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GENETIC COUNSELOR WORKFORCE TRENDS
IN THE UNITED STATES: 2002 TO 2016

by

Charlene J. Schulz

A Dissertation
Submitted to the University at Albany, State University of New York
In Partial Fulfillment of
the Requirements for the Degree of
Doctor of Public Health

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Department of Health Policy, Management, and Behavior

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GENETIC COUNSELOR WORKFORCE TRENDS

IN THE UNITED STATES: 2002 TO 2016

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ABSTRACT

The purpose of this study was to identify and measure trends in genetic counselor (GC) workforce supply in the United States from 2002 to 2016. Using data collected biennially from the National Society of Genetic Counselors’ Professional Status Survey (PSS), I calculated overall percent change in GC employment across specific work settings over the past 14 years. I also measured change in the relative percentage of GCs who provide direct patient counseling (i.e. clinical GCs) to determine if the percentage of clinical GCs decreased over time. Analyses were performed to determine if associations existed between GC work settings and 1) percentage of clinical GCs employed by those work settings, and 2) average number of new patient visits per week.

For several years, investigators have suggested that shortages of clinical GCs exist and that GC shortages could worsen, given increasing demand for genetic counseling and testing services. However, studies quantifying GC supply and demand are limited, and both must be measured and compared to confirm GC shortages. The goal of this study was to focus on measuring change in GC supply across work settings over time, and its impact on direct patient counseling.

From this study’s results, I confirmed that there was a decrease in the percentage of GCs employed by University Medical Centers (UMCs), and an increase in GCs employed by Diagnostic Laboratories (DLs) from 2002 to 2016. I also showed that a greater percentage of GCs employed at UMCs counsel patients than GCs employed by DLs. An increase in DL GCs and a decrease in UMC GCs was temporally associated with a decrease in the percentage of clinical GCs. Although a significantly smaller percentage of DL GCs counseled patients than UMC GCs, clinical DL GCs, on average, counseled significantly more new patients per week.
than clinical UMC GCs. Evidence drawn from this study can help inform strategies to redistribute GC employment across specific work settings in order to increase the percentage of clinical GCs and increase the number of patients receiving genetic counseling services.
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Chapter 1: Genetic Counselor Workforce Research

Statement of the Problem

There is a paucity of peer-reviewed, published research analyzing the Genetic Counselor (GC) workforce in the United States. Only one comprehensive GC workforce report has been made available to the public through a Health Resources and Services Administration (HRSA) project completed in 2000 (Cooksey, 2000). This report was released four years prior to the mapping of the human genome. Sixteen years later, the number of genetic tests clinically available to the public has increased fiftyfold (GeneTests, 2017).

Medical societies recommend that patients who are considering genetic testing receive pre-test genetic counseling to help patients determine whether they want testing, and if so, to increase their ability to provide informed consent. Medical societies also recommend post-test genetic counseling to improve a patient’s understanding and utilization of test results (ACMGG, 2017; ASCO, 2017; ASHG, 2014; NSGC, 2017; Vogel & Weissman, 2012). According to the literature, pre-test and post-test genetic counseling, provided by GCs, increases the efficiency and effectiveness of genetic testing (Bennett, Hampel, Mandell, & Marks, 2003; Bernhardt, Biesecker, & Mastromarino, 2000; Dent, Harper, Kearney, Lieber, & Finucane, 2011; Facio, Lee, & O’Daniel, 2014; Ingles, Yeates, & Semsarian, 2011; Mester, Schreiber, & Moran, 2012; O’Daniel, 2010; Powell, Hasegawa, & McWalter, 2010; Raphael, Verma, Hewitt, & Eisen, 2016). However, past reports suggest that the supply of GCs is not meeting demand for genetic counseling services (Bookman, 2016a; 2016b; Cohen & Tucker, 2016; Cohen, Tucker, & Delk, 2016; Holtzman, 1999; Motulsky, Holtzman, Fullarton, & Andrews, 1994; Rosenthal, 2017; Walker, Scott, Biesecker, Conover, Blake, & Djurdjnovic, 1990; Wallace, 2014; Professional Issues Panel, 2016). For the past 16 years, a variety of sources, from governmental agencies to
lay press articles, have claimed that there are shortages of GCs in the United States (Bookman, 2016a; 2016b; Holtzman, 1999; Motulsky et al., 1994; Rosenthal, 2017; Walker et al., 1990). These claims have been based largely on anecdotal evidence and fail to quantify GC supply and demand. Although the absolute number of GCs has more than doubled from 2000 to 2016, preliminary evidence from the National Society of Genetic Counselors (NSGC) Professional Status Survey (PSS) indicates that the percentage of GCs who provide direct patient counseling has decreased. GCs who provide direct patient counseling are defined as clinical GCs whereas GCs who do not counsel patients are defined as non-clinical GCs. Readers can request PSS executive summaries and reports from the NSGC at nsgc@nsgc.org.

All GCs who graduate from an accredited GC training program are trained to provide genetic counseling services to patients (ACGC, 2014). However, evidence from the National Society of Genetic Counselor’s job exchange reveals that not all GC work settings require GCs to counsel patients (jobconnection.nsgc.org). Certain GC work settings appear to be associated with a greater proportion of clinical GCs than others. A GC’s work setting is defined as the place or institution where a GC is employed. Common GC work settings include University Medical Centers, Public Hospitals, and Diagnostic Genetic Testing Laboratories. Changes in GC work setting distribution could lead to changes in the supply of clinical GCs, which could impact the number of patients receiving genetic counseling services.

**Study Goal**

The goal of this study was to perform a descriptive analysis of GC workforce supply from 2002 to 2016 in the United States. More specifically, the purpose of this research was to analyze trends in GC employment across work settings, as well as trends in the relative percentage of clinical GCs.
**Study Importance**

This research is important because it provides evidence regarding the supply of GCs in the United States. This study is especially relevant today because evidence shows that the demand for genetic testing is rising (Aronson, & Rehm, 2015; Borry, Cornel, & Howard, 2001; Caminiti et al., 2015; Diab, Chintalacheruvu, & Lynch, 2016; Hartzler et al., 2013; O’Daniel, 2010; Pant, Weiner, & Marton, 2014; Roberts, & Ostergren, 2013; Schoen, Santolaya-Forgas, Genc, & Ashkinadze, 2015; Selkirk, Weissman, Anderson, & Hulick, 2013; Wang & Watts, 2007; Wilde, Meiser, Mitchell, Hadzi-Pavlovic, & Schofield, 2011). However, there may be too few GCs available to counsel patients due to change in GC work setting employment.

Since 2000, the human genome project was completed, and the Obama administration launched the Precision Medicine Initiative, allocating federal funding to increase the number of U.S. citizens receiving genetic testing (The White House, 2015). Formation of direct-to-consumer genetic testing laboratories, such as 23 and Me provide further evidence that consumer demand for genetic testing is rising (Park, 2015). According to Kotzera et al. (2014), the utilization of genetic testing has increased more than tenfold since 2000. Therefore, results from this study could provide evidence to inform interventions to re-distribute GCs by work setting in order to increase the relative proportion of clinical GCs, and in turn increase the number of patients receiving genetic counseling services. Increasing access to genetic counseling services could, in turn, lead to improved patient outcomes.
Chapter 2: Background and Literature Review

Fundamental Health Workforce Constructs

Health workforce research is important because it informs opportunities to improve access to high quality, cost effective health care. For example, health workforce research informs decision making for: 1) stakeholders, regarding health care worker supply, training, credentialing and continuing education; 2) policy makers, regarding health care funding and regulation; 3) educational planners, regarding program offerings and curricula; 4) students and new graduates, regarding career choices; and 5) employers, regarding employee recruitment and retention (HWTAC, 2016).

According to the HRSA’s State Health Workforce Data Resource Guide (U.S. DHHS, 2000), key concepts involved in measuring a health workforce include the following: 1) Supply: the number of providers working or available to work; 2) Demand: the number and mix of providers required to meet a population’s expected utilization of healthcare services and the willingness of employers to hire workers; 3) Need: the ideal number of providers to deliver health services to a geographic area or to a specific population; and 4) Requirements for personnel: the skills health care providers require to achieve appropriate health care for a geographic area or population (U.S. DHHS, 2000). This study focused on measuring elements of GC supply.

Health Workforce Supply

Studying health workforce supply is often the first step in health workforce research. According to Benjamin, Gunderson, Lemieux, and Riddell (2007), labor supply includes elements of both quantity and quality. Labor supply quantity elements involve number of workers and number of hours worked, including overtime, part-time work, work sharing and
flexible work time arrangements. Labor supply quality elements include worker education and training and the health of workers, themselves. Workforce demographics such as age, gender, race/ethnicity, and socioeconomic status can also impact labor supply quantity and quality (HWTAC, 2016). This study focused on analyzing change in GC labor supply quantity rather than quality.

McPake et al. (2013) supported the premise that health care delivery is highly labor-intensive. To be effective, a health care system must have the right number and mix of health-care workers, and the health care workers must possess the means and motivation to skillfully perform the functions they are assigned. According to McPake et al. (2013) many countries are currently facing a crisis in human resources for health that involves three dimensions: a) availability, which relates to the supply of qualified health workers; b) distribution, which relates to the recruitment and retention of health workers where their presence is most needed; and c) performance, which relates to health worker productivity and to the quality of care that health workers provide (McPake et al., 2013).

The current study analyzed GC workforce supply trends over time, involving a) availability, in regard to the percentage of clinical GCs; b) distribution, in regard to the percentage of GC’s employed across work settings; and c) performance as it relates to the number of patient visits performed by clinical GCs in specific work settings.

**Health Workforce Shortages, Surpluses and Maldistributions**

According to Boulton et al. (2014), a shortage or surplus of health care providers represents an imbalance between supply and demand. In a shortage situation, there are insufficient health care providers to meet demand for health care services. Shortages can decrease access to services, often through longer wait times to receive care, or by providers not
accepting new patients. This often encourages educational institutions to expand their program offerings in order to produce more health care providers. If supply of providers exceeds demand, a surplus situation can result in which case graduates cannot find jobs. Surpluses can also lead to unnecessary and ineffective provision of services. The goal of health workforce planning is to achieve equilibrium, in other words, a better balance between workforce supply and demand (Boulton et al., 2014).

A health workforce maldistribution is defined as an inappropriate apportionment of health care workers covering a particular geographical area, or covering a particular patient population (Heinrich, 2001). According to analyses by the Agency for Healthcare Research and Quality (AHRQ), a shortage of primary care health professionals is as much a problem of distribution as it is of workforce supply (Heinrich, 2001). Petterson et al. (2012) stated that unlike many Western nations, the United States does not actively regulate the number, type, or geographic distribution of its health workforce. As a result, health care professionals choose where they work. Therefore, the distribution of the health workforce in the United States relies heavily on market forces. When market forces alone cannot produce a well-distributed health workforce, policy is introduced to improve distribution and increase patient access (Petterson et al., 2012). For example, roughly 19% of the U.S. population lives in rural America; however, only 11% of physicians practice in rural locations (Rosenblatt, Chen, Lishner, & Doescher, 2010). To help alleviate this maldistribution of physicians, federally funded programs such as the National Health Service Corps (NHSC) provide scholarship and loan repayment programs to physicians and other primary care providers willing to practice in underserved, rural areas (HRSA, 2017). In theory, a well-distributed health workforce can increase patient access to services, which can improve patient health outcomes (Grobler et al., 2009).
Given the importance of health, workforce distribution on patient access, and outcomes (Grobler et al., 2009; HRSA, 2017; Petterson et al., 2012; Rosenblatt et al., 2010), this study focused on measuring one form of GC distribution, specifically GC employment distribution across work settings.

**Genetic Counselor Value and Justification for Genetic Counselor Workforce Research**

GCs receive specialized graduate degrees in clinical genetics and counseling, and are trained to help individuals and families understand and adapt to the medical, psychological, and familial implications of genetic disease (NSGC, 2017). GCs provide education about disease inheritance, genetic testing, medical management options, disease prevention, patient resources, and research. Informed choices and adaptation to disease and disease risk are promoted by GCs (NSGC, 2017). The National Society of Genetic Counselors (NSGC) supports the GC profession. The society provides a professional network, publishes a professional journal, develops practice guidelines, provides a code of ethics, hosts an annual education conference, and supports a variety of continuing education activities. The Society’s vision is to “integrate genetics and genomics to improve health for all,” and its mission is to “advance the various roles of genetic counselors in health care by fostering education, research, and public policy to ensure the availability of quality genetic services” (NSGC, 2017). Today there are thirty-five accredited, Master’s-level, GC training programs in the United States and Canada (ACGC, 2014). The Accreditation Council for Genetic Counseling (ACGC) is the official body responsible for accrediting genetic counseling training programs. The ACGC website defines and provides information regarding standards for program accreditation and practice-based competencies for GCs. Genetic counseling training curriculum and maintenance of competency for providers must support the development of competencies in the following domains: 1) genetics expertise
and analysis; 2) interpersonal, psychosocial and counseling skills; 3) education; and 4) professional development and practice (ACGC, 2014).

An important graduation requirement of GC students is to accumulate a minimum of 50 core cases. Core cases are defined as documented genetic counseling visits with patients under supervision where the GC student has had significant participation. The 50 core cases must come from a wide variety of clinical settings and service delivery models, reflecting the students’ diverse clinical involvement (ACGC, 2014).

Graduation from an ACGC accredited GC training program allows the graduate to apply and sit for the American Board of Genetic Counselors (ABGC) examination. The ABGC credential, Certified Genetic Counselor (CGC©), recognizes individuals who have met established standards for graduate training and clinical experience, successfully completed a comprehensive genetic counseling examination, and maintain their knowledge and skills by accumulating continuing educational units (CEUs) to obtain recertification every 5 years (ABGC, 2014).

Beyond ABGC certification, nineteen states require that GCs be licensed to practice (NSGC, 2017). In states lacking GC licensure, any person can legally call himself or herself a GC, and engage in genetic counseling. Evidence reveals that GC employers, including University Medical Centers and Private and Public Hospitals, recognize the importance of ABGC certification, and are unlikely to hire an individual for a GC position unless the applicant is ABGC board-certified or eligible (ABGC, 2014). However, with increasing public demand for genetic testing, there is concern that GC roles may be filled by unqualified applicants (Professional Issues Panel, 2016).
As previously stated, a major core competency of all thirty-five accredited GC training programs involves mastering interpersonal, psychosocial and counseling skills (ACGC, 2014). In fact, all GCs trained in the United States and Canada are trained to be clinical GCs, whether or not the GC intends to counsel patients following graduation. When GCs are evaluated for their value and impact, counseling skills are of paramount importance. Although GCs are recognized for contributions in non-clinical roles, such as administration, research, education and policy, counseling patients remains an important, if not the most important, role and attribute of a GC. (Austin & Honer, 2008; Christie et al., 2012; Ellington, Kelly, Reblin, Latimer, & Roter, 2011; Hippman et al., 2013; Kasparian, Wakefield, & Meiser, 2007; Michie, Marteau, & Bobrow, 1997; Resta, 1997; Saleem, Gofin, Ben-Neriah, & Boneh, 1998; Smyth, 2001). Therefore, research to measure the supply of clinical GCs in the workforce is justified.

Other Health Care Professionals Who Provide Genetic Counseling Services

This study focused solely on master’s-level (or higher), board-certified (or licensed) genetic counselors. However, it is important to point out that other clinicians provide genetic counseling services. Two other groups of health care professionals that are specifically trained to provide genetic counseling services include MD geneticists, and RNs with increased training in genetics, namely advance practice genetic nurses (APGN), and genetics clinical nurses (GCN) (ABMGG, 2016; ANCC 2017a, 2017b). In 2016, the overall number of MD geneticists and nurses specially trained in genetics was estimated to be less than 1,500 (ABMGG, 2015; ABMS, 2017; ISONG, 2014). Furthermore, evidence reveals that the number of MD geneticists is decreasing (Cooksey, Forte, Benkendorf, & Blitzer, 2005; Cooksey, Forte, Flanagan, Benkendorf, & Blitzer, 2006). The small numbers of MD geneticists and
specially trained nurses also raises concern that the supply of health care professionals trained in genetic counseling is not meeting demand.

Medical societies and third party payers recognize GCs, MD geneticists, and specially trained nurses as appropriately trained clinicians to provide competent genetic counseling services. However, the genetics community, medical societies, and third party payers are concerned that clinicians, who are not sufficiently trained in clinical genetics, are providing genetic counseling services (ACS, 2012; NCCN, 2014; Priori et al., 2013). Studies have indicated that a significant percentage of patients (60-75%) who receive genetic testing do not receive pre-and post-test genetic counseling, or receive substandard counseling from clinicians not trained in genetic counseling (Armstrong, 2015; Hall, 1978). When health care providers are not sufficiently trained to interpret genetic information this can lead to delayed or inaccurate diagnoses and substandard medical management (Pan, Ashar, Pothast, & Wicklund, 2016). Several researchers have revealed that genetic counseling performed by a GC produces more favorable outcomes than genetic counseling provided by clinicians, who are not specially trained in genetic counseling (Baars, Henneman, & ten Kate, 2005; Baer, Brawarsky, Murray, & Haas, 2010; Burke, & Emery, 2002; Emery, Watson, Rose, & Andermann, 1999; Howlett, Avard, & Knoppers, 2002; PEG, 2013). For example, Koscica et al. (2001) revealed that after an assessment with a prenatal GC, 38% of patients were found to have additional genetic risk factors that were not identified by OB/GYNs. According to Harvey et al. (2007), only 17% of patients who saw a provider, other than a GC, were provided written informed consent prior to receiving a genetic test. Giardiello et al. (1997) revealed that approximately 30% of physicians misinterpreted the results of genetic tests they ordered for their patients. Research from the United Health Center for Health Reform and Modernization (2012) revealed that only 28% of
physicians surveyed felt comfortable interpreting the results of genetic oncology tests and 25% the results of prenatal/newborn tests. While 83% of psychiatrists felt it was their job to discuss genetics; Finn et al. (2005) reported that less than 25% of psychiatrists felt competent doing so. Given the above evidence, increasing the supply of clinical GCs may lead to more favorable patient outcomes than encouraging clinicians, who are not trained in genetic counseling, to take on the provision of such services.

Services rendered by both clinical and non-clinical GCs can reduce healthcare costs, further justifying the need to study GC supply. For example, studies reveal that GC review of genetic test orders for appropriateness and clinical utility reduces healthcare costs to hospitals, insurers, and patients (Burns, 2014; Miller et al., 2014; Venne, 2012). Researchers at the Department of Veterans Affairs Genomic Medicine Service conducted a cursory chart review of their first 100 genetic referrals, in which testing was ordered for 19 patients by a practitioner other than a licensed genetic counselor. These tests would have cost taxpayers $109,369, and after review by a GC, $18,345 of genetic tests were determined to be medically indicated, for a cost savings of $91,024 (Venne, 2012). Priority Health, an insurer in Michigan, estimated that 30% of genetic tests were ordered incorrectly. Therefore, the health insurance company initiated a program that utilized GCs, working with patients and ordering physicians, to increase the likelihood that the most appropriate genetic tests would be ordered. This program saved an estimated $7.2 million in one year (Burns, 2014). A retrospective review of GC-facilitated test changes over a 21-month period at Associated Regional University Pathologists (ARUP) laboratories revealed an average reduction in charges to the referring institutions of $48,000 per month (Miller et al., 2014).
GCs can also save costs by offering more affordable counseling services in comparison to physicians. For example, clinical GCs charge 20-50% less than physicians for a comparable genetic counseling visit with the same diagnosis codes (Coverage and Reimbursement, 2006).

**Limited Research Regarding the Genetic Counselor Workforce**

An extensive literature review shows that there is a scarcity of peer-reviewed research investigating the GC workforce. I used multiple search engines providing the following terms: GC workforce, GC shortages, GC surplus, GC trends, GC work setting, GC distribution, GC maldistribution, GC supply, GC demand, GC access, GC need, and GC utilization. I reviewed literature from books, peer-reviewed journals, journal abstracts, legal papers, organizational reports, conference lectures, conference poster presentations and lay press articles for applicable content. Prior to the 2000 Cooksey report, only a few researchers had published articles discussing the GC workforce. Since the Cooksey report, I found two published articles: Cohen et al. (2016), and Pan et al. (2016); one conference presentation abstract by Lyman (2002); three unpublished studies: Cohen and Tucker (2016), Professional Issues Panel (2016), and Wallace (2014); and a few mass media articles: Bookman (2016a, 2016b), and Rosenthal (2007) addressing the GC workforce in the United States.

Researchers describing GC supply focused primarily on concerns about GC shortages (Bookman, 2016a, 2016b; Cohen et al., 2016; Cohen & Tucker, 2016; Cooksey, 2000; Holtzman, 1999; Lyman, 2002; Motulsky et al., 1994; Rosenthal, 2007; Walker et al., 1990; Wallace, 2014; Professional Issues Panel, 2016). For example, in an early report describing GC supply, Walker et al. (1990) focused on a concern that there was a growing person-power shortage in the provision of genetic services. Therefore, the formation of a doctoral degree in genetic counseling was not supported in 1990, chiefly due to concerns that diversion of individuals providing
genetic counseling into doctoral programs would exacerbate existing person-power shortages. Walker et al. (1990) did not provide statistical analyses to confirm GC shortages. Furthermore, Walker et al. (1990) referred to an overall GC shortage, and did not distinguish between clinical and non-clinical GCs.

Motulsky et al. (1994) described results from an Institutes of Medicine (IOM) study, and discussed concerns about the lack of adequately trained genetic health professionals. In 1994, members of the committee recommended that the number of GC graduates be maintained, and that stipends be used to attract minority students. In addition, committee members recommended development of formal continuing education programs for GCs, due to rapid development and knowledge regarding genetic testing. However, Motulsky et al. (1994) failed to provide measurements of GC supply and demand that would clearly support these recommendations.

In 1997, Holtzman authored a report that was based on a study commissioned by the Human Genome Research Working Group’s Ethical, Legal, and Social Implications (ELSI) committee. A principle concern of members of this Task Force was that the rate of increase in professionals trained and board certified in medical genetics and genetic counseling had not kept pace with the rate of increase in genetic discovery. The researchers did not quantify the rates discussed, but recommended that non-genetic health care professionals take on the responsibility of offering genetic counseling and testing services to their patients to offset the lack of genetic specialists (Holtzman, 1997).

Cooksey (2000) presented the first and only publically available comprehensive workforce study of the GC profession. The question that prompted Cooksey to perform her GC workforce study was whether there should be expansion of GC training programs to increase the supply of GCs. She analyzed data from the 1986-1998 NSGC Professional Status Survey (PSS)
to provide frequencies for GC number, distribution, composition, work setting, and professional practice. Cooksey also performed interviews with the executive director of NSGC, and directors of GC training programs to obtain information regarding GC training programs, certification, job market and GC supply and demand factors.

Cooksey (2000) stated that there were approximately 1,800 GCs in the United States and Canada in 2000. She reported that twenty-four master’s-level GC training programs graduated approximately 125 GC students per year. Cooksey used 1998 PSS data to determine that 95% of GCs were women, and 93% were Caucasian. At the time, GCs traditionally worked in prenatal and pediatric clinics. In 2000, the geographical distribution of GCs was uneven, which Cooksey attributed to training and employment locations in selected urban areas. Most GCs worked in urban, academic, medical centers and hospitals. Cooksey used 1998 PSS data to determine that the overall mean salary for a GC was $43,700. Based on discussions with GC training program directors, Cooksey used evidence regarding the GC job market to assess GC demand. Between 1998 and 2000, Cooksey stated that new GC graduates found jobs shortly before or within two to three months of graduation.

Cooksey (2000) concluded that GC supply was meeting demand, and that training programs should be maintained. However, Cooksey voiced concern that the completion of the human genome project would bring about an increased demand for genetic counseling and testing services. Therefore, she recommended that further research and monitoring be performed in the following areas: 1) demand for genetic testing; 2) demand for GC positions; and 3) output from GC training programs.

Despite Cooksey’s (2000) recommendations for further GC workforce research and monitoring, only a few GC workforce reports have been published since 2000. For example,
Lyman (2002) attempted to determine if there were too few formally trained genetic counselors to fill published job postings. Lyman was the first to quantify GC demand by measuring the number of posted employment positions for GCs. Lyman concluded that, in 2002, there was no shortage of GCs to meet GC demand, because 85% of employer respondents stated that they filled their vacant GC positions with a qualified GC applicant within a three-year, time period. However, Lyman’s analyses did not reach statistical significance, and she received a 17% response rate, on her survey, reducing the internal validity of her study. Furthermore, Lyman did not differentiate between clinical and non-clinical GCs.

Twelve years later, at an NSGC pre-conference symposium, Wallace (2014) presented his study, focusing solely on clinical GCs. He provided evidence describing the geographical distribution and density of clinical GCs in the United States. Figure 1 shows a chart revealing ten metropolitan areas (with 500,000 or more residents) with the lowest coverage of clinical GCs, based on the number of residents per clinical GC.

![Residents per Genetic Counselor](image)

*Figure 1. Ten large metropolitan areas with the smallest clinical genetic counselor supply density.*

(Courtesy of Wallace, 2014.)
Wallace (2014) also identified 10 states with the lowest clinical GC density, based on both number of residents per GC and number of square miles per GC. The states with lowest GC density included: Nevada, Arizona, Wyoming, North Dakota, Iowa, Oklahoma, Louisiana, Mississippi, Alabama, and Florida.

Wallace (2014) measured the geographical supply of clinical GCs in terms of clinical GC density, shedding light on strategies to increase recruitment of clinical GCs in certain areas of the country. Wallace has not published his findings in a peer-reviewed journal, reducing the opportunity for his study to stimulate further GC workforce research, especially by investigators outside the NSGC membership. In this study, I did not investigate GC distribution by geographical location, but rather by GC work setting.

Cohen et al. (2016) surveyed all Indiana GCs (both clinical and non-clinical) from May 1, to May 18, 2015, and ascertained GCs who had changed jobs within the past two years (between May 1, 2013 and May 1, 2015). After analyzing their results, they found a movement of GCs from clinical roles to non-clinical roles. For example, 94.4% of GCs surveyed had a clinical position, in their previous job, compared to 69.6% in their current job. Cohen et al. (2016) also indicated a movement away from university and non-university hospitals into laboratory positions and other industry jobs. More than half of GCs worked in a non-university hospital in their previous position, whereas 41.3% of GCs worked in a non-university hospital in their current position. Nearly 39% of GCs worked in a university hospital in their previous job, versus 28.3% currently. In comparison, 5.6% of GCs worked for a laboratory in their previous job, and 17.4% worked for a laboratory in their current job. Because Cohen et al. (2016) looked at a single state, the GC sample size was small (N=46), reducing internal validity of study results.
Cohen and Tucker (2016) repeated the Indiana state study on a national level, sending an e-blast survey to 4,000 GCs in the United States and Canada registered with the American Board of Genetic Counselors (ABGC) in December of 2015. Cohen and Tucker (2016) presented these findings at a national conference in October 2016. They revealed that GCs who changed jobs between December 2013 and December 2015 showed a decrease in the percentage of GCs providing direct patient counseling, and a decrease in the percentage of GCs working in hospitals/clinics when moving from previous to current jobs. Figure 2 shows that Cohen and Tucker (2016) revealed a 26.8% increase in the number of GCs working in laboratories/industry jobs when measuring GC movement from previous to current job. In their study of Indiana GCs, Cohen et al. (2016) revealed a similar increase (22.7%). In their national study, Cohen and Tucker (2016) revealed a 23.0% decrease in the number of GCs providing direct patient counseling, in comparison to a 24.8% decrease in the Indiana study. Therefore, the researchers found consistent results between their state and national studies.

Figure 2. Work setting and direct patient care frequencies of genetic counselors in previous job in comparison to current job. (Courtesy of Cohen & Tucker, 2016).
The current study differed from the national study by Cohen and Tucker (2016) in that I measured trends in GC supply in the United States over a 14 year time period, sampling all PSS eligible GC respondents. One of my aims, in this study, was to determine if associations existed between specific GC work settings and the relative proportion of clinical GCs employed by those work settings. A second aim was to determine if an association existed between GC work settings and the average number of new patient visits per week.

On September 30, 2016, representatives from the GC Workforce Working Group (WFWG) provided GC workforce findings at the most recent NSGC Annual Education Conference (AEC) in Seattle Washington (Professional Issues Panel, 2016). The WFWG is comprised of representatives from five organizations including: the National Society of Genetic Counselors (NSGC); the American Board of Genetic Counseling (ABGC); the Accreditation Council for Genetic Counseling (ACGC); the Association of Genetic Counseling Program Directors (AGCPD) and the American Society of Human Genetics (ASHG). Formed in 2013, representatives of the WFWG took on the task of assessing the demand for certified GCs in the United States and coordinating strategies to expand the capacity of the workforce.

In 2015, the representatives of the WFWG commissioned an independent, health-economics, consulting firm, Dobson, DaVanzo & Associates, to perform a GC workforce study. Dobson and colleagues (2016) conducted a supply and demand projection study of U.S.-based, certified, GCs focusing on GCs providing direct patient care. They finalized the report in September of 2016, and made a copy of the report available to the NSGC membership online. Readers may request a copy of the Dobson, DaVanzo & Associates report from the NSGC at nsgc@nsgc.org. Dobson and colleagues used two scenarios to determine if a shortage of certified, clinical GCs existed, and how long it may take to reach supply to demand equilibrium.
Scenario #1 assumed that a supply-to-demand ratio of one full-time equivalent (FTE), certified, clinical GC per 100,000 population was appropriate. This ratio was based on a recommendation made by the United Kingdom’s Association of Genetic Nurse and Counselors (NCMG, 2003). Scenario #2 involved a stricter supply-to-demand ratio of one FTE certified, clinical GC per 75,000 population. Considering Scenario #1 and using a 2017 estimated U.S. population of 326,626,000, they calculated that in 2017, there would be a shortage of 791 clinical GCs. Considering Scenario #2, there would be a shortage of 1,879 clinical GCs in 2017. They outlined specific assumptions, in the report in order to calculate the rate of new entrants into the GC profession, as well as the attrition rate. They estimated that the board-certified, clinical GC workforce would grow 5.3% per year over the next 10 years, while the US population would grow 0.8%. Therefore, using Scenario #1, they projected that between years 2023 and 2024 (in 6-7 years), clinical GC supply would meet clinical GC demand. Using scenario #2, they estimated that between years 2029 and 2030 (in 12-13 years) clinical GC supply to demand equilibrium would be reached.

The Dobson, DaVanzo & Associates report commissioned by the WFWG, provided the first quantification and comparison of clinical GC supply-to-demand, including an annual rate of clinical GC increase with dates of projected supply-to-demand equilibrium. Findings, from the current study, add evidence to Dobson, DaVanzo & Associates’ (2016) report and may help inform the WFWG about further research directions and strategies to increase clinical GC supply over the next six to thirteen years.

**Evidence Indicating an Increase in Genetic Counselor Demand**

In the present study, I did not measure GC demand, however, evidence indicating an increasing demand for clinical GCs justified the need to study clinical GC supply. The following
studies suggest an increase in GC demand, but fall short of clear measurements and do not consistently distinguish between demand for clinical versus non-clinical GCs (Aronson, & Rehm, 2015; Borry et al., 2001; Caminiti et al., 2015; Diab et al., 2016; Hartzeler et al., 2016; Kotzera, 2014; Park, 2015; Pant et al., 2014; Roberts, & Ostergren, 2013; Schoen et al., 2015; Selkirk, et al., 2013; Wang & Watts, 2007; Wilde et al., 2011; The White House, 2015). For example, an analysis of GC job postings, on the NSGC website, revealed that job postings doubled from 2013 to 2014 (Cohen & Tucker, 2016). However, the researchers did not distinguish between clinical and non-clinical positions. According to the U.S. Bureau of Labor Statistics (2015), employment of all GCs is projected to grow 29% from 2014 to 2024 (see Figure 3). This growth is significantly faster than the average growth for all occupations, as well as other healthcare practitioners and technical occupations (U.S. BLS, 2015). Again, this report fails to distinguish between clinical and non-clinical GCs. In their report, Dobson and colleagues (2016) projected that the employment of both clinical and non-clinical certified GCs will grow at a compound annual growth rate (CAGR) of 6.2%, from 3,814 to 6,562 GCs between 2017 and 2026. According to Dobson and colleagues (2016), this represents an overall 72% GC employment growth projection, which is more than two-and-a-half times the Bureau of Labor Statistics’ 2014 to 2024 employment growth projection of 29%.

According to Pan et al. (2016), seventy-three percent of GC training program directors felt that the GC workforce was growing too slowly, and programs should actively increase the number of graduates to help meet demand. Program directors provided the following three reasons for believing that the demand for GCs was increasing. First, advances in the use of clinical genetic and genomic information were leading to an increase in the amount of technical
and specialized patient data that GCs were well suited to interpret. Second, GCs were using their skill sets more broadly, creating and filling new expanded roles, beyond traditional clinical roles.

Third, there were many areas in the country still without GC training programs or access to genetic counseling services, increasing the need for genetic counseling services (Pan, 2016). The reasons that program directors provided to increase the supply of GCs tended to focus on an increasing need for GCs rather than an increasing demand. However, Pan et al. (2016) provided evidence that the perception of GC demand was increasing.

As previously mentioned, there is considerable evidence revealing an increasing demand for genetic testing (Aronson, & Rehm, 2015; Borry et al., 2001; Caminiti et al., 2015; Diab et al., 2016; Hartzler et al., 2013; O’Daniel, 2010; Pant et al., 2014; Roberts & Ostergren, 2013; Schoen et al., 2015; Selkirk et al., 2013; Wang & Watts, 2007; Wilde et al., 2011). Genetic tests can be used as an indirect marker for clinical GC demand because patients who receive genetic

![Figure 3. Projected change in genetic counselor employment from 2014 to 2024. (U.S. Bureau of Labor Statistics, 2015).](image)
testing are also recommended to receive genetic counseling services. According to several researchers, the number of genetic and genomic tests clinically available are steadily rising. (Borry et al., 2001; Gene Tests, 2017; Gollust, Wilfond, & Hull, 2003; Roberts, & Ostergren, 2013; Su, Howard, & Borry, 2011). For example, in 2001, GeneTests listed 800 different genetic tests clinically available. In 2013, there were over 2,500 tests. Today, GeneTests lists 39,411 different genetic and genomic tests coming from 648 different testing laboratories, covering 4,044 disorders, and 4,630 genes. Mapping of the first human genome took roughly 13 years and 3 billion dollars to complete (Yirka, 2014). Today, an individual’s entire genome can be sequenced in roughly 10 days for $1,000 (Baldwin LaGrave, Openshaw, Hart, & Tvrdik, 2011). Faster genetic sequencing at lower cost is allowing more patients the opportunity to use genetic/genomic testing to impact their medical management (Park, 2015; Wang & Watts, 2007; The White House, 2015).

Patients may also benefit from genetic counseling services without pursuing genetic testing. In some cases, patients may decide against genetic testing, or a genetic test may not be available or appropriate. Nonetheless, genetic counseling may be helpful by providing patients with education, communication, and support. Therefore, genetic counseling services may be requested outside the context of genetic testing, further increasing clinical GC demand.

Recognition of GCs as the most appropriate clinician to provide genetic counseling services may increase clinical GC demand (Blacker et al., 2005; Burns, 2014; Giardiello et al., 1997; Harvey et al., 2007; Koscica et al., 2001; Miller et al., 2014; O’Daniel, 2010; Pan et al., 2016; SACGHS, 2006; UHCHRM, 2012; Venne, 2012). According to O’Daniel (2010), genome-guided preventive medicine has the potential to improve population health on an individualized level; however, access to accurate genomic information must be
assured. O’Daniel (2010) stated that GCs are poised to play a critical role in facilitating the incorporation of genomic health risks into the field of genome-guided preventive medicine given their unique expertise in genetic science, risk assessment, communication, and a patient-centered practice approach.

Several clinical societies, including the American College of Medical Genetics and Genomics (ACMGG) (2017), American Society of Clinical Oncology (ASCO) (2017), American Society of Human Genetics (ASHG) (2014), National Society of Genetic Counselors (NSGC) (2017), and the Commission on Cancer (CoC) (Vogel & Weissman, 2012) strongly recommend that pre-test genetic counseling be obtained by an appropriately trained health care provider, which includes a GC, genetic nurse specialist, MD geneticist, or MD with expertise in genetic testing. These societal recommendations may increase clinical GC demand.

Health insurance policies may also increase clinical GC demand. For example, some third party payers recognize GCs as the most suitable clinicians to provide genetic counseling services, and GCs are considered cost effective because they are less likely to over-order genetic tests in comparison to physicians (Baldwin et al., 2011; Mayo Clinic, 2010; Scacheri, Redman, Pike-Buchanan, & Steenblock, 2008). Therefore, health insurance companies, such as Cigna, require that their clients receive genetic counseling by a clinical GC (or other genetic specialist) in order to receive reimbursement for a genetic test (Cigna.com, 2017).

Diagnostic Laboratories (DLs) contribute to the demand for genetic testing by advertising and marketing their tests to providers and the public (Borry et al., 2001; Gollust et al., 2003; Roberts, & Ostergren, 2013; Su et al., 2011). This marketing may also lead to
an increased demand for clinical GCs (Bookman, 2016a, 2016b). DLs also increase demand for GCs by directly employing GCs. DLs have been hiring GCs for over 14 years, to fill both clinical and non-clinical roles (jobconnection.nsgc.org, 2016).

Although much of the above evidence fails to directly quantify clinical GC demand, it suggests that demand for clinical GCs is increasing, necessitating further research regarding clinical GC supply.
Chapter 3: Study Aims, Research Questions and Hypotheses

Study Aims

This study aimed to identify and evaluate GC workforce trends in the United States from 2002 to 2016. More specifically, the purpose of this study was to examine whether there had been a decreasing trend in the percentage of clinical GCs over the past 14 years, and whether variation in GC work setting was associated with this decrease. Furthermore, this study analyzed whether GC work setting was associated with number of patient genetic counseling visits. I used secondary data obtained from the National Society of Genetic Counselors (NSGC) biennial Professional Status Survey (PSS) from 2002 to 2016 to address the following research questions and hypotheses:

Research Questions and Associated Hypotheses

**RQ1.** How has the distribution of GCs employed across work settings changed from 2002 to 2016?

\[H_{1A}\]. There has been an increase in the percentage of GCs employed by Diagnostic Laboratories (in relation to all GCs) from 2002 to 2016

\[H_{1B}\]. There has been a decrease in the percentage of GCs employed by University Medical Centers (in relation to all GCs) from 2002 to 2016

**RQ2.** How has the proportion of GCs who counsel patients (i.e. clinical GCs) changed from 2002 to 2016?

\[H_{2}\]. There has been a decrease in the percentage of clinical GCs (in relation to all GCs) from 2002 to 2016.
RQ3. Does GC work setting affect direct patient counseling?

*H3_A.* A significantly greater percentage of GCs employed by University Medical Centers counsel patients (i.e. are clinical GCs) than GCs employed by Diagnostic Laboratories.

*H3_B.* A significantly greater average number of new patient visits, per week, are performed by GCs employed by University Medical Centers than GCs employed by Diagnostic Laboratories.

**Justification of Hypotheses**

**Research Question 1, Hypothesis 1A: Rationale.** According to a NSGC report of GC trends (2016), DLs ranked last in GC employment out of eight possible work settings in the 1990s. The 2016 PSS shows that DLs now rank second in GC employment, behind University Medical Centers (UMCs) (2016). State and national studies by Cohen and colleagues showed an increase in GCs moving from hospital-based jobs to laboratory-based jobs (Cohen et al., 2016; Cohen and Tucker, 2016). Given this evidence, I hypothesized that DLs would show the greatest increasing trend in overall GC employment (including both clinical and non-clinical GCs) in comparison to all other work settings.

**Research Question 1, Hypothesis 1B: Rationale.** Cohen et al. (2016) and Cohen and Tucker (2016), indicated a reduction in GC employment in University Hospital work settings from 2013 to 2015. In addition, directors of GC training programs have voiced concern that there has been a decrease in clinical GCs employed at UMCs, which has reduced their ability to increase student enrollment (Professional Issues Panel, 2016). This is because GC training programs rely on clinical GCs employed by UMCs to supervise GC students during their
required clinical practicums. Given the above evidence, I hypothesized that UMCs would show the greatest decreasing trend in GC employment over time.

**Research Question 2, Hypothesis 2: Rationale.** Representatives from the WFWG reported at the 2016 NSGC Annual Education Conference that the percentage of GCs who counsel patients was decreasing (Professional Issues Panel, 2016). It is a public health concern that the percentage of clinical GCs may be decreasing in light of evidence that more clinical GCs are needed to counsel the increasing number of patients seeking and referred for genetic/genomic testing (Aronson & Rehm, 2015; Borry et al., 2001; Caminiti et al., 2015; Diab et al., 2016; Hartzler et al., 2013; O’Daniel, 2010; Pant et al., 2014; Roberts & Ostergren, 2013; Schoen et al., 2015; Selkirk et al., 2013; Wang & Watts, 2007; Wilde et al., 2011; The White House, 2015). Cohen and Tucker (2016) and Cohen et al. (2016) revealed a movement away from clinical positions to non-clinical positions. Therefore, in this study, I hypothesized that the relative proportion of clinical GCs would reveal a decreasing trend over the past 14 years.

**Research Question 3, Hypothesis 3A: Rationale:** Anecdotal evidence suggests that a larger proportion of GCs, who work at UMCs, counsel patients than GCs employed at DLs (jobconnection.nsgc.org). UMCs have been established as a service delivery model for genetic counseling services since the rise of genetic counseling in the 1950s (Holtzman, 1999). In addition, UMCs have large referral networks and clinical faculty that attract patients with both rare and common genetic diseases, necessitating delivery of genetic counseling services.

A brief review of job postings on the NSGC website revealed that job descriptions for DL GCs less frequently include direct patient counseling than job descriptions for UMC GCs. Provider education, client services, sales, marketing, product development, research, laboratory quality control, and negotiations with third party payers are some of the non-clinical
responsibilities listed in job descriptions for DL GCs. In comparison, job requirements posted for UMC GCs frequently include direct, patient counseling (jobconnection.nsge.org).

Another suspected reason why a smaller proportion of GCs employed by DLs counsel patients is due to conflict of interest. “Conflict of interest is a situation when financial or other personal considerations have the potential to compromise or bias professional judgment and objectivity” (Responsible Conduct of Research, n.d.). Over the years, investigators have questioned the objectivity of GCs who work for DLs and counsel patients. Investigators question whether it is ethical for GCs who counsel patients, on whether to undergo genetic testing, to be paid by the companies that perform the tests (Caufield, 1998; Daley, 2016; Pollack, 2012). Insurance companies and some state regulators are questioning the relationships between clinical GCs and the testing companies (Caufield, 1998; Cigna.com, 2017; Daley, 2016; Pollack, 2012). For example, in 2016, the third party payer United Health Care no longer covered certain genetic tests ordered by GCs who worked for DLs (Pollack, 2012). Cigna has a similar policy (Cigna.com, 2017; Pollack, 2012). These policies may reduce the likelihood that DLs will employ GCs for the purpose of direct patient counseling. Therefore, I predicted that a smaller percentage of GCs employed by DLs counsel patients in comparison to GCs employed by UMCs.

Research Question 3, Hypothesis 3B: Rationale. To date, there have been no studies that report the average number of patients counseled by clinical UMC GCs versus clinical DL GCs. Therefore, it was unknown whether clinical GCs who work for UMCs counsel more or fewer patients than clinical GCs employed by DLs. Given evidence that advertisements for GC positions at UMCs focus on direct patient counseling whereas advertisements for GC positions at DLs tend to focus on other non-clinical responsibilities, I hypothesized that clinical UMC GCs
would counsel, on average, a greater number of new patient visits, per week, than clinical DL GCs.

Study Framework

Figure 4 shows the framework used to guide this study. Viewing the framework from left to right, the first text box lists six major GC work settings and ‘Other’ for which GCs have been employed over the past 14 years. This study confirmed that the six GC work settings (listed in Figure 4) showed the greatest percentages in overall GC employment from 2002 to 2016. All other GC work settings were collapsed into an ‘Other’ category. Next, this study went on to analyze trends in GC employment in each of the six major GC work settings and ‘Other’ from 2002 to 2016. GC work settings with the largest increasing and decreasing trends in GC employment were isolated. Hypothesis 1A predicted that the largest increase in GC employment would be in the DL work setting, and hypothesis 1B predicted that the largest decrease in GC employment would be in the UMC work setting.

Moving to the right, in the framework, the next analysis determined if the relative percentage of clinical GCs, across all work settings, changed over time. Hypothesis 2 predicted that the relative proportion of clinical GCs decreased from 2002 to 2016.

Moving further to the right, the next analyses determined whether or not GC work setting impacted direct patient counseling by a) measuring the percentage of clinical GCs employed by UMCs versus DLs; and b) measuring the average number of new patient visits performed per week by clinical GCs employed by UMCs versus DLs. Hypothesis 3A predicted that there was a greater percentage of clinical GCs employed by UMCs than DLs, and hypothesis 3B predicted that the average number of new patient visits performed per week was greater for UMC GCs than DL GCs.
Figure 4. Study framework

Research Question #1
Change in GC Employment?

Research Question #2
Change in Percentage of Clinical GCs?

Research Question #3
Impact on direct patient counseling?

Hypothesis #1a
GCs in DLs Increasing

Hypothesis #1b
GCs in UMCs Decreasing

Overall Percent Change

Clinical GCs

Overall Percent Change

Hypothesis #2
Clinical GCs Decreasing

Chi square analysis

Hypothesis #3a
UMCs greater % clinical GCs than DLs

T-Test

Hypothesis #3b
UMC GCs counsel more new visits than DL GCs

GCs = Genetic Counselors, DLs = Diagnostic Laboratories, UMCs = University Medical Centers
Chapter 4: Methods

Study Design

This study represented a cross-sectional study using data obtained from eight Professional Status Surveys (PSSs) administered biennially to the GC community from 2002 to 2016. PSS administrators anonymized responses from individual GCs, and therefore, it was not possible to follow changes in individual GCs over time. The GC cohort that completed each PSS changed from 2002 to 2016 as new GCs entered the field and others left. Therefore, the data obtained from each biennial PSS represented a snapshot in time for the GC workforce.

Data Source: Professional Status Survey (PSS)

The PSS survey instrument is a valid and reliable, anonymous, self-administered, emailed survey completed by GCs electronically every other year. The PSS was designed by members of the NSGC to collect data to monitor the GC profession. The PSS collects information regarding GC demographics, professional status, job description, salary and benefits, board certification, licensure and credentialing, career ladder activities, professional activities, and job satisfaction. The first PSS was administered in 1980. Since that time, PSS questions have changed and expanded in order to improve collection of relevant and measurable data as the GC profession evolved. The PSS questions used to ascertain data for this study have not changed significantly from 2002 to 2016, and any small changes are unlikely to affect the validity of study results. I will discuss specific PSS questions, variation in questions, and variation in PSS administrations, over the sampling frame later in this chapter. Readers can request PSS codebooks, executive summaries and reports from the NSGC at nsgc@nsgc.org.
The NSGC administers the PSS biennially and attempts to reach all GCs in the fifty United States, U.S. Territories and Canada. The list of eligible GCs solicited to complete the PSS is generated by combining two lists: the NSGC membership list, and the American Board of Genetic Counseling (ABGC) list of board certified and board eligible GCs. The NSGC membership list includes a small number of GCs who have not sat for the ABGC examination, and therefore are not included on the ABGC list. On the other hand, the ABGC list includes a small number of board-certified GCs who are not NSGC members, and therefore these individuals are not included on the NSGC membership list. Therefore, cross-referencing the NSGC and ABGC lists and removing duplicates represents the most exhaustive system to date to identify and solicit the total number of GCs in the United States and Canada. The NSGC and ABGC lists include email addresses for each GC, and these email addresses are used to deliver and administer the PSS. Therefore, for each year that the PSS is administered, each solicited GC receives one link to complete one PSS, preventing GCs from submitting more than one completed PSS per administration.

Both employed and non-employed GCs are solicited to complete the PSS in an effort to measure the GC unemployment rate. The PSS attempts to measure the number of GCs entering and leaving the profession by asking questions that identify new GC graduates as well as GCs who have retired or left the field temporarily or permanently. PSS data originates from both clinical and non-clinical GCs.

The 2002-2016 PSSs were administered online, with traditional paper surveys offered to GCs who requested one. Paper PSSs were rarely requested (<1%). To provide GCs with flexibility, surveyors used a dynamic, web-based, survey instrument. Survey respondents were able to answer questions in any order, review previous answers, and make corrections or
modifications, and were able to return to the survey several times to complete the instrument at their convenience.

In order to streamline the survey, the PSS changed in 2008, using skip logic and branching questions. In particular, non-clinical GCs were able to skip questions pertaining to clinical patient care. Similarly, some questions were developed that pertained only to non-clinical GCs, and therefore clinical GCs could skip them. From 2008 – 2016, surveyors added hyperlinked definitions to PSSs for specific terms used within the text. Defining these terms provided an opportunity for respondents to use the same definition to address survey questions as a method to increase accuracy and reduce variability between respondent answers.

From 2002 to 2016, the raw survey data were collected in a Structured Query Language (SQL) database by an independent contractor (Boston Information Solutions), and translated into Statistical Package for the Social Sciences (SPSS) format for analysis. Response rates varied from 71% being the highest, to 44% being the lowest, over the eight PSS administrations. See response rates for each PSS in Table 1.

Table 1. Professional Status Survey (PSS) response rates from 2002 to 2016

<table>
<thead>
<tr>
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</tr>
</thead>
<tbody>
<tr>
<td>Solicited</td>
<td>1,615</td>
<td>1,731</td>
<td>1,829</td>
<td>2,130</td>
<td>2,316</td>
<td>3,032</td>
<td>3,605</td>
<td>4,048</td>
<td>20,306</td>
</tr>
<tr>
<td>Completed</td>
<td>856</td>
<td>1,051</td>
<td>1,245</td>
<td>1,142</td>
<td>1,142</td>
<td>1,339</td>
<td>1,935</td>
<td>2,205</td>
<td>11,281</td>
</tr>
<tr>
<td>Response Rate</td>
<td>53%</td>
<td>61%</td>
<td>68%</td>
<td>71%</td>
<td>49%</td>
<td>44%</td>
<td>54%</td>
<td>54%</td>
<td>56%</td>
</tr>
</tbody>
</table>
How Bias Could Impact Study Results

Response rates from the eight PSSs were not ideal, and varied year by year. Response rates above 50% are generally considered favorable for self-administered surveys that are emailed to study participants. According to the faculty innovation center at the University of Texas in Austin, an email survey response rate of 40% is considered average, 50% is considered good, and 60% very good (Response Rates, 2017). All PSS response rates were above 40%. Nonetheless, comparing data over 14 years from eight different surveys with less than 100% response rates could lead to erroneous study results due to non-response bias. Non-response bias could exist within each PSS if GCs who responded to the PSS differed significantly from GCs who did not respond. In addition, there could be non-response bias between PSS years if GCs who did not respond to the surveys in 2002 to 2006, for example, differed significantly from GCs who did not respond to 2008 to 2016 PSSs. I reviewed data collected from the eight PSS time periods for inconsistencies. I will discuss methods to address inconsistencies later in this chapter. Analyzing data from large sample sizes can help reduce study bias. In the present study, sample sizes for analyses generally exceeded 300 respondents.

Bias was a concern when analyzing whether there was an increase in the percentage of GCs employed by diagnostic laboratories from 2002 to 2016 (Hypothesis 1A). For example, if significantly fewer GCs who worked for DLs responded to the early PSSs (i.e. 2002, 2004 and 2006) in comparison to the later PSSs (i.e. 2012, 2014, and 2016) then this non-response bias could lead to results that erroneously support Hypothesis 1A. On the other hand, if significantly more GCs who worked for UMCs completed the early PSSs in comparison to later PSSs, this bias could erroneously support a decrease in the percentage of GCs employed by UMCs from 2002 to 2016 (Hypothesis 1B). In addition, if significantly more clinical GCs completed early
PSSs in comparison to later PSSs, this bias could erroneously support a decrease in the percentage of clinical GCs from 2002 to 2016 (Hypothesis 2). Therefore, I analyzed data separately for each PSS year, and compared values from PSS to PSS to identify inconsistencies.

I used data from the 2016 PSS to support or reject Hypotheses 3A and 3B, which eliminated non-response bias between PSS years. However, non-response bias from the 2016 PSS alone could remain a factor if GCs who completed the 2016 PSS varied significantly from those who did not. Therefore, it is possible that non-response bias could lead to erroneous support of hypotheses 3A and 3B. For example, if a greater proportion of clinical UMC GCs completed the 2016 PSS than clinical DL GCs, this could erroneously support the finding that a significantly greater percentage of GCs employed by UMCs counsel patients than GCs employed by DLs (Hypothesis 3A). Likewise, if DL GCs who counsel fewer new patients completed the 2016 PSS in comparison to DL GCs who counsel greater numbers of new patients, this could lead to erroneously supporting the finding that a significantly greater average number of new patient visits, per week, are performed by clinical UMC GCs than DL GCs (Hypothesis 3B). I analyzed data obtained from 2002 to 2014 PSSs to compare earlier findings with 2016 findings and to check for obvious inconsistencies.

Response bias in this study could also produce erroneous results. Responses from GCs who completed the PSSs from 2002 to 2006 could vary systematically from responses by GCs who completed PSSs from 2008 to 2016, because responses from 2008 to 2016 PSSs may be more accurate given the use of skip logic branching questions and hyperlinked definitions. For example, if a greater frequency of GCs erroneously identified themselves as clinical GCs in the early 2002 to 2006 PSSs but more accurately identified themselves as clinical GCs from 2008 to 2016, this could lead to erroneous support of the result that there has been a decrease in the
percentage of clinical GCs over time. Therefore, clinical GC data were evaluated across the eight PSS years to identify inconsistencies.

**Study Population**

The overall study population consisted of employed, clinical and non-clinical, board-certified GCs practicing within the United States. Over the eight survey years, the PSS consistently ascertained whether a GC was employed, unemployed, or retired. I removed unemployed (N=13) and retired (N=0) GCs from the study population. Given the small number of unemployed and retired GCs that responded to the 2002 to 2016 PSSs it appears that the PSS may not adequately reach the unemployed and retired populations. However, it is also possible that retired and unemployed GCs receive the emailed PSS but feel less inclined to complete and return the survey because they are not currently employed.

PSSs also ascertained data regarding whether a GC works full-time (≥ 37.5 hours per week) or part-time (<37.5 hours per week). I included full-time and part-time GCs in the study analyses for hypotheses 1A -3A. However, I excluded part-time GCs (N=272 from 2016, and N=1,554 across all eight PSS years) from analysis for hypothesis 3B, regarding the average number of new patient visits per week. I excluded part-time GCs from analysis for hypothesis 3B in order to reduce bias between full-time and part-time GCs in regard to new visits performed per week.

PSSs consistently ascertained the geographical location of GC employment across the eight survey years. I removed GCs employed outside the fifty United States (N=686, across all eight PSS years) from the study population.

From 2002 to 2016, the PSS consistently ascertained whether a GC was ABGC board-certified. I also removed GCs who were not ABGC board-certified (N=212, across all eight PSS...
years) from the study population. The total number of excluded GCs across all eight PSS years represented 8.1% (911/11,281) of all PSS respondents. Raw counts and percentages of GCs excluded from the study from 2002 to 2016 can be found in Appendix A.

**Research Variables**

The research variables for this study included: Work Setting, Clinical Genetic Counselor, and New Patient Visits, which are summarized in Table 2.

**Work Setting**

GC work setting was defined as the institution that employs the GC. Because some GCs may be employed by more than one employer, the PSSs consistently asked GCs to provide the one work setting they considered primary. The PSS question allows the GC to select only one primary work setting option, and provides the GC with a list of work settings to choose from, as well as the option to select ‘Other’ and type in a specific response. If a GC considered himself or herself to work in more than one primary work setting simultaneously, the GC could choose only one work setting as primary for all PSSs except the 2014 PSS. In 2014, the PSS committee elected to ascertain whether GCs worked in more than one primary work setting; therefore, in 2014, GCs were allowed to select more than one. Evidence from the 2014 PSS revealed that less than 5% of GCs considered themselves as working in more than one primary work setting, simultaneously. Thus, in 2016, the PSS question reverted back to allowing only one primary work setting per GC respondent. In order to make primary work setting comparisons across all PSS years, the PSS committee reviewers selected only one work setting as primary from the 2014 PSS data, based on the work setting for which the GC worked the greatest number of hours. In summary, PSS language to ascertain the GC’s primary work setting has changed from 2002 to 2016 (see Appendix B). However, the question has remained
Table 2. Summary of Study Variables

<table>
<thead>
<tr>
<th>Variable Name</th>
<th>Variable Definition</th>
<th>Variable Ascertainment</th>
<th>Variable Options</th>
<th>Variable Type</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Work Setting</td>
<td>Institution that employs GC</td>
<td>As of 12/31/15, what was your primary work setting (in other words, what type of company are you employed by for your primary position)?</td>
<td>1. Diagnostic Laboratory (DL)</td>
<td>Categorical</td>
<td>In the 2016 PSS, there were 22 different work setting options from which the GC could select only one. DL and UMC work settings are of major focus</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>2. University Medical Center (UMC)</td>
<td></td>
<td>Previous PSSs simply asked: Do you counsel patients? Yes or no? Therefore, the 2016 PSS responses “A clinical position” and “A mixed position” will be collapsed into a “yes” category indicating a clinical CG</td>
</tr>
<tr>
<td>Clinical GC</td>
<td>GC who counsels patients</td>
<td>How would you classify/describe your current position?</td>
<td>1. Yes</td>
<td>Categorical</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Will include GCs who respond “A clinical position” and GCs who respond “A mixed position”</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>2. No</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Will include GCs who respond “A non-clinical position”</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>New Patient Visits</td>
<td>First-time genetic counseling session between clinical GC and client</td>
<td>How many counseling sessions did you have in a typical work week (as of 12/31/15)? (Please give a single number, not a range; if your weeks are variable, please do your best to come up with an average figure. Please answer numbers per week on average, not a percentage).</td>
<td>GC respondent types in a single, whole-number response for each of the categories:</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>- face-to-face visits with new clients____</td>
<td>Continuous</td>
<td>For 2012 and 2016 PSSs values provided for the following three responses will be collapsed for each GC to obtain the total average number of new patient visits per week:</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>- face-to-face visit with return clients____</td>
<td></td>
<td>- face-to-face with new clients</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>- Telephone visit with new clients____</td>
<td></td>
<td>- telephone with new clients</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>- Telephone visit with return clients____</td>
<td></td>
<td>- web-based with new clients</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>- Web-based/video with new clients____</td>
<td></td>
<td>2014 PSS data cannot be used in analysis for average number of new visits because that year collected categorical data. PSSs prior to 2012 did not ascertain new visits by type.</td>
</tr>
</tbody>
</table>
sufficiently consistent, allowing work setting responses to be compared across the 14-year time period.

GC work setting options have expanded over the years. For example, the 2002 PSS listed 15 different GC work settings as choices in comparison to the 2016 PSS, which listed 22 different work settings (see Table 3).

In the 2002 to 2006 PSSs, one work setting option included *Diagnostic Laboratory*. However, from 2008 to 2014, the PSSs further categorized *Diagnostic Laboratory* into two groups, namely *Diagnostic Laboratory-Academic* and *Diagnostic Laboratory-Commercial*. The 2016 PSS further categorized the *Diagnostic Laboratory* option into the following three groups:

1) Diagnostic Laboratory: Academic, Non-commercial,

2) Diagnostic Laboratory: Commercial, Academic,

3) Diagnostic Laboratory: Commercial, Non-academic.

I collapsed the Diagnostic Laboratory categories into one category prior to this study’s analyses so that values could be compared consistently across the 14-year, time frame (see Appendix C).

**Clinical Genetic Counselor**

Since the early PSSs, surveys have asked GCs whether or not they counsel patients. This question has changed slightly, over the eight PSS administrations. Nonetheless, all PSS respondents can be classified as either clinical or non-clinical GCs. For example, the 2016 PSS asked: *How would you classify/describe your current position? A) A clinical position, B) A non-clinical position (does not involve counseling pts), or C) A mixed position (an equal mix btw counseling and not counseling pts)*. Those who responded “A clinical position” and “A mixed
Table 3. Comparing 2002 and 2016 Professional Status Survey (PSS) work setting options and work settings selected for further analyses

<table>
<thead>
<tr>
<th>2002 PSS Options for Primary Work Setting</th>
<th>2016 PSS Options for Primary Work Settings</th>
<th>Selected Primary Work Settings for Study Analyses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bioinformatics Company/Health Advocacy Organization</td>
<td>Bioinformatics Company</td>
<td>Diagnostic Laboratory</td>
</tr>
<tr>
<td>Diagnostic Laboratory</td>
<td>Diagnostic Laboratory – Academic, Non-commercial</td>
<td>Diagnostic Laboratory</td>
</tr>
<tr>
<td></td>
<td>Diagnostic Laboratory – Commercial, Academic</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Diagnostic Laboratory – Commercial, Non-academic</td>
<td></td>
</tr>
<tr>
<td>Federal/State/County Office</td>
<td>Federal/State/County Office</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Government Organization or Agency</td>
<td></td>
</tr>
<tr>
<td>Health Maintenance Organization</td>
<td>Health Advocacy Organization</td>
<td>Health Maintenance Organization</td>
</tr>
<tr>
<td>Internet/Website Company</td>
<td>Internet/Website Company</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Marketing/Advertising Company</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Not-For-Profit Organization (not otherwise specified)</td>
<td></td>
</tr>
<tr>
<td>Outreach/Satellite/Field Clinic</td>
<td>Outreach/Satellite/Field Clinic</td>
<td></td>
</tr>
<tr>
<td>Pharmaceutical Company</td>
<td>Pharmaceutical Company</td>
<td></td>
</tr>
<tr>
<td>Physician's Private Practice</td>
<td>Physician's Private Practice</td>
<td>Physician's Private Practice</td>
</tr>
<tr>
<td>Private Practice - Self-Employed</td>
<td>Private Practice - Self-Employed</td>
<td></td>
</tr>
<tr>
<td>Private Hospital/Medical Facility</td>
<td>Private Hospital/Medical Facility</td>
<td>Private Hospital/Medical Facility</td>
</tr>
<tr>
<td>Public Hospital/Medical Facility Research</td>
<td>Public Hospital/Medical Facility Research</td>
<td>Public Hospital/Medical Facility</td>
</tr>
<tr>
<td>Development/Biotechnology Company</td>
<td>Development/Biotechnology Company</td>
<td></td>
</tr>
<tr>
<td>University Medical Center</td>
<td>University Medical Center</td>
<td>University Medical Center</td>
</tr>
<tr>
<td>University/Non-Medical Center</td>
<td>University/Non-Medical Center</td>
<td>Other (all unselected and other work settings combined)</td>
</tr>
<tr>
<td>Other (please specify)</td>
<td>Other (please specify)</td>
<td></td>
</tr>
</tbody>
</table>
position” were classified as clinical GCs. Those who responded “A non-clinical position” were classified as non-clinical GCs. See Appendix D for PSS language ascertaining whether GCs are clinical or non-clinical from 2002 to 2016.

**New Patient Visits**

PSSs have uniformly ascertained the average number of patients counseled, per week, per clinical GC, from 2002 to 2016 (see Appendix E). All PSSs from 2002 to 2016 further categorized patient visits into new versus return visits. New visits are defined as the first genetic counseling session between the patient and GC. Return visits are defined as any genetic counseling session between the patient and GC that follows the new visit, and is performed for the same genetic indication. There can be only one new patient visit between the same patient and GC, for the same genetic indication. There may be several return visits between a GC and patient for the same indication. The 2012 to 2016 PSSs asked respondents to further categorize their new and return visits by type including: face-to-face, telephone, or web-based/video visits. The 2002 to 2008 PSSs did not ask the respondent to further categorize new and return visits by type. Whereas, the 2010 PSS asked respondents to provide numbers for new and return, face-to-face visits only. To provide an example of language used to ascertained the number of patient visits, the 2016 PSS asked: *How many counseling sessions did you have in a typical work week (as of 12/31/15)? (Please give a single number, not a range. If your weeks are variable, please do your best to come up with an average figure. Please answer numbers per week on average (not a percentage), even if you are only part time (your % of primary specialty and % part time can be taken into account with the statistical analyses). If you do not counsel patients as part of your specialty, please put 0 in your response.)* This PSS question is very detailed to increase response accuracy. The 2014 PSS (unlike all other PSSs) did not ask the GC to provide a whole
continuous number for patient visits, but rather provided the following categorical options: 0 visits, 1-4 visits, 5-9 visits, 10-14 visits, 15-19 visits, 20-24 visits, 25-29 visits, and 30 or more visits per week. Since categorical and continuous data, for average number of visits could not be combined for t-test analyses, 2014 PSS data were excluded.

Data were available from the PSSs to analyze the average number of visits performed by all clinical GC across all work settings. However, to address hypothesis 3B I focused specifically on measuring the average number of new patient visits between UMCs GCs and DL GCs using 2016 PSS data. Number of new patient visits was a focus rather than return patient visits because new patient visits provide a better understanding of GC reach, or how many different patients are receiving counseling which provides a better understanding of patient access to GC services (Ensor, & Cooper, 2004; Radford, Prince, Lewis, & Pal, 2014). There may be considerable variability in regard to the average number of return patient visits between clinical GCs. For example, clinical GCs who work in certain specialty clinics, such as a pediatric clinic for children with biochemical disorders, may see the same patient several times a year. Other GCs, for example, in a prenatal setting, may rarely see return patients. Therefore, in regard to how GC work setting affects direct patient counseling, I focused on the average number of new visits per week.

Analyses

I analyzed data obtained from PSSs administered biennially from 2002 to 2016 by SPSS Version 24 to address each research question.

Genetic Counselor Work Settings

As previously stated, I collapsed the different Diagnostic Laboratory (DL) categories into one category prior to analyzing how the distribution of GCs employed across work settings
changed from 2002 to 2016 (Research Question 1). I retrieved raw counts of GCs employed by each work setting from the 2002 to 2016 PSS data and totaled the raw counts and percentages across the 14 year time period (see Table 4).

Because several GC work settings had small numbers of GCs employed across the 14 years, I decided to select GC work settings with larger numbers of GCs for further analysis.

I identified six works settings (not including ‘Other’) with a cumulative value of 300 or more employed GCs from 2002 to 2016 (see Appendix F). The six major GC work settings I selected for further analyses included: Diagnostic Laboratory, Health Maintenance Organization, Physician Private Practice, Private Hospital/Medical Facility, Public Hospital/Medical Facility, and University Medical Center. I chose the value of 300 cumulative GCs as an appropriate cut-off because there were clearly more than or fewer than 300 employed GCs within each GC work setting. In addition, I considered employment of 300 or more cumulative GCs from 2002 to 2016 to represent a substantial sample size. Furthermore, GCs employed by the six identified GC work settings represented 87% of the GC workforce from 2002 to 2016.

Next, I collapsed the 14 work settings (with less than 300 cumulative employed GCs) and the ‘Other’ category (with 319 GCs representing many different work settings with small numbers of employment) into a new, combined ‘Other’ category (see Appendix G). I did not use these 14 individual work settings, with small percentages of GC employment, for further analyses due to small numbers making identification of trends difficult.
<table>
<thead>
<tr>
<th></th>
<th></th>
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<td>N</td>
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<td>--</td>
<td>--</td>
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<td>68</td>
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<td>Federal/ State/County Office</td>
<td>6</td>
<td>16</td>
<td>19</td>
<td>10</td>
<td>7</td>
<td>4</td>
<td>7</td>
<td>9</td>
<td>78</td>
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<tr>
<td>Government Organization or Agency</td>
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<td>--</td>
<td>--</td>
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<td>24</td>
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<td>2</td>
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<td>--</td>
<td>7</td>
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<td>42</td>
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<td>--</td>
<td>--</td>
<td>--</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>--</td>
<td>2</td>
</tr>
<tr>
<td>Not-For-Profit Organization</td>
<td>--</td>
<td>--</td>
<td>--</td>
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<td>152</td>
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<td>35</td>
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<td>44</td>
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<td>78</td>
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<tr>
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<td>5</td>
<td>6</td>
<td>3</td>
<td>6</td>
<td>8</td>
<td>6</td>
<td>45</td>
</tr>
<tr>
<td>Private Hospital/Medical Facility</td>
<td>77</td>
<td>124</td>
<td>182</td>
<td>212</td>
<td>179</td>
<td>199</td>
<td>314</td>
<td>299</td>
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<td>1</td>
<td>3</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>13</td>
<td>13</td>
</tr>
<tr>
<td>Public Hospital/Medical Facility</td>
<td>31</td>
<td>43</td>
<td>83</td>
<td>123</td>
<td>107</td>
<td>165</td>
<td>244</td>
<td>286</td>
<td>1082</td>
</tr>
<tr>
<td>Research Development/Biotechnology Company</td>
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<td>4</td>
<td>7</td>
<td>7</td>
<td>6</td>
<td>5</td>
<td>21</td>
<td>15</td>
<td>69</td>
</tr>
<tr>
<td>University Medical Center</td>
<td>155</td>
<td>237</td>
<td>318</td>
<td>374</td>
<td>285</td>
<td>395</td>
<td>551</td>
<td>574</td>
<td>2889</td>
</tr>
<tr>
<td>University/Non-Medical Center</td>
<td>12</td>
<td>18</td>
<td>29</td>
<td>26</td>
<td>26</td>
<td>16</td>
<td>26</td>
<td>20</td>
<td>173</td>
</tr>
<tr>
<td>Other</td>
<td>12</td>
<td>19</td>
<td>25</td>
<td>36</td>
<td>65</td>
<td>28</td>
<td>84</td>
<td>50</td>
<td>319</td>
</tr>
<tr>
<td>Total</td>
<td>368</td>
<td>572</td>
<td>813</td>
<td>1072</td>
<td>921</td>
<td>1127</td>
<td>1729</td>
<td>1937</td>
<td>8539</td>
</tr>
</tbody>
</table>
All additional analyses on GC work settings focused on the six identified GC work settings and more specifically on the DL versus UMC work settings. I calculated change in the percentage of GC employment across each of the six GC work settings over the 14-year time period. A decrease in percent over an advancing two-year-period received a negative percent value, and an increase over an advancing two-year-period received a positive percent value. No change received a zero value. I added values for each GC work setting over the eight PSS time intervals to achieve an overall percent change.

I plotted all six work settings on a line graph with the y-axis representing the percentage of GC employment, and the x-axis representing the PSS sampling year. I evaluated the six lines on the graph to confirm increasing, decreasing and flat trends.

The work setting with the largest positive overall percent change was identified as the work setting with largest increasing trend addressing hypothesis 1A. The work setting with the largest negative overall percent change was identified as the work setting with the largest decreasing trend addressing hypothesis 1B. I plotted values for these two identified work settings together on a line graph for visual comparison.

**Clinical Versus Non-Clinical Genetic Counselors**

I performed a similar trends analysis to address how the percentage of GCs who counsel patients (i.e. clinical GCs) changed from 2002 to 2016 (Research Question 2). I determined overall change in the percentage of clinical GCs, in relation to all GCs, by calculating change in the percentage of clinical GCs for each advancing two-year-period from 2002 to 2016. I added percent change values over the eight PSS time intervals to achieve an overall percent change. A negative overall percent change indicated a decreasing trend in clinical GCs over this 14-year time period, whereas, a positive overall percent change indicated an increasing trend. This
analysis determined whether the relative percentage of clinical GCs was decreasing over time (Hypothesis 2).

I plotted the percent change values for clinical GCs from the eight PSS time periods on a line graph with percent of clinical GCs represented on the y-axis, and PSS year represented on the x-axis. This line graph provides a visual representation of change in relative percentage of clinical GCs over the 14-year time period.

**Genetic Counselor Work Setting and Impact on Direct Patient Counseling**

I performed chi square analyses and t-tests to examine the impact of specific work settings on direct patient counseling (Research Question 3). I performed a chi-Square analysis on 2016 data, specifically, to address whether a significantly greater percentage of GCs employed by UMCs counsel patients than GCs employed by DLs (Hypothesis 3A). I also performed chi-square analyses on 2002 to 2014 PSS data to determine if the same association, found in 2016, was consistent across all survey years. I cross-tabulated UMC and DL GCs with clinical versus non-clinical GCs for the eight PSS sampling years. I calculated a Pearson chi square value for each of the eight PSS time periods. I used a one-sided significance table to determine the significance of the Pearson statistic with one degree of freedom. I considered p values less than 0.05 statistically significant.

Next, I performed a t-test using 2016 data, specifically, to examine if clinical GCs employed by UMCs performed a greater number of new patient visits, per week, than clinical GCs employed by DLs (Hypothesis 3B). I performed similar t-tests using data from all other PSS years (excluding 2014) to determine if the association found in 2016 was consistent across other PSS years. Lastly, I performed t-tests to evaluate the average number of new visits by type, including: face-to-face, telephone and web-based/video visits. As previously indicated, I did not
perform $t$-tests using 2014 PSS data because the 2014 PSS provided categorical rather than continuous data.

Before I performed $t$-tests, I constructed frequency tables including all new visits from 2002 to 2016 to look for potential outliers. I found one outlier of 500 new visits per week performed by one GC respondent in the 2016 data. This value of 500 visits was considerably greater than the next greatest value of 122 new visits per week. I did not detect or remove any other potential outliers in the 2002 to 2016 PSS data.

I calculated the means, standard deviations, and standard error of the means for the average number of new visits per week for UMC and DL clinical GCs. I considered $p$ values less than 0.05 statistically significant.
Chapter 5: Results

Trends in Genetic Counselor Employment Across Work Settings

Overall percent change in GC employment across the six major work settings and ‘Other’ can be found in Table 5. Out of the six major GC work settings, Diagnostic Laboratories (DLs) have experienced the greatest overall percent increase (+16.1%) in GC employment over the past 14 years. Public Hospital/Medical Facility represented the only other work setting that experienced an overall increase in GC employment (+6.3%) from 2002 to 2016. In contrast, University Medical Centers (UMCs) experienced the greatest decrease (-13.0%) in GC employment from 2002 to 2016. Second to the UMCs, Private Hospital/Medical Facility showed the greatest decrease (-5.8%) in GC employment. Over the past 14 years, Health Maintenance Organizations and Private Physician Practices revealed very small overall decreases in GC employment, 1.8% and 0.1% respectively. The ‘Other’ category which included all work settings, other than the six major work settings, revealed an overall small decrease (-1.8%) in GC employment over the 14-year, time period (see Table 5).

Although the UMC work setting experienced the greatest decrease in GC employment over the past 14 years, it has been, and remains, the most common GC work setting. The Private Hospital/Medical Facility had been the second most common work setting for GC employment from 2002 to 2014. However, as the Private Hospital/Medical Facility experienced a moderate decrease in GC employment, the DLs experienced a substantial increase in GC employment. As a result, the DL work setting surpassed the Private Hospital/Medical Facility in GC employment by 2016. The DL now represents the second most common GC work setting. The Public Hospital/Medical Facility experienced a moderate increase in GC employment from 2002 to 2016, which closely mirrored the decrease observed in Private Hospital/Medical Facilities.
Table 5. Overall percent change in GC employment across six major work settings and ‘Other’ from 2002 to 2016

<table>
<thead>
<tr>
<th>WORK SETTINGS</th>
<th>2002 N=</th>
<th>2004 N=</th>
<th>% Δ</th>
<th>2006 N=</th>
<th>2008 N=</th>
<th>% Δ</th>
<th>2010 N=</th>
<th>2012 N=</th>
<th>% Δ</th>
<th>2014 N=</th>
<th>2016 N=</th>
<th>% Δ</th>
<th>Overall % Δ</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diagnostic Laboratory</td>
<td>368</td>
<td>572</td>
<td>6.4</td>
<td>8.8</td>
<td>2.5</td>
<td>-0.2</td>
<td>9.6</td>
<td>1.0</td>
<td>10.8</td>
<td>1.2</td>
<td>11.8</td>
<td>1.0</td>
<td>15.4</td>
</tr>
<tr>
<td>Health Maintenance Organization</td>
<td>5.2</td>
<td>5.6</td>
<td>0.3</td>
<td>4.2</td>
<td>-1.4</td>
<td>4.4</td>
<td>0.3</td>
<td>4.6</td>
<td>0.2</td>
<td>4.1</td>
<td>-0.5</td>
<td>3.2</td>
<td>-0.9</td>
</tr>
<tr>
<td>Physician's Private Practice</td>
<td>3.9</td>
<td>3.6</td>
<td>-0.3</td>
<td>4.4</td>
<td>0.8</td>
<td>6.3</td>
<td>1.9</td>
<td>4.8</td>
<td>-1.5</td>
<td>5.4</td>
<td>0.6</td>
<td>4.5</td>
<td>-0.9</td>
</tr>
<tr>
<td>Private Hospital/Medical Facility</td>
<td>21.3</td>
<td>22.3</td>
<td>1.0</td>
<td>22.9</td>
<td>0.6</td>
<td>20.0</td>
<td>-3.0</td>
<td>19.6</td>
<td>-0.4</td>
<td>17.7</td>
<td>-1.9</td>
<td>18.2</td>
<td>0.5</td>
</tr>
<tr>
<td>Public Hospital/Medical Facility</td>
<td>8.6</td>
<td>7.7</td>
<td>-0.8</td>
<td>10.5</td>
<td>2.7</td>
<td>11.6</td>
<td>1.1</td>
<td>11.7</td>
<td>0.1</td>
<td>14.7</td>
<td>3.0</td>
<td>14.2</td>
<td>-0.5</td>
</tr>
<tr>
<td>University Medical Center</td>
<td>42.8</td>
<td>42.6</td>
<td>-0.2</td>
<td>40.1</td>
<td>-2.6</td>
<td>35.2</td>
<td>-4.8</td>
<td>31.2</td>
<td>-4.0</td>
<td>35.2</td>
<td>4.0</td>
<td>32.0</td>
<td>-3.2</td>
</tr>
<tr>
<td>Other</td>
<td>11.9</td>
<td>9.4</td>
<td>-2.5</td>
<td>9.4</td>
<td>0.0</td>
<td>12.9</td>
<td>3.5</td>
<td>17.3</td>
<td>4.4</td>
<td>11.0</td>
<td>-6.2</td>
<td>12.4</td>
<td>1.4</td>
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<td>100</td>
<td>0</td>
<td>100</td>
<td>0</td>
<td>100</td>
<td>0</td>
<td>100</td>
<td>0</td>
<td>100</td>
<td>0</td>
<td>100</td>
<td>0</td>
</tr>
</tbody>
</table>
Figure 5 represents a line graph, which provides a visual representation of change in GC employment across the six major work settings from 2002 to 2016.

In 2016, Public Hospitals/Medical Facilities reached the same GC employment as Private Hospitals/Medical Facilities. GC employment in Health Maintenance Organizations and Private Physician Practices remained relatively unchanged from 2002 to 2016.

I also plotted the ‘Other’ category on a line graph, which represents many diverse work settings with low numbers of GC employment (see Appendix H). Change in GC employment in the ‘Other’ category was compared to change in the UMC and DL work settings. The ‘Other’
work settings remained fairly level across the 14 years but showed a rise in GC employment in 2010 and an overall 1.8% decrease in GC employment from 2002 to 2016.

Figure 6 provides a visual comparison of change in GC employment between UMC and DL work settings from 2002 to 2016.

![Line graph comparing change in genetic counselor employment between University Medical Centers and Diagnostic Laboratories from 2002 to 2016](image)

*Figure 6.* Line graph comparing change in genetic counselor employment between University Medical Centers and Diagnostic Laboratories from 2002 to 2016

The UMC work setting line shows a decreasing trend in GC employment from 2002 to 2010, with a small spike in GC employment in 2012 and a relatively small decrease in GC employment from 2012 to 2016. In comparison, the increase in GC employment in the DL work setting revealed a more constant and gradual increase from 2002 to 2012 with a greater increasing trend.
from 2012 to 2016. Data from Table 5 and Figures 5 and 6 provide evidence to support hypotheses $1_A$ and $1_B$.

**Trends in Relative Percent of Clinical Genetic Counselors**

Using data from all eligible GC respondents, across all work settings, Table 6 provides evidence that the relative percent of clinical GCs, across all GC work settings, decreased from 2002 to 2016. Adding the advancing two-year percent changes from 2002 to 2016 revealed an overall percent change in clinical GCs of -8.9%. The relative percentage of clinical GCs decreased from 83.4% in 2002 to 74.5% in 2016. Despite this decrease in clinical GCs from 2002 to 2016, the majority of GCs continued to counsel patients.

Figure 7 reflects this data in a line graph. This line graph reveals that the percentage of practicing clinical GCs, in the GC workforce, remained relatively constant from 2002 to 2010. From 2010 to 2012 there was a small increase in the percentage of clinical GCs. However, from 2012 to 2016 there was a substantial decrease in the percentage of practicing clinical GCs relative to previous years. Data from Table 6 and Figure 7 support hypothesis 2.

Figure 8 represents a line graph where change in clinical GCs as well as change in GC employment at DLs and UMCs are all plotted on the same graph using the same scale.
Table 6. Overall percent change in frequency of clinical genetic counselors from 2002 to 2016

<table>
<thead>
<tr>
<th>GC TYPE</th>
<th>2002</th>
<th>2004</th>
<th>% Δ</th>
<th>2006</th>
<th>% Δ</th>
<th>2008</th>
<th>% Δ</th>
<th>2010</th>
<th>% Δ</th>
<th>2012</th>
<th>% Δ</th>
<th>2014</th>
<th>% Δ</th>
<th>2016</th>
<th>% Δ</th>
<th>Overall</th>
<th>% Δ</th>
</tr>
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<tbody>
<tr>
<td>Clinical</td>
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<td>567</td>
<td></td>
<td>811</td>
<td></td>
<td>1072</td>
<td></td>
<td>907</td>
<td></td>
<td>1070</td>
<td></td>
<td>1601</td>
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<td>1853</td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Clinical</td>
<td>83.4</td>
<td>82.0</td>
<td>-1.4</td>
<td>82.2</td>
<td>0.2</td>
<td>82.7</td>
<td>0.5</td>
<td>82.6</td>
<td>-0.1</td>
<td>83.9</td>
<td>1.3</td>
<td>80.4</td>
<td>-3.5</td>
<td>74.5</td>
<td>-5.9</td>
<td>-8.9</td>
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</tr>
<tr>
<td>Non-clinical</td>
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<td>18.0</td>
<td>1.4</td>
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<td>19.6</td>
<td>3.5</td>
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<td></td>
</tr>
<tr>
<td>Total</td>
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<td>100</td>
<td>0</td>
<td>100</td>
<td>0</td>
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<td>0</td>
<td>100</td>
<td>0</td>
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<td></td>
</tr>
</tbody>
</table>
Figure 7. Line graph showing change in relative percent of clinical genetic counselors, across all work settings, from 2002 to 2016.

Figure 8. Line graph comparing change in percentage of clinical genetic counselors and change in genetic counselor employment at University Medical Centers and Diagnostic Laboratories from 2002 to 2016.
The line graph in figure 8 appears most remarkable from 2012 to 2016 showing that there was a steady decrease in the percentage of clinical GCs while, at the same time, there was a steady decrease in the percentage of UMC GCs and a steady increase in the percentage of DL GCs. This line graph shows the temporal association between the decrease in clinical GCs with the decrease in UMC GCs and increase in DL GCs.

This study focused on change in the relative percentage of clinical GCs, across all work settings, from 2002 to 2016. It also focused on change in total GC employment in UMCs and DLs over time without stratifying between clinical and non-clinical GCs. However, data obtained from the 2002 to 2016 PSSs revealed that the percentage of practicing clinical GCs within the UMC and DL work settings remained relatively constant from 2002 to 2016 (see Figure 9). Although there was considerable change in GC employment across DLs and UMCs and a considerable decrease in clinical GCs across all work settings; the percentage of practicing clinical GCs remained relatively constant across the DL and UMC work settings from 2002 to 2016.

**Associations between Work Setting and Percentage of Clinical Genetic Counselors**

Using 2016 PSS data, Table 7 provides raw counts and percentages of DL GCs and UMC GCs who counsel patients (clinical GCs) and those who do not counsel patients (non-clinical GCs). The data revealed that in 2016, 88.4% of UMC GCs counseled patients in comparison to 27.3% of DL GCs.

Chi square analysis, using the 2016 PSS data, shown in Table 7, revealed that significantly more UMC GCs counseled patients than DL GCs (p<0.001). I performed chi square analyses using data from the seven remaining PSS time periods (see Appendix 1). Results revealed that a significantly greater percentage of GCs employed by UMCs counseled patients.
than GCs employed by DLs across all eight PSS survey years with all p values less than 0.001. Therefore, these results supported Hypothesis 3_A.

**Associations between Work Setting and Average Number of New Patient Visits**

I hypothesized that a significantly greater average number of new patient visits, per week, would be seen by clinical GCs employed by UMCs than clinical GCs employed by DLs. However, after evaluating the calculated averages and t-test results using 2016 PSS data, I was not able to support hypothesis 3_B (see Table 8). I found that DL GCs performed on average significantly more new visits, per week than UMC GCs. DL GCs performed on average 19 new visits per week in comparison to UMC GCs who performed 12 new visits per week. After performing a t-test for significance, I found that these two means were significantly different (p<0.001).

![Percent Change in Clinical Genetic Counselors](chart.png)

*Figure 9. Percent change in clinical genetic counselors in University Medical Center and Diagnostic Laboratory work settings from 2002 to 2016*
Table 7. *Raw counts and percentages of genetic counselors at University Medical Centers and Diagnostic Laboratories who counsel and do not counsel patients, using 2016 PSS data, (n=950)*

<table>
<thead>
<tr>
<th>Work Setting</th>
<th>Counsels Patients&lt;sup&gt;a&lt;/sup&gt;</th>
<th>Does Not Counsel Patients&lt;sup&gt;b&lt;/sup&gt;</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>% (n)</td>
<td>% (n)</td>
</tr>
<tr>
<td>University Medical Center (UMC)</td>
<td>88.4 (490)</td>
<td>11.6 (64)</td>
</tr>
<tr>
<td>Diagnostic Laboratory (DL)</td>
<td>27.3 (108)</td>
<td>72.7 (288)</td>
</tr>
</tbody>
</table>

*Note.*
<sup>a</sup>Genetic counselors who counsel patients = clinical genetic counselors
<sup>b</sup>Genetic counselors who do not counsel patients = non-clinical genetic counselors

$\chi^2$ is significant at $p<0.001$

In order to determine if clinical DL GCs consistently counseled a greater average number of new visits over time, I used *t*-tests to analyze 2002 to 2012 PSS data. I did not analyze data from the 2014 PSS because it ascertained categorical visit data rather than continuous. Results from 2002 to 2012 revealed that clinical DL GCs consistently counseled a greater average number of new visits, per week, than clinical UMC GCs. However, these differences only reached statistical significance in 2002 ($p<0.001$), 2010 ($p=0.001$) and 2016 ($p<0.001$) (see Table 8).

I also used 2016 PSS data to analyze new visits further by type. In 2016, DL GCs saw on average significantly more new, face-to-face ($p=0.017$), new, telephone ($p<0.001$) and new, web-based/video visits ($p=0.003$) than UMC GCs (see Table 9).
Table 8. *Average number of ‘new’ visits per week seen by University Medical Center and Diagnostic Laboratory clinical genetic counselors from 2002 to 2016 (rounded to the nearest whole number)*

<table>
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<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>University Medical Center (UMC)</td>
<td>7</td>
<td>7</td>
<td>8</td>
<td>8</td>
<td>7</td>
<td>9</td>
<td>NA</td>
<td>12</td>
</tr>
<tr>
<td>Diagnostic Laboratory (DL)</td>
<td>20</td>
<td>11</td>
<td>12</td>
<td>13</td>
<td>12</td>
<td>11</td>
<td>NA</td>
<td>19</td>
</tr>
</tbody>
</table>

P-value

- <0.001*
- 0.311
- 0.481
- 0.136
- 0.001*
- 0.588
- NA
- 0.001*

NA = Not Applicable (2014 PSS data not included)

*Independent t-test is significant
I also analyzed new visits by type using 2012 PSS data. I could not use PSS data from 2002 to 2010, for this analysis, because prior to 2012, PSSs did not ascertain data regarding type of visit. I could not use 2014 PSS data because, as previously discussed, the 2014 PSS ascertained categorical data for new visits. After performing an independent \( t \)-test using 2012 PSS data, I found that DL GCs counseled, on average, more new, face-to-face, telephone, and web-base/video visits per week than UMC GCs; however, these differences only reached statistical significance for new, face-to-face visits \((p=0.003)\) (see Table 9). The results summarized in Tables 8 and 9 do not support Hypothesis 3B. 

When comparing 2012 to 2016 results, DL GCs counseled substantially more new patients by telephone in 2016 (14) than 2012 (5). In comparison, UMC GCs saw the same number of new visits by telephone in 2012 (3) and 2016 (3).

When evaluating data from the 2002 to 2016 frequency tables for new visits, per week to identify outliers, I observed that a small, but substantial, number of clinical GCs were seeing very high numbers of new patients per week in 2016. For example, after removing one outlier of 500 visits per week from 2016 PSS data, 8.2% (113/1,384) of clinical GCs across all work settings counseled, on average, 50 to 122 new patients per week in 2016 (see Appendix J). Approximately, 14% (16/115) of clinical GCs employed by DLs counseled 50 to 122 new patients per week, in comparison to 5.6% (27/486) of UMC clinical GCs. Whereas, 8.9% (70/783) of clinical GCs other than UMCs and DLs GCs counseled 50 to 122 new visits per week in 2016. In contrast, only 1.1% or less of clinical GCs, across all work settings, saw 50 or more new patients per week from 2002 to 2012.
Table 9. *Average number of ‘new’ visits per week by ‘type’ performed by University Medical Center and Diagnostic Laboratory clinical genetic counselors in 2012 and 2016 (rounded to the nearest whole number)*

<table>
<thead>
<tr>
<th>Work Setting</th>
<th>2012 Average number of new visits by type</th>
<th>2016 Average number of new visits by type</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Face-to-face</td>
<td>Telephone</td>
</tr>
<tr>
<td>University Medical Center (UMC)</td>
<td>8</td>
<td>3</td>
</tr>
<tr>
<td>Diagnostic Laboratory (DL)</td>
<td>12</td>
<td>5</td>
</tr>
<tr>
<td>P-value</td>
<td>0.003*</td>
<td>0.105</td>
</tr>
</tbody>
</table>

*Note. *ANOVA is significant
In addition, zero DL GCs counseled 50 or more new patients from 2012 to 2002 (data not shown). Therefore, counseling these very high numbers of new patients per week appear to be a recent phenomenon. It is unknown whether these high volume, 50 or more, new visits per week represent individual counseling sessions or group counseling.
Chapter 6: Discussion

Trends Observed in the Genetic Counselor Workforce

The purpose of this study was to examine the GC workforce over the past 14 years in order to identify trends in GC supply. Through the results of this study, I was able to show a temporal association between changes in GC employment in UMC and DL work settings, and a decline in the percentage of practicing clinical GCs. As GC employment decreased at UMCs and increased at DLs, the relative percentage of clinical GCs decreased. This pattern was most evident from 2012 to 2016. Although I could not prove with this cross-sectional study that the increase in DL GCs and decrease in UMC GCs caused the decrease in clinical GCs, results suggested that changes in work setting distribution may impact the proportion of GCs providing direct patient counseling. Therefore, market forces that influence the number of jobs available in certain work settings may lead to significant changes in the proportion of clinical GCs in the workforce.

PSS data revealed that the absolute number of GCs increased from approximately 1,615 to 4048 (150%) from 2002 to 2016. The absolute number of practicing clinical GCs increased roughly 125% from 1,340 in 2002 to 3,016 in 2016. One could argue that the supply of clinical GCs is equal to the supply of all GCs because all GCs who graduate from an accredited GC training program are trained to provide direct patient counseling. Therefore, to be precise, I did not conclude that the supply of clinical GCs decreased from 2002 to 2016, but rather the percentage of GCs, who practice as clinical GCs, declined from 2002 to 2016. Further research isolating factors associated with this decline may lead to more effective methods to: 1) prevent further movement from clinical to non-clinical positions; 2) influence non-clinical GCs to return
to clinical positions; 3) increase the number of new GC graduates accepting positions with clinical roles.

Change in GC employment across the six major work settings was rather gradual from 2002 to 2016 (see Figure 6). However, the decrease in UMC GCs and the increase in DL GCs was more substantial from 2012 to 2016. The percentage of practicing clinical GCs remained rather constant from 2002 to 2010, but showed a more substantial decline from 2012 to 2016. It is unknown whether something significant occurred in 2012 that caused these changes in GC supply or if these results may be erroneous due to bias. The change in the percentage of clinical GCs may be attributed to: 1) decline in UMC GCs and increase in DL GCs; 2) loss of clinical GCs in work settings other than the six major work settings studied; 3) accumulative effects of change in GC employment across several work settings; or 4) study error and not a true decline. Further research is needed to monitor and evaluate the number and percentage of practicing clinical GCs in the workforce.

This study was important because it added evidence to previous research performed by Cohen et al. (2016) and Cohen and Tucker (2016). Both the state study by Cohen et al. (2016) and the national study by Cohen and Tucker (2016) showed GC movement from clinical to non-clinical positions and GC movement towards DLs. Both the state and national studies revealed that GCs who recently changed jobs and moved from clinical to non-clinical positions sited higher salaries and opportunities for flexibility (i.e. ability to set own schedule and/or work location) as reasons for changing positions. In reference to the social ecological model (McLeroy, Steckler, & Bibeau, 1988), Cohen and Tucker (2016) and Cohen et al. (2016) focused on individual factors associated with movement from clinical to non-clinical positions. On the other hand, I focused on organizational factors, namely work setting and its association with
movement from clinical to non-clinical positions. Further research exploring factors at multiple levels will help to characterize GC employment trends.

In their state and national studies, Cohen et al. (2016) and Cohen and Tucker (2016) revealed a GC movement away from the hospital work setting. However, their studies did not distinguish between types of hospital settings, that is, whether the hospital was private, public or university-based, due to relatively small sample sizes. Similar to the Cohen et al. (2016) and Cohen and Tucker (2016) findings, I revealed that UMC and Private Hospital work settings decreased in GC employment over the past 14 years. In contrast, however, I revealed that GC employment at Public Hospitals increased. To the best of my knowledge, I was the first to provide evidence that GC employment at Public Hospitals increased over the past 14 years. Additional research should be performed to confirm this increase. Furthermore, this study provided evidence that it may be important to distinguish between hospital types when planning for clinical GC recruitment and retention.

With the results of this study, I also added evidence to concerns raised by representatives of the Work Force Working Group (WFWG). During the NSGC’s 2016 national conference, representatives of the WFWG voiced a need to increase the number of clinical GCs in the workforce. In this study, I concluded that the percentage of practicing clinical GCs has declined over the past 14 years, supporting the WFWG’s recommendation to increase the number of clinical GCs. Representatives from the WFWG also voiced concern regarding the lack of available clinical GCs at University Medical Centers to supervise GC students during their required clinical practicums. I confirmed an overall decrease in the percentage of GCs employed by UMCs over a 14-year time period, adding support to the concern of those in the WFWG. Given the increase in GC employment at Public Hospitals detected in this study, GC training
programs may benefit from investigating opportunities to establish student practicums at Public Hospitals.

Evidence from this study also adds to Cooksey’s (2000) report, filling gaps about GC supply trends between 2000 and 2016. As Cooksey predicted, the completion of the human genome project brought about an increase in genetic sequencing technology and a greater understanding of the role genetics plays in rare and common disease. With this increase in technology and awareness, there has also been an increase in the utilization of genetic testing, and thus a greater demand for genetic counselors. In 2000, Cooksey did not recommend that GC training programs increase in size or number. According to the ACGC (2014) and Dobson, DaVanzo & Associates’s report (2016) there will be approximately seven new accredited GC training programs in the next two years. Four new programs will begin in 2017, and three in 2018, with an average class size of eight students. GC workforce research is needed to determine how the addition of new training programs will impact the number and percentage of practicing clinical GCs.

**Impact on Number of New Patient Visits**

This study was important because it concluded that specific work settings impact the number of new patients seen per week by clinical GCs. From 2002 to 2016, I showed that significantly more GCs employed by UMCs provided direct patient counseling than GCs employed by DLs. Because UMCs employed a greater percentage of clinical GCs than DLs, I assumed that UMCs may support the role of counseling more than DLs, and thus hypothesized that clinical GCs, employed by UMCs, would, on average, counsel greater numbers of new patients, per week than clinical DL GCs. However, the results that I obtained did not support this hypothesis. The average number of new patient visits performed by clinical DL GCs was in
fact significantly greater than that performed by clinical UMC GCs. Clinical GCs who worked at DLs consistently counseled more new patients per week than UMC GCs across all survey years (excluding 2014). To my knowledge, I am the first investigator to report this finding.

In 2016, differences in the number of new visits between DL and UMC clinical GCs were even more significant when stratifying visits by type with DL GCs performing significantly more new visits by telephone and web-based/video visits than UMC GCs. When analyzing 2012 PSS data, DL GCs counseled more new patients by face-to-face, telephone and web-based methods than UMC GCs; however, these differences only reached statistical significance for face-to-face visits. From 2012 to 2016, DL GCs began to counsel substantially more new patients by telephone and web-based/video methods.

In this study, I did not investigate reasons why clinical DL GC counseled more new patients than clinical UMC GCs. However, if telephone and web-based/video visits are more efficient, requiring less time than face-to-face visits, then clinical DL GCs performing more telephone and web-based visits than clinical UMC GCs may explain why DL GCs were able to counsel significantly more new patients in 2016. I did not analyze differences between DL and UMC clinical GCs regarding time spent before, during, and after visits. These time spent differences could significantly impact the number of new visits performed per week per clinical GC.

One potential reason why DL GCs may counsel more new patients than UMC GCs may be due to group counseling. I did not investigate the use of group counseling in this study. However, data from the 2016 frequency table for new visits per week, revealed that 8% of clinical GCs across all work settings counseled an average of 50 to 122 new patients per week (see Appendix J). It appears unlikely that these high volume visits represented response errors.
given that from 2010 to 2016, if a PSS respondent inserted a number greater than 50, the respondent would receive a prompt asking “Are you sure you counsel X new clients…in a typical work week?” See Appendix E. Anecdotally, counseling 50 to 100 new patients a week, individually, without performing group counseling, appears high. These numbers are especially elevated in comparison to the average number of new visits seen per week, which was 19 for DL GCs and 12 for UMC GCs in 2016. Therefore, group counseling is one hypothesis to explain these high numbers of new visits per week. Results revealed that 14% of clinical DL GCs counseled 50 or greater new patients per week in comparison to 6% of clinical UMC GCs (see Appendix J). These high visit numbers could also explain why, on average, DL GCs see more new patients per week than UMC GCs. More research is needed to characterize these high volume visits per week.

In this study, I did not analyze the average number of return visits counseled between UMC and DL GCs. The average number of return visits per week performed by UMC and DL GCs could differ significantly and could impact the average number of new visits seen per week. More research is needed to define and measure both new and return visits in order to more accurately assess the number of patients counseled by the clinical GC workforce.

**Study Strengths**

An important strength of this study was that it added evidence to the paucity of available GC workforce research. Specifically, I added evidence to Cooksey’s (2000) report, to the state and national studies performed by Cohen et al. (2016) and Cohen and Tucker (2016), and to Dobson, DaVanzo & Associates’ (2016) report commissioned by the WFWG.

Another strength of this national, cross-sectional study was that it utilized data consistently collected over a 14-year time period, allowing for identification of GC workforce
trends. In comparison to the Cohen and Tucker (2016) and Cohen et al. (2016) studies that focused on job changers over a two-year period, this national study included all board-certified GCs working in the United States, yielding relatively large sample sizes, increasing study validity. Because I analyzed secondary data, this study was completed in a relatively short, time-frame and at low-cost.

I identified findings in this study not previously reported. For example, I am unaware of previous reports that showed an increase in GC employment at Public Hospitals from 2002 to 2016. Secondly, I revealed that a significantly greater percentage of GCs employed by UMCs provide direct patient counseling than GCs employed by DLs. Lastly, I revealed that clinical DL GCs perform, on average, significantly more new patient visits per week than UMC GCs. Additional studies are needed to confirm these new findings and isolate causal factors.

Study Limitations

Study Design. This study design was cross-sectional, and therefore conclusions cannot be made regarding causal relationships. I cannot conclude that an increasing trend of DL GCs and a decreasing trend of UMC GCs caused a decreasing trend in the proportion of clinical GCs. Likewise, I cannot conclude that employment at a UMC causes a GC to be a clinical GC, and cannot conclude that employment at a DL causes a GC to be a non-clinical GC.

Although I covered a 14-year time period in this study, I obtained data for study analyses from only eight sampling periods. Therefore, I did not use statistical methods such as the Mann-Kendall test for trend significance and the Theil Sen Slope for magnitude of trend to determine if the trends observed were statistically significant. I did not use data for linear regression analyses to create trend lines for each of the six work settings. Trend lines could have been used to predict future GC employment in these specific work settings. However, the purpose of this
study was not to make GC supply predictions but rather measure change over the past 14 years. In addition, trend lines could include a significant degree of error due to the small number of sampling points, in this study, and thus lead to erroneous predictions. Likewise, trend lines could have been used to forecast the percentage of clinical GCs in the future. However, such trend lines could have led to erroneous predictions. More frequent measurements of GC workforce variables, over time, would increase the number of data points available to allow for more appropriate statistical analyses, leading to more accurate workforce predictions.

**Response Bias.** I used data in this study obtained from a voluntary, self-administered survey. Therefore, my results are subject to response bias if GCs did not complete the PSSs accurately or truthfully. If response bias was systematic within a single PSS or across the eight PSS years, this bias could have led to erroneous study results. An independent third party cleaned the PSS data prior to this study’s analyses, reducing the likelihood of study error. I used frequency tables for visits per week to identify and remove potential outliers. Having relatively large GC sample sizes increased the likelihood that results from this study were valid.

**Non-Response bias.** Response rates for the 2002 to 2016 PSSs were not ideal. Response rates from the eight administered PSSs varied from 71% to 44%. Low response rates could introduce non-response bias, which could have led to erroneous study results.

**Confounding and interaction.** Another limitation of this study is that I did not use methods to test for potential confounders and/or effect modifiers. For example, when performing the chi square analysis that determined that significantly more UMC GCs counsel patients than DL GCs, variables that could have been evaluated for confounding and effect modification included 1) age of GC; 2) number of years in the field; 3) gender and; 4) GC’s home and work geographical locations. Likewise, when performing the t-tests to determine if
UMC and DL clinical GCs counseled significantly different numbers of new patients per week, potential confounders and/or effect modifiers may have included 1) GC specialty; 2) patient indication; 3) time spent before, during, and after visits; 4) number of return visits counseled per week; and 5) GC demographics such as age, years in the field, and gender. Stratifying by these variables could have identified confounding and possible errors in study results. Stratifying by these variables could have also isolated effect modifiers identifying improved methods to compare UMC GCs to DL GCs.

In this study, I collapsed diagnostic laboratory categories to consistently measure change in GC employment from 2002 to 2016. If I had stratified by these categories when analyzing the number of new visits per week, I may have received different results. For example, when using 2016 data, I could have stratified by whether or not the DL was commercial. When controlling for commercial I may have found that UMC GCs in fact counseled more new visits per week than DL GCs making my previous results incorrect. Being commercial could also be an effect modifier because commercial DL GCs may counsel a significantly different number of new patients per week than non-commercial DL GCs. I could have also stratified DLs by whether or not they were academic. It is possible that when controlling for academic I could have found that non-academic DL GCs still perform significantly more new visits per week than UMC GCs. In this case, being academic wound not be a confounder but it could still be an effect modifier if academic DL GCs counsel a significantly different number of new visits than non-academic DL GCs. However, stratifying by these variables could also reduce cell sizes making it difficult to obtain statistical significance.

**External validity.** Data for this study were gathered from GCs working in the fifty United States, therefore these results may not be generalizable to GC working in U.S. Territories
or GCs working in other countries. When evaluating a GC’s work setting, I used data that only ascertained a GC’s primary work setting. Therefore, these results may not be generalizable to GCs who are employed at more than one work setting. However, it is estimated that only 5% of GCs work in more than one work setting at a time.

When analyzing the number of new patient visits, per week, I used data from full-time GCs only. Although less than 20% of GCs across all eight PSS time periods combined worked part-time, the results from this analysis may not adequately reflect the entire GC workforce and may not be generalizable to part-time GCs.

Limiting data to only one primary work setting per GC and only full-time GCs helped to remove potential confounders increasing the internal validity of the study results. However, removing these GCs from the study reduced external validity. Lastly, the results of this study are specific to the GC profession and therefore may not be generalizable to other health care professions.

**Recommendations for Additional Research**

In the current study, I generated a number of additional research questions that warrant further investigation. Opportunities for further research are divided into three main areas: 1) Factors; 2) Definitions and Measurements; and 3) GC Supply to Demand Comparisons. Measuring patient outcomes should also be considered when performing research in the above three areas.

**Factors that impact GC work setting employment.** This study did not investigate causes for change in GC employment across the six major GC work settings. For example, what factors caused an increase in GC employment at DLs and a decrease in GC employment at UMCs? Were changes in GC employment historical in nature? Were these factors temporary or
are they likely to persist? What type of studies could isolate these factors? Will identification of these factors provide evidence to inform strategies to change the distribution of GCs across work settings?

**Factors that impact percentage of clinical genetic counselors.** Research questions regarding factors that impact the percentage of practicing clinical GCs include: What factors led to the overall decrease in practicing clinical GCs over time? What factors caused a greater percentage of clinical GCs to be employed by UMCs versus DLs? Did something significant occur in 2012 that led to the relatively substantial decline in clinical GCs? What type of studies could isolate these factors and measure their impact?

**Factors that impact number of patient visits.** Questions regarding factors that may impact the average number of patients counseled by clinical GCs include the following: Are clinical DL GCs more efficient than clinical UMC GCs? If so, how are they more efficient? Do UMC GCs have more competing duties than DL GCs that reduce time available to counsel patients? Are patient indications different between DL and UMC GCs and does this impact number of patient visits? Do DL and UMC GCs spend significantly different amounts of time during the counseling session? Do they spend different amounts of time preparing for a visit or providing follow-up? Are different patient outcomes observed between clinical GCs employed at DLs versus UMCs? Could identification of the above factors inform interventions that could increase the number of patients counseled by the clinical GC workforce?

**Improved definitions and measurements for work setting.** This study revealed significantly different trends in GC employment between private and public hospitals from 2002 to 2016. However, the validity of these results are in question if GCs were not able to accurately determine whether their hospital work setting was private or public. What clearly defines a
public hospital from a private hospital and is there overlap between UMC hospitals and public hospitals? Should researchers use other sources of data, for example records from employers, rather than self-administered surveys, when measuring the distribution of GCs across work settings?

**Improved definitions and measurements for clinical and non-clinical genetic counselors.** In this study, I grouped all eligible GCs into two categories: either clinical or non-clinical GCs. I did not further classify clinical GCs by the number of visits performed or number of hours devoted to counseling patients. More research is needed to define and measure both clinical and non-clinical GCs, and to determine how both groups directly and indirectly impact patient outcomes.

**Improved definitions and measurements for number of visits.** More research is needed to define and measure both new and return visits in order to more accurately assess the number of patients counseled. Specifically, more research is needed to define and measure the characteristics of the very high numbers of visits (≥ 50) performed per week. For example, do all these very high visits accurately represent a bona fide genetic counseling visit? How should a genetic counseling visit be defined? If these very high visits are legitimate then how are these visits performed? Are they face-to-face, by telephone, web-based, involve group counseling or by a different method? What GC work settings, specialties, and patient indications are associated with these high numbers of visits per week? Lastly, are patient outcomes different for GCs who perform high visits per week versus GCs who practice the average number of visits per week?

**Comparing genetic counselor supply to demand.** More research is needed to take the next step and compare GC supply to GC demand. In their study, Dobson, DaVanzo &
Associates, (2016) were the first to quantify both GC supply and demand, and to project future clinical GC supply needs. They stated that when using the clinical GC supply to demand ratio of one FTE clinical GC to every 75,000 population, there would be a shortage of 1,879 clinical GCs in 2017. Furthermore Dobson, DaVanzo & Associates projected that it would take approximately 12-13 years to reach clinical GC supply to demand equilibrium. Although this is a very important GC workforce finding, Dobson, DaVanzo & Associates’ study does not isolate where or why clinical GC shortages are occurring. Additional studies are needed to identify the geographical areas and patient populations where GC demand is greatest and what factors are causal for shortages. Although overall clinical GC supply-to-demand equilibrium may be reached in 12 to 13 years, GC shortages may still exist in the year 2030 in specific areas of the country, or for specific patient populations due to clinical GC maldistributions.

If clinical GC supply-to-demand equilibrium can be reached in 12-13 years, then the more immediate question is what can be done in the next decade to alleviate the clinical GC shortage? Building more new GC training programs may be helpful to alleviate clinical GC shortages; however, building too many GC training programs may cause a surplus of GCs in the more distant future. If the lack of clinical GCs is an immediate concern, then building new GC training programs may not solve the immediate shortage because it may take years before new GC training programs can become accredited and graduate GCs who are able to counsel patients. In the current study, I was able to provide evidence that re-distributing the current GC workforce by work setting may help to convert non-clinical GCs to clinical GCs, and may provide a more immediate answer to the current clinical GC shortage. For example, could recruitment and retention of GCs from non-clinical work settings to clinical work settings help alleviate the more immediate clinical GC shortage? Secondly, could strategies to increase the percentage of GCs
providing direct patient counseling at DLs help to alleviate the shortage? Lastly, more research is needed to understand the roles of both clinical and non-clinical GCs. Although there is a focus to increase the number of clinical GCs to meet patient demand and need for genetic counseling, it is possible that non-clinical GCs play a significant role in facilitating appropriate patient referrals towards genetic counseling services. Therefore, reducing the percentage of non-clinical GCs could reduce the number of patients receiving counseling from clinical GCs. Therefore, more research is needed to measure the demand and need for both clinical and non-clinical GCs and their impact on patient outcomes. Such research and continuous monitoring will help inform strategies to achieve the optimal mix of practicing clinical to non-clinical GCs.

Policy Implications

Advance genetic counselor workforce research, monitoring and dissemination of findings. Policies are needed to support GC workforce research, monitoring and dissemination of results and to help ensure that studies are initiated and completed with proper funding. According to representatives of the WFWG (Professional Issues Panel, 2016) leaders within the represented organizations are engaged in developing collaborative strategies that will address the workforce challenges in the coming months and years. The WFWG states that these strategies may involve collaboration with both public and private entities.

States, in particular, may benefit from taking an active role in GC workforce research and monitoring similar to that already performed for physicians, nurses, and other health care providers. State-based research and monitoring may identify local workforce deficiencies that may not be identified when performing large national studies. Given that states are primarily responsible for providing health care programming and funding, it may be in the states’ best
interest to perform GC workforce monitoring in order to inform strategies to maintain a balanced GC workforce for its residents.

Promote usage of Professional Status Survey (PSS) data for genetic counselor workforce analysis. The PSS is a very comprehensive survey instrument, asking over 200 questions ascertaining information regarding GC demographics, professional status, job description, salary and benefits, board certification, licensure and credentialing, career ladder activities, professional activities, and job satisfaction. Therefore, the PSS generates a wealth of data that could potentially source many more research studies. Policies by NSGC to increase the availability and utilization of PSS data by researchers, both inside and outside the NSGC membership, could lead to more research findings necessary to inform strategies to improve GC workforce equilibrium and outcomes.

Establish additional methods to collect data for genetic counselor workforce analysis. Currently, the PSS is the major instrument used to collect GC workforce data. There are few other sources available to make comparisons with PSS data to check for accuracy. Data collected by self-reported surveys may not consistently provide accurate information. Using employer human resource data from work settings or Medicare and Medicaid data may be used to confirm findings from PSSs, and may help to fill gaps in PSS data. The state licensing boards, in the 19 states currently issuing GC licenses, may consider collecting minimum data sets when issuing a new GC license and at renewal to monitor the GC workforce in their state.

Utilize strategies to increase number of patient visits by clinical genetic counselors. A major goal of the WFWG is to increase the number of board-certified clinical GCs and the number of patient visits performed by clinical GCs. Results from this study provide evidence to inform interventions to increase the percentage of clinical GCs and the number of patients
receiving genetic counseling. For example, I provided evidence that the percentage of clinical GCs could be increased by re-distributing GCs from work settings where GCs do not counsel patients to work settings where direct patient counseling plays a major role.

Another method to increase the percentage of clinical GCs would be to develop policies to enable work settings with typically high percentages of non-clinical GCs to develop and deliver clinical GC services. As previously discussed, some third party payers and state government policies have been working to limit DL GCs from counseling patients directly. Perhaps policies should promote the opposite. Given that this study showed that clinical DL GCs counsel more new patients per week on average than UMC GCs, should we consider increasing the proportion of clinical GCs at DLs rather than limiting the number? Is conflict of interest more a concern at DLs than at UMCs or other work settings? If conflict of interest could be reduced with more effective policies, across all work settings, then strategies to increase direct patient counseling at DLs and other GC work settings, with typically low percentages of clinical GCs, could be initiated.

Lastly, strategies to increase the number of patient visits performed by clinical GCs could focus on the following areas: 1) increasing the percentage of clinical GCs across all or specific work settings; 2) increasing the time devoted by clinical GCs to counsel patients; and 3) increasing GC efficiency as it relates to direct patient counseling. If policies are enacted in the three above areas, continuous GC workforce monitoring should be performed to evaluate whether such policies lead to high-quality, affordable, GC services with positive patient outcomes.
Conclusion

In conclusion, through this study I confirmed that there has been a decrease in the percentage of GCs working at UMCs, and at the same time an increase in the percentage of GCs working at DLs. These changes were temporally associated with a decrease in the percentage of clinical GCs, suggesting that changes in GC employment across work settings impact the percentage of clinical GCs in the workforce. Further research is needed to identify factors that impact 1) differences in GC employment across work settings; 2) movement of GCs from clinical to non-clinical positions; 3) number of patients counseled by clinical GCs; and 4) GC demand and need. Lastly, policy is needed to increase GC workforce research, monitoring and dissemination of findings, along with interventions to improve GC workforce equilibrium. Such policies are needed in light of evidence of increasing demand for genetic testing by the public and evidence that GC involvement improves patient outcomes.
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Appendix A

PSS Respondents Excluded from the Study Analyses from 2002 to 2016: Raw Counts and Percentages

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<th>GCs working outside US</th>
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<th>GCs Retired</th>
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<tr>
<td>%</td>
<td>0.0%</td>
<td>4.2%</td>
<td>2.1%</td>
<td>0.0%</td>
<td>0.0%</td>
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GC = Genetic Counselor
Appendix B

Language from 2002 to 2016 PSSs to Ascertaint a Genetic Counselor’s Primary Work Setting

2016

As of 12/31/15, what was your primary work setting (in other words, what type of company are you employed by for your primary position)?

- [ ] Bioinformatics Company
- [ ] Diagnostic Laboratory – Academic, Non-commercial
- [ ] Diagnostic Laboratory – Commercial, Academic
- [ ] Diagnostic Laboratory – Commercial, Non-academic
- [ ] Federal/ State/County Office
- [ ] Government Organization or Agency
- [ ] Health Advocacy Organization
- [ ] Health Maintenance Organization
- [ ] Internet/Website Company
- [ ] Marketing/Advertising Company
- [ ] Not-For-Profit Organization (not otherwise specified)
- [ ] Outreach/Satellite/Field Clinic
- [ ] Pharmaceutical Company
- [ ] Physician's Private Practice
- [ ] Private Practice - Self-Employed
- [ ] Private Hospital/Medical Facility
- [ ] Professional Organization
- [ ] Public Hospital/Medical Facility
- [ ] Research Development/Biotechnology Company
2014
As of 12/31/13, what was your primary work setting (in other words, who are you employed by)?

*Please select all that apply.* ("Please select all that apply" only appears in 2014 PSS)

- University Medical Center
- University/Non-Medical Center
- Other (please specify)
- Bioinformatics Company
- Diagnostic Laboratory - Academic
- Diagnostic Laboratory - Commercial
- Federal/State/County Office
- Government Organization or Agency
- Health Advocacy Organization
- Health Maintenance Organization
- Internet/Website Company
- Marketing/Advertising Company
- Not-For-Profit Organization (not otherwise specified)
As of 12/31/11, what was your primary work setting (in other words, who are you employed by)?

- Outreach/Satellite/Field Clinic
- Pharmaceutical Company
- Physician's Private Practice
- Private Practice - Self-Employed
- Private Hospital/Medical Facility
- Professional Organization
- Public Hospital/Medical Facility
- Research Development/Biotechnology Company
- University Medical Center
- University/Non-Medical Center
- Other (please specify) _______________________

2012

As of 12/31/11, what was your primary work setting (in other words, who are you employed by)?

- Bioinformatics Company
- Diagnostic Laboratory - Academic
- Diagnostic Laboratory - Commercial
- Federal/ State/County Office
- Government Organization or Agency
- Health Advocacy Organization
- Health Maintenance Organization
- Internet/Website Company
- Marketing/Advertising Company
- Not-For-Profit Organization (not otherwise specified)
- Outreach/Satellite/Field Clinic
- Pharmaceutical Company
- Physician's Private Practice
- Private Practice - Self-Employed
- Private Hospital/Medical Facility
- Professional Organization
- Public Hospital/Medical Facility
- Research Development/Biotechnology Company
- University Medical Center
University/Non-Medical Center

Other (specify):

2010

As of 12/31/09, what was your primary work setting (in other words, who are you employed by)?

- Bioinformatics Company
- Diagnostic Laboratory - Academic
- Diagnostic Laboratory - Commercial
- Federal/State/County Office
- Government Organization or Agency
- Health Advocacy Organization
- Health Maintenance Organization
- Internet/Website Company
- Marketing/Advertising Company
- Not-For-Profit Organization (not otherwise specified)
Outreach/Satellite/Field Clinic

Pharmaceutical Company

Physician's Private Practice

Private Practice - Self-Employed

Private Hospital/Medical Facility

Professional Organization

Public Hospital/Medical Facility

Research Development/Biotechnology Company

University Medical Center

University/Non-Medical Center

Other (specify):

2008

What is your primary work setting?
If it applies, type your “Other” response in the right most textbox below.

Select:

- Bioinformatics Company
- Diagnostic Laboratory
- Federal/ State/County Office
- Government Organization or Agency
- Health Advocacy Organization
- Health Maintenance Organization
- Internet/Website Company
- Marketing/Advertising Company
- Not-For-Profit Organization (not otherwise specified)
- Outreach/Satellite/Field Clinic
- Pharmaceutical Company
- Physician's Private Practice
- Private Practice - Self-Employed
- Private Hospital/Medical Facility
- Professional Organization
- Public Hospital/Medical Facility
- Research Development/Biotechnology Company
- University Medical Center
- University/Non-Medical Center
- Other: (specify)

**2006, 2004, 2002**

What is your primary work setting? *(Choose Only One)*

- Federal/ State/County Office
- Health Maintenance Organization
- University Medical Center
☐ University/Non-Medical Center

☐ Private Hospital/Medical Facility

☐ Public Hospital/Medical Facility

☐ Diagnostic Laboratory

☐ Outreach/Satellite/Field Clinic

☐ Physician's Private Practice

☐ Self-Employed/Private Practice (In 2008-2016 PSSs this appears as “Private Practice - Self-Employed”)

☐ Research Development/Biotechnology Company

☐ Bioinformatics Company/Health Advocacy Organization (In 2008-2016 PSSs: Bioinformatics Company and Health Advocacy Organization appear as two separate work setting options)

☐ Internet/Website Company

☐ Pharmaceutical Company

☐ Other: [ ]
Appendix C

Collapsing Diagnostic Laboratory Categories into One Combined Category Across PSS Years: Raw Counts and Percentages

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<tr>
<td></td>
<td>23</td>
<td>6.3%</td>
<td>49</td>
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<td>68</td>
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<td>--</td>
<td>80</td>
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<tr>
<td>Total</td>
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<td>6.3%</td>
<td>49</td>
<td>8.6%</td>
<td>68</td>
<td>8.4%</td>
<td>102</td>
<td>9.5%</td>
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Appendix D

Language from 2002 to 2016 PSSs to Ascertain Whether the Respondent is a Clinical Genetic Counselor (counsels patients) or a Non-Clinical Genetic Counselor (does not counsel patients)

2016
How would you classify/describe your current position?

☐ A clinical position
☐ A non-clinical position (does not involve counseling pts)
☐ A mixed position (an equal mix btw counseling and not counseling pts)
(First and third options above were added to identify clinical GCs. The middle option was used to identify non-clinical GCs)

2014
In the position you had as of 12/31/13, did you counsel patients?

☐ Yes
☐ No

2012
In the position you had as of 12/31/11, did you counsel patients?

☐ Yes
☐ No
2010

In the position you had as of 12/31/09, did you counsel patients?

- Yes
- No

2008-2002

In your current position, do you counsel patients?

- Yes  - No
Appendix E

Language from 2002 to 2016 PSSs to Ascertain Number of Visits per Week

2016

You indicated your specialty to be X. Answer the following questions ONLY for those patients seen in this specialty as of 12/31/15. (The respondent’s specialty associated with their primary work setting was used to ascertain visits per week)

How many counseling sessions did you have in a typical work week (as of 12/31/15) in X? (Please give a single number, not a range. If your weeks are variable, please do your best to come up with an average figure. Please answer numbers per week on average (not a percentage), even if you are only part time (your % of primary specialty and % part time can be taken into account with the statistical analyses). If you do not counsel patients as part of your specialty, please put 0 in your response.)

Face-to-Face visit with New Clients

Face-to-Face visit with Return Clients

Telephone visit (with whom you do not interact or plan to interact in person)

with New Clients

Telephone visit with Return Clients

Web-based/Video (with whom you do not interact or plan to interact in person)

with New Clients

Web-based/Video visit with Return Clients
(In 2016, if a respondent inserted a number greater than 50, for any of the above categories, they received the following prompt “Are you sure you counsel X new/return clients via face to face/telephone/web-based in a typical work week?

2014

**How many counseling sessions did you have in a typical work week (as of 12/31/13)?**

*(Please pick the best range that fits your average number of counseling sessions per week. Please answer actual numbers per week on average, even if you are only part time (your % of primary specialty and % part time can be taken into account with the statistical analyses.) If you do not counsel patients as part of your specialty, please put 0 in your response.)*

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<td>Telephone Return Clients</td>
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<tr>
<td>Web-based/Video New Clients</td>
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<td>●</td>
<td>●</td>
<td>●</td>
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<tr>
<td>Web-based/Video Return Clients</td>
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<td>●</td>
<td>●</td>
<td>●</td>
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2014 PSS data was categorical versus continuous and therefore was excluded from number of visits per week analyses
How many counseling sessions did you have in a typical work week (as of 12/31/11)? In your primary specialty ONLY

(Please give a single number, not a range. If your weeks are variable, please do your best to come up with an average figure. Please answer actual numbers per week on average, even if you are only part time (your % of primary specialty and % part time can be taken into account with the statistical analyses))

Face to Face New Clients: 

Face to Face Return Clients: 

Telephone (with whom you do not interact or plan to interact in person)

New Clients: 

Telephone Return Clients: 

Web-Based/Video (with whom you do not interact or plan to interact in person)

New Clients: 

Web-based Return Clients: 

(In 2012, if a respondent inserted a number greater than 50, for any of the above categories, they received the following prompt “Are you sure you counsel X new/return clients via face to face/telephone/web-based in a typical work week?”)
2010

In your primary specialty ONLY (as of 12/31/09), how many patients did you see face-to-face in a typical work week? *Please give a single number, not a range. If your weeks are variable, please do your best to come up with an average figure. Currently, this survey is only collecting true face-to-face visits with patients -- not those done by telephone or web.*

*Future Professional Status Surveys will be updated to capture data on these types of patient interactions.*

New Patients: 

Return Patients: 

(In 2010, if a respondent inserted a number greater than 50, for either “New” or “Return” patients they received the following prompt “Are you sure you see X new/return patients face-to-face in a typical work week?"

2008 PSS:

In your primary specialty ONLY how many patients do you counsel in a typical work week? *Please give a single number for each, not a range"

New patients: 

Return Patients: 


In a typical work week, how many patients do you counsel?

New Patients: 

Return Patients: 

111
Appendix F

Selection of six work settings with >300 cumulative genetic counselor employees from 2002 to 2016

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Appendix G

Collapsing 14 Works Settings with <300 Cumulative Genetic Counselor Employees
and ‘Other’ into a New ‘Other’ Category

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<td>2</td>
</tr>
<tr>
<td>Not-For-Profit Organization (not otherwise specified)</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>20</td>
<td>30</td>
<td>22</td>
<td>29</td>
<td>51</td>
<td>152</td>
</tr>
<tr>
<td>Outreach/Satellite/Field Clinic</td>
<td>5</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>1</td>
<td>4</td>
<td>2</td>
<td>1</td>
<td>22</td>
</tr>
<tr>
<td>Pharmaceutical Company</td>
<td>1</td>
<td>3</td>
<td>5</td>
<td>7</td>
<td>7</td>
<td>9</td>
<td>10</td>
<td>13</td>
<td>55</td>
</tr>
<tr>
<td>Private Practice - Self-Employed</td>
<td>8</td>
<td>3</td>
<td>5</td>
<td>6</td>
<td>3</td>
<td>6</td>
<td>8</td>
<td>6</td>
<td>45</td>
</tr>
<tr>
<td>Professional Organization</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>1</td>
<td>3</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>13</td>
</tr>
<tr>
<td>Research Development/Biotechnology Company</td>
<td>4</td>
<td>4</td>
<td>7</td>
<td>7</td>
<td>6</td>
<td>5</td>
<td>21</td>
<td>15</td>
<td>69</td>
</tr>
<tr>
<td>University/Non-Medical Center</td>
<td>12</td>
<td>18</td>
<td>29</td>
<td>26</td>
<td>26</td>
<td>16</td>
<td>26</td>
<td>20</td>
<td>173</td>
</tr>
<tr>
<td>Other</td>
<td>12</td>
<td>19</td>
<td>25</td>
<td>36</td>
<td>65</td>
<td>28</td>
<td>84</td>
<td>50</td>
<td>319</td>
</tr>
<tr>
<td>Total (represents new OTHER category)</td>
<td>49</td>
<td>68</td>
<td>94</td>
<td>147</td>
<td>165</td>
<td>128</td>
<td>221</td>
<td>205</td>
<td>1077</td>
</tr>
</tbody>
</table>
Appendix H

Line Graph Showing Change in Genetic Counselor Employment in ‘Other’ Work Setting in Comparison to Diagnostic Laboratory and University Medical Center Work Settings
Appendix I

Chi Square Analyses Using 2002 to 2014 PSS Data Revealing that Statistically More University Medical Center Genetic Counselors Counsel Patients than Diagnostic Laboratory Genetic Counselors from 2002 to 2014 (consistent with 2016 PSS results)

<table>
<thead>
<tr>
<th>Work Setting</th>
<th>Counsels Patients&lt;sup&gt;a&lt;/sup&gt;</th>
<th>Does Not Counsel Patients&lt;sup&gt;b&lt;/sup&gt;</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>% (n)</td>
<td>% (n)</td>
</tr>
<tr>
<td>University</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medical Center (UMC)</td>
<td>87.1 (135)</td>
<td>12.9 (20)</td>
</tr>
<tr>
<td>Diagnostic</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Laboratory (DL)</td>
<td>26.1 (6)</td>
<td>73.9 (17)</td>
</tr>
</tbody>
</table>

<sup>x</sup><sup>2</sup> is significant at p<0.001

<sup>a</sup>Genetic counselors who counsel patients = clinical genetic counselors

<sup>b</sup>Genetic counselors who do not counsel patients = non-clinical genetic counselors
2004

<table>
<thead>
<tr>
<th>Work Setting</th>
<th>Counsels Patients&lt;sup&gt;a&lt;/sup&gt;</th>
<th>Does Not Counsel Patients&lt;sup&gt;b&lt;/sup&gt;</th>
</tr>
</thead>
<tbody>
<tr>
<td>University</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medical Center (UMC)</td>
<td>87.3 (206)</td>
<td>12.7 (30)</td>
</tr>
<tr>
<td>Diagnostic</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Laboratory (DL)</td>
<td>26.5 (13)</td>
<td>73.5 (36)</td>
</tr>
</tbody>
</table>

$\chi^2$ is significant at $p<0.001$

2006

<table>
<thead>
<tr>
<th>Work Setting</th>
<th>Counsels Patients&lt;sup&gt;a&lt;/sup&gt;</th>
<th>Does Not Counsel Patients&lt;sup&gt;b&lt;/sup&gt;</th>
</tr>
</thead>
<tbody>
<tr>
<td>University</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medical Center (UMC)</td>
<td>88.3 (278)</td>
<td>11.7 (37)</td>
</tr>
<tr>
<td>Diagnostic</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Laboratory (DL)</td>
<td>20.6 (14)</td>
<td>79.4 (54)</td>
</tr>
</tbody>
</table>

$\chi^2$ is significant at $p<0.001$
### 2008

<table>
<thead>
<tr>
<th>Work Setting</th>
<th>Counsels Patients&lt;sup&gt;a&lt;/sup&gt;</th>
<th>Does Not Counsel Patients&lt;sup&gt;b&lt;/sup&gt;</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>% (n)</td>
<td>% (n)</td>
</tr>
<tr>
<td>University</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medical Center (UMC)</td>
<td>92.2 (317)</td>
<td>7.8 (27)</td>
</tr>
<tr>
<td>Diagnostic</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Laboratory (DL)</td>
<td>26.0 (25)</td>
<td>74.0 (71)</td>
</tr>
<tr>
<td>$\chi^2$ is significant at $p&lt;0.001$</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### 2010

<table>
<thead>
<tr>
<th>Work Setting</th>
<th>Counsels Patients&lt;sup&gt;a&lt;/sup&gt;</th>
<th>Does Not Counsel Patients&lt;sup&gt;b&lt;/sup&gt;</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>% (n)</td>
<td>% (n)</td>
</tr>
<tr>
<td>University</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medical Center (UMC)</td>
<td>93.0 (265)</td>
<td>7.0 (20)</td>
</tr>
<tr>
<td>Diagnostic</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Laboratory (DL)</td>
<td>35.4 (35)</td>
<td>64.6 (64)</td>
</tr>
<tr>
<td>$\chi^2$ is significant at $p&lt;0.001$</td>
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<td></td>
</tr>
</tbody>
</table>
### 2012

<table>
<thead>
<tr>
<th>Work Setting</th>
<th>Counsels Patients(^a)</th>
<th>Does Not Counsel Patients(^b)</th>
</tr>
</thead>
<tbody>
<tr>
<td>% (n)</td>
<td>% (n)</td>
<td></td>
</tr>
<tr>
<td>University</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medical Center (UMC)</td>
<td>91.9 (352)</td>
<td>8.1 (31)</td>
</tr>
<tr>
<td>Diagnostic</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Laboratory (DL)</td>
<td>32.8 (42)</td>
<td>67.2 (86)</td>
</tr>
</tbody>
</table>

\(\chi^2\) is significant at \(p<0.001\)

### 2014

<table>
<thead>
<tr>
<th>Work Setting</th>
<th>Counsels Patients(^a)</th>
<th>Does Not Counsel Patients(^b)</th>
</tr>
</thead>
<tbody>
<tr>
<td>% (n)</td>
<td>% (n)</td>
<td></td>
</tr>
<tr>
<td>University</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medical Center (UMC)</td>
<td>85.6 (494)</td>
<td>14.4 (83)</td>
</tr>
<tr>
<td>Diagnostic</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Laboratory (DL)</td>
<td>27.8 (74)</td>
<td>72.2 (192)</td>
</tr>
</tbody>
</table>

\(\chi^2\) is significant at \(p<0.001\)
Appendix J

Distribution Table of New Visits per Week Performed by Clinical University Medical Center and Diagnostic Laboratory Genetic Counselors and All Other Clinical Genetic Counselors Across All Other Work Settings from 2016 PSS Data

<table>
<thead>
<tr>
<th>Work Settings</th>
<th>50</th>
<th>52</th>
<th>54</th>
<th>55</th>
<th>60</th>
<th>65</th>
<th>70</th>
<th>75</th>
<th>80</th>
<th>81</th>
<th>85</th>
<th>90</th>
<th>91</th>
<th>95</th>
<th>98</th>
<th>100</th>
<th>122</th>
<th>Total GCs ≥ 50 visits per week</th>
<th>Total clinical GC respondents</th>
<th>% GCs ≥ 50 visits per week</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diagnostic Laboratory (DL)</td>
<td>2</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>1</td>
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<td>2</td>
<td>1</td>
<td>3</td>
<td>0</td>
<td>16</td>
<td>115</td>
<td>13.9</td>
</tr>
<tr>
<td>University Medical Center (UMC)</td>
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<td>0</td>
<td>0</td>
<td>0</td>
<td>2</td>
<td>0</td>
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<td>4</td>
<td>0</td>
<td>6</td>
<td>3</td>
<td>0</td>
<td>1</td>
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<td>3</td>
<td>0</td>
<td>27</td>
<td>486</td>
<td>5.6</td>
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<tr>
<td>Other (Not including DL and UMC)</td>
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<td>1</td>
<td>1</td>
<td>3</td>
<td>3</td>
<td>10</td>
<td>6</td>
<td>9</td>
<td>1</td>
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<td>1</td>
<td>4</td>
<td>1</td>
<td>70</td>
<td>783</td>
<td>8.9</td>
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<tr>
<td>All Work Settings</td>
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<td>1</td>
<td>2</td>
<td>6</td>
<td>3</td>
<td>14</td>
<td>9</td>
<td>15</td>
<td>2</td>
<td>13</td>
<td>9</td>
<td>1</td>
<td>11</td>
<td>3</td>
<td>10</td>
<td>1</td>
<td>113</td>
<td>1384</td>
<td>8.2</td>
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</tbody>
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