# PREFER Course Companion

# WORKBOOK

PREFER CHW TRAINING

Empowering Communities through Genomics Education

# About this Workbook

This workbook is designed to accompany the live and self-paced content of the PREFER CHW training. Most modules will include an assignment, reflection, or other interactive activity at the end – use this document to keep track of your work and prepare for the live sessions.

## Table of Contents

## Activity #1: Genetics 101

Each scenario listed below is either an example of Genetics Research or Clinical Practice. Decide if it is research or clinical practice and explain.

1. A community member with Lynch syndrome (hereditary colorectal cancer) consents to be randomized to a different colonoscopy schedule for 10 years and the outcomes are recorded.

☐ Research ☐ Clinical Practice

**Explain:**

_____

_____

2. A doctor helps a patient with a genetic predisposition to breast cancer receive care that is based on national guidelines.

☐ Research ☐ Clinical Practice

**Explain:**

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3. After a family member is diagnosed with a genetic condition, a patient visits with a genetic counselor, agrees to genetic testing and sends a biospecimen to a genetics lab. The genetic counselor contacts the patient in the following weeks to disclose testing results.

☐ Research ☐ Clinical Practice

**Explain:**

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4. A patient is asked to take part in a program that tests a new type of breast cancer screening, where some patients get 3D mammograms instead of usual 2D mammograms.

☐ Research ☐ Clinical Practice

**Explain:**

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5. A doctor suggests a patient with Familial Hypercholesterolemia try to follow a heart healthy diet and to start a food log.

☐ Research ☐ Clinical Practice

**Explain:**

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# Activity #2: Genetic Conditions- CDC Scavenger Hunt

*Using the CDC Tier 1 Genomics Applications Tool Kit, complete the following scavenger hunt! Find the kit at: [https://archive.cdc.gov/www_cdc_gov/genomics/implementation/toolkit/index.htm](https://archive.cdc.gov/www_cdc_gov/genomics/implementation/toolkit/index.htm)*

## **Part 1**: Tier 1 Genomic Applications and their Importance to Public Health

1. Tier 1 genomic applications are those that have the potential for positive impact on public health based on evidence-based guidelines and recommendations.
   ☐ True
   ☐ False

2. Fill in the Blank:
   Nearly _____ people in the United States are at increased risk of Hereditary Breast and Ovarian Cancer, Lynch syndrome and/or Familial Hypercholesterolemia.

3. Fill in the Blank:
   - Hereditary Breast and Ovarian Cancer Syndrome (HBOC) increases the risk of breast, ovarian, tubal, peritoneal and other cancers due to mutations in the _____ or _____ gene.
   - Lynch Syndrome (LS) increases the risk of _____, endometrial, ovarian, and other cancers associated with mismatch repair genes.
   - Familial Hypercholesterolemia (FH) is associated with increased risk of _____ _____ or stroke due to mutations leading to very high _____ levels from an early age.

## **Part 2:** Reflection Questions

1. In your own words, write a simple definition of a genetic condition that you could use to explain it to a community member or client

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2. Choose one common genetic condition (e.g., sickle cell, HBOC, Lynch syndrome, FH) and write how you would explain this condition in plain, culturally appropriate language. What visuals or tools could you use to help clients understand it?

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3. What is one new thing you learned from this module that will help you in your CHW role?

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4. What additional resources or support would help you feel more confident in educating patients and genetic conditions?

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## Activity #3: Family Health History (Part 1)

*Use the following checklist to create your own family health history. Put a check in the columns for breast, ovarian, or any other cancer for each family member.*

*If you are unsure put a "?".*

| Family Member | Breast Cancer | Ovarian Cancer | Any Other Cancer | Cardiac Events |
|---|---|---|---|---|
| Yourself | | | | |
| Mother | | | | |
| Sister | | | | |
| Daughter | | | | |
| Grandmother (mother's side) | | | | |
| Aunt (mother's side) | | | | |
| Grandmother (father's side) | | | | |
| Aunt (father's side) | | | | |
| 2 or more cases of cancer after age 50 on same side of family | | | | |

| Family Member | Breast Cancer | Ovarian Cancer | Any Other Cancer | Cardiac Events |
|---|---|---|---|---|
| Male with cancer at any age in any relative | | | | |
| Any relative with coronary artery disease or heart attack before age 50 | | | | |

Reflection: After completing your family health history, what challenges did you experience? How would you assist a client in addressing these and other challenges that arise when recording their own family health history?

## Activity #4: Family Health History (Part 2)

*Download the **FamGenix** app from the Google Play store or Apple app store.*

1. Try entering your family health history.

2. What are some pros and cons of utilizing this technology?

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3. How might this technology be used by your community members?

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4. What other strategies could be used to keep track of family history (e.g., notes app in phone, notes section on person's contact card, sending patient portal message)

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## Activity #5: Genetic Counseling and Testing (Part 1) *Myth or Fact*

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**

# Activity #6: Genetic Counseling and Testing (Part 2)
## *Case Studies and Resource Identification*

*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?

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2. What websites or resources could you direct her to for support?

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**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?

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2. What advice would you give about checking insurance policies or financial assistance programs?

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**Try it out!**

1. Go to the NSGC "Find a Genetic Counselor" website: https://findageneticcounselor.nsgc.org/?reload=timezone

2. Identify a genetic counselor in your area that is available: 1) in person and 2) telehealth

3. What was your experience like trying to find a genetic counselor? How do you think it would be for your clients and community members?

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## Activity #7: CHW Dos and Don'ts in Genomics

*For each scenario below, decide if the CHW is operating within the scope of their role as it pertains to genomics. Why or why not?*

1. As a trusted member of the community, a CHW regularly helps patients record comprehensive personal and family health histories.

- Is this appropriate for the CHW role? Why or why not?

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2. A patient reaches out to the CHW with a genetic report from a direct-to-consumer test. The CHW proceeds to interpret the report and to provide formal counseling to the patient and the patient's children.

- Is this appropriate for the CHW role? Why or why not?

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3. A patient reaches out to the CHW with a genetic report from a direct-to-consumer test. The CHW proceeds to refer the patient to a genetic counselor to interpret the results and provide formal counseling to the patient.

- Is this appropriate for the CHW role? Why or why not?

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4. After genetic counseling and testing, a patient is found to have a pathogenic genetic variant in BRCA1 and is diagnosed with HBOC. The patient works with a CHW to learn more about their diagnosis and connect their family members to genetic counselors.

- Is this appropriate for the CHW role? Why or why not?

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5. After genetic counseling and testing, a patient is diagnosed with FH. The patient's CHW assists the patient in finding a primary care provider that is familiar with the diagnosis.

- Is this appropriate for the CHW role? Why or why not?

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6. A patient comes to a CHW for more information on genetic testing. The patient informs the CHW that she cannot take time off work to visit with a genetic counselor but would like the test to be performed as soon as possible. To save the patient some time, the CHW obtains a cheek swab from the patient to send to a genetics lab.

- Is this appropriate for the CHW role? Why or why not?

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## Activity #8: Genetics in Research

*Using existing resources (research articles, media, real-life examples, etc.), locate an example of a precision medicine or genetics research study.*
*Using the guiding questions below, prepare a brief reflection on the example of your choice to discuss in the next live session. This example could be from the past or can be more recent.*

- What was the purpose of this study? Who were the participants?
- What do you think of the recruitment and consent materials for this study? Are there any ways that recruitment or consent processes could have been improved?
- What precautions or guidelines could the research team have put in place to prevent unethical medical research?
- Did the study adequately represent diverse populations? Why or why not?
- How could CHWs have played a role in this research?

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## Activity #9: Ethical, Legal, and Social Issues in Genomics

*You are working with a community member who has been referred for genetic testing to assess their risk for a hereditary condition.*

*The patient is hesitant about the test and has concerns about:*

- **Privacy**: who will have access to their genetic information?
- **Discrimination**: could this test affect their insurance or job?
- **Understanding results**: what will the results mean for them and their family?
- **Emotional impact**: how will they cope with this information?

*Reflect on this situation and provide a brief response to the following questions:*

1. How would you describe genetic testing and why it was recommended?
2. How would you address the patient's concerns about genetic privacy and data security?
3. What information would you provide about genetic discrimination and legal protections (e.g., GINA, HIPAA)?
4. What steps could you take to ensure the patient feels empowered to make their own informed decision?

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## Activity #10: Communicating about Hereditary Conditions: Case Study

1. Michelle is a 30-year-old female with a family history of breast cancer in her mother (diagnosed at 42) and maternal grandmother (diagnosed at 56). Her father is deceased, and she does not know much about her paternal side of the family. Michelle is interested in genetic testing for hereditary breast cancer but is unsure of how she would access this in her community and comes to you for help.

- *How would you advise Michelle on next steps?*

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2. After navigating Michelle to the appropriate resources, she decides to pursue germline genetic testing for HBOC. She is found to have a pathogenic variant in BRCA1. Michelle's family is small, but she does have a paternal half-sister who lives nearby. Michelle is unsure if she should contact her half-sister and comes to you for advice.

- *How might you guide Michelle?*

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3. David is a 45-year-old male with a family history of colorectal cancer. His father was diagnosed at age 50, and his paternal uncle was diagnosed at age 58. David has heard of Lynch syndrome but is unsure what it means for him or his family. He is also worried about his younger brother, who is 40 and has not yet had any colorectal cancer screenings. David is hesitant to bring up genetic testing with his family and comes to you for guidance.

- *What steps would you take to help David understand Lynch syndrome and encourage him to talk to his family about his concerns?*

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## Activity #11: Telehealth: Think and Reflect

*With your specific community in mind, please answer the following questions:*

1. What feelings do individuals in your community have about telehealth and electronic communication?

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2. What are some barriers and facilitators in utilizing telehealth for genetics in your community?

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3. How may telehealth resources for genetics be best implemented in your community? What are some precautions to take to ensure telehealth equity?

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4. Are there community resources in place that may allow patients to use this technology (i.e. telehealth rooms at the public library, etc.)? If so, what are they and how may they be best utilized?

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## Activity #12: Local Resource Guide

*Using the following template, create a list of 5 local resources relevant to genetic conditions.*

*Start with resources in your zip code, if you can't find the resource in your zip code, then expand to your city, and then your state.*

| Organization #1 | |
|---|---|
| Resources | |
| Phone Number | |
| Address | |
| Hours of Operation | |
| Languages Spoken | |
| Eligibility | |
| Referral needed | |
| How to access | |
| Materials to bring | |
| Other notes | |

| Organization #2 | |
|---|---|
| Resources | |
| Phone Number | |
| Address | |
| Hours of Operation | |
| Languages Spoken | |
| Eligibility | |
| Referral needed | |
| How to access | |
| Materials to bring | |
| Other notes | |

| Organization #3 | |
|---|---|
| Resources | |
| Phone Number | |
| Address | |

| | |
|---|---|
| Hours of Operation | |
| Languages Spoken | |
| Eligibility | |
| Referral needed | |
| How to access | |
| Materials to bring | |
| Other notes | |

| Organization #4 | |
|---|---|
| Resources | |
| Phone Number | |
| Address | |
| Hours of Operation | |
| Languages Spoken | |
| Eligibility | |
| Referral needed | |

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|---|---|
| How to access | |
| Materials to bring | |
| Other notes | |

| Organization #5 | |
|---|---|
| Resources | |
| Phone Number | |
| Address | |
| Hours of Operation | |
| Languages Spoken | |
| Eligibility | |
| Referral needed | |
| How to access | |
| Materials to bring | |
| Other notes | |

# NOTES