

Geographical Barriers to Genetic Counseling for Hereditary Cancer and Cardiovascular Disease

Stephanie E. Wallace, MS, Cynthia L. Neben, PhD, Will Stedden, PhD, Erica Vaccari, MS, Lauren Ryan, MS, Lily Servais, MS, Alicia Y. Zhou, PhD
Color Genomics, Burlingame, CA



Introduction

Genetic counseling is an integral part of helping individuals understand genetic testing and its implications for care. It is often provided through an in-office visit, however, several barriers of access exist using this model. To attend in-office appointments, some individuals must manage additional logistics such as arranging child-care or requesting time off work to attend appointments. Others may need to overcome physical limitations, whether due to disability or finding means to travel to a clinic. These barriers can limit genetic testing access to those with the financial and physical means to seek care further from home when needed. Here we examine the distance individuals would have had to travel to meet in-person with a genetic counselor.

Methods

The data set included 4181 de-identified, research-consented individuals who 1) had a positive result (defined as a pathogenic or likely pathogenic variant) on a multi-gene next generation sequencing panel for hereditary cancer or hereditary cardiovascular disease, 2) had completed telecounseling, and 3) provided a city of residence within the United States. Location and specialty of genetic counselors were obtained from the National Society of Genetic Counselors Member Directory. Google Maps was utilized to measure the distance between an individual's city of residence and the nearest genetic counselor with the appropriate specialty. The United States Census was used to determine state income.

Figure 1. Number of genetic counselors specializing in cancer by state*

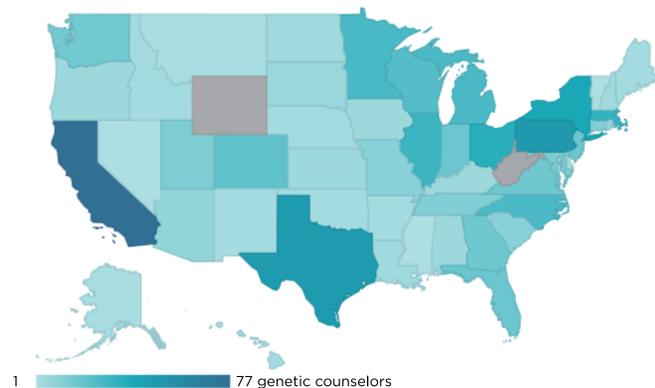
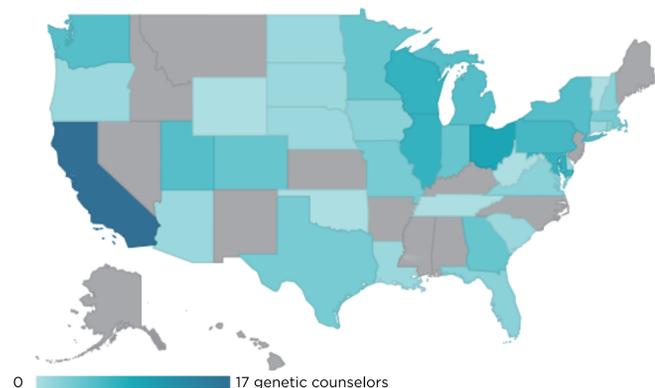


Figure 2. Number of genetic counselors specializing in cardiovascular disease by state*



*States shown in grey have no genetic counselors listed on the NSGC Member Directory.

Conclusions

- The data presented suggest that access to genetic counselors in the United States varies by location and specialty of genetic counselor.
- The distance required to travel to see a genetic counselor specializing in cardiovascular genetics was almost double ($p \leq 0.0001$) the distance required to see a genetic counselor specializing in cancer genetics.
- Reducing the geographical barriers to genetic counseling, such as through alternative delivery models that use telecounseling, may allow individuals to receive care sooner and utilize their resources to receive follow up care in a multidisciplinary setting.
- Telecounseling options decrease the healthcare inequity that may affect individuals in states with lower incomes, particularly in specialized care areas such as cardiovascular disease.

Results

Figure 3. Distance required to meet with genetic counselor specializing in cancer genetics

For individuals with a positive result on the hereditary cancer test ($n = 3987$, 50 states), the average distance required to meet with a genetic counselor specializing in cancer genetics was 28.3 miles (standard deviation [SD] 1.9).

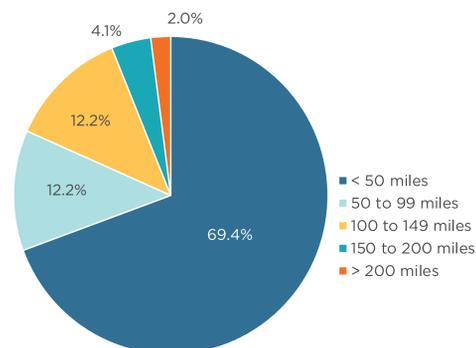


Figure 5. State-by-state heat map showing distance traveled in miles to meet with genetic counselor specializing in cancer genetics

Individuals in 16 (32%) states did not have access to a genetic counselor within 50 miles. The majority (69%) had access to a genetic counselor specializing in cancer genetics within 50 miles. Individuals in Wyoming, North Dakota, and Nevada had to travel the furthest.

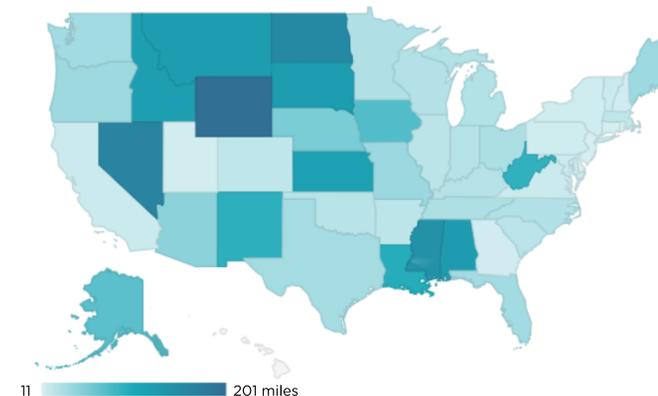


Table 1. Comparison of resources: distance versus average state income for individuals with a positive result in hereditary cancer

The average income for an individual who had a pathogenic or likely pathogenic cancer gene variant did not differ in states that required them to travel less than 50 miles compared to states that required them to travel more than 50 miles ($p = 0.27$).

Distance (miles)	States (n)	Average income (US\$ ± SD)
< 50	34	58,776 ± 9536
> 50	16	55,508 ± 9671

Figure 4. Distance required to meet with genetic counselor specializing in cardiovascular genetics

For those with a positive result on the hereditary cardiovascular disease test ($n = 194$, 35 states), the average distance to be traveled to see a genetic counselor that specializes in cardiovascular genetics was 49.7 miles (SD 72.0).

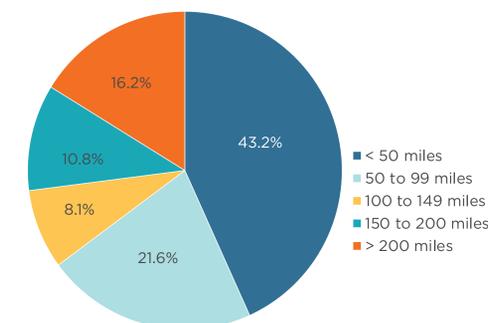


Figure 6. State-by-state heat map showing distance traveled in miles to meet with genetic counselor specializing in cardiovascular genetics

Individuals from 9 (25%) states did not access to a genetic counselor within 50 - 149 miles. Individuals from 10 (29%) states, including Wyoming, Arkansas, and New Mexico, had to travel more than 150 miles to see a genetic counselor. States that did not have an individual with a positive result for cardiovascular disease as shown in grey.

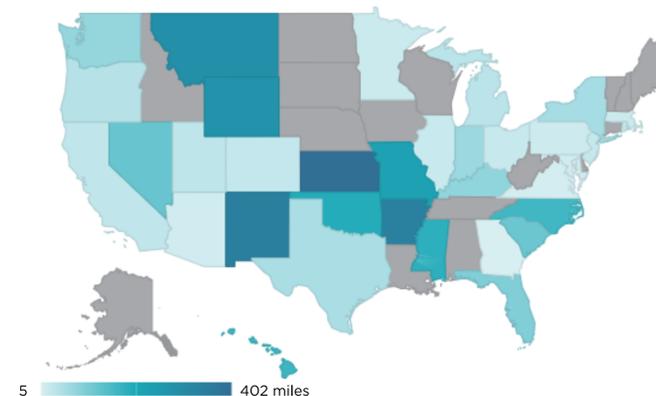


Table 2. Comparison of resources: distance versus average state income for individuals with a positive result in hereditary cardiovascular disease

The average income for an individual who had a pathogenic or likely pathogenic cardiovascular gene variant was lower in states that required them to travel more than 50 miles compared to states who had a genetic counselor within 50 miles ($p = 0.006$).

Distance (miles)	States (n)	Average income (US\$ ± SD)
< 50	15	63,214 ± 8671
> 50	18	54,512 ± 8931

References

1. U.S. Census Bureau. (September 2017). Household Income 2016. Washington, DC: U.S. Government Printing Office.