

## 2009 JEMF Project

### Survey to Inform Development of the Genetic Counseling Cultural Competence Toolkit (GCCCT)

The perspectives of the major target groups for this project (practicing genetic counselors, genetic counseling program directors, and genetic counseling graduate students) were sought by developing a survey. The survey results informed the process of developing the content and format of the online cultural and linguistic competence toolkit for genetic counseling, according to Objective 1 of the project proposal:

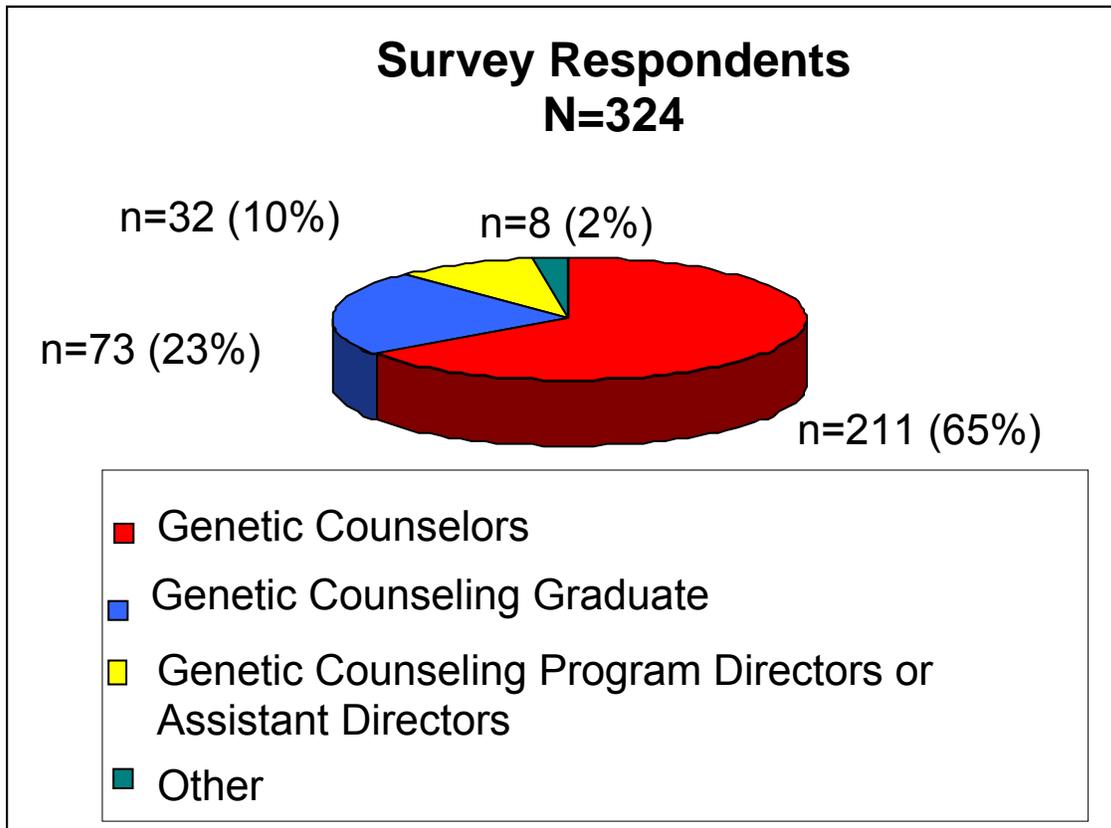
*Objective 1: Determine needs and identify strategies to promote cultural and linguistic competence in the genetic counseling profession. We will perform needs assessments of genetic counseling training program directors and students, and practicing counselors. The resulting quantitative and qualitative formative needs assessment data will be reviewed with the project advisors, and the GCCCT content outline will be developed.*

**Survey Development:** A short questionnaire was developed by Nancy Steinberg Warren. The content was reviewed by several project advisors, genetic counselors and undergraduate students. Based on the feedback, minor modifications to the survey content and wording were made. The questionnaire was set up in SurveyMonkey, and consisted of seven questions: two demographic questions (one closed-ended, one open-ended), one closed-ended question about continuing education approval, three multiple choice questions regarding content and format, and one comments box asking for general suggestions.

**Implementation:** The survey was piloted with four undergraduate students and no changes were made based on the piloting. An email with the link to the questionnaire was posted to the National Society of Genetic Counselors (NSGC) and Association of Genetic Counseling Program Directors (AGCPD) listservs on July 22, 2009 and re-posted on August 4, 2009. Genetic Counseling Program Directors were asked to forward the email with the survey link to their current and incoming graduate students. Approximately 2000 genetic counselors have access to the NSGC listserv. Approximately 50 program directors and assistant directors have access to the AGCPD listserv. Approximately 400 genetic counseling students are enrolled in all accredited genetic counseling programs. The survey was closed on September 1, 2009.

**Results:** 319/324 (98.2%) of the respondents completed the short survey.

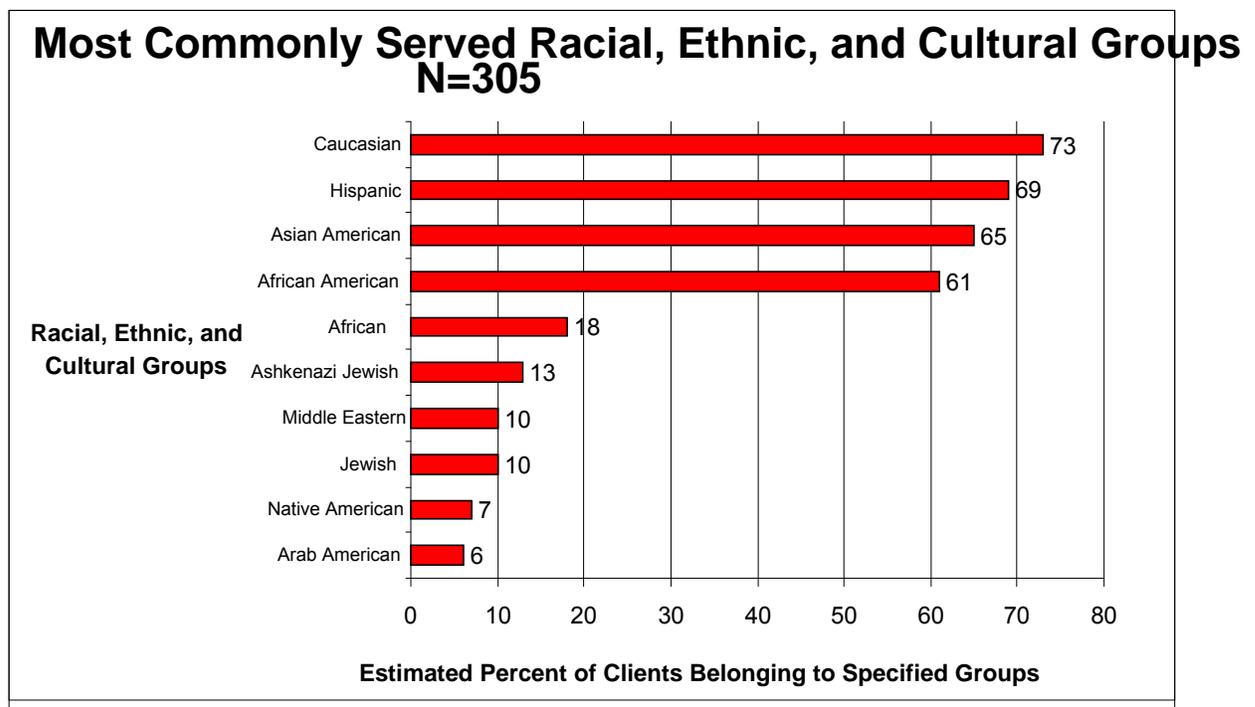
**Question 1:** This question asked respondents to categorize their affiliation with genetic counseling. Responses to this question were received from 324 individuals, including 211 genetic counselors, 73 genetic counseling graduate students, 32 genetic counseling program directors or assistant directors, and 8 individuals who checked “other,” including prospective genetic counseling students, genetics nurses, and other descriptors.



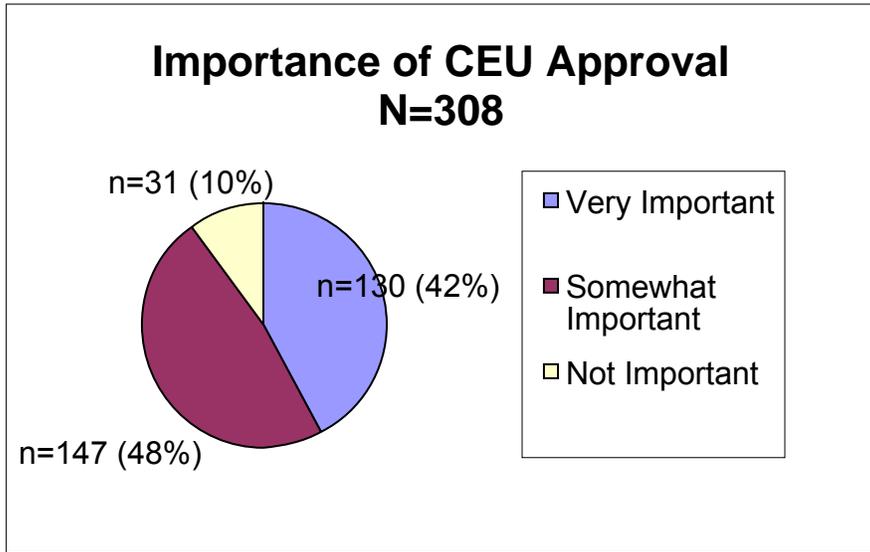
**Question 2:** This open-ended question asked respondents to list the major racial, ethnic, and cultural groups served in their work setting in an open-ended text box to allow participants to generate their own descriptors.

Respondents most commonly serve clients from these racial, ethnic and cultural groups: Caucasian, Hispanic, Asian, African American, African, Ashkenazi Jewish, Middle Eastern, Native Americans, Jewish religious beliefs, and Arab Americans. There were several other *ethnic groups* named including Bosnian, Russian, Polish, Kurdish, Armenian, Bulgarian, French Canadian, Portuguese, Brazilian, and Haitian. *Religious groups* mentioned included Muslim, Mormon, Mennonite, Christian, Hindus, Buddhists, Latter Day Saints and Orthodox Jewish. Groups of people committed to a specific *lifestyle* included Appalachian, Amish, Quakers, and Aboriginal. *Other cultural groups* mentioned were of people with intellectual disabilities, the deaf community, the blind community, people from varying SES, those from rural or urban communities, individuals on Medicaid, military families, same-sex couples, prisoners, and persons who have a high school or lower education level.

### Ten Most Commonly Served Racial, Ethnic, and Cultural Groups

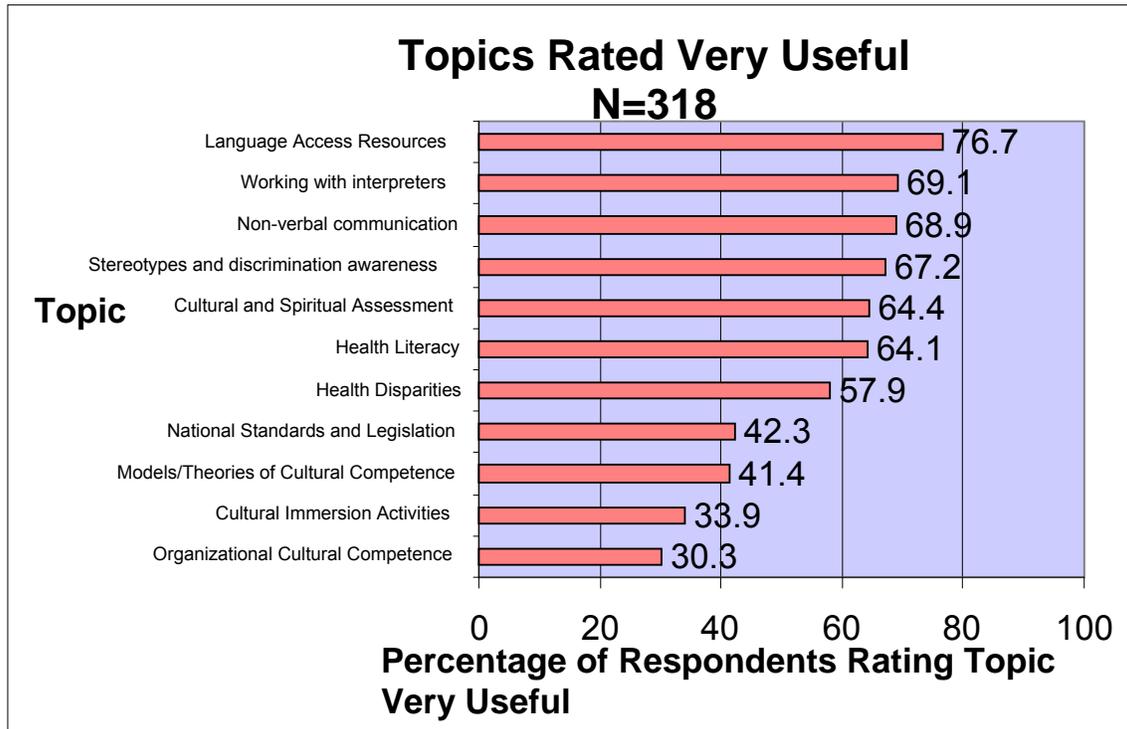


**Question 3:** This question asked the respondents to indicate how important (very important; somewhat important; not important) it is for the toolkit content to be approved for category 1 genetic counseling CEUs. A total of 308 respondents answered this question. A large group (90%) of the respondents indicated that having CEU approval was very or somewhat important.



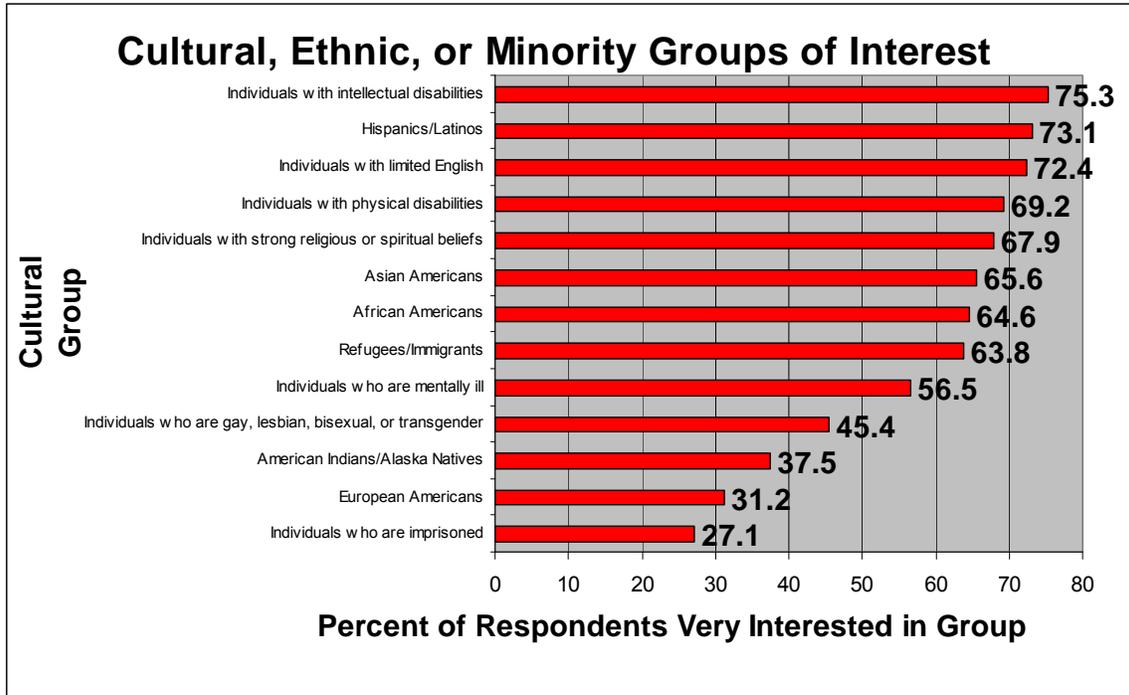
Importance of CEU Approval		
Degree of Importance	Percentage	Responses
Very Important	42.0%	130
Somewhat Important	47.7%	147
Not Important	10.1%	31
<b>Total</b>	<b>100.0%</b>	<b>308</b>

**Question 4:** This question asked respondents to indicate how useful (very useful, somewhat useful, not useful, not sure what this topic is) it would be to include certain topics in the online toolkit for personal learning or teaching purposes. The results below indicate the percentages of respondents who indicated a topic would be very useful to include in the toolkit.

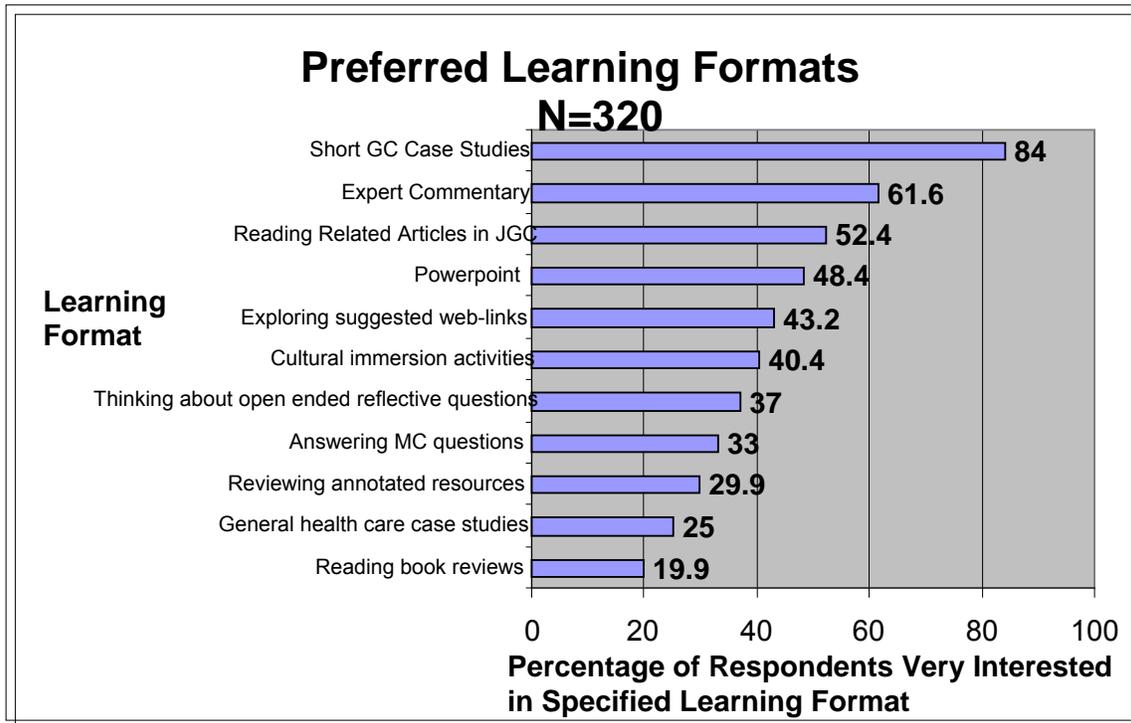


**Question 5:** This question asked the respondents to indicate their interest (very interested, somewhat interested, not interested) in learning more about various cultural groups to improve their relationship with their clients or for teaching purposes. There were 322 respondents to this question. The following table summarizes the very interested responses.

## Cultural Groups of Most Interest N=322



**Question 6:** This question asked respondents to indicate their interest (very interested, somewhat interested, not interested) in presenting information in the toolkit in specific learning formats. There were 320 respondents to this question. The table below summarizes the responses of individuals indicating they were very interested in specific learning formats.



**Question 7:** This open-ended question requested suggestions for the online genetic counseling cultural and linguistic competence toolkit. 31 respondents answered this question. Their responses were categorized into three thematic areas:

### **1. Suggestions for Toolkit Content**

1. Quotes/commentary from various cultural/lay groups about:
  - a. Expectations of healthcare providers
  - b. Experiences with health care insensitivities and discrimination
  - c. Experiences of culturally sensitive encounters
  - d. Experiences with genetic counseling (or health care providers in general)
  - e. How genetic counselors can provide better service to them
2. Consider Deaf culture
3. Consider inter-generational issues since the cultural and counseling experiences of younger counselors are likely to be quite different from middle-aged counselors.
4. Write or edit cases from the perspectives of non-Caucasian-Americans, i.e. Asian Americans, African Americans, etc.
5. Offer self-assessment tools
6. Tips regarding assessment of patient understanding with non-English speaking clients
7. Access to pre-recorded "webinars" with audio and visual content regarding these issues
8. "Cheat Sheet" summaries of key points for genetic counselor to refer to before sessions
9. Activities that challenge each counselor to identify their own bias (aside from assessments), or cultural hot button issues in a dynamic and constructive way. For instance- watching excerpts from "Crash", "Transamerica," etc. and having a blog discussion about it.

### **2. Suggestions for Resources**

1. Translations of clinical documents into other languages i.e. Chinese (four requests)
2. Tip Sheets on various cultures (three requests)
3. Blog – Link to new GC blog

### **3. Opinions on Toolkit**

1. This content would work great as background information, theory, links to resources and some limited case study work but would not replace most current curriculum information.
2. Fantastic project (several comments)
3. Keep it short

### **Summary of Survey Results to Inform Development of the GCCCT:**

- Exceptional interest in this project was expressed by genetic counselors, program directors and genetic counseling students. We base this statement on the 98.2% survey completion rate by over 300 individuals, as well as the supportive comments that were offered in the comments section.
- The overall response rate to the survey was limited. This is very likely due to the summer timing of the survey posts. We received many out of the office automatic responses. In particular, there was a poor response rate to the survey from genetic counseling students. We believe that the summer timing of the survey was responsible for students' lack of access and/or interest at a time when they are not in school. Also, we cannot be sure how many program directors actually forwarded the survey link to their current and entering students.
- The respondents are serving clients from a variety of racial, ethnic and cultural groups.
- There was strong interest in obtaining Category 1 CEU approval.
- Respondents ranked many suggested topics as very useful. Language access resources, working with interpreters, issues around non-verbal communication, stereotypes and discrimination awareness, cultural and spiritual assessment, health literacy and health disparities were rated as the most useful topics.
- Respondents were very interested in many cultural, ethnic or minority groups. The groups of most interest included individuals with intellectual disabilities, Hispanics/Latinos, individuals with limited English, individuals with physical disabilities, individuals with strong religious or spiritual beliefs, Asian Americans, African Americans, refugees/immigrants, and individuals who are mentally ill.
- Respondents prefer diverse learning formats including short case studies, comments from experts, directed readings from the JGC, PowerPoint presentations, weblinks, cultural immersion activities, and other formats.
- Respondents are interested in quick tips sheets, and hearing from experts, consumers and others who may be able to share unique perspectives.

Disclaimer: While we could not incorporate all the suggestions, we made a good faith effort to meet the expressed needs of potential toolkit users when developing the format and content of the toolkit.