

Medical, Social, Financial Evaluation

ELIMINATING COST-SHARING FOR CANCER GENETIC TESTING

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Mandate Evaluation Process



Lewis & Ellis (L&E) was engaged to address the medical, social, and financial impact of eliminating cost sharing for genetic testing for individuals with a personal or family history of cancer, and the follow-up, evidenced-based, screenings for individuals with an increased risk of cancer.



Resources included publicly available literature and statistics, provider interviews, insurer surveys, and gathered data from the Maryland All-Payer Claims Database (APCD).



The National Human Genome Research Institute (NHGRI) defines genetic testing as the use of a laboratory test to examine an individual's DNA for variations, typically performed in the context of medical care, ancestry studies, or forensics.



The type of genetic testing relevant to this analysis is known as presymptomatic or predictive testing. The Mayo Clinic defines this type of testing as genetic testing before symptoms are present that may show if an individual is at risk of developing a certain condition, typically utilized if there is a family history of the condition.

Medical and Social Evaluation

Medical Effectiveness

- Although genetic testing is highly accurate in identifying genetic variations, detecting a variation associated with an increased risk of cancer does not guarantee that the patient will develop the disease. About 10% of all cancers may be caused by genetic inheritance.
- For example, it is estimated that 55-65% of women with the BRCA1 gene variation and 45% of women with the BRCA2 gene variation will develop breast cancer by age 70. In comparison, the average risk of a woman developing breast cancer is about 13%.
- However, overall, less than 10% of women diagnosed with breast cancer have a BRCA mutation.
- Additionally, providers noted that the percentage of individuals that will test positive for a cancer genetic variation are in the minority.
- Research indicated that prevalence of harmful BRCA gene changes in the general population is about 0.2 - 0.3%.

Service Availability & Usage

- A 2020 National Trends Survey (NTS) found that approximately a quarter of genetic tests completed were for cancer gene testing purposes. The most common type of cancer gene tests utilized are for detecting genes associated with breast cancer, ovarian cancer, and colorectal cancer.
- Direct-to-consumer (DTC) genetic testing, which allows individuals to order tests without a doctor's prescription, is widely available to the public. However, DTC tests are generally less accurate compared to those conducted through a healthcare provider.
- During provider interviews, a key piece of feedback emphasized the importance of clearly defining clinical guidelines for what qualifies as 'an individual with a personal or family history of cancer,' should legislation regarding genetic testing coverage or cost-sharing be introduced. This clarity is essential to ensure that testing is efficiently targeted, minimizing undue patient anxiety and preventing unnecessary overutilization.



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Utilization and Insurance Coverage

A 2020 National Trends Survey (NTS) found that while approximately 35% of people were aware of cancer genetic testing, only about 5% had undergone such testing.

Most private health insurers cover genetic counseling and testing at little to no out-of-pocket cost for individuals who meet specific personal or family cancer history criteria.



Medical and Social Evaluation

Barriers and Disparities

The National Trends Survey (NTS) revealed that individuals with an income of less than \$50K per year are about 25% less likely to be aware of genetic testing and nearly half as likely to have utilized it.

Clinical guidelines advise that women at high risk of breast cancer, for example, should consider a range of risk-management options (incl. genetic counseling, genetic testing, etc.), yet these options remain significantly underutilized. Inductive analyses have identified three main categories of health-related financial constraints: (a) lack of insurance, (b) underinsurance, and (c) other financial burdens such as medical debt, raising children, and managing comorbidities.

Financial Evaluation and Assumptions

L&E leveraged data from provider interviews, insurer surveys, the APCD, and publicly available sources to develop estimates for each variable that could influence cost or utilization, categorizing them into low-end, mid-range, and high-end assumptions.

These ranges aren't confined to just the three scenarios of low, mid, and high illustrated; instead, they are designed to encompass the various uncertainties inherent in each assumption. This approach aims to offer a spectrum of potential outcomes.

Each assumption range is discussed in further detail within L&E's official report.

Financial Evaluation Results

Estimated Fiscal Impact Range

	Low	Mid	High
Cancer Genetic Testing Premium Cost PMPM	\$0.02	\$0.17	\$0.53
Maryland Projected 2025 Premium PMPM	\$869.06	\$869.06	\$869.06
Cancer Genetic Testing Percentage Impact	0.00%	0.02%	0.06%

- L&E notes that the estimated impact range is considered to take on a normal curve, or bell curve, where the low- and high- estimates represent less likely impacts.
- L&E also notes that the estimated impact applies to the Maryland insurance market as a whole, but individual insurers may not be affected equally. The impact for each insurer may vary depending on the characteristics of their underlying population, potentially leading to higher or lower effects compared to the overall average.

