PRECISION MEDICINE

LESSON PLAN

PERSONAL GENETICS EDUCATION & DIALOGUE

Table of Contents

Created by Personal Genetics Education & Dialogue | Updated 2025 | for EDUCATIONAL PURPOSES ONLY.

ACADEMIC STANDARDS ALIGNMENT

COMMON CORE

STANDARD	DESCRIPTION
CCSS.ELA-LITERACY.RST.11-12.6	Analyze the author's purpose in providing an explanation, describing a procedure, or discussing an experiment in a text, identifying important issues that remain unresolved.
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-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

To equip students with knowledge of a rapidly evolving field of medicine so they can apply their knowledge to personal health decisions in the future.

Guiding Questions

- How are genetic technologies being used to diagnose and treat human health conditions?
- What health or lifestyle factors should doctors consider when deciding how to treat their patients?
- What are some of the challenges in making precision medicine available for everyone?

Learning Objectives

By completing this lesson, students will be able to…

- Define precision medicine in their own words.
- Explain how a person's genetic makeup can be important for deciding what types of medications and/or treatments are best suited for them.
- Identify key challenges that affect the adoption of precision medicine in healthcare.
- Reflect on how precision medicine could impact their future healthcare.

Students demonstrate success by…

- Engaging in open-minded discussions.
- Demonstrating a willingness for their ideas to be challenged.
- Communicating respectfully on topics that can be personal or sensitive.

Created by Personal Genetics Education & Dialogue | Updated 2025 | for EDUCATIONAL PURPOSES ONLY.

Long-Term Outcomes

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

- Make health decisions using information about both their biology and lifestyle.
- Apply scientific, ethical, and social influences to medical scenarios, such as patient-doctor communications, when making important healthcare decisions.
- Seek out reliable information about new medical technologies to help guide their future health decisions.

Time & Preparation

This lesson takes approximately 45 minutes to present, with an additional 30+ minutes to complete the project, depending on the desired level of complexity. The project can be completed during class time or as a homework assignment.

Activities

This lesson includes:

- 'Do Now'/'Think About It' exercises (10-15 minutes)
- ELSI Notes Organizer (used throughout the lesson)
- Reflection Activity (5-10 minutes)
- Precision Medicine Project (30-60 minutes) - *can be done in or outside of class*

Materials

- Projector/Smartboard
- Laptop with an internet connection
- Student Handout: Precision Medicine Project
- ELSI Organizer: The organizer encourages students to align their ideas, questions, and comments about the material with real-world connections.
- Vocabulary List
- Printer and paper

Created by Personal Genetics Education & Dialogue | Updated 2025 | for EDUCATIONAL PURPOSES ONLY.

Background Information

Precision medicine holds great promise to improve healthcare. According to the National Human Genome Research Institute (Oct 2025), precision medicine "...is an innovative approach that uses information about an individual's genomic, environmental, and lifestyle information to guide decisions related to their medical management."

As the cost of genetic analysis decreases and research advances, it is becoming increasingly possible to include a person's genetic makeup in the repertoire of tools that inform their healthcare. High school students will soon take charge of their own healthcare, and having a foundation in the concepts of precision medicine may help them become informed advocates for themselves as they enter adulthood.

Foundational Concept: Genetic Technologies are Revolutionizing Medicine

Doctors and scientists are exploring several approaches to connecting genetics and healthcare:

- **Genome sequencing:** can be used to diagnose patients with rare conditions when other approaches have failed. Genetic information is also increasingly used to predict a person's susceptibility to developing medical conditions.
- **Pharmacogenomics:** A growing number of medications are prescribed based on a person's genetic makeup. Treatments are being developed for certain diseases that are linked to specific genetic variants.
- **Genome editing:** Making alterations to a person's genetic makeup to reduce or eliminate their symptoms associated with a genetic condition is now a possibility, albeit one that is out of reach for many due to high costs.

In this lesson, students will consider the hopes and challenges of precision medicine and explore these applications of genetic analysis for health. Students will be asked to write about the goals of precision medicine as well as the broader medical, scientific, and social issues as they develop their own educational brochures.

Interdisciplinary Connections & Preparation

This lesson presents concepts and examples that introduce students to the social and ethical issues of genetic technologies. The material presented crosses into multiple subjects, including biology, medicine, health, social studies, 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:

- People share DNA with their biological relatives, and traits can be passed down from a parent to a child through their genes.
- 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 short video, several points of interaction through discussion activities, and a reflection exercise. Accompanying slide notes for the presentation are provided in the sections below.

Access the Slides

Update once slides are complete

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

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 – Precision Medicine: Healthcare of the future?

Today, we are diving into a topic that many are calling the 'Healthcare of the Future': Precision Medicine.

SLIDE 2 – Learning Goals

Our goal today is to understand what this new approach to health looks like. By the end of this session, you should be able to do four things:

1. Define what 'precision medicine' is.
2. Learn how our genes can directly affect medical treatment.
3. Explore some powerful, real-world examples of precision medicine in action.
4. Consider both the benefits and the important challenges of this type of medicine.

SLIDE 3 – Community Agreements

Before we begin, let's quickly review our community agreements. When we discuss complex topics like health and genetics, it's important that we: speak honestly from our own experience, own the impact of our words, and listen to understand, not just to respond. We are here to focus on learning and to embrace the capacity to change our opinions.

Created by Personal Genetics Education & Dialogue | Updated 2025 | for EDUCATIONAL PURPOSES ONLY.

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 and to learn how to create your own classroom agreements.

SLIDE 4 – Do Now: "Warm Up"

Take a moment to look at our 'DO NOW' question: What do you think are the goals of medicine? Jot down your thoughts and discuss them with a neighbor.

Notes for Teachers

Students may respond to this question with ideas such as "To treat patients", "To cure diseases", "Caring for people who are sick", "Giving sick people medications", or other gut reactions. Don't be concerned if student responses seem a bit surface-level– the next few slides intentionally dig into this question to prepare students for the rest of the lesson.

SLIDE 5 – The Goals of Medicine

When we think about healthcare, the goals generally fall into three categories:

1. **Prevention:** This means recommending behaviors, like diet or exercise, to decrease the chances of developing a condition.
2. **Diagnosis:** This is the act of identifying the cause of symptoms.
3. **Treatment:** This involves providing effective therapies to alleviate symptoms or manage a condition.

SLIDE 6 – What Kinds of Information are Used by Doctors?

To achieve these goals, doctors use a lot of information about their patients. Standard information includes a patient's age, body size (height and weight), current medications, and the results of medical tests like blood tests, imaging, or tissue samples. Doctors also pay close attention to organ function, particularly the kidneys

and liver, because these organs help our bodies process medications. And, doctors are increasingly using DNA as a source of information.

SLIDE 7 – What Can We Learn from DNA Tests?

So, why are doctors now using DNA in medicine? What insight can we gain from testing our DNA?

In some cases, knowing a person's genetic code can reveal key pieces of information for a healthcare provider:

- The cause of a disease, especially for people who have experienced a "diagnostic odyssey". This means that they have been undergoing tests and treatments for their symptoms for a long time, but have not received an accurate diagnosis.
- The risk of developing a future disease.
- And how a person's body may respond to treatment.

For a healthcare professional, knowing this information can help them best care for their patients.

SLIDES 8-11 – Genes & Caffeine

Let's look at a common example that relates to how your body handles a drug—or in this case, caffeine. How many of us consume caffeine daily, whether it's through coffee, tea, energy drinks, or some other form?

The CYP1A2 gene helps people metabolize, or break down, caffeine. Different variations of this gene impact the way people respond to their caffeine intake:

(Slide 9): Fast metabolizers make up about 40% of the population. They experience a quick energy boost and a reduced risk of heart attacks.

(Slide 10): Moderate metabolizers make up 45% of the population.

(Slide 11): Slow metabolizers make up about 15% of the population. They experience a slower energy boost, but they also have an increased risk of heart attacks from consuming caffeine.

(Optional Discussion question) If a doctor told you that you were a 'slow metabolizer' for caffeine based on your gene variants, how much caffeine do you think they would recommend you take in daily, compared to someone who is a fast or moderate metabolizer? How might that information change your personal decisions about how much coffee or soda you drink?

SLIDE 12 – One Size Does Not Fit All

The caffeine example highlights a key idea: one size does not fit all, even for a substance as commonly consumed as caffeine. Given that we know individual bodies respond differently based on their unique combination of factors, a new approach to medicine is emerging: precision medicine.

SLIDES 13-14 – Think About It…

Why might a medicine work well for one person but not another? *(Pause for student responses.)*

(Slide 14): The differences can be due to many things, including body differences, allergies, lifestyle choices, or the effects of other medications. And now, we know that **genetics** can play an important role as well.

SLIDE 15 – Approaches to Medicine

This brings us to a definition of two major approaches to medicine:

- **Conventional Medicine** is what we traditionally know; it uses a one-size-fits-all approach, designed to work for the 'average patient'.
- **Precision Medicine** is different. It evaluates differences in a patient's genes, environments, and lifestyle to tailor their medical treatments.

SLIDE 16 – Think About It…

For doctors, how might knowing their patients' genetic information improve the quality of their healthcare?

Notes for Teachers

By having knowledge of a patient's biological foundation, doctors can learn the genetic differences that would cause a health condition to manifest uniquely between people. They could understand why a particular medicine or treatment works well for one person and not another with the same health condition. With access to genetic information, doctors can optimize their patient care by taking a more tailored approach.

SLIDE 17 – Video: What is Precision Medicine?

We're going to watch a short video that explains what precision medicine is and why it matters. As you watch, pay attention to any examples or definitions that help clarify how precision medicine differs from traditional healthcare approaches. After watching the video, jot down one quick thing that surprised you. You will need this later for our activity.

SLIDE 18 – Precision Medicine Holds the Power to Change Lives…

Precision medicine has incredible potential to improve people's health. But not everyone has equal access to the healthcare they need. Some people who could benefit the most may never get the chance to learn about precision medicine or use it. This raises important questions about fairness, access, and equity in healthcare. These key aspects must be addressed before precision medicine is utilized equitably to treat patients. We won't necessarily generate the answers to these questions, but with you all as tomorrow's leaders, it's beneficial to start generating ideas about these issues today.

SLIDE 19 – Genes & Precision Medicine

Today, we are going to explore three specific ways genetic information is being used in precision medicine: **Genome sequencing, Pharmacogenetics, and Genome editing**.

SLIDE 20 – ELSI & Precision Medicine

As we discuss these powerful applications of genetics, we must also consider the **Ethical, Legal, and Social Implications (ELSI)**.

These implications are defined as:

- **Ethical:** This concerns the moral principles that guide the use of genetic information, such as ensuring fairness, preventing harm, and respecting individual autonomy.
- **Legal:** This refers to the laws and regulations created to protect individuals from discrimination, ensure the privacy of genetic data, and govern informed consent for genetic testing.
- **Social:** This addresses how genetic information affects individuals, families, and communities, including issues of social stigma, equity, access, and understanding.

This lesson comes with an ELSI topic organizer, where you can write down questions, ideas, or other notes as we move through the presentation. You will use your notes to help you with this lesson's project, so be sure to fill out the organizer during class.

SLIDES 21-22 – Genome Sequencing

Our first precision medicine application is **Genome Sequencing**. Sequencing simply means reading a DNA code. This process can be used to diagnose conditions known to have a genetic cause, identify risk factors, and guide prevention and treatment decisions.

Created by Personal Genetics Education & Dialogue | Updated 2025 | for **EDUCATIONAL PURPOSES ONLY.**

SLIDE 23 – Do Now: "Genome Sequencing"

Let's start with a 'DO NOW' discussion: Why might a person want to get their genome sequenced? And conversely, why might they be concerned about getting their genome sequenced?

Notes for Teachers

Students may shape this conversation by responding with ideas about the benefits and risks of sharing personal information or private data. A person may want to get their genome sequenced for several reasons, including but not limited to: (1) they are seeking an accurate diagnosis as a rare disease patient, (2) they are curious to know about potential health risks that standard genetic tests or direct-to-consumer kits do not cover, and (3) their doctor suspects that they may have a late-onset genetic condition or other risk factor that can be mitigated by an early diagnosis. Risks commonly cited include (1) discrimination based on genetic information for opportunities in employment, health insurance, athletics, and more, (2) fear of learning about health risks that cannot be easily addressed, and (3) revealing new information about biological family members that they feel unprepared to handle.

SLIDES 24-27: Sequencing for a Diagnosis (Case Study)

We are going to look at the case of Fitz Kettler. In June 2019, Christina and Daniel Kettler were barely home from the hospital with their newborn son, Fitz, when they received an urgent phone call telling them to rush back.

(Slide 25): A routine newborn screening, called the heel stick test, revealed that Fitz had a rare condition called **Severe Combined Immunodeficiency, or SCID**. Because SCID compromises the immune system, Fitz was immediately quarantined. Sadly, some babies with SCID do not live for very long because even a common cold can be deadly.

(Slide 26): To guide treatment, doctors performed **Rapid Whole-Genome Sequencing**. This allowed them to identify the specific type of SCID Fitz had, diagnosing him with 'Artemis,' or ART-SCID, in less than four days. This diagnosis was important because

there are several different SCID types based on different gene variants, and ART-SCID is not the most common type.

(Slide 27): Because the clinicians could name the specific gene mutation, they knew Fitz was eligible for a specialized gene therapy clinical trial. Thanks to this precision diagnosis, Fitz was able to receive a life-saving gene therapy.

SLIDES 28-29 – Pharmacogenomics

The second area is **Pharmacogenomics**. This field involves using a person's DNA to determine medication safety, efficacy, and dosing, and it helps guide the development of new drugs.

SLIDES 30-33: Examples of Medication

Many medications are already leveraging a precision medicine approach. For example, pharmacogenomics can inform dosing for Simvastatin (for high cholesterol) or help determine the effectiveness of Trastuzumab (for breast cancer).

(Slide 31): Let's focus on **Warfarin**, a drug used to treat blood clots. Warfarin works by blocking the liver's ability to use Vitamin K, which is an essential nutrient for creating blood-clotting proteins.

(Slide 32): Dosing Warfarin is critical. If the dose is too high, it can cause dangerous bleeding; if it's too low, it won't be effective at preventing clots.

(Slide 33): This is where precision medicine comes in. Variations in genes such as CYP2C9 and VKORC1 influence how effective Warfarin will be in a person's system. By knowing a patient's genetic variants, doctors can safely and effectively tailor the starting dose.

SLIDE 34 – Do Now: "Pharmacogenomics"

Why might a person want to use genetic information to make decisions about which medications and treatments to receive?

Created by Personal Genetics Education & Dialogue | Updated 2025 | for EDUCATIONAL PURPOSES ONLY.

Notes for Teachers

Since the previous slides focused on specific drug examples, students are likely to feel comfortable responding with explanations such as “Patients need to take the right dose for their body”, “To avoid negative side effects”, and “To be safer”.

SLIDES 35-38: Cystic Fibrosis & Trikafta (Case Study)

Next, we have the case of Emily Trout. At 26 years old, Emily was on the waiting list for a double-lung transplant due to her cystic fibrosis (CF).

(Slide 36): She spent two years on that list. She had declined significantly during that time, and she admitted she 'felt silly for ever questioning whether [she] was sick enough to require such a radical surgery'.

(Slide 37): The challenge was that Emily was born with two rare CF gene variants. Her doctors told her that the newest CF treatment, called **Trikafta**, wasn’t designed to work for her specific variants. However, one doctor offered to prescribe Trikafta for her under 'compassionate use'. Compassionate use is a pathway for a patient with a serious or life-threatening disease to access an unapproved investigational drug or device for treatment outside of a clinical trial when no comparable or satisfactory alternative therapy is available. This process is often called "expanded access" and requires a physician to request permission from both the drug's manufacturer and regulatory bodies like the FDA.

(Slide 38): The results were astonishing. Within five days, Emily was out of the hospital, and she stopped coughing severely. Her lung function increased by about 35%, and she was subsequently taken off the transplant list.

SLIDES 39-40 – Genome Editing

Our final application is **Genome Editing**.

(Slide 40): Scientists are developing tools that target the underlying genetic cause of certain conditions to ease symptoms. While this is a highly promising field, only a few gene editing treatments have been approved for clinical use so far.

Created by Personal Genetics Education & Dialogue | Updated 2025 | for EDUCATIONAL PURPOSES ONLY.

SLIDE 41 – Do Now: "Genome Editing"

If you were offered a genome editing-based treatment for a health condition, what questions would you have for your doctor?

Notes for Teachers

Students' questions often include those along the lines of: "Is it safe?" "How much does it cost?" "Has it already been tested?" "What happens if it fails/goes wrong?" "Will it cure me forever?". The purpose of this discussion activity is not to make students fearful of genome editing therapies, but to encourage them to think critically about novel treatments and practice their role as informed healthcare consumers.

SLIDES 42-45 – Sickle Cell Disease (Case Study)

We'll look at the case of **Victoria Gray**. In 2019, she became the first person to undergo a clinical trial using gene editing to modify her red blood cells to treat **sickle cell disease (SCD)**. Sickle cell disease is an inherited blood disorder where red blood cells are abnormally crescent-shaped and can block blood flow, causing pain and other complications known as a "sickling crisis". This occurs because of a genetic mutation that affects hemoglobin, the protein in red blood cells that carries oxygen. These sickled cells are stiff, don't last as long as normal red blood cells, and can get stuck in small blood vessels, preventing oxygen from reaching the body's tissues.

(Slide 43): Victoria was diagnosed with SCD at just three months old, and her painful crises continued and worsened throughout her life. Eventually, she experienced a crisis that left her unable to use her arms and legs. She was desperate for a treatment that would ease her pain.

(Slide 44): After over 30 years of crises and severe pain, she was preparing for a traditional bone marrow transplant when a doctor asked if she had heard of **CRISPR gene therapy**.

(Slide 45): She proceeded with the experimental cell treatment. After months of treatment, chemotherapy, and blood transfusions, Victoria woke up pain-free after 34

years of suffering from sickle cell pain. In a 2023 NPR interview, she stated that the difference was 'night and day' and that she felt like she 'got a second chance'.

SLIDE 46 – Do Now: Summary

We have reached the end of our lesson. Let's use our final 'DO NOW' to summarize what we've learned. First, how is 'treating the patient' different from 'treating the condition'? Second, how might precision medicine change the future of health?

Notes for Teachers

By this point in the lesson, students are likely to immediately understand the difference between 'treating the patient' and 'treating the condition'. They may reference the "one size does not fit all" statement from earlier in the lesson. You might find it helpful to encourage them to focus on how conventional medical practices generate treatments for the "average patient/condition" rather than the individual, which can lead to lower quality medical care or even cause patients to never get the correct diagnosis or care they need.

SLIDE 47 – Reflection Activity

We're going to take a moment to reflect on what you've learned. First, think of one benefit and one risk of using precision medicine. Then consider the ethical, legal, and social issues—often called ELSI—that arise when we use genetic information in healthcare. Finally, think about how you feel about your own genetic information being used in the future. What excites you? What worries you? There are no right or wrong answers.

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.

Created by Personal Genetics Education & Dialogue | Updated 2025 | for EDUCATIONAL PURPOSES ONLY.

SLIDE 48 – Precision Medicine Project

Your final assignment for this lesson is the Precision Medicine Project. Your task is to choose one content area we covered today—Genome sequencing, Pharmacogenomics, or Genome editing—and create an informational product that helps patients understand precision medicine.

Your main goal is to break down the information in a way that someone without a science background could understand. You can present your findings as a brochure, webpage, slide presentation, video, or some other creative medium that we agree on. Let's turn our attention to the handout to learn more about the project requirements.

SLIDES 49-51 – Thanks for Listening, Optional Science Supplement, & Image Credits

Created by Personal Genetics Education & Dialogue | Updated 2025 | for EDUCATIONAL PURPOSES ONLY.

ADDITIONAL RESOURCES FOR TEACHERS

PGED has several other resources that explore the impact of genetic technologies on modern medicine, which can be found in the Resource Hub on www.PGED.org:

Lesson Plans

Full-length lessons with presentations and activities included.

- Introduction to Personal Genetics
- Genome Editing and CRISPR
- Reproductive Genetic Testing: Technology, Access, and Decision Making
- Consumer Genetics

Mini-Lessons

Short-format lessons with student-facing activities.

- Am I a Carrier for a Genetic Condition? Exploring Carrier Screening Through Cystic Fibrosis
- Are My Genes My Destiny? Examining Determinants of Health
- Direct-to-Consumer Testing in the Genomic Age
- Intro to Genetics & Medicine
- Who Are Genetic Counselors?
- Genome Editing & Organ Transplants
- Rare Diseases: When New Treatments Come with Big Hopes & a Big Price Tag
- Mitochondrial Replacement Therapy: The Science, Benefits, & Implications of a New Reproductive Genetic Therapy
- Meet Tess Bigelow: Identifying & Understanding Rare Genetic Conditions

TEACHER INFORMATION: GROUP PROJECT

Teacher Directions

Divide students into pairs or small groups to create an informational product that showcases the hopes, breakthroughs, and limits of precision medicine. Product options include a brochure, website, slide deck, video, or other creative ideas you would like students to attempt.

The products should provide an overview of precision medicine, addressing both the success stories and challenges in the field. Students can choose from the three main topics of this lesson to focus the content of their brochure: 1. genome sequencing, 2. pharmacogenomics, and 3. genome editing. The instructions are formatted as a student handout on page 26 of this document.

Additional Resources

1. "Next-gen sequencing: The clinical conundrum," by Craig Hildreth, May 2018, *Medpage Today*.
2. "DNA on Drugs: How genetic tests could make prescriptions more precise," by Carolyn Abraham, March 2018, *Globe and Mail*.
3. "What's Behind Many Mystery Ailments? Genetic Mutation, Study Finds", By Carl Zimmer, March 2018, *New York Times*.
4. "When Even Genome Sequencing Doesn't Give a Diagnosis," by Emily Mullin, April 2017, *MIT Technology Review*.
5. "Turning Piglets Into Personalized Avatars for Sick Kids," by Ed Yong, December 2017, *The Atlantic*.
6. "The Paradox of Precision Medicine," by Jeneen Interlandi, April 2016, *Scientific American*.
7. "Precision Medicine's Post-Racial Promise," by Vann Newkirk II, June 2016, *The Atlantic*.
8. "Pharmacogenetics: The right drug for you," by Liam Drew, September 2016, *Nature*.

9. "Perspective: The precision-oncology illusion," by Vinay Prasad, September 2016, *Nature*

For additional information about the science of pharmacogenomics and its medical applications, we recommend the materials on Pharmacogenomics at yourgenome.org.

Archived Articles

Reading archived articles can help us reflect on how the genetics field has changed over time. Below, we've listed 10+ year-old articles that were used in a prior version of this lesson.

1. "A New Treatment's Tantalizing Promise Brings Heartbreaking Ups and Downs," by Gina Kolata, July 2012, *New York Times*.
2. "In Treatment for Leukemia, Glimpses of the Future," by Gina Kolata, July 2012, *New York Times*.

ELSI NOTES ORGANIZER

Name:_____ **Date:**_____

As the field of genetics continues to advance, it is important that individuals and society examine the **Ethical, Legal, and Social Implications (ELSI)** of these new technologies and weigh potential benefits against risks. The implications can be broken down into three categories:

> **Ethical**: Moral principles guiding the use of genetic information, such as ensuring fairness, preventing harm, and respecting individual autonomy.
>
> **Legal**: Laws and regulations that protect individuals from discrimination, ensure the privacy of genetic data, and govern informed consent for genetic testing.
>
> **Social**: How genetic information affects individuals, families, and communities, including issues of social stigma, equity, access, and understanding of genetic information.

Directions: Keep track of the ELSI-related questions or observations that come to mind as you explore this lesson. As you write them down, try to think of ways that your idea might pose a barrier to widespread adoption of the technology. By the end of the lesson, you should have several questions/observations and barriers listed for each core concept. You can discuss your questions or ideas in small groups.

Created by Personal Genetics Education & Dialogue | Updated 2025 | for EDUCATIONAL PURPOSES ONLY.

ELSI Notes Organizer		
	Questions/Observations	**Barriers to Widespread Adoption**
Genome sequencing		
Pharmaco-genomics		
Genome editing		

VOCABULARY LIST

Codeine: An opioid medication derived from the opium poppy plant, used to treat mild to moderate pain and suppress cough.

Conventional medicine: A form of medicine that uses an evidence-based approach to diagnose and treat illness and disease.

CYP1A2: A gene that helps people metabolize caffeine.

CYP2D6: A gene that helps people metabolize codeine.

Cystic fibrosis: A genetic condition that develops when a person inherits a disease-causing gene variant from each of their parents. People with cystic fibrosis experience difficulty breathing and persistent lung infections, among other symptoms.

Diagnosis: The identification of an illness by examination of the symptoms or by evaluating other clinical factors, such as test results.

DNA: (short for DeoxyriboNucleic Acid) – Hereditary material that encodes information to build and maintain an organism.

Efficacy: The ability to produce a desired or intended result.

Ethics: Moral principles guiding the use of genetic information, such as ensuring fairness, preventing harm, and respecting individual autonomy.

ELSI: Ethical, legal, and social implications of genetic advances —

> Ethical: Moral principles guiding the use of genetic information, such as ensuring fairness, preventing harm, and respecting individual autonomy.
>
> Legal: Laws and regulations that protect individuals from discrimination, ensure the privacy of genetic data, and govern informed consent for genetic testing.

Social: How genetic information affects individuals, families, and communities, including issues of social stigma, equity, and access to and understanding of genetic information.

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

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

Genetic risk factor: Inherited traits or variations in an individual's DNA that influence their likelihood of developing certain diseases or health conditions.

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

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.

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.

Genome editing: Making a change to an organism's DNA at a specific site.

Genome sequencing: Decoding a person's DNA to identify the cause of a genetic condition or identify future health risks.

Metabolism: A process in which cells break down ingested compounds, such as food or medicine, into smaller molecules for the body to use.

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

Precision medicine: A form of medical care that is informed by a person or population's biological information to tailor their prevention, treatment, and management plans uniquely.

Sickle cell disease (SCD): A genetic blood disorder that affects hemoglobin, the protein that carries oxygen through the body.

Severe combined immunodeficiency (SCID): A genetic condition that causes individuals to have a severely weakened or non-functional immune system, making them highly susceptible to infections.

Trikafta: A drug developed to treat people with specific cystic fibrosis gene variants.

Variant: Variation of a gene.

Warfarin: A drug used to treat blood clots.

Whole genome sequencing: A DNA sequencing method used to decode the entire genetic code, or genome, of an organism.

STUDENT HANDOUT: GROUP PROJECT

Name:_____ **Date:**_____

Directions

Create an informational product to help patients understand precision medicine, with a focus on a content area of your choosing: genome sequencing, pharmacogenomics, or genome editing. Options for your product include:

- Brochure
- Website
- Slide deck
- Video
- Another idea approved by your teacher

The audience for the brochure is a member of the general public who encounters this brochure in a doctor's office or health center and may benefit from personalized medicine, but is unfamiliar with the field. In your own words, you must:

1. Define precision medicine
2. Explain how your chosen technology works
3. Explain the challenges/barriers to the adoption of precision medicine that patients should be aware of for treatment with your chosen technology
4. Include one or more interesting facts from an article written in the last five years about the technology and its impact on the field of precision medicine.
    - You must include a link to the article as a reference.
    - You may use one or more of the articles linked below or find other reputable sources on your own.
5. You must also include additional information for the topic you chose:

Created by Personal Genetics Education & Dialogue | Updated 2025 | for EDUCATIONAL PURPOSES ONLY.

Genome Sequencing	Pharmacogenomics	Genome Editing
The difference between genome sequencing to determine a diagnosis vs. calculating disease risk Examples of conditions that can be diagnosed with genome sequencing versus those whose risk can be estimated	How a person's genetic makeup can be used to determine what types of medications and treatments are best suited for them A specific example of pharmacogenomics, focusing on one of these medications: • Warfarin (blood clots) • Simvastatin (cholesterol) • Trastuzumab (HER2+ breast cancer) • Amitriptyline (depression) • Ivacaftor (CF) • Tramadol (pain)	Explain one ethical or technical challenge of creating a genome editing-based treatment. A specific example of genome editing-based therapy, focusing on one of these conditions: • Sickle cell disease • Spinal muscular atrophy • Leber congenital amaurosis (inherited retinal disorder)

Articles for Project Research

Below, we have provided links to articles for students to reference. We suggest assigning specific articles and topics to individual students within the groups so each student can be accountable for reading and synthesizing the information for the group. We also encourage teachers to support independent student exploration of reputable articles and resources outside of those listed below.

Note: The statistics quoted in the following articles are accurate for the time of their publication. However, they may not reflect today's statistics, though the challenges and main ideas shared remain true. We encourage students to find updated statistics when referencing numbers reported in older articles.

Precision Medicine:

- "What Is Precision Medicine?," by Cleveland Clinic, September 2023, *Cleveland Clinic*
- "What doctors wish patients knew about precision medicine," by Sara Berg, July 2023, American Medical Association

Genome sequencing:

- "Children's Hospital Colorado Announces Innovative In-House Whole-Genome Sequencing Lab," Children's Hospital Colorado Media, March 2025, *Children's Hospital Colorado*
- "Bringing equity to genomic sequencing in newborns: BabySeq 2.0," by Nancy Fliesler, October 2023, Boston Children's Hospital
- "A deep dive into newborns' DNA can reveal potential disease risks — but is the testing worth it?," by Andrew Joseph, January 2019, *STAT News*

Pharmacogenomics:

- "These Patients Got the Cure. Then It Went Away," by Gina Kolata, September 2025, *The New York Times*
- "The Slow and Winding Path to Pharmacogenomic Test Adoption," by Helen Albert, August 2025, *Inside Precision Medicine*
- "When a Genetic ID Card Is the Difference Between Life and Death," by Ed Yong, October 2015, *The Atlantic*.
- "Genetic Testing Falls Flat in Large Patient Drug Trials," by Susan Young Rojahn, November 2013, *MIT Technology Review*.

Genome editing:

- "Science that gives humans more say over their destinies," by Yahya Chaudhry, June 2025, *Harvard Gazette.*
- "Creating the World's First CRISPR Medicine, for Sickle Cell Disease | Harvard Medical School," by Harvard Medical School Communications, February 2025, *Harvard Medical School News.*

- "Gene Editing Improves Vision in Some People With Inherited Blindness | Harvard Medical School," by Mass General Brigham Communications, May 2024, *Harvard Medical School News*.

Challenges of precision medicine:

- "Promising New Cancer Drugs Won't Go Far Unless Everyone Gets Genetic Testing," by Emily Mullin, June 2017, *MIT Technology Review*.
- "To advance medicine's future, the NIH tries to win the trust of communities mistreated in the past," by Lev Facher, September 2017, *STAT*.
- "The $300,000 drug," by Joe Nocera, July 2014, *New York Times*.

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.

pged
@pged_org
@pgEDorg
@PersonalGeneticsED
pged@pged.med.harvard.edu

Written by the PGED team; updated on December 2, 2025, by R. Bowman, G. McNeil, & M. Gelbart.

SEPA SCIENCE EDUCATION PARTNERSHIP AWARD
Supported by the National Institutes of Health

This project was supported by the National Institute of General Medical Sciences, the National Institutes of Health under Award Number R25GM129172. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.