## UCLA

# ArmGenia and Genetic Research

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## Abstract

This project identified strengths, resources, and priority health needs related to access to genomic screening, counseling, and preventive services/treatment for the Armenian population from the Artsakh region.

## **Description of Community**

The Armenian diaspora communities play a vital role in preserving Armenian culture, identity, and heritage. They actively promote language, arts, literature, and traditions through community centers, and churches. Strong bonds and connections exist between the diaspora and the homeland, with many contributing resources, investments, and advocacy efforts. The Armenian diaspora communities face some unique healthcare challenge. Access to culturally-competent healthcare providers and services specific to Armenian genetics and conditions can be limited, especially in areas with smaller Armenian populations. Education and awareness about Armenian genetic risks may be lacking.

## **Ethics and Methods**

Ethical Stance: Ethics of Non-Interference

As an outsider to the Armenian community my goal is to actively listen to understand their challenges from their perspectives. Once I've gathered data from community members, I can then develop solutions tailored specifically to address the community's identified problems. My role is not to dictate, but to thoughtfully synthesize the voiced concerns into meaningful proposals after an open listening process.

Data Collection Methods: Interviews, Data Walks, Online Resources

### Resources

The diaspora communities maintain ties to the homeland that serve as partners for outreach, education, and promoting genetic screening. Within Armenia there is growing healthcare infrastructure an emerging genomic research sector through partnerships with universities. While gaps remain, the Armenian community can build upon its strong collective identity, community institutions, developing urban healthcare capabilities, diaspora relationships, and dedication to furthering genomic understanding of Armenian populations. Leveraging these existing resources through collaboration will be essential for overcoming barriers and implementing effective solutions.

## Definitions

Armenian Diaspora: Armenians living outside Armenia, usually in ethnic enclaves. Artsak: An isolated region of Armenia with low genetic diversity.

<u>Genetic Screenings:</u> Screenings for diseases with higher prevalence in Armenians like FMF.

## **Needs Statement**

There is a pressing need to increase access to affordable genomic screening, counseling services, and follow-up preventative care for Armenian populations globally by addressing limited service availability in rural/remote areas, high costs, low awareness and education about Armenian genetic risks.

## Results

The assessment identified strengths like Armenian identity/diaspora connections and emerging urban genomic capabilities, but revealed priority needs for policy reforms, rural infrastructure improvements, workforce expansion, awareness campaigns reducing stigma, and increased investment despite threats like instability and provider shortages to realize opportunities for expanding tailored genomic services equitably across Armenia.



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#### Images

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