

# Genetic Counseling and Testing



**PREFER CHW  
TRAINING**

Empowering Communities through  
Genomics Education

# Learning Objectives

- Name the steps involved in genetic counseling and testing
- Describe the purpose and importance of genetic counseling and testing
- Identify services patients can access during a genetic counseling session



# Genetics for Clinical Practice



Care can be **personalized** based on a someone's genes.



Helps individuals and their care teams make better health care decisions.

1. Find out what's wrong (diagnosis)
2. Choose the right treatment
3. Guide prevention



Example: Pharmacogenomics

Some bodies react differently to certain medicines. Genes can help doctors decide what will work best.

# Genetic Counseling



# Genetic Counseling

Health professional shares information about genetic conditions

Counseling involves discussing:

- Family history
- Risk of cancer
- Genetic test results
- Management and treatment options

Can occur before or after genetic testing

Helps patients with decision making



# Genetic Counselor

A genetic counselor is trained to:

- Understand genetics
- Help people understand test results
- Give support and guidance around genetic decisions

In the United States, genetic counselors:

- Have a master's degree in genetic counseling.
- May have a background in nursing, social work, and similar fields
- Are certified by the American Board of Genetic Counseling.
- Must complete continuing education to stay certified.
- May need a license in their state to work.



# Genetic Testing



# Genetic Testing

Helps identify pathogenic variants ('mutations')

Contributes to early detection

Usually performed when there is a family history or increased risk

Can involve testing multiple family members

Multiple testing options for other genes associated with breast cancer



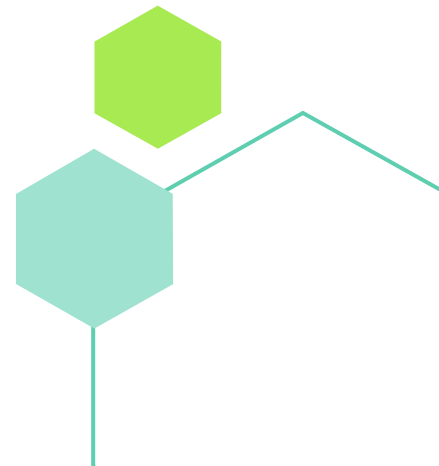
# Genetic Testing

## How it works:

- Take a blood or saliva sample
- Send sample to a lab for testing

## Test results:

- Positive
  - higher risk of disease
- Negative
  - no increased risk of disease detected
  - may require further evaluation



# Types of Genetic Testing



## Diagnostic tests:

Find out if a person has a genetic condition

See if someone might develop a condition in the future

See if a person could pass a condition to their children



## Population-based testing:

Offered to everyone in a group or community

Looks for genetic variants that doctors can act on



## Cascade testing:

Testing of family members of someone with a known genetic condition

# Genetic Counseling and Testing: What to Expect

## Discussions around:

- Your personal medical history and ethnic and geographic background
- Your family's medical history
- The likelihood of an inherited mutation that increases cancer risk
- The value of genetic testing in your specific case
- Which types of genetic tests might be recommended

# Costs Associated with Genetic Tests

Before testing, get a genetic consultation

- Typically costs **\$150** per hour.

If you don't have health insurance:

- The cost of genetic testing can vary
- Many labs offer discounted self-pay prices between **\$250-\$300**.

If you do have health insurance:

- It is often covered if your doctor recommends it
- Potential costs include:
  - Provider visit
  - Laboratory co-pays

# Importance of Genetic Counseling



# Common Misconceptions about Genetic Counseling and Testing

Misconception	Reality
Genetic testing is only for people who are sick	Genetic counseling and testing is useful for healthy individuals who want to learn about their risk of passing on genetic conditions, or for making informed decisions
Genetic tests can predict every health problem I will ever have	Genetic tests provide information about risks for certain conditions but cannot predict everything. Many health conditions are influenced by both genes and environmental factors

# Common Misconceptions about Genetic Counseling and Testing

Misconception	Reality
Genetic testing is too expensive and not covered by insurance	Genetic testing may be covered by insurance, especially if medically necessary or part of a preventive care plan.
I can only get genetic testing at a specialist office	Genetic tests can be ordered by many providers, including primary care providers
If I get a genetic test, I will be at risk for discrimination or stigmatization	There are protections in place, such as the Genetics Information Nondiscrimination Act (GINA) that prevents discrimination for employment and health insurance based on genetic information

# How to Find a Genetic Counselor?

- [NSGC Find a Genetic Counselor](#) website
  - An up-to-date list of over 3,300 certified genetic counselors
  - Includes options for telehealth and in-person visits



# Workbook Activity #5

## Myth or Fact: Genetic Testing and Counseling

Identify each of the following statements as Myth or Fact. If the statement is untrue (Myth), please correct the statement to make it true.

1. Genetic testing is only useful if you have not been diagnosed with a genetic condition before.

**Myth**

**Fact**

2. Genetic counselors play a vital role in guiding patients through the genetic testing process and the disclosure of genetic testing results.

**Myth**

**Fact**

3. Genetic counseling is more effective in person.

**Myth**

**Fact**

4. Patients most often have to pay out of pocket in full for genetic testing.

**Myth**

**Fact**

5. Patients should be prepared to share both their personal health history and family health history in a genetic counseling appointment.

**Myth**

**Fact**

# Workbook Activity #6

## Myth or Fact: Genetic Testing and Counseling

Imagine you are helping a community member navigate genetic counseling and testing. Based on what you've learned from this module, answer the following:

### Scenario 1: Connecting to a Genetic Counselor

- A 45-year old woman is concerned about her risk for breast cancer because many of her relatives have had the disease. She has heard about genetic counseling but doesn't know how to access it.
  1. What steps would you take to help her find a genetic counselor?
  2. What websites or resources could you direct her to for support?

### Scenario 2: Explaining the Cost of Genetic Testing

- A man you are helping is interested in genetic testing but worries that he cannot afford it. He assumes insurance won't cover it.
  1. What information could you provide to help him understand the potential costs and coverage options?
  2. What advice would you give about checking insurance policies or financial assistance programs?