

National Society of Genetic Counselors Code of Ethics: Explication of 2017 Revisions

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The National Society of Genetic Counselors Code of Ethics Review Task Force
(COERTF)

Received: 7 August 2017 / Accepted: 4 October 2017 / Published online: 27 October 2017
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Abstract The Code of Ethics (COE) of the National Society of Genetic Counselors (NSGC) was adopted in 1992 and was later revised and adopted in 2006. In 2016, the NSGC Code of Ethics Review Task Force (COERTF) was convened to review the COE. The COERTF reviewed ethical codes written by other professional organizations and suggested changes that would better reflect the current and evolving nature of the genetic counseling profession. The COERTF received input from the society's legal counsel, Board of Directors, and members-at-large. A revised COE was proposed to the membership and approved and adopted in April 2017. The revisions and rationale for each are presented.

Keywords Genetic counseling · Ethics · Ethical principles · Genetics

Introduction

The National Society of Genetic Counselors' (NSGC) Code of Ethics (COE) was adopted in 1992 (Benkendorf et al. 1992). In 2004, legal counsel proposed a revision, at which time a COE working group was convened to conduct an in-depth review of ethical codes from other professional organizations to search for themes that were not already represented in the NSGC COE. Based on their review, another set of revisions was proposed, feedback was received from the NSGC membership, legal counsel, and the NSGC Board of Directors. The second revision was approved by majority vote of the membership and adopted in 2006 (Bennett et al. 2006).

Given that ten years had passed since the last revision of the COE and in response to the American Board of Genetic Counseling (ABGC) Exam Eligibility Task Force's request to review and revise or reaffirm the NSGC COE, the NSGC COE Review Task Force (COERTF) was convened in 2016. The ABGC Exam Eligibility Task Force proposed the use of the NSGC COE as the definition of ethical practice in fulfillment of the Institute for Credentialing Excellence criteria for certification. For this reason, and to maintain the relevancy of the COE for the NSGC membership, periodic review is critical. The COERTF reviewed the COE as outlined in the Methods section. Proposed changes then were approved by the NSGC Board of Directors. Both the NSGC membership and the NSGC Conflict of Interest Task Force provided feedback on the proposed changes, which were incorporated into the final document. The final version of the COE was approved by membership vote and adopted in April 2017.

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Here, we explain the process of review and revisions to the current COE.

Methods

Composition of the NSGC Code of Ethics Review Task Force

The COERTF was appointed by the NSGC BOD and chaired by Leigha Senter and included Robin Bennett, a representative from the 2004 COE Work Group; Kelli Swan, past Chair of the NSGC Ethics Advisory Group and recipient of a Master of Arts in Medical Humanities and Bioethics; Sarah Noblin, NSGC Board member and ABGC Exam Eligibility Task Force member; Anne Madeo, ABGC board member; Kelly Ormond and Alice Virani, both of whom have formal ethics training; and NSGC member at large Kami Wolfe Schneider. NSGC executive office staff and attorney also reviewed and provided feedback on proposed revisions. The composition of the COERTF was aligned with prior recommendations (Bennett et al. 2006).

The Process for Review and Revisions

The COERTF used a similar process to the 2004 COE Work Group in reviewing the COE. First, codes of ethics or professional conduct from 9 other health care professional organizations were reviewed (Table 1). All COERTF members reviewed the COE in its entirety, and each section of the COE was assigned to a pair of COERTF members for in depth analysis. The COERTF reviewed the COE with respect to

changes in the genetic counseling profession that have occurred since the last set of revisions was adopted. Careful attention was paid to situations faced by genetic counselors of all specialties and in different practice settings, including those based in industry, and in light of new technologies and modes of communication (e.g. telemedicine and the impact of social media on genetic counseling practice). In general, the COERTF felt that the COE was a strong and concise document that has served the NSGC membership well over many years.

The COERTF proposed changes that were brought to the NSGC membership for feedback from January 4, 2017 until January 25, 2017. Communication occurred via Membership eBlast and was promoted through the NSGC Member News section of the NSGC website (www.nsgc.org). The revised COE was approved by majority vote of the NSGC membership in April 24, 2017 after a 3-week voting period.

Explication of Revisions to the Code of Ethics of the NSGC

The revised NSGC COE is published in this issue of the *Journal of Genetic Counseling*. The following sections explain each 2017 revision to the NSGC COE. The COE is written in *italics* with explanations provided after each section.

Preamble

Genetic counselors are health professionals with specialized education, training, and experience in medical genetics and counseling. The National Society of Genetic Counselors

Table 1 Codes of ethics and/or professional conduct reviewed by COETF

Organization	Title	URL
Australasian Society of Genetic Counsellors	Code of Ethics	https://www.hgsa.org.au/documents/item/22
Genetic Counsellor Registration Board	Code of Conduct	http://www.gcrb.org.uk/media/6374/gcrb-code-of-conduct.pdf
American Counseling Association	Code of Ethics	http://www.counseling.org/docs/ethics/2014-aca-code-of-ethics.pdf?sfvrsn=4
Association of Genetic Nurses and Counsellors	Code of Ethics	http://www.agnc.org.uk/about-us/code-of-ethics/
European Board of Medical Genetics	Code of Professional Practice for Genetic Counsellors in Europe	https://www.eshg.org/fileadmin/GCGN_Downloads/EBMG_CodeofprofessionalpracticeforgeniccounsellorsinEurope.pdf
Canadian Association of Genetic Counsellors	Code of Ethics	https://www.cagc-accg.ca/doc/code%20of%20ethics%20e-070628.pdf
American Psychological Association	Ethical Principles of Psychologists and Code of Conduct	http://www.apa.org/ethics/code/
Coalition of National Health Education Organizations	Code of Ethics for the Health Education Profession	http://cnheo.org/ethics.html
Association of American Educators	Code of Ethics for Educators	https://www.aateachers.org/images/pdfs/aaecodeofethicsforeducators.pdf

(NSGC) is the leading voice, authority and advocate for the genetic counseling profession. Through this code of ethics, the NSGC affirms the ethical responsibilities of its members. NSGC members are expected to be aware of the ethical implications of their professional actions and work to uphold and adhere to the guidelines and principles set forth in this code.

Introduction

A code of ethics is a document that attempts to clarify and guide the conduct of a professional so that the goals and values of the profession are best served. The NSGC Code of Ethics is based upon the distinct relationships genetic counselors have with 1) themselves, 2) their clients, 3) their colleagues, and 4) society. Each section of this code begins with an explanation of the relevant relationship, along with the key values and characteristics of that relationship. These values are drawn from the ethical principles of autonomy, beneficence, nonmaleficence and justice, and they include the professional principles of fidelity, veracity, integrity, dignity and accountability.

No set of guidelines can provide all the assistance needed in every situation, especially when different values appear to conflict. In certain areas, some ambiguity remains, allowing for the judgement of the genetic counselor(s) involved to determine how best to respond to difficult situations.

Revisions to Preamble and Introduction

- Revisions were made to reduce redundancy but contextual meaning was generally not changed.
- The professional ethics principles of fidelity, veracity, integrity, dignity, and accountability were added to the code to better recognize and highlight the importance of professional ethics values, as well as already included traditional bioethical principles, in such a code. These principles are first mentioned in the introduction and included throughout the Code.

Section I: Genetic Counselors Themselves

Genetic counselors value professionalism, competence, integrity, objectivity, veracity, dignity, accountability and self-respect in themselves as well as in each other. Therefore, genetic counselors work to:

1. Seek out and acquire balanced, accurate and relevant information required for a given situation.
2. Continue their education and training to keep abreast of relevant guidelines, regulations, position statements, and standards of genetic counseling practice.
3. Work within their scope of professional practice and recognize the limits of their own knowledge, expertise, and competence.
4. Accurately represent their experience, competence, and credentials, including academic degrees, certification, licensure, and relevant training.
5. Identify and adhere to institutional and professional conflict of interest guidelines and develop mechanisms for avoiding or managing real or perceived conflict of interest when it arises.
6. Acknowledge and disclose to relevant parties the circumstances that may interfere with or influence professional judgment or objectivity, or may otherwise result in a real or perceived conflict of interest.
7. Assure that institutional or professional privilege is not used for personal gain.
8. Be responsible for their own physical and emotional health as it impacts their professional judgment and performance, including seeking professional support, as needed.

Revisions to Section I

The first section of the COE highlights the responsibility that genetic counselors have to themselves. It clearly states what qualities genetic counselors value in themselves and in each other. In the opening statement the values of professionalism, competency, integrity, objectivity, veracity, dignity, accountability, and self-respect are identified. Professionalism and accountability were added to this section to both recognize and highlight the importance of professional ethics, as well as emphasize the importance of accountability, particularly in light of the changes made to this section (described below) in relation to recognizing and managing conflicts of interest.

One new statement was added to Section I (number 7), and the original statements 2 and 3 were combined. Wording changes were made to all statements, as described below:

- Statement I.1 was expanded to include the words “balanced” and “accurate” to add more specificity to what should be considered relevant information.
- Statement I.2 now combines the previous statements 1.2 and 1.3 as both sought to address continued training. The previous version only referenced “standards of practice” and the current version elaborates to include guidelines, regulations and position statements.
- Statement I.3 was revised to include reference to the NSGC Genetic Counselor Scope of Practice, which was developed in 2007 (<http://www.nsgc.org/p/cm/ld/fid=18>).
- Statement I.4 is an amended version of the previous statement 1.5, and now includes certification and licensure as relevant indicators of expertise.

- Statement I.5 is an amended version of the previous statement 1.6. It has been amended to include the addition of a genetic counselors' responsibility to follow their organization(s) and institution(s) conflict of interest guidelines.
- Statement I.6 is an amended version of the previous statement 1.7. It has been amended to recognize that conflicts of interest cannot always be avoided. In situations in which they cannot be avoided, they should be acknowledged and managed appropriately.
- Statement I.7 is a new statement to elaborate upon the concept of conflicts of interest, emphasizing that any such privileges arising from institutional or professional association should not be used for personal gain. This statement was added to highlight the potential overlap between professional and personal roles.
- Statement I.8 was amended to include a responsibility of genetic counselors to seek professional support, where necessary, to address physical or emotional health issues. This addition is in keeping with other COEs from other health professionals.

Section II: Genetic Counselors and Their Clients

The counselor-client relationship is based on values of care and respect for the client's autonomy, individuality, welfare, and freedom in clinical and research interactions. Therefore, genetic counselors work to:

1. Provide genetic counseling services to their clients within their scope of practice regardless of personal interests or biases, and refer clients, as needed, to appropriately qualified professionals.
2. Clarify and define their professional role(s) and relationships with clients, disclose any real or perceived conflict of interest, and provide an accurate description of their services.
3. Provide genetic counseling services to their clients regardless of their clients' abilities, age, culture, religion, ethnicity, language, sexual orientation and gender identity.
4. Enable their clients to make informed decisions, free of coercion, by providing or illuminating the necessary facts, and clarifying the alternatives and anticipated consequences.
5. Respect their clients' beliefs, inclinations, circumstances, feelings, family relationships, sexual orientation, religion, gender identity, and cultural traditions.
6. Refer clients to an alternate genetic counselor or other qualified professional when situations arise in which a genetic counselor's personal values, attitudes and beliefs may impede his or her ability to counsel a client.
7. Maintain the privacy and security of their client's confidential information and individually identifiable health

information, unless released by the client or disclosure is required by law.

8. Avoid the exploitation of their clients for personal, professional, or institutional advantage, profit or interest.

Revisions to Section II

The second section of the NSGC COE describes the relationship that genetic counselors have with their clients. The COERTF debated at-length the appropriateness of including different client-types in this section given the varied nature of these relationships for genetic counselors in current practice. The COERTF concluded that it was important to maintain this section to address genetic counselor interactions with clinical and research clients and thus, this was defined in the introductory sentence as a "counselor-client" relationship with values of care and respect to the client's autonomy, individuality, welfare, and freedom in clinical and research interactions.

One guideline was added (number 3) to this section, and seven guidelines were revised to add clarity to previous statements and minimize ambiguous or lofty statements. Detailed changes are as follows:

- Statement II.1 was revised to clarify that services to clients should be provided within genetic counselors' scope of practice, and to add the expectation of referral to other providers for unmet needs.
- Statement II.2 was revised to include disclosure of real or perceived conflict of interest.
- Statement II.3 was added to specify factors of abilities, age, religion, ethnicity, language, sexual orientation, and gender identity for which the services to clients should be provided without discrimination.
- Statement II.5 was revised to include sexual orientation, religion, and gender identity.
- Statement II.6 was revised to distinguish this statement from statement II.1 and clearly specify the appropriate action when the personal values of the genetic counselor impede his or her ability to counsel a client.
- Statement II.7 was revised to better reflect the laws already in place regarding identifiable health information and its confidentiality.
- Statement II.8 was revised to include avoidance of exploitation for professional and institutional advantage.

Section III: Genetic Counselors and Their Colleagues The genetic counselors' professional relationships with other genetic counselors, trainees, employees, employers and other professionals are based on mutual respect, caring, collaboration, fidelity, veracity and support. Therefore, genetic counselors work to:

1. Share their knowledge and provide mentorship and guidance for the professional development of other genetic counselors, employees, trainees and colleagues.
2. Respect and value the knowledge, perspectives, contributions, and areas of competence of colleagues, trainees and other professionals.
3. Encourage ethical behavior of colleagues.
4. Assure that individuals under their supervision undertake responsibilities that are commensurate with their knowledge, experience and training.
5. Maintain appropriate boundaries to avoid exploitation in their relationships with trainees, employees, employers and colleagues.
6. Take responsibility and credit only for work they have actually performed and to which they have contributed.
7. Appropriately acknowledge the work and contributions of others.
8. Make employers aware of genetic counselors' ethical obligations as set forth in the NSGC Code of Ethics.

Revisions to Section III

This version of the COE maintains the importance of genetic counselors' relationships, and to reflect the broader workplaces and roles of genetic counselors, has added "employers, employees and other professionals" to reflect interactions with colleagues that do not necessarily fall into the healthcare category. The term "students" was changed to "trainees" to reflect the broad range of individuals with whom genetic counselors interact, but who may not be "students" per se. These changes were made in the introduction for this section and in several statements (III-1, III-2, and III-5) described below.

- Statement III.2 was edited to remove "highest quality of service" as it is difficult to define.
- Statements III.6 and III.7 were added because statements of this nature are included in many other professional codes of ethics, and reflect the desire to collaborate in a truthful manner with colleagues and peers, and is especially relevant in an academic or research setting.
- Statement III.8 was added in light of the addition of employers to this section of the COE. This was done in order to clarify the importance of transparency with our employers regarding our professional COE, of which they may not otherwise be aware.

Section IV: Genetic Counselors and Society

The relationships of genetic counselors with society include interest and participation in activities that have the purpose of promoting the well-being of society and access to genetic

services and health care. These relationships are based on the principles of veracity, objectivity and integrity. Therefore, genetic counselors, individually or through their professional organizations, work to:

1. Promote policies that aim to prevent genetic discrimination and oppose the use of genetic information as a basis for discrimination.
2. Serve as a source of reliable information and expert opinion on genetic counseling to employers, policymakers, payers, and public officials. When speaking publicly on such matters, a genetic counselor should be careful to separate their personal statements and opinions made as private individuals from statements made on behalf of their employers or professional societies.
3. Participate in educating the public about the development and application of technological and scientific advances in genetics and the potential societal impact of these advances.
4. Promote policies that assure ethically responsible research in the context of genetics.
5. Adhere to applicable laws and regulations. However, when such laws are in conflict with the principles of the profession, genetic counselors work toward change that will benefit the public interest.

Revisions to Section IV

The relationships of genetic counselors with society include interest and participation in activities that have the purpose of promoting the well-being of society and access to genetic services and health care. This section addresses the ethical responsibilities that genetic counselors have in this regard. The introductory paragraph was revised to add the more specific phrase "access to genetic services" in addition to the broader "access to health care." This paragraph was also revised to reflect the overall addition of principles (veracity, objectivity and integrity) across the revised COE.

In the revisions of Section IV, two statements were removed (IV-1, IV-4) and the list was reorganized. Each of these changes is described below.

- Statement IV.I from the previous version of the COE, which stated "keep abreast of societal developments that may endanger the physical and psychological health of individuals," was removed. After discussion, the COERTF agreed that the scope of this statement was not specific to genetics and society, and that such a broad statement could be outside the scope of practice of a genetic counselor. Similarly, the previous statement IV.4 which stated "participate in activities necessary to bring about socially responsible change," was removed. This

statement was not sufficiently specific to genetics and its essence is captured in the remaining statements encouraging genetic counselors to promote the well-being of society and access to genetic services.

- Statement IV.1 is now a combination of the previous version's IV.2 and IV.3 because they complement each other in protecting an individual's genetic information and discouraging genetic discrimination.
- Statement IV.2 refers to being a reliable source of information and expert in "genetic counseling." Based on review of other health professions' codes of ethics and member feedback, the COERTF considered the phrases "on human genetics" or "on genetics" instead of "on genetic counseling." After much discussion, it was agreed that "on genetic counseling" was most appropriate to maintain genetic counselors' scope of expertise. Employers and payers were added to this statement with the current revisions to reflect the increasing number of situations where a genetic counselor may be called upon to provide expertise. Additionally, the following was added: "When speaking publically on such matters, a genetic counselor should be careful to separate their personal statements and opinions made as private individuals from statements made on behalf of their employers or professional societies." The new COE attempts to reflect the current landscape of media and the many possible outlets available to genetic counselors to express their opinions while expecting that genetic counselors will maintain a professional boundary between personal and professional statements.
- Statement IV.3 reflects revisions made to the previous statement IV.6 to narrow the focus of the statement and make it specific to genetics rather than applicable to "technological and scientific advances" in general.
- Statement IV.4 reflects revisions made to the previous statement IV.7 to narrow the focus of the statement and make it specific to genetics, similar to above.

- Statement IV.5 reflects revisions made to the previous IV. 8. The word "applicable" was added to limit the laws and regulations with which genetic counselors would be expected to be familiar within their professional settings.

Discussion

Future Revisions to the NSGC COE: Recommendations for the Review Process

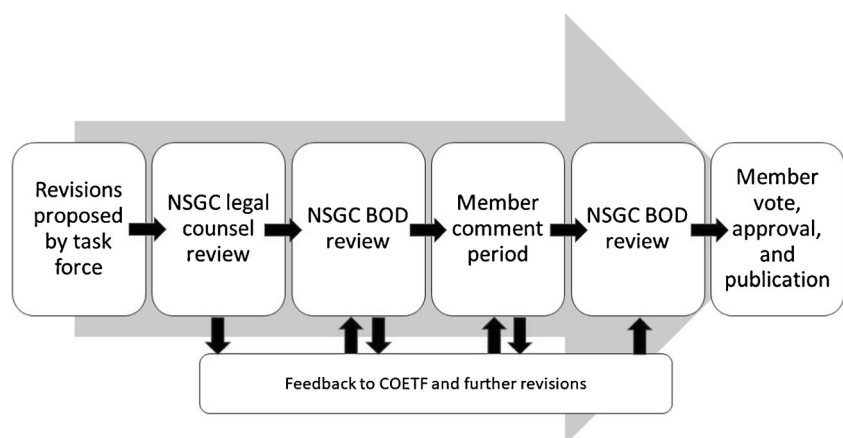
Bennett et al. (2006) made recommendations for the continued review of the NSGC COE. We agree with these recommendations and have reiterated them here. Given the substantial number of revisions made to this COE, review and revision or reaffirmation of the COE should be conducted on an interval shorter than every 10 years. The previous COE work group suggested a 5-year interval between reviews, and we agree with this approach. Special care was taken to make statements specific yet broadly applicable, which should lend to longevity of the relevance of the COE, but documentation of review is essential to maintain the integrity of the COE. We recommend that documentation of review become an NSGC policy.

Composition of Revision Task Force

A task force should be appointed by the NSGC President. We recommend that representation include, but not be limited to:

- one individual from each of the past COE revision groups (if available);
- the current Chair(s) of the NSGC Ethics Subcommittee;
- at least one NSGC member at large, not previously involved in drafting or revising the COE, and not serving on the Ethics Subcommittee;

Fig. 1 Revision approval process



- a member with relevant leadership experience within the ABGC;
- a member with relevant leadership experience within the Association of Genetic Counseling Program Directors
- a member with relevant leadership experience within the Accreditation Council for Genetic Counselors
- a representative from the current NSGC Board of Directors (BOD).

Timeline

COE should undergo review with the possibility of revision at least every 5 years from the date of the previous revision, or sooner if there is a need based on membership request, legal counsel, or substantial changes in genetic counseling practice. Resources should be allocated to the task force so that their work can be completed in a timely fashion (e.g., budget for conference calls, working meetings, executive office staffing, etc.).

Basis for Revision

The task force should consider changes to the COE based on recognition of changes to the field of genetic counseling since the last revision, and based on their review of codes of ethics and professional conduct for other professional organizations with similar interests or goals (e.g., counseling, social work, healthcare education, etc.). All revisions should carefully maintain the original framework and philosophy of the COE, as initially adopted.

Approval Process

All proposed revisions should be sent to the NSGC legal counsel, and to the BOD for review. After their review, comments should be solicited from the membership. After adequate time has been provided for comment and feedback, the revisions should be submitted to the membership for majority vote (Fig. 1).

Summary

The NSGC COE was revised July 2016–April 2017 through the work of the COERTF appointed by the NSGC leadership,

with considerable input from the NSGC general membership. These revisions were adopted after majority vote of the NSGC membership in April 2017. The core principles, structure and conciseness of the original 1992 COE has served the development and expansion of the genetic counseling profession well. Continued revisions to the COE at regular intervals will be necessary as the landscape of genetic counseling continues to shift and expand in exciting and unanticipated directions.

Acknowledgements We would like to acknowledge Judith Benkendorf, a member of the original COE author group, who provided input to the COERTF and actively solicited feedback from the original COE author group.

Funding The work represented in this manuscript was unfunded.

Compliance with Ethical Standards

Conflict of Interest

Leigha Senter has served as paid consultant for AstraZeneca, Clovis Oncology, and MyGeneCounsel.

Robin Bennett has received royalties from John Wiley and Sons, Inc.

Ann C. Madeo declares that she has no conflict of interest.

Sarah Noblin declares that she has no conflict of interest.

Kelly E. Ormond declares that she has no conflict of interest.

Kami Wolfe Schneider declares that she has no conflict of interest.

Kelli Swan is currently an employee of Myriad genetics and owns stock from Myriad genetics.

Alice Virani declares that she has no conflict of interest.

Human Studies and Informed Consent The work submitted in this manuscript did not involve human subjects.

Ethical Approval The work submitted in this manuscript was not subject to institutional approvals.

Animal Studies There were no animal studies involved in this publication.

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