

# TEACHING THE GENOME GENERATION

## *Introduction to Ancestry Testing*



## Sam's Story: What is ancestry testing?

Sam is a high school student who is about to turn 18 years old. They are at home with their Grandma and cousin Tan. Grandma reveals that the family wants to all contribute to buy Sam a present to celebrate this big milestone birthday. Sam shares that they want a DNA ancestry test for their birthday gift, but gets an unexpected reaction from Grandma.

Read the scene below from Sam's life. If you're in a class or group, assign one person as Sam, one person as Tan, and one person as Grandma, and read the scene out loud.

**Tan:** *Happy 18<sup>th</sup> birthday, Sam! I can't believe you're an adult now. You're so OLD!*

**Grandma:** *It feels like just yesterday we were waiting for your arrival in the hospital, Sam. Ah, how time flies!*

**Tan:** *Grandma, tell him about the gift idea! Tell him!*

**Grandma:** *Right. Sam, this is a big birthday, so the family wants to come together and all chip in to buy you something special. What would you like as a birthday gift?*

**Sam:** *Oh, I know exactly what I want! I'm finally old enough, so I want one of those ancestry DNA test kits!*

**Tan:** *An-ses-tree? What's that??*

**Sam:** *Haven't you seen those commercials? You just spit in a tube and send off your DNA and find out where you're from in the world! It even tells you about your health, like what diseases you'll get!*

**Tan:** *SO cool! I can't wait to take one when I'm old enough! I want to know all about MY own DNA!*

**Sam:** *What's wrong, Grandma? Aren't you excited to learn more about our family's roots?*

**Grandma:** *Oh, Sam. We know enough about where our family is from. What's this test going to tell us that we don't already know? And sending your DNA off to a company like that? I just don't like this idea...*

## Prediction

Sam wants an ancestry test for their 18<sup>th</sup> birthday. List 2 reasons why someone would want to take an ancestry test.

1.

2.

Grandma has concerns about the ancestry test. List 2 reasons why someone would not want to take an ancestry test.

1.

2.

Sam and Tan talk about being old enough to take an ancestry test. Why might there be age restrictions on DNA ancestry tests?

## Background

Sam shares with their family that they want a DNA ancestry test for their 18<sup>th</sup> birthday, and is surprised to find that Grandma and cousin Tan have different feelings about it. Familiarize yourself with this type of genetic test, its purpose and how it works, as well as important considerations about privacy and genetic data sharing.

## Genetic Testing

**Genetic testing** is a category of laboratory tests that examines an individual's genes or other biological factors that influence genetic functions and traits. A small sample of cells, typically from blood or saliva, is taken from an individual and **DNA**, **RNA**, and/or **protein** molecules are examined. The goal of genetic testing is to better understand a person's DNA features, RNA patterns, or protein levels and how they influence a person's health, traits, or genetic heritage. Many types of genetic tests have been developed for a variety of purposes, including **karyotype** tests that count the number of **chromosomes** per cell to look for genetic conditions such as trisomy 21 (Down Syndrome); **tumor** tests that examine tumor cells to determine drivers of and treatments for cancer; and paternity tests that reveal an individual's biological relatives.

Most genetic tests are conducted through healthcare professionals like doctors; these types of tests are called **clinical genetic tests**. Doctors often determine a test is needed due to a specific medical reason, such as a family history of a genetic disorder or symptoms that suggest a genetic condition. Samples like blood or saliva are collected in a medical setting and analyzed in a clinical laboratory. Once the test is complete, the results are sent to the healthcare professional who then shares them with the individual. With clinical genetic tests, health insurance may cover some or all of the cost of the test.

In contrast, **direct-to-consumer genetic tests** are tests that can be purchased directly by people without a doctor's order. They are often advertised as a way to learn about your ancestry, genetic traits, or health risks directly from your DNA. Individuals choose what test they want, and collect and send their own samples to the testing company. Results are sent directly to the individual. With direct-to-consumer genetic tests, the individual pays for all of the cost of the test.

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### *Thought questions:*

*Have you ever had a test performed at the doctor's office? Was it a genetic test?*

*Have you seen advertisements for direct-to-consumer genetic tests? What information would the test reveal?*

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## Ancestry Testing

DNA **ancestry tests**, or genealogical DNA tests, are a type of direct-to-consumer genetic test that examines specific locations in an individual's DNA to find similarities between groups of people and predict their ancestral origins. Since DNA is passed from biological parents to their offspring, it is possible to trace genetic ancestors by examining a person's DNA. This process relies on comparing an individual's DNA to reference databases containing genetic information from populations of people worldwide. Each company uses a different approach to for the ancestry test, and may offer additional features such as health reports and family matching.

Ancestry testing has gained popularity in recent years due to its ability to uncover previously unknown family connections, shed light on migration patterns, and help individuals better understand their roots and cultural identities.

## Genetic Information & Privacy

Genetic tests offer valuable insights into in individual's genetic makeup, and can advance understanding of a person's ancestry, disease predisposition, and personalized medical treatments. However, they also raise profound concerns about privacy and ethical implications of sharing one's most intimate biological data. The sharing of genetic data can expose individuals and families to risks such as genetic discrimination, breaches of confidentiality, and unauthorized access to sensitive information.

In the United States, the Genetic Information Nondiscrimination Act (GINA) provides protection for genetic information. This federal law protects the confidentiality of genetic information, and orders that genetic information be part of a person's confidential medical record to be stored and shared under strict privacy standards. GINA also specifically protects against discrimination based on genetic information for health insurance and employment. GINA prohibits health insurance companies from using genetic information to alter a person's health insurance benefits. This law also prohibits employers from making decisions about hiring, firing, or promotions based on genetic information.

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### *Thought question:*

*GINA protects genetic information specifically regarding health insurance and employment. In what other contexts might genetic information privacy be relevant?*

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## Quick Knowledge Check

Check your understanding of the background material by answering these questions.

1. List two types of genetic tests.
  1. \_\_\_\_\_
  2. \_\_\_\_\_
  
2. What distinguishes clinical genetic tests from direct-to-consumer genetic tests?
  
3. According to the Genetic Information Nondiscrimination Act, which scenario is true?
  - a. Your clinical genetic test results are private, even your doctor is not allowed to view the results without your consent.
  - b. Your clinical genetic test results are public, because genetic information should be accessible to everyone.
  - c. Your genetic test results will be used by your health insurance company to find specific medical procedures and treatments based on your unique genetic code.
  - d. Your genetic test results cannot be used by your employer to make decisions about your employment status.

## Activity

Sam and their family have different views on DNA ancestry tests. Why do some people feel excited about ancestry tests while others feel hesitant? Use this activity to explore different ancestry testing companies, learn the information these tests can reveal and what features they offer. At the end of the activity, consider stories from people who took these tests and explore jobs that relate to the themes discussed throughout this lesson.

### Part 1. Research different ancestry testing companies

There are many companies that offer ancestry testing, each with their own approach and features. Use the internet to find two ancestry testing companies to research thoroughly. You can select any two companies that analyze human ancestry, but if you need some options, you could select *23andMe* or *AncestryDNA*. As you perform your research, use **Table 1 Ancestry Testing Companies** to record key information about each company and what they offer.

**Table 1. Ancestry Testing Companies**

Company name		
Website		
Types of tests offered (like autosomal DNA or Y-chromosome DNA)		
Geographic regions covered in ancestry analysis		
Depth of ancestry analysis provided (like migration patterns or breakdown of ethnicities)		
Additional features or services (like family matching or health insights)		
Privacy policies or considerations for genetic data sharing		
Other interesting features		

Compare your research into both ancestry testing companies and observe the similarities and differences between the companies. Answer the following questions.

1. What are the most notable differences between the two companies?
2. Did one company offer a broader range of tests or more specialized analysis?

3. Consider the geographic regions covered in ancestry analysis in each company. Did you notice any differences between the two companies in terms of depth or specificity of regional data provided?
4. Consider the additional features and services from each company. Did one company offer unique insights or tools that stood out to you?
5. How did each company discuss genetic data privacy? Was this information easy to find?
6. Do you have any lingering questions or areas for further exploration that arose from your research and comparison?
7. How might the information you gathered influence your decision to choose a testing service for yourself or your family?



## Part 2. Ethics

Ancestry testing can reveal fascinating insights into a person's genetic heritage, providing a glimpse into the unknown histories of a person's origins. However, along with these discoveries come important ethical questions about the potential impact of unexpected information on individuals and families.

First, hear from real people about their experiences with ancestry tests. Choose one of the resources below and read, listen, or watch what is presented. Answer the following questions about the resource you chose.

- ARTICLE from BBC News: [These people took DNA tests. The results changed their lives.](#)
- PODCAST from In Those Genes: [Up In Dem' Genes](#)
- VIDEO from The National Human Genome Research Institute: [The Human Genome: Who Do We Think We Are?](#)

1. What was the primary message of the resource you explored?
  
2. What surprised you most about the information discussed?

Next, explore hypothetical scenarios to delve into the complex ethical dilemmas that can arise from ancestry testing results. Consider the emotional, psychological, and social implications of unexpected findings and the ethical responsibilities of both individuals and ancestry testing companies.

Choose one scenario from the list below and carefully read and analyze it. Be sure to consider the emotions, dilemmas, and ethical considerations faced by the individual(s) involved. Answer the following questions.

- Scenario 1: A person's ancestry test results reveal they have a different biological father than the one they grew up with.
  - Scenario 2: Siblings take ancestry tests and find out they have different ethnic backgrounds, leading to questions about their shared family history.
  - Scenario 3: A person learns about a previously unknown half-sibling through an ancestry test match.
  - Scenario 4: An individual takes an ancestry test that also offers health results and uncovers a predisposition to a hereditary health condition, causing anxiety and uncertainty about their future health.
3. How might the individual(s) in the case study feel upon receiving unexpected information from their ancestry test results?
  
  4. What are the potential emotional, psychological, and social implications of discovering such information?

5. How might unexpected information impact family dynamics and relationships?
6. What ethical considerations should be taken into account when sharing or acting on unexpected ancestry test results?

Finally, reflect on the work you just completed and think about yourself, your family, and your own feelings. Answer the following questions.

7. How do you think you would react if you received unexpected information from an ancestry test?
8. What responsibilities do ancestry testing companies have in disclosing potentially sensitive or surprising information to their customers?
9. Should individuals have the right to choose whether to receive certain types of genetic information from ancestry tests?
10. What role does informed consent play in ancestry testing, particularly regarding potential surprises or unexpected findings?

## Part 3. Careers

Explore jobs and career paths that relate to this activity.

1. Navigate to any job search site. Some recommended ones are
  - Indeed: <https://www.indeed.com/salaries>
  - Zippa: <https://www.zippia.com/careers>
  - JobViz: <https://www.galacticpolymath.com/jobviz>
2. Search for the jobs from this activity. You can also find more jobs using keywords from the activity or explore jobs and categories on the site.

Genetic Counselors advise people before and after genetic tests. Similar jobs include Genetic Counseling Assistant and Research Genetic Counselor.

Computational Biologists use data, modeling, and computers to understand biological phenomena. Similar jobs include Computer Scientist and Bioinformatician.

Data Privacy Officers work on issues of cyber security like protecting data. Similar jobs include Information Security Analyst and Cyber Security Specialist.

3. Fill in the table below with 2 jobs that interest you. Record the job title, degree(s) and training needed, and the salary estimate. You can also write a description of the work and any other notes about why you found the job interesting. Continue filling the table with more jobs if you want to.

Job title	Degree(s)/training needed	Salary estimate	Description of work	Notes

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4. Hear from people in some of the jobs you just discovered. Choose 1 resource, then use the table below to record the resource you explored, as well as your thoughts about the people and the jobs they do. Continue filling the table with more jobs if you want to.
- [JAX Career Chats: Genetic Counselor](#)
  - [I Am A Scientist: Computational Biologist](#)
  - [LabXChange Narrative: Cyber Security Specialist](#)

Resource you explored	Person name and job title	In your own words, describe the work they do	Which of their traits match your skills and interests?	What do you want to learn more about?

## Glossary

**Ancestry tests** – a type of direct-to-consumer genetic test that examines common DNA variations in groups of individuals to find similarities and predict their most likely global ethnic origins.

**Chromosome** – A structure that contains DNA, the genetic information of an organism.

**Clinical genetic tests** – A category of genetic tests that are done through healthcare providers like doctors.

**Deoxyribonucleic acid (DNA)** – A biological molecule of which the primary role is the storage of genetic information. DNA is made of deoxyribonucleotides. The nitrogenous bases found in DNA include adenine (A), guanine (G), cytosine (C), and thymine (T).

**Direct-to-consumer genetic tests** – A category of genetic tests that are purchased by customers.

**Genetic tests** – A broad category of laboratory test that looks for changes in DNA, RNA, or proteins.

**Karyotype** – The complete set of chromosomes in the cells of an individual.

**Protein** – A biological molecule composed of amino acids. Proteins are essential for life and have many important functions in the body.

**Ribonucleic acid (RNA)** – A biological molecule that contains genetic information. RNA is made of ribonucleotides and can take different forms, such as messenger RNA (mRNA), transfer RNA (tRNA), and microRNA (miRNA). The nitrogenous bases found in RNA are adenine (A), guanine (G), cytosine (C), and uracil (U).

**Tumor** – An abnormal growth of tissue that can be either benign or malignant (cancerous).