

Projecting the Supply and Demand for Certified Genetic Counselors

A Workforce Study

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A Workforce Study

Submitted to:

American Board of Genetic Counselors (ABGC)

Accreditation Council for Genetic Counseling (ACGC)

Association of Genetic Counseling Program Directors (AGCPD)

American Society of Human Genetics (ASHG)

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Executive Summary

Information about the certified genetic counselor workforce, while subject to uncertainty given rapid changes in technology, is critical to determining trends in employment, to addressing professional training needs, to quantifying barriers to quality service delivery, and to informing relevant policy and advocacy efforts. The Genetic Counselor Workforce Working Group (WFWG)¹ commissioned Dobson DaVanzo & Associates, LLC (Dobson | DaVanzo), a Washington, D.C. metropolitan-area based health economics consulting firm, to conduct a workforce supply and demand projection study of U.S.-based certified genetic counselors over the next decade (2017-2026).

Workforce studies attempt to understand the various forces that create demand for and supply of workforce at various price levels. Workforce supply is driven by demand, as well as training, certification and licensure requirements, retirement trends, and other exits/transitions from the genetic counselor workforce. This study comes at a critical time for the genetic counselor profession to understand and anticipate how demand for, as well as training, licensure and certification of genetic counselors, could change the workforce supply in the future.

We collaborated with expert representatives from the WFWG to inform key model assumptions, conducted informational interviews with professional and industry stakeholders, and examined the available literature and available data sources. In considering two different demand scenarios, this study is designed to inform stakeholders and policy makers about the workforce implications of alternative futures and policies.

Key Findings

Future Supply of Certified Genetic Counselors: Projection Results

We calculated the number of certified genetic counselors as the active supply of genetic counselor graduates who became certified, along with the net flow of new entrants into the profession. We estimate the effective supply of all certified genetic counselors will increase from 3,814 to 6,562 between 2017 and 2026, or by approximately 72% over 10 years. The

¹ The Genetic Counselor Workforce Working Group (WFWG) includes the following organizations: Accreditation Council for Genetic Counseling (ACGC), American Board of Genetic Counselors (ABGC), American Society of Human Genetics (ASHG), Association of Genetic Counseling Program Directors (AGCPD), and National Society of Genetic Counselors (NSGC).

majority of certified genetic counselors will provide direct patient care, with industry making up the next largest group.

Future Demand for Certified Genetic Counselors: Reported Findings

While anecdotal evidence is supportive of an increased demand for certified genetic counselors, we were unable to precisely quantify a growing shortage (or excess) of U.S. certified genetic counselors using information found in either the peer-reviewed or grey literature. We limited our demand projection to only those certified genetic counselors in direct patient care, as this group comprises approximately 65% of the overall certified genetic counselor population.

Using two different rate scenarios – one FTE for a certified genetic counselor per 100,000 U.S. population (‘Scenario 1’) and one FTE for a certified genetic counselor per 75,000 U.S. population (‘Scenario 2’), we calculated the number of direct patient care certified genetic counselors needed to meet the demand of an estimated U.S. population of 326,626,000 in 2017. Under Scenario 1, an adequate certified genetic counselor workforce would include 3,266 full-time providers in 2017, whereas under Scenario 2, 4,355 certified genetic counselors would be required.

When we compared the anticipated supply of direct patient care certified genetic counselors for each year between 2017 and 2026 to the number of genetic counselors demanded under Scenarios 1 and 2, we find, in 2017, a shortage of between 791 and 1,879 certified genetic counselors, respectively. Since our supply projection has the direct patient care certified genetic counselor population outpacing overall U.S. population growth (5.2 versus 0.8% per year over 10 years), overcoming provider shortages under either scenario is inevitable given a long enough projection window.

Conclusions

Our projections demonstrate that supply will meet demand within the 10-year period only under the assumption of one direct care certified genetic counselor per 100,000 persons; otherwise, a stricter model of one per 75,000 persons demonstrates that equilibrium will not be reached until 2029 or 2030.

In the short run, provider shortages appear to be inevitable; however, these shortages would be overcome over a long enough projection window under our “best” estimates of supply and demand growth. That said, neither of our demand models account for large-scale exogenous factors, such as the introduction of blockbuster tests and changes in commercial/public reimbursement. This uncertainty is what makes any workforce study somewhat tentative. Estimating demand for future certified genetic counseling services is particularly challenging in the current, rapidly changing healthcare environment. Thus, the demand for genetic counseling services will need to be carefully monitored over the next several years, in order to account for changing technology and payer preferences.

Purpose and Introduction

Purpose

In 2013, the Genetic Counselor Workforce Working Group (WFWG)² was tasked with assessing the growing demand for certified genetic counselors in the U.S. and coordinating strategies to expand the capacity of the certified genetic counselor workforce.

In 2015, the WFWG commissioned our firm, Dobson DaVanzo & Associates, LLC, a Washington, D.C. metropolitan-area based healthcare economics consulting firm with expertise in modeling healthcare professional workforces, to conduct a supply and demand workforce projection study of U.S.-based certified genetic counselors over the next decade (2017-2026). In developing this model, we collaborated with expert representatives from the WFWG to inform key model assumptions, conducted informational interviews with professional and industry stakeholders, and examined the available literature and available data sources.

Introduction

From a health economics standpoint, workforce demand represents the dynamic relationship between “price and quantity,” provided all other things are equal. Workforce studies attempt to understand the various forces that create demand for and supply of workforce at various price levels. Workforce supply is driven by demand, as well as training, certification and licensure requirements, retirement trends, and other exits/transitions from the genetic counselor workforce. This study comes at a critical time to understand and anticipate how demand for, as well as training, licensure and

² The Genetic Counselor Workforce Working Group (WFWG) includes the following organizations: Accreditation Council for Genetic Counseling (ACGC), American Board of Genetic Counselors (ABGC), American Society of Human Genetics (ASHG), Association of Genetic Counseling Program Directors (AGCPD), and National Society of Genetic Counselors (NSGC).

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certification of genetic counselors could change the workforce supply in the future within a transformed health care marketplace.

Genetic counseling has kept pace with technological advances and changes to health care delivery by evolving and expanding. Not only do certified genetic counselors have an increased presence in diverse settings (e.g., public health departments, academic medical centers, genetic test laboratories, education, etc.), but their roles and responsibilities have changed, as well.

Going forward, the increased use of value-based purchasing by health care payers as well as the growth of Accountable Care Organizations and population health management are likely to contribute to future changes in the roles and responsibilities of genetic counselors.

Several factors may affect demand for genetic counseling. The increasing emphasis in clinical settings on genetic predisposition to common complex diseases may result in a large increase in demand for patient-facing direct care genetic counselors. As the genetic origins of numerous diseases become more generally understood, risks and prognoses will be better assessed, and certified genetic counselors will be needed to communicate these risks and prognoses to both patients and other clinicians.

Genetic testing is becoming an increasingly common and important component of personalized disease management. Studies conducted over the past decade have identified genetic variants underlying many Mendelian diseases and genetic risk factors associated with common diseases, such as cancer, heart disease, and neurological disorders. These discoveries have led to greater insights in clinical evaluation, which offer the possibility of better targeting therapeutic strategies to prevent or mitigate diseases and, in certain instances, to potentially reduce overall healthcare costs (e.g., by better targeting expensive cancer drugs and medicines). Susceptibility to particular diseases can be detected before diseases manifest symptoms, which allows for earlier intervention.

Genetic counseling has become increasingly specialized in recent years. According to a National Society of Genetic Counselors (NSGC) Professional Status Survey (PSS) in 2014, 29% of genetic counselors practiced in the area of cancer – a 19 percentage point increase from 1994. Emerging specialties also include cardiovascular and neurological genetic disorders.³ The expanded interest in genetic counseling may be associated with the increasingly complex nature of the testing, its rapid growth, and how it is seen as being a useful component of high-quality and efficient care. These factors may drive future demand as the health care marketplace moves to value-based purchasing, and

³ National Society of Genetic Counselors. (2014). 2014 professional status survey: Executive Summary.

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payers begin to understand the value of genetic counseling in ensuring that genetic testing is used most appropriately.

Since the early 1980s, the demand for genetic counselors has increased due to a number of factors, including the explosion of new genetic tests coming to market, expansion of genetics into various specialty areas of medicine and the significant demographic trend of delayed child-bearing.

For example, between 2000 and 2014 the percent of first births among women 35 years and older increased by 23%, from 7.4% to 9.1%.⁴ Delayed child-bearing is associated with an increased risk of infertility, pregnancy complications, and adverse pregnancy outcome. Many believe that a growing rate of delayed child-bearing profoundly influenced not only the genetic counselor job market but also the very practice of genetic counseling.⁵ Delayed child-bearing rates may continue to increase as socioeconomic forces change and reproductive preferences fluctuate.

In addition to demographic trends, the increasing number of new genetic tests has influenced the demand for genetic counselors. There are approximately 60,482 genetic testing products on the market and an average of 8-10 new products enters the market every day.⁶ Genetic testing panels account for a significant portion of the recent growth in tests. The increasing number of tests and complexity of panels has driven demand for genetic counselors who understand how to identify the correct tests and interpret those tests once results are available.

Although there is little available data on the genetic counseling profession, there are a considerable number of studies in the literature that discuss the value proposition of certified genetic counselors. Those studies suggest that the use of genetic counselors to better target genetic testing yields significant savings in healthcare spending for patients with cancer, neurologic, and cardiac disorders, or those concerned with inheriting genetic diseases.^{7,8,9} Several payers and providers have calculated the savings realized within their programs once certified genetic counselors become involved in genetic testing for their members, and several health plans, such as Cigna,¹⁰ have implemented policies

⁴ Mathews TJ, Hamilton BE. Mean age of mothers is on the rise: United States, 2000–2014. NCHS data brief, no 232. Hyattsville, MD: National Center for Health Statistics. 2016.

⁵ The Society of Obstetricians and Gynaecologists of Canada: Committee Opinion. Delayed Child-bearing. No. 271, January 2012.

⁶ <https://www.nextgdx.com/insights>; <http://docs.nextgdx.com/genetic-testing-infographic.jpg>

⁷ Mvundura M, Grosse SD, Hampel H, et al. The cost-effectiveness of genetic testing strategies for Lynch syndrome among newly diagnosed patients with colorectal cancer. *Genet Med* 2010; 12(93-104).

⁸ Kotzer KE, Riley JD, Conta JH, et al. Genetic testing utilization and the role of the laboratory genetic counselor. *Clin Chim Acta* 2014; 427:193-5.

⁹ Miller CE, Krautscheid P, Baldwin EE, et al. Genetic counselor review of genetic test orders in a reference laboratory reduces unnecessary testing. *Am J Med Genetic A* 2014; 164(5):1094-101.

¹⁰ Cigna Genetic Testing and Counseling Program. Available online at: <http://www.cigna.com/healthcare-professionals/resources-for-health-care-professionals/genetic-testing-and-counseling-program>

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mandating genetic counseling by certified genetic counselors or other trained genetics providers for precertification for certain genetic tests to be approved. This, and other similar requirements, may help drive additional demand for certified genetic counselors.

Certified genetic counselors in direct patient care are critical members of multidisciplinary teams, serving as integrators of information that helps patients understand and adapt to the medical, psychological, and familial implications of genetic contributions to disease.¹¹ Based on a thorough assessment of a patient's family medical history and interpretation of genetic test results, certified genetic counselors provide critical information to patients regarding genetic testing and to physicians aiding decision-making concerning the optimal course of treatment. This information helps both patients and physicians understand the impact of genetics on the course of disease. Certified genetic counselors also provide information and support to individuals and families concerned with genetic disorders, birth defects, or those at risk for a variety of inherited conditions.

In this report, we triangulated the published literature, information provided by the WFWG, and anecdotal reports as the basis for quantifying provider shortages for a subset of certified genetic counselors providing direct patient care. Here, we modeled two workforce scenarios that show the growth in the supply of direct patient care certified genetic counselors will likely not meet population demand over the next seven to 10 years. The extent to which the results of these models track with actual future demand is largely unknown, and is likely highly sensitive to how the genetic counseling profession responds to pressures that could impact the provision of genetic services and the genomic medicine landscape at large.

The implications of these model results are important to the WFWG's goals of better integrating genetic counseling services in various clinical environments in order to improve individual and public health. The WFWG is aware of the impact that a potential shortage of certified genetic counselors would have on their mission to facilitate the delivery of high-quality, professional services over the long-term.

While the supply section of this report estimates the future supply of certified genetic counselors for each job category and overall, the report's demand section primarily focuses on certified genetic counselors with direct patient care responsibilities. This job category has, historically, represented the largest employer for certified genetic counselors, and would potentially be most responsive to changes in coverage and reimbursement. Outside direct patient care opportunities, however, the demand picture is less clear, as we were unable to identify a quantifiable demand trend in the literature that

¹¹ Genetic Counseling Definition Task Force. (2006). A new definition of genetic counseling: National Society of Genetic Counselors' Task Force Report. *Journal of Genetic Counseling*; 15(2): 77-83.

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could be generalized to non-direct patient care certified genetic counselors. Interviews with industry representatives were also inconclusive on this point.

Supply Projection for the Certified Genetic Counselor Workforce

Introduction

The objective of this section is to present our estimates of the supply of certified genetic counselors over a 10-year period (2017-2026). These estimates can be used in conjunction with demand estimates in the next section to identify and address potential gaps in training. In this section, we discuss our methodology and estimates of the long-term supply of certified genetic counselors in the U.S. workforce.

Methodology

We estimated the aggregate supply of certified genetic counselors in terms of the following job classifications: direct patient care, genetic test and pharmacogenomics industries ('industry'), education, research and public health.

The certified genetic counselor workforce is defined as those providers who are board certified and working in the U.S. The supply model for certified genetic counselors is based on the number of active, board-certified genetic counselors in the U.S., the number of new entrants to the workforce, and the number of individuals exiting the profession (attrition). For new entrants, we considered the capacity of known extant training programs – now and in the future, and the limited number and capacity of clinical sites to provide clinical internships for trainees. We conducted a literature review to identify exogenous factors that might affect supply, such as counselor age distribution, program costs, tuition fees, scholarship availability, median salary, and state licensure. We also conducted 18 semi-structured interviews with certified genetic counselors and healthcare stakeholders who rely on or provide genetic counseling services.

Supply Projection for Certified Genetic Counselors

To construct supply models of certified genetic counselors, we first calculated the total supply of certified genetic counselors in 2016 based on historical graduation and certification data provided by the American Board of Genetic Counselors (ABGC) and available in the 2016 NSGC PSS data.

Future Supply of Genetic Counselors: Model Framework

Given our baseline estimates, we projected the active supply of certified genetic counselors from 2017 to 2026. Supply projections of genetic counselor workforce are based on the model framework shown in Exhibit 1.

Exhibit 1: Supply Model Framework for Certified Genetic Counselors

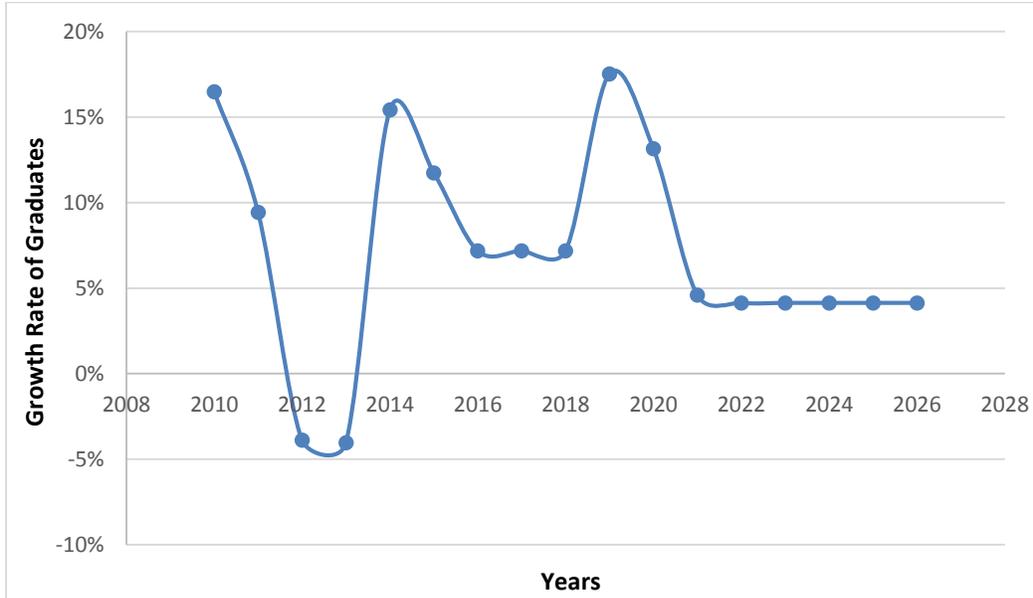


Our projection begins with the number of board-certified genetic counselor professionals estimated for our base-year 2016 and adds new entrants into the model each additional year. Attrition consists of genetic counselors who leave the workforce (e.g., retirement).

We calculated the number of certified genetic counselors as the active supply of genetic counselor graduates who become certified, along with the flow of new entrants into the profession. Historical trends and projected growth rates of graduation over time are shown in Exhibit 2. Projecting forward, all certified genetic counselors were estimated using the total number of certified genetic counselors.

Supply Projection for Certified Genetic Counselors

Exhibit 2: Historical Trend and Projected Growth Rates of Graduates



Future Supply of Certified Genetic Counselors: Baseline Estimation

We used ABGC historical data on numbers of graduates and certifications as a baseline for our estimates. Certification data are available from 1982 to 2015, and graduation data are available from 2009 to 2015.

After calculating the total number of certified genetic counselors in 2015, we restricted that total to include only those providers working within the U.S. Two NSGC sources estimated the percentage of certified genetic counselors working outside the U.S. to be 5.4% (2016 NSGC membership data) and 9.0% (2016 NSGC PSS). A lower-end estimate of 6% was used in the model.

Based on extant literature,¹² we calculated the attrition rate for certified genetic counselors at 2.3% (see below). In order to estimate the supply of certified genetic counselors in 2016 and forward, we used 2009 to 2015 ABGC graduation data to calculate a compound annual growth rate (CAGR) of graduation of 7.2%.

We next calculated the number of graduates in 2016 by assuming that 95% of graduates would eventually receive professional certification, and then extended supply growth into future years (2017-2026).

¹² A Model to Project the supply and demand of physical therapists 2010-2025. American Physical Therapy Association. Available online at: <http://www.apta.org/WorkforceData/ModelDescriptionFigures/>. Accessed on: April 1, 2016.

Supply Projection for Certified Genetic Counselors

Future Supply of Certified Genetic Counselors: Calculation of Our Projection

The following assumptions were made in order to calculate new entrants into the genetic counselor profession and the subsequent attrition rate:

ASSUMPTION-I: There will be approximately 7 new accredited training programs in the next two years. Four new programs will begin in 2017 and three new programs will begin in 2018 according to the Accreditation Council for Genetic Counseling (ACGC).

ASSUMPTION-II: Average class size of these new programs will be 8 over the forecast time period.

ASSUMPTION-III: From 2021 to 2026, the graduation growth rates for existing programs and new programs will be constrained so that the 10-year CAGR will be 7.2%, thus the overall supply will roughly double from 2017 to 2026.

ASSUMPTION-IV: To take into account the availability of clinical sites, the growth rate of graduation for 2021-2026 is limited to 90% of the anticipated growth rate according to Association of Genetic Counseling Program Directors (AGCPD) and ACGC.

ASSUMPTION-V: 95% of all graduates of accredited programs eventually receive professional certification according to ABGC.

We assumed that 85% of certified genetic counselor professionals aged 55 years and older will retire over the next 10 years, and 14.3% of the professionals under 55 will retire over the same period.

Using age distribution information from the NSGC 2016 PSS survey, we first determined the number of certified genetic counselors who are over and under 55 years old. We then applied the aforementioned attrition rates for these age groups to calculate the weighted average growth rate of attrition for both age groups over the 10-year period. We calculated the CAGR for attrition as -2.3%.

We assumed that the distribution of positions will change over time to reflect changes in job postings. Table 1 shows our assumptions regarding the change in distribution of job categories between 2016 and 2026.

Supply Projection for Certified Genetic Counselors

Table 1: Changes in the distribution of job categories over time

Job Categories	Distribution in 2016	Distribution in 2026
Direct Patient Care	65%	60%
Industry	32%	35%
Education	1%	3%
Research & Public Health	2%	2%
Total	100%	100%

Future Supply of Certified Genetic Counselors: Projection Results

We estimate the effective supply of all certified genetic counselors will increase from 3,814 to 6,562 between 2017 and 2026, or by approximately 72% over 10 years. The majority of certified genetic counselors will provide direct patient care, with industry making up the next largest group.

This distribution—with a large majority of certified genetic counselors in direct patient care—strongly influenced our decision to focus our demand model (in the next chapter) on the demand for direct patient care. It is worth noting that the projected number of certified genetic counselors employed in direct patient care is modeled to grow at a slightly slower rate than total certified genetic counselors to account for possible saturation in clinical sites and the expectation that future certified counselors will devote a portion of their work time to educating other healthcare providers. See Table 2.

Table 2: Projected Supply of Certified Genetic Counselors

Providers	2017	2018	2019	2020	2021	2022	2023	2024	2025	2026
Total Certified Genetic Counselors	3,814	4,021	4,276	4,570	4,875	5,190	5,516	5,853	6,202	6,562
Direct Patient Care	2,476	2,588	2,729	2,891	3,058	3,228	3,400	3,576	3,755	3,937
Industry	1,217	1,297	1,394	1,505	1,623	1,745	1,874	2,008	2,149	2,297
Education	46	56	69	82	98	114	132	152	174	197
Research & Public Health	75	80	85	91	97	103	110	117	124	131

Through our review of the literature, we believe it is likely that genetic counselors may play a larger role in the education of primary care providers in the near future; these providers may then incorporate more extensive genetic care into their daily practice. Certified genetic counselors in industry will grow at a faster rate than any of the other provider types due to the rapid growth in commercial genetic testing, the availability of competitive salaries, and changing dynamics within healthcare infrastructure and policy.

Supply Projection for Certified Genetic Counselors

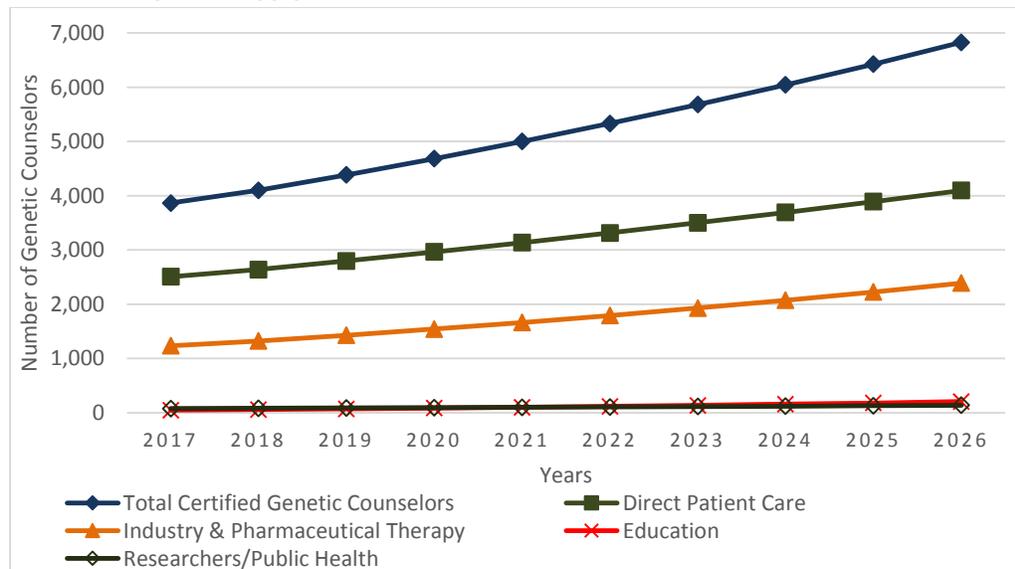
Overall, we project that the total number of **active certified genetic counselors** will grow at a CAGR of 6.2%, from 3,814 to 6,562 between 2017 and 2026, or 72% overall, a rate more than two-and-a-half times the Bureau of Labor Statistics’ 2014 to 2024 employment growth projection of 29%.¹³ We predict that there will be substitution among different job sectors, and the growth rates for the four job categories reflect that trend. Supply of certified genetic counselors in the direct patient care category will grow at a CAGR of 5.3% from 2017 to 2026, while the supply of certified genetic counselors in industry will grow at CAGR of 7.3% within the same study time period. See Table 3.

Table 3: Compound Annual Growth Rate by Job Classification

Job Classification	CAGR
Total Certified Genetic Counselors	6.2%
Direct Patient Care	5.3%
Industry	7.3%
Education	17.6%
Research & Public Health	6.4%

Among these four categories, genetic counselors who are serving within the education sector will grow at the fastest rate over the same study period; the CAGR for this group is 17.6%. The number working within research and public health will grow at 6.4% annually from 2017 to 2026. Exhibit 2 demonstrates the projected supply of genetic counselors over the 10-year period.

Exhibit 2: Projected Supply of Genetic Counselors



Supply Projection for Certified Genetic Counselors

Conclusions

Our interview results indicated that there are exogenous factors (such as age distribution, program costs, tuition fees, scholarship availability, median salary and state licensure) that could affect the supply of certified genetic counselors. Underlying all CAGR projections were assumptions for historical certification trends, and those CAGR projections were directly informed by our projected changes in graduation, such as anticipated expansion of existing programs and launching of new programs, as well as qualitative assessments provided through interviews with stakeholders and the profession. Should the profession undertake new initiatives to rapidly increase the number of new programs beyond the anticipated 7 programs planned through 2018, our supply estimates would likely underestimate actual growth.

Demand Model for Direct Patient Care Certified Genetic Counselors

Overview of Demand Model

To determine whether our overall projected supply of certified genetic counselors, which is expected to grow from 3,814 to 6,562 between 2017 and 2026 (or 6.2% per year) is sufficient to meet future demand, we conducted 18 interviews with stakeholders actively practicing in the major employment settings of most certified genetic counselors. These included: direct patient care, industry, education, and research-based settings.

The purpose of these interviews was to identify and understand the factors expected to impact demand for certified genetic counselor services in different segments of the profession. We also examined the peer-reviewed and grey literature with a similar intent, and we more broadly considered how large-scale market dynamics could disrupt genetic service marketplaces, including the genetic test pipeline and pharmacogenomics, changes in regulatory approval pathways for genetic tests, changes in commercial and public coverage and reimbursement for genetic services, and growing public awareness of personalized genomic medicine.

Future Demand for Certified Genetic Counselors: Reported Findings

There is a general expectation within the profession and the larger genetics community that the demand for certified genetic counselor services will increase moderately, if not markedly, over the next 10 years across all major employment settings. This expectation is

The subset of certified genetic counselors primarily employed in healthcare settings with direct patient care responsibilities comprised 65% of all CGCs in 2014.

Demand Model for Direct Patient Care Certified Genetic Counselors

grounded in multiple factors, which include growing public awareness of genomic medicine and recent adoption of precertification requirements for genetic testing by some health plans (e.g., Cigna and UnitedHealth) that mandate genetic counseling in order to approve coverage for certain genetic tests.

Additionally, the explosion of new genetic tests in recent years,^{14,15} coupled with genetic counseling services becoming an increasingly common and important component of personalized disease management, a near-zero unemployment rate for certified genetic counselors,¹⁶ and near 20% annual growth in job postings for certified genetic counselors between 2013 and 2016,¹⁷ appear to all support a ‘bull-market’ demand outlook for the profession, with increases across all fields of direct patient care, education, and industry.

Despite our 10-year projected supply of genetic counselors growing by 72%, the profession’s current education, certification and program accreditation processes are unlikely to generate enough trained providers to satisfy the expected growth in demand according to the profession.¹⁸ Thus, the profession expects the current shortage of genetic counselors to increase in the future.¹⁹ Proactive initiatives that anticipate potential shortages through targeted education, outreach, advocacy, and certification may facilitate closing the gap in the later years modeled in this report with respect to growth in the profession.

Future Demand for Certified Genetic Counselors: Stakeholder Interview Findings

In reviewing the transcripts from the 18 stakeholder interviews conducted in March 2016, we find conflicting understandings of the concept of ‘demand’ for certified genetic counselors, which may provide some insight into the current shortage and expected future shortage of certified genetic counselors. Nearly all direct patient care certified genetic counselors we interviewed reported increases in patient volume in recent years, which, for some, translated into longer patient wait times for appointments. From the perspective of these providers and their patients, this increased demand for services feels like a growing shortage of genetic counselors.

¹⁴ NextGxDx, Inc. The current landscape of genetic testing: Market size, market growth, and the practical challenges of the clinical workflow. March 1, 2016. Available online at: <https://www.nextgdx.com/insights>.

¹⁵ McKinsey & Company. The outlook for personalized medicine – the path forward. 2013. Available online at: http://www.mckinsey.com/~media/mckinsey/dotcom/client_service/pharma%20and%20medical%20products/pmp%20new/pdfs/mckinsey%20on%20personalized%20medicine%20march%202013.ashx.

¹⁶ National Society of Genetic Counselors. 2016 Professional Status Survey: Work environment.

¹⁷ National Society of Genetic Counselors analysis of *Job Connection* job postings between June 2013 and June 2016.

¹⁸ National Society of Genetic Counselors. Workforce Working Group Memo – Genetic counselor Workforce demand projection. June 20, 2016.

¹⁹ Ibid.

Demand Model for Direct Patient Care Certified Genetic Counselors

On the other hand, these and other interviewees also observed more certified genetic counselors leaving patient care for what, today, are sometimes higher-paying industry positions, a phenomenon also observed in data reported in the last three NSGC Professional Status Surveys. The number of vacant direct patient care positions has also increased according to Job Connection data provided by NSGC. Reportedly, the increase in the number of open positions in direct patient care, combined with a flow of certified genetic counselors into industry positions is resulting in difficulty filling direct patient care positions with the existing supply of certified genetic counselors. According to survey reports, the percentage of certified genetic counselors who identified their primary employment setting as ‘clinical’ (versus ‘non-clinical’) decreased from 84% to 65% between 2012 and 2016.²⁰

Thus, while genetic counselors who are currently active in a direct patient care role may perceive a growth in demand for genetic counselor services, we hypothesize that many of the healthcare systems and clinical practices that employ these providers may not view it the same way. If, for example, a hospital is unwilling to compete with industry salaries at this time, or if genetic counseling services generate inadequate revenue, then the hospital may not hire more genetic counselors and the perceived shortage will not translate into actual demand. It is important to note, however, that this dynamic and our interpretation of it does not obviate the possibility of a serious shortage of patient-facing certified genetic counselors; indeed, from the perspective of a patient trying to access a certified genetic counselor, there is a potentially significant growing shortage of providers.

Additionally, some organizations’ inability to retain genetic counselors and to fill vacancies in a timely manner is likely a consequence of current reimbursement structures. However, there are emerging trends in coverage and reimbursement that are favorable to direct patient care demands. For example, the Affordable Care Act requires Marketplace Health Plans to provide genetic counseling as a preventive service when testing for the BRCA gene. That said, there is salary competition from industry in the short-run, and many industry positions are not in direct patient care. Although certified genetic counselors can bill certain counseling services under Medicare incident to a supervising provider with independent billing status, several interviewees noted that many genetic counselors’ salaries are heavily subsidized by the employing institution – usually an academic medical center – as the revenue generated from genetic counseling services often falls short of costs. State licensure of certified genetic counselors allows independent practice and this may further improve the reimbursement landscape.

²⁰ Liberman, S. et al. To Be a Clinical or Non-Clinical Genetic Counselor, That is the Question. Abstract submitted to the 2016 NSGC Annual Education Conference. Seattle, Washington. September, 2016

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This relative balance may be changing as health plans continue to evaluate their payments and policies for genetic counseling services, as demonstrated in updated HRSA guidelines, released by HHS in 2011, which better facilitate access to breast cancer screenings. Furthermore, some health plans have enacted policies requiring genetic counseling prior to authorizing coverage of genetic tests. For example, Cigna required counseling for BRCA, colorectal cancer syndromes, and Long QT syndrome; beginning July 15th, 2016, they will also require counseling for all cancer and cardiac testing as well as whole exome sequencing, hereditary cardiomyopathies, and microarray analysis for pediatric cases.²¹

Increasing the productivity of certified genetic counselors could alleviate some unmet patient demand and hospital costs. According to the 2016 NSGC PSS,²² the mean caseload of a patient-facing certified genetic counselor was approximately 36 patient visits per month. Several interviewees noted that improving genetic counselor productivity was needed and possible, yet cautioned that significant productivity gains were unlikely due to the inherently time-intensive nature of providing genetic counseling services.

To enhance the overall productivity of certified genetic counselors, some interviewees were open – others were not – to having other providers manage and/or triage less complicated patients, thereby allowing genetic counselors to focus on more complicated cases- referred to as the “substitution effect.” This arrangement, which currently is taking place (although not in a consistent and purposeful way), could conceivably alleviate some genetic counseling patient access issues in some communities by increasing the size of the effective workforce. Similarly, interviewees noted that educating physician specialties about genetic tests and when to refer patients to certified genetic counselors could present an opportunity to improve patient access. These efforts also appear to be reflected in the recent NSGC PSS survey data, which show a large majority of respondents dedicating time to teaching and educational activities designed to inform other healthcare professionals of various available genetic services.²³

²¹ Cigna Genetic Testing and Counseling Program. Available online at: <http://www.cigna.com/healthcare-professionals/resources-for-health-care-professionals/genetic-testing-and-counseling-program>.

²² National Society of Genetic Counselors. 2016 Professional Status Survey: Work environment.

²³ National Society of Genetic Counselors. 2016 Professional Status Survey: Work environment.

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Demand Projection Models: Quantifying Adequacy of Supply of Direct Patient Care Certified Genetic Counselors

While anecdotal evidence is supportive of an increased demand for certified genetic counselors, we were unable to precisely quantify a growing shortage (or excess) of U.S. certified genetic counselors using information found in either the peer-reviewed or grey literature. The literature, to our knowledge, simply does not offer a firm numerical relationship between provider supply and the demand for genetic counseling services.

Because of the uncertainty in demand factors cited above, we were unable to find information that would enable us to quantify the number of U.S. certified genetic counselors needed to meet population demand. We did find, however, that the United Kingdom's Association of Genetic Nurse and Counsellors recommends one full-time equivalent (FTE) certified genetic counselor per 100,000 population.²⁴ A similar rate of one FTE certified genetic counselor per 75,000 covered lives has, anecdotally, been attributed to a large U.S. health system. Both rates describe services provided by direct patient care certified genetic counselors.

Using these two rate scenarios – one FTE per 100,000 ('Scenario 1') and one FTE per 75,000 ('Scenario 2'), we calculated the number of direct patient care certified genetic counselors needed to meet the demand of an estimated U.S. population of 326,626,000 in 2017. Under Scenario 1, an adequate certified genetic counselor workforce would include 3,266 full-time providers in 2017, whereas under Scenario 2, 4,355 certified genetic counselors would be required.

Assuming these rates remain constant over the next 10 years, the number of certified genetic counselors needed would increase proportionately with U.S. population growth, which is expected to increase at an average annual rate of 0.8% between 2017 and 2026.²⁵

Table 4 shows the number of full-time direct patient care certified genetic counselors needed between 2017 and 2026 under Scenarios 1 and 2 for a U.S. population growing at 0.8% each year.

²⁴ National Centre for Medical Genetics. Inadequate staffing levels. Available online at: <http://www.genetics.ie/clinical/inadequate-staffing-levels/>.

²⁵ U.S. Census Bureau. 2014 National Population Projections. U.S. Census Bureau: Washington, DC. Available online at: <http://www.census.gov/population/projections/data/national/2014.html>.

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Table 4: Number of Direct Patient Care Certified Genetic Counselors Needed between 2017 and 2026: Scenarios 1 and 2

	2017	2018	2019	2020	2021	2022	2023	2024	2025	2026
Per 1,000 U.S. Pop	326,626	329,256	331,884	334,503	337,109	339,698	342,267	344,814	347,335	349,826
Scenario 1: 1 FTE GC per 100k pop										
	3,266	3,293	3,319	3,345	3,371	3,397	3,423	3,448	3,473	3,498
Scenario 2: 1 FTE GC per 75k pop										
	4,355	4,390	4,425	4,460	4,495	4,529	4,564	4,598	4,631	4,664

Demand Projection Models: Estimating Future Direct Patient Care Certified Genetic Counselor Shortages

Our projected supply of certified genetic counselors with direct patient care, which currently represents approximately 65% of all certified genetic counselors, is expected to increase, on average, by 5.3% per year over the next 10 years.

In our supply model, the rate of increase for direct patient care genetic counselors is slower than the overall increase in the certified genetic counselor supply growth rate of 6.2%. This reflects historical trends that show fewer new graduates pursuing direct patient care positions. By 2026, we estimated the supply of direct patient care certified genetic counselors will increase to 3,937, or 60% of all employed certified genetic counselors expected by that year. This assumes no dramatic/extraordinary intervention on behalf of genetic counseling organizations with regard to education and advocacy; however, in discussion with the WFWG, initiatives to increase the number of graduates are likely.

When we compared the anticipated supply of direct patient care certified genetic counselors for each year between 2017 and 2026 to the number of genetic counselors demanded under Scenarios 1 and 2, we find, in 2017, a shortage of between 791 and 1,879 certified genetic counselors, respectively. Since our supply projection has the direct patient care certified genetic counselor population outpacing overall U.S. population growth (5.2 versus 0.8% per year over 10 years), overcoming provider shortages under either scenario is inevitable given a long enough projection window.

In Table 5, Scenario 1 shows that between 2023 and 2024 the number of direct patient care certified genetic counselors would satisfy a one FTE per 100,000 population demand. Scenario 2 shows a consistent provider shortage through 2026, with 727 certified genetic counselors still needed that year. Indeed, under Scenario 2, shortages would persist at the one per 75,000 ratio until between 2029 and 2030. These models

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suggest that the projected direct patient care certified genetic counselor supply would not catch-up with demand until 2024, under Scenario 1, or 2030, under Scenario 2.

Table 5: Expected Shortage of Direct Patient Care Certified Genetic Counselors under Scenarios 1 and 2.

	2017	2018	2019	2020	2021	2022	2023	2024	2025	2026
Shortage at 1 genetic counselor per 100k pop (Scenario 1)	(791)	(704)	(590)	(454)	(313)	(169)	(23)	128	281	439
Shortage at 1 genetic counselor per 75k pop (Scenario 2)	(1,879)	(1,802)	(1,696)	(1,569)	(1,437)	(1,302)	(1,163)	(1,022)	(876)	(727)

Conclusions and Recommendations

Our projections demonstrate that supply will meet demand within the 10-year period only under the assumption of one direct care certified genetic counselor per 100,000 persons; otherwise, a stricter model of one per 75,000 persons demonstrates that equilibrium will not be reached until 2029 or 2030.

In the short run, provider shortages appear to be inevitable; however, these shortages would be overcome over a long enough projection window under our “best” estimates of supply and demand growth. That said, neither of our demand models account for large-scale exogenous factors, such as the introduction of blockbuster tests and changes in commercial/public reimbursement. This uncertainty is what makes any workforce study somewhat tentative.

Estimating demand for future certified genetic counseling services is particularly challenging in the current, rapidly changing healthcare environment. For example, if barriers to certified genetic counselor coverage and reimbursement fall or the uptake of genomics in medicine rises quickly over the next decade, we would expect both estimates modeled under Scenarios 1 and 2 to underrepresent the effective demand that could arise from any single factor.

On the other hand, new policies that restrict reimbursement to direct patient care certified genetic counselors who are not affiliated with a commercial laboratory would likely reduce the effective demand for care, while at the same time reducing the ability of providers to meet patient need.

Given the extant uncertainty, demand growth – and the factors contributing to said growth – should be closely monitored so as to provide for supply growth commensurate with increased demand pressures. This is especially important for training programs and

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the advocacy and policy activities of certified genetic counselor organizations and certification bodies.

At the opposite extreme, the profession should closely monitor factors that may undercut the demand for certified genetic counselors, such as the substitution effect (i.e., use of non-certified genetics professionals to meet patient need). Restrictions on payer coverage and application of value-based purchasing policies to genetic and genomic services, wherein every dollar spent is examined for comparative clinical and economic value should also be monitored.

Under such arrangements, the rate of growth of healthcare expenditures could be curtailed by eliminating services and procedures that have not been proven to be clinically efficacious. Efforts to improve coverage and payment must be continued if patient need is to be met. Likewise, value-based purchasing could increase the demand for patient-facing care if managers in organizations involved in value-based payment schemes believe that certified genetic counselors can reduce population health expenditures. Thus, while the future of technology is uncertain, many factors that influence the demand for certified genetic counselors might be influenced such that need is more adequately served in coming years.