

personal genetics education project

Social, Legal and Ethical Issues in Personal Genetics

Title: "Panel of Experts" Debate: Genomes for all? Debating the merits and risks of direct-to-consumer online genetic testing

Aim: What are the potential benefits and risks of genetic testing?

Time: 2 – 3 days

Guiding questions:

1. How do people react to learning about their DNA?
2. If you were to learn about information contained in your genome (all of your genes), could that change how you think about your identity?
3. Should people be able to buy genetic tests directly from a company, without going through a doctor or a genetic counselor?

Learning objectives:

By the end of the lesson, students will be able to:

- Analyze the benefits and risks of genetic testing
- Evaluate why people seek genetic testing and genome sequencing
- Debate the issues surrounding direct-to-consumer genetic testing

Materials: articles (links provided), handout (at end of lesson plan)

Common Core Standards:

RH.9-10.6. Compare the point of view of two or more authors for how they treat the same or similar topics, including which details they include and emphasize in their respective accounts.

RH.9-10.8. Assess the extent to which the reasoning and evidence in a text support the author's claims.

RH.9-10.9. Compare and contrast treatments of the same topic in several primary and secondary sources.

RH.11-12.2. Determine the central ideas or information of a primary or secondary source; provide an accurate summary that makes clear the relationships among the key details and ideas.

Before the lesson:

Students should read the *New York Times* article: [Heavy Doses of DNA Data, With Few Side Effects](#). The article discusses the impact on people when they learn genetic information about themselves, including whether or not they have a genetic predisposition for diseases such as Alzheimer's or breast cancer.

Do Now: Homework response (7 minutes)

Students will discuss the homework article using this specific strategy, called 3-2-1, which will clarify the article and inform students who may not have done the reading. (technique from Facing History and Ourselves: <http://www.facinghistory.org/resources/strategies>)

Step one: Have students answer the following questions in their journal or on a separate piece of paper:

- Three things that they learned from the article.
- Two questions that they still have.
- One aspect of the text that they found interesting or surprising.

Step two: After students have answered the questions, discuss students' answers as a whole class and be sure to clarify the main ideas of the article.

1. Classroom Activity: Panel of Experts – Testifying before Congress

One of the central objectives of this lesson is for students to think about how people can learn about their DNA. This is a highly controversial issue that becomes even more complex when thinking about whether parents have the right to learn about their child's DNA.

Note: Some people think that people should only learn about their DNA from a doctor or genetic counselor - and some feel that patients should only learn about risks for disease when they become "medically actionable," i.e. when screening, therapeutics or a change in lifestyle can help to avoid or treat the disease. Other people find these views to be paternalistic and think that people have a right to learn about their own DNA if they want to. For some, this means that doctors should be allowed to report any information, even risks of diseases with no treatment. For others, this means that consumers should have the option to learn about their own DNA directly, without the involvement of their doctor. This option is currently available in the form of direct-to-consumer (DTC) genetic test kits.

For this activity, students will research different opinions about the

controversy surrounding direct-to-consumer (DTC) genetic test kits, and role-play a Congressional hearing. The hearing is for senators to learn about the pros and cons of genetic analysis, as they are trying to decide if they need to write new laws governing the sale of and access to genetic testing. Typically, DTC testing does not involve DNA sequencing. Instead, it involves looking at as many as 1 million sites in our DNA that commonly differ between individuals. As prices for DNA sequencing decline, it is likely that these services will be offered directly to consumers as well.

Students will be assigned roles, research their position, and testify before Congress in a variation on a debate format.

Step one: All students should read the *New York Times* article above before the lesson, as well as additional information related to their assigned role during class. Below is the full list of articles we recommend. Each student is assigned a side and a role. Even though they become an “expert” on that perspective, they should listen carefully during debate to hear both sides before forming their opinion.

Step two: Break students into 7 groups of 3-4 students and assign each group a role (this role-play has a large number of characters, so feel free to modify the number of roles depending on class size; i.e. you could easily have one senator instead of two). Each group should read the article(s) and use the information to make an argument in support of or against direct-to-consumer genetic tests. Senators should create at least 4 questions to ask each person testifying, which will be one of the main ways that the discussion will move forward.

Note: the teacher should help ensure that the students come up with good questions for panelists, as this is how the main ideas of the different perspectives will come out.

Each group should choose one person to be the speaker, who must be able to answer the questions asked by the senators. You may want to assign the other students in the group to act as “aides,” so that they can add to what the speaker says in order to both hold all the students accountable for the work as well as to ensure that the answers are as thorough as possible. See [Assigning Roles](#) from Facing History and Ourselves to create other roles for students within each group.

Roles and articles: Below are the roles and news articles. The teacher should choose which articles will work best for their students and decide whether students should read the same article(s) or different articles, which may add a diversity of viewpoints and arguments. Articles vary in depth and length.

Characters in support of Direct-to-Consumer (DTC) genetic testing

1. Doctor A - Believes DTC testing is beneficial
2. Patient A – Wants access to DTC genetic testing
3. Founder of a DTC company
4. Senator A – Leaning toward supporting DTC tests; questions witnesses

[Genetic Testing Brings Heart Hope](#) (video)

[How Do People Respond to Bad Genetic News? Just Fine.](#)

[Learning of Alzheimer’s Risk Seems To Do No Harm](#)

[What if genetic testing shows an increased risk of getting cancer?](#)

[Cancer Free at 33, but Weighing a Mastectomy](#)

[Genetic testing can help people whose DNA may hold risks](#)

[American Medical Association: You Can't Look At Your Genome Without Our Supervision](#)

[Genetics Privacy and Legislation](#)

Characters against or doubtful of Direct-to-Consumer genetic testing

1. Doctor B - Thinks genetic testing through a doctor is valuable, but is skeptical of DTC kits
2. Patient B – Against DTC genetic testing
3. Senator B – Is skeptical of DTC tests; questions witnesses

[Buyer Beware of Home DNA Tests](#) - New York Times

[What are the risks and limitations of genetic testing?](#)

[Insurance Fears Lead Many to Shun DNA Tests](#) - New York Times

[In DNA Era, New Worries About Prejudice](#) - New York Times

[Gene test mix up brings scrutiny to industry](#) - San Francisco Chronicle

[Indian Tribe Wins Fight to Limit Research of its DNA](#) - New York Times

[American Medical Association letter against DTC genetic testing](#)

Students should read the article(s) that will provide information about their point of view; if you have time, we recommend that you assign at least one reading with the opposite point of view, so that they can understand and respond to the opposite position. The senators should create questions for the witnesses, but should know enough about their side to make an opening statement explaining why they do or do not support direct-to-consumer tests.

Questions/Ideas that each group should consider:

1. Doctor A - Believes direct-to-consumer (DTC) testing is beneficial to patients
 - How could DTC tests improve health care for patients?
 - How can these tests give people a better understanding of their

genetics and their health?

- How might DTC testing save money and lives?
2. Doctor B – Thinks genetic testing through a doctor is worthwhile, but is doubtful about the usefulness of direct-to-consumer kits.
 - Patients won't be able to understand the results without help from a doctor.
 - How helpful is it to know about genetic risks from a test - isn't family medical history much more useful?
 - Most diseases or conditions are not caused by a single genetic variant (change). So how useful do you think these tests are for most people?
 3. Patient A – Against DTC genetic testing
 - How might someone who wants to know about his or her DNA, but then finds out he or she has a high likelihood to develop a serious disease, react to this news without it being explained by a doctor?
 - Could people be discriminated against if their employer finds out, or if their health insurance wants to drop them from coverage, because they have a genetic variant that may lead to disease, and the insurer is worried about costs? How could people be impacted in unexpected ways?
 - What if my brother takes a test and finds out something that impacts me too, but I don't want to know?
 4. Patient B - Supports DTC genetic testing
 - How can discovering you are likely to develop a disease help you to prepare before you start to have symptoms?
 - Should Congress be allowed to say you can't have direct access to your own genetic information? If you can't have access, who can?
 5. Founder of a DTC company
 - Thinks that the science of personal genetics is moving forward no matter what, and that more information will improve people's health.
 - If we are a reputable company, why should we be punished because some other companies might be unethical or make claims they can't prove?
 6. Senator A – Leaning toward supporting DTC tests; questions witnesses
 - How can we say people can't learn about their own genetic information? It's patronizing to think adults who seek this information can't handle what they learn.
 - Are we positive a typical general practitioner doctor is able to explain the science and its implications to their patients?
 7. Senator B – Is skeptical of DTC tests; questions witnesses

- How can we protect consumers from being harmed or cheated by these tests?
- How do we know the tests are accurate if they aren't regulated?
- What could happen if insurance companies or employers access your genetic information? Can the Genetic Information Non-Discrimination Act really protect everyone?

Step 3: Research

As a group, students should read the article(s) that will help them develop their argument. If you only have 2 days, assign one reading; if you have 3 days, include additional readings. Each student should complete the Congressional Testimony worksheet (see below) to hand in.

Step 4: Congressional Testimony (30-40 minutes)

This debate format will allow students to discuss the benefits and risks surrounding personal genetic testing from a specific point-of-view, and the discussion afterward will allow them to voice their personal opinions and reactions to the topic.

You can set up the room in whichever way works best with your students and classroom, but suggestions would be to have the main speakers sit at one long table (or move desks) facing the rest of the class; or to have the people testifying sit at a separate table opposite the senators.

If you prefer to have all students in a group able to respond, rather than a single speaker, you may want to move desks into a circle, with groups sitting together.

Each speaker should make an opening statement, explaining his or her position for or against personal genetic testing (1-2 minutes). Students should discuss both whether DTC testing should be allowed, as well as the risks and benefits of genetic testing in general (i.e. finding out you have a genetic predisposition for a disease, the possibility of a personalized treatment, discovering information that is unwelcome).

Each senator should make his or her opening statement first. (**Senators need to state what the goal is: i.e., we are deciding on a law, we are making new rules, we are deciding if we need rules, etc.).

Next, choose the order in which each student/group will testify; we suggest alternating between the two sides of the debate. Have each student make an opening statement, explaining his or her group's main reasons for supporting or not supporting DTC testing. Senators should then ask each panelist questions that will elicit the main ideas and the controversies

surrounding the issue.

After all students have explained their positions and answered questions from the senators, if time permits, open up the discussion so that students can question each other and further discuss the pros and cons of DTC testing, still in the role of their character.

Step 5: Wrap-up (5-10 min)

After students have testified in the role of their character, give them the opportunity to discuss their own reactions and opinions to the topic. Ask if they have changed their minds from what they originally believed and why.

Homework: Have students write a page (or longer) explaining their personal opinion about whether they think the benefits of knowing about one's genetic predisposition toward disease outweigh the risks. Students should use the information learned in preparing for and participating in the debate to explain their argument. They should address the following questions as well:

Would you want to know more about your own genetic make-up? Why do you want to know this information, or not know it? Should people be allowed to order a direct-to-consumer kit and to learn about one's genetic make-up on their own, or should people have to go through a doctor? Explain.

Name _____
Congressional Testimony worksheet

Date _____

Arguments that support my group's position	Arguments that oppose my group's position	Supporting details from the article(s) we read
1.	1.	1.
2.	2.	2.
3.	3.	3.