



# Personal Genetics Education Project

## Ethical, Legal and Social Issues in Personal Genetics

**Title:** Introduction to personal genetics

**Aim:** How might new advances in personal genetics impact our lives, our medical decisions and society?

**Time:** This lesson can be adjusted to fill 1 or 2 days.

**Guiding Questions:**

- How would you decide whether or not to get your genome sequenced?
- How might genome sequencing change health care?
- What are the benefits and concerns for you and other stakeholders?

**Learning objectives:**

After completing this lesson, students will be able to:

- Define a personal genome sequence.
- Grasp the rapid rate at which sequencing technology is developing.
- Analyze why people would or would not want to know about their genome.

**Materials:** Projector or Smartboard, laptop, paper, tape, handouts.

**Common Core Standards:**

RH.11-12.1. Cite specific textual evidence to support analysis of primary and secondary sources, connecting insights gained from specific details to an understanding of the text as a whole.

RST.11-12.2. Determine the central ideas or conclusions of a text; summarize complex concepts, processes, or information presented in a text by paraphrasing them in simpler but still accurate terms.

RST.11-12.7. Integrate and evaluate multiple sources of information presented in diverse formats and media (e.g., quantitative data, video, multimedia) in order to address a question or solve a problem.

**Background information and note to teachers:**

Technological developments are making it possible to read a person's entire genetic code, or genome, more rapidly and at a lower cost than ever before. Personal genome sequencing is allowing scientists and doctors to better

understand the connections between genes and human health, improve medical care and help extend people's lives. As the cost of genetic analysis decreases and research advances, it is becoming increasingly possible to include a person's genetic make-up in the repertoire of tools that inform his or her healthcare. The growing field of personal genetics is at the intersection of science and society; it is both an exploration into the complex interactions through which our genes and our environment influence our physical, mental and behavioral states as well as an on-going conversation on the meaning for individuals and society.

There are many reasons people choose to learn about their genetic make-up. Some people decide to get their genome analyzed so they can take steps to try to prevent a disease for which they are at increased risk, such as heart disease or diabetes, or to learn how their genetic make-up might influence the effectiveness of certain drugs. People who learn that they will likely develop a disease with no cure might opt to buy long-term care or disability insurance, write a will, name a healthcare proxy or take other steps to plan for the future. Some may decide to become activists and educators or engage in research studies. Others might decide not to have biological children or to use preimplantation genetic diagnosis (PGD), a reproductive technology for screening embryos created by in vitro fertilization (IVF), in an effort to avoid passing on a genetic disorder.

High school and college age students are likely to become independent health care consumers at about the time that personal genome sequencing becomes an affordable and accessible option for many people in the United States and elsewhere. This lesson introduces students to the recent advances in genetics and medicine, genetic testing and personal genome sequencing, and presents some of the decisions and ethical challenges individuals may face regarding the use of this technology. The lesson also highlights some of the likely benefits of personal genetics, such as gaining the ability to act on one's genetic risks, tailoring medicines and interventions, and becoming more active and engaged healthcare consumers.

Students do not need to have a background in genetics, as this lesson focuses mainly on social and ethical issues related to genetic testing. The material in this lesson is relevant to multiple subjects, including biology, health, social studies, law, physical education and psychology. If you have not done a full unit on genetics, explain to students some fundamental concepts in genetics, specifically that many diseases are passed down from parent to child through their genes and that complex human traits are often the result of genes in combination with environmental factors. Students can learn more on their own about heredity, genes and traits at the award-

winning website from the [Genetic Science Learning Center](#) at the University of Utah. In particular, we recommend that students watch the "What is heredity?" and "What is a trait?" videos found at: <http://learn.genetics.utah.edu/content/inheritance/>.

Here is an outline of the resources and activities in this lesson.

1. Reading for students (page 3)
2. Do Now exercise (page 3)
3. PowerPoint slideshow (page 4, slide notes on pages 4-10, graphic organizer handout on page 16)
4. Four Corners discussion (pages 10-14)
5. Homework assignment (page 14, handout on page 17)
6. List of additional resources (page 15)
7. Short quiz (answer key on page 15, handout on page 18)

\*\*\*After teaching this lesson, we would appreciate your feedback via this quick [survey](#), as well as your student's feedback via this brief [survey](#).\*\*\*

### **Reading for students:**

To give students a sense of the "big picture" in genetics, we recommend Mary Carmichael's excellent 2010 series "[DNA Dilemma: Should I take a genetic test?](#)" in *Newsweek*. If you can read only one piece from the six-part series, we recommend the second article in the series, "[What Do Genetic Tests Show?](#)" While the regulatory landscape for the sale of direct-to-consumer genetic tests continues to evolve, the issues explored in this series related to privacy, practicality and the question "what do I want to know about my DNA?" remain very current.

**Activities:** Do Now exercise (7 minutes), slideshow (15-20 minutes), four corners discussion (15-25 minutes).

### **Part 1. Do Now exercise (7 minutes)**

Have students answer the following questions individually or in pairs and then share their answers in a brief classroom discussion. These questions are on Slide 2 in the slideshow.

1. What are the potential benefits to knowing more about your genetic predisposition to (chance of developing) a disease?
2. What are the possible downsides to knowing?
3. Aside from health and medical information, what else might you be curious to learn about from your DNA?

## **Part 2. Interactive Slideshow** (15-20 minutes)

We provide a PowerPoint slideshow that explores what types of information people can learn from genome sequencing, the hopes and limits of sequencing, and how this information may impact us. The slideshow is located at <http://www.pgEd.org/lesson-plans/> along with this lesson, and accompanying explanatory notes for the slideshow are provided below.

One important point to make to students is that your physical, mental and behavioral states are influenced both by your genetic make-up and by the unique circumstances in which you have lived your life, including everything that has ever happened to you. We often refer to these two inputs as “nature,” the unique genome you carry, and “nurture,” the environment in which you have lived your life. The intricate and sometimes unclear relationship between genetics and environment is key to our understanding of behavior and health. By analyzing the genome sequences and characteristics of many people, personal genome sequencing has the potential to link traits to certain genes. The most obvious benefit of these analyses will be to better understand the interplay of nature and nurture in known diseases, with the hope that they would lead to better treatments, cures, preventative measures and healthier generations of children.

You may want students to take notes to help evaluate their understanding, particularly if you will be using additional [pgEd lesson plans](#), and students will later participate in a debate and/or writing activity. One excellent method for note-taking is [Two Column Note Taking](#). A sample graphic organizer is included on page 16.

### ***Slideshow notes:***

**Slide 2:** The questions for this “Do Now” activity are a good way to start discussions. Allow students a few minutes to respond and discuss. Refer to the “Do Now” section on page 3.

**Slide 3:** New DNA sequencing technologies are quickly making it faster and less expensive to learn about one’s DNA. The cost of finding out your entire DNA sequence is anticipated to decrease so quickly that, within ten years, your physician might request your genome be sequenced as part of routine blood-work, possibly covered by health insurance. Some genetic tests are directly available to consumers with a doctor’s approval. Typically, companies sell kits via the Internet that provide a tube for saliva and instruct customers to spit into the tube and then mail the tube back to the company. The company then isolates DNA from the saliva and analyzes the DNA, often looking at a small fraction of the genome rather than the entire genome. Customers and doctors receive a report that provides an interpretation of

the DNA analysis; this often includes genetic predictions about their traits such as their genetic predisposition for various diseases.

Your DNA can reveal important information about your traits. It is important to remember that your physical, mental and behavioral states are the result of complex interactions between multiple genes in combination with your environment and lifestyle. Learning about your DNA is highly personal and also raises many questions about how we as a society are going to handle the accessibility of genetic information. For example, if you learn about your risk for Alzheimer's disease, this may raise concerns for your mother, who might not want to know anything about her risk for Alzheimer's disease. Might easy access to genetic predispositions affect dating relationships? Should insurance companies be able to know information about your DNA? These are a few of the issues that this lesson will explore.

**Slide 4:** The generation that is now in middle and high school likely will be impacted more by the increase in genetic information than any previous generation. Doctors and scientists think of the "\$1,000 genome" as an important milestone because at this cost (or less), personal genome sequencing will be comparable in cost to other routine medical tests, such as an MRI, and may become a common tool to help diagnose disease and indicate treatment options. In 2015, some companies began to offer a human genome sequence for roughly \$1,000 (US).

*Note: Slides 5-9 offer a brief overview of some of the ways that genetic testing and genome sequencing are being used and impacting real people.*

**Slide 5:** Genome sequencing has already had real-world impact on patients, including twins Alexis and Noah Beery. The twins exhibited a number of developmental delays and were diagnosed with cerebral palsy at the age of two. However, their mother, Retta, never felt that this diagnosis was correct, particularly since their symptoms worsened over the course of the day. Through their mother's research and advocacy, the twins were diagnosed with a genetic disorder called dopa-responsive dystonia and began taking a medication that seemed to successfully treat the condition. However, some symptoms persisted and escalated, particularly for Alexis, including serious breathing problems. The Beery family had the twins' genomes sequenced, leading to the identification of a mutation in the SPR gene which, when disrupted, causes deficiencies in two neurotransmitters, called dopamine and serotonin. Upon treatment to restore dopamine and serotonin, the twins' symptoms quickly improved, permitting them to resume full, active lives. To read more about the Beery's story, see "[Genome Study Solves Twins Mystery Condition](#)" by Erika Check Hayden, June 2011, *Nature*.

**Slide 6:** In May 2013, actress Angelina Jolie revealed that she had undergone a double mastectomy because she carries a mutation in the BRCA1 gene that greatly increased her risk of breast and ovarian cancer. According to Jolie's op-ed "[My Medical Choice](#)" in the *New York Times*, her chances of developing breast cancer dropped significantly. This is a great way to engage students with a real-life example of a well-known person making a major medical decision based on genetic information. To learn more about breast cancer, BRCA1 and other risk factors, see the following link from the American Cancer Society:

[www.cancer.org/cancer/breastcancer/detailedguide/breast-cancer-risk-factors.](http://www.cancer.org/cancer/breastcancer/detailedguide/breast-cancer-risk-factors)

**Slide 7:** It is now possible to analyze DNA from a fetus through a test performed on a blood sample from the pregnant mother. This is known as non-invasive prenatal testing (NIPT). Every individual begins from the fusion of an egg with a sperm, which results in an embryo that eventually develops into a fetus. Except for the very earliest stages of embryonic development, the embryo and the fetus is connected to the mother by an organ called the placenta. The placenta facilitates nutrient uptake and waste disposal. Sometimes placental cells break open, releasing fragmented fetal DNA into the blood. This "cell-free" fetal DNA can then enter the mother's bloodstream. There, it mixes with cell-free DNA that has been released from cells in the mother's body. Cell-free fetal DNA makes up a small fraction of the cell-free DNA found in the mother's bloodstream. Since the mother's blood circulates throughout her body, a blood sample taken from the mother's arm will contain cell-free fetal DNA. Extracting cell-free DNA from the mother's blood will give a mix of maternal and fetal DNA. Physicians and researchers have now found a way to analyze this cell-free DNA to reveal information about the developing fetus. While sorting maternal from fetal DNA can still be challenging, the technology has developed to a point where it is being used for NIPT.

**Slide 8:** DNA tests can be used to help people learn about their ancestry, particularly when a person's family history is unknown for various reasons. For example, because of the history of slavery in the United States, many people of African ancestry do not know in what part of Africa their ancestors lived. Other people may not know any ancestry information or family health history if they are adopted or conceived from a donor egg or sperm. DNA testing can fill in these gaps and may allow people to feel more connected to a past of which they were previously unaware.

Gary Payne, pictured in the slide, was interested in his family's genealogy but his mother and other relatives only had limited information that went back a couple of generations. He had his DNA tested in an attempt to

discover more specific information about his background. He was shocked to learn that his father was of Chinese descent, with his DNA test indicating a strong link to the Han people. His story is an example of the many people who have limited information from oral or written family histories and are able to fill in the gap with genetic information, and with the ways in which this new information can impact identity.

**Slide 9:** The first sequence of the human genome was achieved with hundreds of sequencing machines working for years. Now a single machine can sequence a full human genome in a matter of days. (Note, the analysis takes much longer than the actual process of sequencing.) To make the sequencing technology more accessible, there has also been a push to make sequencing machines smaller and more affordable. For example, some companies (e.g., Genia, Genapsys and Oxford Nanopore) are developing sequencing machines that are the size of a loaf of bread or even a bar of soap.

**Slide 10:** In 2016, companies continue to compete to reduce the cost of sequencing a human genome. In the coming years, perhaps reading human genomes might be as routine as blood tests and might be carried out in your doctor's office. The graph in the slide is regularly updated by the National Human Genome Research Institute and is available at <http://www.genome.gov/sequencingcosts/>.

**Slide 11:** There is a variety of information people may learn from genetic testing. People can learn about their genetic predisposition for certain diseases, including diabetes, various cancers, and Alzheimer's Disease. They can learn whether they carry a genetic variant or mutation that may be passed on to their children, and about their ancestry. People may learn how their DNA can impact how they respond to certain drugs as well as how they metabolize certain drugs. The field of pharmacogenomics is one area where there have already been many successes. The goal is to use information about a person's genetic make-up to identify medications that will be most effective with minimal side effects.

**Slide 12:** In addition to information about disease risk, genetic testing can reveal information about interesting but not particularly consequential traits, such as whether or not one has a genetic predisposition that causes people to sneeze when going into the sun, known as photic sneeze reflex. People can learn about the genetic basis of traits such as having dimples, whether their index or ring finger is longer, and a variety of other traits that are unrelated to medical conditions.

**Slide 13:** The market for direct-to-consumer (DTC) genetic testing has undergone significant change over the last several years. In 2016, the Food and Drug Administration requires that a doctor request a genetic test for a patient. With a doctor's permission, a patient can order a kit, spit into a tube and send it back to the company for analysis. The doctor and patient both receive the results, and ideally will discuss any questions the patient has, and /or the doctor can refer the patient to a specialist for further consultation.

In the past, customers could buy kits online without a doctor's permission. People could obtain results about their genetic predisposition for serious diseases, their carrier status for mutations that, if inherited from both parents, can cause serious childhood diseases in their children, as well as interesting but not particularly consequential information about their traits. In 2013, the United States Food and Drug Administration (FDA) intervened, and, in response, 23andMe stopped providing most health information to new customers. At the time of this writing, the FDA has given approval to 23andMe to offer carrier status and information about ancestry and non-medical traits to customers.

There has been much debate over DTC genetic testing, and pgEd has an entire [lesson](#) on this topic. One question is whether a genetic testing kit should be considered a medical device. As a medical device, it would be subject to the extensive rules and regulations that oversee safety and quality. In 2016, there are still a number of questions on the path forward for DTC testing.

**Slide 14:** The potential benefits of personal genetics in medicine are tremendous. Nevertheless, there are scientific, societal and individual challenges as well. Here, we provide information for teachers that can be condensed for students.

1. Clinical utility: Scientists are still learning how to interpret genomes; research is progressing quickly, but much remains to be discovered. There is no simple explanation as to how genes and environment interact to contribute to complex characteristics. Sometimes, there is a strong link between a single gene and a person's risk for disease; however, this is not always the case. For example, scientists have uncovered over 150 genetic loci that impact a person's susceptibility for type-2 diabetes and obesity, and it is likely that more remain to be identified. One challenge is to integrate this information in combination with a person's environmental factors into a meaningful assessment of a person's risk. One of the concerns about DTC testing is how companies calculate a person's risk for various diseases. Furthermore, a person's risk estimates are subject to

change over time as new discoveries are made. Individuals who choose to learn about their genetic make-up should therefore be aware of the challenges in making disease risk predictions and have the interpretation of their genome reassessed periodically.

A second question is whether learning about a person's medical condition or risk for disease is accompanied by a clear medical action for treatment or prevention. Already, there are a few remarkable stories, such as that of the Beery twins for whom genome sequencing has brought both a diagnosis and an effective treatment. For others, genome sequencing has brought a diagnosis without a cure or has not pointed to a diagnosis at all. Improving the clinical utility of personal genetics will require continued efforts in basic and clinical research and medicine.

2. Personal impact: Would you want to know if you are at increased genetic risk for a disease such as cancer, for which there may be a number of steps one can take for prevention or early detection? What about Alzheimer's disease, which currently has no effective treatment or cure? For some individuals, knowledge is power; information about their disease risks might affect how they choose to live and plan for their future. Others would prefer not to know; one reason might be that it would be impossible to go back and "unknow" this information.

Family impact: Since biological relatives share portions of their DNA, information that people learn about their own genetic make-up may have implications for their family members. For example, imagine a woman whose mother's family has a history of breast cancer. If she learns that she carries a BRCA1 mutation that puts her at increased risk, there is a good chance that her mother is at increased risk as well. Should she ask her mother's permission before getting tested? Should she ask her husband's opinion, because knowing whether she carries the BRCA1 mutation has implications for their long-term planning and for their children?

3. Equality of access: How can we ensure that everyone who wants it can access his or her genetic information? There is general agreement that everyone, regardless of socioeconomic status, should know about the potential benefits of genome sequencing as well as the concerns, but it will take time to implement a comprehensive educational program. Can we ensure equal access? Will insurance companies pay for genome sequencing? Will people enroll in research studies? Will prices continue to fall? Ensuring the accessibility of genome sequencing to all who are interested is a growing issue if we as a society hope to see personal genetics play an increasingly important role in healthcare.

4. The influence of factors beyond genetics: Our physical, mental and behavioral states are the result of complex interactions between many genes in combination with our environment and our lifestyle. For example, a person may have a higher genetic risk for developing obesity or diabetes, but be raised in a family where healthy food choices and exercise counterbalance their genetic predisposition. Similarly, a person may have a higher genetic risk for addiction, but never try alcohol or cigarettes and avoid any likelihood of addiction. Genetic complexity is a key concept in personal genetics, and one that is explored in greater depth in several of pgEd's lessons, including "[Athletics and genetics](#)" and "[Genes, environment and genetic complexity: Aggression in humans.](#)"

**Slides 15-23:** These slides are for use in the Four Corners activity described below in Part 3.

### **Part 3. Four Corners Discussion (15-25 minutes)**

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

#### ***Step one: Preparation***

Before students enter the classroom, label the four corners of the room with signs reading: *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 offer students a chance to express their opinion and discuss some of the issues based on what they learned in the slideshow.

#### ***Step two: Introducing statements***

Read each statement and have students move to the corner of the room depending on whether they strongly agree, agree, disagree or strongly disagree with the statement. The statements are included on Slides 16-23 of the slideshow to help students understand the statement and prevent the teacher from having to read it several times. The statements are also listed below on pages 11-14 along with teacher notes.

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; they should cite information from the homework article or slideshow 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 his or her position, you can allow students to question each other's evidence and ideas. Before beginning the discussion, remind students about norms for having a respectful, open discussion of 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 give students the opportunity 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 an individual's genetic make-up. In addition, the genetic basis of many traits is extremely complex and beyond our current understanding.

***Statements and teacher notes:***

- People should get counseling from a doctor or genetic counselor when they get genetic testing because they will not be able to handle the information otherwise.
- People should have the right to learn whatever they want about their DNA because it is their own body.

Note: The first two statements show conflicting viewpoints about genetic testing, particularly in regard to direct-to-consumer (DTC) testing. As discussed in Slide 11, 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. In 2013, the FDA ordered one of the leading DTC genetic testing companies to halt the sale of its product that returned health information to customers. In 2015, there are still a number of questions on the path forward for DTC testing.

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 own DNA if they choose. To learn more about both of these points of view, read the following two links: [American Medical Association](#) comments on DTC testing and a critique by biologist Daniel MacArthur in *Wired* magazine, "[American Medical Association: You can't look at your genome without our supervision.](#)"

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

Note: Even in the absence of medical interventions, some people 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 overall that 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 mutations likely to cause a serious disease.

Note: Some prospective parents who know they carry a genetic mutation 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 mutation. Any embryos that are free of the genetic mutation for which they are being tested are then considered for transfer into the woman's 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 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. pgEd has a complete [lesson](#) on the topic of PGD and reproductive technology.

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

Note: 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. It is possible to screen for cosmetic traits such as eye or hair color, although pgEd is not aware of any clinics in the United States that provide that type of service in 2015.

After discussing the statement, ask students to imagine in the future that 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? An important concept to raise 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 an individual's genetic make-up. In addition, the genetic basis of many traits is extremely complex and beyond our current understanding. pgEd has a complete [lesson](#) on the topic of athletics and genetics.

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

Note: The Genetic Information Nondiscrimination Act (GINA) was passed by the United States Congress in 2008, prohibiting employers from making hiring or firing decisions based on genetic information. 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 get students thinking about genetic traits and career choices. It raises a number of interesting questions. Can everyone be a professional athlete? Truck driver? Professor? Soldier? Although people should not be discriminated against based on genetics, this question helps students think about the role genetics may play in the career choices people make. pgEd has a complete [lesson](#) on the topic of genetics, jobs and privacy rights. We also have a [video message](#) about GINA from Representative Louise Slaughter and a [5-question quiz](#) about genetic discrimination on our Map-Ed platform.

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

Note: This statement is intentionally broad to encourage students to consider how much information could be available to parents through genome sequencing. There is an on-going debate about how much parents should find out about their child's DNA, before age 18 when the child becomes a legal adult. What about prenatal analysis of fetal DNA? While genome sequencing can help to predict, diagnose or treat certain diseases, it may uncover genetic risks for disease later in life or other information that might affect how a child is raised. Many people are concerned about the availability of this information before the child is able to give informed consent. Should testing be limited to only look for a specific subset of genetic markers? If genome sequencing is performed, should only specific types of information be provided to parents? What kind of pressures might genetic testing for complex traits and abilities create for a child?

The American College of Medical Genetics and Genomics (ACMG) released new guidelines in March 2013 regarding the reporting of incidental, or secondary, findings when performing genome sequencing: "The guidelines recommend that doctors tell patients (and the families of children or impaired adult patients) if their genome analysis reveals the presence of one of several types of genomic variants in 50 or so genes that have been strongly associated with about two dozen diseases. A key factor in selecting these genes and diseases was that the disorder is serious and that there are practical things that the patient and doctor can do to mitigate the associated risks. If genome sequencing reveals any of these, the standard of care will now be for the laboratory to return the information to the doctor and for the doctor to then tell the patient, prompting appropriate follow-up care to keep the patient healthy." In 2015, additional guidelines were added that include an opt-out choice for patients 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](#)." Also: "[ACMG Updated Policy Statement](#)" (2015).

- I would want to know if someone I was dating had a strong genetic predisposition to a serious disease.

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

### ***Step three: Debriefing***

You can debrief the lesson as a class discussion or 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.

### ***Homework assignment:***

Have students answer the questions below (see page 17 for handout).

1. Explain some of the reasons people choose to get genetic analysis. What are some of the possible benefits? What are some of the possible disadvantages? Explain.
2. Do you think people should be able to get genetic testing directly from companies, instead of going through their doctors? Why or why not?

3. Would you consider getting genetic testing to learn more about your health? Why or why not? If yes, under what circumstances might you consider it?

**Additional resources for teachers:**

1. Amy Harmon's "[DNA Age](#)" series in the *New York Times* has news, analysis and video clips related to personal genetics. While some of the science has progressed, the issues Harmon examines are still timely.
2. The [Hastings Center](#) is an independent, nonpartisan and nonprofit bioethics research institute with many resources and articles about ethics, genetics and society.

**"Introduction to Personal Genetics" quiz answer key (see page 18 for quiz)**

1. D
2. T
3. T
4. F

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?

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## **Homework:**

Answer the following questions using the information from the slideshow and/or ideas from the class discussion. Each answer should be at least one paragraph long.

1. Explain some of the reasons people choose to get genetic analysis. What are some of the possible benefits? What are some of the possible disadvantages? Explain.
2. Do you think people should be able to get genetic testing directly from companies, instead of going through their doctors? Why or why not?
3. Would you consider getting genetic testing to learn more about your health? Why or why not? If yes, under what circumstances might you consider it?

Name \_\_\_\_\_

Date \_\_\_\_\_

### **"Introduction to Personal Genetics" quiz**

1. People may consider having their DNA analyzed to learn about A) ancestry  
B) elevated or lowered health risks C) the genetic bases for traits including hair color, eye color and taste sensitivities D) all of the above
2. Noah and Alexis Beery were diagnosed and treated as a result of genome sequencing. T/F
3. The Genetic Information Nondiscrimination Act protects people's genetic information in the workplace. T/F
4. The cost of genome sequencing is rising and becoming more expensive. T/F