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Running head: CANCER G.C. AND TESTING FOR UNDERINSURED PATIENTS

**Identifying the gap:  
Cancer genetic counseling and testing for underinsured patients**

by

Bailey Sanderson

Submitted in Partial Fulfillment of the Requirements  
For the Degree of Master of Science in Human Genetics and Genetic Counseling  
School of Pharmacy and Health Sciences  
Keck Graduate Institute

2020

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## **Dedication**

I would like to dedicate my thesis and all of my hard work to my loving husband, Nicholas, my daughter, Thaden, family, friends and amazing program directors. If it was not for their love, support and understanding, I would not have been able to accomplish everything I have. They have been there through all of my highs and lows, and I want to thank them from the bottom of my heart. If it was not for all of you, I would not be where I am today.

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### Abstract

**Background:** Health care costs have increased faster than Consumer Price Index leading to patients weighing their options of medical treatment and services. One such service, genetic counseling, has grown 20% annually, in part due to the increased demand of genetic testing. Oncology care is one need for testing because 5-15% of all cancer diagnoses in the United States are inherited. Due to the fact that the Affordable Care Act does not cover all genetic counseling testing needs, and ethnic minorities are less likely to seek testing due to insurance coverage and costs, an increased effort is needed to reach high risk individuals in medically underserved population.

**Methods:** Health care providers in the oncology health practicing in the state of California were reached through Listservs and asked to fill out a survey provided through Qualtrics. The survey included practitioner demographics, patient demographics, and an assessment of needs of oncology patients. The univariate analyses and bivariate analyses were completed using IBM SPSS Statistics for Windows, Version 26.0.

**Results:** Twenty-six individual responses were analyzed and plotted. No statistically significant findings emerged when analyzing the type of insurance a patient had versus patient barriers to access, nor when analyzing the patient barriers to access by practice size. Participants who work with medically underserved populations were more likely to cite health insurance and immigrant status as barriers to adherence.

**Conclusion:** Barriers exist for the medically underserved population. Due to study limitations including small sample size, volunteer bias and instrumentation bias, further research is needed

for a state wide initiative to promote genetics in an underserved population to address discrepancies in medical care.

*Key Words: genetic counseling, genetic testing, health care costs, insurance, underserved population*

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## Introduction

Inherited cancer syndromes comprise of 5-15% of cancer diagnoses in the United States (U.S. Preventive Services Task Force., 2014). One example of inherited cancer syndromes is hereditary breast and ovarian cancer (HBOC), which is associated with an increased risk for breast cancer, ovarian cancer, prostate cancer, melanoma and pancreatic cancer. Another example is Lynch syndrome, a syndrome that increases the risk for colorectal cancer, endometrial cancer and ovarian cancer amongst others. Carrier rates in the population can range from 1/40 to 1/400 for HBOC and 1/300 to 1/400 for Lynch syndrome (“Genetic/Familial High-Risk Assessment: Breast and Ovarian.,” 2019; “Genetic/Familial High-Risk Assessment: Colorectal.,” 2019; U.S. Preventive Services Task Force\*, 2005). These carrier rates, among other health implications, such as personal and family history, make it crucial for individuals who are at risk for cancer to meet with genetic counselors. Genetic counseling is an important component of holistic cancer care and can inform treatment, diagnostic, surveillance and preventative health recommendations.

As genetic testing advances and patients become more aware of available testing, the demand for genetic counselors will grow and evolve across different areas of employment such as commercial laboratories, education, public health and policy. As of today, the demand for genetic counselor services has grown 20% annually since 2013 and will continue to rise due to the expansion of genetics and genomics into mainstream medicine (Hoskovec et al., 2018). The importance of genetic testing is becoming more relevant as demand grows for testing for multiple disorders with genetic etiology outside of cancer syndromes. These disorders include

Alzheimer's disease and prenatal diagnostic testing for chromosomal abnormalities (Caughey et al., 2004; Han & Jemal, 2017; Kieran et al., 2007; Komenaka et al., 2016; Kopits et al., 2011; Levy et al., 2011). These tests may identify genetic changes and health risks where increased screening and management is indicated to help mitigate disease.

With the increasing demand for testing, the costs of the tests, the importance of insurance costs, and the question of an individual having to compensate for the lack of coverage are all concerns that come into play for a patient. All of these topics contribute to new roles being undertaken by genetic counselors, one of which is genesurance counseling. This particular aspect of genetic counseling includes a conversations about the costs and insurance/third party coverage for genetic testing (Brown et al., 2018). The purpose is to confirm the responsibility of the financial burdens imposed on the patient, and this will typically be discussed during the informed consent process. Genetic counselors not only have to take into account the diverse types of insurances their patients have, they also have to navigate what testing is suggested from government and private agencies.

Health care costs have increased for the past 40 years faster than the Consumer Price Index leading to a strain on patients because they are paying for services out-of-pocket (OOP) due to either being uninsured, or by paying pricey copayments, coinsurance or deductibles (Ubel et al., 2013). Patients are often having to choose between paying for medical bills or other necessary expenses which leads to anxiety and stress. This decision is being made by the patient weighing their willingness to pay (WTP). This measurement is used to assess the value of the given healthcare option and its value compared to their disposable income, education and severity of the illness (Kopits et al., 2011). Individuals should not have put their health on the line because of medical costs.

To help improve the lives of patients battling cancer and their families' lives, it is imperative to be able to reach all patients in need of genetic counseling regardless of insurance coverage. The first step to being able to provide for all patients, is determining whether or not there is a lack of genetic counseling and genetic testing in oncology care for underinsured patients.

## Literature Review

### Insurance Coverage Protocol

The Affordable Care Act (ACA) is meant to eliminate cost sharing for preventive services which includes genetic counseling and testing for certain cancer mutations. However, it does not cover all genetic testing and counseling costs that some patients might need, and the ACA does not cover all insurance types (Fox & Shaw, 2015; Han & Jemal, 2017). Specifically, under Medicare guidelines, current signs or symptoms of cancer must be present for services to be covered, even when there is a known inherited mutation in the family (Klug, 2019).

Alternatively, the National Comprehensive Cancer Network (NCCN) recommends that genetic risk assessments should be obtained from qualified professionals for women with a greater than 20 to 25% risk predisposition for breast cancer and for women with a greater than 5 to 25% risk for ovarian cancer (“Genetic/Familial High-Risk Assessment: Breast and Ovarian.,” 2019). The United States Preventative Services Task Force (USPSTF) recommends that women with a positive family history of breast, ovarian, tubal or peritoneal cancer after being properly screened should see a genetic counselor for possible *BRCA* testing (U.S. Preventive Services Task Force\*, 2005). The American Society of Clinical Oncology (ASCO) recommends genetic testing for individuals with a personal and family history suggestive of susceptibility, and that these tests should be adequately interpreted because the results will aid in diagnosis or medical management. ASCO also recommends that the pre-test and post-test counseling should be included in the patient’s oncology care (U.S. Preventive Services Task Force\*, 2005). Private companies like Cigna further deviate by requiring patients receive counseling from independent

genetics professionals before undergoing genetic testing. This is based on the patients' need to be fully informed about the complex topics to be able to make informed decisions (Cigna, 2020). This range of recommendations may result in some patients paying OOP or choosing to not receive genetic counseling at all.

There is a reason that these agencies deem these risk assessment appointments necessary. A qualified health care worker provides risk management not only for a patient's need to be fully informed but it is also vital to exclude non-carriers with no strong family history of cancer from intense cancer screening and unnecessary surgery (Willis et al., 2017). This not only helps decrease the stress and anxiety of going through these undue processes but also saves people money and potentially benefits insurance companies in the long run.

### **The Patient's Need to Pay Out of Pocket**

Diverse studies have shown that depending on the testing and the test price, the desire to pay OOP will vary. In cases where patients knew their chances of developing Alzheimer's disease (AD) was great, over 60% of patients would still ask for testing if it required self-pay. These patients had already undergone susceptibility testing through volunteering in a research study and might have been highly motivated in their preference because they were first degree relatives of AD patients. Their willingness to pay did decrease as the hypothetical test cost increased from \$100 to \$1,000, although, this survey might be biased due to homogenous sample size based on ethnicity, education and income (Kopits et al., 2011). Study subjects desire to receive testing no matter what the cost might be based on their value to obtain knowledge over its potential to improve their health. Although there is no treatment for AD, this study showed the importance of testing for individuals so they could start planning for the future, make changes in their personal life and potentially prepare family members for the onset of AD. This

study can also be used to assess other individuals that are weighing their options for testing, such as cancer patients.

Another study examined women's opinions on invasive prenatal diagnostic testing for chromosomal disorders. The study revealed that 45% of those women would be willing to pay OOP when told the cost would be \$1,300, while 18% would not be willing to pay any amount of money for the testing (Caughey et al., 2004). This survey included a range of ethnicities, ages, education status and income levels. The WTP did vary between income and education, indicating that individuals making a greater income and having a higher education status would be more willing to pay OOP for the prenatal diagnostic testing. The results also varied between ethnicities, where Asian women were less likely willing to pay for the testing. These women were also typically at a higher risk for giving birth to an infant with a chromosomal disorder. The benefit of this type of testing is primarily to improve quality of life for the patients, but the relative benefit is confounded by income and unfortunately not offered to women as a cost-effective option (Caughey et al., 2004). Individuals who have low income and are potentially underinsured might opt for not testing, which can drastically change medical management when this study is applied to patients in the oncology field.

A recent study determined the role that financial factors play when accepting clinical genetic testing. There was a discrepancy in the individuals that would benefit from the testing but still would choose not have the test done because of cost (Cappelli et al., 1999; Kieran et al., 2007). As previously noted, financial factors do prohibit testing, specifically in *BRCA* testing, but the need for the testing can be life-saving for some individuals. Testing for high-risk women can be used for tailoring and modifying breast and ovarian cancer risk assessment. These tests ultimately lead to individuals making decisions about their cancer surveillance, treatment and



potentially prevention of the cancer (Burke, 1997; Kieran et al., 2007). Over 50% of the respondents noted that they would not test because they would not be able to afford the cost. Interestingly, some of the individuals who were surveyed noted that they would still not do testing even if they could afford it just because their relatives who also needed the test could not afford the cost (Kieran et al., 2007). These examples specifically looked at genetic testing alone, but are there also monetary issues with patients' willingness to receive genetic counseling?

In another case, individuals that have been referred to a genetic counselor to test for *BRCA1* or *BRCA2* due to their family history could have the option of undergoing cascade testing and receive pertinent risk information for themselves and family members. Some of these patients do not follow up though because of a multitude of barriers including low income and insurance coverage. Individuals were asked to rate their level of agreement to the following statements: "my health insurance coverage meets my health care needs," "not having health insurance stops me from getting health care services I may need," and "I am concerned about the cost of more genetic tests." This was done to gauge the factors that impacted their decision on whether or not to return to a clinic for genetic counseling and testing. The responses to this survey were grouped into three categories on their intent to return to a clinic: 'yes', 'no', and 'undecided'. Of the 'no' group, 11.3% cited that it was due to insurance coverage as well as the 28.5% of the undecided group (Chadwell et al., 2018). These individuals were highly concerned due to the cost of genetic testing. This cohort of participants noted that a follow-up appointment would be valuable but still did not intend to return. These cases allowed researchers to further pinpoint factors influencing non-uptake of testing in various settings and can help to further develop interventions that would eventually enable individuals to use results for risk management (Kieran et al., 2007).

### **The Effect of Being Underinsured On the Decision Making Process**

Decision making is vital part of a genetic counseling session in which a patient is encouraged to discuss their options, communicate their preferences, and then be guided toward their best course of action. It is pertinent that patients make informed decisions based on their ability to afford medical recommended genetic tests (Brown et al., 2018). Patients' process of decision making differs between ethnicities and socioeconomic classes. Low income Latina women have a tendency to allow a health care provider to give more prescriptive advice, which is the opposite of what is seen in genetic counseling sessions which is patient focused. Latina women have a tendency to feel confused and may question the genetic counseling session's value (Kamara et al., 2018).

To better inform patients and to create an autonomous environment, genetic counselors are practicing genesurance counseling, a portion of a genetic counseling session that is devoted to the costs and insurance party coverage of counseling and testing (Brown et al., 2018). As high as 95% of the counselors in a study, suggested that the genesurance counseling had influence over the patient's decision to proceed with testing or not (Brown et al., 2018). The timing of when counselors would provide the information in combination with the information being given could be why the decision was influenced on whether or not the patient decided to go through with testing. Ultimately, this leads to another burden of being underinsured, the patient has to determine if the costs of testing and counseling are too high, causing many patients to decline getting testing (Brown et al., 2018; Kieran et al., 2007; Kopits et al., 2011).

### **Underinsured Individual's Demographic Representation in Genetic Counseling**

The benefits of genetic testing and counseling have been readily documented, but ethnic minorities are less likely to undergo testing let alone be offered the opportunity of testing

(Komenaka et al., 2016; Levy et al., 2011). According to the United States Preventive Services Task Force, it is recommended that “woman whose family history is associated with an increased risk for deleterious mutations in *BRCA1* or *BRCA2* genes be referred for genetic counseling and evaluation for *BRCA* testing” (U.S. Preventive Services Task Force\*, 2005); high-risk African American women are less likely to receive testing for breast cancer than are Caucasian women (Levy et al., 2011). One study reported that black women had a 75% lower chance of receiving referrals for testing and counseling, many of these women being underinsured or uninsured. This study sparked future investigation of education related differences and the effect of socioeconomic status on test uptake. Another study determined that high-risk African American women had one fifth the chance of even pursuing genetic testing, which unfortunately also indicates that provider behavior is also an important barrier (Armstrong et al., 2005). One goal might be to also target provider education and outreach efforts to include additional resources for service delivery infrastructure.

Other minorities that have an increased likelihood of developing breast cancer, such as Hispanic and Latina women, are less likely to seek testing because of inadequate insurance coverage and cost (Komenaka et al., 2016). This is alarming because these women would obtain great benefit to the testing because it is the leading cause of cancer death within the Hispanic community and it is shown that the demand is higher for younger breast cancer patients. It is reported that 66.4% of the women who were offered genetic counseling and risk assessment through a safety net hospital did not have insurance while the rest were underinsured. Seventy-two percent of these women ended up being affected with breast cancer. This safety net hospital served a large population in Arizona, which included 78% of the minority community (Komenaka et al., 2016). It is indicated that if testing and counseling are offered, a high

proportion of patients will participate. The costs of treating patients without insurance was accomplished by leveraging other resources from other institutions that had greater funding and resources, which is obviously not sustainable in all settings. An important takeaway from this study is that a significant proportion of patients who met with a genetic counselor did not need to undergo genetic testing, which ultimately decreased medical costs. By allowing the patient to choose whether or not they wanted testing, this decrease in medical cost expenditure benefitted hospitals and insurance companies.

This problem has been mirrored in other aspects of medical care as well. Barriers that have inhibited women from seeking postpartum HIV care in low income populations, which unfortunately mostly affect minority women, are lack of social support outside of immediate family members, limited transportation access, and experiences of institutionalized stigma (Buchberg et al., 2015). While insurance might not play as important of a role in their care, the author's mixed method approach to obtaining the knowledge will be a vital resource for future research and shows a national problem of health care policy neglecting the lower socioeconomic class. Future work and research should continue to check for patterns of genetic testing discrepancies among high risk populations and the impact of policy change (Han & Jemal, 2017).

### **Underinsured Patients' Effect On a Genetic Counselor**

Genetic counselors are participating more frequently in their role as genesurance counselors. This role is vital for patients to be able to be informed about the cost of treatments, testing and overall coverage of services. Being an educated genetic counselor comes at a cost. Not only do they need to be knowledgeable about billing codes, barriers to payer utilization and reimbursement, they need to be able to address these issues with patients while still maintaining

rapport. It is estimated that approximately six minutes or about 10% of a session is spent on genesurance and over three hours a week on genesurance related topics. These can include researching coverage plans, determining OOP costs and following up with patients regarding payment options, which has increased from just 3 years ago (Brown et al., 2018).

While 87% of genetic counselors surveyed find genesurance counseling important and a necessary part of their job, counselors frequently are left feeling responsible for managing health care costs which is distracting them as their main role as genetic counselors (Brown et al., 2018). One quote from the survey that was particularly impactful was:

*“I feel like I should be able to provide my patients with relevant information regarding their genetic testing options without being burdened with the minutiae of insurance and costs. However, patients cannot make truly informed decisions without knowing the financial impact of the testing. Unfortunately, I find that genesurance counseling does impact a session and the rapport established with my patients. I have to take off my genetic counseling ‘hat’ and instead put on my ‘financial counselor hat’, which is not my primary role.”*

As far as 32% of the genetic counselors surveyed said that covering genesurance negatively impacted their rapport with patients, leaving both the counselor and the patient uncomfortable. Often the intentions of the genetic counselor are misconstrued by the discussion of money in a clinical setting. Although critical in the decision making, insurance topics are complex for both the counselor and the patient (Brown et al., 2018).

### **Identifying the Gap in Underinsured Patients in Oncology Care**

It has been cited that there are patients that would utilize genetic counseling and genetic testing if offered, but they are hindered by lack of coverage and increased costs of healthcare. A

gap in current research exists in California for a statewide initiative to promote genetic counseling and genetic testing in underserved populations. With the setback of the current administration and possible changes in the Affordable Care Act, further research is necessary to determine how to specifically cover patients that do not have complete access to genetic counseling or genetic testing. This is necessary because it is foreseen that this subset of the population might continually increase over the years. It is frustrating on many levels because they should be entitled to all the same healthcare opportunities as insured individuals when it comes to genetic counseling and genetic testing. Unfortunately, safety net hospitals are not sustainable in all parts of America. Many of them are not large enough to even incorporate genetic counseling and testing.

A state-wide initiative was proposed in Massachusetts to promote genetic testing in an underserved population. They found that individuals from diverse or limited resource settings are less likely to access genetic testing and counseling and that continued research efforts is necessary to promote access to genetic testing (Underhill et al., 2017). This study can be an important guide for future research and implementation of genetic testing and counseling in states such as California.

Affected individuals that have come in for testing but cannot provide the cost for follow up and/or patients that have been referred for testing due to a relevant family history but cannot afford the cost of the testing, still need this pertinent information. Although, effort is needed to ensure underinsured patients have access to valuable clinical information, it is first important to find the gap in underinsured individuals in oncology care in California. This research has taken the initial step by gathering hospital and patient demographic information, purpose of genetic counseling cancer referrals from professionals practicing in the oncology health care field,

potential barriers to genetic testing and counseling. The goal after analyzing this data and finding out how often genetic counseling and testing is utilized in underinsured individuals and potential reasons why it might not be utilized, is helping clarify the need to reach out to this underserved population and potentially lead to the next steps of a state-wide initiated process to promote genetic testing and genetic counseling.

## Methods

### Participants

Inclusion criteria to participate in this study restricted responses to oncology health care professionals currently practicing in the state of California. Participants were reached through different Listservs, including the Southern California Coalition of Genetic Counselors (around 150 members) and the Northern California Coalition of Genetic Counselors (283 members). The individuals from the Listserv were asked to refer the survey to colleagues in the oncology field, resulting in snowball sampling.

### Baseline Survey

The Claremont Graduate University Institutional Review Board (CGU IRB) reviewed the study and deemed it as exempt from IRB supervision. Informed consent was obtained at the beginning of the survey. Then an assessment was given to obtain the demographics of participants, including variables such as age, gender, race/ethnicity, years of practice, hospital size and an assessment of genetics attitude. The patients' demographics included age, gender, race/ethnicity and insurance coverage. Ultimately the crux of the survey included patient barriers to adherence to oncology care and the likelihood of referring oncology patients to genetic counselors for testing. The survey was administered via Qualtrics (Appendix A), and was available from June 2019 to March 2020. A total of 26 individuals responded.

### Quantitative Analysis

All analyses were run using IBM SPSS Statistics for Windows, Version 26.0 (*IBM SPSS Statistics for Windows*, 2019). Univariate analyses included the calculation of measures of



central tendency (e.g. means), dispersion (e.g. SD), frequencies, and valid percentages. Data were visualized with tables and bar charts. Bivariate analyses included independent samples t-tests and chi-square tests of independence to examine the relationships between key variables in the study. Statistical significance was determined using the 0.05 level of significance, unless otherwise noted. Supporting values (e.g. degrees of freedom, effect sizes, etc.) were reported where necessary.

## Results

### Data Cleaning

Data cleaning was performed in order to detect invariant or careless respondent answers and ensure that all participants qualified to participate in the study. A total of 26 subjects responded to the survey, with all subjects providing at least partial data. No invariant responses were offered, and all written feedback reflected good-faith answers, so no subjects were ultimately removed from the dataset.

### Demographics

The data set included 26 responses and participant characteristics and patient demographics are detailed in Table 1. Of these, 96.2% were female, the majority described themselves as white (65.4%), and were practicing genetic counselors (76.9%). The majority of patients being seen were in the adult category (19-64 years old), white, female, and had obtained insurance through their employer.

*Table 1*  
*Demographic characteristics of overall sample (n = 25 - 26)*

Demographic	Overall	
	M (SD)	Freq (%)
<b>Practitioners</b>		
Age	37.96 (9.96)	
Years in Practice	9.27 (7.42)	
Gender		
Male		1 (3.8)
Female		25 (96.2)
Other		0 (0)
Ethnicity		
Asian		4 (15.4)
Black / African American		0 (0)
Hispanic or Latin American		1 (3.8)

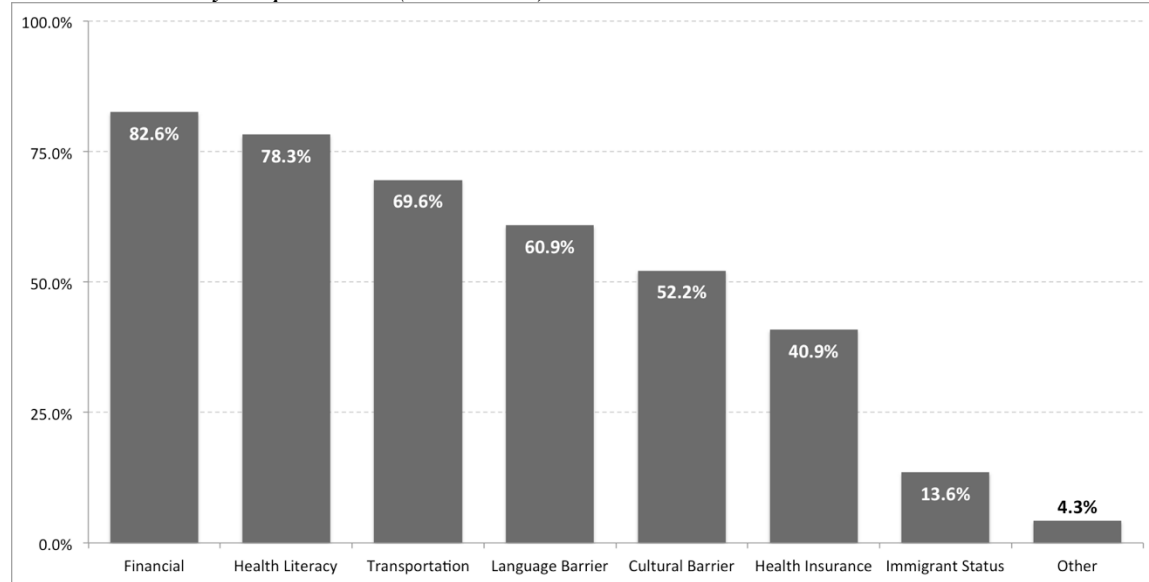
Native Hawaiian or Pacific Islander	0 (0)
White	17 (65.4)
Biracial	3 (11.5)
Other	1 (3.8)
<b>Job Title/Degree</b>	
MD/DO/PA Oncologist	2 (7.7)
Oncology Nurse Practitioner	2 (7.7)
Oncology Nurse	0 (0)
Genetic Counselor	20 (76.9)
Other	2 (7.7)
<b>Patients</b>	
<b>Proportion (%) of Patients Seen by Age Group</b>	
Pediatrics (0-18)	2.17 (0.98)
Adult (19-64)	34.73 (16.84)
Older Adults (65+)	17.63 (13.10)
<b>Proportional (%) of Patients Seen by Gender</b>	
Female	80.91 (13.15)
Male	18.83 (12.95)
Other	2.33 (2.31)
<b>Proportional (%) of Patients Seen by Ethnicity</b>	
Asian	15.68 (9.13)
Black	13.63 (17.75)
Hispanic or Latin American	20.11 (11.17)
Native American	0.32 (1.16)
Native Hawaiian or Pacific Islander	2.11 (3.35)
White	48.03 (21.94)
Other	0.84 (2.43)
<b>Proportion (%) of Patients Seen by Type of Insurance Coverage</b>	
Self-Purchased	22.36 (24.20)
Insurance through employer	43.50 (23.50)
Medicare	20.44 (13.13)
Medicaid	14.00 (23.28)
Other Government	1.94 (6.28)
No Insurance	0.31 (1.01)

## Univariate Analyses

### Barriers to adherence.

In order to better understand the barriers to adherence to oncology care that respondents' patients face, the proportion of respondents citing each of 8 barriers as relevant to their patient populations was plotted on a bar chart (see figure 1). The responses indicate that the majority were reportedly due to finances, followed by health literacy, with only 40.9% reporting that health insurance would be a barrier.

Figure 1  
Barriers cited by respondents (n = 22-23)



**Practice characteristics.**

In order to better understand the characteristics of respondents’ practices, frequencies and valid percentages were tabulated (see Table 2). The hospital size varied considerably between participants. The majority of the participants did not work with medically underserved population, while no one worked in a medically underserved area.

Table 2  
Practice characteristics (n = 17-24)

	n	Valid Percent
Hospital Size, Beds		
6-49	0	0
50-99	2	11.8
100-199	3	17.6
200-299	5	29.4
300-399	2	11.8
400-499	1	5.9
500+	4	23.5
Medically Underserved, Population	4	16.7
Medically Underserved, Area	0	0
Referral Type		
Internal	11	55.0
External, Clinical Testing	1	5.0
External, Telegenic	1	5.0

Other	0	0
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### Genetics referrals.

In order to better understand the frequency with which respondents order genetics referrals, means were calculated on a 6-point frequency scale ranging from Very Rarely to Very Often (see Table 3). The responses indicate that the majority of oncology cases are referred to genetics due to an early age of cancer diagnosis, a family history of cancer and due to the specific type of cancer being diagnosed.

*Table 3*  
*Characteristics of Genetics Referrals*

Indication	Frequency Made*
	M (SD)
Early Age of Cancer Onset	5.13 (1.81)
Family History of Cancer	4.75 (1.75)
Specific Cancer Tumor Type	4.13 (1.73)
Somatic Genetic Test Results	3.38 (2.33)
Reproductive Indications	2.13 (1.36)

\* Indicated on a 6pt scale where 1 = Very Rarely and 6 = Very Often

### Preparation to discuss genetics issues.

In order to better understand respondents' preparation to discuss genetics issues, means were calculated on a series of 6-point, self-report items measuring preparation (see Table 4). Of the 23 respondents, all of them seemed prepared to discuss a variety of genetic issues with their patients.

*Table 4*  
*Preparation to Discuss Genetics Issues (n = 23)*

Genetics Issue	Preparation*
	M (SD)
Inheritance	5.83 (0.49)
Testing for Family Members	5.78 (0.67)
Results Disclosure	5.83 (0.58)
Medical Management Recommendations	5.70 (0.64)

\* Indicated on a 6pt scale where 1 = Very Unprepared and 6 = Very Prepared

## Research Questions

### Research Question #1: Does patients' insurance coverage differ by the barriers cited?

Table 5

Percentage of Patients Covered by Healthcare Plans by Barriers Cited (n = 13-16)

Barrier * Insurance Type	% of Patients Covered M (SD)		t	df	p	Hedges' G
	Barrier Cited	Barrier Not Cited				
<b>Self Purchased Insurance</b>						
Transportation	21.3 (24.3)	25.0 (27.0)	-0.25	12	.81	0.15
Financial	22.8 (25.5)	20.0 (21.2)	0.14	12	.89	0.11
Health Insurance	27.3 (30.8)	17.0 (11.0)	0.71	11	.50	0.40
Health Literacy	20.7 (23.3)	28.3 (32.1)	-0.47	12	.65	0.30
Language	18.7 (25.9)	29.0 (21.9)	-0.75	12	.47	0.42
Culture	18.3 (29.7)	26.4 (18.6)	-0.61	12	.55	0.37
Immigrant Status	4.0 (1.4)	26.8 (25.6)	-1.22	11	.25	0.93
<b>Employer-Based Insurance</b>						
Transportation	43.0 (23.4)	45.0 (27.4)	-0.14	14	.89	0.08
Financial	44.4 (25.1)	37.5 (3.5)	0.38	14	.71	0.29
Health Insurance	37.9 (27.8)	48.3 (15.7)	-0.83	13	.42	0.44
Health Literacy	43.9 (22.6)	41.7 (32.5)	0.15	14	.89	0.09
Language	44.2 (23.7)	42.0 (25.6)	0.17	14	.87	0.09
Culture	45.1 (26.0)	41.4 (21.7)	0.30	14	.77	0.15
Immigrant Status	43.3 (36.7)	41.8 (21.5)	0.10	13	.92	0.06
<b>Medicare</b>						
Transportation	20.6 (14.7)	20.0 (8.2)	0.07	14	.94	0.04
Financial	21.2 (12.6)	15.0 (21.2)	0.61	14	.55	0.46
Health Insurance	19.1 (12.0)	23.3 (16.3)	-0.58	13	.57	0.30
Health Literacy	20.5 (14.1)	20.0 (10.0)	0.06	14	.95	0.04
Language	20.6 (10.9)	20.0 (18.7)	0.09	14	.93	0.04
Culture	18.3 (10.3)	23.1 (16.6)	-0.72	14	.49	0.36
Immigrant Status	15.0 (13.2)	22.3 (13.7)	-0.82	13	.43	0.54
<b>Medicaid</b>						
Transportation	17.8 (25.8)	2.5 (5.0)	1.15	14	.27	0.67
Financial	13.9 (24.3)	15.0 (21.2)	-0.06	14	.95	0.05
Health Insurance	17.7 (30.2)	10.0 (10.5)	0.59	13	.56	0.31
Health Literacy	17.2 (24.8)	0 (0)	1.17	14	.26	0.31
Language	16.7 (16.9)	8.0 (12.6)	0.68	14	.51	0.55
Culture	18.8 (29.4)	7.9 (11.1)	0.93	14	.37	0.47
Immigrant Status	38.3 (49.1)	8.7 (10.1)	1.04	2.04*	.41	1.38
<b>Uninsured</b>						
Transportation	0.4 (1.2)	0 (0)	0.70	14	.50	<sup>a</sup>
Financial	0.4 (1.1)	0 (0)	0.45	14	.66	<sup>a</sup>
Health Insurance	0.6 (1.3)	0 (0)	1.01	13	.33	<sup>a</sup>
Health Literacy	0.4 (1.1)	0 (0)	0.58	14	.57	<sup>a</sup>
Language	0.5 (1.2)	0 (0)	0.82	14	.43	<sup>a</sup>
Culture	0.1 (0.3)	0.6 (1.5)	-0.89	14	.39	0.50
Immigrant Status	0.3 (0.6)	0.3 (1.2)	0.00	13	1.00	0.00

\* The assumption of the equality of variance was violated, so degrees of freedom were adjusted

<sup>a</sup> Hedge's G could not be computed for these analyses

In order to determine whether the estimated proportion of patients insured under differing healthcare plans varied between providers based on the barriers to adherence to oncology care cited, a series of independent samples t-tests were conducted (see Table 5). While no statistically significant findings emerged from the analyses ( $p$ 's > 0.05), this was anticipated as a likely outcome given the limited sample size. Interestingly, while no results were statistically significant, four analyses did yield effect sizes greater than the threshold for Medium-sized effects (Hedges'  $G = 0.50$ ) and two had even larger effect sizes exceeding the threshold for Large-sized effects (Hedges'  $G = 0.80$ ; Cohen, 1988). While care must be taken not to over-extrapolate from non-significant findings, this is suggestive that replication with a larger sample may be warranted and ultimately detect significantly significant findings (Cohen, 1988).

### Research Question #2: Do the barriers cited differ by hospital size?

Table 6  
Barriers Cited by Practice Size ( $n = 14$ )

Barrier	Hospital Size, n (valid %)		X <sup>2</sup>	df	Cramer's V	p*
	50-299 beds	300+ beds				
Transportation			0.09	1	.07	.77
Yes	7 (77.8)	5 (71.4)				
No	2 (22.2)	2 (28.6)				
Financial			0.76	1	.22	.38
Yes	6 (66.7)	6 (85.7)				
No	3 (33.3)	1 (14.3)				
Health Insurance			0.04	1	.05	.84
Yes	3 (33.3)	2 (28.6)				
No	6 (66.7)	5 (71.4)				
Health Literacy			0.79	1	.22	.79
Yes	8 (88.9)	5 (28.6)				
No	1 (11.1)	2 (71.4)				
Language			2.05	1	.36	.15
Yes	7 (77.8)	3 (42.9)				
No	2 (22.2)	4 (57.1)				
Culture			0.25	1	.13	.61
Yes	5 (55.6)	3 (42.9)				
No	4 (44.4)	4 (57.1)				
Immigrant Status			0.04	1	.05	.85
Yes	1 (11.1)	1 (14.3)				
No	8 (88.9)	6 (85.7)				

In order to determine whether the barriers to adherence to oncology care cited differed between the largest practices compared to smaller ones, a series of chi-square tests of independence were conducted. As shown in Table 6, no statistically significant association between hospital size and barriers cited emerged ( $p$ 's > 0.05).

**Research Question #3: Do the barriers cited differ for medically underserved populations versus non-underserved populations?**

Table 7

*Barriers Cited by Whether Respondents Serve a Medically Underserved Population (n = 23)*

Barrier	Medically Underserved, n (valid %)		X <sup>2</sup>	df	Cramer's V	p*
	Yes	No				
Transportation			0.07	1	.05	.80
Yes	3 (75.0)	13 (68.4)				
No	1 (25.0)	6 (31.6)				
Financial			1.01	1	.21	.31
Yes	4 (100)	15 (78.9)				
No	0 (0)	4 (21.1)				
Health Insurance			7.06	1	.57	.008
Yes	4 (100)	5 (27.8)				
No	0 (0)	13 (72.2)				
Health Literacy			0.03	1	.04	.86
Yes	3 (75.0)	15 (78.9)				
No	1 (25.0)	4 (21.1)				
Language			0.42	1	.13	.52
Yes	3 (75.0)	11 (57.9)				
No	1 (25.0)	8 (42.1)				
Culture			1.01	1	.21	.32
Yes	3 (75.0)	9 (47.4)				
No	1 (25.0)	10 (52.6)				
Immigrant Status			15.63	1	.84	<.001
Yes	3 (75.0)	0 (0)				
No	1 (25.0)	18.0 (100)				

In order to determine whether the barriers to adherence to oncology care cited differed by whether the practitioners work with medically underserved population, a series of chi-square tests of independence were conducted. As shown in Table 7, two statistically significant



associations emerged. Specifically, participants who work with medically underserved populations were more likely to cite health insurance and immigrant status as barriers to adherence ( $p$ 's < 0.05).

**Research Question #4: Do the barriers cited differ in medically underserved areas versus non-underserved areas?**

The question asking whether respondents work in medically underserved areas turned out to be a Constant, with no respondents ultimately working in such areas. As a result, Research Question #4 could not be explored with this sample.

### Discussion

Our findings show that there are still major barriers for individuals to receive genetic counseling and genetic testing. Among the barriers that were cited, health insurance was reported to be a barrier 40.9% of the time, showing that there is a discrepancy for individuals who cannot afford to pay for health insurance. Evidence on sociodemographic factors, including availability of health insurance, as indicators for receiving genetic counseling and testing have been inconsistent in past research (Stamp et al., 2019; Willis et al., 2017). With this in mind, these specific responses could be due to a variety of reasons. Many of these respondents were practicing genetic counselors, who are already seeing patients for genetic testing and counseling, meaning that the patients have already overcome these barriers to follow through with the appointment. Many of the patients that are being seen needed to have health insurance to even have an appointment, which imposes bias. Additionally, many of the respondents worked within areas and with patient populations that did not represent medically underserved individuals. Knowing that the uptake of genetic counseling and genetic testing has primarily been utilized in non-Hispanic White, educated females (Stamp et al., 2019), we are missing crucial data from a wide range of potential patients. Looking within our population and out to the general population, reducing barriers to accessing testing still needs to be addressed.

The characteristics of genetics referrals might have been skewed because the respondents were primarily genetic counselors. Genetic counselors are intensively trained to know when to offer appropriate testing and resources. In accordance to NCCN guidelines, individuals should be referred to genetics for testing due to the age of diagnosis of specific cancers, if there is a family

history of cancer, and if specific types of cancer are being seen (“Genetic/Familial High-Risk Assessment: Breast and Ovarian.,” 2019; “Genetic/Familial High-Risk Assessment: Colorectal.,” 2019) Further analysis is needed to dive into the barriers versus the specific ethnicities of the patients. Again, if the primary population that is seen in genetic counseling is homogenous, are more diverse populations being missed for referrals? It is reported that high risk black woman and other racial/ethnic minorities are less likely to be counseled than high risk white women, which mirrors racial disparities in cancer care (Komenaka et al., 2016; Levy et al., 2011). This is despite the fact that Hispanic women with no medical insurance were significantly more likely to undergo testing (Komenaka et al., 2016). This indicates that many of these individuals are not having their medical needs met, even though there are clear guidelines for referrals from NCCN. Efforts to educate providers about these discrepancies and about the benefits of genetic assessment may further stimulate additional usage in the future.

Due to the majority of respondents being genetic counselors and that the average time in practice is 9.27 years, it is not surprising that they are prepared to discuss genetic counseling issues. There are many genetic issues that need to be discussed in oncology genetic counseling to make sure that patients have all the proper information to make informed decisions. Genetic counselors and other providers need to be able to provide this information to a diverse group of individuals, including those with varying education levels. As the demand for genetic counseling grows, new avenues including video-teleconferencing, are emerging to reach high-risk underserved individuals outside of major metropolitan areas (Mette et al., 2016). Incorporating similar technologies may be an effective way to reach all potential patients, which will help eliminate the disparities in access to services, and genetic counselors need to become comfortable applying their knowledge within these varying types of sessions.

No statistically significant findings emerged when assessing the types of insurance coverage for patients and barriers cited. However, trends were identified that suggest significant correlations may be obtained if this study were to be replicated with a larger sample. By running Hedges' G, a necessary test for smaller sample sizes, we observed medium size effects (Hedges'  $G=0.50$ ). There was a medium size effect for Medicare patients and immigrant status ( $g=0.54$ ). Majority of Medicare patients in 2017 were White, non-Hispanic individuals (75%) that are most likely not seeking to immigrate into the United States (Med Pac, 2017). Generally, White, non-Hispanic people are not hindered by an immigration status, therefore they would have less barriers involving immigration while accessing genetic counseling. Another medium size effect was seen with Medicaid individuals and transportation ( $g=0.67$ ) and language ( $g=0.55$ ) as a barrier to care. Medicaid provides health coverage and services for children, people with disabilities, and seniors and low-income adults. Many of the populations face financial difficulties, which would make it difficult for people to rely on transportation to get to and from medical appointments. The state of California provides Medicaid to over over 5 million Hispanics, 2 million white, non-Hispanics, 700,000 African Americans, and over 1 million individuals identified as other (West, Rachel, 2017). With many of these individuals not speaking English as their primary language, it would be difficult to have medical appointments in English, let alone the difficulty of overcoming the technical genetic language provided in genetic counseling sessions. Lastly, there was a medium size effect seen in uninsured individuals might not have culture as a barrier ( $g=0.5$ ). It is hard to conclude what caused this because we do not have data providing information on who these uninsured individuals might be.

There are also some large effect sizes seen when running Hedges' G (Hedges'  $G=0.80$ ). One large effect size seen is that individuals with self-purchased insurance might not have a

problem with immigrant status ( $g=0.93$ ). Again, many individuals that are seen for genetic counseling are of homogenous demographics. Along with these demographics and the fact that many of the respondents work for hospitals or facilities that require insurance, it is not surprising that immigrant status would not be a barrier for these individuals. Another large effect size seen is that Medicaid individuals might have immigrant status as a barrier to access genetic counseling services ( $g=1.38$ ). Over 5 million Hispanics have Medicaid in California (West, Rachel, 2017), it is likely that many of these individuals are immigrants. This is reflective of the difficulties immigrants have receiving proper medical care. Although it is important to avoid erroneous extrapolation with these non-significant findings, further work should be done to replicate this study with a larger sample size (Cohen, 1988).

While non-significant findings were anticipated in Table 6, examination of Cramer's V revealed a moderate-sized effect (Cramer's  $V = .30-.49$ ) for Language and small-effects (Cramer's  $V = .10 - .29$ ) for Financial, Health Literacy, and Culture. While care must be taken not to over-extrapolate from non-significant findings, this is suggestive that replication with a large sample may ultimately detect different barriers cited across differing hospital sizes (Cohen, 1988).

Barriers did differ for medically underserved populations versus non-underserved population. First, health insurance was a barrier for all participants that reported working with a medically underserved population ( $p=0.008$ ). There is conflicting data regarding sociodemographic predictors and their indication on whether or not an individual will participate in genetic counseling (Mette et al., 2016; Stamp et al., 2019; Underhill et al., 2017; Willis et al., 2017). Our data indicates that there is a barrier, but further studies should be done with a larger sample size. It should be further analyzed in the state of California to be able to potentially

implement a state-wide initiative to promote genetic testing to an underserved population. Second, immigrant status was a barrier for participants that reported working with medically underserved population ( $p < 0.001$ ). Knowing that many immigrants are of Hispanic descent, especially in the state of California and that there are disparities in diagnosis and treatment outcomes for cancer (Mette et al., 2016), it is vital to be able to reach this community for proper medical care.

### **Limitations**

The study has important limitations to be considered. First, response rate was limited to only 26 individuals. Due to the small sample size, we were limited in our ability to achieve significant findings and, as such, make conclusions. The small sample size could be due to the attempt to rely on participants to snowball the survey to other qualified individuals instead of reaching out directly to oncologist or oncology nurses. There should be a better utilization of Listservs to reach the proper respondents, such as reaching out to groups like the Association of Community Cancer Centers.

Second, we were limited in our ability to capture information from respondents outside of the genetic counseling field. The number of genetic counselors responding would not have been a problem if we were able to get a significant amount of responses from oncology health care providers in the oncologist field, nursing field, and the nurse practitioner field. This was a problem because the survey was meant for a wider range of responses, and genetic counselors were limited in what questions they could even respond to. Also, many of the respondents were working within facilities that required patients to be insured. Therefore, this data might not be representative of the current landscape of individuals accessing genetic counseling.

Third, the crux of the survey could have asked more specific and robust questions to gather information to assess the needs of oncology patients. There were limited questions asking about the needs, and something that can be expanded upon in future surveys. Finally, the survey was run for a limited amount of time. Health care professionals could have been overwhelmed with work and the current conditions, which could have prohibited them from taking extra time to fill out a survey. This can be seen by the low response rate of 54.2%, meaning that half of the individuals that started the survey did not finish the survey.

### **Future Research**

Future research is necessary to be able to implement a possible state-wide initiative to promote genetic testing in an underserved population. This survey potentially laid the groundwork but larger sample size should be used. Future research should reach out specifically oncology professionals and potentially exclude genetic counselors. There could also be further analysis into these specific barriers, and other barriers that are seen which could be limiting care to underserved populations. Survey participants could possibly rank these barriers based on the population that they are seeing in practice. Finally, actual sampling of patient populations should be utilized as well.

### **Conclusion**

In conclusion, the results from this study are useful in discovering barriers for attendance of genetic counseling sessions for medically underserved populations. Due to conflicting reports, future work is needed to evaluate these barriers in a larger sample size and potentially from individuals who are not practicing in the genetic counseling field. Continued research efforts should be devoted to promoting access to genetic testing and counseling in the high-risk underserved community. This study highlights a need for a state-wide initiative to promote genetic testing in an underserved population to address the discrepancies in medical care to underserved populations.



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## Appendix A

### Qualtrics Survey

#### Identifying the gap: genetic counseling and testing for underinsured oncology patients.

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#### Start of Block: Consent Form

C1

Thank you for participating in a research project being conducted as part of a Master's Thesis at Keck Graduate Institute. While volunteering to complete the survey will probably not benefit you directly, the information you provide will help explore the genetic counseling and genetic testing needs of underinsured and uninsured oncology patients. Volunteering for this study does not involve risk beyond what a typical person would experience on an ordinary day and the survey should take about 20 minutes of your time. Your involvement is entirely voluntary, and you may withdraw at any time for any reason. If you are uncomfortable answering any question on the survey, you may leave it blank.

By clicking "Next" you are consenting to take the survey.

Next

#### End of Block: Consent Form

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#### Start of Block: Demographic and knowledge based questions for the oncology health care provider:

**1 The following questions aim to assess the demographics and knowledge base of the oncology health care provider:**

Q1 Practice/Facility Name:

---

Q2 Age:

---

---

Q3 Gender:

- Male
- Female
- Other (Please specify): \_\_\_\_\_
- 

Q4 What race/ethnicity best describes you (select all that apply)?

- White, not Hispanic
- Black or African American
- Hispanic or Latin American
- American Indian or Alaska Native
- Asian
- Native Hawaiian or Pacific Islander
- Other (Please specify): \_\_\_\_\_
-

Q5 Job Title/Degree:

- MD/DO Medical Oncologist
- MD/DO Surgical Oncologist
- MD/DO Radiation Oncologist
- Oncology Nurse Practitioner
- Oncology Nurse
- Genetic Counselor
- Other (Please specify): \_\_\_\_\_
- 

Q6 Years in oncology practice:

\_\_\_\_\_

---

Q7 Where is the location of your practice?

Zip Code: \_\_\_\_\_

---



Q8 What type of hospital do you currently practice? (Check all that apply)

- Federal Qualified Health Center
  - Federally Designated Health Professional Shortage Area
  - Rural Health Clinics
  - National Health Service Corps
  - Migrant Health Centers
  - Health Care for the Homeless Grantees
  - Indian Health Service Sites/Tribal Health Sites
  - Other (Please specify): \_\_\_\_\_
- 

Q9 What licensed bed size is your hospital?

- 6-49 beds
  - 50-99 beds
  - 100-199 beds
  - 200-299 beds
  - 300-399 beds
  - 400-499 beds
  - Over 500 beds
  - Other (Please specify): \_\_\_\_\_
  - Not applicable
-

Q10 Genetics Attitude: Please state your level of agreement with the following statements:

	Strongly Agree	Agree	Somewhat agree	Neither agree or disagree	Somewhat disagree	Disagree	Strongly disagree
It is a physician's duty to inform patients of genetic tests when they're available	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Patients with positive genetic test results are at risk for insurance discrimination	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Genetic tests for cancer susceptibility have too many inaccurate or ambiguous results	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

-----

Q11a Genetics Knowledge: What percentage of breast cancer patients have an inherited susceptibility to breast cancer?

- 5%
  - 10%
  - 20%
  - 30%
  - 40%
  - Unsure
- 

Q11b What is the approximated increased risk to age 70 of developing breast cancer for carriers of a predisposing mutation in BRCA1?

- 20%
  - 40%
  - 60%
  - 80%
  - 100%
  - Unsure
-

Q11c Which features of breast cancer are associated with an inherited susceptibility? (Select all that apply):

- Earlier age of onset
  - Dominant inheritance pattern
  - Transmission of susceptibility only through females
  - Characteristic histologic features
  - Bilateral primary breast cancers
  - Unsure
- 

Q11d The cancer risks of patients with a negative hereditary cancer genetic test result will always be reduced down to population risk.

- True
  - False
- 

Q11e Which of the following cancer risk assessment model calculates the risks of a patient carrying a Lynch syndrome mutation?

- Gail
- Claus
- IBIS
- PREMM5
- BRCAPRO

End of Block: Demographic and knowledge based questions for the oncology health care provider:

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Start of Block: Demographic questions for oncology health providers: These questions aim to asse

**2 The following questions aim to assess the demographics of your patients (please fill out to the best of your knowledge):**

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Q12 To the best of your knowledge, how many patients in the following ranges have you seen during the last month?

Pediatrics (0-18): \_\_\_\_\_

Adults (19-64): \_\_\_\_\_

Older Adults (65+): \_\_\_\_\_

---

Q13 What percentage of your patients are:

Male: \_\_\_\_\_

Female: \_\_\_\_\_

Other: \_\_\_\_\_

---

Q14 What percentage of your patients are:

White, not Hispanic: \_\_\_\_\_

Black or African American:  
\_\_\_\_\_

Hispanic or Latin American:  
\_\_\_\_\_

American Indian or Alaska Native:  
\_\_\_\_\_

Asian: \_\_\_\_\_

Native Hawaiian or Pacific Islander:  
\_\_\_\_\_

Other (Please specify):  
\_\_\_\_\_

Q15 Do you work with a **population** that is designated as medically underserved? (<https://bhw.hrsa.gov/shortage-designation/muap-process>). The designation of an area that is medically underserved is typically determined by the following criteria:

- Percentage of Population Below Poverty Level
- Percentage of Population Age 65 and Over
- Infant Mortality Rate
- Ratio of Primary Care Physicians per 1,000 Population

Yes

No

Q16 Do you work in an **area** that is designated as medically underserved (<https://bhw.hrsa.gov/shortage-designation/muap-process>) The designation of an area that is medically underserved is typically determined by the following criteria. • Percentage of

Population Below Poverty Level • Percentage of Population Age 65 and Over  
 Infant Mortality Rate • Ratio of Primary Care Physicians per 1,000 Population

Yes

No

Q17 Approximately what percentage of the patients you see at your primary practice have health insurance?:

\_\_\_\_\_

Q18 On average, what percentage of patients at your primary practice have the following insurance options?

Self-purchased insurance:

\_\_\_\_\_

Insurance through employer:

\_\_\_\_\_

Medicare: \_\_\_\_\_

Medicaid: \_\_\_\_\_

Other Government Program:

\_\_\_\_\_

No insurance: \_\_\_\_\_

Other (Please specify):

\_\_\_\_\_

Not applicable

Q19 Approximately what percent of the patients you see at your primary practice qualify for Medicare?:

---

Q20 Please indicate your degree of agreement or disagreement with the following statement: "On an average patient encounter at your primary work setting you experience time pressure"

- Strongly agree
- Agree
- Somewhat agree
- Neither agree nor disagree
- Somewhat disagree
- Disagree
- Strongly disagree
- Not applicable

End of Block: Demographic questions for oncology health providers: These questions aim to asse

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Start of Block: The following questions aim to assess the needs of your oncology patients (pleas

***3 The following questions aim to assess the needs of your oncology patients (please fill out to the best of your knowledge):***

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Q21 What barriers to adherence to oncology care do your patients face? (Check all that apply):

- Transportation
  - Financial
  - Health Insurance
  - Health Literacy
  - Language Barrier
  - Culture Barrier
  - Immigrant Status
  - Other (Please specify):  
\_\_\_\_\_
- 

Q22 Have you ever referred an oncology patient for genetic testing related to their cancer?

- Yes
  - No
  - Not applicable
- 

Q23 Approximately what proportion of your patients, per 100, would you say you typically refer for cancer-related genetic testing?:

\_\_\_\_\_

---

Q24 What percentage of patients have access to genetic counseling services and follow through with a visit to genetic counseling?:

\_\_\_\_\_

---

Q25 Please indicate how often you make genetics referrals for each of the following indications:

	Very Often	Often	Somewhat Often	Somewhat Rarely	Rarely	Very Rarely
Family History of Cancer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Specific Cancer Tumor Type Encountered (ex: carcinoid tumors, leiomyosarcoma, etc)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Early Age of Cancer Onset	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Somatic Genetic Test Results	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Reproductive Indications	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



Q26 Please indicate how prepared you feel to discuss each of the following genetics issues with your patients:

	Very Prepared	Prepared	Somewhat Prepared	Somewhat Unprepared	Unprepared	Very Unprepared
Inheritance	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Testing for Family Members	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Results Disclosure	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Medical Management Recommendations	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other (Please specify):	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other (Please specify):	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q27 Where, if at all, do you access information about the benefits of genetic counseling for oncology care? (Check all that apply):

- Resources/classes provided during school/training
- Colleagues
- Physicians
- Genetic Counselors
- Internet
- Other (Please specify):

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Q28 Where do you refer your patients if they need a genetic counselor? (Check all that apply):

- Internal referral
- External referral- Clinical Setting
- External referral- Telegenetic
- Other (Please specify):  

---
- Not applicable

End of Block: The following questions aim to assess the needs of your oncology patients (pleas

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