Policy

Title: Code of Ethics for Genetic Counsellors

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Purpose

These guidelines aim to identify the fundamental professional commitments of genetic counsellors and to provide a basis for self-reflection, which enables consistent, ethical practice. Genetic counsellors have a primary responsibility to provide professional services which are appreciative of and responsive to individual, group, and community needs. Genetic counsellors are personally accountable for their practice and conduct, which must respect the reasonable interests of individual clients, aim to enhance the general health and wellbeing of the community, justify public trust, and enhance the reputation of the profession. Genetic counsellors must regard competence, integrity and dignity as essential attributes in themselves, their colleagues and other members of the health service team.

Preamble

Genetic counselling is a communication process, which aims to help individuals, couples and families understand and adapt to the medical, psychological, familial and reproductive implications of the genetic contribution to specific health conditions. Genetic counsellors have attained the relevant academic qualification but not yet completed their certification requirements. Certified genetic counsellors are specifically trained and certified health professionals who work within a healthcare team to provide this education and support to individuals, families and communities. For the purpose of this document, the term ‘genetic counsellor’ will represent both genetic counsellors and certified genetic counsellors.

Genetic counsellors work within a Scope of Practice. The HGSA acknowledges that various health professionals, other than genetic counsellors and clinical geneticists, will engage in genetic counselling. However, it is the belief of the HGSA that the core provision of genetic counselling is conducted by appropriately trained and regulated professionals.

The Code of Ethics (CoE) for Genetic Counsellors articulates and promotes ethical principles and sets specific standards to guide both genetic counsellors and members of the public to a clear understanding and expectation of what is considered ethical professional conduct by genetic counsellors. The CoE expresses
Genetic counsellors’ responsibilities to their clients, to the community and society at large, as well as colleagues and members of other professions with whom they interact. Practising genetic counsellors are required to declare that they abide by the Code of Ethics annually.

The following statements have been developed with reference to the fundamental principles of medical ethics: autonomy, beneficence, nonmaleficence and justice, as well as recognition of the demand of economic utility and distributive justice in Australian and New Zealand healthcare service provision. There are also elements related to the ethics of care, deontology (duty-based ethics) and virtue ethics. These guidelines only provide the basis for the ethical practice of genetic counselling and are intended to encourage consistency in our goals for the highest professional standards. In their training and practice, genetic counsellors must continually develop critical skills in logical philosophical reasoning in order to rationally resolve the individual cases of ethical conflict that arise in the work setting.

The statements derived from ethical principles provide the minimum expectations with regard to genetic counsellors’ professional conduct. Professional conduct that does not meet these standards is unethical and is subject to review in accordance with the Professional Concerns and Complaints Committee. These statements are not exhaustive. Where specific conduct is not identified by the standards, general ethical principles will apply.

Genetic counsellors respect and act in accordance with the laws of the jurisdictions in which they practise. The CoE should also be interpreted with reference to, but not necessarily in deference to, any organisational rules and procedures to which genetic counsellors may be subject.

The following four sections aim to clarify the most important ethical aspects for the genetic counsellor and her or his relationship with clients, colleagues and society.

**Section 1: Genetic Counsellors**

To achieve and maintain best practice, genetic counsellors will:

1. keep abreast of current standards of practice
2. be involved only in practices which are legally and ethically sound
3. review and acquire relevant and adequate information as required
4. recognise and honestly disclose the limits of their own training, knowledge, expertise or experience and therefore competence in any given situation
5. avoid relationships and activities that interfere with professional integrity, and identify and manage conflicts of interest
6. continue their education and training, achieve full HGSA certification, and engage in continuing professional development (CPD) activities
7. engage in regular supervision that encourages self-reflection and continued development of personal practice
8. maintain membership of the professional associations (HGSA and ASGC) and contribute to the ongoing development of the profession by attending meetings and conferences, giving presentations, participating on committees and holding office
9. strive to be responsible for their personal physical and emotional health to optimise professional performance and wellbeing.
Section 2: Genetic Counsellors' Responsibilities to their Clients

The interests and wellbeing of the client are of primary importance. To respect the client’s confidentiality, rights to self-determination/individual autonomy (within limits of law, reason and economic constraints), as well as their personal history, values, culture and beliefs, genetic counsellors will:

1. firstly, clarify their own professional role and determine a mutually acceptable agenda for any counselling session
2. provide genetic services to all individuals in a non-discriminatory manner
3. discuss relevant clinical and support information and options in plain language at the client’s level of understanding
4. advocate for qualified interpreters to be provided for counselling sessions as appropriate
5. recognise and respect that some individuals, particularly within certain cultural groups, do not primarily value their autonomy above their collective responsibility
6. follow currently acceptable informed consent processes and document these prior to genetic testing or recruitment to research studies
7. disclose confidential information only as consented to by the client and/or required for medical management or as permitted/required by law
8. recognise when their own experiences, values, and responses may influence the process and outcomes of a genetic counselling session and manage the situation appropriately
9. provide genetic counselling services to their clients within their scope of practice regardless of personal interests or biases, and refer clients as needed to appropriately qualified professionals
10. abstain from the exploitation of their clients for personal, professional, or institutional advantage, profit or interest.

Section 3: Genetic Counsellors’ Responsibilities to their Colleagues

Genetic counsellors may work with a diverse range of health professionals and community-based organisations. To initiate, build and maintain effective working relationships, genetic counsellors will:

1. function as an integral team member, collaborating with other professionals and co-workers to achieve a comprehensive provision of service for each client
2. respect the knowledge, areas of competence, experience, perspective and contribution of other team members accordingly
3. encourage and support ethical decision-making and behaviour of colleagues
4. maintain a peer support network based on the principles of confidentiality and trust
5. if qualified, provide mentoring, supervision and education for colleagues, students and other health professionals
6. ensure colleagues comply with all legal duties owed to their employer
7. take responsibility and credit only for work they have actually performed and to which they have contributed
8. appropriately acknowledge the work and contributions of others.
Section 4: Genetic Counsellors’ Responsibilities to Society

A complex interplay between social, political, and economic factors and medical/scientific discovery directs the development and utilisation of genetics services. It is of paramount importance that genetic counsellors, as individuals and as members of a professional group, contribute to ongoing community and professional debate about the potential associated ethical implications of the use of genetic technologies. Therefore, genetic counsellors will:

1. promote the equality of all individuals and equity of access to genetics services
2. make themselves aware of, respect, and adhere to local, state and federal laws and regulations (professional and personal liability is not reduced by lack of awareness)
3. advocate, within law, reason and economic constraints, for individual rights with respect to medical services and prevention of discrimination
4. strive to be critically aware of the potential political, economic, and social challenges associated with the development and application of genetic technologies
5. serve as a source of reliable, balanced information and expert opinion on human genetics issues as appropriate, particularly in development of health policy
6. strive to promote public understanding through education and rational debate of technological and scientific advances, and their potential impact on society
7. positively engage with community stakeholders (consumers of genetics services or parties directly affected by such services) in order to understand their concerns and needs.

Review Process

Henceforth, the Code of Ethics for Genetic Counsellors will be reviewed every three years, or sooner if necessary. A working group shall be formed by the Board of Censors for Genetic Counselling no later than six months before the end of the third year. The size of the working group shall be determined by the Board of Censors Chairperson.

Representation within the working group shall include, but not be limited to:

- a member of the previous working group
- a genetic counsellor, or academic interested in the process of genetic counselling, with training in medical ethics
- at least one member of the Board of Censors for Genetic Counselling, who shall be the Chair of the working group
- a member of the ASGC executive.

Apart from the medical ethics representative, all other members shall be practicing genetic counsellors with at least two years of experience.

The working group shall review the CoE in the light of current and emerging trends in the practice of genetic counselling and will benchmark the CoE internationally and against other allied health professions. A draft of the revised CoE must be circulated to the ASGC executive for comment and feedback before being circulated to the membership for a period of four weeks. Feedback will be considered and incorporated by the working group as appropriate. A final draft should be approved by the Board of Censors for Genetic Counselling ratified by the HGSA Council.
The final version of the revised CoE will be posted on the Board of Censors for Genetic Counselling webpage.

**Review History**


**References**


Glossary

Australasian Society of Genetic Counsellors (ASGC)
A special interest group of the Human Genetics Society of Australasia, formed in 1993, comprising individuals who practice genetic counselling, or who have a qualification or professional interest in the discipline of genetic counselling.

Autonomy
The ability to be self-determining and self-governing; the capacity to make reasoned choices on the basis of adequate information.

Client
Person/s who seeks the services of a suitably qualified and experienced practitioner.

Colleagues.
Person/s similarly qualified and/or working in the same healthcare team.

Confidentiality
Entrusted in confidence, either spoken or written, with the client’s information. Based on the idea of creation of personal identity, principle of privacy and trust between client and care provider.

Healthcare team
Healthcare professionals working directly and indirectly to contribute to the total healthcare needs of the client.

Health professionals
Groups of individuals within the healthcare team who have the following attributes:
- recognised skill pertaining to their profession
- adherence to a certain standard of practice
- a recognised training program to achieve their skill.

Human Genetics Society of Australasia
An association formed in 1977, composed of persons united by a common interest in the field of human genetics.

Informed consent
Consent obtained on the basis of the non-coercive provision of adequate current, relevant, balanced information, which can be readily understood by the person expected to give consent. The person to give consent must also have been afforded adequate time and opportunity to consider the information and seek clarification from other sources or support persons before making their decision.

Interpreter
A qualified person with the training to interpret medical and family information from a foreign language to English.

Practising genetic counsellor
A genetic counsellor who draws on their relevant professional skills and knowledge in the course of their
work to contribute to safe and effective delivery of services within their profession. It encompasses the provision of direct clinical care, working in management, administration, education, laboratory, research, advisory, regulatory or policy development roles, for example.

Privacy

In the context of genetic counselling, privacy rights involve the affirmation of confidentiality and freedom of choice. These privacy rights may not always be absolute.

Scope of practice

Outlines the range of responsibilities of genetic counsellors in the course of their work to contribute to safe and effective delivery of services within their profession. The Code of Ethics for Genetic Counsellors should be referred to in conjunction with the Scope of Practice for Genetic Counsellors.

Self-determination

Fixing of purpose or intent by oneself, using one’s free will.

Supervisor

A person who is suitably qualified and experienced to discuss, assess and provide support to enhance the performance of the counsellor.