INTRODUCTION TO PERSONAL GENETICS

LESSON PLAN

PERSONAL GENETICS EDUCATION & DIALOGUE

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ACADEMIC STANDARDS ALIGNMENT

COMMON CORE

STANDARD	DESCRIPTION
CCSS.ELA-LITERACY.RST.11-12.1	Cite specific textual evidence to support analysis of science and technical texts, attending to important distinctions the author makes and to any gaps or inconsistencies in the account.
CCSS.ELA-LITERACY.RST.11-12.2	Determine the central idea or conclusions of a text; summarize complex concepts, processes, or information presented in a text by paraphrasing them in simpler but still accurate terms.
CCSS.ELA-LITERACY.RST.11-12.7	Integrate and evaluate multiple sources of information presented in diverse formats and media (e.g., quantitative data, video, multimedia) to address a question or solve a problem.

NEXT GENERATION SCIENCE

STANDARD	DESCRIPTION
HS—LS1: From Molecules to Organisms – Structures and Processes	**LS1.A:** Systems of specialized cells within organisms help them perform the essential functions of life. All cells contain genetic information in the form of DNA molecules. Genes are regions in the DNA that contain the instructions that code for the formation of proteins. **LS1.B:** The organism begins as a single cell (fertilized egg) that divides successively to produce many cells, with each parent cell passing identical genetic material (two variants of each chromosome pair) to both daughter cells. Cellular division and differentiation produce and maintain a complex organism, composed of systems of tissues and organs that work together to meet the needs of the whole organism.
HS-LS3: Inheritance and Variation of Traits	**LS3.A:** Each chromosome consists of a single very long DNA molecule, and each gene on the chromosome is a particular segment of that DNA. The instructions for forming species' characteristics are carried in DNA. All cells in an organism have the same genetic content, but the genes used (expressed) by the cell may be regulated in different ways. Not all DNA codes for a protein; some segments of DNA are involved in regulatory or structural functions, and some have no as-yet known function. **LS3.B:** Environmental factors also affect expression of traits, and hence affect the probability of occurrences of traits in a population. Thus the variation and distribution of traits observed depends on both genetic and environmental factors.

TEACHER OVERVIEW

Aim

Students will analyze and discuss how personal genetics impacts health, identity, and society, as well as the ethical and social implications of advances in genetic technology.

Guiding Questions

- How are advances in genetic science shaping healthcare now and in the future?
- What factors, aside from genetics, can impact a person's traits and health?
- How is genetic testing being used in healthcare, ancestry research, and law enforcement?
- What are the benefits and risks of using genetic information for each of these purposes?

Learning Objectives

By completing this lesson, students will be able to…

- Explain what personal genetics means and what other factors interact with a person's DNA to influence their traits and health.
- Analyze real-world scenarios to determine how genetic information can influence personal decisions.
- Reflect on the ethical and social implications of genetics.
- Discuss the personal and societal impact of advances in genetic technology.

Successful students learn by…

- Engaging in open-minded discussions.
- Demonstrating a willingness to be challenged.
- Communicating about sensitive topics with respect.

Long-Term Outcomes

Two to three years after completing this lesson, students will…

- Understand that genetic information is linked to and shapes individual and societal decisions regarding healthcare and technological advancements.
- Confidently navigate personal genetic information, making informed choices about if, why, how, and when to engage with genetic data across disciplines.
- Engage in meaningful conversations about genetics, appreciating how identity, experiences, and cultural contexts shape individual perceptions and attitudes toward science and technology.

Time & Structure

This lesson takes approximately 60 minutes to present. We have organized this lesson into discrete parts, each focusing on a major theme in personal genetics. Teachers may choose to present some or all parts, or break the presentation into smaller sections to delve deeper into each topic. The parts of this lesson include:

- Personal Genetics Overview (Slides 4-11)
- Health (Slides 12-33)
- Ancestry & Identity (Slides 34-40)
- Privacy & Law Enforcement (Slides 41-47)
- Summary (Slide 48)
- Classroom Discussion: Four Corners Activity (Slides 49-54)
- Reflection (Slide 55)
- Closing & Credits (Slides 56 & 57)

Activities

This lesson includes:

1. Do Now discussion activities (15 minutes - 5 minutes per slide)
2. Slide presentation (35 minutes)
3. Four Corners discussion activity (10 minutes)

Materials

- Projector or Smartboard
- Laptop with an internet connection
- Student Handouts (printed in advance)
- Notes Organizer: The two-column notes organizer encourages students to identify important information and form a response to the key ideas, questions, and comments about the material.
- Vocabulary List
- Homework Assignment
- Printer paper and tape (to create signs for the four corners activity)

Background Information: What is Personal Genetics?

Technological developments have made it possible to read a person's entire genetic code, or genome, more rapidly and at a lower cost than ever before. DNA sequencing enables scientists and medical professionals to understand better the connections between a person's genes and their health. Using genetic information to improve human health is one facet of a growing field we call "personal genetics."

Personal genetics exists at the intersection of science and society. By looking at technological advances through a personal genetics framework, we explore the complex ways our genes and environment influence our physical, mental, and behavioral states. Learning personal genetics also encourages discussions about how technological advancements impact people and society as a whole.

Today's students will become independent healthcare consumers during a time when genetic technologies are increasingly used in medical care, allowing them to assess their genetic risks and have medicines and interventions tailored to their individual needs. As one of the most critical aspects of personal genetics, this lesson introduces students to genetics and health, as well as ancestry testing and the use of DNA in law enforcement. This lesson's content places genetic developments into a broader social context and highlights different perspectives on how genetic information should be used personally and in society at large.

Foundational Concept: Genetics, Behavior, & Environment

A critical theme of this lesson is that people's traits are influenced by both their genetic makeup and the unique circumstances in which they have lived their lives. These two inputs are often referred to as "nature," a person's biological makeup, and "nurture," the combined influence of the environments they have lived in and their behavioral choices, such as diet and exercise. "Nature" and "nurture" are not independent of each other. Environmental factors can impact how a person's genes are "expressed" (the degree to which they are functionally active), and can even lead directly to changes in the DNA sequence. For example, prolonged exposure to the sun's UV radiation can damage DNA and cause skin cancer.

A thorough understanding of human traits requires taking into account the interconnected genetic, behavioral, and environmental influences.

Interdisciplinary Connections

This lesson presents concepts and examples that focus on the social and ethical issues of genetic technologies. The material presented crosses into multiple subjects, including biology, medicine, health, social studies, law, forensics, and ethics. If you are presenting this lesson at the beginning of a genetics unit, you might plan first to explore some fundamental genetics concepts, such as:

1. People share DNA with their biological relatives, and traits can be passed down from a parent to a child through their genes.
2. Complex human traits are often the result of genes in combination with behavioral and environmental factors.

Students can learn more about fundamental genetics at the Genetic Science Learning Center (University of Utah).

Lesson Plan Guide

This lesson is presented as a slide deck, which includes a 'Do Now' activity and a 'Four Corners' activity. Accompanying explanatory notes for the presentation are provided in the sections below.

Access the Slides

Community Agreements

This lesson includes a slide dedicated to sharing ‘community agreements’ with students. The purpose of these agreements is to foster a “brave space”–one that is intentionally shaped by, and inclusive of, all identities and social groups.

In a classroom environment, the agreements are designed to encourage equitable participation of all students by setting expectations for how they will work together. Agreements often include guidelines for what it means to be respectful, expectations for communication, and/or how to structure a welcoming and collaborative environment. We encourage teachers to consider implementing community agreements in their classrooms if they haven’t yet done so.

For more information and suggestions for creating your own community agreements, refer to the resource linked below.

Read PGED’s Guide to Community Agreements

STUDENT READING

To give students a sense of the "big picture" in personal genetics, we recommend Carl Zimmer's 2016 "Game of Genomes" series in *STAT News*. It is a lengthy series, and teachers may want to recommend reading only episode 1 or 2 (of season 1) in advance of this lesson.

While the regulatory landscape for the sale of direct-to-consumer genetic tests evolves, and the technology and costs are constantly changing, the issues explored in this series related to privacy, health, identity, and the question "What do I want to know about my DNA?" remain very current.

If you or your students are unfamiliar with terms in the reading or this lesson's presentation, you are encouraged to reference and/or print copies of the Vocabulary List as a handout.

SLIDE NOTES

How to Use: These notes provide suggested verbal explanations to accompany the content on each slide. The teacher notes provide additional context to aid in answering student questions and references for those interested in delving deeper into the topics.

SLIDE 1 – Title Slide: Introduction to Personal Genetics

This lesson is called 'Introduction to Personal Genetics'. Rather than delving deeply into a single topic, this lesson offers a "sampler platter" of several important and popular topics in personal genetics.

SLIDE 2 – Topics We Will Cover

We will learn what personal genetics means, how it is relevant to our daily lives, and explore three areas of personal genetics: health, ancestry and identity, and law enforcement.

SLIDE 3 – Community Agreements

Before we begin, we first want to establish some community agreements as a group so we have clear expectations of how we interact with one another. We want everyone to feel welcomed into the discussion and encouraged to participate.

Notes for Teachers

Community agreements aim to create a "brave space" that is intentionally shaped by, and inclusive of, all identities and social groups, encouraging the equitable participation of all students. Read PGED's Community Agreements Guide for more information.

SLIDE 4 – Part 1: Personal Genetics Overview

Let's begin by learning about personal genetics.

SLIDE 5 – Personal Genetics

What is personal genetics? Personal genetics is an exploration of how genetics impacts people, families, and communities. In addition to the social impacts of genetics, personal genetics also highlights the benefits and concerns related to the use of genetic technologies. This is the lens through which we will talk about genetics today.

SLIDE 6 – How Genetics Becomes Personal

This presentation provides an overview of how genetics is becoming relevant to our everyday lives—or, in other words, how genetics becomes personal. We will examine how technological developments in personal genetics relate to people's health, personal or familial decisions, and societal challenges. Specifically, we will look at the role of personal genetics in:

1. Health & Medicine
2. Ancestry & Identity
3. Privacy & Law Enforcement

SLIDE 7 – What is DNA?

DNA is a code consisting of four letters: A, G, C, and T. It is found in nearly every cell in our bodies, and the total code is around 3 billion letters long. A complete copy of this DNA code is referred to as a genome.

You can think of the DNA code as a sort of cookbook full of recipes that interact with the environment to create you, me, and every other living being on this planet. Your DNA code is exclusive to you and is part of what makes you unique.

SLIDE 8 – DNA Alone Does Not Define Us

During this lesson, we're going to talk quite a bit about how powerful DNA can be - for helping people learn about themselves, for sharing information with relatives, and for addressing big societal challenges, to name a few examples - but I want to clarify that our DNA is not the most important thing about us.

People used to think of our genes as information that defines who we are. However, scientists have discovered that our genes often interact in complex ways with our behavior and environment to impact our health and traits. The truth is, we have a significant amount of control over how we grow and develop based on how we take care of ourselves, and that is not written in our DNA code.

SLIDE 9 – The Science is Moving Fast

Although our DNA isn't the most important thing about us, scientists have been interested in decoding human DNA since the discovery of the molecule. What do you think these machines are? (*in reference to the pictures on the slide. Give them time to respond.*)

What we see here are two types of DNA sequencers. 'DNA sequencing' is a method of decoding a segment of DNA or an entire genome.

The Human Genome Project, an international effort to sequence the first human genome, took 13 years (1990-2003) and cost $3 billion US to complete. Pictured on the left is one of the oldest types of DNA sequencers, which was used to complete the Human Genome Project. These machines were large and heavy, and took a long time to complete a sequencing run.

In 2025, sequencing a human genome can cost as little as $600 US and can be done within 24 hours. Pictured on the right is the MinION ('min-ion') - it can sequence parts of a genome in just a few hours, and is the size of a small TV remote! Both the cost and time for analysis continue to decrease as new technologies and processes improve sequencing efficiency.

SLIDE 10-11 – What We Do Today Matters

Personal genetics focuses on the ethical dilemmas of the field for three critical reasons:

1. The field is ever-evolving, and the technology is rapidly changing to meet the demands of consumers and scientific innovation. These changes then influence

public and policy discourse, generating a need to keep pace with the rapid advancements in science.
2. Access to genetic products and services is limited due to geographic distribution and cost, and
3. Genetics has been used in the past to harm people and communities. The decisions we make today can help us avoid repeating these harms.

With these facts in mind, we aim to have balanced discussions about genetics, recognizing that there are benefits and risks associated with genetic advances in society.

[*Next Slide*] And you may one day influence how genetics may or may not impact people's lives.

SLIDE 12 – Part 2: Genetics & Health

Part 2 of the presentation provides examples of how advances in genetics have led to medical breakthroughs and potential health benefits.

The first area of personal genetics we will discuss today is health.

SLIDE 13 – Do Now: Genetic Testing

Discuss the following questions:

- What can you learn from taking a genetic test?
- What are the potential benefits of knowing your genetic information?
- What are the possible downsides to knowing?

Notes for Teachers

Question 1: Students often mention learning about their health and/or ancestry. Another idea that frequently surfaces is that genetics will provide a person with definitive, life-altering answers, often including a specific cause of death. It is essential to clarify that genes are just one part of a very complex puzzle. Factors related to environment and lifestyle also contribute to a person's health outcomes.

Question 2: Students might share ideas about preventing or seeking early treatment for a potential health condition. You may suggest that even if they learned of conditions without a current treatment, they could choose to participate in clinical trials or advocacy work.

Question 3: 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 Nondiscrimination Act (GINA), a federal law in the United States that prohibits the use of genetic information to discriminate against people in employment and health insurance.

SLIDE 14 – Genetic Testing for Health

Health conditions may have many different causes. Viruses or bacterial infections may cause a person to feel unwell for a short time, but changes to a person's DNA can also affect their health. It's normal for people to have differences in their DNA code–these are called genetic variants. Variants can impact our health in a variety of ways: some can be beneficial (e.g., a variant in the FUT2 gene is protective against norovirus infection), while others can be harmful (e.g., a variant in the CFTR gene can cause cystic fibrosis), and some appear to have a neutral effect. Because genetics can play a significant role in shaping a person's health and susceptibility to developing certain health issues, we can use genetic tests to identify these differences. For example, genetic tests can be used to:

- Reveal whether an illness is genetic when other tests have failed to produce an accurate diagnosis.
- Identify future health risks.
- Provide information about how a person's DNA may impact their response to certain medications.
- Reveal information about future generations

SLIDE 15 – Genetic Tests Are Not All the Same

Some genetic tests require the participation of a medical professional–these are known as 'clinical genetic tests'. There are a few key components to clinical genetic testing. They typically:

- Require a medical referral.
- Require the participation of a medical professional, such as a genetic counselor.
- Range widely in price; the cost of some tests may be covered by insurance.
- Require a blood sample or a cheek swab.

SLIDE 16 – Genetic Tests Are Not All the Same

Other tests can be purchased without a doctor's request or participation. Genetic tests that you can purchase on your own are called direct-to-consumer (DTC) tests. Genetic tests have become so accessible that consumers can now buy testing kits online or in pharmacies and department stores across the US. Compared to clinical genetic testing, DTC testing has a few important distinctions. DTC tests:

- Are available for purchase online or in retail stores.
- Do not usually come with the support of a genetics professional to understand the results.
- Are often much cheaper, priced in the $50-$200 range.
- Typically require a spit sample or cheek swab.
- Are analytically limited, with some variants excluded from the health tests. (For example, out of the several thousand variants that clinical tests analyze for the BRCA1/2 genes in a cancer panel, some DTC testing companies only analyze three variants that can increase a person's risk of developing breast and ovarian cancer. This is a significant difference in comprehensiveness.)

Since DTC testing first emerged in the early 2000s, millions of people have sent their DNA samples for testing, seeking information about their genetic traits, ancestry, and health. While many people are excited to learn about their genetic makeup, others are concerned about providing people with genetic information without the support of a

medical professional. There is a risk that people will misinterpret results, feel a false sense of security, or make medical decisions based on the limited information provided by the tests.

SLIDES 17-20 – Genetic Tests Are Not All the Same

By now, you may be realizing that not all genetic tests are created equal.

[*Next Slide*] Some tests read a person's entire genome,

[*Next Slide*] while others focus on specific sections of genes,

[*Next Slide*] or even a tiny portion of DNA. How much or how little a genetic test covers in a person's genome depends on what exactly they are looking to uncover.

SLIDE 21 – How is Genetic Testing Performed?

So, how is genetic testing done? The process differs slightly between clinical and DTC contexts. First, samples are collected. Clinical tests typically use a blood sample (or cheek swab, in some cases) while DTC tests use spit-in tubes. The samples are then analyzed in a lab, and a results report is generated. Clinical test results are returned to the clinician for discussion with the patient, while DTC customers receive their results directly by logging onto the company's website.

SLIDE 22 – Genetic Testing: Diagnosis vs Risk

Genetic tests can identify genetic factors associated with a person's health issue. These tests have a range of functions, from diagnosing hereditary conditions like Huntington's disease to identifying increased risks for health issues, such as certain types of cancer or heart disease.

Analyzing a person's DNA is often the key to diagnosing patients with rare conditions when other approaches have failed. The information gathered from genetic tests not only aids in accurate diagnosis but also plays an important role in disease management and prevention, ultimately improving patient outcomes and quality of life.

While some people have their genomes analyzed to look for answers to the health problems they are currently experiencing, others seek genetic testing to identify potential future health risks. Genetic tests are increasingly used to predict a person's susceptibility to developing a medical condition.

SLIDE 23 – Real-Life Example: BRCA1

Let's take a look at a real example of a person who made medical decisions based on knowledge of an increased genetic health risk.

In May 2013, actor Angelina Jolie revealed that she had undergone a double mastectomy, which is a surgery where breast tissue is removed. She did this because a genetic test identified a variant in the BRCA1 gene that greatly increased her risk of breast and ovarian cancer. Some believe a preemptive double mastectomy was a drastic and potentially unnecessary choice since Jolie neither had cancer nor knew with certainty that she ever would. However, instead of waiting to see if she would develop cancer, she opted for surgery that greatly decreased her chances.. She has since also had her ovaries removed for the same reason. Jolie advocates for increasing the accessibility of genetic testing for all who want to pursue it.

Notes for Teachers

This story is a great way to engage students with a real-life example of a celebrity who used the results of a genetic test to inform a major medical decision aimed at reducing her risk of disease. To learn more about her story, read Jolie's op-ed "My Medical Choice" in the New York Times.

SLIDE 24 – Genetic Testing for Medications

Many people have had the experience of taking a medication that seems to work well for other people, only to find it does not work for them. The reason could be found in their genes.

Some genetic tests (called pharmacogenetic tests) are used to help a healthcare provider identify the most effective medication or dosage for a person based on their

DNA. This type of testing can reveal how well a medication may work for a person and how likely they are to experience adverse side effects or even a fatal reaction.

SLIDE 25 – Real-Life Example: CYP2D6

Codeine is a specific example of a medication that works differently in different people based on their DNA. Codeine is an opioid drug that is frequently prescribed for pain. For the drug to be effective, the body must convert the codeine to morphine. This conversion is done with the help of an enzyme called CYP2D6.

Variants in the CYP2D6 gene can significantly impact how quickly an individual metabolizes this drug. If the dosage is not calibrated correctly, it can have serious, sometimes fatal, consequences.

Some people are born with a version of CYP2D6 that causes them to metabolize codeine without any issues. These so-called 'typical metabolizers' will experience the expected effects from a typical dose of the medication. People who have a version of CYP2D6 that makes them 'slow metabolizers' convert codeine to morphine at a much slower rate, meaning that they will get a limited effect from the same dose of the drug as a typical metabolizer. Conversely, people who are 'rapid metabolizers' will convert that same dose of codeine into morphine at a much faster rate, causing a potentially life-threatening spike of morphine in the person's body.

SLIDE 26 – As a Result…

The FDA has approved genetic tests for determining whether a person is a rapid metabolizer; however, these tests are not routinely used in the clinical setting. Individuals who have a personal or family history of not responding to medications as expected may want to seek genetic analysis for a possible explanation, especially before they are prescribed codeine by a medical professional.

Because of the potential for adverse reactions, in 2017, the FDA restricted the use of codeine as a treatment for children. The agency also recommends that breastfeeding women avoid taking codeine to prevent adverse effects for their nursing baby.

SLIDE 27 – Genetic Testing for Future Generations

In addition to testing for individual health reasons, people may seek genetic testing before trying to get pregnant or during pregnancy to determine if they might have a child with a genetic condition.

Reproductive genetic technologies can help people conceive, learn more about the health of their pregnancy, and have some choice about the genetic makeup of their children.

SLIDES 28-31 – Reproductive Genetic Testing

People may seek genetic testing before trying to get pregnant or during pregnancy to determine if they carry genetic variants that would cause their child to have a genetic condition. This type of genetic test is called carrier screening. Carrier screening results can help prospective parents determine whether they wish to conceive biological children and, if so, how they might want to do so.

[*Next Slide*] Genetic testing can also be used to learn about the genetic makeup of embryos created by *in vitro* fertilization (IVF). For this test, called preimplantation genetic diagnosis (PGD), a sample of cells is taken from the developing embryo for testing. PGD is a process used to screen embryos for genetic variants that can cause disorders. The results of IVF with PGD may be used to select which embryos prospective parents will transfer.

[*Next Slide*] Additionally, a screening procedure called noninvasive prenatal testing (NIPT) can analyze small fragments of fetal DNA obtained from a pregnant person's blood sample.

[*Next Slide*] This cell-free fetal DNA (cfDNA) is released into the bloodstream from the placenta, the organ that connects the fetus to the carrier and is responsible for the exchange of oxygen, nutrients, and waste.

Notes for Teachers

NIPT provides a safer way to access fetal DNA than other techniques, such as amniocentesis or chorionic villus sampling, which each carry a small risk of causing miscarriage.

PGED uses the term "pregnant person" in recognition that not everyone who becomes pregnant identifies as a woman or would see themselves as a "mother" (e.g., in the case of surrogacy).

SLIDE 32 – Gene Editing for Health

Since some health conditions have a genetic cause, researchers are exploring genetically based treatments to address them at their source. These types of treatments are called 'gene therapies.' Gene or genome editing is one form of gene therapy.

Genome editing technologies allow scientists to target specific segments of a person's DNA and make changes that impact its function. If a known genetic change causes a person's health condition, a gene editing approach might offer an effective treatment or at least prevent the condition from worsening.

SLIDE 33 – Real-Life Example: Sickle Cell Disease

Sickle Cell Disease (SCD) is a specific example of a genetic condition for which scientists are exploring gene editing-based therapies. SCD affects millions of people worldwide. SCD is caused by a single change in a person's DNA at the HBB gene.

In 2019, Victoria Gray became the first person to undergo a clinical trial using genome editing to modify her red blood cells. The treatment ended her lifetime of sudden pain attacks and debilitating fatigue. The first successful genome-editing-based treatments for sickle cell disease and beta-thalassemia (another genetic blood disorder) were launched in 2023.

While the success of these treatments is exciting to scientists, clinicians, patients, and their families, and provides hope for treating other genetic conditions, many questions

remain. With the cost of treatment at several million dollars in 2025, how can this therapy reach people around the globe who need it?

Notes for Teachers

SCD is a prime candidate for gene therapy, as it is a condition caused by a change at a single base pair in the DNA. However, it is important to note that most human traits and conditions are much more complex, such as heart disease, diabetes, and many forms of cancer. These conditions result from an interplay of many areas within DNA, other biological interactions, a person's environment, and lifestyle choices, including nutrition, exercise, stress management, and other factors.

SLIDE 34 – Part 3: Ancestry & Identity

Now, let's move on to discuss personal genetics and ancestry testing.

SLIDE 35 – Genetic Testing for Ancestry

Another area of research where genetics plays a key role is analyzing people's DNA to gain insights into the ancestral histories of human populations. As the cost of DNA testing decreases, ancestry tests have been directly marketed to consumers, enabling them to discover their ancestry.

SLIDE 36 – Do Now: Ancestry Tests

Discuss:

- Have any of your relatives taken an ancestry test?
- Would you be interested in taking a DNA ancestry test? Why or why not?

Notes for Teachers

Question 1: Students may share that a parent or other close relative is interested in genealogy or researching their family's history. Other students may report that their relatives are skeptical or uninterested in ancestry tests.

Question 2: Some students may claim that they have taken an ancestry test themselves, or that they learned information about their DNA from the results of a relative's test. Often, there is a wide variety of responses to this question. Some may be immediately interested and excited about the idea of learning about their ancestry, and others may be pensive or reject the idea of an ancestry test.

To ensure all students feel heard, it's important to give everyone a chance to share their perspectives. Avoid validating certain opinions without also validating opposing viewpoints. You may even mention that "there are no right or wrong answers."

SLIDES 37-38 – What the Results of an Ancestry Test May Suggest

For some people, a genetic ancestry test can add a layer of information to decades or centuries of family history records. On the other hand, for individuals without access to their family history, genetic testing can provide some insight into their ancestral origins. This includes people who have never heard about their family history, people who were adopted, as well as people whose ancestors were brought to the US through the slave trade, and do not know in what part of Africa their ancestors lived.

In addition to shedding light on someone's ancestors, ancestry tests can identify current living relatives. Finding unknown relatives may be an exciting discovery for some people, and may even be the reason they choose to do ancestry testing. For others, this discovery may be a painful and unwelcome experience. Information learned during ancestry testing may support or conflict with a person's individual and familial identity.

[*Next Slide*] Although millions of Americans have taken ancestry tests since they came onto the market, many people are not interested in taking an ancestry test. Some believe that these tests make inaccurate presumptions about their family histories, to the extent that they can be offensive. Others' values of cultural belonging and recent familial lineage surpass what an ancestry test may suggest about their biological connections to people or places in the world.

SLIDE 39 – Ancestry Testing Process

Ancestry testing starts when a person provides a DNA sample to the testing company. The company zeroes in on a tiny fraction of the DNA where variation is common among people. Then, the DNA variants are compared to reference populations (individuals who can demonstrate that their family has lived in one region of the world for several generations) to determine which population a person is most likely to share ancestry with. Although hundreds of thousands of DNA sites are analyzed to obtain a more reliable result, these tests only provide a probability of a person's ancestry, not a definitive percentage.

It is important to note that reference populations are constructed using DNA from modern-day people, not from those who were alive during the time of our ancestors. Why does this matter? Migration is a common theme throughout human history, and social identities change over time. For example, suppose someone shares ancestors with people living in Sicily today; it is possible that those ancestors might have come from another part of the world or would not have identified themselves as Sicilian. Moreover, because reference populations differ between ancestry testing companies and can change over time, a person's ancestry testing results can vary widely.

SLIDE 40 – One Person, Two Tests

Here, we will examine the test results one person received from two separate genetic ancestry testing companies: *23&Me (left) and Ancestry.com (right*).

What observations can you make from comparing the two images? What questions do you think this customer had after comparing their test results?

Notes for Teachers

These are real test results from a relative of a PGED staff member. Emphasizing that these are real images from one person's testing experience may help students connect with the concepts presented about ancestry testing, especially the points about conflicting results or questions about inaccuracies.

Question 1: Some observations that students may present include… the colors of the maps cover different regions; one map seems more "sparse" than the other; the percent breakdowns differ; generally, this person appears to have majority European ancestry; company A provided more details in their results; company A may seem like it's representing migratory patterns rather than isolated regions, and more.

Question 2: Questions that students may present include…

- Which results are more accurate?
- Why are the results different between the two companies?
- Was there a technical error that caused the results to differ?
- Do the companies have different reference populations?
- Students may also ask questions about the customer's experience, such as:
    - Did getting these results conflict with their personal or family identities?
    - Was this experience surprising? How did they feel?

SLIDE 41 – Part 4: Privacy & Law Enforcement

Now let's move on to discussing DNA, privacy, and law enforcement.

SLIDE 42 – Do Now: Proof of Criminal Activity?

Discuss: Does finding someone's DNA at a crime scene mean they were involved in the crime?

Notes for Teachers

Students typically respond to this question with a resounding 'no'. However, there may be students who are unsure how to respond. Sometimes, TV shows and movies about criminal investigations portray DNA as a unique identification tool that has no flaws or technical limitations. This portrayal ignores the realities of DNA contamination and issues with quality. To reinforce that there are some limitations to using DNA for forensic purposes, you may mention that we all 'shed' our DNA in our environments constantly, which might cause DNA from innocent people to be found at the scene of a crime.

SLIDES 43-44 – DNA, Crime, & Law Enforcement

While learning about your DNA is highly personal, the ability to do so raises complicated questions about how we, as individuals and as a society, should handle access to genetic information. Who has access to your DNA? And what privacy concerns does that raise?

DNA is used in law enforcement to identify suspects, find missing persons, and exonerate individuals who have been wrongly convicted of a crime. Some people believe that having a database of all people's DNA could help keep society safe.

[*Next Slide*] However, DNA as a forensic tool has its limitations.

SLIDE 45 – Genetic Info Privacy

As we have seen in this presentation, the scientific advances of the past few decades have brought us to a time in which individuals have more access to their genetic information than ever before. And, they can have access to their relatives' genetic information, as we all share a portion of our DNA with our biological relatives. Therefore, analysis of our genes can provide insights into the genes of our relatives, and vice versa.

SLIDE 46 – Familial Searching

Because of this familial connection, law enforcement officers have been able to identify suspects of crimes by using information from their family members' DNA through a technique called familial searching. It is a controversial method that first requires investigators to upload the DNA of a suspect to an ancestry or genealogy database. Then, they create a fake profile for the suspect. By using the familial connections generated by the service, investigators create a family tree of information, ultimately enabling them to identify the suspect by their real name and charge them with the crime.

SLIDE 47 – Real Life Example: The Golden State Killer Case

After failing to find a match in the government-created databases, investigators in "The Golden State Killer" case uploaded what they believed to be the notorious rapist and murderer's DNA to an open-source genealogy database, called GEDmatch. GEDmatch is a privately created database that invites people to upload their DNA analysis from private companies like 23andMe or Ancestry.com, in the hopes of building a large community for people seeking familial connections. Law enforcement found a genetic connection in the database – a distant cousin of the suspected killer. Using genealogical research to construct a family tree, investigators narrowed down the possible suspects and, with additional DNA testing, an arrest was made: Joseph James DeAngelo.

Though GEDmatch was not developed to be a legal tool, in the months after the arrest of the suspected "Golden State Killer", law enforcement agencies used the database to make arrests in several other "cold cases." Some people have reacted positively to this news by saying that all methods are justified in the pursuit of solving crimes. Others have voiced concern that if even one biological relative uploads their DNA to a genealogy database like GEDmatch, then some of their shared DNA is also part of a system that is now being used for law enforcement reasons. Additionally, decisions about law enforcement's access to the GEDmatch database were largely in the hands of two private citizens who founded the organization.

Notes for Teachers

In May 2019, GEDmatch updated its terms of service so that DNA profiles would be, by default, opted out of use in law enforcement investigations. Users can opt in if they wish. As of June 2019, only 5% of the 1 million members of GEDmatch had opted in. In December 2019, GEDmatch was taken over by the forensic genomics firm Verogen.

SLIDE 48 – Here's What We've Learned

Whether seeking answers to medical questions, tracing our ancestry, or addressing larger community-level issues such as the privacy of genetic information and access to genetic technologies, personal genetics is playing an increasing role in our daily lives.

SLIDES 49-57 – Four Corners Activity

Now that we've explored three key areas of personal genetics, let's do an activity to discuss them further. We're going to do an activity called 'Four Corners'.

[*Next Slide*] Here's how it works. I will present a statement about genetics and society. Then, you will be invited to share your opinion on the statement. Depending on your opinion, you will move to one of five areas of the room labeled strongly agree, agree, unsure/neutral, disagree, or strongly disagree. Then, I will facilitate the discussion.

Notes for Teachers

Students will read several statements and move to the labeled corners of the room based on the degree to which they agree or disagree with each statement. They will share and discuss their opinions with the class. If you have established community agreements, it might be helpful to remind students of them before beginning the activity.

See Classroom Discussion for further guidance on facilitating the Four Corners activity.

SLIDE 58 – Time for Reflection

Consider how genetics is impacting your life now or might impact you in the future.

- What information shared during this presentation surprised you?
- What information, if anything, do you want to share with family or friends?

Notes for Teachers

You can choose to use some time at the end of class for a quick reflection on the materials covered. It may be helpful to assign this reflection for homework if you run out of time during class.

SLIDE 59 – Thanks for Listening!

SLIDE 60 – Image Credits

CLASSROOM DISCUSSION

Four Corners Activity Directions

Students will hear several statements and move to labeled corners of the room based on the degree to which they agree or disagree with each statement. They will share and discuss their opinions with the class.

Step 1: Prepare

Before students enter the classroom, label the four corners of the room with signs that read "*Strongly Agree,*" "*Agree,*" "*Disagree,*" and "*Strongly Disagree*." Depending on your classroom, you could also use a straight line across the room and ask students to place themselves on the continuum between strongly agree and strongly disagree.

Remind students that new advances in genetics and genome sequencing offer great hope for medicine and health; at the same time, there are questions to consider on a personal and societal level. The statements below provide students with an opportunity to express their opinions and discuss some of the issues based on what they learned from the presentation.

Step 2: Introduce the Statements

We have provided four statements, included on slides 51-54 of the slide deck. Teachers can select the statements that will work best for their classroom. Before beginning the discussion, remind students of the agreements for having a respectful and open discussion of ideas.

Read each statement and have students move to the area of the room corresponding with whether they strongly agree, agree, are unsure/undecided, disagree, or strongly disagree with the statement. (Displaying the statements on the slides will help students understand the statement and prevent the teacher from having to read it several times.) After students are in their places, have them discuss in their groups why they agree/disagree. Then, ask for volunteers to explain their position to the group, citing information from the homework article or presentation discussion that supports their

position. Encourage students to switch corners if someone presents an idea that causes them to change their opinion. After a representative from each corner has defended their position, you can allow students to question each other's evidence and ideas. If you have longer class periods or will use this as a pre-writing activity for either an essay or debate, you can distribute statements and allow students to respond to them in writing before discussing.

Note: An important concept to raise throughout this discussion is that many physical, mental, and behavioral traits are very difficult to predict or ensure. This is because such traits are the result of an individual's environment and lifestyle as well as their genetic makeup. Additionally, the genetic basis of many traits is highly complex and exceeds our current understanding.

Step 3: Debrief the Activity

You can debrief the lesson through a class discussion or an individual writing assignment. Discuss or have students write about how the activity changed or reinforced their original ideas. To clarify ideas shared during the discussion, chart the main arguments on the board as a whole-class activity.

Statements & Teacher Notes

People should have the right to learn whatever they want about their DNA because it is their own body.

Note: The previous two statements show conflicting viewpoints about genetic testing, particularly regarding direct-to-consumer (DTC) testing. As mentioned during the presentation, there has been much debate over DTC genetic testing. One question is whether genetic testing kits should be considered medical devices, subject to the extensive rules and regulations that oversee safety and quality.

Some people opposed to DTC testing argue that people should only learn about their DNA from a doctor or genetic counselor to ensure that the results are clearly explained. People who support DTC testing often find this argument paternalistic and believe that individuals have the right to learn about their DNA if they choose.

I want to find out my likelihood of developing a disease *only* if there are ways to prevent or treat it.

Even in the absence of medical interventions, some individuals may use this information to guide lifestyle changes and financial planning or may be spurred into advocacy or participation in research. Other people feel that concerns about discrimination and the emotional impact override the benefits of having this information. Some studies have shown that overall learning about heightened genetic risk for disease does not appear to do long-term harm.

To read more, see "Learning of Risk of Alzheimer's Seems to Do No Harm," by Denise Grady, July 2009, New York Times.

Parents undergoing *in vitro* fertilization should have the option to screen embryos for genetic variants likely to cause a life-limiting health condition.

Some prospective parents who know they carry a genetic variant that would likely cause serious disease or death in a child opt to get special testing, called preimplantation genetic diagnosis (PGD), to test embryos for that variant. Any embryos that are free of the genetic variant for which they are being tested are then considered for transfer into the uterus. Some people see this as a great advance that can reduce serious and deadly diseases, while others believe that any testing of embryos is unethical because it involves the removal of one or more cells from the embryo. Another concern is that screening embryos will alter individual and societal acceptance of disability and human genetic variation.

Parents should be able to choose a child's traits, such as eye color and sex, for non-medical reasons.

Many clinics that offer PGD for medical reasons, such as to avoid X-linked diseases, also allow parents to select the sex of the child for social reasons. While the service is not widely available, at least one clinic in the US now offers eye color selection as well.

After discussing the statement, ask students to imagine a future when it becomes possible to analyze fetal genomes to test for athletic ability or perfect pitch (the ability to identify or recreate a musical note without a reference pitch). Would they change their answer? A key concept is that many physical, mental, and behavioral traits are challenging to predict or ensure. This is because such traits are the result of an individual's environment and lifestyle, as well as their genetic makeup. In addition, the genetic basis of many traits is highly complex and beyond our current understanding.

Employers should be allowed to use genetic information to make hiring or firing decisions about employees.

In addition to prohibiting health insurers from discriminating based on genetic information, the Genetic Information Nondiscrimination Act (GINA), passed by the United States Congress in 2008, prohibits employers from using genetic information to make hiring or firing decisions. Therefore, from a legal standpoint, the correct answer is simply no, employers cannot use genetic information in hiring, firing, or promotion decisions. However, this statement may prompt students to think about genetic traits and career choices. It raises several interesting questions. Can everyone be a professional athlete? Truck driver? Professor? Soldier?

Parents should be able to find out whatever they would like to know about their child's DNA before they turn 18.

This statement is intentionally broad to encourage students to consider the potential for parents to access a significant amount of information 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. Teachers may want to point out that students may have already had their DNA assessed in some way via prenatal genetic screening. While genetic testing can help predict, diagnose, or treat certain diseases, it may also reveal genetic risks for diseases 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 can give informed consent. Should testing be limited to only looking for a specific subset of genetic markers? If genome

sequencing is performed, should only specific types of information be provided to parents?

The American College of Medical Genetics and Genomics (ACMG) guidelines regarding the reporting of incidental, or secondary, findings when performing genome sequencing recommend that doctors only inform patients about findings of specific genetic variants that are associated with serious disorders, and 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.

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".

I would want to know if someone I was dating had a strong genetic predisposition to a life-limiting health condition.

The goal of this statement is to encourage students to consider how the availability of genetic information might impact our social perceptions and how private or accessible they want their information to be.

ADDITIONAL RESOURCES FOR TEACHERS

PGED has several other resources that explore the science and societal implications of personal genetics, which can be found in the Resource Hub on www.PGED.org:

Lesson Plans: Full-length lessons with presentations and activities included.

- DNA, Crime, and Law Enforcement
- Genetics, Jobs, and Your Rights
- Genome Editing and CRISPR
- Reproductive Genetic Testing: Technology, Access, and Decision Making
- Sex, Genetics, and Athletics

Mini-Lessons: Short-format lessons with student-facing activities.

- Admixture Testing: How Can Your DNA Provide Insights into Your Ancestry?
- Am I a Carrier for a Genetic Condition? Exploring Carrier Screening Through Cystic Fibrosis
- Ancestry & Identity in the Genomic Age
- Are My Genes My Destiny? Examining Determinants of Health
- Direct-to-Consumer Testing in the Genomic Age
- Intro to Genetics & Medicine
- The Many Faces of Sickle Cell Disease
- Meet GINA: Privacy Protections for Genetic Information
- Sickle Cell & Sports: After 10 Years of Testing All College Athletes for Sickle Cell Trait, What Have We Learned?
- Who Are Genetic Counselors?

PGED learning materials are created using a variety of trusted sources. We recommend checking out the following to learn more about the concepts covered in this lesson.

- 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 remain timely.
- The Hastings Center is an independent, nonpartisan, and nonprofit bioethics research institute that offers many resources and articles on ethics, genetics, and society.
- Scientific background for some of the ancestry concepts.

NOTES ORGANIZER

Name:_____ **Date:**_____

Key Ideas: What ideas are most important to remember? What new terms or concepts have been introduced?	**Response:** What questions does this information raise for you? What other ideas, events, or texts does this information remind you of? Why do you think this information is important? How does this information connect to your own life? What do you think of these ideas?

VOCABULARY LIST

Gene – A sequence of DNA code that determines some specific characteristic(s) of an organism.

Genetic test – A procedure used to identify genetic variants in DNA. Often performed on a sample from saliva, blood, or a cheek swab.

Genetic variant – One of several possible DNA sequences at a particular location in the genome.

Genome – An individual's full set of genetic information, including all genes as well as other sections of DNA that may regulate the activity of those genes.

Genetics – The field of research that studies DNA. One way to learn more about our genome is by reading the DNA code.

Pharmacogenetic testing – A genetic test performed to evaluate the efficacy of a drug or treatment based on a person's genetic makeup.

Carrier screening – A test that can determine whether a person is at risk of passing on genes that can cause a child to be born with or develop a genetic disorder.

***In vitro* fertilization –** In vitro fertilization (IVF) is the joining of a woman's egg and a man's sperm in a laboratory dish. In vitro means 'outside the body'.

Preimplantation genetic diagnosis – A technique used to screen for genetic variants that cause disorders and used to select embryos for transfer during the IVF process.

Noninvasive prenatal testing – A method of screening small fragments of cell-free fetal DNA (cfDNA) circulating in a pregnant person's blood to identify genetic abnormalities.

Cell-free fetal DNA – Small fragments of fetal DNA obtained from a pregnant person's blood sample.

Genetic counseling (clinical) – The process of investigating individuals and families affected by or at risk of genetic disorders to help them understand and adapt to the medical, psychological, and familial implications of genetic contributions to disease.

Gene therapy – A treatment that adds a new gene or replaces or repairs a disease-causing gene variant inside the body's cells to help prevent or treat certain diseases.

Gene or genome editing – Making a change to an organism's DNA at a specific site.

Sickle cell disease – A genetic blood disorder that affects hemoglobin, the protein that carries oxygen through the body.

DNA ancestry testing – A service that analyzes a person's DNA to provide an estimate of the population(s) that an individual is descended from or to identify probable biological relatives.

Reference population – People who can demonstrate that their family has lived in one region of the world for several generations.

HOMEWORK ASSIGNMENT

Name:_____ **Date:**_____

Answer the following questions using the information from the presentation and/or ideas from the class discussion.

1. What is personal genetics? Define it using your own words.

2. Provide one specific example (with a case either referenced during class or researched on your own) of how genetics impacts people's lives.

3. How do genetic, behavioral, and environmental factors interact to influence a person's traits and health?

4. List some factors individuals may want to consider before pursuing genetic testing.

    a. What are some benefits of genetic testing?

    b. What are some disadvantages of genetic testing?

    c. Would you consider getting genetic testing to learn more about your health? Why or why not?

THANKS FOR USING PGED'S LESSON PLAN!

Want to tell us how your lessons are going?
Share your experiences with us.

For more resources about genetics and society,
check out our complete library at pged.org.

Join our mailing list to learn about our upcoming programs,
new resources, workshop offerings, and other news.

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