



# Personal Genetics Education Project

## Ethical, Legal and Social Issues in Personal Genetics

### SNAPSHOT

## Direct-To-Consumer Testing in the Genomic Age

Adapted for PBS LearningMedia in partnership with WETA for use with



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## SNAPSHOT

# Direct-To-Consumer Testing in the Genomic Age

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## Big Picture

The effort to read the human genetic code – to identify and sequence the ~20,000 human genes (and all the DNA in between) – was a huge accomplishment. Known as the Human Genome Project, it has laid the foundation for many new discoveries, tools, and medical tests that have emerged in the years since its completion in 2003.

Technological developments are making it possible to read a person's entire genetic code, or genome, more rapidly and at a lower cost than ever before. Personal genome sequencing is allowing scientists and doctors to better understand the connections between genes and human health, improve medical care, help extend people's lives, and provide information about our shared human ancestry. As the cost of genetic analysis decreases and research advances, it is increasingly possible to include a person's genetic make-up in the toolkit that informs their healthcare.

The growing field of personal genetics is at the intersection of science and society. It is an exploration into the complex interactions through which our genes and our

environment influence our physical, mental and behavioral states. As this field moves forward, conversation is needed about the meaning for individuals and society.

**Watch the following videos and answer the questions on the student worksheet (page 3).**

- [Direct-to-Consumer Testing in the Genomic Age](#)
- [PBS Learning Media: DTC Testing](#)



## Student Worksheet - Extension

State whether you agree or disagree with the following statement and justify your answer.

***Parents should be able to find out whatever they would like about their children's DNA, whether it be about ancestry or health, before they turn 18.***

## Teacher's Guide

### Foundational Concept

An important theme throughout this lesson is that your physical, mental and behavioral traits are influenced both by your genetic make-up and by the unique circumstances in which you have lived your life, including everything that has ever happened to you. We often refer to these two inputs as “nature,” the genome you carry that is unique to you, and “nurture,” the environment in which you have lived your life. However, “nature” and “nurture” are not independent of each other – environmental factors affect how genes are “expressed” (turned on or off), and even lead directly to changes in your DNA sequence. The intricate and sometimes unclear relationship between genetics and environment is key to our understanding of behavior and health. Researchers are seeking to study the genome sequences and characteristics of many people to develop a better understanding of the interplay of nature and nurture in known diseases, with the hope that this would lead to better treatments, cures, preventative measures and healthier generations of children.

### Related pgEd lesson plans

- This module was adapted from pgEd's lesson, [Introduction to Personal Genetics](#).
- pgEd offers a full lesson on [Consumer Genetics](#), which delves deeper into this topic and includes an activity for setting up a classroom debate on this topic.

## Additional Resources for Teachers

Amy Harmon's "[DNA Age](#)" series in the *New York Times* has news, analysis and video clips related to personal genetics. While some of the science has progressed, the issues Harmon examines are still timely.

The [Hastings Center](#) is an independent, nonpartisan and nonprofit bioethics research institute with many resources and articles about ethics, genetics and society.

## Student Worksheet: Teacher Notes

### 1. What are the potential health benefits to knowing about your genetic makeup?

You can expect students to answer this question with ideas related to taking steps to prevent or seek early treatment for a potential health condition. You may suggest that even if students learned of conditions without a current treatment, they could choose to become active in clinical trials or advocacy.

### 2. What are the possible downsides to knowing about it?

Students frequently raise concerns related to privacy and discrimination, as well as the emotional burden of learning about one's genetic information. This can be an opportunity to tell students about the Genetic Information Non-discrimination Act (GINA), a US federal law that forbids the use of genetic information to discriminate against people in the areas of employment and health insurance.

**Read more:** pgEd's lesson [Privacy Protections for Genetic Information: Meet GINA](#) focuses on the protections extended by GINA.

Students often think that genetics will give them definitive, life-altering answers, including a specific cause of death. It is important to clarify these misconceptions and instead emphasize the concept of genetic complexity. Remind students that genes are part of a much more complex story in concert with the environment, and scientists still have much to learn about the links between a person's genetic makeup, environment, and health.



**3. Aside from health and medical information, what else might you be curious to learn from your DNA?**

Students frequently mention learning about their ancestry and finding biological relatives. Many students will be familiar with the concept of ancestry testing, and as time goes on, some may have direct experience with it. Students who are adopted or living apart from biological relatives often will specifically mention these possibilities and may be interested in reading any one of the hundreds of news stories about people's direct experiences with using ancestry tools to locate biological family connections.

## Extending the Lesson: Teacher Notes

*Parents should be able to find out whatever they would like about their children's DNA, whether it be about ancestry or health, before they turn 18.*

This statement is intentionally broad to encourage students to consider how much information could be available to parents through genetic testing. There is an ongoing debate about how much parents should find out about their child's DNA before age 18, when a child becomes a legal adult. Many students may have already had their DNA assessed in some way via prenatal genetic screening or newborn screening. While genetic testing can help to predict, diagnose or treat certain diseases, it may uncover genetic risks for disease later in life or other information that might affect how a child is raised. Many people are concerned about the availability of this information before the child is able to give informed consent. Should testing be limited to only look for a specific subset of genetic markers, such as those for diseases with childhood onset? If genome sequencing is performed, should only specific types of information be provided to parents? Is ancestry information considered "sensitive" or not?

In the realm of medical genetic testing, the American College of Medical Genetics and Genomics (ACMG) offers guidelines regarding the reporting of incidental, or secondary, findings when performing genome sequencing. It recommends doctors only tell patients about findings of specific genetic variants that are associated with serious disorders that have practical things that can be done to mitigate the associated risk. Patients are allowed to opt-out of receiving these results during pre-testing counseling.

**Read more:** More on the ACMG's recommendations, which generated much debate and discussion, can be found here: "[Considering ACMG's practice guidelines for incidental genomic findings](#)" and "[ACMG SF 2.0](#)".