

**Assessing Utilization, Integration and Impact of the Genetic Counseling  
Cultural Competence Toolkit (GCCCT):  
A Survey of Genetic Counseling Graduate Program Directors**

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The Faculty of the Graduate School of Arts and Sciences

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of the Requirements for

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by

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## **ABSTRACT**

Assessing Utilization and Impact of Genetic Counseling Cultural Competence Toolkit (GCCCT): A Survey of Genetic Counseling Graduate Program Directors

A thesis presented to the Department of Biology, Genetic Counseling Program

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Cultural competence is an ongoing process in which healthcare providers strive to effectively work within the cultural context of a client, individual, family or community. Enhanced cultural competence builds stronger provider-patient relationships, improves knowledge, skills and attitudes of health professionals, improves client trust and satisfaction, and prevents serious diagnostic or treatment errors that stem directly from provider-patient differences. Funded by the Jane Engelberg Memorial Fellowship (JEMF), Warren developed the Genetic Counseling Cultural Competence Toolkit (GCCCT) in 2009 as an on-line resource to promote culturally competent care within the genetic counseling profession. The aim of our

current study was to assess the extent to which genetic counseling training programs are using the GCCCT, how it is being integrated into program curricula, and to obtain feedback from program directors about the usefulness of the GCCCT as an on-line resource. We invited genetic counseling program directors to participate in an on-line anonymous survey. Of the 34 eligible program directors, eleven (32%) completed the survey. All program directors that responded to the survey endorsed the idea that cultural competency training was important for their students. Eight respondents indicated that they had increased time spent or emphasis on cultural competence training in the past three years. All respondents strongly agreed or agreed that the GCCCT is as a valuable tool for students, noting that it could be useful to students in a variety of clinical and nonclinical situations, particularly in working with diverse clinical populations, working with interpreters and exploring cultural differences. However, only three directly cited inclusion of the GCCCT in their curricula. Future recommendations to promote cultural competence in genetic counseling graduate programs include: the sharing of helpful GCCCT resources amongst programs, providing the GCCCT as a resource to clinical supervisors and faculty, and the institution of multicultural competencies in ACGC accreditation guidelines.

**Keywords:** genetic counseling graduate training programs; genetic counseling program directors; cultural competency training (CTT); genetic counseling cultural competence toolkit (GCCCT); patient education and support; online resource

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## **INTRODUCTION**

Health disparities, or differences in health outcomes between segments of a population as defined by social, demographic, environmental or geographical attributes, are common in the United States (CDC, 2011). The sources of disparity are complex, rooted in historical and contemporary inequities, and involve discrimination at the interface of many societal-institutional dimensions. Ethnic and racial minorities face barriers to equal access and quality care, which include low health literacy, lack of health insurance, provider biases, and poor patient-provider communication (Johnson et al., 2004; AHRQ, 2012; Office of Minority Health, 2009). Compared to their Caucasian counterparts, data show that ethnic minorities have lower life expectancy, higher infant mortality, increased prevalence of chronic disease, and more significant complications from preventable or treatable conditions such as heart disease and diabetes (Smedley, Stith & Nelson, 2003; Office of Minority Health, 2009; CDC 2011).

Healthcare reform legislation built within The Patient Protection and Affordable Care Act (ACA) is an unprecedented opportunity to improve health equity in the U.S. by extending healthcare to 30 million uninsured Americans. The ACA also includes a number of provisions aimed at reducing health disparities, particularly within minority populations. Andrulis et al. (2010) summarizes provisions in the ACA to improve healthcare of vulnerable populations, including: extensive data collection and care follow-up, promotion of preventative medical

services, increased funding to community-based clinics that serve low income populations, development of cultural competency training for providers, and diversification of the medical workforce.

For healthcare practitioners, becoming culturally competent is a life-long pursuit of striving to work effectively within the cultural context of a client, individual, family or community (Campinha-Bacote, 2002). Culture refers to the integrated patterns of human behavior within racial, ethnic, social, or religious groups and includes the group's language, thoughts, actions, customs, beliefs, and institutions (Cross et al., 1989). Culture is a shared, learned, dynamic and evolutionary construct (Schim et al., 2007). Numerous models exist that describe the integral pieces needed to achieve cultural competency. Each model takes into account varying aspects of cultural awareness, cultural sensitivity and culturally competent behaviors, which are measured in the enhancement of clinical skills. Many models are also applicable to research, training and the full scope of interpersonal interactions that occur in healthcare settings (Cross et al., 1989; Campinha-Bacote, 2002; Schim et al., 2007). Irrespective of framework, cultural competence is driven by the personal investment of individual healthcare providers to actively engage in the process of becoming more culturally aware, knowledgeable and clinically skillful (Campinha-Bacote, 2002). Practitioners must approach each new situation free of bias and with a genuine openness, willingness to learn and cultural humility (Schim et al., 2007). Cultural competence is the most organic manifestation of patient-centered care (Betancourt, 2004; Betancourt et al, 2005;

Silow-Carroll, Alteras & Stepnick, 2006; Schim et al., 2007; Saha, Beach & Coop, 2008).

Despite growing ethnic minority populations in the U.S. and recommendations to develop cross-cultural education for all healthcare providers, few professions have developed curricula or implemented training related to cultural competence (Smedley, Stith and Nelson, 2003; Beach et al., 2005; AAMC, 2005; Schim et al., 2007; AHRQ, 2011). Lack of diversity continues to persist in the provider population, as less than 9% of nurses and 6% of physicians themselves identify as belonging to an ethnic minority (Hixson, Hepler, & Kim, 2011). Enhanced cultural competence of the entire healthcare workforce and increased diversity of health professionals is predicted to: increase access to care; build stronger provider-patient relationships; enhance knowledge, skills and attitudes of health professionals; improve client trust and satisfaction; and reduce serious diagnostic or treatment errors that stem directly from poor communication between providers and patients (Constantine, 2002; Fuertes & Brobst, 2002; Beach et al., 2005; Fuertes et al., 2006; Doorenbos et al., 2005; Mittman & Downs, 2008; Saha, Beach & Coop, 2008; Wang & Kim, 2010).

As of 2013, the genetic counseling profession is one that does not require or recommend specific curricula, experiences or learning tools for enhancing student cultural competence in the formal training of genetic counseling graduate students (ACGC, 2013). However, graduates are expected to provide quality care to a diverse client population despite the lack of diversity among practicing genetic counselors (Weil, 2001; Benkendorf, 2004; Paniagua & Taylor, 2008; Suther & Kiros, 2009).

According to the National Society of Genetic Counselors (NSGC) 2012 Professional Status Survey: 96% of genetic counselors are female; 92% are Caucasian non-Hispanic; 5% are Asian American; 1% are African American, Hawaiian, and Native America; 14% fluently speak another language besides English; and 12 out of a total of 1,139 respondents identify themselves as a member of the disability community; and (NSGC, 2012; NSGC, 2010). While the NSGC and the American Board of Genetic Counseling (ABGC) have communicated a commitment to “caring for clients using cultural self-awareness and familiarity with a variety of ethno-cultural issues, traditions, health beliefs, attitudes, life styles and values” and support for “socially responsible change”, efforts to recruit underrepresented minorities have made slow progress (NSGC, 1992; Mittman & Downs, 2008; Kopesky et al., 2009; Oh & Lewis, 2005; Schoonveld, Veach and LeRoy, 2007). Genetic counseling program directors as a group are also interested in expanding minority recruitment and understand the importance of training students to become more culturally competent (Wang, 1994; Warren, Wolfe & The Midwest Consortium, 2005; Oh & Lewis, 2005; Warren & Ormond, 2009; Tsipis, 2013).

Training to facilitate cultural competence should promote self-awareness, challenge stereotypes, illuminate personal biases, enhance clinical skills, and aid in identifying disparities and barriers to care within the healthcare system (Wang, 1994; Mittman & Downs, 2008; Wusik, 2007). In the past, genetic counseling training programs have “focused on simplistic knowledge of client health beliefs and cultural customs, professional cultures, and biased theoretical models” that failed to appreciate intragroup variability and individual differences (Wang, 2001). In 2007,

Wusik evaluated first and second year genetic counseling students with the Cultural Competency Assessment instrument (CCA), a universal, validated tool to assess cultural competence in all healthcare providers and to gauge their level of cultural awareness, cultural sensitivity and cultural competency behaviors. Regardless of year or ethnicity, genetic counseling graduate students exhibited high levels of cultural awareness and sensitivity but lacked cultural competency behaviors. Deficits in clinical competency behaviors highlighted the need for the development of more culturally sensitive clinical skills and additional learning experiences in genetic counseling training program curricula (Doorenbos et al., 2005; Wusik, 2007).

Researchers from a range of medical specialties advise that the most effective curricular methods for increasing student knowledge and confidence in working with diverse patients include hands on, experiential or immersive education, such as standardized patient cases, role plays, or cultural immersion rotations (Wusik, 2007; Klotz, 2009; Bednarz, Schim & Doorenbos, 2010; Long, 2012). Moreover, research shows that cultural competency training is most beneficial when it is woven into all aspects of clinical education, rather than in isolated assignments, classes or workshops (Beach et al., 2005; Warren, Raymond & Wusik, 2006; Watts, Cuellar & O'Sullivan, 2008; Sumpter & Carthon, 2011). Specific recommendations for increasing cultural competency training for genetic counselors include: the development of multicultural practiced-based competencies; the formation of interdisciplinary or state-based collaborative partnerships; the development of specialized training for educators such as faculty, mentors and supervisors; the

utilization of cultural informants; the identification of barriers to communication or care in diverse populations; and the creation of highly specific patient education and professional resources (Beach et al., 2005; Mittman, Bowie & Maman, 2007; Watts, Cuellar & O'Sullivan, 2008; Lee, Veach & LeRoy, 2009; Saleh et al., 2009; Bednarz, Schim & Doorenbos, 2010; Sumpter & Carthon, 2011; Warren, 2011; Mittman & Sullivan, 2011; Kline, 2012; Abad, 2012; Vandenlangenburg et al., 2012).

In response to the dearth of interventions in genetic counseling to promote cultural competence, Warren (2009) developed the Genetic Counseling Cultural Competence Toolkit (GCCCT) as a highly accessible online resource. The main goals of the Jane Engelberg Memorial Fellowship (JEMF) award funded project were to assess needs for cultural competence training within the genetic counseling profession and then to develop an outcome that could be used to promote cultural competence for practicing genetic counselors and genetic counseling students. Results of the needs assessment survey guided the development of an online resource portal composed of links to outside resources, video clips from other healthcare fields, and genetic counseling-specific resources, including cases and cultural competence tips from practicing counselors (Warren, 2009; <http://www.geneticcounselingtoolkit.com/>). The GCCCT format consists of six sections: Background, Health Disparities, Cross Cultural Communication, Cases, Teaching Tools and Clinical Tools (Warren, 2010; Warren, 2011). The GCCCT became publicly available in February 2011.

The aim of this research is to assess how many programs are using the GCCCT, how it is being integrated into graduate program curricula, and to obtain

feedback from genetic counseling training program directors about the usefulness of the GCCCT as an online resource. Feedback from program directors about the GCCCT can be used to tailor this and other resources to further support the development of cultural competency curricula and the growth of cultural competence in genetic counseling graduate students and their mentors.



## **METHODS**

### **Study Design**

This study queried genetic counseling graduate program directors about their experiences with the GCCCT as an online resource, as a tool for curriculum enhancement and as a resource for their students through an online anonymous survey. The survey consisted of 18 questions that were a combination of multiple choice and Likert scales, with some open-ended responses (see Appendix C). The majority of the data was quantitative but qualitative data was also collected for free responses.

### **Sample and Recruitment**

Current genetic counseling graduate training program directors from graduate training programs in the United States and Canada with full, provisional or probationary accreditation status per the Accreditation Council of Genetics Counselors (ACGC) were eligible to complete the survey. We emailed the survey recruitment notice (see Appendix A and Appendix B) to each program director twice, once in January of 2013 and again in February 2013. Emails were collected and verified on the affiliated Graduate Program public webpage (ABGC, 2013). The study was open for a period of four weeks. The Brandeis University Committee for Protection of Human Subjects approved the study protocol (#13068).

## **Data Collection and Analysis**

Quantitative and qualitative data was collected using an anonymous, online survey designed and administered through Qualtrics® software. We analyzed survey data using SPSS 19.0.0 to calculate descriptive statistics. For questions nine and ten, maximum use was calculated by purpose and by section. Free response questions were analyzed based on response and theme.

## **RESULTS**

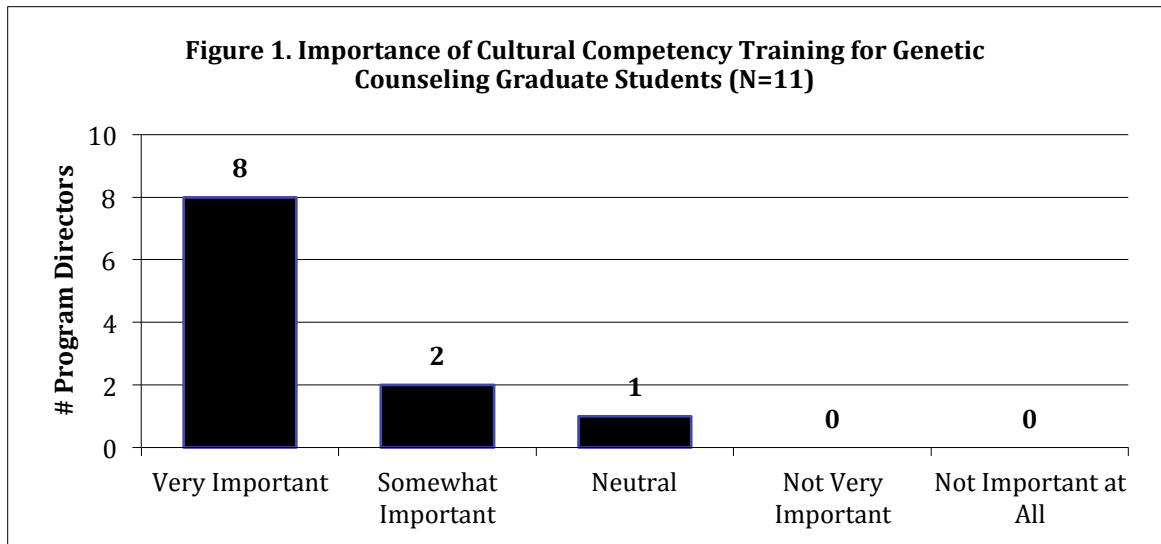
Of the 34 eligible program directors, eleven completed the survey in its entirety. Two other program directors started but did not finish the survey. These responses were excluded from the data analysis. Nine of the respondents (81.8%) identified their program as located within a major city and two (18.2%) identified their program as located within 30 miles of a major city.<sup>1</sup> Additional demographic characteristics of programs or program directors were not collected in order to maintain anonymity.

### **Importance of Cultural Competency Training**

We assessed the importance of cultural competency training and the status of cultural competency training in each program to provide context for later analyses (Figure 1 and Table 1). The overwhelming majority of program director respondents stated that cultural competency training was “very important” for their students (n=8, 72.7%) or “somewhat important” (n=2, 18.2%), and only one director (10%) felt neutral. None of the respondents indicated that cultural competency training is “not very important” or “not important at all.”

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<sup>1</sup> Major city is defined as a population size of 500,000 or more residents.



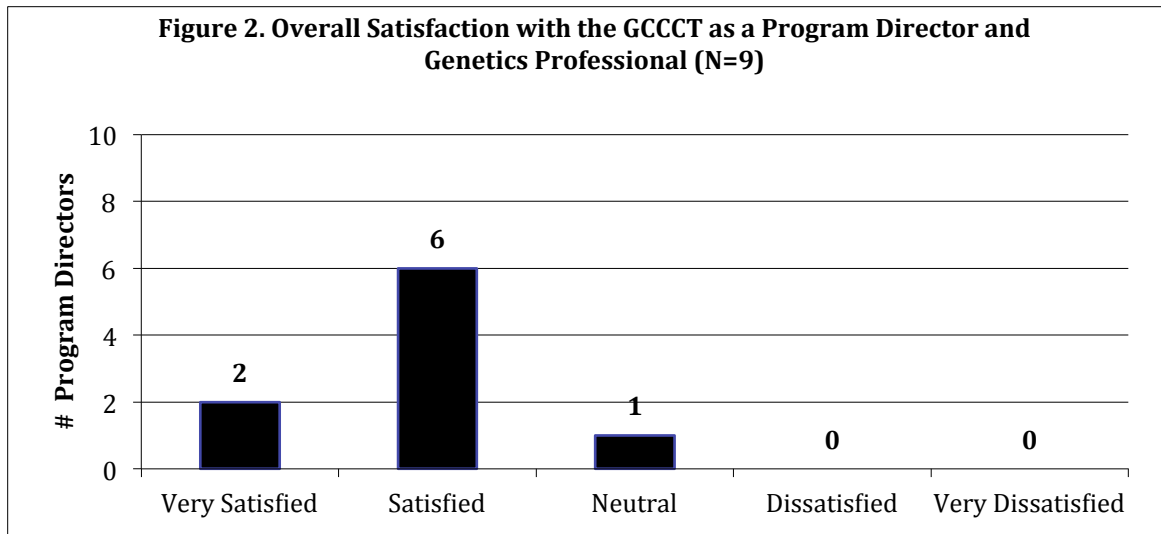
When asked about changes to their program’s cultural competency curriculum in the last three years, eight program directors (72.7%) reported increased emphasis or time spent on cultural competency training in their program. Respondents commented that expanded curricula included more speakers, thematic incorporation into classes, elective classes on cultural competency, focused readings and new educational content on diverse cultures, such as the GLBT community. Of the eight respondents who expanded CCT, three (37.5%) specifically cited use of the GCCCT. When asked about plans to change their cultural competency curriculum in the next three years, three program directors (30.0%) reported they plan to increase emphasis or time spent on cultural competency. Two respondents commented they plan to use the GCCCT and spend more class time on the topic.

**Table 1. Cultural competence curriculum emphasis and changes over time**

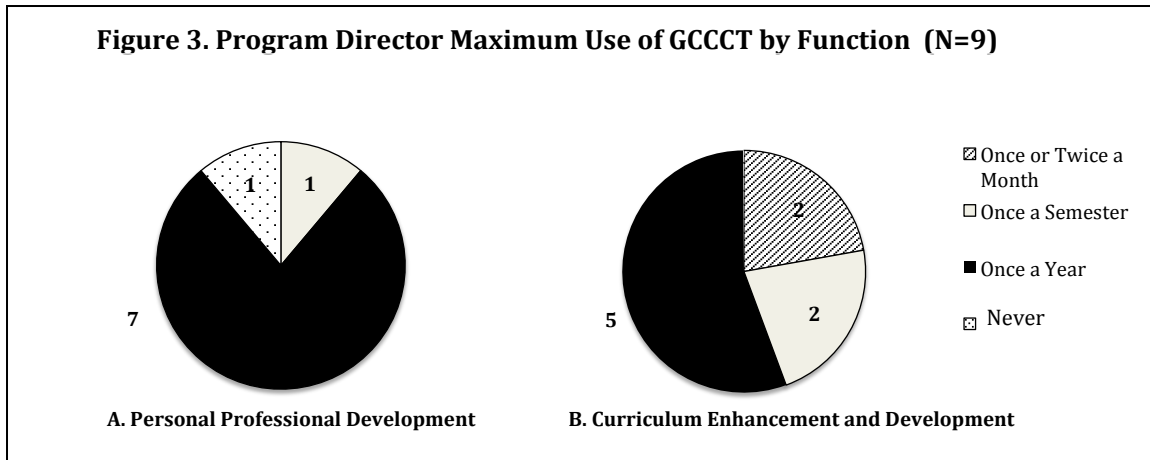
In the past three years, have you increased emphasis or time spent on CCT? (N=11)	Comments
Yes 8 No 3	The introduction of the toolkit provided a way to incorporate genetic counseling specific cultural competency across our counseling courses.
	Incorporated content on GLBT issues resulting in a small overall increase in time spend on CCT.
	We have brought in more speakers and expanded readings a bit.
	Added elective course and included the toolkit in one of classes.
	We have incorporated it into our Social, Cultural, Ethical issues in genetics course.
	More time devoted to topic.
	Included in 1 <sup>st</sup> and 2 <sup>nd</sup> year.
	Not sure we've increased time on Cross Cultural issues, but our program now uses the CCT in particular.
In the next three years, do you plan on increasing emphasis or time spent on CCT? (N=10)	Comments
Yes 3 No 7	I'm going to make use of the Cultural Competence toolkit!
	Hope to spend more class time on it.

### **Program Director Utilization of the GCCCT**

Ten of eleven program directors (91.0%) indicated they have personally explored the GCCCT. When asked to rate overall satisfaction with the GCCCT on a Likert scale, nine program directors answered this question. Two respondents (22.2%) were “very satisfied”, six respondents (66.7%) were “satisfied”, and one (11.1%) was “neutral.” None of the program directors who had personally explored the GCCCT reported any degree of dissatisfaction.

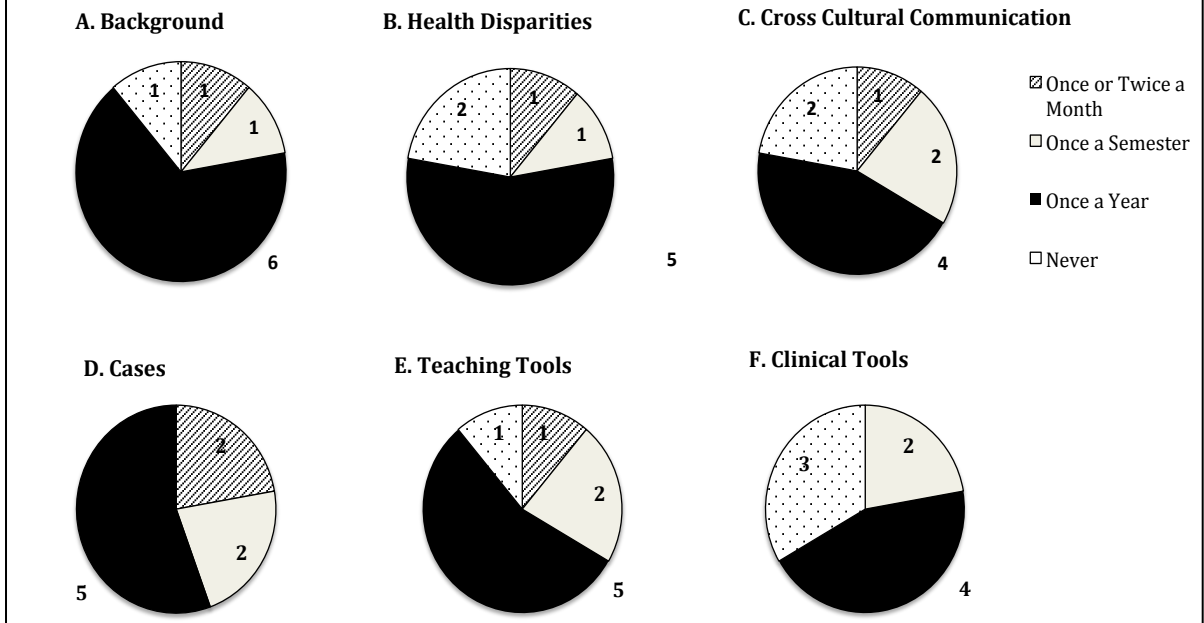


When asked to report how frequently they used the GCCCT and whether the use was for personal or professional endeavors, nine program directors responded. Responses were analyzed for maximum use by function and section (Figure 3 and Figure 4). With regard to personal professional growth and development, seven respondents (77.8%) used the GCCCT once a year, one respondent (11.1%) used it once a semester and one respondent (11.1%) reported never using it. For curriculum enhancement and development, five respondents (55.6%) used the GCCCT once a year, two respondents (22.2%) used it once a semester and two (22.2%) used it once or twice a month.



The majority of respondents used each section of the GCCCT once a year (A. n=6, 67%; B. n=5, 56%; C. n=4, 45%; D. n=5, 56%; E. n=5, 56%; F. n=4, 44.4%). Program directors consulted the Cases section most frequently, with two respondents (22.2%) reporting use once or twice a month and another two respondents (22.2%) reporting use once a semester. The Clinical Tools section was used least frequently, with two program directors (22.2%) reporting use once a semester and three (33.3%) reporting no use. The other four sections, Background, Health Disparities, Cross Cultural Communication and Teaching Tools, were used at varying intervals.

**Figure 4. Program Director Maximum Use of GCCCT by Section (N=9)**



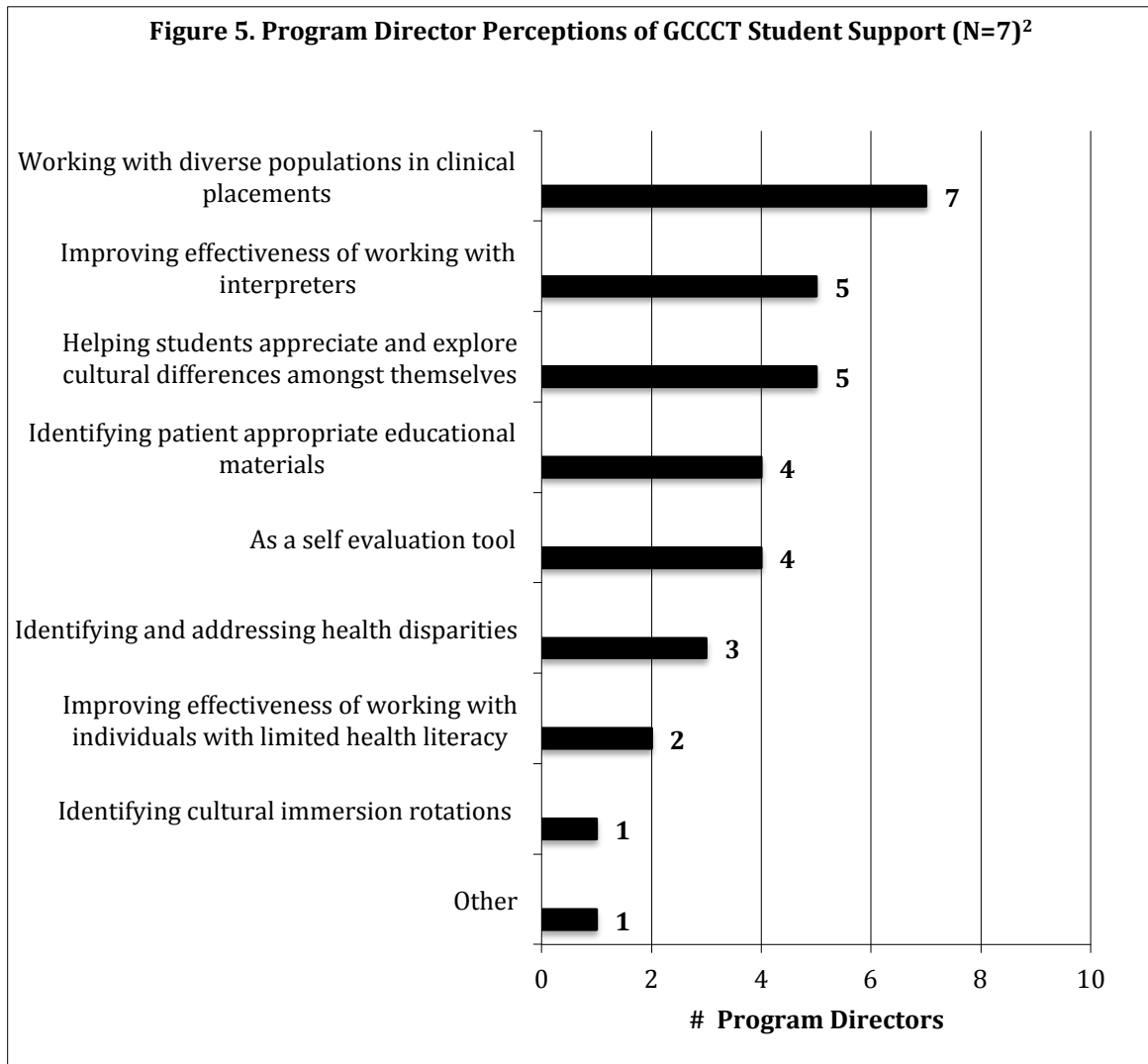
**GCCCT Integration into Genetic Counseling Graduate School Training**

Of the ten program directors that have personally explored the GCCCT, nine have used it for curriculum enhancement and development. Additionally, three of the eight programs (35.7%) that have increased cultural competency curricula in the last three years specifically cited use of the GCCCT.

All program directors “agreed strongly” (n=2, 25.0%) or “agreed” (n=6, 75.0%) the GCCCT has served as a valuable tool and resource for educating their students with regards to cultural competency. Seven of the eleven program directors (63.6%) believed that their students were currently utilizing the GCCCT in some capacity. We asked respondents to identify areas in genetic counseling graduate school training that they believed have been supported or enhanced by



content in the GCCCT for their students (Figure. 5). Program directors believed that the GCCCT helped their students work with diverse clinical populations (n=7), work with interpreters (n=5) and explore cultural differences amongst themselves (n=5).



<sup>2</sup>Eleven total program directors responded to this question. Along with the above areas of impact, four respondents selected “not currently being utilized.” Those four respondents were excluded from this analysis.

## DISCUSSION

### **CCT, the GCCCT and the Genetic Counseling Profession**

This study surveyed genetic counseling graduate program directors to assess their utilization of the GCCCT, integration of the GCCCT into their graduate program curricula, and its usefulness for genetic counseling graduate school students as an online resource. We invited thirty-four eligible program directors to participate in this study through personal email, of which eleven responded and completed the survey. All respondents recognized cultural competence as “very important” or “somewhat important” in training for genetic counseling graduate students. One quoted:

“We live in a diverse world yet [genetic counselors] are not a very diverse population. So, CCT is very important in really good [genetic counseling].”

As genetic counselors we face the challenge of discussing highly technical information in the context of extremely personal and sensitive issues to people of varying educational backgrounds and ethnicities (Mittman & Downs, 2008). Cultural competence of providers is an essential component of any healthcare system designed to provide delivery of high-quality, high-value care to individuals regardless of race, ethnicity, culture, language proficiency, health literacy, gender, sexual orientation or ability to access technology (Doorenbos et al., 2005; Betancourt et al., 2005; Smith et al., 2009; AHRQ, 2012).

Consistent with their belief that cultural competency training is important, the majority of program directors have expanded cultural competency curricula in the last three years to include additional speakers, elective classes, readings, content on specific minority communities, and some have specifically incorporated the GCCCT into their curricula. This parallels recent efforts in the genetic counseling community to define interactions with specific minorities populations and develop educational patient-provider resources (Smedley, Stith & Nelson, 2003 ; Kopesky et al., 2009; Saleh et al., 2009; Warren 2011; Kline, 2012; Abad, 2012; Vandenlangenburg et al., 2012).

A small number of respondents either did not expand training curricula in the last three years or have no plans to increase it in the next three years. However, this does not necessarily indicate a lack of interest or value in cultural competency. These programs may already have extensive educational methodologies for cultural competence training in place.

### **Program Director Utilization of the GCCCT**

The majority of program directors who responded to the survey have personally explored the GCCCT and were satisfied with their experience. This study shows that program directors used the GCCCT more frequently as a tool for curriculum enhancement than for personal professional development. Program directors mainly consulted the GCCCT annually, but some used it as often as once or twice a month. The Cases section was used most frequently by program directors. One respondent stated, “students were able to readily see the applicability.”

Literature supports that hands-on training involving standardized patient cases or immersion experiences produce the greatest improvement in student cultural awareness and confidence in working with diverse patients (Klotz, 2009; Bednarz, Schim, & Doorenbos, 2010; Long 2012).

The frequent use of the Cases section and lack of pattern or consensus for use of the other sections could also reflect a superficial knowledge of the resources available within the GCCCT. The case studies within the Cases Section are flexible enough to serve in many different educational capacities, such as self-directed learning assignments or as the foundations of class discussions. Some of the other sections within the GCCCT may require further exploration of content, evaluation of how to incorporate the content, faculty trainings for incorporating the content or even modification of existing curriculum. While the Clinical Tools section was used least by program directors, the Teaching Tools section was also used in a limited capacity. The Teaching Tools section was specifically included in the GCCCT to support cultural competency training or development of cultural competence curricula in genetic counseling graduate programs. The Teaching Tools section includes self-assessment tools, sample course syllabi, ideas for cultural immersion experiences for students and videos to promote culturally competent care for students, new graduates or practicing genetic counselors. While this content was targeted for genetic counseling graduate programs, implementation of strategies or content contained within the Teaching Tools section could require additional time and training. As with the other sections, this could be a contributory factor to decreased use.

## **GCCCT Integration into Graduate School Training**

All program director respondents “strongly agreed” or “agreed” that the GCCCT has served as a valuable tool and resource for educating their students. One program director said,

“ This has been a very helpful resource. I have incorporated some of the information into class assignments.”

Another said,

“We try to raise cultural issues in every class session of our psychosocial course series, and the GCCCT is often the manner we choose.”

Others reported that faculty members used materials embedded within the Cases to generate class discussion. Some programs also plan to include the GCCCT in a course for second year students designed to include self-directed, online learning.

Two-thirds of program director respondents believed that their students were currently using the GCCCT in some capacity, with a wide range of applications. Some reported that students most enjoy the cases, the informational links and the interpreter information. The other one third of program directors thought it was not currently used by any of their students.

## **Recommendations**

The GCCCT is an online portal with resources that can serve as a springboard upon which to expand and promote open discussions surrounding cultural differences and medical management among genetic counseling students, practicing genetic counselors, and professionals from other medical specialties. The GCCCT content is applicable to a variety of different clinical and nonclinical interactions in

graduate program training. Data indicate that program directors and students are using select pieces of the GCCCT but they may not appreciate the many resources within multiple sections that could support infusing cultural competence teaching and learning into the programs. There also seems to be a general uncertainty among program directors with how to best incorporate the resources found in the GCCCT into their curricula. As recommended by one respondent, a representative could be appointed in each program to review the GCCCT, identify one or two useful resources and suggest how the GCCCT content could be incorporated into their curriculum. Program directors could also share the GCCCT as a resource with their students, graduate program faculty and clinical supervisors. One program director commented, "it would be a good addition to a supervisor workshop."

Additional feedback from program directors to further enhance and support the development of the GCCCT include frequent maintenance of content to keep it current and the addition of more case studies. Critical commentary from a program director respondent posited that, "some of the content is too specific to very small minority population[s]." This statement contradicts a fundamental purpose of the GCCCT, which is to house and make available patient-provider resources that are specific to unique groups of people but also profile transferable principles that can be generalized to other populations. By supporting dissemination of excellent and peer-reviewed resources, culturally congruent genetic counseling and effective communication can be promoted within numerous populations. On the other hand, the program director could be expressing the concern that content within the GCCCT is stereotypical or misrepresents small minority populations. While

knowledge and resources can serve as a foundation to developing cultural competence, it is crucial to remember that correct interpretation and proper application of this knowledge is a learned skill. To reduce stereotyping, our profession must seek to recognize, respect and be open to learn from individual and cultural similarities and differences, whether these are encountered in case studies, clinic, or research studies (Wang, 2001). A limitation of the GCCCT as an online informational forum is that it can only provide information, not offer interpretation. This study reveals the challenges to genetic counseling programs to thoroughly explore available resources and consider if, when, and how to modify curricula to accommodate valuable resources. Each student and each student cohort is culturally unique. Nevertheless, the overarching goal of infusing respect for diversity, cultural humility, and ethnocultural awareness into all aspects of graduate school training is universal to all programs (Wang 1994; Warren, Raymond & Wusik, 2006; Lee, Veach, & LeRoy, 2009; Bednarz, Schim & Doorenbos, 2010; Sumpter & Carthon, 2011).

This study also highlights the absence of standardized educational benchmarks or specific cultural competency guidelines for genetic counseling graduate programs. The lack of standardized criteria with regards to cultural competency curricula allows for a great variability to exist between training of current students. New ACGC Accreditation Guidelines for genetic counseling graduate programs list “Multicultural Sensitivity and Competency” in psychosocial content needed to support ABGC Practice-Based Competencies (ACGC, 2013). ABGC

Practice-Based Competencies, under Domain I: Communication Skills, states that students must be able to:

“...care for clients using cultural self-awareness and familiarity with a variety of ethno-cultural issues, traditions, health beliefs, attitudes, lifestyles, and values.” (ABGC, 2013)

While lack of standardized cultural competency training criteria allows for flexibility within the programs, absence of guidelines may also discourage sharing of cultural competence training materials, experiences and tools among programs, graduate students or even among practicing genetic counselors.

In conjunction with previous studies, we recommend: the incorporation of multicultural competencies into ACGC accreditation guidelines; curriculum mapping to identify strengths and weaknesses in each program; utilization of tools to track student progress in cultural competence; the inclusion of hands-on, experiential based learning activities or experiences; further education of the educators; and the sharing of helpful resources, advice and experiences among programs to promote cultural competency training in genetic counseling graduate school training (Warren, Raymond & Wusik, 2006; Warren & Ormond, 2009). Programs will also need to be flexible enough to modify curricula in response to ongoing changes in patient-provider demographics and emerging data on health disparities in genetics services.

### **Study Limitations**

Program director participation in this study was low (N=11), with a participation rate of 32%. Self selection introduces the possibility of obtaining



feedback from only those directors who have a specific interest in cultural competency training, have used the GCCCT, have had positive experiences with it, or are located in more urban locations with a greater diversity in clinic population.<sup>3</sup> Program directors were also asked to infer impact and effectiveness of the GCCCT for their students. Greater accuracy would have been obtained from directly asking students about their experiences with the GCCCT.

Additionally, this study did not capture or assess the proportion of any program's cultural competency curriculum that was based on the GCCCT or the degree of informal curriculum, such as discussions, that extended from the GCCCT. Lastly, anonymous online survey allows for questions to be interpreted differently between participants without opportunity to clarify with researchers.

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<sup>3</sup> There were two program directors that started but did not finish the survey. Nine of the respondents (81.8%) identified their program as being located within a major city and two (18.2%) identified their program as being located within 30 miles of a major city.

## **CONCLUSIONS**

The purpose of this study was to assess use of the GCCCT in genetic counseling graduate program directors as a personal resource, a curriculum enhancement tool and as a resource for their students.

The majority of program directors recognized cultural competency training was important for their students and had increased time spent or emphasis on CCT in their programs over the last three years. Respondents used the GCCCT more frequently for curriculum development than for personal use. It was mainly consulted annually but some program directors consulted the Cases Section as often as once or twice a month.

This was the first study to characterize use of the GCCCT and collect feedback regarding the GCCCT in genetic counseling graduate program directors. Further research is needed to assess use and obtain feedback from practicing genetic counselors, genetic counseling graduate students, and undergraduates interested in pursuing the field of genetic counseling. It would also be interesting to assess cultural competency awareness, knowledge and comfort level in individuals who have used the GCCCT versus individuals who have not used the GCCCT. Effective cross-cultural genetic counseling is an important component to promote high quality care and equal access to care, and is more than just the ability to identify knowledge, facts and resources. The challenge remains to create both a graduate training program environment and a professional environment that fosters open

discussion, self-reflection, cultural humility, and the ability to translate information, such as that found in the GCCCT, into culturally congruent clinical behaviors.

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## APPENDICES

### Appendix A. Recruitment Notice

**Subject:** Attn Program Directors: Student Research Project on Use of Genetic Counseling Cultural Competence Toolkit in Genetic Counseling Programs

Dear Program Director,

I invite you as a program director to participate in a research study investigating the utilization, integration and impact of the Genetic Counseling Cultural Competence Toolkit (GCCCT). This research is being conducted in collaboration with Nancy Steinberg Warren, MS, CGC, Sheetal Parmar, MS, CGC and Judith Tsipis, as part of my Master's Thesis at Brandeis' Genetic Counseling program.

Funded by the 2009 JEMF award, the Genetic Counseling Cultural Competence Toolkit (GCCCT) was developed as an online resource to enhance and promote culturally competent care within the genetic counseling profession. The purpose of this study is to assess how many programs are using the GCCCT, how it is being integrated into graduate program curricula, and to obtain feedback from genetic counseling training program directors about the usefulness of the GCCCT for promoting cultural competence.

This study is open to all program directors from ACGC Accredited Genetic Counseling Graduate Programs in the United States and Canada. Participation is anonymous, voluntary and confidential. The survey should take approximately 15-30 minutes to complete. At any time you may choose to opt out.

Upon completion of the survey, you will have the opportunity to enter a raffle for one of two copies of the book "Telling Genes: The Story of Genetic Counseling in America" by Alexandra Minna Stern. Entry into the raffle will not be linked in any way to your survey responses.

Please follow the link below to let us know about your experiences with the Genetic Counseling Cultural Competence Toolkit:

[https://brandeis.qualtrics.com/SE/?SID=SV\\_1XFmehMO6ygJ9Fr](https://brandeis.qualtrics.com/SE/?SID=SV_1XFmehMO6ygJ9Fr)

If you any questions or concerns, please feel free to contact me by email at [mis@brandeis.edu](mailto:mis@brandeis.edu), or the Principal Investigator, Judith Tsipis, at [tsipis@brandeis.edu](mailto:tsipis@brandeis.edu). Thank you in advance for your participation.

Sincerely,

Mia Salimbene  
Brandeis University Genetic Counseling Program, Class of 2013

## **Appendix B. Recruitment Reminder**

**Subject:** Attn Program Directors: Reminder – Research Project on Use of Genetic Counseling Cultural Competence Toolkit in Genetic Counseling Programs

Dear Program Director,

This is a reminder to participate in research study on the utilization, integration and impact of the Genetic Counseling Cultural Competence Toolkit (GCCCT) in your graduate program. We welcome responses from those who have already incorporated the GCCCT as well as those who have not yet done so.

Thank you if you have already completed the survey.

Sincerely,

Mia Salimbene

## Appendix C. Survey

Q1 Assessing Utilization, Integration and Impact of Genetic Counseling Cultural Competence Toolkit (GCCCT): A Survey of Genetic Counseling Graduate Program Directors.

Thank you for taking the time to participate in this survey. I'm a master's degree candidate at the Brandeis University Genetic Counseling Program conducting thesis research in collaboration with Nancy Steinberg Warren, MS, CGC, and Sheetal Parmar, MS, CGC.

Funded by the 2009 JEMF award, the Genetic Counseling Cultural Competence Toolkit (GCCCT) was developed as an online resource to enhance and promote culturally competent care within the genetic counseling profession. The aim of this research is to assess how many programs are using the GCCCT, how it is being integrated into graduate program curricula, and to obtain feedback from genetic counseling training program directors about the usefulness of the GCCCT for promoting cultural competence.

Participation is anonymous, voluntary and confidential. The survey should take approximately 15-30 minutes to complete. At any time you may choose to opt out. By taking this survey, you are giving consent to participate in this research project and permission for your responses to be used in our analysis. Upon completion of the survey, you will have the opportunity to enter a raffle for one of two copies of the book "Telling Genes: The Story of Genetic Counseling in America" by Alexandra Minna Stern. Entry into the raffle will not be linked in any way to your survey responses.

If you have comments, questions or concerns about the survey, please contact Mia at [mis@brandeis.edu](mailto:mis@brandeis.edu) or Principal Investigator, Judith Tsipis, at [tsipis@brandeis.edu](mailto:tsipis@brandeis.edu). This research protocol has been approved by the Brandeis University IRB.

Proceed to the survey by selecting "Next" below.

NEXT (1)

Q2.A Cultural competence can be described as the demonstration of knowledge, attitudes, and behaviors based on diverse and relevant cultural experiences. Cultural Competency Training (CCT) can include readings or literature about different cultures, hosting speakers or workshops to address cultural competence in genetic counseling, role plays to address issues that might arise due to cultural differences, identification of barriers to equal and appropriate health care, diverse clinical rotations with different populations or use of interpreters, individual experiences with special population groups, and other strategies.

How important do you think Cultural Competency Training (CCT) is for your students?

- Very Important (1)
- Somewhat Important (2)
- Neutral (3)
- Not very Important (4)
- Not Important at all (5)

Q2.B There are comment boxes located beneath select questions if you would like to share additional thoughts. Comments: \_\_\_\_\_

Q3. In the past three years, have you increased emphasis or time spent on CCT in your curriculum?

- Yes. If so, please comment on the changes that you/your program have made. (1)  
\_\_\_\_\_
- No (2)

Q4. In the next three years, do you plan on increasing emphasis or time spent on CCT?

- Yes. If so, please describe briefly what you are thinking of adding to the curriculum to improve CCT. (1) \_\_\_\_\_
- No (2)

Q5. Have you personally had the opportunity to explore the Genetic Counseling Cultural Competence Toolkit (GCCCT)?

- Yes (1)
- No (2)

If No Is Selected, Then Skip To End of Block (Q.13.1)

Q6.A Rate your overall satisfaction with the GCCCT as a resource for you as both a program director and genetics professional.

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

Q6.B Comments: \_\_\_\_\_

Q7. The GCCCT is organized into six main sections: Background, Health Disparities, Cross Cultural Communication, Cases, Teaching Tools and Clinical Tools.

Please rate how often you have referred to each section of the GCCCT for your personal professional development and growth since September of 2011.

	Once or Twice a Week (1)	Once or Twice a Month (2)	Once a Semester (3)	Once a Year (4)	Never (5)
Background (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Health Disparities (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Cross Cultural Communication (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Cases (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Teaching Tools (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Clinical Tools (6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q8. Please rate how often you have referred to each section of the GCCCT for curriculum enhancement and development since September of 2011.

	Once or Twice a Week (1)	Once or Twice a Month (2)	Once a Semester (3)	Once a Year (4)	Never (5)
Background (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Health Disparities (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Cross Cultural Communication (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Cases (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Teaching Tools (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Clinical Tools (6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q9.A The GCCCT has served as a valuable tool and resource for educating our student with regards to cultural competency.

- Agree Strongly (1)
- Agree (2)
- Neutral (3)
- Disagree (4)
- Disagree Strongly (5)

Q9.B Comments: \_\_\_\_\_

Q10 Have you introduced the GCCCT to your faculty members? If so, how did you let them know about it? If not, do you have plans to introduce it? \_\_\_\_\_

Q11 Have you introduced the GCCCT to clinical supervisors? If so, how did you let them know about it? If not, do you have plans to introduce it? \_\_\_\_\_

Q12 How could the GCCCT be improved to further benefit and support the development of CCT in your program?

Q13.1 Have you introduced the toolkit to your current student population?

- Yes (1)
- No (2)

If No Is Selected, Then Skip To (Q.13.2)

If Yes Is Selected, Then Skip To (Q14)

Answer If Have you introduced the toolkit to your current student p... No Is Selected

Q13.2 Do you have future plans to introduce the GCCCT to your students? If so, how do you think it will be used? \_\_\_\_\_

Q14 The GCCCT was designed to facilitate cultural competence in many settings and clinical situations. For which of the following has the GCCCT been especially helpful for your students:

- Aiding in identifying patient appropriate educational materials (1)
- Improving effectiveness of working with interpreters (2)
- Identifying cultural immersion rotations or opportunities for working with individuals from different cultural backgrounds (3)
- Improving effectiveness of working with individuals with limited health literacy in the clinic (4)
- Identifying and addressing health disparities (5)
- Helping students appreciate and explore cultural differences amongst themselves (6)
- Working with diverse populations in clinical placements (7)
- As a self evaluation tool (8)
- Not currently being utilized (9)
- Other. Please describe below. (10) \_\_\_\_\_



Q15.A Please rate the effectiveness of each section of the GCCCT for enhancing and improving overall cultural competence in your students.

	Highly Effective (1)	Somewhat Effective (2)	Neutral (3)	Somewhat Ineffective (4)	Ineffective (5)	NA (6)
Background (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Health Disparities (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Cross Cultural Communication (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Cases (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Teaching Tools (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Clinical Tools (6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q15.B Comments: \_\_\_\_\_

Q16 How could the GCCCT be improved to further support the education of genetic counseling graduate students? \_\_\_\_\_

Q17 Please comment on any feedback you have received from students about the GCCCT. \_\_\_\_\_

Q18 Please describe the location of your Graduate Training Program with regard to distance from a major city. For this purpose, major cities are defined as having a population of more than 500,000 residents.

- Within Major City (1)
- Suburban locale within 30 miles of Major City (2)
- Town within 30-60 miles of Major City (3)
- Greater than 60 miles from Major City (4)

Q19 You have now reached the end of the survey. Thank you for taking the time to participate.

To enter the raffle for a copy of "Telling Genes: The Story of Genetic Counseling in America" by Alexandra Minna Stern, please send an email to [mis@brandeis.edu](mailto:mis@brandeis.edu) to confirm you have completed the survey and would like to be entered in the drawing.

## Appendix D. Open-Ended Responses

Q2.A How important do you think Cultural Competency Training (CCT) is for your students?

Q2.B There are comment boxes located beneath select questions if you would like to share additional thoughts. Comments: \_\_\_\_\_

We live in a diverse world yet GC's are not a very diverse population. So, CCT is very important in really good GC.

Q3. In the past three years, have you increased emphasis or time spent on CCT in your curriculum?

The introduction of the **toolkit** provided a way to incorporate genetic counseling specific cultural competency across our counseling courses. Incorporated content on GLBT issues resulting in small overall increase in time spent on CCT.

We have brought in more speakers and expanded readings a bit.

Added elective course and included the **toolkit** in one of classes.

We have incorporated it into our Social, Cultural, and Ethical issues in genetics course.

More time devoted to topic.

Included in 1<sup>st</sup> and 2<sup>nd</sup> year

Not sure we've increased time on Cross Cultural issues, but our now using the CCT in particular.

Q4. In the next three years, do you plan on increasing emphasis or time spent on CCT?

I'm going to make use of the Cultural Competence toolkit!  
Hope to spend more class time on it.

Q6.A Rate your overall satisfaction with the GCCCT as a resource for you as both a program director and genetics professional.

Q6.B Comments: \_\_\_\_\_

Like the case based approach, students readily see the applicability. This is based on reviewing the materials on the web. Some of the content is too specific to very small minority population.

Q9.A The GCCCT has served as a valuable tool and resource for educating our student with regards to cultural competency.

Q9.B Comments: \_\_\_\_\_

This has been a very helpful resource. I have incorporated some of the information into class assignments.  
We try to raise cultural issues in every class session of our psychosocial course series, and the GCCCT is often the manner we choose  
This is because we did not have our students purchase the toolkit, but we are considering this for the fall 2013.

Q10 Have you introduced the GCCCT to your faculty members? If so, how did you let them know about it? If not, do you have plans to introduce it? \_\_\_\_\_

No  
No  
No  
No and unlikely  
No but it would be a good addition to a supervisor workshop.  
Yes, I sent the link to two of my instructors and directed them to specific areas relevant to content areas I know they cover.  
Yes. Learned about it through NSGC and personal contact with Nancy.  
Yes, the three instructors teaching psychosocial courses are familiar with it.

Q11 Have you introduced the GCCCT to clinical supervisors? If so, how did you let them know about it? If not, do you have plans to introduce it? \_\_\_\_\_

No  
No, but a great idea...  
No  
No. Will consider it for future faculty development.  
No and probably.  
No, but that is a good idea, so maybe I will do that soon.  
Let them know about the resource  
I sent the link with a general announcement to clinical supervisors to peruse if interested

Q12 How could the GCCCT be improved to further benefit and support the development of CCT in your program?

Please keep the site and resources available.  
The formatting could be improved. Some cases print with the editing comments included.

I think it is fairly comprehensive as if but I wonder what the plans are for keeping it current/updated so it remains relevant (in areas it might become outdated)  
Addition of more cases if possible  
It would be really helpful if each program could 1 person (PD or faculty members) look at the entire toolkit to judge what parts to use, etc...

Q13.2 Do you have future plans to introduce the GCCCT to your students? If so, how do you think it will be used? \_\_\_\_\_

I have a course for 2<sup>nd</sup> year students which is designed to include many, self-directed, online learning activities. I will incorporate the toolkit into this course.

Q15.A Please rate the effectiveness of each section of the GCCCT for enhancing and improving overall cultural competence in your students.

Q15.B Comments: \_\_\_\_\_

Just a note to say that I really don't know how effective this is since I did not measure effectiveness but this is my opinion.  
Same comment as above.  
The faculty member that accessed the cases available on the web used that material to generate ideas for her class discussion.

Q16 How could the GCCCT be improved to further support the education of genetic counseling graduate students? \_\_\_\_\_

Unsure

Q17 Please comment on any feedback you have received from students about the GCCCT. \_\_\_\_\_

They like the cases.  
They like the cases—have opened their eyes to issues they might not have previously considered  
Great links, keep them updated!!  
Students really enjoy the cases.  
The best part was working with interpreters.