



The Need for Increased Access to Genetic Counselors

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Precision medicine uses information about a person's own genes, proteins, and personal environment to prevent, diagnose, and treat cancer. The same type of cancer can be different from person to person, depending on genetic variability. For years scientists have tried to determine why some patients respond to certain treatments whereas others with the same diagnosis do not respond to the same treatment. There are many factors to consider, but looking at both hereditary genetics and tumor DNA sequencing (i.e., biomarkers) is essential for oncology teams to tailor patient treatment recommendations and achieve the best potential outcomes.

About 5 to 10 percent of all cancers are attributed to inherited variants. Genetic counselors work in and with cancer programs to:

- Meet with patients and educate them about potential benefits, risks, and limitations on genetic testing.
- Order testing best suited for a specific diagnosis and patient.
- Communicate genetic testing results to both patients and providers.

Not every person with cancer requires genetic testing, but those who do benefit from meeting with certified genetic counselors (CGC®)—experts with advanced training in offering comprehensive genetic counseling services. As with many healthcare services, insurance only covers genetic testing if the payer deems it “medically necessary.”

Currently, the Centers for Medicare & Medicaid Services only covers genetic testing for a known mutation in a family if an

individual has “signs and/or symptoms of cancer. Testing of an unaffected Medicare eligible individual or family member is not a covered Medicare benefit.”¹ To many in the cancer advocacy community, it is unacceptable that individuals with Medicare who have a relative with the BRCA1 or BRCA2 gene mutation with breast, ovarian, pancreatic, or prostate cancer cannot get their genetic testing covered until they have a diagnosis of cancer themselves—especially considering that risk reduction strategies, such as increased screening, chemoprevention, and risk-reducing surgeries can be performed.

Currently, Medicare does not cover testing for patients without signs and symptoms of breast or ovarian cancer. Though some people who are positive for BRCA1 or BRCA2 variants never develop breast cancer, there is an increased risk. Consider these data: 13 percent of women in the general population will develop breast cancer in their lifetime.² By contrast, between 55 and 72 percent of women who inherit a BRCA1 variant and 45 to 69 percent of women who inherit a BRCA2 variant will develop breast cancer by age 70 to 80.²

Recent Legislation Impacting Access to Genetic Counselors

The National Comprehensive Cancer Network recommends genetic testing services for patients with many cancer types. Earlier this year, S.1450/H.R. 2144 were introduced in both the Senate and House to increase access to genetic counseling for Medicare beneficiaries. ACCC, along with other stakeholders, signed a letter of support for

this legislation, which would recognize certified genetic counselors as healthcare providers, giving beneficiaries improved access to the services these professionals provide. Currently, genetic counselors must provide services under “direct” supervision, which means that genetic counselors are only available to beneficiaries when they are supervised by a Medicare-certified healthcare provider (i.e., physician or nurse practitioner). This legislation would allow genetic counselors to bill Medicare directly and be reimbursed for their services at 85 percent of physician billing.

Trends Impacting Access to Genetic Counseling

Currently the Government Accountability Office estimates that there are about 4,700 genetic counselors and 1,240 medical geneticists certified to provide care in the United States.³ Though both numbers have increased in recent years, many have raised concerns about whether there are enough providers to meet current and future demand for genetic testing and counseling services. A map on the Government Accountability Office website shows the distribution of genetic counselors per 500,000 people by state in 2019, and several states have three or fewer trained genetic counseling staff per 500,000 people (see Figure 1, right).³

Telehealth expansion prompted by the COVID-19 pandemic has increased the availability and job satisfaction of genetic counselors in many areas, as well as increased access in rural areas where physically seeing a genetic counselor in

person is more difficult due to travel time and specialist availability. Many cancer advocates are hopeful that telehealth services for genetic counseling will continue to be reimbursed to maintain and potentially improve access to these services in the future.

Another factor affecting patient access: currently, only 27 states issue licenses for genetic counselors.⁴ According to the Centers for Disease Control and Prevention, “State licensure ensures that genetic counselors who are trained through accredited programs and are certified through the American Board of Genetic Counseling are able to provide genetic counseling and order genetic testing.”⁴ The National Society of Genetic Counselors has a state licensure map on its website and notes that many states are making progress in advancing state licensure.⁵

An increased focus on workforce growth, state licensure, and reimbursement for genetic counseling services is needed to continue to advance precision medicine and quality oncology care. Please feel free to email me at KFerguson@acc-cancer.org about any workforce, reimbursement, or cancer care delivery trends you are seeing. I look forward to hearing your thoughts and learning more about how ACCC can play a role. 

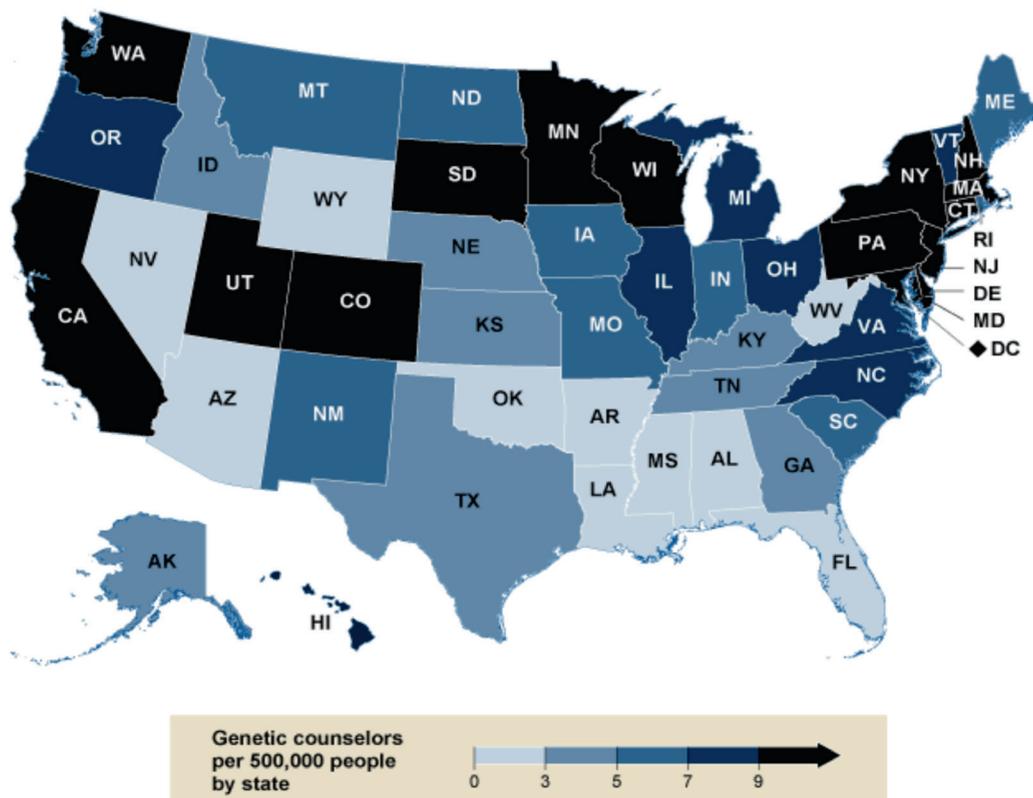
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Figure 1. Geographic Distribution of Genetic Counselors



Source: GAO analysis of data from the American Board of Genetic Counseling and Census Bureau: Map Resources | GAO-20-593