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Accreditation Council
for Genetic Counseling

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Practice-Based Competencies for Genetic Counselors

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Accreditation Council for Genetic Counseling
7918 Jones Branch Drive, Suite 300, McLean, VA 22102
(703) 506-7667
www.gceducation.org

Practice-Based Competencies for Genetic Counselors

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.
2. Integrate knowledge of psychosocial aspects of conditions with a genetic component to promote *client* well-being.
3. Construct relevant, targeted and comprehensive personal and family histories and pedigrees.
4. Identify, assess, order, facilitate, and integrate genetic/genomic testing options in genetic counseling practice (including molecular and non-molecular testing that directly impacts assessment of inherited risk).
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.
6. Demonstrate the skills necessary to successfully manage a genetic counseling case.
7. Critically assess genetic/genomic, medical and social science literature and information.

Domain II: Interpersonal, Psychosocial and Counseling Skills

8. Establish a mutually agreed upon genetic counseling agenda with the client.
9. Employ active listening and interviewing skills to identify, assess, and empathically respond to stated and emerging concerns.
10. Use a range of genetic counseling skills and models to facilitate informed decision-making and adaptation to genetic risks or conditions.
11. Promote client-centered, informed, non-coercive and value-based decision-making.

12. Understand how to adapt genetic counseling skills for varied service delivery models.

13. Apply genetic counseling skills in a culturally responsive and respectful manner to all clients.

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.
15. Write concise and understandable clinical and scientific information for audiences of varying educational backgrounds.
16. Effectively give a presentation on genetics, genomics and genetic counseling issues.

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.
18. Demonstrate understanding of the research process.
19. Advocate for individuals, families, *communities* and the genetic counseling profession.
20. Demonstrate a self-reflective, evidenced-based and current approach to genetic counseling practice.
21. Understand the methods, roles and responsibilities of the process of clinical supervision of trainees.
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.

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, order, facilitate, and integrate genetic/genomic testing options in genetic counseling practice (including molecular and non-molecular testing that directly impacts assessment of inherited risk).

- 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/genomic testing.

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- d) Coordinate, facilitate, and execute the ordering of appropriate genetic/genomic testing for the client.
- e) Interpret the clinical implications of genetic/genomic test reports.
- f) Recommend and coordinate additional testing and appropriate referrals based upon test results.
- g) 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.

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.

- 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.

- 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, non-coercive 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 non-verbal 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.

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.
- 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 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.

22. Establish and maintain professional *inter-disciplinary 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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