

personal genetics education project

Social, Legal and Ethical Issues in Personal Genetics

Lesson One: Social, Legal, and Ethical Issues in Personal Genetics:

Genome sequencing and ethical issues: Who, what, why, and when?

Introduction:

Ask students to read “ [Life with a Lethal Gene](#)” in advance of the lesson.

High school and college age students are likely to become independent health care consumers at about the time that personal genome sequencing becomes an affordable and accessible option. This lesson introduces students to the recent advances in genetics, genetic testing, and personal genome sequencing, and presents some of the decisions and ethical challenges an individual may face regarding the use of this technology. It also introduces some of the likely benefits of personal genomes, such as gaining the ability to act on one’s genetics risks, tailoring medicines and interventions, and becoming more active and engaged healthcare consumers. Via class discussion and the readings, students will be able to generate ideas about the possible risks, in addition to the potential benefits.

Guiding Questions:

How does one decide to get sequenced? What are the benefits and risks?

Learning Objectives:

After completing this lesson, students will be able to:

Define what a genetic test is

Define a personal genome sequence

Outline the likely risks and benefits of personal sequencing

The Lesson:

The lesson presented below is intended for a lecture/discussion format, with a short small group discussion activity.

1. Begin with a question and answer about the NYT article "Life with a Lethal Gene". Ask students what they would have done Katharine's shoes – would they have gotten tested? Would they tell their mother, against her wishes?

Note some of the more powerful aspects of the story:

- The difficulty of deciding to get tested for a single disease
- The emotional impact
- Her actions (planning ahead, activism) as a result of a positive test
- How it changes her outlook about marriage, kids, career, and her identity
- Getting tested impacts not just her, but her family and friends

2. The NYT article can segue into talking about the types of genetic testing available, and also can frame this discussion in terms of its timeliness and relevance to their lives. Example:

Human Genome Project took 12 years and cost 3 billion dollars, and it is widely predicted that the cost of a doing a "Human Genome Project" on individuals will be reduced to \$1,000 within the next five years and take only a few days to complete.

Imagine the "Life with a Lethal Gene" story with the added dimension of having learned about a number of other genetic risks she or her relatives might have...

3. Ask students to name some genetics tests they have heard of.

Examples might include the "predictive" type, which are done before symptoms are present, such those for increased risk of breast or colon cancer.

Prenatal tests, performed in the early weeks of pregnancy, often include cystic fibrosis and Down's syndrome.

Explain that some of the more common types of genetic tests examine the pattern of nucleotides (A, G, T, C) in a specific gene or set of genes, looking for differences from the typical sequence that would cause the gene to malfunction. Resources about the technology and process behind genetic testing can be found at [Human Genome Project Information](#).

Genetic tests can be obtained from one's physician, online retailers such as [DNA Direct](#) or [Consumer Genetics](#), and recently in some drugstores. The costs of genetic tests are sometimes covered by health insurance, but fear persists that the results will be used to discriminate in health insurance and employment (See "[Insurance fears leads many to shun DNA tests](#)" from the NYT for examples that could be used in the discussion).

Part of the appeal of the "direct to consumer" approach of selling tests via the web or at pharmacies is the belief that this approach will give consumers more control over their privacy and genetic data. Others argue that more oversight and regulation is needed to ensure the quality and accuracy of genetic tests. The [Genetics and Public Policy Center](#) and the [Personalized Medicine Coalition](#) have a number of articles on this subject, available free on their websites.

4. New to the marketplace in 2007 and 2008, private companies are offering a form of whole-genome analysis. The services differs from a traditional "genetic test" as they that do not directly sequence specific genes but determine the presence or absence of small DNA changes, called SNPs (single nucleotide polymorphisms). SNPs are statistically indicative of the presence or absence of a nearby piece of DNA associated with a trait or disease.

These so called "genome scans" are generally believed to be an early pre-cursor to full personal genome sequences, and signal the start of "consumer genomics". It is expected that this particular technology will be obsolete in the next few years, as low cost full sequencing becomes technically possible.

SNP testing does not necessarily examine a specific gene associated with a trait or disease, but is designed to look at nearby areas in the genome where a difference from the average is strongly associated with certain traits. Examples of companies offering genome scans include [23andMe](#), [Navigenics](#), and [DeCodeMe](#). 23andme has a very accessible series about the so-called "SNP chip" analysis that is appropriate for high school and college students.

5. What, why, and how it works:

Explain that a personal sequence is essentially a genetic analysis performed on most or all the genes in an individual's body, all at the same time. A useful way to frame this might be as a " Human Genome Project performed on YOU" or as taking every known and future genetic test simultaneously. Many of the genes sequenced are not well understood, and it is unclear what roles they play in the development or function of the body. The ability to sequence a genome will dramatically outpace the ability to understand or interpret a genome.

Genome sequencing is thought to have enormous potential to link genetic mutations and changes to diseases, physical characteristics, and even some complex human traits and behaviors. If thousands of people were to be sequenced, and then share some of that information with the research and medical community, many believe it will be possible to find connections that are significant, translating into better and more personalized health care. For more on the concept of the link between genotype and phenotype, please see [pgEd's](#) summary.

6. Ask students for a show of hands as to who would consider getting their genome sequenced. Why or why not?

From here, a discussion of the risks and benefits will likely ensue. The risks and benefits are outlined in the slides and also at [pgEd.org](#)

Often students respond to this question as if it is still a theoretical one. It is not. [Knome](#), based in Cambridge MA, will sequence a human genome from \$350,000 – and the price is expected to fall over the next few years.

[The Personal Genome Project](#) (PGP) is a unique research study at Harvard Medical School that is currently enrolling volunteers. They are currently sequencing the first ten volunteers, as well as collecting detailed medical histories, health records, and 3-D facial photographs. [9 of the first 10 volunteers](#) have agreed to full public disclosures of their genotypes and phenotypes. Future participants (they hope to have 100,000 volunteers) will have the option to make all their data publicly available.

The first ten volunteers have been carefully chosen in part because they are taking on unknown risks by making their information available to all. Many believe such openness about one's genetic profile and medical history will:

- A. Lead to individuals playing a more active role in their own health

- B. Encourage people to become active and engaged stakeholders in scientific research through their participation.
- C. Aid in the discovery of cures and treatments that could benefit many people.
- D. Encourage discussion as to whether or not genetic information requires special privacy considerations.

Future PGP volunteers may be interested in public information sharing, but it is thought to be likely that the majority of volunteers in this project and others would prefer a more measured level of disclosure, if at all.

Many organizations and scholars have stated concerns about personal genomics and the approaches some of these projects have taken. These include:

- A. Promises of privacy and anonymity are misleading – people should be aware that it may not be possible to have their data truly protected.
- B. The service and interpretation of direct to consumer genome scans are ahead of true clinical usefulness, and may be unfairly taking advantage of consumer's enthusiasm for this new product.
- C. The emphasis on the genetic basis of disease and complex social traits is at the expense of a more nuanced understanding of the multifactorial nature of human health and experiences.
- D. Although the technical capability is just around the corner – the legal, social, moral, political, religious, and medical (to name just a few) infrastructure needed to use and regulate genomic information is not yet in place.

See the [Council for Responsible Genetics](#) and the [Biopolitical Times](#) for news and opinions in this area.

Classroom activity:

Begin by describing a vision of a possible future, where humans have learned to control their genetic profile at a very sophisticated level. For example, the average human life span might be 100 years, cancer may be unheard of, and all medication may be tailored specifically to an individual's genetic profile. Genetic technology may also allow people to pass only their "best" traits to their children, traits such as good vision, a strong immune system, and freedom from allergies.

Break students into small discussion groups to share what they think some other desirable attributes might be. (Common answers are intelligence, athletic ability, good looks, and nice personality).

Students can then debate the feasibility and wisdom of such a scenario. Is it even possible? Appealing?

Other classroom tools:

The following PowerPoint slides can be used to supplement some of the discussion. Feel free to modify and reorganize as needed. Brief notes accompany some of the slides, please leave the "personal genetics education project" label in the lower right hand corner.

Discussion questions:

A. What are the major considerations in the decision to get sequenced? How do you decide if the benefits outweigh the risks?

B. How might the information you learn from sequencing come to have different kinds of meaning or import over the years?

C. If you don't want to be sequenced now, what might be some of the times in my your future that you would want to (Answers you may hear are marriage, planning a family, getting older)? What are best arguments for waiting, and for acting now?

Assessment:

Students can complete a short paragraph or essay explaining what personal genome sequencing is, and why or why not they would like having their genome sequenced.

They should outline and support what they see as the single biggest benefit, and also the greatest risk of sequencing.

Essay can also include 3 things they might learn from their personal sequencing, and 3 things that likely will not be revealed by sequencing.

If time permits, students can discuss their ideas in a debate format.

Additional resources

More on genetic tests and their common uses can be found at University of Washington's excellent site, www.genetests.org.

For more on biological determinism, and writings on social vs. biological traits, and the limits of genetic inheritance, please see:

Human Genome Project: [Behavioral Genetics](#) unit

The Mismeasure of Man. SJ Gould. New York, W.W. Norton, 1996

A daily round-up of genomic research developments and interesting posts from some of the well-respected science blogs can be found at [Genome Technology Online](#)

MIT's [Technology Review](#) has an excellent "Biotech" section with excellent in-depth stories and news items that are challenging but appropriate for high school and college students.