



Code of Ethics & Scope of Practice

Genetic counsellors are health professionals with specialized education, training, and experience in medical genetics and counselling.

The Board of Genetic Counsellors India (BGCI) is the body that provides, guidance, sets standards, and lends a voice of authority and advocacy for the genetic counselling profession. It is an organization that seeks to monitor and maintain the professional standard of genetic counsellors in India. This code of ethics affirms the ethical responsibilities of its board and certified members and provides them with guidance in their profession.

1: RESPONSIBILITIES AND SCOPE OF PRACTICE

1.1 'Genetic Counsellors'

In order to protect patients and professionals it is anticipated that the title 'Certified Genetic Counsellor' will be protected in law and genetic counselling will be recognized as a profession. 'Certified Genetic Counsellor' can only be used after an individual has undergone the process of genetic counsellor registration as stipulated by the Board of Genetic Counsellors - India. It is mandatory for genetic counsellors to renew their registration every 2 years whilst they continue to practice.

1.2 Genetic counsellors' code of ethics and scope of practice

Ethicality is essential in the clinical practice of Genetic Counsellors. Four main areas of responsibility have been identified and adopted by various regulatory bodies worldwide. These are - self-awareness and development, relationships with patients, relationships with colleagues and responsibilities within the wider society. The BGCI Code of Ethics adopts these tenets for competent practice guidelines.

CODE OF ETHICS

The BGC Code of Ethics is intended to guide practicing genetic counsellors in the in the performance of their practice. It embodies and amplifies on widely held principles of medical ethics: non-maleficence, beneficence, justice, and autonomy.

This Code encapsulates the minimum standards expected of each genetic counsellor in the course of his/her practice. Along with the Scope of Practice, and applied under the prevailing laws of India, this Code is intended to lay out a roadmap for the conduct of a professional, so that he/she may best serve the goals and values of genetic counselling.

BGC members are expected to be aware of the ethical implications of their professional actions and to adhere to the guidelines and principles set forth in this code.

Responsibility to the Self:

Genetic counsellors highly regard competence, integrity, truthfulness, dignity, and self-respect in themselves as well as in each other. Therefore

A genetic counsellor shall strive to:

1. A genetic counsellor has the responsibility of self-honesty, self-evaluation and integrity to maintain a reflective practice.
2. A genetic counsellor shall be aware that the care and well-being of themselves and their colleagues is the responsible way to practice their profession and shall endeavor to maintain both at all times.
3. A genetic counsellor should be aware of their own limitations and remain cognizant of how his/her environment, professional, social and cultural context may influence his/her practice.
4. Recognize the limits of their own knowledge, expertise, and competence in any given situation, and refer their patients to other qualified professionals when they are unable to provide suitable support.
5. Accurately represent their experience, competence and credentials, including training and academic degrees.

6. Acknowledge and disclose circumstances that may result in a real or perceived conflict of interest.
7. Avoid associations and activities that may interfere with professional judgment or objectivity.
8. Be responsible for their own physical and emotional health as it impacts on their professional performance

Responsibility to Their Patients

The primary concern of genetic counsellors is the interests of their patients. Therefore, genetic counsellors shall strive to:

1. Serve those who seek services regardless of demonstrate respect for others, regardless of their race, religion, creed, sexual preference, gender, ability, and socio-economic or genetic background. A genetic counsellor shall treat every patient with respect, dignity and compassion, respecting their beliefs, inclinations, circumstances, feelings, family relationships and cultural traditions.
2. Outline the scope of their professional role with patients, and provide an accurate description of their services.
3. A genetic counsellor guides and supports individuals through understanding of the options available to him/her and in decision-making.
4. Equip themselves with sufficient and relevant information required for diligent practice of the profession of genetic counselling, through continuing education and training, and keeping abreast of current knowledge and standards.
5. The autonomy of patients and non-judgmental provision of genetic counselling services is of utmost importance. A genetic counsellor enables his/her patients to make informed decisions, free of coercion, by providing the necessary facts, and clarifying the options available to them and the anticipated consequences.
6. A genetic counsellor accepts and respects the fact that individuals and families are best placed to balance the risks and benefits of genetic counselling services offered, in order that they may make treatment choices appropriate for their unique situation.

7. A genetic counsellor will act in the best interest of their patients at all times
8. A genetic counsellor ensures that patients and their families understand and provide informed consent for procedures, testing, and research.
9. A genetic counsellor understands, protects and respects their patients' confidentiality, and follows existing laws, rules and regulations applicable to medical and research settings.
10. A genetic counsellor will maintain information received from patients as confidential, unless released by the patient or disclosure is required by law.
11. A genetic counsellor has a separate and special responsibility towards the vulnerable patient, such as the young, or the indigent, to ensure they are treated with due care of their position in the family or in society.
12. A genetic counsellor shall be committed to the principles of justice and fairness and the goals of equal access to medical services, and seek to make these available to their patients.
13. A genetic counsellor will avoid the exploitation of their patients for personal advantage, profit, or interest.

Responsibility to Their Colleagues

The genetic counsellors' relationships with other genetic counsellors, students, health professionals and other publics are based on mutual respect, caring, cooperation, and support. Therefore, genetic counsellors shall strive to:

1. Share their knowledge and provide mentorship and guidance for the professional development of other genetic counsellors, students and colleagues.
2. Respect and value the knowledge, perspectives, contributions, and areas of competence of colleagues and students, and collaborate with them in providing the highest quality of service.
3. Encourage ethical behaviour of colleagues.
4. Keep abreast through and should seek opportunities for continuing education, cooperation and mentorship between genetic and non-genetic colleagues

5. Provide services in association with other healthcare professionals, and shall communicate their expert opinions, and knowledge to patients and colleagues.
6. Keep abreast of societal developments that may endanger the physical and psychological health of individuals. And colleagues.
7. Assure that individuals under their supervision undertake responsibilities that are commensurate with their knowledge, experience and training.
8. Maintain appropriate limits to avoid the potential for exploitation in their relationships with students and colleagues.

Responsibility to Society

The relationships of genetic counsellors with society include interest and participation in activities that have the purpose of promoting the well-being of society and access to health care. Therefore, genetic counsellors, individually or through their professional organizations, strive to:

1. Be responsible for creating awareness of his/her professional field, through participation in public and education programs for colleagues, advocacy and public/government policy-making.
2. Understand that he/she is a representative and flag-bearer of the profession of genetic counselling in India, and shall endeavor to be a source of reliable and peer-reviewed genetic information, to patients, society and institutional bodies.
3. Foster competence and accountability within the genetic counselling community, working in cooperation with other genetic counsellors in the best interest of the patient and the profession.
4. Shall seek advice from his/her colleagues, supervisors, other professionals and governing bodies and/or ethics committees when faced with concerns regarding the clinical or ethical behaviour of colleagues
5. Promote policies that aim to prevent discrimination on the basis of genetic information.

And oppose the use of genetic information as the basis for discrimination.

6. Participate in activities necessary to bring about socially responsible change.

7. Serve as a source of reliable information and expert opinion for policymakers and public officials.
8. Keep the public informed and educated about the impact on society of new technological and scientific advances and the possible changes in society that may result from the application of these findings.
9. Support policies that assure ethically responsible research.
10. Adhere to laws and regulations of society. However, when such laws are in conflict with the principles of the profession, genetic counsellors work toward change that will benefit the public interest.

Note: This Code of Ethics does not intend to replace the supervision and guidance offered to genetic counsellors working in hospitals, universities, research settings and/or private organizations. When a serious ethical matter arises, a genetic counsellor is expected to confer with supervisors and/or an institutional ethics committee.

No set of guidelines can provide all the assistance needed in every situation, especially when different relationships appear to conflict. Therefore, when considered appropriate for this code, specific guidelines for prioritizing the relationships have been stated. In other areas, some ambiguity remains, allowing for the experience of genetic counsellors to provide the proper balance in responding to difficult situations.

Scope of practice

1. RESPONSIBILITIES OF PRACTICE

Genetic counsellors have a responsibility to maintain high standards of professional and personal conduct. They shall seek to

- 1.1. Collect and interpret comprehensive patient information, including medical,
- 1.2. Psychological and genetic family history.
- 1.3. Make appropriate and accurate genetic risk assessments.
- 1.4. Use therapeutic counselling and communication skills with patients to help them:

- 1.5. Comprehend medical facts about a genetic disorder.
- 1.6. appreciate the way heredity contributes to the disorder, and the risk of
- 1.7. Recurrence in specified relatives.
- 1.8. Understand options for dealing with the risk of recurrence.
- 1.9. Choose the course of action that seems to them appropriate.
- 1.10. make the best possible adjustment to the disorder in an affected family
- 1.11. Member and/or the risk of recurrence of that disorder.
- 1.12. Make psychosocial assessments of patient need, providing support and referral to other agencies as appropriate.
- 1.13. Plan, organize and deliver professional and public education in genetic healthcare.
- 1.14. Serve as a genetic healthcare resource for professionals and the general public.
- 1.15. Liaise with other members of the genetics multidisciplinary team to provide optimum services for patients.
- 1.16. Delegation of duties

Genetic counsellors who delegate duties to others, such as genetic counsellor students and trainees who are not Certified Genetic Counsellors must be satisfied that the person is competent to undertake that duty and provide an appropriate level of supervision. Genetic counsellors delegating duties to genetic counsellor students and trainees will retain responsibility for the care provided for the patient at all times.

2: DUTY OF CARE

Genetic counsellors should always act in the best interests of patients, respecting the patient as an individual, avoiding causing harm, and promoting and protecting the interests and dignity of the individual, irrespective of gender, age, race, ability, sexuality, economic status, lifestyle, culture and religious or political beliefs.

2.1 Relationships with patients

Genetic counsellors should:

2.1.1 Enable patients to make informed independent decisions, free from coercion

2.1.2 Respect the patient's personal beliefs and their right to make their own decisions.

2.1.3 Respect patients, irrespective of their ethnic origin, sexual orientation, religious beliefs, gender and age.

2.1.4 Avoid any abuse of their professional relationship with patients.

2.1.5 Protect all confidential information concerning patients obtained in the course of professional practice: disclosures of such information should only be made with the patient's consent, unless disclosure can be justified because of a significant risk to others. Where this occurs, disclosure should only occur after discussion with suitably qualified colleagues.

2.1.6 Report to an appropriate person or authority any circumstance, action or individual that may jeopardize patient care, or their health and safety.

2.1.7 Seek all relevant information required for any given patient situation

2.1.8 Refer patients to other competent professionals if they have needs outside the remit or professional expertise of the genetic counsellor.

3: RESPECTING CONFIDENTIALITY

Genetic counsellors must respect the confidentiality of patients and families.

Genetic counsellors should be familiar with and act within the requirements of Consent and Confidentiality.

4: OBTAINING INFORMED CONSENT

Genetic counsellors must obtain and record informed consent in accordance with professional guidance and current legislation.

Genetic counsellors should be familiar with and act within the requirements of consent and confidentiality.*

5: COLLABORATION WITH COLLEAGUES

Genetic counsellors should work collaboratively with other health care professionals in the interests of patients, teaching and research.

5.1 Relationships with colleagues

Genetic counsellors should:

5.1.1 Collaborate and co-operate with other colleagues in order to provide the highest quality of service to the patient.

5.1.2 Foster relationships with other members of the clinical genetics team, to ensure that patients benefit from a multidisciplinary approach to care.

5.1.3 Assist colleagues to develop their knowledge of clinical genetics and genetic counselling

5.1.4 Report to an appropriate person or authority any circumstance or action which may jeopardize the health and safety of a colleague.

6: MAINTAINING PROFESSIONAL KNOWLEDGE AND COMPETENCE AND MINIMISING RISKS TO PATIENTS

Genetic counsellors' practice must be evidence-based, recognizing professional boundaries and referring on to other health professionals if appropriate.

Knowledge and skills must be maintained through continuous professional development, genetic counselling supervision and registration and comply with statutory health and safety policies.

7: PERSONAL AND PROFESSIONAL INTEGRITY AND HONESTY

Genetic counsellors must ensure that they act within legal and ethical boundaries and carry out duties in a professional and ethical way, behaving with integrity and honesty.

7.1 Self-awareness and development

Genetic counsellors should:

7.1.1 Be aware of their own physical and emotional health and take appropriate action to prevent an adverse impact on their professional performance.

7.1.2 Report to an appropriate person or authority any conscientious objection that may be relevant to their professional practice.

7.1.3 Maintain and improve their own professional education and competence.

7.2 Responsibilities within the wider society

Genetic counsellors should:

7.2.1 Provide reliable and expert information to the general public.

7.2.2 Adhere to the laws and regulations of society. However, when such laws are in conflict with the principles of practice, genetic counsellors should work toward change that will benefit the public interest.

7.2.3 Seek to influence policy makers on human genetic issues, both as an individual and/or through membership of professional bodies.

8: PROFESSIONAL INDEMNITY

It is recommended that Certified Genetic Counsellors have professional indemnity insurance. This is in the interests of registrants and patients in the event of claims and professional negligence.

8.1 Independent practice

Whilst some employers have vicarious liability for the negligent acts and/or omissions of their employees, such cover does not normally extend to activities undertaken outside the registrant's employment. Independent practice would not be covered by vicarious liability. It is the individual registrant's responsibility to establish their insurance status and take appropriate action.

We wish to acknowledge the guidance provided by these documents.

Statement of Specific Principles for Human Genetics Research ICMR Ethical Guidelines for Biomedical Research on Human Subjects 2000, pages 49-66

Ethical Policies on Human Genome, Genetic Research and Services Department of Biotechnology, GOI, January 2002

Consent and Confidentiality in Genetics Practice: Guidance on genetic testing and sharing genetic information' produced by the Royal College of Physicians, U.K.(www.bshg.org.uk)

Association of Genetic Nurses and Counsellors (2003). AGNC Code of Ethics.(www.agnc.org.uk/About%20us/codeofethics.htm)

American College of Medical Genetics (ACMG) Practice Guidelines (<https://www.acmg.net/>)

National Society of Genetic Counsellors (NSGC) Guidelines nsgc@nsgc.org

Canadian Guidelines for Genetic Counsellors (<http://www.cagc-accg.ca>)

Universal Declaration on the Human Genome and Human Rights, UNESCO 1997

International Declaration on Human Genetic Data, UNESCO 2003 <http://www.unesco.org/ibc>

WHO's International Guidelines on Ethical Issues in Medical Genetics
<http://www.who.int/genomics/elsi/resources>

Nuffield Council on Bioethics <http://www.nuffieldbioethics.org/geneticscreening>