Key Takeaways after Completing PREFER CHW

Genomics is about people, not just genes

Genomics connects family history, lived experience, and health, not just DNA. CHWs play a critical role in helping community members understand how genetics relates to their lives, values, and concerns.

CHWs are trusted messengers in genomic education

CHWs' existing skills such as trust-building, listening, cultural humility, and advocacy are essential for effective genomics engagement. CHWs do not need to be genetic experts to make a meaningful impact.

CHWs can explain complex genomic concepts in plain language

Breaking down terms such as genetic testing, genomic screening, and results help reduce fear and confusion. Stories, analogies, and everyday examples make genomics more accessible and less intimidating.

Informed decision-making is central

The goal of genomic education is not persuasion, but support. CHWs help individuals make informed decisions that align with their values, respecting questions, hesitations, and choices.

Mistrust is real and must be acknowledged

Historical and ongoing harms contribute to valid concerns about privacy, misuse of data, and discrimination. CHWs help create safe spaces for open, honest conversations about trust, protections, and participant rights.

CHWs serve as a bridge between communities and health systems

CHWs translate complex medical and research information for communities and communicate community needs back to clinical and research teams, strengthening relationships and improving program delivery.

Collaboration with clinical and research teams is essential

Working alongside genetic counselors, clinicians, and researchers allows CHWs to know when to refer questions and how to support participants throughout the genomic screening and results process.

CHW involvement advances genomic equity

Without CHW engagement, genomic medicine risks widening health disparities. CHWs help ensure that genomic programs are inclusive, respectful, and responsive to the needs of diverse communities.

CHW voices strengthen programs

CHWs provide critical feedback based on lived experience and community insight, helping improve the design, implementation, and sustainability of genomic research and clinical initiatives.

CHWs belong in genomics

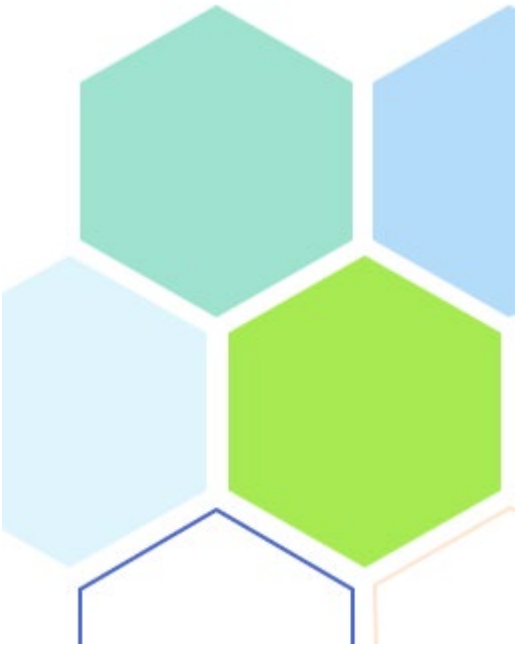
Genomics is not only for scientists or clinicians. CHWs are essential leaders, educators, and advocates in ensuring that genomic advances benefit all communities.

Steps for CHWs to Navigate Genetic Resources

1. **Assess Patient Needs**
    a. Understand patient goals (e.g., testing, counseling, family education)
    b. Identify barriers such as financial constraints or language preferences.
2. **Identifying Appropriate Resources**
    a. Match patients with services tailored to their genetic risk and needs.
    b. Verify the availability of culturally competent care providers.
3. **Facilitate Referrals and Appointments**
    a. Help patients schedule appointments with genetic counselors or specialists.
    b. Ensure they have necessary documentation for referrals.
4. **Provide Follow-Up Support**
    a. Assist with understanding genetic test results.
    b. Encourage ongoing communication with healthcare providers.

Resources

- Facing Hereditary Cancer Empowered (FORCE)
- Patient Advocate Foundation
- Susan G. Komen (Breast Cancer)
- National Society of Genetic Counselors
- Genomics Education Resource Center (GenomeEd)
- Genetic Counseling | Genomics and Your Health | CDC



Key Terms

Advocacy- is the active, strategic process of supporting a cause, influencing, policy, and empowering communities to reduce health inequalities.

Chromosome- are threadlike structures made of protein and a single molecule of DNA that serve to carry the genomic information from cell to cell. In plants and animals (including humans), chromosomes reside in the nucleus of cells. Humans have 22 pairs of numbered chromosomes (autosomes) and one pair of sex chromosomes (XX or XY), for a total of 46. Each pair contains two chromosomes, one coming from each parent, which means that children inherit half of their chromosomes from their mother and half from their father. Chromosomes can be seen through a microscope when the nucleus dissolves during cell division.

CHW (Community Health Worker)- are trusted frontline public health workers who are members of the communities they serve. They act as liaisons between residents and health/social services to improve health access, promote wellness, and reduce disparities.

Genetic Counseling- Genetic counseling refers to guidance relating to genetic disorders that a specialized healthcare professional (genetic counselor) provides to an individual or family. A genetic counselor might provide information about how a genetic condition could affect an individual or family and/or interpret genetic tests designed to help estimate the risk of a disease.

Genetic Counselor- specialized healthcare professionals with advanced training in medical genetics and counseling, supporting individuals and families assessing risks of inherited conditions, such as birth defects or genetic disorders, as defined by NHGRI-related sources (NCI, NCBI).

Genome- is the entire set of DNA instructions found in a cell. In humans, the genome consists of 23 pairs of chromosomes located in the cell's nucleus, as well as a small chromosome in the cell's mitochondria. A genome contains all the information needed for an individual to develop and function.

Genomic Medicine- is a medical discipline that involves using a person's genomic information as part of their clinical care. Other similar terms include individualized medicine, personalized medicine and precision medicine. For some conditions, genomic information can be used to help diagnose disease, predict outcomes and guide treatment.

Genomics- is a field of biology focused on studying all the DNA of an organism — that is, its genome. Such work includes identifying and characterizing all the genes and functional elements in an organism's genome as well as how they interact.

Health disparities- preventable differences in the burden of disease, injury, violence, or opportunities to achieve optimal health experienced by socially disadvantaged populations.