

2013 Review and Update of the Genetic Counseling Practice Based Competencies by a Task Force of the Accreditation Council for Genetic Counseling

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Abstract The first practice based competencies (PBCs) for the field of genetic counseling were adopted by the American Board of Genetic Counseling (ABGC), 1996.

Since that time, there has been significant growth in established and new work settings (clinical and non-clinical) and changes in service delivery models and the roles of

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genetic counselors. These changes prompted the ABGC to appoint a PBC Task Force in 2011 to review the PBCs with respect to their current relevance and to revise and update them as necessary. There are four domains in the revised PBCs: (I) Genetics Expertise and Analysis (II) Interpersonal, Psychosocial and Counseling Skills (III) Education and (IV) Professional Development and Practice. There are 22 competencies, each clarified with learning objectives or samples of activities and skills; a glossary is included. New competencies were added that address genomics, genetic testing and genetic counselors' roles in risk assessment, education, supervision, conducting research and presenting research options to patients. With PBCs serving as the pre-defined abilities or outcomes of training, graduating genetic counselors will be well prepared to enter the field with a minimum level of skills and abilities. A description of the Task Force's work, key changes and the 2013 PBCs are presented herein.

Keywords Genetic counseling · Practice based competencies (PBCs) · Graduate program accreditation · Genetic counselors · Training · Curriculum

Introduction

Competencies are defined as the measurable or observable knowledge, skills, abilities, and behaviors critical to successful job performance (*Oxford Dictionaries*). In clinical education, competencies are intended to define the end goals of training in a measurable way (*WA State HR*). While entry level practitioners' expertise and skill sets will improve with time, competencies set the standards for proficiency and inform learners and other stakeholders of the expectations for individuals trained in a profession (Albanese et al. 2008).

The first practice-based competencies (PBCs) for the field of genetic counseling were adopted in 1996 by the American Board of Genetic Counseling (ABGC), the credentialing organization for the genetic counseling profession (Fiddler et al. 1996; Fine et al. 1996). The PBCs defined the practice areas and skills that all genetic counseling training programs were expected to develop in their students and were an essential component of the ABGC Required Criteria for Graduate Programs. The workgroup that developed the initial PBCs included genetic counseling program directors, practicing genetic counselors and expert consultants in education and accreditation (Fiddler et al. 1996; Fine et al. 1996).

A case-based narrative process was utilized to develop the initial PBCs. (Fiddler et al. 1996). The workgroup identified discrete components of genetic counseling and defined expectations as they related to typical genetic counseling scenarios at that time: advanced maternal age/prenatal diagnosis counseling; pediatric counseling; adult counseling; and carrier screening counseling. The original PBCs consist of 27

competencies organized into four domains of skills: Communication; Critical Thinking; Interpersonal Counseling and Psychosocial Assessment; and Professional Ethics and Values (Fine et al. 1996).

In 2005, the PBCs were reviewed at a retreat attended by the ABGC Board of Directors and invited past board members. Following this review, no substantive changes were made. However, the group noted the expanding field of genetic counseling and recommended the PBCs be periodically reviewed. (Personal Communication ABGC Executive Director October 2011)

Since 2005, global advances in knowledge about human genetics and genomics, new molecular technologies, and changes in the fields of clinical genetics and genetic counseling emerged (Table 1). Some of the changes were documented in the first Genetic Counseling Practice Analysis (PA), conducted by the ABGC in 2008. The PA solicited information from practicing genetic counselors concerning what they need to know, the tasks they perform, how often these tasks are performed and the relative importance of each. Data collected from PAs are used to ensure the ABGC certification examination's validity. In the PA, five major content domains were identified: 1) case preparation and history 2) risk assessment and diagnosis 3) testing 4) psychosocial assessment and support and 5) ethical/legal/research/resources (Hampel et al. 2009). Furthermore, the National Society of Genetic Counselors (NSGC) Professional Status Survey results indicated changes within the field with more genetic counselors working in different clinical specialties and non-clinical work settings (e.g., laboratories), an increase in genetic counseling by telephone or telemedicine and greater involvement in professional activities including conducting research, publishing and presentations to professional and lay audiences (NSGC Professional Status Survey 2010).

Given these changes along with a continuing paradigm of competency-based education for healthcare providers where curriculum are organized around pre-defined abilities or outcomes (Frank et al. 2010), the ABGC appointed a Practice Based Competency Task Force (PBCTF) in 2011 with the purpose of undertaking a comprehensive review and revision of the PBCs. Here, we describe the review process, discuss key changes incorporated, and present the 2013 Practice Based Competencies for Genetic Counselors (Practice-based Competencies for Genetic Counselors 2013). This summary will provide background and context for the revised PBCs and serve as a reference for future reviews and revisions.

Appointment of the Practice Based Competencies Task Force (PBCTF)

The ABGC adopted a PBCTF Charter in April 2011 that called for up to 24 volunteer members to serve on the task

Table 1 Global Changes Resulting in the Need to Review and Revise the Practice Based Competencies**Changes Initiated by the American Board of Genetic Counseling**

The board certification exam for genetic counselors became a stand-alone ABGC administered test in 2009. This exam was previously jointly administered with the American Board of Medical Genetics.

The first genetic counseling Practice Analysis was conducted in 2008. This represents “best practice” in the credentialing industry because the analysis results in the development of a certification examination that accurately reflects current genetic counseling practice (Hampel et al. 2009).

A separate organization, the Accreditation Council for Genetic Counseling (ACGC) was proposed in 2012 and was established in 2013 to serve as the accrediting body for the genetic counseling profession. Prior to this time, accreditation functions were conducted under the American Board of Genetic Counseling (ABGC).

A work group was established in 2011 to review and revise the Required Criteria for Graduate Programs, renamed the Standards for Program Accreditation, with program compliance stipulated for 2014.

Research was added as a requirement for genetic counselor training in 2002 by ABGC to the Required Criteria for Accreditation of training Programs (now known as the ACGC Standards for Program Accreditation).

More genetic counseling training programs were accredited by the ABGC and the number of genetic counselors trained increased.

Global Changes in the Field of Genomics and Genetic Counseling

NSGC revised the definition of genetic counseling in 2005 (Resta et al. 2006).

NSGC issued a Scope of Practice for Genetic Counselors in 2007.

Increase in number and growth of different genetic counseling specialties.

Introduction and wider use of different genetic service delivery models.

Licensure for genetic counselors was either achieved or initiated in multiple states.

Use of internet resources and electronic medical records increased.

Emergence of genomics and faster translation of research advances into clinical application.

Advances in genetic testing resulted in increased availability of genetic tests, more test options and lower costs.

force. The ABGC board members nominated, discussed, and selected potential task force member names with consideration for attaining diversity in the task force membership. The demographics of interest included geographic (representation from different regions of the country and Canada), work setting (university and non-university based genetics clinics, public health, research, commercial genetic testing companies), years of experience, primary role in genetic counseling (e.g., prenatal, pediatric, adult, specialty care, research), and representation of genetic counseling program directors. Because well-established PBCs were already in place, the Board believed the invited genetic counselors and medical geneticists held the expertise necessary for the review and update; individuals outside of the genetics profession were therefore not included. Nineteen invitees agreed to participate

and included one MD clinical geneticist with expertise in education and accreditation, two PhD medical geneticists (one of whom is also a practicing genetic counselor), six genetic counseling program directors, and eleven practicing genetic counselors (clinical, lab and research).

PBC Review and Update Process

The PBCTF Charter also operationalized the review process that included an emailed survey of the Association of Genetic Counseling Program Directors (AGCPD) to ascertain their views on the PBCs, their value, use in training (e.g., for teaching purposes, as a required guide to structure curriculum) and how the PBCs influenced their program and practice. The survey asked program directors to describe whether there were elements missing or gaps in the existing PBCs and if any changes were needed. Thirty two program directors were sent the survey and fourteen provided comments for a 43 % response rate which included a small number of PBCTF members. Responding program directors conveyed that the PBCs serve as a foundation for the training of genetic counselors – driving curriculum development and learning objectives, teaching, evaluation of students during clinical training, students’ self-evaluation and alumni surveys. Some directors reported using the PBCs outside of their training programs, for example, to explain curriculum and assist administrators in understanding the profession of genetic counseling. The main “gaps” identified were the need to:

- 1) capture the responsibilities of genetic counselors who work in expanded roles (e.g., lab, public health);
- 2) recognize research roles of genetic counselors, including conducting research, raising research options with patients and complying with federal regulations for the protection of human subjects;
- 3) include integrating new technologies into clinical practice;
- 4) recognize genetic counselors’ educational roles, including targeting education to audience’s needs; and
- 5) recognize supervision roles while acknowledging that full supervisory roles would not be possible until after board certification.

A Different Approach to PBC Development

While the case-based approach worked well in 1996, a different approach was developed for this review. There are different strategies and methodologies for creating and modifying professional competencies and none has ever been declared a “standard.” Three models for arriving at a set of competencies are typically used: 1) an internally created, theory-based

normative model that may be applied to measure desired skills, traits, and perspectives of existing practitioners that are then correlated with ‘real life’ performance as one means of validating the competency set; 2) adoption of a previously designed and written set of what would serve as existing or pre-set competencies that are adapted with minor rather than *de novo* expressions of skill, traits, and perspectives; and, 3) creation of a profession-specific set of competencies based on critical incident interviews or other narrative processes that are analyzed, abstracted, and validated by one of a number of qualitative techniques. Ultimately, the test of the quality of a set of professional competencies lies in the extent to which each is assessable in the course of educational activities, professional activities, or both depending on the competencies use (Fiddler, M. personal communication 11/29/15). Thus, the task force made some choices given the task and purpose with which it was charged.

The task force recognized the role the third strategy played in the creation of the first set of competencies approximately 20 years ago. It made a decision to rely upon its collective knowledge of the profession, the changes in context and applications experienced by genetic counselors, and the gaps in the original set of competencies that have become more evident over time and were noted in the previous section. Consequently, the task force adopted a blend of the first method comparing existing competencies with, and looking to augment these competencies by utilizing survey tools that measured skills and perspectives of real life practitioners.

To initiate the PBC update, a 2-day face-to-face PBCTF meeting was held in Chicago, Illinois in October 2011. PBCTF members were provided the following documents to review prior to the meeting:

- 2011 Genetic Counseling Practice Analysis (PA) descriptive statistics and all respondent written text data provided by the ABGC that included roles and responsibilities reported by the majority as well as the minority of counselors
- *Journal of Genetic Counseling* article by Hampel et al. (2009) describing the process and outcome of the 2008 ABGC PA
- *Journal of Genetic Counseling* articles by Fiddler et al. (1996) and Fine et al. (1996) describing the development of the original PBCs
- ABGC Required Criteria for Graduate Programs inclusive of the existing PBCs (Required Criteria for Graduate Programs in Genetic Counseling Seeking Accreditation by the American Board of Genetic Counseling Adopted January 25, 1996; Last Revised May 2010. Personal communication with Executive Director of ABGC/ACGC)
- De-identified survey comments submitted by AGCPD respondents regarding their perceptions of PBC use, utility and potential gaps.

These meetings were facilitated by a genetic counselor with professional training and experience in utilizing multiple facilitation techniques. A consensus approach was emphasized and throughout the review process, any area of disagreement was captured in a “parking lot.” These tended to be competencies that did not clearly fit in a specific domain or could be in multiple domains. At the end of every meeting a decision was made that either a consensus was reached as demonstrated through voting on that issue or it remained a “parking lot” item. By the end of the process, decisions were reached for all “parking lot” issues.

During the initial 2-day meeting, two facilitation techniques aimed at maximizing creative thinking and encouraging full group participation were utilized. The first approach was a focused conversation method, commonly called ORID (Objective, Reflective, Interpretive, Decisional) (Spencer 1998), which helps groups identify and concentrate on the task before them. The review of documents *prior* to the meeting helped forge a common experience that enabled a more productive dialogue and provided opportunities for task force members to offer differing perspectives. PBCTF members were asked specific questions that stimulated a dialogue that included objective facts, reactions and reflections about the information, as well as decision making on how to move forward. (Table 2). Through the ORID focused conversation, the PBCTF collectively agreed that the revised PBCs required an overall philosophical change to be broader in scope and definition, as described below. For example, the competencies now include genomics as well as genetics concepts and include various forms of providing service beyond the face-to-face clinic visit.

The second facilitation method deployed was a Consensus Workshop approach (Spencer 1998). While the focused conversation set the stage or context of the work to be completed, the workshop method allowed the PBCTF to delve deeper into specific content. This approach consists of:

Context (what we accomplished through ORID),
Brainstorming (generating new ideas),
Group (putting old and new ideas on half-sheets of paper, placing similar ideas next to each other and discussing reasons for or against grouping),
Name (generating domain or header names for the groupings); and
Resolve (arriving at consensus on work, implications and next steps).

Through this process, PBCTF members organized the competencies and confirmed via consensus the significance of each domain and competency. It was during this phase of the work, for example, that PBCTF members chose to highlight as Domain I: Genetics Expertise and Analysis, recognizing the unique skills of genetic counselors. It was also during the Consensus Workshop approach that PBCTF members decided that incorporating objectives or samples of activities and

Table 2 The ORID Focused Conversation

Steps	Focused questions	Response examples
Objective (sensory impressions, eliciting facts)	Share with the group an “aha” moment you had after reviewing the pre-meeting materials.	It is remarkable how many of the competencies developed back then still hold true today. The data from the practice analysis clearly shows growth in the field in both laboratory and research responsibilities.
Reflective (associations, emotions, images)	What were some of the findings that were striking to you in the shared data/documents?	I was surprised to see not much change between the two practice analyses. I appreciated how thoughtful they were in creating the case scenarios in 1996 but I don't know that we could construct 'typical' cases today.
Interpretive (significance, purpose, implications)	What, if any, gaps or suggested changes do you have based on the preliminary work so far?	The definition of a client needs to be broader. The competencies must take into account genomics and all of the varied roles of genetic counselors.
Decisional (future direction, next steps)	After we conclude our work, how will we know we've been successful (i.e. what will “success” look like?)	When the PBCs are reviewed again in 5 years or so, they will still be completely relevant. Graduating genetic counselors will be well prepared to enter the field with a minimum level in all of these competencies.

skills for each competency would be useful particularly in explicating the competencies and what needed to be achieved. Ultimately, the group used Bloom's Revised Taxonomy as a resource in selecting the most appropriate wording for each objective. Bloom's Taxonomy, developed to promote higher forms of thinking in education, categorizes growth in knowledge, skills and attitudes (Anderson et al. 2001). Bloom's taxonomy was not used to connect each objective to a specific Bloom's level, but merely as a guide for the PBCTF to use in reaching a consensus on word choices. In other words, Bloom's taxonomy informed the group's choice of verbs or action words for each objective. For example words such as “assess,” “employ,” or “utilize” were intended to describe higher level skills (i.e., application or analysis) while words such as “demonstrate” or “understand” were intended to signify lower level skills.

After the meeting in Chicago, the PBCTF members were sub-divided into smaller workgroups to facilitate timely and comprehensive review of the revised PBCs. Each smaller group was tasked with further refining the language and intent of each competency within the Domain to which they were delegated. After this work was completed, the PBCTF met in person for a second time in Tempe, Arizona August 14–16, 2012. In addition, four subsequent conference calls were held utilizing GoTo™ Meeting to review all changes recommended by the smaller workgroups. During these reviews, the PBCTF voted unanimously (i.e., reached consensus) to combine previously separate domains and competencies believing that there was significant overlap between them.

During the time that the PBCTF was working on the PBCs, The Canadian Association of Genetic Counsellors (CAGC) published their PBCs (CAGC 2012). This was shortly after the PBCTF met in Chicago so these were considered in the work of the PBCTF in addition to data from the most recent NSGC Professional Status Survey and the documents noted above that were provided prior to the initial PBCTF meeting. DRAFT PBCs were presented to the AGCPD twice for their input. Both the ABGC and ACGC (Accreditation Council for Genetic Counseling) reviewed and provided feedback on the PBCTF's proposed PBCs. After revisions were incorporated, the PBCs were adopted by the ACGC in 2013. While the ABGC appointed the PBCTF, the PBCs were adopted by the ACGC, which was established in 2013 and assumed the role of accreditation of genetic counseling training programs from ABGC.

Key Changes to the PBCs

The number of domains stayed the same but the domain names changed to: (I) Genetics Expertise and Analysis; (II) Interpersonal, Psychosocial and Counseling Skills; (III) Education; and (IV) Professional Development & Practice. Two new competencies were added and the original compe-

tencies were reworded or combined resulting in 22 competencies. While there are actually fewer competencies compared to the original PBCs, there was an intentional expansion or broadening of past PBCs. The former PBCs focused almost entirely on students and the clinical genetic counselor's role. The new PBCs recognize that "clients" may include other healthcare providers, researchers, study participants, students or teachers and are not limited to "patients." The PBCs also include genomics as part of the scope of practice and recognize that the delivery of services may involve various electronic technologies (e.g., telephone counseling, internet-based services).

To highlight and recognize the importance of genetic counselors' skills and expertise in family-history taking, pedigree construction, risk assessment and genetic testing, the "Genetics Expertise and Analysis" Domain was intentionally labeled as Domain I. Competencies recognizing genetic counselors' research roles, both in conducting research (Domain IV – 18) and in presenting research options to patients (Domain I – 4f, 6d), are included in the PBCs. There are also competencies recognizing genetic counselors' roles as educators (Domain III) and clinical supervisors (Domain IV – 21). These came as a direct result of the typical activities reported by genetic counselors in the 2011 PA (2011 ABGC Practice Analysis). Given the PBCTF deliberations over terminology and specific word meanings, a glossary was added to define 18 terms used in the PBCs.

Learning objectives were developed for each competency that replaced the summary text approach used in the 1996 PBCs. These specific objectives are intended to help students, teachers, supervisors and practitioners understand each competency by providing some of the activities and skills that demonstrate achievement of the competency.

There was a great deal of thoughtful debate among PBCTF members as well as voiced by some AGCPD members upon their review of the PBCs over whether or not these objectives should be included. Some feared that the ACGC would require these objectives be included in training programs' curricula and that students would be assessed as to their ability to perform each objective rather than the intended purpose of the objectives providing general illustrative guidance for training programs and students. The PBCTF agreed the objectives should be viewed as examples and elected to emphasize this point by creating a preamble to the PBCs that clearly stated this belief. However, the ACGC board eliminated the sentence within the preamble that stated the objectives were only intended to be examples before formally adopting the PBCs. They felt such a statement was unnecessary since the ACGC standards regarding curriculum and instruction (Standards of Accreditation for Graduate Programs in Genetic Counseling. Adopted 02/13/2013, Compliance Start Date 06/01/2014 [http://gceducation.org/Documents/Standards%20Final%20approved%20Feb%](http://gceducation.org/Documents/Standards%20Final%20approved%20Feb%202013.pdf)

[2013.pdf](http://gceducation.org/Documents/Standards%20Final%20approved%20Feb%202013.pdf) (last accessed 12/30/2013) specifically state, "The ACGC Practice-Based Competencies (PBCs) serve as guidelines for preparing entry-level genetic counselors. Each program will maintain its own curriculum and unique methods for supporting the development of these competencies." Furthermore, because the PBCs have a wider audience than strictly training programs the sentence was deleted so that the document could apply towards many different uses including exam content, legislative requirements, and scope of practice. Others questioned whether the PBCTF set the bar too high for competencies that needed to be achieved by entry-level genetic counselors and whether practicing genetic counselors could realistically meet all of the competencies.

The PBCTF reviewed and deliberated on all feedback received and ultimately concluded that the inclusion of objectives would facilitate understanding of the expected practice standards by genetic counselors, both entry-level and experienced. For some of the competencies, it is expected that an entry-level genetic counselor may have limited skills. For example, a supervisory role is performed by the majority of counselors (2011 Practice Analysis) and subsequently was included in the ABGC certification examination outline. Therefore, it seems reasonable that entry-level genetic counselors should have some understanding of the supervisory role, even if this is limited to reflecting on how they were evaluated by their own supervisors.

Discussion and Conclusions

The 2013 PBCs presented here reflect the deliberative and thoughtful conclusion of a 2-year process to revise and update the genetic counseling competencies. The competencies are intended to apply to all genetic counselors irrespective of whether the genetic counselor's primary role is purely clinical or predominantly in research, public health, academia or a laboratory setting. The competencies establish a base, understanding that the depth and breadth of knowledge and skills encompassed by the competencies will vary depending on the genetic counselor, their role and work setting. While the PBCs are an integral part of the ACGC Standards for Program Accreditation and hence educational objectives for genetic counseling students, we hope that they will also be of use to practicing genetic counselors and serve as a reference for the wider health care community in defining the expertise and skills of genetic counselors.

Language is important to the usefulness and application of competencies. The task force found universal agreement that the key element of a competence statement lies in the choice of the verb and utilized Bloom's taxonomy (Anderson et al. 2001) as a guide in selecting the most appropriate verb. There was also agreement that the level of competency for the set of PBCs was directed to the graduate of a genetic counseling training

program. Therefore, a primary target of the PBCs is the curricula that comprise the national effort to train and develop “entry-level” genetic counselors. The task force recognizes that higher-level competency expectations are both appropriate and necessary for counselors to continue to develop and deepen their progress toward levels of expertise. Though Bloom’s taxonomy (Anderson et al. 2001) was not a formal and strict guide in the many discussions regarding the framing and wording of competencies, the task force recognized that this hierarchy of complexity is intrinsically both a powerful and very useful linchpin for extending the outcome of the task force’s work into applications beyond graduate education.

Fine et al. in 1996 noted that “it will be essential to periodically review the competencies for their effectiveness and appropriateness as a template for training and practice standards.” As the evidence-base to inform the practice of genetic counseling matures, competencies will continue to evolve and likely need to be further revised and updated. The value of the competencies will lie in their capacity to be adapted without compromise to an expanding set of contexts in which genetic counselors function. The task of “using while reviewing” requires the continuing involvement of those in the profession who will serve as stewards of the education and the ongoing development of experienced practitioners. These competencies, as with all standards, require two commitments: validation, formally and informally, to test their usefulness and provide the data for modifications; and assessment, both profession-wide and on an individual basis (i.e., self-assessment). We hope that these competencies will be formally monitored and assessed concurrently with their implementation and continue to be refined in the years ahead as the field of genetic counseling evolves.

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Compliance with Ethical Standards

Conflict of Interest Debra Lochner Doyle, Rawan I. Awwad, Jehannine C. Austin, Bonnie J. Baty, Amanda L. Bergner, Stephanie J. Brewster, Lori A. H. Erby, Cathi Rubin Franklin, Anne E. Greb, Robin E. Grubs, Gillian W. Hooker, Sarah Jane Noblin, Kelly E. Ormond, Christina G. Palmer, Elizabeth M. Petty, Claire N. Singletary, Matthew J. Thomas, Helga Toriello, Carol S. Walton, Wendy R. Uhlmann declare that they have no conflict of interest.

Human Studies and Informed Consent No human studies were carried out by the authors for this article.

Animal Studies No animal studies were carried out by the authors for this article.

Practice-Based Competencies for Genetic

Counselors © 2014 Accreditation Council for Genetic Counseling - edited to include how past competencies (Fine et al. 1996; Uhlmann et al. 2009), identified by number, are included in the current competencies.

This document defines and describes the twenty two practice-based competencies that an entry-level provider must demonstrate to successfully practice as a genetic counselor. It provides guidance for the training of genetic counselors and an assessment for maintenance of competency of practicing genetic counselors. The didactic and experiential components of a genetic counseling training curriculum and maintenance of competency for providers must support the development of competencies categorized in the following domains: (I) Genetics Expertise and Analysis; (II) Interpersonal, Psychosocial and Counseling Skills; (III) Education; and (IV) Professional Development & Practice.

These domains describe the minimal skill set of a genetic counselor, which should be applied across practice settings. Some competencies may be relevant to more than one domain. *Italicized words are defined in the glossary.*

Domain I: Genetics Expertise and Analysis

1. Demonstrate and utilize a depth and breadth of understanding and knowledge of *genetics* and *genomics* core concepts and principles. (formerly #12 and #6)
2. Integrate knowledge of psychosocial aspects of conditions with a genetic component to promote *client* well-being. (formerly #11 and #12)
3. Construct relevant, targeted and comprehensive personal and family histories and pedigrees. (formerly #2, #3, #4 and #12)
4. Identify, assess, facilitate, and integrate genetic testing options in genetic counseling practice. (formerly #6 and #12)
5. Assess individuals’ and their relatives’ *probability of conditions with a genetic component* or carrier status based on their pedigree, test result(s), and other pertinent information. (formerly #10 and #12)
6. Demonstrate the skills necessary to successfully manage a genetic counseling case. (formerly #7, #12, #13, and #15)
7. Critically assess genetic/genomic, medical and social science literature and information. (formerly #12 and #16)

Domain II: Interpersonal, Psychosocial and Counseling Skills

8. Establish a mutually agreed upon genetic counseling agenda with the client. (formerly #1 and #17)
9. Employ active listening and interviewing skills to identify, assess, and empathically respond to stated and emerging concerns. (formerly #7, #14 and #17)
10. Use a range of genetic counseling skills and models to facilitate informed decision making and adaptation to genetic risks or conditions. (formerly #14, #17, #19 and #20)

11. Promote client-centered, informed, noncoercive and value-based decision-making. (formerly #18 and #21)
12. Understand how to adapt genetic counseling skills for varied service delivery models. (Not present in past PBCs)
13. Apply genetic counseling skills in a culturally responsive and respectful manner to all clients. (formerly #7)

Domain III: Education

14. Effectively educate clients about a wide range of genetics and genomics information based on their needs, their characteristics and the circumstances of the encounter. (formerly #5 and #6)
15. Write concise and understandable clinical and scientific information for audiences of varying educational backgrounds. (formerly #5 and #8)
16. Effectively give a presentation on genetics, genomics and genetic counseling issues. (formerly #8 and #9)

Domain IV: Professional Development & Practice

17. Act in accordance with the ethical, legal and philosophical principles and values of the genetic counseling profession and the policies of one's institution or organization. (formerly #23)
18. Demonstrate understanding of the research process. (formerly #25)
19. Advocate for individuals, families, *communities* and the genetic counseling profession. (formerly #24)
20. Demonstrate a self-reflective, evidenced based and current approach to genetic counseling practice. (formerly #26 and #27)
21. Understand the methods, roles and responsibilities of the process of clinical supervision of trainees. (Not present in past PBCs)
22. Establish and maintain professional *interdisciplinary relationships* in both team and one-on-one settings, and recognize one's role in the larger healthcare system. (formerly #22)

Appendix: Samples of Activities and Skills that may assist in Meeting Practice-Based Competencies These samples may assist in curriculum planning, development, implementation and program and counselor evaluation. They are not intended to be exhaustive nor mandatory, as competencies can be achieved in multiple ways.

Domain I: Genetics Expertise and Analysis

1. Demonstrate and utilize a depth and breadth of understanding and knowledge of *genetics* and *genomics* core concepts and principles.
 - a) Demonstrate knowledge of principles of human, medical, and public health genetics and genomics and their related sciences. These include:

- Mendelian and non-Mendelian inheritance
 - Population and quantitative genetics
 - Human variation and disease susceptibility
 - *Family history* and *pedigree* analysis
 - Normal/abnormal physical & psychological development
 - Human reproduction
 - Prenatal genetics
 - Pediatric genetics
 - Adult genetics
 - Personalized genomic medicine
 - Cytogenetics
 - Biochemical genetics
 - Molecular genetics
 - Embryology/Teratology/Developmental genetics
 - Cancer genetics
 - Cardiovascular genetics
 - Neurogenetics
 - Pharmacogenetics
 - Psychiatric genetics
 - b) Apply knowledge of genetic principles and understand how they contribute to etiology, clinical features and disease expression, natural history, differential diagnoses, genetic testing and test report interpretation, pathophysiology, recurrence risk, management and prevention, and *population screening*.
2. Integrate knowledge of psychosocial aspects of conditions with a genetic component to promote *client* well-being.
 - a) Demonstrate an understanding of psychosocial, ethical, and legal issues related to genetic counseling encounters.
 - b) Describe common emotional and/or behavioral responses that may commonly occur in the genetic counseling context.
 - c) Recognize the importance of understanding the lived experiences of people with various genetic/genomic conditions.
 - d) Evaluate the potential impact of psychosocial issues on client decision-making and adherence to medical management.
 3. Construct relevant, targeted and comprehensive personal and family histories and pedigrees.
 - a) Demonstrate proficiency in the use of pedigree symbols, standard notation, and nomenclature.
 - b) Utilize interviewing skills to elicit a family history and pursue a relevant path of inquiry.
 - c) Use active listening skills to formulate structured questions for the individual case depending on the reason for taking the family history and/or potential diagnoses.
 - d) Elicit and assess pertinent information relating to medical, developmental, pregnancy and psychosocial histories.
 - e) Extract pertinent information from available medical records.
 4. Identify, assess, facilitate, and integrate genetic testing options in genetic counseling practice.
 - a) Investigate the availability, analytic validity, clinical validity, and clinical utility of screening, diagnostic and predictive genetic/genomic tests.

- b) Evaluate and assess laboratories and select the most appropriate laboratory and test based on the clinical situation.
 - c) Identify and discuss the potential benefits, risks, limitations and costs of genetic testing.
 - d) Coordinate and facilitate the ordering of appropriate genetic testing for the client.
 - e) Interpret the clinical implications of genetic test reports.
 - f) Recognize and differentiate specific considerations relevant to genetic versus genomic and clinical versus research testing in terms of the informed consent process, results disclosure, institutional review board (IRB) guidelines, and clinical decision-making.
5. Assess individuals' and their relatives' *probability of conditions with a genetic component* or carrier status based on their pedigree, test result(s), and other pertinent information.
- a) Assess probability of conditions with a genetic component or carrier status using relevant knowledge and data based on pedigree analysis, inheritance patterns, genetic epidemiology, quantitative genetics principles, and mathematical calculations.
 - b) Incorporate the results of screening, diagnostic and predictive genetic/genomic tests to provide accurate risk assessment for clients.
 - c) Evaluate familial implications of genetic/genomic test results.
 - d) Identify and integrate relevant information about environmental and lifestyle factors into the risk assessment.
6. Demonstrate the skills necessary to successfully manage a genetic counseling case.
- a) Develop and execute a *case management* plan that includes case preparation and follow-up.
 - b) Assess and modify the case management plan as needed to incorporate changes in management and surveillance recommendations.
 - c) Document and present the genetic counseling encounter information clearly and concisely, orally and in writing, in a manner that is understandable to the audience and in accordance with professional and institutional guidelines and standards.
 - d) Identify and introduce research options when indicated and requested in compliance with applicable privacy, human subjects, regional and institutional standards.
 - e) Identify, access and present information to clients on local, regional, national and international resources, services and support.
7. Critically assess genetic/genomic, medical and social science literature and information.
- a) Plan and execute a thorough search and review of the literature.
 - b) Evaluate and critique scientific papers and identify appropriate conclusions by applying knowledge of relevant *research methodologies* and statistical analyses.
 - c) Synthesize information obtained from a literature review to utilize in genetic counseling encounters.
 - d) Incorporate medical and scientific literature into evidenced-based practice recognizing that there are limitations and gaps in knowledge and data.

Domain II: Interpersonal, Psychosocial and Counseling Skills

8. Establish a mutually agreed upon genetic counseling agenda with the client.
- a) Describe the genetic counseling process to clients.
 - b) Elicit client expectations, perceptions, knowledge, and concerns regarding the genetic counseling encounter and the reason for referral or contact.
 - c) Apply client expectations, perceptions, knowledge and concerns towards the development of a mutually agreed upon agenda.
 - d) Modify the genetic counseling agenda, as appropriate by continually *contracting* to address emerging concerns.
9. Employ active listening and interviewing skills to identify, assess, and empathically respond to stated and emerging concerns.
- a) Elicit and evaluate client emotions, individual and family experiences, beliefs, behaviors, values, coping mechanisms and adaptive capabilities.
 - b) Engage in relationship-building with the client by establishing rapport, employing active listening skills and demonstrating empathy.
 - c) Assess and respond to client emotional and behavioral cues, expressed both verbally and non-verbally, including emotions affecting understanding, retention, perception, and decision-making.
10. Use a range of genetic counseling skills and models to facilitate informed decision making and adaptation to genetic risks or conditions.
- a) Demonstrate knowledge of psychological defenses, family dynamics, family systems theory, coping models, the grief process, and reactions to illness.
 - b) Utilize a range of basic counseling skills, such as open-ended questions, reflection, and normalization.
 - c) Employ a variety of advanced genetic counseling skills, such as anticipatory guidance and in depth exploration of client responses to risks and options.
 - d) Assess clients' psychosocial needs, and evaluate the need for intervention and referral.
 - e) Apply evidence-based models to guide genetic counseling practice, such as short-term *client centered* counseling, grief counseling and crisis counseling.
 - f) Develop an appropriate follow-up plan to address psychosocial concerns that have emerged in the encounter, including referrals for psychological services when indicated.
11. Promote client-centered, informed, noncoercive and value-based decision-making.
- a) Recognize one's own values and biases as they relate to genetic counseling.
 - b) Actively facilitate client decision-making that is consistent with the client's values.

- c) Recognize and respond to client-counselor relationship dynamics, such as transference and countertransference, which may affect the genetic counseling interaction.
 - d) Describe the continuum of non-directiveness to directiveness, and effectively utilize an appropriate degree of guidance for specific genetic counseling encounters.
 - e) Maintain professional boundaries by ensuring directive statements, self-disclosure, and self-involving responses are in the best interest of the client.
12. Understand how to adapt genetic counseling skills for varied service delivery models.
- a) Tailor communication to a range of service delivery models to meet the needs of various audiences.
 - b) Compare strengths and limitations of different service delivery models given the genetic counseling indication.
 - c) Describe the benefits and limitations of *distance encounters*.
 - d) Tailor genetic counseling to a range of service delivery models using relevant verbal and nonverbal forms of communication.
 - e) Recognize psychosocial concerns unique to distance genetic counseling encounters.
13. Apply genetic counseling skills in a culturally responsive and respectful manner to all clients.
- a) Describe how aspects of culture including language, ethnicity, life-style, socioeconomic status, disability, sexuality, age and gender affect the genetic counseling encounter.
 - b) Assess and respond to client cultural beliefs relevant to the genetic counseling encounter.
 - c) Utilize multicultural genetic counseling resources to plan and tailor genetic counseling agendas, and assess and counsel clients.
 - d) Identify how the genetic counselor's personal cultural characteristics and biases may impact encounters and use this knowledge to maintain effective client-focused services.
- e) Communicate both orally and in writing using a style and method that is clear and unambiguous.
 - f) Present balanced descriptions of lived experiences of people with various conditions.
 - g) Explain and address client concerns regarding genetic privacy and related protections.
 - h) Employ strategies for successful communication when working with interpreters.
15. Write concise and understandable clinical and scientific information for audiences of varying educational backgrounds.
- a) Develop written educational materials tailored to the intended audience.
 - b) Recognize the professional and legal importance of medical documentation and confidentiality.
 - c) Assess the challenges faced by clients with low literacy and modify the presentation of information to reduce the literacy burden.
16. Effectively give a presentation on genetics, genomics and genetic counseling issues.
- a) Assess and determine the educational goals and learning objectives based on the needs and characteristics of the audience.
 - b) Develop an educational method or approach that best facilitates the educational goals of the presentation and considers the characteristics of the audience.
 - c) Present using a delivery style that results in effective communication to the intended audience that is clear and unambiguous.
 - d) Assess one's own teaching style and use feedback and other outcome data to refine future educational encounters.

Domain III: Education

14. Effectively educate clients about a wide range of genetics and genomics information based on their needs, their characteristics and the circumstances of the encounter.
- a) Identify factors that affect the learning process such as intellectual ability, emotional state, socioeconomic factors, physical abilities, religious and cultural beliefs, motivation, language and educational background.
 - b) Recognize and apply risk communication principles and theory to maximize client understanding.
 - c) Communicate relevant genetic and genomic information to help clients understand and adapt to conditions or the risk of conditions and to engage in informed decision-making.
 - d) Utilize a range of tools to enhance the learning encounter such as handouts, visual aids, and other educational technologies.
15. Write concise and understandable clinical and scientific information for audiences of varying educational backgrounds.
- a) Develop written educational materials tailored to the intended audience.
 - b) Recognize the professional and legal importance of medical documentation and confidentiality.
 - c) Assess the challenges faced by clients with low literacy and modify the presentation of information to reduce the literacy burden.
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 - b) Develop an educational method or approach that best facilitates the educational goals of the presentation and considers the characteristics of the audience.
 - c) Present using a delivery style that results in effective communication to the intended audience that is clear and unambiguous.
 - d) Assess one's own teaching style and use feedback and other outcome data to refine future educational encounters.

Domain IV: Professional Development & Practice

17. Act in accordance with the ethical, legal and philosophical principles and values of the genetic counseling profession and the policies of one's institution or organization.
- a) Follow the guidance of the National Society of Genetic Counselors Code of Ethics.
 - b) Recognize and respond to ethical and moral dilemmas arising in genetic counseling practice and seek outside consultation when needed.
 - c) Identify and utilize factors that promote client autonomy.
 - d) Ascertain and comply with current professional credentialing requirements, at the institutional, state, regional and national level.
 - e) Recognize and acknowledge situations that may result in a real or perceived conflict of interest.
18. Demonstrate understanding of the research process.
- a) Articulate the value of research to enhance the practice of genetic counseling.

- b) Demonstrate an ability to formulate a research question.
 - c) Recognize the various roles a genetic counselor can play on a research team and identify opportunities to participate in and/or lead research studies.
 - d) Identify available research-related resources.
 - e) Apply knowledge of research methodology and *study design* to critically evaluate research outcomes.
 - f) Apply knowledge of research methodology and study designs to educate clients about research studies relevant to them/their family.
 - g) Describe the importance of human subjects' protection and the role of the Institutional Review Board (IRB) process.
19. Advocate for individuals, families, communities and the genetic counseling profession.
- a) Recognize the potential tension between the values of clients, families, communities and the genetic counseling profession.
 - b) Support client and community interests in accessing, or declining, social and health services and clinical research.
 - c) Identify genetic professional organizations and describe opportunities for participation and leadership.
 - d) Employ strategies that to increase/promote access to genetic counseling services.
20. Demonstrate a self-reflective, evidenced based and current approach to genetic counseling practice.
- a) Display initiative for lifelong learning.
 - b) Recognize one's limitations and capabilities in the context of genetic counseling practice.
 - c) Seek feedback and respond appropriately to performance critique.
 - d) Demonstrate a scholarly approach to genetic counseling, including using available evidence based principles in the preparation and execution of a genetic counseling encounter.
 - e) Identify appropriate individual and/or group opportunities for ongoing personal supervision and mentorship.
 - f) Accept responsibility for one's physical and emotional health as it impacts on professional performance.
 - g) Recognize and respect professional boundaries between clients, colleagues, and supervisors.
21. Understand the methods, roles and responsibilities of the process of clinical supervision of trainees.
- a) Engage in active reflection of one's own clinical supervision experiences.
 - b) Identify resources to acquire skills to appropriately supervise trainees.
 - c) Demonstrate understanding of the dynamics and responsibilities of the supervisor/supervisee relationship.
23. Establish and maintain professional *interdisciplinary relationships* in both team and one-on-one settings, and recognize one's role in the larger healthcare system.
- a) Distinguish the genetic counseling *scope of practice* in relation to the roles of other health professionals.
- b) Develop positive relationships with professionals across different disciplines.
 - c) Demonstrate familiarity with the *health care system* as it relates to genetic counseling practice including relevant privacy regulations, referral and payment systems.
 - d) Demonstrate effective interaction with other professionals within the healthcare infrastructure to promote appropriate and equitable delivery of genetic services.
 - e) Assist non-genetic healthcare providers in utilizing genetic information to improve patient care in a cost-effective manner.
 - f) Promote responsible use of genetic/genomic technologies and information to enhance the health of individuals, communities, and the public.

Glossary

Case management: The planning and coordination of health care services appropriate to achieve a desired medical and/or psychological outcome. In the context of genetic counseling, case management requires the evaluation of a medical condition and/or risk of a medical condition in the client or family, evaluating psychological needs, developing and implementing a plan of care, coordinating medical resources and advocating for the client, communicating healthcare needs to the individual, monitoring an individual's progress and promoting client-centered decision making and cost-effective care.

Client centered: A non-directive form of talk therapy that was developed by Carl Rogers during the 1940's and 1950's. The goal of client-centered counseling is to provide clients with an opportunity to realize how their attitudes, feelings and behavior are being negatively affected and to make an effort to find their true positive potential. The counselor is expected to employ genuineness, empathy, and unconditional positive regard, with the aim of clients finding their own. (This is also known as person-centered or Rogerian therapy.)

Client: Anyone seeking the expertise of a genetic counselor. Clients include anyone seeking the expertise of a genetic counselor such as individuals seeking personal health information, risk assessment, genetic counseling, testing and case management; health care professionals; research subjects; and the public.

Contracting: The two-way communication process between the genetic counselor and the patient/client which aims to clarify both parties' expectations and goals for the session.

Distance Encounters: At present, and even more so in the future, clinical genetic services will be provided to patients/clients by providers who are not physically in the same location as the patient/client. These encounters can be called Distance Encounters, even if the provider and patient are not physically located at great distances from each other. Ways in which this care can be provided include interactive two-way video sessions in real time; asynchronous virtual consultations by store-and-forward digital transmission of patient images, data, and clinical questions from the patient/client's healthcare provider to the genetic services provider; telephone consultation between genetic provider and patient/client; and perhaps additional forms of interaction between providers and patients/clients unimagined at present.

Family history: The systematic research and narrative of past and current events relating to a specific family that often include medical and social information.

Genetics: The branch of biologic science which investigates and describes the molecular structure and function of genes, how gene function produces effects in the organism (phenotype), how genes are transmitted from parent to offspring, and the distribution of gene variations in populations.

Genetic counseling: The process of helping people understand and adapt to the medical, psychological and familial implications of genetic contributions to disease. Genetic counselors work in various settings and provide services to diverse clients.

Genomics: The branch of biology which studies the aggregate of genes in an organism. The main difference between genomics and genetics is that genetics generally studies the structure, variation, function, and expression of single genes, whereas genomics studies the large number of genes in an organism and their interrelationship.

Health care system: The organization of people, institutions, and resources to deliver health care services to meet the health needs of target populations. The laws, regulations and policies governing healthcare systems differ depending on the country, state/province, and institution.

Interdisciplinary relationships: Connections and interactions among members of a team of health care staff from different areas of practice.

Pedigree: A diagram of family relationships that uses symbols to represent people and lines to represent relationships. These diagrams make it easier to visualize relationships within families, particularly large extended families.

Population screening: Testing of individuals in an identified, asymptomatic, target population who may be at risk for a particular disease or may be at risk to have a child with a particular disease. Population screening may allow for the provision of information important for decision-making, early diagnosis, and improved treatment or disease prevention.

Probability of conditions with a genetic component: The chance, typically expressed as a fraction or a percentage, for an individual or a specific population to experience a condition that has a genetic component.

This terminology is used intentionally rather than “genetic risk” because the concept of “risk” is not synonymous with “probability.” The origin of a probability can come from principles of Mendelian inheritance or from epidemiology. The probability of genetic disease is differentiated from risk of genetic disease in that probability conveys the numerical estimate for an individual patient or a specific population while risk includes additional elements including the burden of disease.

Population Genetics: The study of allele frequency distribution and change under evolutionary processes, and includes concepts such as the Hardy-Weinberg principle and the study of quantitative genetic traits.

Research methodologies: The process to define the activity (how, when, where, etc.) of gathering data.

Scope of practice: Genetic Counselors work as members of a health care team in a medical genetics program or other specialty/subspecialty; including oncology, neurology, cardiology, obstetrics and gynecology, among others. They are uniquely trained to provide information, counseling and support to individuals and families whose members have genetic disorders or who may be at risk for these conditions. The genetic counseling scope of practice is carried out through collaborative relationships with clinical geneticists and other physicians, as well as other allied healthcare professionals such as nurses, physicians and social workers.

Study design: The formulation of trials and experiments in medical and epidemiological research. Study designs can be qualitative, quantitative, descriptive (e.g., case report, case series, survey), analytic-observational (e.g., cross sectional, case-control, cohort), and/or analytic-experimental (randomized controlled trials).

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