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Exploring the Implementation of Non-Traditional / Expanded Training for Genetic Counselors

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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Abstract

With over a third of Genetic Counselors working in a Non-Traditional or expanded role, there is no denying that their knowledge and skills are transferable and being increasingly applied to roles outside the clinic. However, as of 2018, the Accreditation Council for Genetic Counselors (ACGC) practice standards require 50 core cases from a clinical setting while placements outside the clinic, such as a laboratory, research studies, or public health settings are considered enhancements, not requirements. Yet, the ACGC also states that “training should reflect current trends in the workplace,” leaving it up to training programs to decide how best to prepare students for the profession. Clinical coordinators from training programs and Hiring Managers for Non-Traditional settings were interviewed to understand their opinions on student training as well as to compare and contrast the opinions of those preparing students to be hired to the expectations of those doing the interviewing and hiring.

Note: Interviews for this study took place before the proposed revisions to the standards were made available for public comment by ACGC in 2019.

Key terms

American Board of Genetic Counseling (ABGC), Accreditation Council of Genetic Counselors (ACGC), Clinical Coordinator (CC), Clinical Training, Experience, Exposure, Genetic Counselor (GC), Hiring Manager (HM), National Society of Genetic Counselors (NSGC), Non-Traditional (NT), Practice-Based Competencies (PBCs), professional status survey (PSS), Rotation.

Introduction

The late 1960s saw the birth of the Genetic Counselor in a climate of changing policies, advances in the field of genetics, and a revolution of bioethics with an increased emphasis on patient autonomy (Stern, 2009). Traditionally, the field has been dominated by middle-aged, white women working directly with patients in clinical settings. Thus, the term ‘traditional role’ has been applied to describe a counselor

providing direct patient care, typically in a medical setting. Almost 50 years later, however, Genetic Counseling has become a high-demand profession with almost 5,000 counselors in practice. Today's counselors include men and women ranging in age from their mid-twenties to late-sixties from various ethnic backgrounds. (NSGC, 2018a). Departure from the traditional Genetic Counselor mold is most evident in the evolution of the Genetic Counselor's role within the genetics field.

According to the Professional Status Survey (PSS) published in 2018 by the National Society of Genetic Counselors (NSGC), 59% of counselors reported providing direct patient care as their primary role and 25% providing non-direct patient care as their primary role, with 16% working in both capacities (NSGC, 2018b). Compared to the 2016 NSGC PSS, there has been a 10% decrease from the 69% of counselors who reported providing exclusively direct patient care. With 74% of counselors reporting working in traditional roles in NSGC's 2014 PSS, this is a staggering 15% decrease of Genetic Counselors providing direct patient care as their primary role in the span of four years (NSGC, 2016; NSGC, 2014).

A Genetic Counselor's Scope of Practice

Since the establishment of the Genetic Counselor role in the 1960s, the medical field has seen revolutionary advancements redefining the possibilities of healthcare. In response, Genetic Counselors have adapted by expanding and redefining their role within the system (Christian, Hume, Scott, & Sommerville, 2011). No longer limited to the clinical setting, Genetic Counselors are now fixtures in laboratories, health insurance companies, and biotechnology and pharmaceutical research institutions (Field, Brewster, Towne, & Camption, 2016).

The completion of the Human Genome Project in 2003 resulted in the consideration of genetics when treating disease, leading to technological innovations that enabled genetic testing and the quest to provide personalized medicine, an approach to healthcare that takes into account the relationship between genetics and environment (Shelton & Whitcomb, 2015). The increased demand for testing resulted in a deluge of

data, requiring individuals with specialized genetic training, such as Genetic Counselors, to interpret results, not only to patients who may be anxious to understand the outcome of their testing but to the healthcare team working to provide individualized care.

As Genetic Counselors expand their areas of practice, they continue to exceed their historic role. Genetic counselors report performing a variety of Non-Traditional roles including customer liaison, administrative duties, sales/marketing, and management (Christian et al., 2011). Genetic counselors are found in settings such as public health, research, and biotechnology, where responsibilities may include recruiting/hiring, study coordination, participation on an internal review board (IRB), and writing for publication (NSGC, 2018a). As Genetic Counselors continue to permeate the healthcare system, they prove to be assets in a variety of duties, beyond their originally defined skills and roles.

Exposure to Genetic Counselors working in industry settings, such as in laboratories, pharmacogenetics, and research, is limited and varied among the accredited training programs in the United States and Canada. In 2016, a study of both experienced and newly graduated Genetic Counselors working in the biotechnology and pharmaceutical industries concluded that 72% felt their graduate training did not adequately prepare them for their roles (Field et al., 2016). A number of studies have been published in recent years, detailing the skills and roles of Genetic Counselors in Non-Traditional settings with suggestions to equip students with the necessary tools to excel in industry roles. As the PSS statistics have indicated a changing of the tides, there is a push for training programs to adapt their curriculum and allow for more variety in student exposure in their field assignments (Christian et al. 2011); (Waltman et al., 2016); (Field et al., 2016). While some Genetic Counseling training programs have started to integrate some variety into their lessons, the core curriculum remains stagnant despite the rapid evolution of the field.

Graduate Program Curriculum

Training programs design their curriculum based on standards set forth by the Accreditation Council of Genetic Counselors (ACGC) in order to establish and maintain their accreditation status. The ACGC is the organization responsible for establishing the fundamental knowledge and skills essential for all Genetic Counselors in the United States and Canada, the Practice-Based Competencies (PBCs) (Doyle et al., 2016). Each program is responsible for curating their curriculum and fieldwork experiences to reflect the PBCs, establishing a baseline standard of education for all graduates. The PBCs were officially updated in 2013 to include 22 skills organized within the following four domains, 1. Genetics Expertise and Analysis, 2. Interpersonal, Psychosocial, and Counseling Skills, 3. Education, and 4. Professional Development and Practice (ACGC, 2015). The ACGC notes that the defined PBCs are the minimum requirements necessary for a practicing Genetic Counselor.

The Standards of Accreditation adopted in 2014 required programs to provide courses designed to “support the development of practice-based competencies” as well as working clinical experience with a minimum of 50 (20 prenatal, 12-13 cancer, 12-13 pediatrics, and 5 adult cases) core cases needed to graduate based on a Practice Analysis conducted by the ABGC in 2011 (ACGC, 2014; ABGC, 2016; “Practice Analysis and Information,” n.d.). Although the Standards of Accreditation dictate the necessity of rotation opportunities such as laboratory work or research experience, these placements are not requirements (ABGC, 2016).

In their master’s thesis completed in 2017, Kaneko and Rigabello established the need for Genetic counselors to receive expanded training to reflect the increasing opportunities for Genetic Counselors in Non-Traditional roles (Kaneko & Rigobello, 2017). Moving forward, the questions are: when, where, and how? What is the best way to prepare Genetic Counselors for the myriad of career opportunities available to them?

Methods

For the purposes of this study, the term ‘Non-Traditional’ was used to describe any Genetic Counselor working in a setting outside of a medical office, conducting in-person sessions in any clinical setting as their primary role (>50% of their time), including: prenatal, cancer, pediatric, and specialty clinics (i.e. cardiology, neurology). The term was used to describe any role that falls beyond the original role of the Genetic Counselor as an in-person resource and advocate for patients making decisions based on their genetic information.

Recruitment

Individuals were recruited in a purposive method, based on their current role in the field of genetic counseling: Clinical Coordinators and Hiring Managers.

As all 49 ACGC accredited genetic counseling training programs were recruited for participation using homogeneous sampling as well as total population sampling. Clinical coordinators were identified by accessing each training program’s website for faculty contact information. Prospective participants from all accredited training programs located in the United States and Canada were individually sent an email explaining the purpose of the study and inquiring if they were the person responsible for arranging clinical rotation placements for students. In some cases, the initial contact was not a Clinical Coordinator but facilitated contact with the appropriate individual for that institution. Identified Clinical Coordinators were sent another email including an overview of the study and a time frame for interviews along with an attached consent form and list of interview questions.

Homogeneous sampling was used when recruiting Hiring Manager participants, meaning that only individuals who are responsible for the hiring and management of genetic counselors in a Non-Traditional setting were contacted. Contact information for Hiring Managers in Non-Traditional settings was provided by the supervisor of this study, Lindsey Alico, CGC, using homogeneous sampling. Ms. Alico

made the initial contact via email to 27 Hiring Managers working in a variety of Non-Traditional settings. Those who expressed interest were sent another email including an overview of the study and a time frame for interviews along with an attached consent form and list of interview questions. Additionally, initial Hiring Manager contacts helped to recruit participants by reaching out to colleagues in a similar roles who might be interested in taking part in the study, resulting in snowball sampling.

Data Collection

Participants were interviewed via recorded phone call. Interviews were conducted from January 8, 2019 through March 21, 2019. The interview questions varied between the two cohorts, with 17 predetermined prompts for the Clinical Coordinators (CCs) and 24 pre-determined prompts for the Hiring Managers (HMs). Interviews were conducted in a semi-structured manner, using the predetermined prompts as a guide. The number of questions for each interview varied for each participant depending on the applicability of certain questions, the need for clarification, and respondent elaboration.

The first 8 interview questions were the same for both cohorts and included information regarding demographics, interpretation of terminology, training and work experience, and opinions on training expectations for students enrolled in genetic counseling graduate programs. Questions specific to the CCs included information regarding the level of experience as a Clinical Coordinator, student interest in Non-Traditional roles, availability of rotation placements, and alternatives to rotations for students to gain Non-Traditional awareness and understanding. The questions specific to HMs elicited information regarding time in field before taking a Non-Traditional role, how well their graduate training program prepared them for their Non-Traditional role, level of experience within a Non-Traditional role, training provided by their employer, expectations of applicants, desired level of experience for candidates, and their employer's involvement in training of genetic counseling students. The types of questions asked were open-ended, leading, and scales.

Data Analysis

Interviews were transcribed using NVIVO transcription and qualitative data analysis was performed using ATLAS.ti version 8.4.0. The data obtained from the interviews are reported as averages, counts, percentages, and standard deviations. Transcription, coding, and analysis were all performed by a single investigator. After transcription, each interview was de-identified and assigned an identifier. The Clinical Coordinator cohort interviews are labeled 1-32 while the Hiring Manager cohort interviews are labeled as A – O, with a specific number or letter assigned to each individual. Data from the two cohorts were analyzed independently. Responses to scale questions were arranged in frequency distributions. If a respondent provided a range, values were averaged and rounded up to the nearest whole number. Free response questions were analyzed using inductive coding to identify themes and cluster participant responses.

Results

A total of 47 individuals, 32 CCs and 15 HMs, consented to participate in this study and were interviewed via recorded phone calls.

For the purposes of this study, Clinical Coordinators (CCs), are individuals responsible for assigning field training/rotation placements for students to obtain the requirements outlined by the ACGC in order to be considered board eligible. Of the 32 Clinical Coordinator interviews conducted, one was excluded. A participant misinterpreted the interview questions; their responses were in reference to immersive experiences in disability communities with a focus on individuals with disabilities and their daily lives, not in terms of the various ways Genetic Counselors could contribute their skills to the community. Attempts to redirect the participant were unsuccessful. As the data from this interview were unrelated to the roles or skills of a Genetic Counselor, it was not utilized in this study.

The Hiring Manager (HM) cohort includes individuals responsible for hiring Genetic Counselors to work in a diagnostic laboratory, pharmaceutical, or research setting, all based in the United States. This cohort consisted of 15 representatives from nine diagnostic laboratories, one pharmaceutical company, and one research project. Therefore, some of the workplace settings had multiple participants represented in the study.

Demographic Information

The average number of years since graduating from a genetic counseling training program for the 31 remaining Clinical Coordinators, was 17 years. Time in the field ranged from 5 to 38 years, ($\sigma = 9$). The years of experience working as a Clinical Coordinator was an average of 6.5 years, with responses ranging from 1 year to 30 years ($\sigma = 7.11$). Three responses (14, 27, and 32) surpassed $+2\sigma$ from the average, reporting 30, 22, and 21 years working as a Clinical Coordinator, respectively.

The average time since graduating from various training programs for the HMs was 15.6 years with responses ranging from 5 to 34 years ($\sigma = 8.22$). One response (M) exceeded $+2\sigma$ from the average, with 31 years in the field. The Hiring Manager cohort's time between graduating and moving into a Non-Traditional role averaged 6.27 years with responses ranging from 0 to 20 years ($\sigma = 6.27$). Considering the number of years working in a Non-Traditional setting, the average for Hiring Manager respondents was 8.4 years with respondents ranging from 2 to 15 years of experience in Non-Traditional roles ($\sigma = 3.42$). *See Figure 1.*

Defining Non-Traditional

When prompted to define the term 'Non-Traditional,' respondents from both cohorts answered similarly, identifying 4 general categories, including: non-clinical, non-patient facing, roles that deviate from prenatal/pediatric/ cancer clinical counseling, and emerging roles. From there, interpretations of each category were highly variable between the participants.

Participants from both cohorts mentioned moving away from the term 'Non-Traditional.' There was a general sentiment that the term was limiting and did not serve the profession well. "The way that we use these words is limiting. I think defining what people mean by them and breaking that down a little is really critical when we have these conversations because I think there can often be a lot of confusion and different understandings of what is meant by 'Non-Traditional' or 'expanded' role" (Clinical Coordinator: 31). Hiring manager F believed defining roles outside of the clinical setting as "Non-Traditional," allows these roles to be considered 'other' and to be overlooked by training programs, explaining that, "if we really viewed this profession as Non-Traditional and rare and don't prepare people for that, people still do it and they still do really well, but there are other people that are not being exposed to it as they should."

Others expressed concern that the label was stigmatizing and non-inclusive. There's "still some stigma associated with working in a lab for example which is the biggest chunk of 'Non-Traditional'" explained participant 13. Clinical coordinator 32 hoped that counselors would move away from the terminology "so that sort of everything looks like a level playing field, so one's not considered more traditional than the other and we all just can sort of consider it a part of potential opportunities for Genetic Counselors." Many held the opinion that, as the profession has evolved, 'Non-Traditional' simply isn't applicable anymore. "a third of new grads are going into Non-Traditional roles, and I think, when you start talking about a third of people, you stop talking about Non-Traditional (Hiring Manager: G). Clinical coordinator 5 struggled with what was considered Non-Traditional, explaining that "it's hard to bucket them into black and white buckets like we used to a long time ago where it really was so limited, you either just did clinic or you did...research. Now there's just huge variety in this field."

Non-Traditional Exposure During Graduate Training

Participants from both cohorts were asked if they personally had a Non-Traditional rotation or co-curricular assignment during their graduate training, and, if so, how they would rate the value of that

experience on a scale of 1 (not at all valuable) to 10 (extremely valuable). 15 / 31 Clinical Coordinators reported Non-Traditional exposure during their graduate training. Of those 15 participants, 8.6 / 10 was the average value for a personal experience with responses ranging from 5 - 10 ($\sigma = 1.50$). Participant 24's value ranking of 5 fell outside -2σ from the average. When asked the same question, 7 of the 15 HMs reported Non-Traditional exposure during their training program. These graduate exposures were rated from 3 - 10 with an average of 7.43 ($\sigma = 2.94$). *See Figure 2.*

Those who assigned a high-value rating expressed that their Non-Traditional training during school allowed for a unique perspective on the profession. Hiring manager K said that their rotation through a diagnostic laboratory gave them “an angle on the field that no other experience could...I think it prepared me very much.” Others explained how Non-Traditional exposure lent to their clinical practice, stating that “those opportunities can really help you to have a stronger understanding of what's going on in other settings outside of just the clinic and you could incorporate that then into your clinical practice” (Clinical Coordinator: 30). Participants with low value ratings felt that their experiences either weren't long enough to get a full understanding of a Genetic Counselor's role in that setting, were in a highly specific setting where skills weren't transferable, or felt that it was not necessary for them to do their job as a Genetic Counselor. “I don't know that it was really necessary actually for me to do my job” (Clinical Coordinator: 8).

Hiring managers specifically were asked how prepared they felt to go into their Non-Traditional roles based on their graduate training. Those who did report having Non-Traditional exposure during school had an average preparedness rating of 4.86 / 10, with responses ranging from 2 to 8 ($\sigma = 2.04$). Those who did not report exposure during their graduate training had a preparedness average of 4 / 10 with responses ranging from 2 to 6 ($\sigma=1.73$).

There was mention that exposure in one setting may not lend itself to another due to the variability between the myriad of Non-Traditional genetic counseling roles. “When I came into this role, what we were doing was so specialized and so different than anybody else at the time that I’m not sure really much of anything could have prepared me for what I was going to do” (Hiring Manager: L). Hiring managers discussed certain components that would have been helpful, had they been taught during graduate training such as basic business/marketing skills, testing options and technologies, variant interpretation skills, utilization of population databases and protein predictors, customer service, sales skills and presentation skills.

Importance of Non-Traditional training for current students

Both cohorts were asked to rate on a scale of 1-10, 1 being not at all important and 10 being essential, the importance of Non-Traditional exposure during graduate training. 30 of 31 in the Clinical Coordinator cohort provided a quantitative value for the importance of Non-Traditional exposure for their students (Participant 9 failed to provide a numerical value). Ratings of importance were an average of 8.73 / 10, ranging from 4 - 10 ($\sigma = 1.28$), (*Figure 3*). Participants 8 and 23’s responses were outliers, falling outside -2σ from the average. Neither participant 8 nor 23 reported having Non-Traditional exposure during their graduate school training.

Using the same scale, 15 of 15 NMs responded with a quantitative rating of importance. Responses ranged from 4 to 10, with an average of 8.3 ($\sigma = 1.86$), (*Figure 3*). With an importance rating of 4, participant M’s response was an outlier. Participant M did report having exposure to Non-Traditional during graduate training.

The rationale for respondents’ higher importance ratings included, student knowledge of career options, holistic understanding of the field, increased placement options for larger class sizes, more qualified applicants for Non-Traditional roles, and reflecting the current job market. As they expressed when rating

the value of their own Non-Traditional (NT) experience during training, participants from both cohorts saw Non-Traditional rotations as an opportunity to see all the ways in which their degree could be applied. Hiring Manager L expressed their opinion that “it's important programs give an overview of what we do, what the roles are, what the opportunities are as a GC, and kind of a little bit about what those roles might look like. Clearly, you can't cover all of them, but I think ... it's important that students understand what the possibilities and what they might be exposed to just so they can prepare themselves if they do seek out a role like that.” It was also mentioned again that Non-Traditional experience would prove to be helpful in a clinical genetic counseling role. “I think it helps [Genetic Counselors] be better clinicians, and I think it helps them interface better with the laboratories that they work with and...working with a laboratory is not something that Genetic Counselors do infrequently, it comes up quite a bit” (Hiring Manager: G).

The rationale for respondents' lower importance ratings included, training will take place on the job, not essential to becoming a Genetic Counselor, and student preference for clinical roles. “Our profession is deeply rooted in the clinical aspects, that traditional core will always be there” (Clinical Coordinator: 5). Participants emphasized the importance of a strong clinical foundation upon which additional skills and applications could be built. Clinical Coordinator 3 was in agreement with that sentiment, saying “someone could potentially get a job in a non-clinical [role] and still be prepared to do it without having the exposure.” There was also concern that Non-Traditional experiences are taking away from students' mastery of the fundamental skills expected of a Genetic Counselor. Hiring Manager M mentioned “noticing...that the broadness of the programs has resulted in less training in clinical, reproductive genetics, and for [their] purposes as a Hiring Manager, what [they] need are counselors who have very strong clinical skills in reproductive genetics.” Many of the respondents who gave a lower importance rating felt that a graduate program's sole responsibility is to prepare students to sit for their boards.

When comparing the importance ratings of participants who reported Non-Traditional exposure during their own personal graduate training and those who did not, CCs with exposure averaged 9.43/10 whereas the CCs without exposure averaged 8.13/10 (*Figure 4*). Similarly, the HMs with exposure during graduate training averaged 8.57/10 and the HMs without Non-Traditional exposure average importance rating was 7.88 / 10 (*Figure 5*).

In regard to the extent for which training programs are responsible for providing Non-Traditional training, 94% of Clinical Coordinators believed that graduate programs are entirely/mostly, 6% said partially/somewhat, and 0% said not at all. When asked the same question, 67% of Hiring Managers said entirely/mostly. The outlier rating from Hiring Manager respondent M did report having exposure to Non-Traditional during graduate training, 20% said partially/somewhat, and 13% said not at all (*Figure 6*).

Those who responded with a high importance rating rationalized that exposure during training helps to get students thinking about the variety of career options and lends to a more qualified resume. Others believed that, as the career continues to evolve, it's the responsibility of programs to update curricula to reflect the current job market. Per participant 27, "programs have a responsibility to make sure that students know what the types of expanded roles are out there that they might want to pursue either...after graduation or at some point in their future careers." Respondents also explained that having knowledge of Non-Traditional roles will be beneficial for those who go into clinical counseling roles by creating awareness about what happens once a sample is sent out for testing as well as an understanding of the roles of other Genetic Counselors (GCs) with whom they'll be interfacing.

Non-Traditional rotations as a requirement

Both cohorts were asked if Non-Traditional rotations should be required as a prerequisite to graduating. Of the Clinical Coordinator participants, 22/31 (71%) respondents were against making a rotation requirement and 9/31 (29%) respondents were in favor. Similarly, the majority of the Hiring Manager

cohort were opposed to having a full rotation requirement as a graduation prerequisite, with 9/15 (60%) response in opposition and 6/15 (40%) respondents in favor (*Figure 7*).

When looking at the responses of Clinical Coordinator participants who did report having Non-Traditional exposure during school 64% were opposed and 36% were in favor. Considering the Clinical Coordinator participants without Non-Traditional training while in school 76% responded no and 24% responded yes (*Figure 8*).

When isolating the responses of Hiring Manager participants who reported Non-Traditional exposure during school, 43% were against a rotation requirement and 57% were in favor. HMs without Non-Traditional training while in school, 71% responded no and 39% responded yes (*Figure 9*). When combining the responses for both cohorts regardless of exposure (N=46), 67% were opposed to requiring a Non-Traditional rotation for students while 33% were in support.

Barriers to access

A common sentiment from all respondents referenced barriers to access for Non-Traditional rotation placements. The three main barriers mentioned by both cohorts included availability, affiliation agreements, and time limitations.

The most common concern expressed for making a Non-Traditional rotation requirement was the lack of availability for certain programs. Clinical Coordinator 25 explained that “we have done a really good job, as a profession, convincing clinical supervisors that they should be providing opportunities to have students work with them. I think, as a profession, we need to be doing that more with the counselors who are in industry roles or in public health roles or in research roles and getting them to open up the opportunities for students across all programs.” Some respondents reported that potential Non-Traditional supervisors are hesitant to take on students. “Counselors in our area that I reached out to, who work in

industry only, have this view of training students in a clinical setting. So if they're not interacting with patients directly, they tend to say 'no' to me when I ask them if they would be willing to host a student in a placement, because they don't really understand that [exposure to NT Genetic Counseling roles] is also valuable" (Clinical Coordinator 21). Geographical limitations were also reported. As some explained, "there's limited counselors [near our program available] to supervise and too many students to place" (Clinical coordinator 2). In regard to establishing affiliation agreements outside of a medical office setting, many CCs mentioned the difficulty and extensive time commitment required. Participant 10 "found that creating [affiliation agreements] with a private company is even more time-consuming and arduous than traditional rotations." Participant 1 explained that there is a "lack of understanding between academic institutions and commercial entities." Participant 1 also mentioned that sometimes they felt as though "the institution versus the commercial entities just speak a different language and have different requirements so it's difficult to translate in all circumstances." With the 2-years allotted by most programs to prepare students to become practicing Genetic Counselors, many mentioned a concern for having inadequate time to add in another rotation without having to make a cut somewhere else in the curriculum. "This is definitely a challenge that I think programs face right now and...there's so much to learn and only a fixed amount of time in which students can learn it" (Hiring Manager: G). Hiring manager N believes that "the responsibility of the training program is to get people ready to practice and pass the boards"; participant M explained that mastery of the clinical skills should come first and "these other Non-Traditional skills, so to speak, can be self-taught or learned through experience."

Alternatives to a Non-Traditional rotation

Clinical coordinators were asked what alternative ways their students could obtain exposure to Non-Traditional Genetic Counseling roles outside of a rotation setting. Common responses included didactic work, observational exposure, individual pursuits, and looking to literature. Many of the Clinical Coordinators report hosting individual speakers or panels of Genetic Counselors in Non-Traditional roles to introduce students to the various responsibilities associated with their part. While some programs may

not be able to accommodate full rotations, Clinical Coordinator participants discussed getting their students into some short term or observational rotations in a larger group setting in an effort to, at the very minimum, provide exposure to roles a Genetic Counselor can serve outside of a clinic setting. Clinical Coordinator respondents also mentioned various opportunities for students to seek exposure individually, including internships offered by Myriad Genetics and the Mayo Clinic, the online lecture series offered by GeneDx, research or capstone projects, and seeking out a mentor in a Non-Traditional role for insight and guidance. Others suggest that students who have a particular interest in Non-Traditional roles should look to the literature to gain a better understanding of available opportunities.

Discussion

The scope of Genetic Counseling practice is rapidly expanding. The NSGC's 2018 PSS reported 59% of Genetic Counselors providing direct patient care exclusively, leaving a remainder of 41% of counselors working either in both capacities or exclusively providing non-direct patient care (NSGC, 2018b). As more counselors are employed in increasingly varying roles outside of the clinical setting, additional knowledge and skills are being asked of them. As of now, much of this additional knowledge is obtained after being employed, either through formal training provided by their employer or on-the-job experience. According to Kaneko and Rigobello's 2017 study, counselors working in these expanded roles are reporting a lack of preparation by their graduate training and an established need for increased training.

The purpose of this study was to determine when, along a Genetic Counselor's career timeline, it would be best to receive this additional training, where this training should be obtained, and how best to go about providing counselors with the skills necessary to thrive in a variety of specialties and settings. Participants in this investigation were either involved in preparing Genetic Counselors to be hired or hiring Genetic Counselors for Non-Traditional roles to determine where the two cohorts were in agreement and where they differed.

Upon beginning the interview process, it immediately became clear that there was more ambiguity around the terms used in the interview prompts than predicted. When defining Non-Traditional/expanded roles, it was evident there were countless interpretations, some of which directly contradicted others. There were also conflicting definitions of the terms ‘rotation’, ‘experience’, and ‘exposure’.

When defining Non-Traditional or expanded roles, to some, this meant any role outside of a prenatal, pediatric, or cancer clinic setting. Others considered subspecialties, such as cardiogenetics or neurogenetics, to still be classified as “traditional,” and anything outside of the clinic or medical office setting was Non-Traditional. Many preferred using ‘non-clinical’ rather than Non-Traditional. To some, ‘non-clinical’ means not working in person, face-to-face with patients in a clinic or medical office as the primary role. To others, ‘non-clinical’ meant duties outside of providing patient care, identifying Genetic Counselors working in diagnostic laboratories as clinical counselors and those working in sales or administration as non-clinical.

Respondents expressed the opinion that providing counseling to patients over the phone was still “traditional” while others described any position where a Genetic Counselor is working remotely, whether working with patients, doing variant interpretation, or writing test reports, is defined as ‘Non-Traditional’. Others still described ‘Non-Traditional’ and ‘expanded’ as having different meanings, where ‘expanded’ describes roles that fall within the scope of Genetic Counseling (subspecialties, laboratory counselors, educators, etc.) and ‘Non-Traditional’ roles are outside of the clinic setting and beyond the scope of Genetic Counseling.

Participants also tended to differentiate the meaning of ‘rotation’, ‘experience’, and ‘exposure’. In general, ‘rotation’ was interpreted as a 6- to 10-week, formal placement for students to accrue their core cases; ‘experience’ implied a first-hand interaction for a short amount of time, such as an observational

rotation or a day spent in the field; and ‘exposure’ was inferred as second-hand information from speakers, mentors, or didactic class work.

With such murkiness surrounding the terminology, it’s difficult to imagine that all Genetic Counselors are entering the workforce on equal footing. When comparing two GCs who list research experience on their resumes, one may have had a 10-week formal rotation in a research setting while the other may have had a 3-day observational rotation. When also considering their interpretation, a Hiring Manager’s expectations of an applicant’s knowledge based on the word ‘experience’ could vary greatly.

While there were varying interpretations of what it actually meant, both Hiring Managers and Clinical Coordinators share a similar attitude about the term ‘Non-Traditional’ and the obstacles the word creates. Many participants felt the word was stigmatizing and detrimental to the growth of the field. Others resisted placing certain roles in the “other” category, making some positions more legitimate than others. One HM respondent proposed looking at the title ‘Genetic Counselor’ not as a job description, but as a qualification. Just as all physicians went to medical school and have the title ‘Doctor’ but specialize in a certain field, ‘Genetic Counselor’ indicates the type of training but not the specialty. Examples include a Genetic Counselor who works in pediatrics, a Genetic Counselor who works in research, or a Genetic Counselor who works in test utilization management. This type of reframing allows for the recognition of the core skills of the profession without limiting the scope of possible roles or contributions.

There appeared to be an association between participants’ own experiences with Non-Traditional training and their opinions of what training students should be getting during their graduate studies. With both Clinical Coordinator and Hiring Manager cohorts combined, participants who reported Non-Traditional or expanded role experiences during their training had a higher average importance rating for students receiving “Non-Traditional” training than those who reported not having Non-Traditional training in school. Additionally, those who had Non-Traditional training in school were more likely to want Non-

Traditional rotations to be required as a prerequisite for graduating than those who did not have Non-Traditional exposure in school. These trends indicate that those who had NT training during graduate school place increased value and importance on the experience when entering the workforce.

While those with NT experience were more likely to be in favor of making formal Non-Traditional rotations a requirement, the majority of both cohorts were opposed to requiring NT rotations. This was the expected response from the Clinical Coordinators, who are charged with the responsibility of navigating the semantics of placing their students in their various rotation sites. It was not as expected from the Hiring Managers, who, presumably would prefer experienced candidates to fill prospective roles within their companies. Based on the responses from both cohorts, it appears that NT experience for students is viewed as more of an additional perk than a necessity.

When assessing the extent to which training programs should be responsible for providing Non-Traditional training, a shocking 13% of HM respondents reported ‘not at all responsible,’ indicating a higher value on clinical training. This may indicate a preference for a strong foundation in the core knowledge and clinical skills, from which they could build expanded training. On the other hand, 94% of the CC cohort felt that graduate programs are “entirely/mostly” responsible for providing Non-Traditional training for their students. Yet, when asked if formal Non-Traditional rotations should be required as a prerequisite for graduating, only 29% said yes. It could be that CCs believe students should have access to NT opportunities if desired, but a formal rotation should not be a requirement. Another possibility is that CCs want to incorporate more NT training into their curricula, yet, due to barriers to access, making formal rotations a requirement for all students is not feasible.

Of the barriers to access, the one mentioned most frequently was geographical barriers. Many respondents felt as though making formal NT rotations a requirement would be impossible for certain programs who may be isolated or have limited access to work with Genetic Counselors in person. There was also

mention that if every student were required to have a formal NT rotation, the few sites that are available to programs would not be able to accommodate the influx of students. It was suggested, however, to utilize remote rotations (such a telephone counseling, variant interpretation, report writing, etc.) as an option to overcome this barrier. A variety of alternative options for students to obtain exposure to NT Genetic Counseling roles were provided by both CC and HM cohorts and are listed in *Appendix E*.

Finally, terminology commonly used in the field, such as ‘Non-Traditional’, ‘non-clinical’, ‘expanded’, ‘non-patient facing’, ‘exposure’, ‘experience’, and ‘rotation’ were found to have varying implications or meaning depending on the respondent. These conflicting interpretations may account for the stigma mentioned by many participants. Another consideration is the possibility of compromised or discordant training of students between the various graduate training programs, depending on the programs’ interpretations. One option is to standardize these terms or create a universal language to better outline intent and expectations when using these words. An alternative approach could be to move away from using Genetic Counselor as a type of job description to using it as a title, where the common ground is Genetic Counselor and the differentiation is an individual’s specialty.

Limitations:

Recruiting of study participants was performed using the purposive sampling method, disposing the entire study sample to researcher bias. Additionally, although the purposive sampling method known as total population sampling was utilized for the Clinical Coordinator cohort and all 49 ACGC accredited Genetic Counseling programs were contacted to participate in this study, only 32 Clinical Coordinators consented and were interviewed. Data collected from the CC cohort may not be representative of the all Clinical Coordinators from ACGC accredited Genetic Counseling programs.

Participants from the Hiring Manager Cohort were recruited using the purposive sampling method called homogenous sampling, meaning that individuals recruited for participation were selected based on their

occupation, again disposing the sample population to researcher bias. Additionally, those who were initially contacted helped to recruit additional participants by reaching out to colleagues with similar duties, resulting in snowball sampling. While this allowed for a larger sample size, it is possible that initial contacts reached out to colleagues who may be of a similar mindset, resulting in a bias participant pool, sampling bias.

Additionally, when drafting the interview questions, ‘Non-Traditional’, ‘non-clinical’, ‘non-patient facing’, and ‘expanded’ were all used to describe any Genetic Counseling role outside of an in-person session conducted in a clinic or medical office setting. Similarly, ‘rotation’, ‘experience’, and ‘exposure’ were intended to be used interchangeably to mean formal, in-person, experiential training for Genetic Counseling students. As there was so much discordance between the participants’ interpretation of the questions, it is possible the data may not be an accurate representation of respondent opinions. That being said, coding was performed with attempts to determine the participants' interpretation of the terminology.

Related to the varying definitions of terminology, the Kaneko and Rigobello capstone project, the basis of this research project, used the term ‘non-clinical’ rather than ‘Non-Traditional’. For the purposes of this study, ‘non-clinical’ and ‘Non-Traditional’ were synonymous; however, it is possible that respondents from the 2017 investigation may have differentiated between ‘non-clinical’ and ‘Non-Traditional’, meaning that the findings from the initial 2017 project may have been misinterpreted by the researcher of this study. If this was the case, the data collected may have different implications when being compared to the previous research.

Conclusions

Based on the ascertainments from the 2017 study conducted by Kaneko and Rigobello, there is a call from the Genetic Counseling community for Non-Traditional training to be implemented in graduate training programs. With this in mind, this study sought to establish how best to prepare both current and future

Genetic Counselors for these expanding career opportunities as well as the expectations of Genetic Counselors when hired for these positions.

In assessing the data from this investigation, it appears as though there is dissonance between Clinical Coordinator and Hiring Manager cohorts and the Genetic Counselor respondents from the 2017 study. While Genetic Counselors expressed feeling unprepared for Non-Traditional roles and the belief that training during graduate studies would be beneficial, the Clinical Coordinator and Hiring Manager participants of this study seem to view NT experience as a valuable extracurricular rather than a necessary prerequisite of success in Non-Traditional or expanded Genetic Counseling roles. Instead, there is a general consensus that a strong clinical background allows for the development of fundamental skills which can then be applied in a variety of settings. Whether this is from the point of view of understanding that applicants currently seeking employment will likely not have had a NT rotation during their training is uncertain.

Ultimately, this research illuminated the desire of both Clinical Coordinators and Hiring Managers to increase Non-Traditional training opportunities for students, an association between personal NT experience and perceived value and importance for students to receive NT training, a resistance to shifting the main focus of graduate training from core competencies and clinical experience, and a reaffirmed rejection of the term ‘Non-Traditional’. This study also served to highlight the inconsistencies in defining terms that are being liberally used in the profession and the need for standardization/establishment of common understanding to limit misinterpretation moving forward.

Areas for Future Study

In addition to providing valuable insight, this project also helped to identify additional subjects to be investigated including the possible standardization of commonplace terms, inquiry into the disconnect between CC opinion on the extent to which programs are responsible for providing NT training and

requiring NT training, in-depth rationale behind NT experience being perceived as a perk but not a necessity (Is this based on the current climate/preparedness of prospective applicants? Are clinical skills truly a necessary prerequisite to excel in NT roles?), and investigation into the value of a possible database or toolkit as a resource for graduate training programs to identify NT training opportunities for their students.

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Conflicts of Interest:

Dergham, Katia, researcher, declares that he has no conflict of interest.

Human Studies and Informed Consent:

All procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation (institutional and national) and with the Helsinki Declaration of 1975, as revised in 2000 (5). Informed consent was obtained from all patients for being included in the study.

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Appendix A: Figures

Figure 1. Years of experience for both the Clinical Coordinator and Hiring Manager cohorts

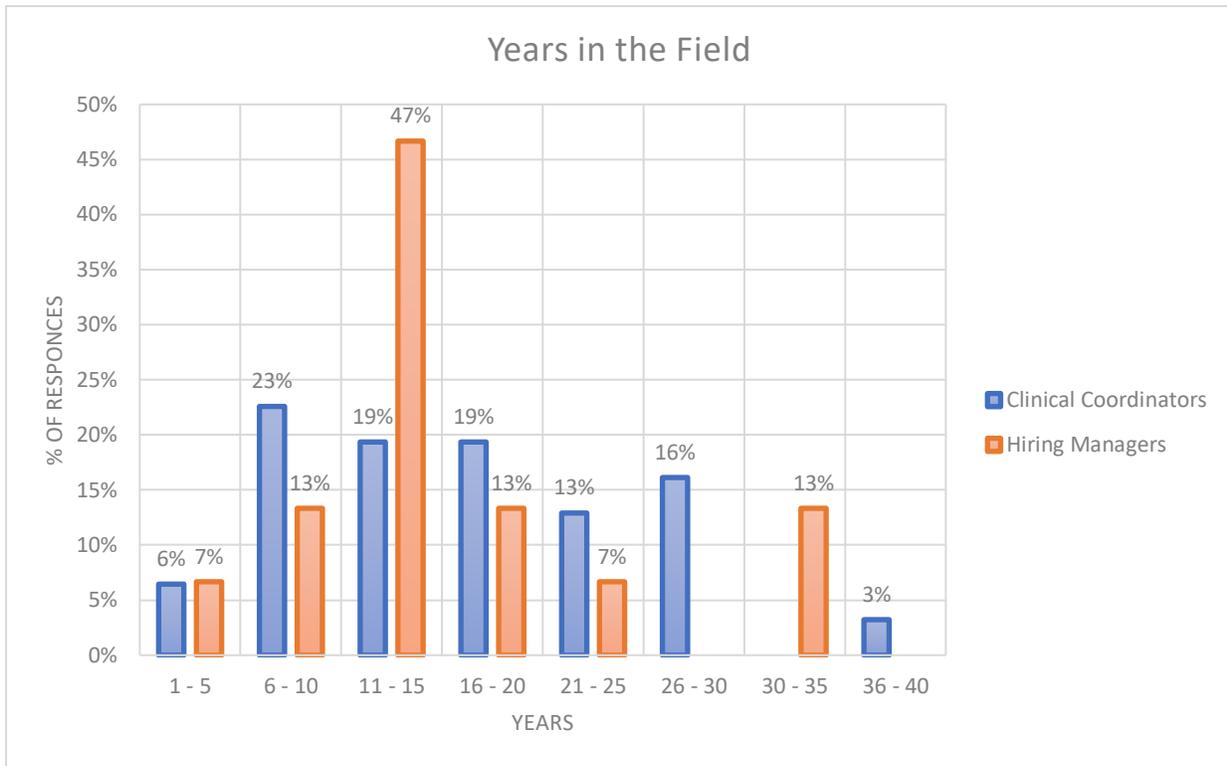


Figure 2. Respondent value rating of Non-Traditional exposure during their graduate training

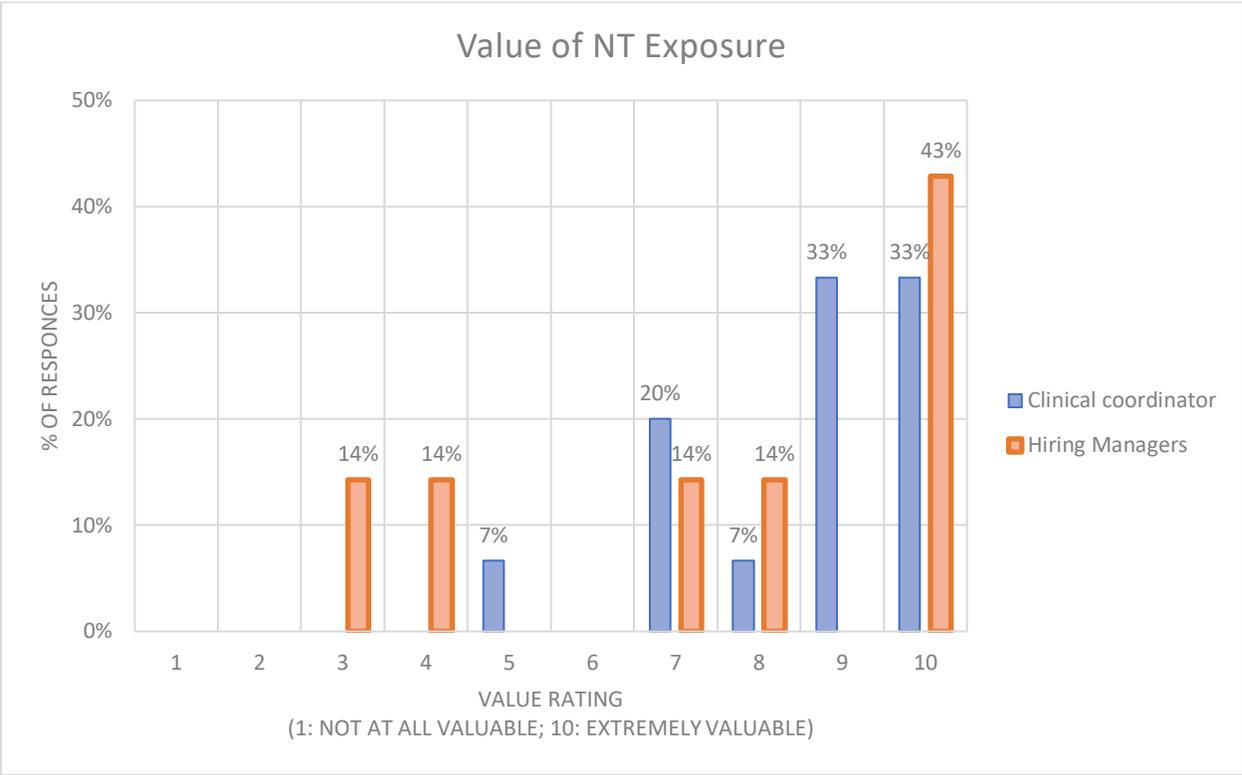


Figure 3: Rating of importance from all study participants (N=46) for Genetic Counseling students having Non-Traditional training during their graduate studies.

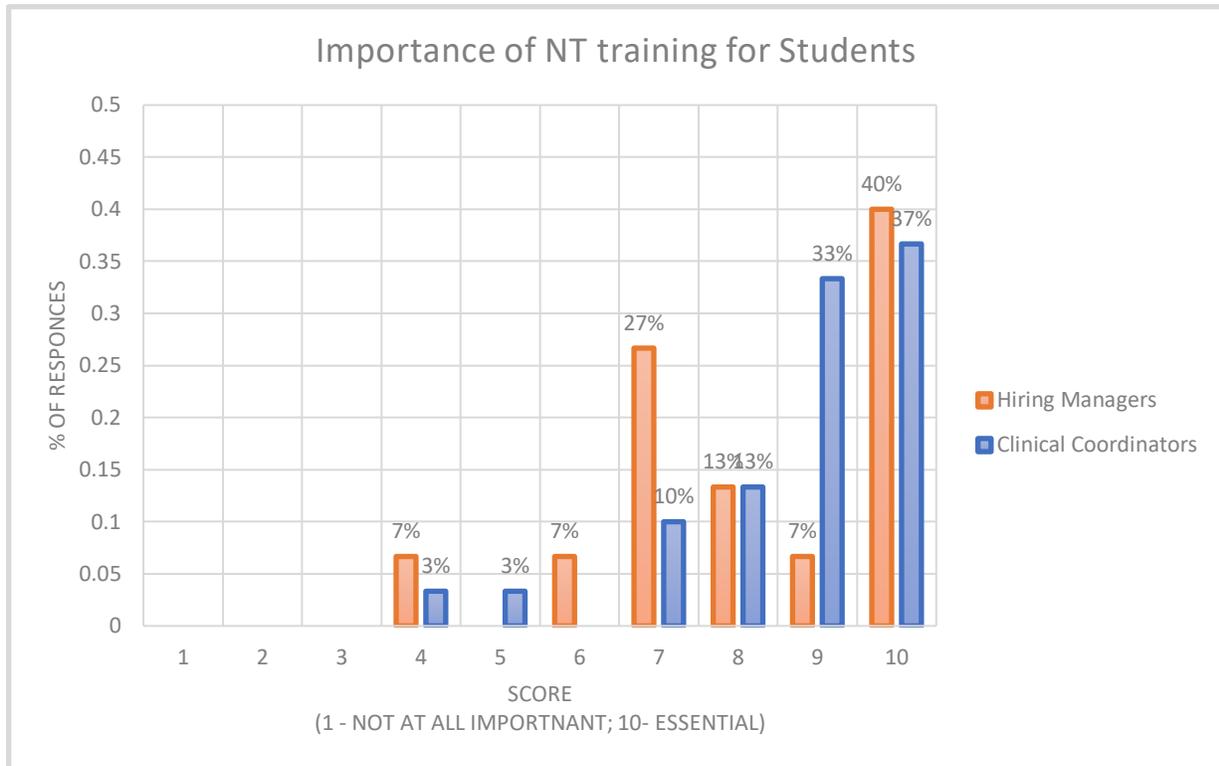


Figure 4: Importance ratings: Comparison of ratings of the Clinical Coordinators (N=31) who reported personal Non-Traditional experience during graduate training to the Clinical Coordinators who did not.

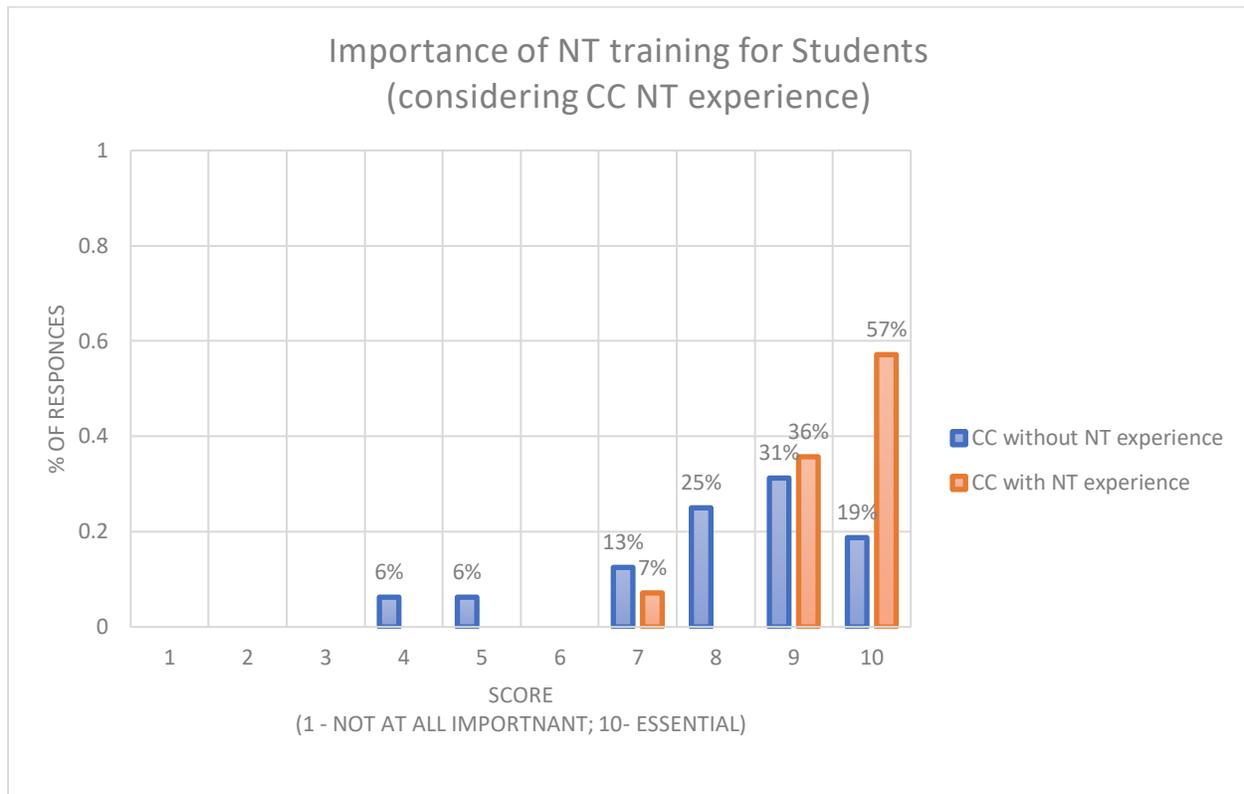


Figure 5: Importance ratings: Comparison of ratings of the Hiring Managers (N=15) who reported personal Non-Traditional experience during graduate training to the Hiring Managers who did not.

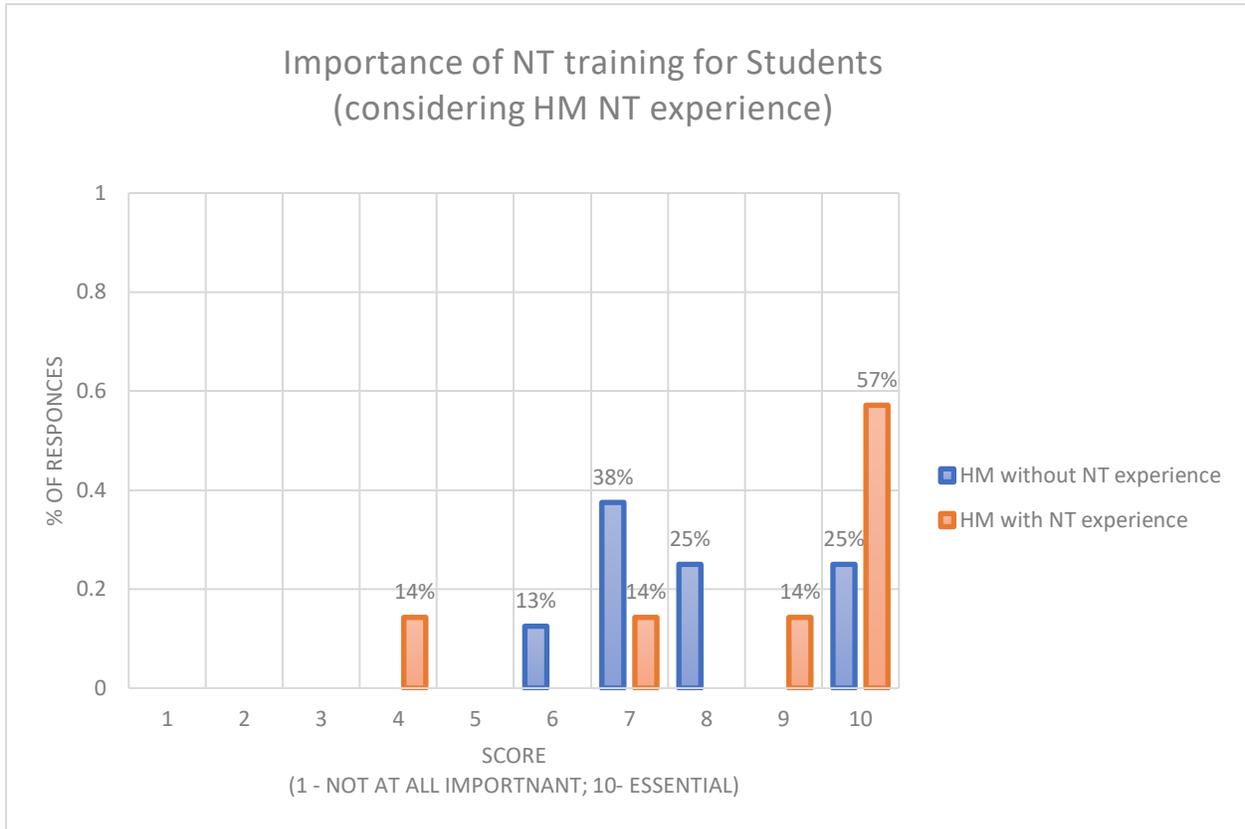


Figure 6: Extent to which respondents believe genetic counseling graduate programs are responsible for providing Non-Traditional training.

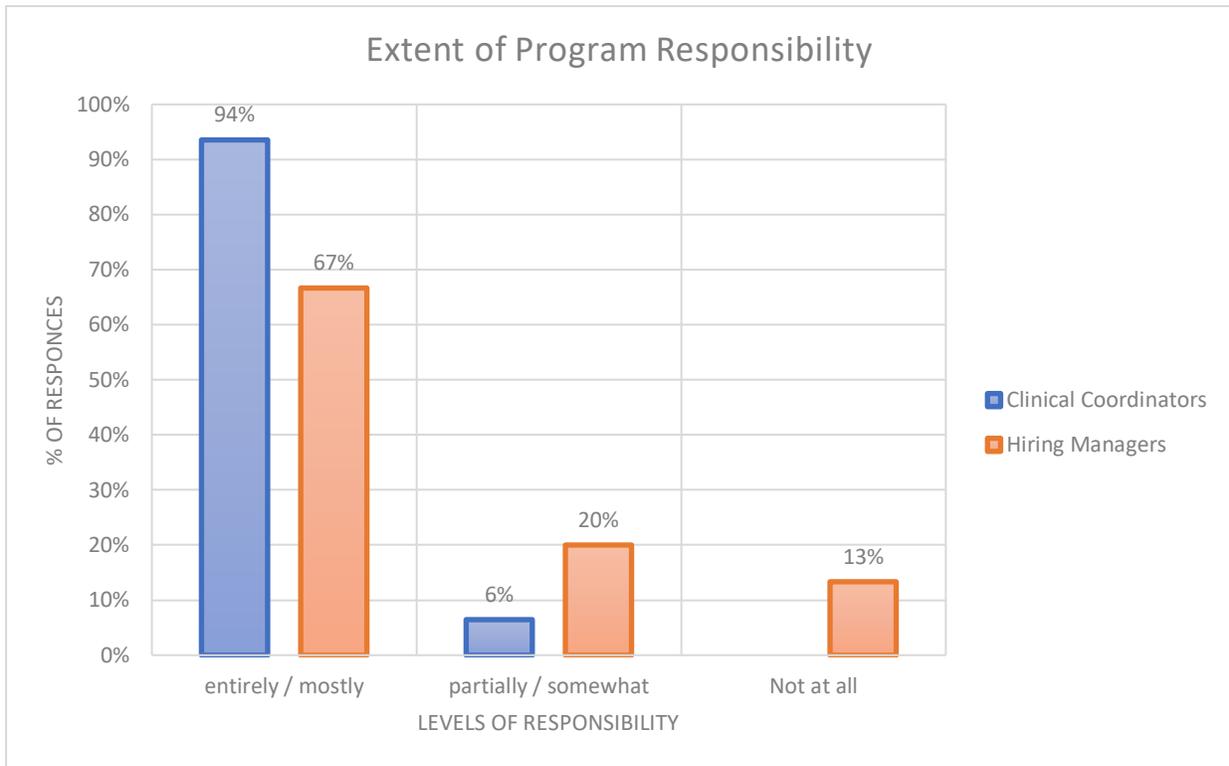


Figure 7: Respondents' opinion on whether formal Non-Traditional rotations should be required as a prerequisite to graduating.

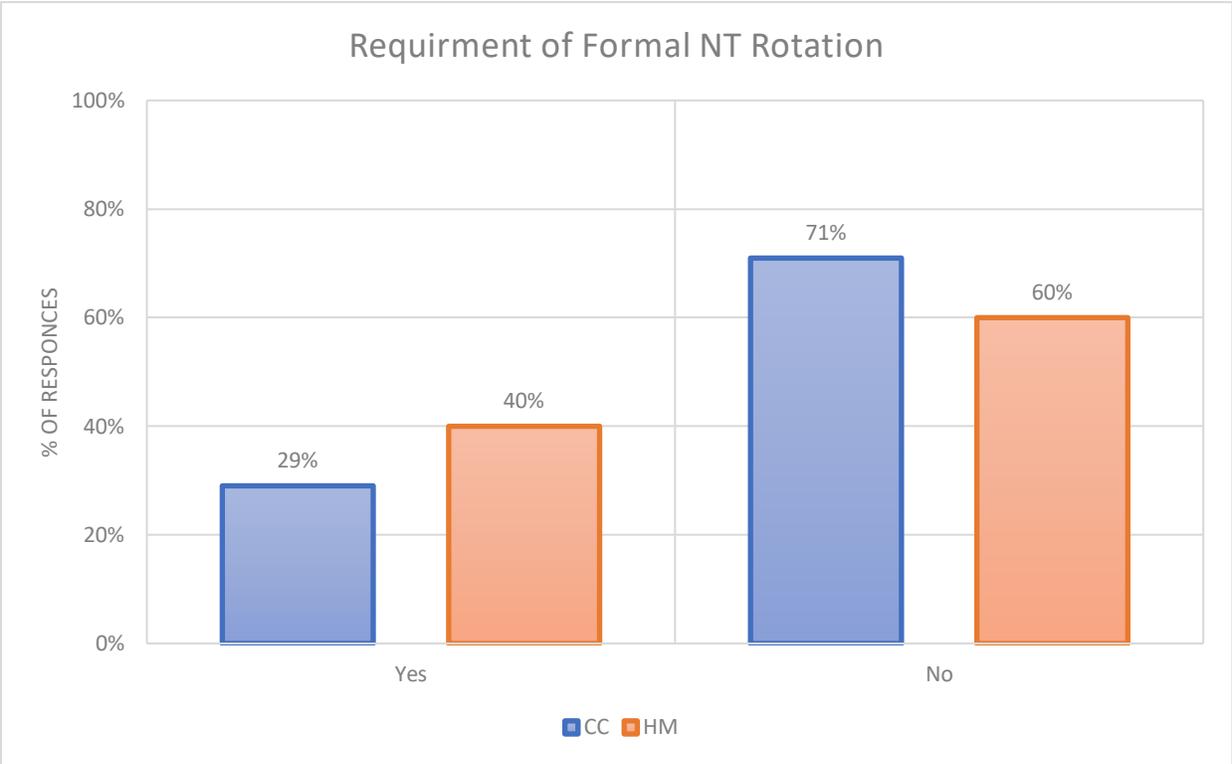


Figure 8: Requiring formal Non-Traditional rotations: comparing responses of Clinical Coordinators who did report Non-Traditional experience during training to those who did not.

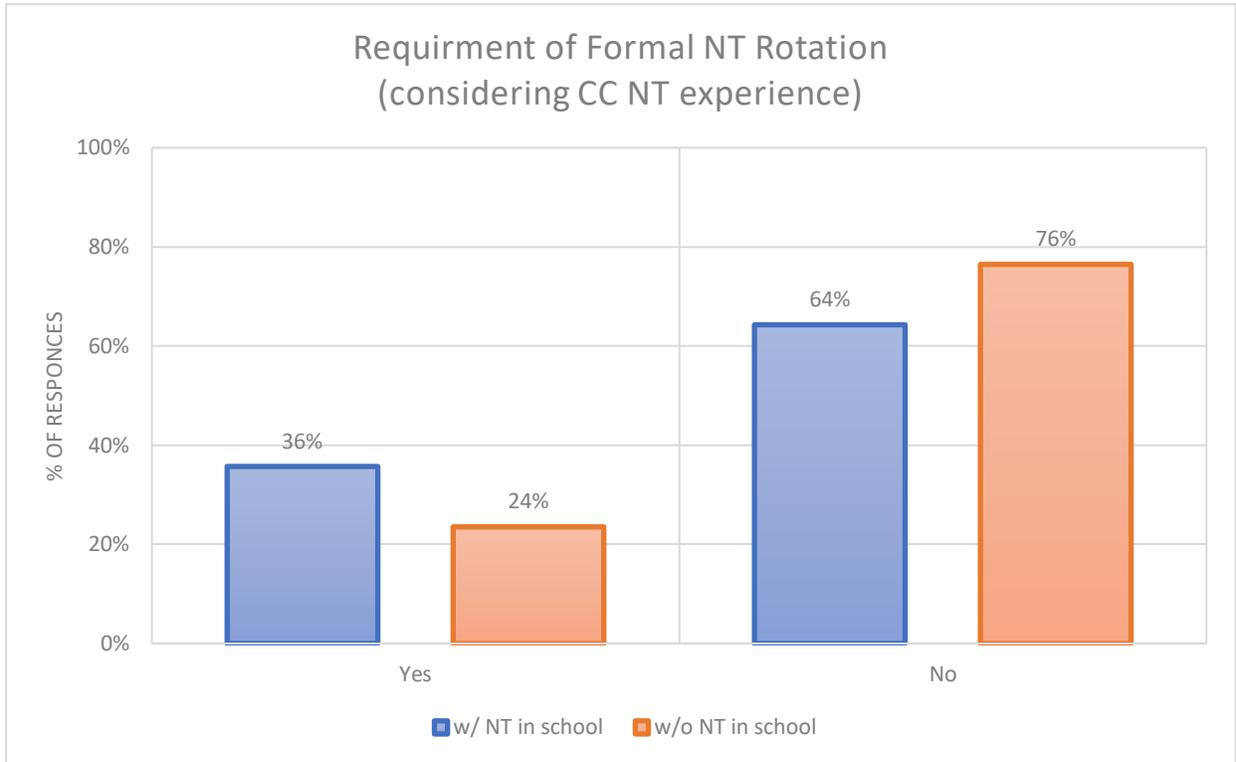
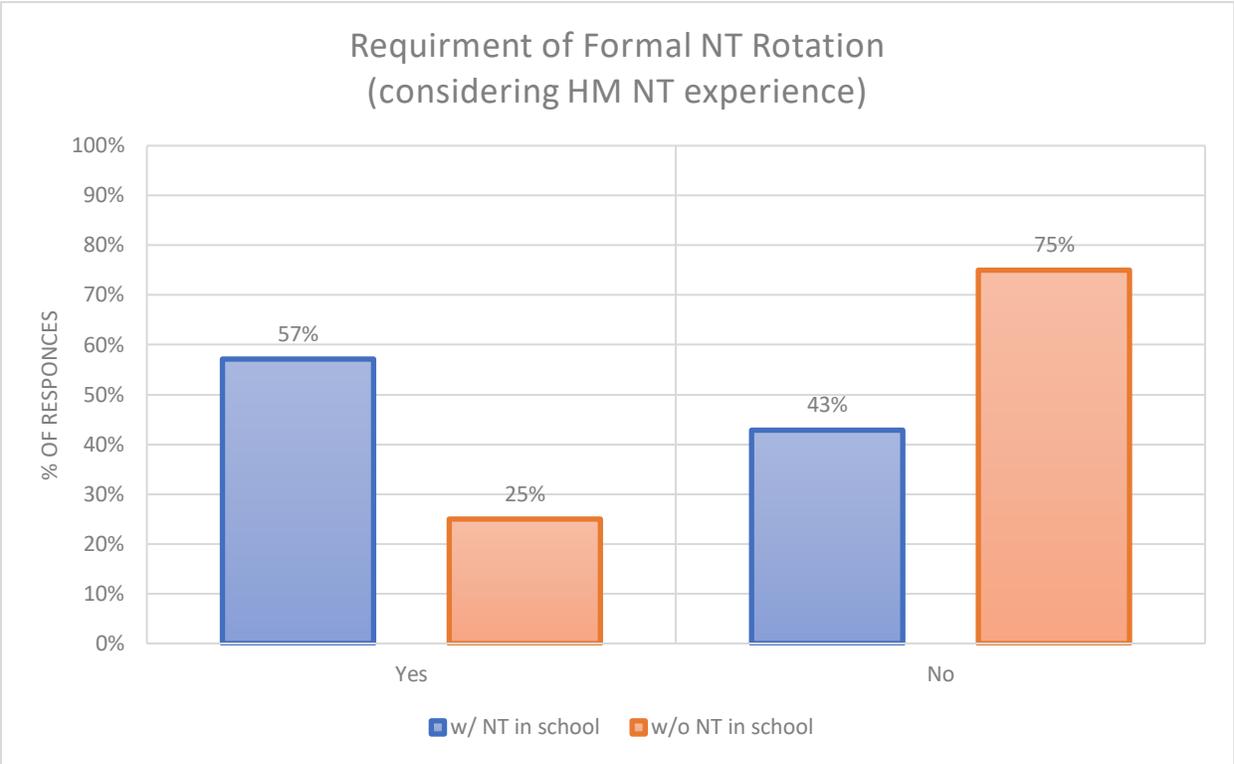


Figure 9: Requiring formal Non-Traditional rotations: comparing responses of Hiring Managers who did report Non-Traditional experience during training to those who did not.



Appendix B: Consent Form

I am asking you to take part in a research study at Sarah Lawrence College. Please read through the following questions and responses and *ask any other questions* that will help you to decide whether or not to participate.

What is the purpose of this study?

You are being asked to take part in a research study on perspectives and opinions regarding Non-Traditional training for genetic counseling students. This study seeks to assess at what point Non-Traditional / expanded training for Genetic Counselors would be most efficacious, either within a graduate level training program's curriculum or through on-the-job experience.

Why am I being asked to participate?

You are being asked to participate because you are a Genetic Counselor who either currently works to coordinate clinical rotations for a Genetic Counseling training program, or you are working as a manager of Genetic Counselors in a Non-Traditional / expanded role in the US or Canada.

What will I be asked to do?

In addition to demographic questions, you will be asked about your experiences with and opinions regarding genetic counseling training.

This interview should take no more than 30 minutes.

Is my participation voluntary?

Your participation is voluntary, and you can choose to stop the interview 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 possible discomfort when discussing opinions about genetic counseling training.

Will I be compensated for my participation?

Participants will not be compensated. There will be no direct benefit to you.

Will the information I provide be kept confidential?

With your permission, the interview will be audio recorded but will be de-identified before transcription and 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 Katia Dergham (kdergham@gm.sl.c.edu), or Lindsey Alico (lalico@sarahlawrence.edu).

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

The IRB co-chairs Professors Elizabeth Johnston (914 323 6672) at irb@sarahlawrence.edu

Please indicate with your signature on the space below that you understand your rights and voluntarily agree to participate in the study.

Appendix C: Clinical Coordinator Survey Questions

1. What training program did you attend?
2. What year did you graduate from your training program?
3. How would you define a Non-Traditional/expanded genetic counseling role?
4. What kinds (if any) of Non-Traditional exposure did you have before you started coordinating clinical training?
5. Did you have a Non-Traditional rotation / co-curricular assignment while in school?
 - a. On a scale of 1 (being not at all valuable) – 10 (being extremely valuable), how valuable did you find that experience when going into the workforce?
 - b. Explain.
6. How would you rate the importance of a student getting Non-Traditional experience before graduating on a scale of 1 (being not at all important) -10 (essential)?
 - a. Explain.
7. To what extent do you believe training programs should be responsible for providing Non-Traditional training?
8. Do you think that Non-Traditional rotations should be *required* for GC students as a prerequisite to graduating?
9. How many years have you been coordinating clinical training?
10. To what extent do you believe that students are interested in getting exposure to Non-Traditional genetic counseling roles?
11. Do you find that there are sufficient Non-Traditional placements in your area where you can send students for a rotation? (reference question #7)
 - a. Is your response based on availability of placement location or other factors?
12. What are other ways your students can gain Non-Traditional genetic counseling experience?
13. Is there anything that you'd like to add about this topic?

Appendix D: Hiring Manager Survey Questions

1. Are you certified Genetic Counselor?
 - a. What training program did you attend?
 - b. What year did you graduate from your training program?
 - c. How would you define a Non-Traditional/expanded genetic counseling role?
 - d. What kinds (if any) of Non-Traditional exposure did you have before you started working in a Non-Traditional position?
 - e. Did you have a Non-Traditional rotation / co-curricular assignment while in school?
 - i. On a scale of 1 (being not at all valuable) – 10 (being extremely valuable), how valuable did you find that experience when going into the workforce?
 - ii. Explain.
2. How would you rate the importance of a student getting Non-Traditional experience before graduating on a scale of 1 (being not at all important) -10 (essential)?
 - a. Explain.
3. To what extent do you believe training programs should be responsible for providing Non-Traditional training?
4. Do you think that Non-Traditional rotations should be *required* for GC students as a prerequisite to graduating?
5. How many years after graduating did you take on your first Non-Traditional / expanded role?
6. On a scale of 1 (being not at all prepared) – 10 (being extremely prepared), how prepared did you feel to take on a Non-Traditional role based on your graduate training?
 - a. Explain.
7. How many years have you been working in a Non-Traditional/expanded role?
8. What type of training does the company provide?
9. When hiring for a Non-Traditional role, how much experience/knowledge do you expect an applicant to have?
 - a. In your experience, are new graduates adequately prepared to succeed in a Non-Traditional / expanded role?
 - b. How important it is to you that a Genetic Counselor have clinical experience before coming into a Non-Traditional role? (scale 1-10)
 - c. What experiences do you find most valuable when coming into a Non-Traditional position?
 - d. Do you prefer that a prospective employee not have previous experience, so you can train them in a company specific way?
10. Do you offer training opportunities for genetic counseling students?
11. Is there anything that you'd like to add about this topic?

Appendix E: Suggested alternative options for student exposure to “Non-Traditional” roles outside of rotation setting (*only CC respondents asked this question*)

- Didactic work / lectures / coursework
- NT Genetic Counselor speakers
 - Individual
 - Panel
 - In person
- Individual / personal time
 - Shadowing
 - Research / capstone projects
 - Student projects / individual assignments
 - Advocacy project
 - meetings or interviews with NT counselors
 - networking (conferences, gatherings, etc.)
 - programs providing resources / contacts
- Readings / literature
- GeneDx lab lecture series
- Myriad summer lab rotation
- Mayo Clinic Laboratory internship
- Observational / short term exposure
- Mentor programs

Appendix F: Valuable skills when coming into a “Non-Traditional” role *(only HM respondents asked this question)*

- Clinical experience
- Industry background
- Research knowledge
- Laboratory experience
- Previous work experience
 - Related
 - Unrelated
- Interest in learning
- Flexibility
- Proactive work ethic
- Interest in growing / developing
- Sales experience
- Marketing experience
- Open mind
- Easy to work with / personality / team player / likeability
- Interest in variant assessment
- Basic understating of what the role will entail
- Passion for the role / subject / field
- Time management skills
- Presentation skills
- Communication skills
- Multitasker
- Influential
- Business savvy
- Negotiation skills
- Problem solving skills
- Customer service experience
- Innovative
- Project management skills
- Potential
- Active listening
- Empathy
- Non-directive approach