

personal genetics education project

Social, Legal and Ethical Issues in Personal Genetics

How will knowing more about our genes change us? Exploring personal, family, and psychological issues

Introduction:

This lesson is meant to stimulate discussion on how people might feel and act when they learn about their genomes, and includes data on reactions people have had in the past. Students are given “scenarios” in which they learn hypothetical pieces of information as a result of having their genome sequenced, and reflect on the underlying questions and issues within each scenario.

One of the most debated issues in genetic testing and personal genome sequencing is if and how it will cause people to think differently about themselves, their future, and their potential.

While it is not yet known how widespread personal genome sequencing will impact individual’s emotions and actions, there are a number of organizations and movements that provide a look at what may lie ahead.

Some people look to the growing accessibility of genetic information as a catalyst for change in the fields of medicine, research, activism, and social networking. This is in contrast to another vision in which genetic information is a sort of “sentence”, carving one’s future health and choices in stone. Fears around genetic discrimination and privacy remain significant and legitimate concerns.

Historically, predictive genetic testing is most commonly performed on individuals who have reason to suspect they are at increased risk for certain diseases. Such individuals would include those with a family history, or being a member of an ethnic group with a higher incidence of certain conditions than average. Often times these individuals have lived with the specter of genetic disease hanging over their heads for many years. As the cost of personal genome sequencing drops, and for-profit companies and medical providers are able to offer genetic analysis more broadly, the

opportunity to learn a great deal about one's genome is rapidly becoming a viable option.

It remains unclear how people might feel about and act on the information gleaned from a personal genome sequence. For instance, research addressing the psychological impact and behavior changes people make based on genetic testing is still limited. Some studies indicate that people are relieved, whether or not they learn they carry a deleterious mutation. Two papers (with excellent bibliographies for more reading) that examine this question are:

1. [Psychological responses to genetic testing](#) (full text), TM Marteau and RT Croyle. *BMJ*. 1998 February 28; 316(7132): 693-696
2. [A systematic review of perceived risks, psychological and behavioral impacts of genetic testing](#) (abstract only), JT Heshka, C Palleschi, H Howley, B Wilson, PS Wells. *Genet Med*. 2008 Jan; 10 (1):19-31

In advance of teaching this lesson, read and visit the following sites:

(If you have time for just one site, the first reading and video is the one we recommend)

1. [After DNA Diagnosis: "Hello, 16p11.2. Are you just like me?"](#) By Amy Harmon, New York Times

This article can be matched with the accompanying video, "[The DNA Age: Genetic Kin](#)", which is about families with children carrying the same chromosomal disorder meeting for the first time. It is excellent and can be used to introduce this lesson in the classroom.

2. "[Insurance Fears Lead Many to Shun DNA Tests](#)" By Amy Harmon, New York Times

3. From NPR, "[Genetic Testing, Part 1: Reading Genes for Disease Tests Reveal Answers that Can Offer Relief, or Despair](#)". This podcast gives a personal look at a family and the impact genetic testing has on some of its members. One could make a connection between the issues this family faces and the likely similarities a family might confront if they were to get sequenced.

3. For a discussion of the practical and emotional issues around predictive genetic testing, see "[Cancer Free at 33, but Weighing a Mastectomy](#)". The video, "[Story of a Previsor](#)" could be used as the basis for a homework or in-class response essay. Certain aspects of the video material may be best suited for college students or a more mature high school class.

4. The [REVEAL study](#) at Boston University found that, when given information about increased risk of Alzheimer's Disease (AD), some people take a number of proactive and preventative measures, despite the fact that there is no clinically valid course of prevention. This study, therefore, refutes the common belief that people (and mostly famously, [Nobel Laureate James Watson](#) with respect to AD) will not seek to determine their risk for diseases for which there is no known cure.

5. [Research ethics and the challenge of whole-genome sequencing](#) (abstract only), A McGuire, T Caulfield, M Cho. Nature Reviews Genetics, 2008 vol. 9 (2): 152-156. This represents one of the first papers that directly addresses some of the practical, ethical dilemmas of personal genomics, from the perspective of the researchers.

6. Examples of patient advocacy groups and individuals seeking and advocating for cures, better treatments, political action, and the development of communities and support systems:

[Patients Like Me](#): Community of patients looking to share medical information and support.

[My Daughter's DNA](#): A father searches for answers about his daughter's rare genetic condition.

[Genetic Alliance](#): National coalition of patient and research advocacy organizations with an emphasis on legislation and funding.

[Unique](#): The rare chromosome disorder support group, members of which are often one of only a handful of people in the world sharing a rare disorder.

Guiding Questions

How would learning more about your genetic profile make you feel if the news was “good”? “bad”? “unclear”?

Learning about one’s genes can impact a whole family – what sort of considerations should be made when the decision of an individual may have serious repercussions for others?

What kinds of information might be in your genome that could change how you think about your identity?

What will not be “discovered” about you in your genome?

Learning Objectives

Students learn about the varied responses to genetic information.

Student will reinforce their grasp on the patterns of genetic inheritance

Students see the human element and impact of science on real people.

Students see that genetics, and more broadly, research and medicine are changing. They realize their generation will be asked to solve novel ethical, legal, clinical, and research challenges.

Students can articulate some of the risks and benefits of personal genome sequencing.

The Lesson

1. The theme for this lesson is that there are many ways in which people might respond to genetic testing, when the news is “good” or “bad” and that sometimes what people fear about their genes can be cause for empowerment and action.

Students will be divided into small groups and given a scenario in which they “receive” their hypothetical personal genome sequence data. They will be asked to explore and then share their responses to the information they have been given.

2. The lesson can begin with a discussion of the basics of personal genome sequencing (see overview and lesson one if this is the only lesson you plan

to use in class). Ask students with whom they would talk when deciding to get sequenced or not. Siblings? Parents? Current boyfriend/girlfriend? Nobody?

This will likely provide a segue to questions concerning the impact of genome information on the family unit and the psychological well-being of its members. Ask if they see any moral or practical reasons to consult with family members as they come to a decision.

One of the most commonly discussed risks of learning about one's genes, especially "all at once", is the potential negative psychological consequences. How might someone feel? Fearful? Overwhelmed? Possibly, but there is a growing body of research that indicates people may eventually feel relieved, even if the diagnosis is positive for the mutation (i.e., "bad news") as worry and wonder will no longer be hanging over their heads and taking action will become possible. (see accompanying slides for more).

3. The following is a list of news articles about people who have learned surprising things about themselves and their family as a result of genetic testing. You may want to highlight one or two of these stories as a way to bring home some of the risks and benefits that will be raised in the scenarios, and also the concepts of "unintended consequences" and "genetic secrets revealed"!

- A. "[Boy Tracks his Sperm Donor Father](#)"
- B. "[Best Friends Discover They Are Also Sisters](#)" (with video clip)
- C. "[Genetic Testing Reveals Surprises](#)", "[Why Race Isn't as 'Black' and 'White' as we Think](#)", "[Cheney, Obama are Eighth Cousins](#)"

4. Divide students into discussion groups, then assign each group one scenario to discuss. There are six scenarios included in this lesson. The scenarios can be found here ([LINK to scenarios](#)). One student from each group should be chosen to be the spokesperson. After a 10-minute discussion, ask each group to explain its scenario to the class and share their thoughts on the discussion questions. Were all members of the group in agreement on the issues? What were the points of disagreement, excitement or worry?

Note: This activity is very adaptable. If more than one class period can be devoted to this activity, you could work through two or three scenarios per day, allowing for a more detailed discussion. Many of the discussion questions given at the end of each scenario could be assigned as exam or homework questions.

Classroom tools:

PowerPoint slides, designed to guide the lecture and highlight the main points of the lesson can be found here ([link to slides](#)). They are intended to be easily modified and to accommodate individual teacher's style and needs.

Assessment:

We suggest several options:

1. Students write a short paper reflecting on how the workshop in which they just participated impacts their original response to the question of whether they would get their genome sequenced, and whom they would include in their decision making.
2. Students research and write a paper on an example of "citizen science". Examples might include parents who started a blog about an ill or disabled child as a way to build support, families who have battled the establishment for a cure or innovative procedure (e.g., the movie *Lorenzo's Oil*, see [BBC story](#) about the family on whom the movie was based), or the history of the activist movement around certain diseases, such as autism, breast cancer or Down's syndrome.
3. Students research the psychological and behavioral impacts of genetic testing for a condition or disease of their choosing, using some of the open-source electronic libraries.
4. Students interview a family member or friend about whether or not he or she would consider getting his or her genome sequenced. Students should also ask their subject to put himself or herself in the shoes of a child, sibling or parent of someone getting sequenced – what are the concerns from that perspective?

More resources

Continue to weave this line of thinking through the semester by asking students if they would get tested for various genetic diseases or mutations that you may touch upon as the class progresses (e.g., Cystic Fibrosis while doing a chapter on human reproduction).

Students can read about and contribute to a public discussion of these and other issues related to genome sequencing at the following websites:

Science Blogs: <http://scienceblogs.com/>

The DNA Network: <http://networks.feedburner.com/The-DNA-Network>

Very few first-person accounts of what it is like to have one's genome sequenced exist at the moment. However, several of the Personal Genome Project's "PGP-10" have talked publicly about their reasons for getting sequenced. See "[Full Disclosure](#)" by Esther Dyson in the Wall Street Journal and Misha Angrist's "[Genome Boy](#)" blog, which is part of the DNA Network. Dr. John Halamka's thoughts (and SNP data) are at [GeekDoctor](#).

Drs. James Watson and Craig Venter both have had their genomes sequenced, and make them public (with a few exceptions). There was extensive media coverage of both events, below are a few examples:

"[The 2 million dollar genome](#)", in MIT's Technology Review

"[Craig Venter's Genome](#)", in MIT's Technology Review

Craig Venter [talking about his genome](#) on YouTube.

For a more social-sciences based perspective, read the American Psychological Association's "American Psychologist" journal from January 2005. The issue focuses on genes, race and psychology. Some of the articles are open access, such as "[Genes, Race and Psychology in the Genome Era](#)" by Norman Anderson and Kim Nickerson.