test—Americans may be more likely to, in Duster’s words, “reify race” as a scientific truth (Duster 2005).

Furthermore, in considering the relationship between today’s racial science and Henrietta Lacks, it strikes me that today’s racial science might be seen, in some way, as the inverse of the science that marks Lacks’s legacy. Henrietta Lacks’s cells are not just immortal, they have also become universal. This poor Black woman’s biological material is now the cellular model for everything and everyone. But today’s racial science does the opposite. No longer does science, however unethically, look for a model for all of us. Instead, it subdivides humanity into smaller pieces and looks to profit off of these supposed differences, even where the evidence for said differences is scant.

Teaching the Debate: Race as Science or Social Construction?

There is a vast array of teaching resources available for teaching about the social construction of race, and I will not review them all here. For those instructors without a strong background in this area, a good starting point would be a different PBS mini-series: *Race: The Power of an Illusion* (California Newsreel n.d.). This mini-series, which debunks racial science, is not available for free, but it is excellent and widely-used teaching tool. The series website, <http://www.pbs.org/race>, provides suggested background readings, class exercises geared to K-12 students, and a useful teacher’s guide with discussion questions and class activities (California Newsreel 2003). My favorite is an exercise in which students sort themselves into groups on the basis of a wide variety of biological characteristics including those we conventionally associate with race, like skin color or hair texture, as well as those we tend not to think about, like whether one’s earlobes are attached or detached, and then consider why we make racial classifications the way they do. Instructors who have the time may wish to contrast *Race: The Power of an Illusion* with excerpts from *The Faces of America* to further highlight the shortcomings of more popular conceptions of racial difference. A fruitful class discussion could focus on the implications of these different perspectives on the biology of race for our understandings of and responses to contemporary (and historical) racial inequality.

Instructors who wish to connect issues of racial science back to *The Immoral Life of Henrietta Lacks* may find it useful to assign students to write an essay drawing on these issues. Here, I propose two potential questions for such essays; instructors could also adapt these to structured class discussions, debates, or other genres.

- 1) How might conceiving of race as biological and of racial groups as genetically distinct affect the future of medical science? Consider, for instance, whether the HeLa cell line would still be seen as broadly generalizable to all people, what sorts of new drugs might be developed—and what the limitations to their development might be—and how continuing racial inequalities in access to health care and in participation in medical research might be perpetuated.
- 2) Henrietta Lacks’s descendants are powerfully affected by her experiences and legacy. Put yourself in the shoes of the next generation of her family and imagine that you are a middle school student charged with writing a family history essay for school. Then, write the same essay from the perspective of a Henrietta Lacks descendent who had not known about his or her family history but who had discovered his or her family’s past by participating in a *Faces of America*-style show.

CONCLUSION

Rebecca Skloot tells us three stories simultaneously in *The Immoral Life of Henrietta Lacks*: she tells the story of a remarkable and vital development in biomedical science; she tells the story of a family devastated by the loss of its matriarch and suffering from poverty and oppression; and she tells the story of her own quest to uncover the first two stories. As a tool for teaching and learning, then, the material that can be mined from Skloot’s book is bountiful. It can provide the material for discussions of storytelling, of scientific progress, of the power of family, and of continuing inequities in health care in the United States. This teaching guide has focused on another set of issues: those related to the history of race and science in the United States. We don’t talk much about the way racial inequality has shaped and been shaped by scientific thought—we tend to want to believe in science as an unqualified good that brings progress to our world. But that progress has had costs, costs like the unethical treatment of the most powerless members of our society, and costs like long detours into science and pseudoscience that have been used to further racial subjugation. Indeed, the same is true of Henrietta Lacks’s story itself. Lacks’s cellular material has been a source of so much progress for biomedical science and has undoubtedly saved many lives. But to make these gains, the Lacks family suffered mightily, and did so without any compensation. They and their mother, like many poor Blacks in the history of American biomedical science, were treated unethically and unfairly, while the rest of us have reaped the benefits. Therefore, I think we owe it to them to remember the history of racial inequalities in scientific research and scientific thought. By keeping these memories alive and by developing an understanding of the inequities, errors, and atrocities committed by past generations as well as in today’s scientific world, we have at least the hope of a future in which such inequities, errors, and atrocities are reduced.

APPENDIX :

<<Building Name>> Institutional Review Board

Today we will be considering four research proposals (all are based on real research projects). Brief descriptions of each proposal appear below. <<Instructor Name>>, chair of the <<Building Name>> Institutional Review Board, has read the complete documentation submitted by the Principal Investigator of each study and will be available to answer any questions and issue any clarifications you might feel are necessary as you evaluate each of the three proposals. Please read each proposal before the Institutional Review Board meeting begins and note at least one question or concern about each proposal.

PROPOSAL 1

Dr. Charoen (2011) wishes to study the ease of persuading individuals to provide sensitive financial information over the internet. He proposes sending “phishing” emails to MBA students that provide a link to a website which requests that students enter their electronic banking username and password, their bank account numbers, and their social security numbers. He promises that the information will be discarded after it is entered and that those participants who do enter information will be told of the deception and invited to participate in a focus group afterwards. Should the IRB approve this study? If so, under any specific conditions? If not, why not?

PROPOSAL 2

Mr. Rik Scarce (2005) is a graduate student in sociology. He is proposing to conduct dissertation research on radical environmental activists, some of whom engage in illegal activities. He would like to interview these activists about the reasons they became involved in environmental activism, what such activism means for their lives, and the tactics they use in engaging in activism. Should the IRB approve this study? If so, under any specific conditions? If not, why not?

PROPOSAL 3

Ed Moloney and Anthony McIntyre spent a number of years conducting in-depth oral history interviews with former members of the Irish Republican Army. The recordings of these interviews have been placed in an archive at the campus library; interview participants were assured that the recordings would be kept secret during their lifetimes. The British government, however, has requested that the recordings be turned over to criminal investigators, and the U.S. federal courts have issued a subpoena for them (Mole 2012). Should the IRB support Moloney and McIntyre in their efforts to quash the subpoena, or should the IRB recommend the release of the recordings? Explain.

PROPOSAL 4

In the late 1940s, the American Public Health service conducted a study in Guatemala of syphilis and gonorrhea infection. Infected prostitutes were paid to have sex with prison inmates. Other individuals were directly infected by the placement of pus into cuts on their faces or genitals, by spinal puncture, or directly into bodily orifices. About 5,500 Guatemalans were enrolled in the study, of whom 1,300 were deliberately infected with a disease. 83 died; about 700 received treatment with antibiotics (McNeil 2011). Records, which are haphazard, still remain. Should researchers be allowed to publish based on the results of this study? If so, under what conditions? If not, why not?

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