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## Genetic Counselor Drift: Exploring contributors to the recent growth of non-clinical genetic counseling positions and the resulting impact on the profession.

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**Genetic Counselor Drift: Exploring contributors to the recent growth of non-clinical genetic counseling positions and the resulting impact on the profession.**

**Master's Thesis**

**Presented to**

**Joan H Marks Graduate Program in Human Genetics**

**Sarah Lawrence College**

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**Master of Science**

**In**

**Human Genetics**

**By**

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**and**

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**Submitted in Partial Completion of the Master of Science Degree at Sarah Lawrence College, May 2017**

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## **Abstract**

The field of genetic counseling has been traditionally centered around the clinical setting. In recent years, an increasing number of genetic counselors have taken non-clinical positions with limited patient contact. This shift has created a spectrum of genetic counselors working across clinical and non-clinical roles. Available literature on the issues relevant to both groups is limited. We surveyed 305 genetic counselors employed in diverse work settings to better understand opinions regarding professional issues and training while in genetic counseling programs. Respondents reported several opportunities to increase satisfaction of clinical counselors and preparedness among non-clinical counselors. Furthermore, significant differences in the perceptions between clinical and non-clinical counselors regarding professional issues were identified. Our study serves as a foundation for future research into topics affecting both clinical and non-clinical genetic counselors.

## **Keywords**

clinical genetic counselor, non-clinical genetic counselor, workforce issues, job satisfaction, genetic counseling programs, curriculum development

## **Introduction**

Careers in genetic counseling have traditionally been clinically oriented, with genetic counselors being responsible primarily for coordinating patient care with doctors and other healthcare professionals. As the field continues to evolve, however, there has been a noticeable shift away from the clinic and toward other roles. Currently, almost a quarter of all counselors do not directly counsel patients as part of their jobs (National Society of Genetic Counselors 2016a). These non-clinical counselors have taken on roles such as laboratory coordinators, science liaisons, product managers, and public health workers. Many of these roles have no analogue in the clinical sphere.

There are several factors that have contributed to the growth of the non-clinical counselor population. This shift in the profession has partially arisen as a result of more diverse employment opportunities available to genetic counselors. The rise of commercial genetics laboratories and the subsequent need for health professionals with an understanding of the products they offer has been a major boon to genetic counselors seeking roles outside of the clinic (Eisenstein 2015). Similar expansions for genetic counselors have been observed among government agencies, disability awareness groups, and other organizations which need the skill set and knowledge base of a trained genetic counselor (National Society of Genetic Counselors 2016b).

Beyond the greater availability of non-clinical positions, the growth of the non-clinical workforce has been spurred on by the benefits reported by counselors in these positions. The Professional Status Survey (PSS) is a bi-annual study of self-reported

professional data from genetic counselors that is organized, analyzed, and written by the National Society of Genetic Counseling (NSGC). In 2008, the PSS began partitioning data from clinical and non-clinical respondents (National Society of Genetic Counselors 2008). Since that time, non-clinical counselors responding to the PSS have consistently reported higher satisfaction with several aspects of their positions, including: salary, career advancement opportunities, and administrative support within the respondent's institution (National Society of Genetic Counselors 2008, 2012, 2016a).

Salary differences between clinical and non-clinical counselors have been consistently reported as a significant concern among clinical counselors. The median salary for all counselors employed in non-clinical positions who responded to the 2016 PSS was reported as \$89,781 versus \$72,000 for their clinical peers (National Society of Genetic Counselors 2008, 2012, 2016a). When asked about their level of satisfaction with their salary, 71% of non-clinical respondents in 2008, 77% in 2012, and 79% in 2016 reported being satisfied or very satisfied with their salary. Across clinical respondents, only 57% in 2008, 59% in 2012, and 58% in 2016 reported this same level of satisfaction (National Society of Genetic Counselors 2008, 2012, 2016a). Salary was reported to be the most significant reason to switch to an industry-based, non-clinical position (Lieberman 2016). As has been shown with previous studies, salary differences between peers can affect job satisfaction as well as job-seeking behavior (Card et al. 2012).

Non-clinical genetic counselors also report increased opportunities for career advancement compared to clinical counselors. While satisfaction in career advancement

opportunities reported by non-clinical respondents has increased from 57% in 2008 to 71% in 2016, only 40% of clinical counselors have consistently reported being satisfied with available advancement opportunities across recent PSSs (National Society of Genetic Counselors 2008, 2016a; National Society of Genetic Counselors Inc. 2012). Career advancement opportunities have improved for non-clinical counselors in recent years in large part due to the recognition of the broad utility of genetic counselors' skills set and its ready application toward novel roles (Lieberman 2016; Rabideau et al. 2016). Within the clinical realm, counselors have a fairly well-defined role, and thus opportunities for professional growth have stagnated (Hampel 2013).

Administrative support is another area in which non-clinical counselors report greater satisfaction than clinical counselors. Each of the following areas have either maintained or shown improved satisfaction among non-clinical genetic counselors: Supervisor/Director Support, Institutional/Organizational Support, and Administrative Responsibilities (National Society of Genetic Counselors 2008, 2012, 2016a). Increasing patient loads are a likely cause of this disparity in satisfaction, as 61.6% of clinical genetic counselors reported an increase in patient volume, but only 33.5% reported that staffing numbers have increased compared to two years ago (National Society of Genetic Counselors 2016b). Clinical burnout stemming from a lack of sufficient administrative support has been reported as one of the primary reasons for clinical counselors to leave or considering leaving the profession (National Society of Genetic Counselors 2016b). Increasing clinical case loads without commensurate growth of administrative staff was reported as a reason that up to 37.5% of current counselors

and students see industry as an advantageous setting compared to clinical care (Lieberman 2016). Some counselors and students (20.7%) have also reported feeling that a greater degree of respect was offered to them from industry peers compared to hospital staff (Lieberman 2016).

The existing literature suggests a number of issues affecting counselors employed within clinical settings. As the field continues to evolve, understanding the needs of genetic counselors and the genetic counseling students who will eventually join their ranks is an important task that has received limited attention thus far. As the nature of a genetic counselor's role continues to shift and expand, concern has arisen that the clinical workforce may fail to meet the increasing demand for services given the profession's continuing shift toward non-clinical roles as well as a continually increasing clinical case load. Practical solutions to address the disparity in clinical versus non-clinical genetic counselors' salary, advancement opportunities, and sufficient administrative support have not yet been identified, but are clearly needed in order to help close the gap in satisfaction levels between clinical and non-clinical positions. (National Society of Genetic Counselors 2008, 2012, 2016a). Several solutions have been proposed to help increase satisfaction among clinical counselors, including the introduction of genetic counseling assistants into the workforce, creation of clinical career ladders, and the development of a genetic counseling advanced practice degree. However, these solutions have been sparsely implemented across the clinical sphere, if at all (Kofman et al. 2016; Pirzadeh-Miller et al. 2016; Reiser et al. 2015; Robinson et al., 2014). A better understanding of practical solutions that these issues is clearly needed



if the gap in satisfaction between clinical and non-clinical genetic counselors is to be closed.

In addition, issues regarding student training for non-clinical positions have also been identified. Given the increase in non-clinical opportunities for genetic counselors, it is important to understand the issues non-clinical counselors face in terms training. Data regarding potential issues for this group have not been as well-studied compared to clinical counselors thus far. Several authors have noted that genetic counseling programs do not offer coursework, rotations, or electives that support development of skills specific to non-clinical positions. Practicing genetic counselors expressed interest in greater coverage of public health, biotechnology, and business topics as part of genetic counseling training programs. The skills required to succeed in these settings often differ from those taught through traditional clinical training models that have been used by genetic counseling programs thus far (Field et al. 2016; Powell et al. 2010). For example, business development, drug development, clinical trials, regulatory affairs, and organizational leadership have been listed as additional skills that were not taught in genetic counseling programs but were needed by counselors in biotechnology and pharmaceutical industry (Field et al. 2016).

The need for greater exposure to laboratory-related topics as a part of training curriculums, given the large percentage of genetic counselors employed in these settings, was identified previously (Linderman et al. 2015; Swanson et al. 2014; Waltman et al. 2016). While the number of laboratory positions available for genetic counselors continues to grow, student involvement in laboratories has been difficult to quantify. Currently, there are no practice-based competencies within the field that are specific to working in a laboratory

setting (Accreditation Council for Genetic Counseling 2013). Programs which do offer laboratory exposure vary considerably in both length and types of opportunities they provide to students. The absence of structured laboratory exposure may impede further interest and development of laboratory counseling positions (Goodenberger et al. 2014). A pilot genomic course with a laboratory component was created by the Icahn School of Medicine at Mount Sinai in 2012 to assess the utility of having a formalized course available to genetic counseling students. A majority of students taking the course reported finding the course helpful (80%, N = 15) and had the opportunity to apply the information they learned toward professional activities (66.6%, N = 15) (Linderman et al. 2015).

Rotation requirements for graduation from genetic counseling programs are another area in which calls for change have been made. The requirements for the case logbook are currently focused almost entirely on face-to-face clinical interactions with patients within the traditional prenatal, pediatric, cancer, and adult domains (Accreditation Council for Genetic Counseling 2013). The requirements for a case to be used for the logbook have been considered a barrier in the training of students interested in non-clinical roles, and relaxation of these requirements has been suggested (Swanson et al. 2014). When asked whether non-clinical rotations should be able to fulfill logbook requirements, 77.1% (n = 271) of students and 78.3% (n = 416) of graduates report agreeing with this statement (Lieberman 2016).

Besides the skills and settings to which students have limited exposure in genetic counseling programs, genetic counselors can face other challenges when they move from

clinical to non-clinical positions. Groepper et al. (2015) surveyed 111 laboratory genetic counselors and asked them to identify ethical and professional challenges they faced at work (Groepper et al. 2015). The frequency of these challenges was compared to previously identified challenges faced by clinical genetic counselors (Bower et al. 2002). One of the challenges that was more prominent among non-clinical genetic counselors had to do with professional identity issues related to perceived negative attitudes from clinical genetic counselors as well as non-clinical genetic counselors' own doubts regarding their roles (Groepper et al. 2015). The view that non-clinical counselors have somehow "sold out" or "gone to the dark side" may be related to the fact that clinical as well as non-clinical counselors regard laboratory counselors as having conflict-of-interest issues (Groepper et al. 2015). While this study was limited to laboratory genetic counselors, more studies are needed to find out whether these challenges are universal to non-clinical GCs.

Another concern is that current training programs may not have sufficient flexibility to equip their students to move into non-clinical roles. As the counseling workforce becomes more non-clinically oriented, efforts to encourage students and recent graduates to evolve the field have been viewed as crucial for the continued success of the profession. A better understanding of the relevant issues is needed to better equip current and future counselors to continue the momentum the profession has gained. At this point, the few studies that have dealt with these issues have been limited to one particular sub-sector of non-clinical genetic counseling such as those in the biotechnology and pharmaceutical industry or diagnostic laboratories, or provide an opinion in the form of a review article (Christian et al. 2012, Field

et al. 2016, Swanson et al. 2014). Future research involving a survey of a larger number of genetic counselors who have taken a non-clinical position or who have seriously considered taking a non-clinical position is needed to collect a broader scope of opinions and better understand what, if anything, training programs can do to provide graduates with the tools they need to excel outside of the clinic.

In summary, the existing research has revealed several reasons behind this workforce shift of genetic counselors from clinical to non-clinical settings. There is also evidence suggesting that the traditional education at genetic counseling programs has not prepared counselors for certain aspects of their roles in non-clinical work settings. In our study, we further explore these workforce issues to fill in the gaps in our knowledge. We also asked respondents to identify actions that may help improve the job satisfaction and training of genetic counselors in clinical as well as non-clinical positions.

## **Materials and Methods**

### **Recruitment**

Eligibility criteria required that participants be genetic counselors currently living in the United States or Canada. We recruited participants through the Listserv of the National Society of Genetic Counselors. An email invitation to participate in the study, along with a link to the survey itself, was sent as part of an e-blast through the Listserv. Approximately two weeks after the initial recruitment email was sent, a reminder email to complete the survey was sent.

### Data Collection

A 40-question survey was created using SurveyMonkey. The survey was approved by the Sarah Lawrence College Institutional Review Board through an expedited process because it presented minimal risk to participants and fully informs participants. This survey was open from January 12, 2017 to February 2, 2017. Questions included information about demographics, work setting, whether the participant counseled patients, areas of professional satisfaction, material covered in the curriculum as a student in a genetic counseling program, non-clinical rotations completed while a student, and others issues related to non-clinical counseling. Types of questions on this survey included multiple choice, Likert scales, and free response. Participants were not compensated for taking the survey. Information collected from surveys was stored on a password-protected file on the investigator's computers.

### Data Analysis

We analyzed quantitative data using SPSS version 24. Skip logic was used for this survey, so not every question was answered by every participant. Data are presented as counts, percentages, means, and standard error of the mean. We performed chi square tests to determine if there were any differences by categorical variables. To compare means of Likert scales or other numerical variables, we performed two-tailed Student's t-tests assuming unequal variance. When multiple comparisons were performed on the same set of data, the significance level was adjusted by the Bonferroni correction.

For free response questions, analysis was performed using inductive coding. Responses for each question were read and major themes were identified separately by each

investigator. Major themes were discussed and compiled to generate a single list of codes used by each investigator during the second read-through. Responses were read again and meaningful units were identified and coded with the relevant code. Themes appearing in at least 5% of responses were considered common enough to be described in detail.

## **Results**

A total of 306 genetic counselors responded to the survey out of the 3,551 counselors on the NSGC membership list for a response rate of 8.6%. Data from one survey was excluded as that participant worked outside of the U.S. or Canada. Of the remaining 305 surveys submitted, 261 responses were considered complete (the participant answered Question 38 which was the last multiple-choice question). Data from incomplete surveys was incorporated into overall analysis.

### **Demographic Information**

In the first part of the survey, participants answered demographic questions including age, gender, race, geographic location, year of graduation from genetic counseling program, advanced degrees held, year of graduation, and whether they were board certified. Table 1 lists the demographic information collected from participants. Among participants, the majority were 40 and under (74.8%). 96% of participants identified as female and 92.7% identified as Caucasian. All six of the regions within the PSS were represented, with Region IV (Midwest) having the most participants. Eighteen (6.8%) participants reported holding advanced degrees other than a master's degree in genetic counseling. The number of participants reporting their graduation year as 2009 or earlier or 2010 or later was nearly the

same (48.5% and 51.5%, respectively). 93.2% of participants were board-certified.

### Work Setting

Participants were asked to report their current or most recent work setting as well as whether they counseled patients in this position. Information regarding work setting is summarized in Table 2. One hundred and seventy-five (59.9%) participants reported counseling patients in their most recent position while 118 (40.1%) did not. For participants that counseled patients (these participants were assigned to the “C” group), the most common employment settings were university medical centers (n=71, 40.6%), public hospitals (n=36, 20.6%), and private hospitals and clinics (n=28, 16.0%). Among participants who did not counsel patients (these participants were assigned to the “NC” group), the most common employment settings were private diagnostic laboratories (n=73, 61.9%), academic diagnostic laboratories (n=14, 11.9%), and biotechnology companies (n=8, 6.8%). Figure 1 illustrates all settings reported by C and NC participants.

Participants in each group were asked to report which roles from a list of those provided were relevant to their current/most recent position. Figure 2 shows the proportion of C and NC participants reporting each role. The only role reported significantly more frequently among the C group was report and letter writing ( $p<.001$ , C: n=126, 72.0%; NC: n=44, 37.7%). The following roles were significantly more often performed by the NC group: customer liaison services ( $p<.001$ , NC: n=60, 50.8%; C:n=29, 16.6%), laboratory support ( $p<.001$ , NC: n=58, 49.2%; C:n=27, 15.4%), marketing ( $p<.001$ , NC: n=30, 25.5%; C:n=18, 10.3%), and sales ( $p<.01$ , NC: n=17, 14.4%; C:n=6, 3.4%).

When we compared job roles of clinical and non-clinical GCs between those who graduated in the last 7 years versus those that graduated prior to that, significantly more recent graduates counsel patients and write reports ( $p<0.001$ ), while earlier graduates were significantly more likely to work in management positions ( $p<0.01$ , see Figure 3). No significant difference was found in the year of graduation for clinical and non-clinical genetic counselors who are in laboratory support, customer liaison, education, sales, and marketing.

### Job Satisfaction

C and NC participants were asked to report their satisfaction with their current/most recent position as a whole, as well as their satisfaction with eight specific areas of their position (salary, opportunities for advancement, work-life balance/flexibility, respect from peers/superiors, autonomy, patient contact, learning opportunities, scientific content). This information was ascertained using a 5-point Likert scale (1=very dissatisfied, 5=very satisfied). Both groups ( $N=162$  for C;  $N=115$  for NC) reported being satisfied with their positions overall, though NC participants have greater overall job satisfaction on average than do their C peers ( $NC=4.43$ ,  $C=4.09$ ;  $p<0.01$ ). Regarding specific areas of satisfaction, the NC group reported significantly greater satisfaction in six of the eight areas assessed: salary ( $p<0.001$ ), opportunity for advancement ( $p<0.001$ ), work-life balance/flexibility ( $p<0.001$ ), respect of peers and higher-ups ( $p<0.01$ ), learning opportunities ( $p<0.01$ ), and scientific content ( $p<0.001$ ), while the C group had significantly greater satisfaction with the area of patient contact ( $p<0.001$ ) (see Figure 4). 48.7% of NC respondents ( $n=56$ ) reported their satisfaction with patient contact as “neutral” (=3), while 43.5% ( $n=50$ ) reported being



satisfied or very satisfied with the level of patient contact in their position. The largest disparities in reported satisfaction between the C and NC groups were salary, opportunities for advancement, work-life balance/flexibility, and scientific content (Figure 3). Opportunity for advancement was the area of lowest satisfaction among C counselors, and second-lowest among NC ones.

#### Incentives to Remain In or Switch to a Clinical Position

Participants in both groups were asked to rate seven different incentives in terms of how likely these incentives would be to keep the C group in clinical positions or entice the NC participants to switch to a clinical position (see Figure 5). These incentives were rated using a 5-point Likert scale (1=very unlikely, 5=very likely). Participants in the C group (N=162) were significantly more likely to agree that all seven of the incentives would encourage them to stay in their clinical positions as compared to the likelihood that the incentives would encourage NC participants (N=115) to switch to a clinical position ( $p<0.001$ ). All incentives except for “a reduction in case load” were reported by C participants as “likely” (Likert scale = 4) to make them remain in their current position. Generally, NC participants felt “neutral” (Likert scale = 3) about each of the incentives. The incentive “option to work from home” was rated the highest (3.42) among NC participants.

An open-ended question was used to invite participants to suggest other implementations or reasons that would incentivize them to stay in a clinical position or to leave a non-clinical position for a clinical one, and to clarify any previous responses to the incentives listed. Sixty-nine (24.9%) participants responded to this question. Five responses

were excluded as these responses did not answer the question (answers included “n/a”). Common themes found in the remaining 60 answers are listed in Table 3. While many of the responses could be considered as related to the categories previous listed, it is of note that five respondents (7.2%) indicated that “Fewer issues dealing with insurance” would be an incentive to remain in/return to a clinical position. While many of these responses brought up improvements to specific areas of job satisfaction, it is worth noting that more than 15% of all responses contained the “Not Willing to Return” theme, which included lack of interest in clinical work, clinical work not highlighting individual strengths, and loss of job, forcing a return to a clinical position. Within the “New Opportunities” theme, which was reported by 21.7% of respondents, common sub-themes included the ability to have designated time for research and other non-clinical duties as well as the opportunity to only counsel patients part-time while taking on other roles.

#### Clinical or Non-Clinical Preference Before Graduate School

Participants (N=268) were asked to evaluate their preference for clinical versus non-clinical work prior to entry into a genetic counseling program. Preference was rated using a 5-point Likert scale (1=“strong preference for non-clinical work”, 5=“strong preference for clinical work”). “Did not know” was a separate answer available for this question. As a whole, most respondents had a preference for clinical jobs rather than non-clinical jobs (n=213, 79.5% clinical; n=14, 5.25% non-clinical). There was no statistically significant difference in job preference before graduate school between those graduating in 2010 or later and those graduating in 2009 or earlier ( $t = 1.19, p = 0.23$ ).

However, GCs in non-clinical roles were less likely to have had preference for a clinical position than those who are currently in clinical roles ( $t=-2.1$ ,  $p=0.037$ ). Almost 10% of participants reported not knowing which setting they preferred at that time ( $n=26$ , 9.7%).

#### Preparation in Non-Clinical Topics

All participants who had ever worked in a non-clinical position ( $N=168$ ) were asked to evaluate how well their genetic counseling program had prepared them for their position overall, as well as in four specific areas pertaining to non-clinical work. Responses were recorded using a 5-point Likert scale (1=“prepared me barely at all for my position”, 5=“prepared me very well for my position”). The responses are summarized in Figure 6. More recent graduates reported a somewhat higher overall preparedness (3.19) compared to less recent graduates (2.87), although this result was not statistically significant. In general, those graduating in 2009 and before reported lower preparedness across the four topics specified compared to their peers who graduated after 2010 ( $p<0.05$ ). Both groups felt least prepared in the area of “exposure to non-clinical settings” (2.69 for recent graduates, 1.98 for less recent graduates).

In an open-response question, participants were asked to identify any additional non-clinical areas in which they did not feel sufficiently prepared. Fifty-three (31.5%) participants responded to this question. Of the answers collected, five did not contain interpretable information (such as “n/a”). Common themes found in the remaining 48 answers are shown in Table 4. The most common theme reported only by those graduating in 2009 and before, was the lack of non-clinical positions existing for those participants when

they were attending a genetic counseling program (n=19, 39.6%). The remaining responses related to specific skill sets and knowledge pertaining to non-clinical GC roles.

#### Acquisition of Information Not Learned in Graduate School

Both C and NC participants (n=263) were asked to report what methods they had utilized to gain skills and knowledge that were not acquired during their graduate training at a genetic counseling program. Informal methods such as “On the job” (n=257, 96.3%), “From coworkers” (n=173, 64.8%), and “From a supervisor” (n=143, 53.6%) were more commonly employed than formal methods, such as “From an outside course I took” (n=52, 19.5%) or “From a training course offered by the institution” (n=38, 14.2%). Eleven respondents (4.1%) also reported that previous professional experience in a non-genetic counseling role was useful in gaining these skills.

#### Availability of Non-Clinical Rotations in Genetic Counseling Programs

All participants (N=263) were asked to indicate whether they had a non-clinical rotation at some point during their genetic counseling program, and if so, how long this rotation was in increments of 5 days from “1-5 days” up to “More than 25 days”, and what the focus of the rotation was (laboratory, industry, etc.). Approximately 60% (n=157) of respondents reported having a non-clinical rotation with an average length of  $9.7 \pm 0.7$  days. Of those that specified the focus of the rotation (N=154), the most common focus reported was “laboratory” (n=131, 85.1%). Participants in a rotation with a laboratory focus reported exposure to cytogenetic, molecular, and biochemical subspecialties. Other rotation focuses reported included research (n=12, 7.8%), public health (n=11, 7.1%), and industry (n=11,

7.1%).

Two hundred and sixty-three participants were then asked “Do you think genetic counseling programs should require a laboratory/industry rotation?”, and “If ‘Yes’ was your response to the previous question, how long should the rotation last?” using the same increments as those above. Eighty-seven percent of participants (n=230) felt that rotations in laboratory or industry settings should be required. The average desired length of rotation reported was  $16.5 \pm 0.6$  days. There was no statistical significance between responses based on the employment setting of the participants. In addition, the desired length of rotation did not significantly differ between participants working in a clinical or non-clinical setting or between recent graduates and those graduated prior to 2010.

#### Suggested Improvements to Genetic Counseling Training Programs

Participants (N=264) were asked to evaluate the utility of six different changes that genetic counseling programs could implement to better train students interested in non-clinical roles. Their responses were rated using a 5-point Likert scale (1=“very disinterested”, 5=“very interested”). Mean ratings for each change by C versus NC participants is shown in Figure 7. Four changes, (“non-clinical rotations can be used to fulfill logbook requirements”, “greater coverage of non-clinical topics in curricula”, “greater visibility of non-clinical work”, and “increased number of faculty who have worked in non-clinical settings”) had mean ratings of approximately 4 (=“interested”) across both the C and NC groups. The NC group rated each of these four changes of higher interest than the C group. Differences between the ratings given to two of these changes by C and NC were

found to be statistically significant (“increased number of faculty who have worked in non-clinical settings”,  $p < 0.001$ ; “greater visibility of clinical work”  $p < 0.025$ ). The option “Different tracks for students desiring clinical or non-clinical work” was rated the lowest by both groups, with an average score of 2.89. Genetic counselors who graduated in 2010 or later were somewhat more interested in the option of “non-clinical rotation to fill the logbook cases” than those counselors who graduated prior to 2010. However, the difference was not statistically significant ( $p = 0.026$ ;  $\alpha = 0.025$  using Bonferroni correction). Genetic counselors’ levels of interest in other program improvements were not significantly affected by the year of graduation ( $0.38 < p < 0.76$ ).

#### Conflict of Interest Among Non-Clinical Genetic Counselors

Two hundred and sixty-one participants responded to the question “Do you think non-clinical genetic counselors have greater conflict of interest than do clinical genetic counselors?”. Available answers for this question were “Yes”, “No”, and “Not Sure”. Ninety-four (36.0%) participants responded “Yes”, 111 (42.5%) responded “No”, and 56 (21.5%) responded “Not Sure”. When the data from C and NC groups was separated, 50.3% of participants in clinical jobs thought that non-clinical counselors had a greater conflict of interest than clinical counselors, while only 16.4% of those in non-clinical jobs thought this was true (chi-square ( $df=2$ ) = 37.03,  $p < 0.001$ ). A statistically significant difference in responses was also noted when graduation year was factored in. Recent graduates (43.4%) were more likely to think that non-clinical genetic counselors have greater conflict of interest compared to those who graduated prior to 2010 (28.0%) (chi-square ( $df=2$ ) = 12.24,  $p < 0.01$ ).

When offered an open-ended question to clarify their position on conflict of interest, 98 survey participants provided responses (see Table 5). Two responses were excluded as they did not contain interpretable information. Among the themes derived from responses, more than half said that COI depends on the organization and job's roles. Approximately a quarter of respondents felt that both clinical and non-clinical genetic counselors have COI. Some respondents felt that the genetic counseling code of ethics ensure that counselors prioritize patients' needs.

#### Genetic Counseling Program Bias

Two hundred and sixty-one participants responded to the question "Do you think genetic counseling programs are biased against applicants interested in non-clinical work during the admissions process?" Available answers for this question were "Yes", "No", and "Not Sure". Forty (15.3%) participants responded "Yes", 68 (26.1%) responded "No", and 153 (58.6%) responded "Not Sure". There was a statistically significant difference in responses between the C and NC groups. While 35.1% of those in clinical positions thought that genetic counseling training programs were not biased against those interested in non-clinical work, only 13.1% of non-clinical counselors felt this way (chi-square (df=2) = 15.92,  $p < 0.001$ ). The tendency to think that programs are biased against students interested in non-clinical work was not significantly different when compared by year of graduation (chi-square (df=2) = 5.00  $p = 0.08$ ).

As a follow-up question, participants were asked to provide more information regarding their answer to the previous question. Forty-one (15.6%) of respondents to the

previous question elaborated on their answer (see Table 6). More than one third of respondents were either not familiar enough with the process because they graduated too long ago, or were not closely associated with a genetic counseling program at this time. The remaining responses varied widely from those thinking curriculum has a bias against students interested in NC jobs to those who think clinical training takes precedence over non-clinical training. More than 10% of the respondents also thought that bias either never existed or is improving in recent years.

#### Attitudes Regarding Genetic Counselors Employed in Non-Clinical Settings

Two hundred and sixty-one participants responded to the question “Do you think genetic counselors working in clinical positions view non-clinical counselors negatively?”. Available answers were “Yes”, “No”, and “Not Sure”. 108 (41.4%) responded “Yes”, 92 (35.2%) “No”, and 61 (23.4%) “Not Sure”. Fifty-six percent of participants in the NC group reported thinking that clinical genetic counselors viewed non-clinical counselors negatively, whereas only 31.1% of C participants had this same viewpoint. This difference was found to be statistically significant (chi-square (df=2)=17.76,  $p<0.001$ ). Perceptions regarding attitudes toward non-clinical genetic counselors did not differ significantly by year of graduation (chi-square (df=2) = 1.34,  $p = 0.51$ ).

Ninety-five respondents elaborated on their response to the question, “Do you think counselors working in clinical positions view non-clinical genetic counselors negatively?” (see Table 7). Almost 60% of the respondents admitted to currently or previously having negative feelings towards non-clinical genetic counselors, while more than 15% of them said



that attitudes toward non-clinical GCs are improving. Forty participants (41.7%) elaborated on the reasons why counselors in NC roles are viewed negatively. Responses included: “selling out”, “going to the dark side”, “counselors in NC roles are not as good with patients”, and “envy for better salary and cushier jobs”.

#### Attitudes about the Shift of Genetic Counseling Profession to Non-Clinical Positions

Two hundred sixty-one participants responded to the question “Do you think the recent increase of genetic counselors working in non-traditional roles is beneficial to the field as a whole?”. Available answers were “Yes”, “No”, and “Not Sure”. Two hundred ten (80.5%) participants responded “Yes”, 10 (3.8%) “No”, and 41 (15.7%) “Not Sure”. More non-clinical counselors (89.1%) than clinical counselors (74.2%) thought the recent increase of genetic counselors working in non-traditional roles is beneficial to the field as a whole (chi-square (2) = 9.94,  $p < 0.01$ ).

Participants had the opportunity to provide additional information regarding their answer to the previous question, and 86 (32.6%) chose to do so. These responses were codified and are shown in Table 8. More than half of the responses submitted contained the theme of “greater respect for the genetic counseling profession than was previously given”. Sub-themes included: “greater ‘brand-name’ appeal”, “recognition by others of the skillset genetic counselors have”, and “increased ability to receive proper compensation for services provided”. However, 34.9% of respondents also reported concern about the shift toward non-clinical positions causing an increased strain on the clinical workforce as well as difficulties with training students clinically. Some of respondents specifically expressed

concern about new graduates taking non-clinical jobs directly out of school, as they believe that postgraduate clinical experience is foundational and beneficial for non-clinical roles. Almost half (n=14, 46.7%) of the responses with this theme also included other themes espousing the benefits of such a shift (greater recognition, diversity of roles, utility of genetic counselor skillset). Differences between how clinical and non-clinical participants responded and how recent and earlier graduates responded were not found to be statistically significant.

#### What Can Be Done to Better Prepare Students for “Non-Traditional” Roles?

Participants were given the opportunity to provide their thoughts with the following question: “Please give us your opinion on what genetic counseling programs can do, if anything, to better prepare students for nontraditional roles.” One hundred and seven participants responded to this question. Common themes identified across these responses are shown in Table 9. The majority (71.0%) of respondents reported that genetic counseling programs should devote more of their curriculum to non-clinical topics. Sub-themes included the idea of offering more coursework in non-clinical areas as well as longer rotations in less traditional positions (particularly laboratory and industry settings). Almost half (46.7%) of respondents also reported that greater exposure to and awareness of the non-clinical side of the field would be beneficial to students. This included more non-clinically-oriented faculty, mentorship with non-clinical genetic counselors outside of programs, and more opportunities to meet non-clinical counselors (such as career days or professional events). Removing stigma around non-clinical employment and normalizing this part of the profession as a legitimate route for graduating students was also reported as important by many respondents

(19.6%). Some respondents (8.4%) were more reserved about expansion of non-clinical training, and indicated that genetic counseling programs should continue to focus most of their resources towards clinical training and that current non-clinical offerings are largely adequate for students. Recent graduates were more likely to have reported desiring a greater portion of the curriculum devoted to non-clinical topics compared to earlier graduates (chi square (df=1) = 4.3  $p < 0.05$ ). Other themes were not significantly different between recent and earlier graduates, or between clinical and non-clinical respondents.

### **Discussion**

To date, only a handful of studies, including the NSGC's Professional Status Survey have looked into topics pertaining to job satisfaction, preparedness, and suggestions for improvement to the field of genetic counseling (Cohen et al. 2016; Field et al. 2016; Liberman 2016; National Society of Genetic Counselors 2016a; Powell et al. 2010). This study has taken a different approach compared to previous research in this area. To our knowledge, this is the first study to survey a large number of both clinical and non-clinical genetic counselors on these topics. It is also the first study to broadly assess the challenges facing both clinical and non-clinical counselors, and to elicit potential solutions to these challenges, particularly those relevant to non-clinical counselors. In addition, it is also the first study to inquire about attitudes regarding the shifting nature of the profession. This study also replicates some findings of previous studies done in this area.

Perhaps reassuringly, several of the findings of this study have paralleled previously reported data, such as the fact that a real difference in overall job satisfaction as well as

satisfaction with specific areas such as salary, advancement opportunities, and patient contact between clinical and non-clinical counselors does exist. These findings are consistent with data from the PSS surveys ever since data from non-clinical counselors was first reported separately in 2008 (National Society of Genetic Counselors 2008, 2012, 2016b). Many of the “Workforce Statements” about which Liberman (2016) surveyed participating genetic counselors and genetic counseling students were also replicated in this study. For example, our results indicate that most genetic counselors think non-clinical jobs are beneficial to the profession, which mirrors Liberman’s (2016) Workforce Statement, “It strengthens the profession for genetic counselors to work in non-clinical positions.” In addition, the data on Liberman’s Workforce Statement, “Genetic counseling trainees should be able to obtain logbook credit for rotations with counselors in non-clinical positions” matched responses regarding the suggestion that, “Non-clinical rotations can be used to fulfill logbook requirements.” Some findings which had not been previously shown to have statistical significance achieved statistical significance in this present study (Liberman, 2016). The need to increase the diversity of curricula across genetic counseling programs to account for the growth of the non-clinical side of the profession has similarly been reaffirmed (Field et al. 2016; Powell et al. 2010).

Regarding the topic of job satisfaction and areas of improvement, several points should be addressed. Clinical counselors, as stated previously, are less satisfied with a greater number of aspects of their jobs compared to their non-clinical peers, though not to the point of dissatisfaction in any area. This disparity likely partially explains why clinical counselors

as a group are more receptive to beneficial changes to the clinical workplace. The lukewarm response to such changes by non-clinical respondents may have several explanations; some respondents explicitly stated they simply would never willingly go back to a clinical position because it doesn't fit their strengths, or that they are much more satisfied with non-clinical employment. For these individuals, an entirely intrinsic explanation for their employment choice could be at play such that changes to clinic (unless almost impossibly enticing) would not sway them to return. For others, there could be some level of extrinsic motivation (pay, location, other benefits) to remain in a non-clinical setting and swaying them to take/return to a clinical position would have to involve matching their current motivations, at a minimum. Some motivations, such as salary or recognition, could be feasible if clinical institutions adjusted scales and practices to be more accommodating of such factors. Other motivations, like more diverse opportunities, might feasibly be outside the realm of standard full-time clinical employment, depending on the institution.

Given that patient contact is one area in which clinical counselors do report greater satisfaction, enhancing this aspect may also attract more counselors back to clinical positions as opposed to attempting to focus on bolstering administrative support. The most recent PSS reported that patient volume had increased at most institutions while available staff had, for the most part, remained the same (NSGC, 2016). While we assumed that reduction of caseload would be highly supported by clinical respondents, this change was rated as the least valuable among clinical respondents for improving the clinical experience. Our interpretation of this finding is that genetic counselors highly value patient interaction, thus it

is an increase in support systems and not a decrease in patient volume that need to be addressed within the clinic. It is clear from our data that a significant percentage of clinical counselors struggle with the level of administrative support they are provided, and that a change in this area (increasing administrative support), along with improvements in salary, were the highest rated areas among clinical respondents for incentives to staying in a clinical position. Part of this issue is that some respondents also reported experiencing a significant burden from billing and insurance issues. Outlets that genetic counselors could use to divert such administrative and logistical issues would undoubtedly help to provide more time to focus on patient interactions. One option to address this issue would be to hire a genetic counseling assistant or other administrative staff; an option which many respondents were in favor of implementing.

Another avenue for improving clinical job satisfaction, based on reported desire to have a greater range of available professional opportunities as well as improved flexibility in scheduling, would be for institutions to offer more positions where genetic counselors take on mixed clinical and non-clinical duties. Such a diversified role may optimally address the desire for patient contact while providing clinical counselors an opportunity to pursue other non-clinical interests such as laboratory work, research, marketing, or other opportunities that are also beneficial to their institution. Such a shift would require increasing support staff who could work alongside the counselor to tackle any logistical problems that may be encountered. The feasibility of implementing such a diversified role may be limited at smaller institutions, but may be more likely at major care centers.

Regarding interest in and awareness of non-clinical employment options among applicants to genetic counseling programs, our study confirmed that the majority of applicants enter genetic counseling programs with the intention of taking a position in the clinical workforce. As there was no statistically significant difference between recent and earlier graduates in their preferences for clinical versus non-clinical positions, it seems that attitudes regarding the choice to take a clinical versus a non-clinical position has not changed appreciably, even in light of the shift toward non-clinical work. Previous studies on this topic have identified an improved awareness of non-clinical positions among more recent graduates (Lieberman, 2016). Awareness of non-clinical positions among more recent graduates was limited in our study population, though the preference of clinical versus non-clinical positions does not appear to stem from ignorance of the availability of non-clinical opportunities. That being said, some individuals do begin their genetic counseling training with an interest in non-clinical work and it is important for genetic counseling programs to provide unbiased consideration of these students, and regard them as equivalent to other clinically-interested peers during the admissions process.

Based on the fact that more recent graduates were prepared for several aspects of NC jobs than those graduated earlier, coverage of topics related to NC jobs may be improving in recent years. While a minority of genetic counselors who are working in NC positions indicated that they preferred NC jobs before they entered a genetic counseling program, the majority were likely to have gained exposure to such roles primarily during or after graduate school. With the increasing awareness and coverage of non-clinical positions by genetic

counseling graduate training programs, more students may become interested in NC positions during graduate school as opposed to after graduation. There is a strong interest in further implementing changes to genetic counseling training programs to continue the trend of greater coverage of non-clinical topics in curricula as well as adding or lengthening non-clinical rotations. The strength of this interest to expose students to non-clinical positions has not been captured by previous survey studies of genetic counselors in biotechnology and the pharmaceutical industry (Field et al. 2016), and underscores the importance of addressing non-clinical topics for both clinical and non-clinical genetic counselors. There was also a great deal of variability in the specific topics and the amount of coverage these topics should receive among respondents. While greater coverage of non-clinical topics is most likely desired, programs would face challenges in deciding what information they should add to an already packed curriculum, and how much time should be dedicated to such non-clinical topics.

Along with increasing coverage of non-clinical topics in the curricula, there is also the issue of expanding non-clinical rotations in genetic counseling graduate programs. Regardless of employment setting or year of graduation, respondents were largely in favor of a required rotation in a laboratory or industry setting. Similarly, participants suggested existing rotations in these areas be lengthened, with many respondents wanted such rotations to be as long as a regular clinical rotation. Given such a prevalent attitude about both the requirement for and length of laboratory and industry rotations, several benefits may accrue to programs expanding this aspect of training. Bolstering the knowledge base and skillset of



students planning to enter the non-clinical workforce and normalizing this setting for clinically-focused students who might not otherwise experience this part of the field could be integral to developing a modern genetic counseling workforce. However, this expansion may be complicated by the clinical logbook requirements which students must complete before graduation. Clinical and non-clinical counselors were found to be somewhat receptive to allowing non-clinical rotation work to count towards cases logged, which reinforces an opinion identified previously by Liberman (2016).

Yet another area of potential improvement to graduate training with respect to non-clinical topics was interest in recruiting more faculty from non-clinical backgrounds. Enlisting faculty with experience in areas outside of those encountered in clinic would be particularly useful in building greater awareness among students regarding available non-clinical opportunities. As shown by our data, there is a strong desire for greater exposure to these opportunities regardless of whether more structured implementations to the curriculum are made. Mentorship with non-clinical faculty can bring to light many topics and issues that would not otherwise be sufficiently explored, which parallels the reported interest in greater visibility of non-clinical coursework. Given the connections non-clinical faculty are likely to have with former coworkers and training sites, they may also serve to facilitate development of rotations and related non-clinical activities for students.

Reported attitudes about non-clinical counselors thought to be held by clinical counselors are clearly mixed. Among the surveyed participants, many seem to hold the belief that non-clinical employment is, to some degree, stigmatized despite, or perhaps in some

ways because of, the growth of this side of the profession. While stigma regarding non-clinical counseling has been anecdotally reported from a number of sources, to our knowledge, this study is the first to quantify such attitudes. As the trend within the genetic counseling profession continues toward greater non-clinical emphasis, it is essential to normalize the path these counselors have taken, lest further rifts develop that impact the solidarity of the profession. Genetic counseling graduate programs, which serve as a primary source for students to familiarize themselves with the profession, are especially important in setting the foundation that legitimizes clinical and non-clinical work. Providing coursework and rotations covering non-clinical roles as well as mentorships by non-clinical faculty members would be likely to make non-clinical work seem less foreign and to normalize these settings for future students.

Besides stigma regarding non-clinical counselor positions, greater perceived COI of non-clinical counselors is another attitude held primarily by clinical counselors. Such concerns regarding COI may relate to stigma regarding these roles. Another possibility is that non-clinical genetic counseling experience somehow reduces perceptions of COI among non-clinical counselors. Since this study measured perceptions, the underlying reasons for this change in the perception is not clear. Possible explanations may include: there could be less COI in non-clinical jobs than was previously expected; clinical GCs have similar levels of COI as non-clinical GCs; COI has been adequately attended to through profession-wide attention and debate; GCs sufficiently self-monitor the potential for COI using via GC code of ethics. The finding that clinical genetic counselors are more likely to think that

non-clinical genetic counselors have greater levels of COI might be contrasted with the great majority of clinical as well as non-clinical genetic counselors thinking that non-clinical jobs are beneficial for the profession. This suggests that while COI might yet be an unresolved concern, the overall impact of non-clinical roles is viewed positively. If additional training on COI were included in graduate training, perceptions regarding COI and non-clinical roles could be normalized.

In contrast to how participants thought clinical counselors viewed non-clinical counselors, the shift toward more non-clinical positions in general has been seen as beneficial in many ways to the profession as a whole. Greater acknowledgement of these benefits might prove useful towards reducing stigma and raising awareness of less traditional career choices for genetic counselors. However, significant concern about the ramifications of this growth for the clinical side of the profession and training new genetic counselors was also expressed by study participants. Although there is no data to suggest that there is a deficiency in the ability of the clinical realm to maintain itself moving forward, this topic should be further investigated to determine if such concerns exist, and how they are related to shifts within the profession.

Given the continuing shift from traditional clinical jobs to non-clinical positions in recent years, and in light of the information provided by this study, it is not surprising that survey participants were largely in favor of increasing the coverage of non-clinical topics in genetic counseling training programs. Providing students more structured opportunities, such as non-clinical coursework and rotations, would be essential in providing the foundation that

allows these concepts to be further developed post-graduation. Parallel to this expansion would be the improvement of the visibility of non-clinical jobs to provide students with ample opportunities to learn more about non-clinical work in a way that meets the individual interest level of the student, and by which avenues the student decides would be most suitable for themselves. Such flexibility would provide significant benefit to genetic counseling training programs by allowing clinical training to remain the primary focus of the program while implementing changes that are likely to make non-clinical work seem less foreign and to normalize these settings for future students.

### **Limitations**

In most of our survey questions, we defined clinical and non-clinical genetic counselors as those who are currently counseling patients versus those who are not counseling patients, respectively. The reason behind this definition is that it is the same definition is used by NSGC Professional Status survey (National Society of Genetic Counselor 2008, 2012, 2016a). The only exception was when we asked whether counselors were prepared for non-clinical jobs, as we asked them to answer the question only if they have ever worked as non-clinical genetic counselors. Fifty-seven counselors who are currently counseling patients answered this question. This means that many clinical counselors define themselves as having non-clinical work experience. It is also true that 43 (36.8%) clinical counselors spend less than 40% of their work time counseling patients. Had we defined non-clinical genetic counselors as those having positions where patient counseling was a minority of their role, or we analyzed the data by job roles, our results

might have been different. The scope of our study did not include refining the NSGC's definition of clinical counseling, so our data was not analyzed to account for such alternative definitions. Further studies exploring whether such positions are viewed as clinical or non-clinical by genetic counselors as a whole may refine the definition currently used by the NSGC. Similarly, we divided our data into two groups by year of graduation: those who graduated in 2010 or later, and those who graduated in 2009 or earlier for the purposes of statistical analyses; however, the field of genetics changes rapidly, and it is possible that trends are different between people who graduated in 2010, and those who graduated in 2016.

Our survey might have attracted more non-clinical genetic counselors than clinical genetic counselors, due to the title of the survey. Approximately 40% of our respondents do not counsel patients whereas only 25.0% of participants in 2016 Professional status survey do not counsel patients (National Society of Genetic Counselor 2016a). While our data was useful in comparing the opinions of clinical and non-clinical counselors, the respondent population may not be the representative of the whole genetic counselor community, and may be enriched for non-clinical genetic counselors.

Our survey respondents were diverse in their experience, age, and years since graduation. While this can be regarded a strength of our study, because we collected a wide variety of opinions, some of our questions were better suited for targeted subgroups. For example, the question regarding bias against non-clinical genetic counselors by genetic counseling programs and the question about preference in position prior to entering school

may be more suited to current students and faculty members rather than practicing genetic counselors.

### **Conclusion**

The goal of our exploratory study was to illuminate issues facing genetic counselors employed in both clinical and non-clinical settings and report on attitudes regarding potential solutions to minimizing the gap between job satisfaction between clinical and non-clinical genetics counselors that have been previously suggested in the literature. This study identified several areas where improvements could be made to increase satisfaction within and preparedness for the various roles that genetic counselors have taken on. Furthermore, we identified significant differences in the perceptions of clinical and non-clinical counselors regarding several key topics. As the profession's understanding of these topics is relatively nascent, additional research to build on the findings of this study should be pursued so that the potential benefits to all counselors can be more fully realized.

### **Acknowledgements**

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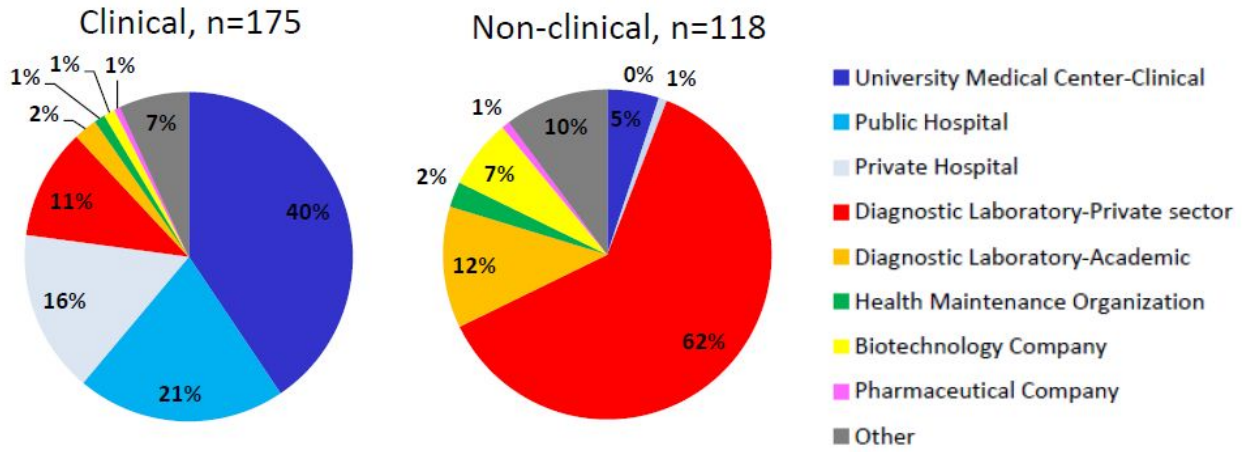
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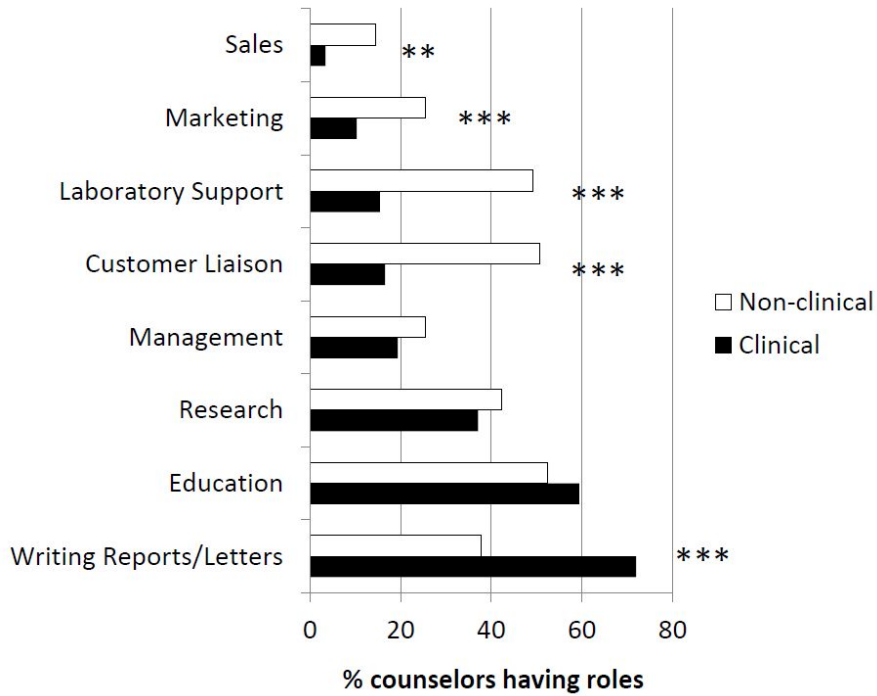
**Appendix A: Figures**

**Figure 1: Work setting of clinical and non-clinical participants**



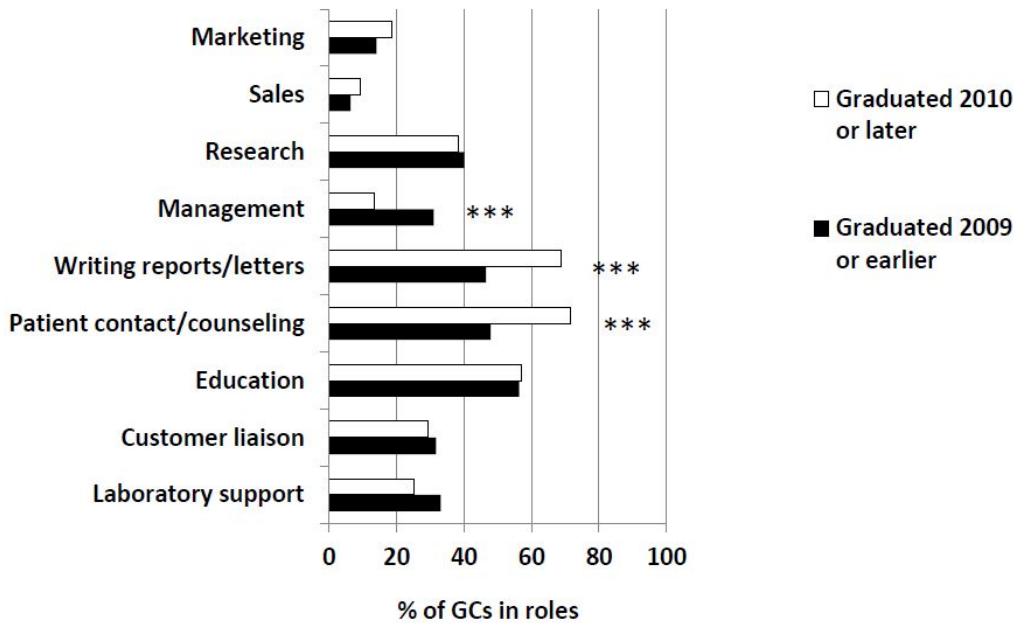
Pie charts demonstrating difference in work-setting between C and NC counselors.

**Figure 2:** Roles performed at current/most recent job



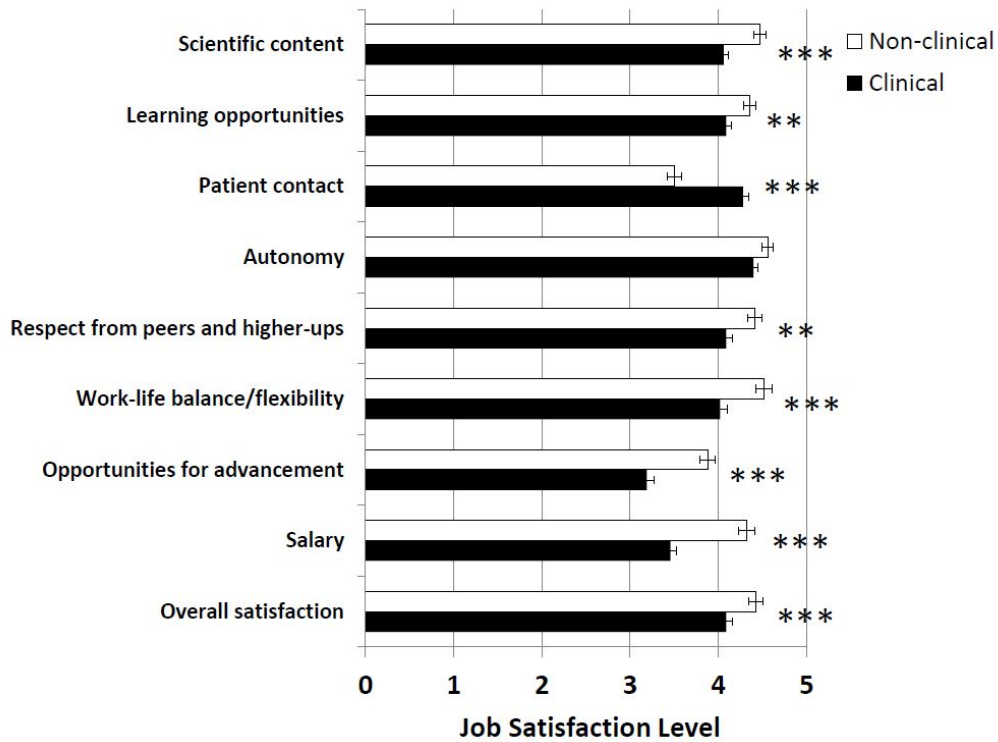
Survey participants were asked whether their work involved each of these different roles. Chi-square testing was performed to evaluate the difference in number of GCs performing each role in clinical and non-clinical counselors. Asterisks indicate that there was a significant difference in the proportion of clinical and non-clinical GCs. Three asterisks:  $p < 0.001$ ; two asterisks:  $p < 0.01$ .

**Figure 3:** Roles at current/most recent position by year of graduation



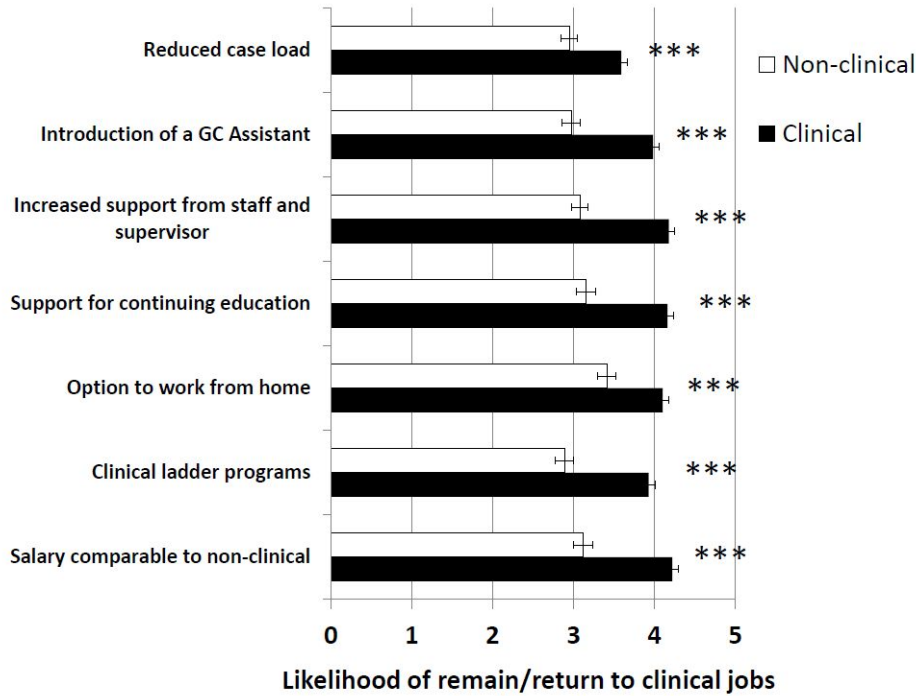
Survey participants were asked whether their work involved each of the different roles. Chi-square testing was performed to evaluate the difference in the number of GCs performing each role in recent versus earlier graduates. Asterisks indicate that there was a significant difference in the proportion of GCs who graduated in 2009 or earlier and those graduated more recently. Three asterisks:  $p < 0.001$ .

**Figure 4:** Job satisfaction of clinical and non-clinical GCs



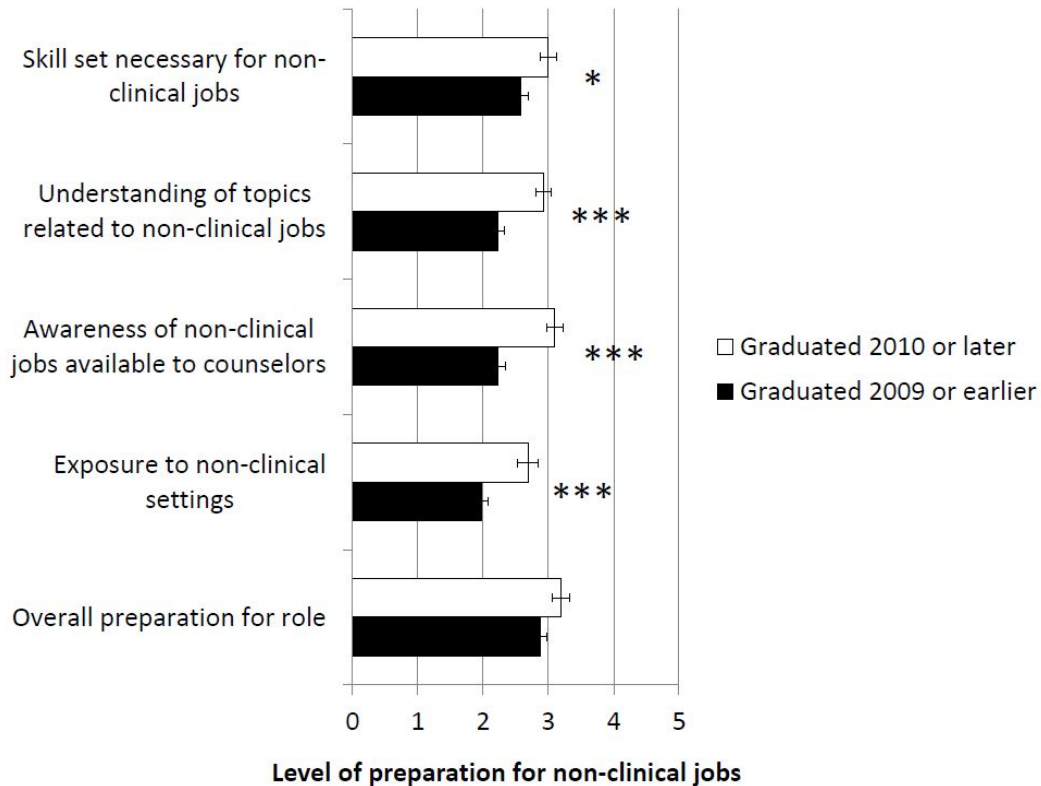
Survey participants were asked to rate the level of job satisfaction on a Likert scale where 1 = Very dissatisfied to 5 = Very satisfied. Error bars: standard error of the mean. Student's t test was performed to evaluate the difference in satisfaction levels between clinical and non-clinical GCs. Asterisks indicate that there was a significant difference in the level of job satisfaction between clinical and non-clinical GCs. Three asterisks:  $p < 0.001$ ; two asterisks:  $p < 0.01$ .

**Figure 5:** Likelihood of genetic counselors to remain or return to clinical jobs if attributes or programs are present



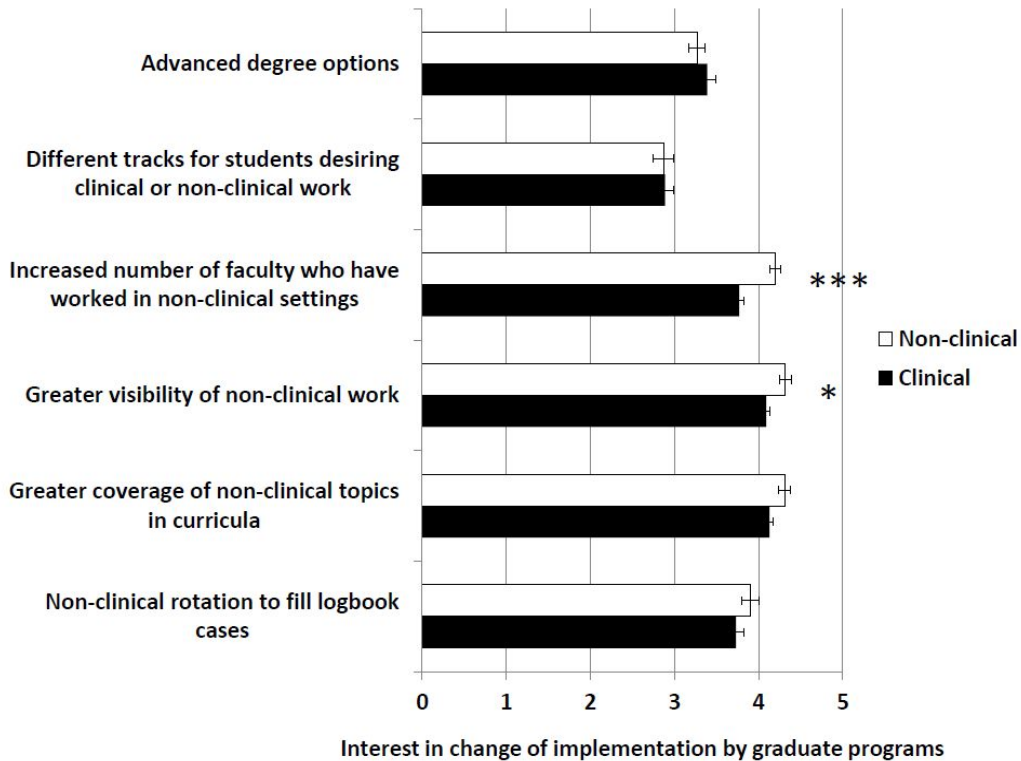
Survey participants were asked to rate how likely they would be to remain in/return to a clinical position based on an attribute/program using a Likert scale of 1 = Very unlikely to 5 = Very likely. Error bars: standard error of the mean. Student's t test was performed to evaluate the difference in likelihood of remaining in/returning to a clinical position between C and NC GCs. Asterisks indicate that there was a significant difference in how much each attribute would entice clinical and non-clinical GCs to remain or return to clinical positions. Three asterisks:  $p < 0.001$ .

**Figure 6: Preparedness for non-clinical roles**



Survey participants who have worked as non-clinical GCs were asked to rate how prepared they were for non-clinical positions when they graduated from a GC program using a Likert scale of 1 = Prepared me barely at all for the position to 5 = Prepared me very well for the position. Error bars: standard error of the mean. Two-tailed Student's t test was performed to evaluate the difference in preparedness levels between clinical and non-clinical GCs. Asterisks indicate that there was a significant difference in preparedness for non-clinical jobs between GCs who graduated prior to 2010 and those who graduated in 2010 or later. Three asterisks:  $p < 0.001$ ; one asterisk:  $p < 0.05$ .

**Figure 7:** Interest in changes to genetic counseling programs



Survey participants were asked to rate their interest in changes to genetic counseling programs using a Likert scale of 1 = Very disinterested to 5 = Very interested. Error bars: standard error of the mean. Two-tailed Student’s t test was performed to test the difference in satisfaction levels between clinical and non-clinical GCs. Asterisks indicate that there was a significant difference in clinical and nonclinical GC’s interest in different implementations by genetic counseling programs. Three Asterisks:  $p < 0.001$ ; one asterisk:  $p < 0.025$ . The significance level was adjusted for multiple comparisons by Bonferroni correction ( $\alpha = 0.025$ ).



## **Appendix B: Tables**

**Table 1:** Participant demographic information

Variable	n	%
Age (N=301)		
≤30	114	37.9
31-40	111	36.9
41-50	45	15.0
≥50	31	10.3
Gender (N=301)		
Female	289	96.0
Male	12	4.0
Race (N=301)		
Caucasian	279	92.7
Other or Multi-Racial	21	7.0
Prefer not to answer	1	0.3
Geographic Region (N=301)		
Region I (Northeast)	51	16.9
Region II (Mid-Atlantic)	53	17.6
Region III (Southeast)	28	9.3
Region IV (Midwest)	89	29.6
Region V (Mountain + TX)	38	12.6
Region VI (West)	42	14.0
Other Degrees Held (N=293)		
MPh	7	2.4
MBA	5	1.7
PhD	4	1.4
MD	1	0.3
BSN	1	0.3
Graduation Year (N=293)		
2009 or Earlier	142	48.5
2010 or Later	151	51.5
Board Certified (N=293)		
Yes	273	93.2
No	20	6.8

**Table 2** Current or Most Recent Work Setting

Work Setting		
University Medical Center Clinical	77	26.3
Public Hospital	36	12.3
Private Hospital/Clinic	29	9.9
Health Maintenance Organization	5	1.7
Diagnostic Laboratory-Academic	18	6.1
Diagnostic Laboratory-Private Sector	92	31.4
Pharmaceutical Company	2	0.7
Biotechnology Company	10	3.4
Other	24	8.2

**Table 3:** Other incentives to remain in clinic or to leave a non-clinical position for a clinical position

<b>Theme</b>	<b>n</b>	<b>%</b>
New opportunities (research, learning, career ladder)	15	21.7
Recognition and respect	12	17.4
Flexibility (scheduling, workload, location)	11	15.9
Not willing to return	11	15.9
More clinical, administrative, or institutional support	6	8.7
Less issues dealing with insurance	5	7.2
Increased salary	5	7.2

**Table 4:** Themes identified in responses for insufficient preparedness for non-clinical positions

<b>Theme</b>	<b>n</b>	<b>%</b>
Lack of availability/awareness of non-clinical positions	19	39.6
Business, marketing, and sales	13	27.1
Laboratory work, variant curation	13	27.1
Research, grant writing	5	10.4
Billing and insurance	3	6.3

**Table 5:** Themes among responses regarding conflicts of interest (COI)

<b>Themes</b>	<b>n</b>	<b>%</b>
Depends on the role, organization	57	58.2
Both clinical and non-clinical GCs have COI	25	25.5
GC code of ethics should protect GCs from COI	16	16.3
Inherent in non-clinical roles	9	9.2

**Table 6:** Open responses regarding non-clinical applicant bias

<b>Theme</b>	<b>n</b>	<b>%</b>
Not familiar enough to know	15	36.6
Curriculum has a bias against students interested in non-clinical	10	24.4
Depends on the program	9	22.0
Bias against students interested in non-clinical is improving/never existed	5	12.2
Clinical training takes precedence over non-clinical interests	4	9.8
Applicants still not aware of non-clinical roles when applying	3	7.3

**Table 7:** Open responses regarding clinical GC's attitudes toward non-clinical GCs

<b>Theme</b>	<b>n</b>	<b>%</b>
Used to/still have negative feeling toward NC counselors	56	58.9
Going to the dark side/selling out/motivated only by salary	15	15.8
There is less negative feeling now	15	15.8
NC counselors are not good counselors	14	14.7
Appreciate NC GCs	13	13.7
Envy for cushier jobs	11	11.6
Depends on the person and organization	8	8.4

**Table 8:** Open response data collected regarding shift toward growth of non-clinical positions

<b>Theme</b>	<b>n</b>	<b>%</b>
Greater recognition of and respect for the genetic counseling profession	48	55.9
Concern about clinical workforce diminishing/not being able to clinically train students	30	34.9
Demonstrates the diversity of roles that genetic counselors can assume	30	34.9
Demonstrates the utility of genetic counselor skillset	20	23.3
We will see/go with the times	10	11.6

**Table 9:** Common Themes Identified Regarding Better Non-Traditional Role Preparation

<b>Theme</b>	<b>n</b>	<b>%</b>
Greater portion of curriculum devoted to non-clinical topics	76	71.0
More exposure to non-clinical roles	50	46.7
Normalize perception of non-clinical roles	21	19.6
Clinical training must remain the main focus of training	9	8.4
Greater emphasis on business issues in genetic counseling programs	9	8.4

### **Appendix C: Survey Recruitment Notice**

Hello,

We are genetic counseling students at Sarah Lawrence College and would like to invite you to participate in our thesis project. We are exploring professional issues facing genetic counselors employed in clinical as well as non-clinical settings, factors influencing shifts from clinical to non-clinical roles, and opinions on genetic counseling training related to non-clinical roles.

We are asking you to complete a survey, which should take no more than 30 minutes of your time. In order to participate in this study, you must be a genetic counselor currently working in the United States or Canada.

The link to the survey is as follows:

[LINK]

As part of our thesis project, we intend to conduct interviews to better understand themes emerging from analysis of the survey data. If you are willing to be interviewed, please provide your name and email address when prompted at the end of the survey so we can contact you to schedule the interview.

Thank you for your time and consideration.

Sincerely,

Robert Rigobello and Maki Kaneko

This thesis project is overseen and endorsed by Claire Davis, MS, CGC, Associate Director of the Joan H. Marks Graduate Program in Human Genetics at Sarah Lawrence College, and Michelle Strecker MS, CGC, LGC, Senior Director of Genetic Counseling Services at CombiMatrix.

## **Appendix D: Survey Consent**

You are being asked to take part in a research study on perspectives and opinions of clinical and non-clinical genetic counseling roles. Our study seeks to identify factors underlying shifts from clinical to non-clinical roles as well as how training might be adjusted to prepare genetic counselors for both types of positions.

Why am I being asked to participate?

- You are a genetic counselor who currently works, or has worked, in a non-clinical or clinical genetic counseling position in the US or Canada.

What will I be asked to do?

- In addition to demographical questions, you will also be asked about your job satisfaction, reasons for job changes, and opinions about genetic counseling training.
- This survey should take no more than 30 minutes.

Is my participation voluntary?

- Your participation is voluntary and you can choose to stop the survey at any point.
- You can also choose not to answer specific questions without having to justify your choice.

Are there any benefits or risks associated with my participation in this study?

- The risks associated with participation include discomfort when considering job satisfaction, reasons for job changes, and opinions about genetic counseling training.

Will the information I provide be kept confidential?

- This is an online anonymous survey; your responses will not be connected with any identifying information.
- If you choose to provide your contact information, it will be separated from your responses prior to analysis.
- You will not be identified in any written or oral report of the research study.
- All responses will be stored in password protected files.

If I have any questions or concerns after the study how can I contact you?

- If you have any questions or concerns, please contact Robert Rigobello (rrigobello@gm.slc.edu), Maki Kaneko (mkaneko@gm.slc.edu), or Claire Davis (cdavis@sarahlawrence.edu).

Who can I contact if I have questions about my rights as a research participant?

- You may contact the IRB co-chair, Professor Elizabeth Johnston, at 914.323.6672 or irb@sarahlawrence.edu.

By clicking “NEXT”, you confirm that you have read the above information and agree to participate in this study.

## **Appendix E: Survey Questions**

Title: Survey of genetic counselors in clinical and non-clinical settings

Q1 If you have read the above information and agree to participate in this study, click yes.

Q2 How old are you?

-21-25

-26-30

-31-35

-36-40

-41-45

-46-50

-51-55

-56-60

-61-65

-Over 65

Q3 What is your gender?

-Male

-Female

-Other

-Prefer not to answer

Q4 What is your ethnicity? (Please select all that apply.)

-American Indian or Alaskan Native

-Asian or Pacific Islander

-Black or African American

-Hispanic or Latino

-White / Caucasian

-Prefer not to answer

-Other (please specify)

---

Q5 Where are you from?

-Alabama

-Alaska

-Arizona

-Arkansas

-California

-Colorado

-Connecticut

-Delaware

-District of Columbia



- Florida
- Georgia
- Hawaii
- Idaho
- Illinois
- Indiana
- Iowa
- Kansas
- Kentucky
- Louisiana
- Maine
- Maryland
- Massachusetts
- Michigan
- Minnesota
- Mississippi
- Missouri
- Montana
- Nebraska
- Nevada
- New Hampshire
- New Jersey
- New Mexico
- New York
- North Carolina
- North Dakota
- Ohio
- Oklahoma
- Oregon
- Pennsylvania
- Rhode Island
- South Carolina
- South Dakota
- Tennessee
- Texas
- Utah
- Vermont
- Virginia
- Washington
- West Virginia
- Wisconsin
- Wyoming
- Alberta

- British Columbia
- Manitoba
- New Brunswick
- Newfoundland and Labrador
- Northwest Territories
- Nova Scotia
- Nunavut
- Ontario
- Prince Edward Island
- Quebec
- Saskatchewan
- Yukon
- Other Country

Q6 What year did you graduate from your Genetic Counseling program?

- 2016
- 2015
- 2014
- 2013
- 2012
- 2011
- 2010
- 2009 or earlier

Q7 What advanced degrees do you hold?

- MS
  - MA
  - MPH
  - PhD
  - MD
  - MBA
  - JD
  - None
  - Other (please specify)
- 

Q8 Are you ABGC board certified?

- Yes
- No

Q9 How many years of practice do you have?

- Less than 1 year
- 1 year

- 2 years
- 3 years
- 4 years
- 5 years
- 6-10 years
- 11-15 years
- 16-20 years
- More than 20 years

Q10 What is your current/most recent work setting?

- University Medical Center-Clinical
  - Public Hospital
  - Private Hospital/Clinic
  - Health Maintenance Organization
  - Diagnostic Laboratory-Academic
  - Diagnostic Laboratory-Private Sector
  - Pharmaceutical Company Biotechnology Company
  - Other (please specify)
- 

Q11 What is/are your major area(s) of specialty in your current/most recent job? (Please select all that apply.)

- Prenatal
  - Pediatrics
  - Cancer
  - Other (please specify)
- 

Q12 Do/did you counsel patients in your current/most recent job?

- Yes
- No

Q13 If "Yes" was your answer to the previous question, what percentage of time do/did you spend counseling patients?

- 81-100%
- 61-80%
- 41-60%
- 21-40%
- 1-20%

Q14 What roles did you have at your most recent job? (Please select all that apply.)

- Laboratory support
- Customer liaison

- Education
  - Patient contact/counseling
  - Writing reports/letters
  - Management
  - Research
  - Sales
  - Marketing
  - Other (please specify)
- 

Q15 What was/were the reason(s) for taking your most recent position? (Please select all that apply.)

- Higher earning potential
  - Opportunity for career advancement
  - Wanted to learn something new
  - Job flexibility
  - Location/geography
  - Burnout at the previous job
  - Patient contact
  - Autonomy
  - Support by staff and supervisors
  - Other (please specify)
- 

Q16 How satisfied are you with your most recent position?

- 1 Very Dissatisfied
- 2 Dissatisfied
- 3 Neutral
- 4 Satisfied
- 5 Very Satisfied

Q17 Rate how satisfied you are with the following areas within your most recent position.  
5 (Very Satisfied), 4 (Satisfied), 3 (Neutral), 2 (Dissatisfied), 1 (Very Dissatisfied)

- Salary
- Opportunities for advancement
- Worklife balance/flexibility
- Respect from peers and higherups
- Autonomy
- Patient contact
- Learning opportunities
- Scientific content

Q18 If there is an area you have significant satisfaction or dissatisfaction with that is not listed above, please state that area and whether you are satisfied or dissatisfied with it.

---

Q19 How likely are you to remain/return to a clinical position if the following attributes/programs are available?

5 (Very Likely), 4 (Likely), 3 (Neutral), 2 (Unlikely), 1 (Very Unlikely)

- Salary comparable to non-clinical positions
- Clinical ladder program
- Option to work from home
- Support for continuing education
- Increased support from staff and supervisors
- Introduction of a Genetic Counseling Assistant
- Reduced case load

Q20 If there is an attribute/program that you feel would make you very likely to remain/return to a clinical position which is not listed above, please state what that attribute/program would be below.

---

Q21 Before you entered your genetic counseling program, did you have a preference for clinical or non-clinical work?

- 5 Strong preference for clinical work
- 4 Slight preference for clinical work
- 3 Neutral
- 2 Slight preference for non-clinical work
- 1 Strong preference for non-clinical work
- Did not know

Q22 If you have worked as a non-clinical/industry genetic counselor, rate how well do you think your education at your genetic counseling program prepared you for the role?

- 5 Prepared me very well for my position
- 4 Prepared me moderately well for my position
- 3 Prepared me somewhat for my position
- 2 Prepared me only slightly for my position
- 1 Prepared me barely at all for my position

Q23 (If you answered the previous question) Evaluate each of the following areas based on how well your program prepared you in them.

5 (Prepared me very well for my position), 4 (Prepared me well for my position), 3 (Prepared me somewhat for my position), 2 (Prepared me slightly for my position), 1 (Prepared me barely at all for my position)

- Exposure to nonclinical settings
- Awareness of nonclinical jobs available to counselors
- Understanding of topics relating to nonclinical jobs (laboratory techniques, public health,

business, etc.)

-Skill sets necessary for nonclinical jobs

Q24 If there was an area in which your program did not sufficiently prepare you for a non-clinical position that is not listed above, please specify what that area was.

---

Q25 How did you learn skills and knowledge that were not taught in graduate school? (Please select all that apply.)

-From a training course offered by the institution

-From an outside course I took

-From coworkers

-From a supervisor

-From meetings

-On the job

-Other (please specify)

---

Q26 Did you have laboratory or other non-clinical rotation while you were at your genetic counseling program?

-Yes

-No

Q27 If "Yes" was your response to the previous question, how long was this rotation?

-1-5 Days

-6-10 Days

-11-15 Days

-16-20 Days

-21-25 Days

-More than 25 days (please specify)

---

Q28 Specify the focus of the non-clinical rotation (laboratory, industry, public health etc.).

---

Q29 Do you think genetic counseling programs should require a laboratory/industry rotation?

-Yes

-No

Q30 If "Yes" was your answer to the previous question, how long should the rotation last?

-1-5 Days

-6-10 Days

-11-15 Days

- 16-20 Days
  - 21-25 Days
  - More than 25 days (please specify)
- 

Q31 Please rate your interest in the implementation of the following changes into genetic counseling programs.

5 (Very Interested), 4 (Interested), 3 (Neutral), 2 (Disinterested), 1 (Very Disinterested)

- Non-clinical rotations can be used to fulfill logbook requirements
- Greater coverage of non-clinical topics in curricula
- Greater visibility of non-clinical work
- Increased number of faculty who have worked in non-clinical settings
- Different tracks for students desiring clinical or non-clinical work
- Advanced degree options

Q32 Do you think non-clinical genetic counselors have greater conflict of interest than do clinical genetic counselors?

- Yes
- No
- Not sure

Q33 If you want to provide further clarification for your answer to the previous question, please provide it here.

---

Q34 Do you think genetic counseling programs are biased against applicants interested in non-clinical work during the admissions process?

- Yes
- No
- Not sure

Q35 If you want to provide further clarification for your answer to the previous question, please provide it here.

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Q36 Do you think genetic counselors working in clinical positions view non-clinical counselors negatively?

- Yes
- No
- Not sure

Q37 If you want to provide further clarification for your answer to the previous question, please provide it here

---

Q38 Do you think the recent increase of genetic counselors working in non-traditional roles is beneficial to the field as a whole?

-Yes

-No

-Not sure

Q39 If you would like to share additional information regarding your answer to the previous question, please provide that here.

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Q40 Please give us your opinion on what genetic counseling programs can do, if anything, to better prepare students for nontraditional roles

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