

ACMG STANDARDS OF PROFESSIONALISM

Preamble

The Mission of the American College of Medical Genetics (ACMG) is to provide education, resources, and a voice for the medical genetics profession. In order to make genetic services available to and improve the health of the public, the ACMG promotes the development and implementation of methods to diagnose, treat and prevent genetic disease. (ACMG Mission Statement). The Members of the ACMG have the ethical duty to act in the best interest of their patients and society, to do no harm to their patients, and to respect the rights of each individual to make his or her own health care decisions. The following Code of Conduct is to serve as a set of professional guidelines that medical geneticists should observe in their clinical and scientific activities.

This document is not designed to be a static document but a dynamic foundation that can be revised and adapted as advances in the practice and science of medical genetics occur. Although underlying ethical principles do not change, the applications may as new challenges arise.

This document examines the ethical foundations of the medical genetics profession. It reviews how those foundations relate to: the ACMG member's interactions with patients, colleagues and society; the practice of medical genetics including potential conflicts of interest; and research in medical genetics.

I. The ACMG Member and the Patient

1. The ACMG member is the patient's advocate and should exercise all reasonable means to ensure provision of appropriate care to the patient.
- 2.. The ACMG member should continually assure her or his competence by pursuing appropriate, up-to-date, and comprehensive continuing education in medical genetics.
3. In respecting the right of every patient to self-determination, the ACMG member should ensure that appropriate informed consent of the patient or individual legally responsible for the patient has been obtained for any diagnostic, therapeutic, or preventive measure. The ACMG member must respect the right of a competent adult patient to transfer decision-making authority to another adult for personal or cultural reasons.
4. As part of the informed consent process, the ACMG member should include, as appropriate, an explanation of the pertinent medical facts and recommendations to the patient or responsible person in understandable terms and in an appropriate language.

This explanation should include the objectives, risks, benefits, limitations, possible complications, anticipated results of the test(s) or therapy(ies), and available alternatives to the proposed course of action. The anticipated outcome of not following the proposed course of action or inaction should also be explained.

5. The ACMG member must respect the right of privacy of their patients and safeguard their personal and medical information. However, as part of the informed consent process, the patient should be informed that it may be necessary to provide the results of their evaluation and genetic information to insurance providers or government agencies under certain circumstances.

6. Regardless of the ACMG member's own personal beliefs, or those of the health care institution, he/she must respect the patient's autonomy by disclosing all legally-available options.

7. In respecting the rights of every patient to self-determination, the ACMG member should include minors in medical decision making, as appropriate for their developmental capacity and the nature of the medical issue involved.

8. It is the ACMG member's responsibility to respect the privacy and confidentiality of the patient. When the patient's genetic status has medical implications for relatives, the member should strongly encourage the patient to share this information with the family. The member should explain to the patient that confidentiality concerns prevent us from initiating direct contact with a relative.

9. The ACMG member should not knowingly provide or prescribe diagnostic tests or therapies that are of no benefit to the patient.

10. The ACMG member must not discriminate against patients based on race, color, religion, national origin, gender, sexual orientation, age, ability to pay or engage in any discrimination prohibited by law.

11. The ACMG member should strive for cultural competence.

12. Sexual contact or a romantic relationship with a current patient on the part of the ACMG member is an abuse of power, respect, and honesty and violates patient trust. It is always unethical.

13. The member should not use his or her professional status or relationship to gain personal influence over a patient.

14. The patient and the ACMG member are free to establish or dissolve the patient- professional relationship. In discontinuing the patient – professional relationship, the ACMG member must abide by all legal and contractual constraints.

II. The ACMG Member and Colleagues

1. The ACMG member should interact with other health care professionals with respect and courtesy. He/she should work with them in a spirit of cooperation, and collaborate as a member of a team when appropriate.
2. The ACMG member should respond promptly to requests for consultation.
3. The ACMG member should recognize any personal limitations of competence and seek further consultation when appropriate.
4. The ACMG member should be alert to the possibility of colleagues being impaired, abide by local reporting procedures regarding impaired colleagues, and be willing to aid such colleagues as they seek rehabilitation.
5. The ACMG member should consider it a duty to educate colleagues in other medical specialties about the principles and applications of medical genetics and be willing to be educated by colleagues regarding their specialties.
6. The ACMG member should work with trainees to educate them in the principles and practices of medical genetics.
7. Trainees are a vulnerable populations and the ACMG member should work with them with respect, understanding and good will.

III. The ACMG Member and the Public

1. While keeping in mind the primary responsibility is to the patient, the ACMG member should consider the public interest.
2. The ACMG member should acknowledge that access to comprehensive medical genetics services is a right of everyone.
3. The ACMG member should act with integrity and honesty when presenting his or her credentials and competence to the public neither withholding nor misrepresenting information.
4. The ACMG member should always be truthful in all communications with the public. This includes communications regarding efficacy, utility, and costs of screening programs for genetic disorders, diagnostic and research testing and interventions including clinical trials.

5. The ACMG member should recognize and support credentialing procedures and be willing to participate in peer review activities.
6. The ACMG member has a right to fair reimbursement for services provided. The ACMG member should only bill for services personally rendered.
7. The ACMG member should recognize that there are certain inequities – financial, geographic and others - in the provision of health care services and should work toward assuring equitable provision of medical genetics services to all. In some situations this may involve providing free care to those without financial resources.
8. The ACMG member should be a good citizen, a resource to society and is encouraged to be a volunteer in his or her community.
9. The ACMG member should not use illicit drugs, abuse alcohol or prescribed medications.
10. The ACMG member whose performance is impaired should seek appropriate rehabilitative services.
11. The ACMG member should respect and cooperate with regulatory boards of medical practice and with community and hospital peer review procedures.
12. The ACMG member should provide education to public officials, policy makers, medical insurers and the general public regarding advances in science and technology, in the fields of genetics and genomics, and the impact those changes will have on the delivery of medical genetics services to the public.
- 13.. If laws or regulations are felt to be in conflict with this code of conduct, the ACMG member should work toward change in those laws or regulations that will benefit the public interest.

IV. Conflicts of Interest

1. An ACMG member's clinical judgment or medical recommendations must not be influenced by commercial, research, academic or personal interests.
2. The ACMG member should disclose to the patient any commercial, academic, research or personal interest which could give the appearance of bias to the member's clinical judgment or medical recommendations.
3. The member should assist in transferring care of a patient to another provider if a conflict of interest cannot be resolved by disclosure.

V. Conduct of Research

1. As an ethical principle, the ACMG member should conduct all research in full compliance with the Ethical Principles for Medical Research Involving Human Subjects as outlined in the most recent report of the World Medical Association ("Declaration of Helsinki") and with institutional, governmental and ACMG guidelines.
2. The ACMG member must protect the privacy of research subjects and their families including keeping private all clinical and laboratory data obtained in course of the study.
3. The ACMG member must safeguard access to all biologic samples, including samples containing DNA, provided by research subjects.
4. The ACMG member must avoid bias in the collection, interpretation and reporting of data.
5. The ACMG Member must fully and fairly acknowledge the contributions of others in the conduct of the research

Reference was made to the Codes of Medical Ethics of The American College of Emergency Medicine, The American College of Radiology, The American College of Obstetrics and Gynecology, The American College of Physicians, The American Academy of Neurology, The American Academy of Ophthalmology, The American Academy of Orthopedic Surgeons and the American Society of Plastic Surgeons, in preparation of this Code.