



## HUMAN GENETICS SOCIETY OF AUSTRALASIA

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### Policy

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### Purpose

These guidelines aim to identify the fundamental ethical commitments of genetic counsellors and to provide a basis for self-reflection, which supports 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 are specifically trained allied health professionals who work to research, improve, assist, or provide genetic counselling services to individuals, families, and communities. Although various health professionals will engage in aspects of genetic counselling (such as taking a pedigree, obtaining informed consent, etc.), the Human Genetics Society of Australasia (HGSA) view is that core provision of genetic counselling should be 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 conduct for professional genetic counsellors. The COE sets out genetic counsellors' responsibilities to their clients and society at large, as well as colleagues and members of other professions with whom they interact. On an annual basis, practising genetic counsellors who are listed on the HGSA [Register of Genetic Counsellors](#) are required to sign a mandatory declaration that they abide by the COE (see the HGSA [Mandatory Declarations for Registered Genetic Counsellors](#)).

The following statements have been developed by considering the key ethical principles and theories needed for robust and inclusive engagement of genetic counsellors in their fields of work. It is also important to consider key stakeholders and perspectives that may have a relationship with genetic counsellors. In this code of ethics, the following four are used: genetic counsellor, client, colleagues, and society. There are complex relationships between and within each group, but the acknowledgement of each will help inform how the genetic counselling profession should ethically engage and (if needed) should act.

Three overarching principles have been used to inform the development of the following statements. These are: veracity, dignity, and accountability. We feel these principles are nuanced and work in conjunction with familiar ethical principles (such as autonomy, beneficence, non-maleficence) and other fields of ethical inquiry (such as care ethics, feminist ethics and disability ethics). Together, these concepts support ethical debate and engagement to guide actions as situations, cases, and contexts require. Importantly, a basis of justice through health equity and equality is fundamental to the work and practice of genetic counsellors and should be implicit within their professional practice.

In their training and practice, genetic counsellors are expected to learn and continually develop their critical analysis and logical reasoning skills and apply them to ethical and professional dilemmas that may arise during their professional practice. The statements derived from ethical principles provide the minimum expectations with regard to genetic counsellors' conduct and are not exhaustive. Conduct that does not meet these standards is subject to review in accordance with the [HGSA Professional Concerns and Complaints Procedure for Genetic Counsellors](#).

Genetic counsellors are expected to respect and act in accordance with the laws of the jurisdictions in which they practise. This document applies to genetic counsellors in conjunction with *A National Code of Conduct for health care workers*<sup>1</sup> in Australia, and *Articles of the Code of Practice for Health Workers*<sup>2</sup> in New Zealand. 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. Therefore, it is an expectation that all genetic counsellors practice ethically, with reference to the respective guidelines and codes of ethics as defined by their roles.

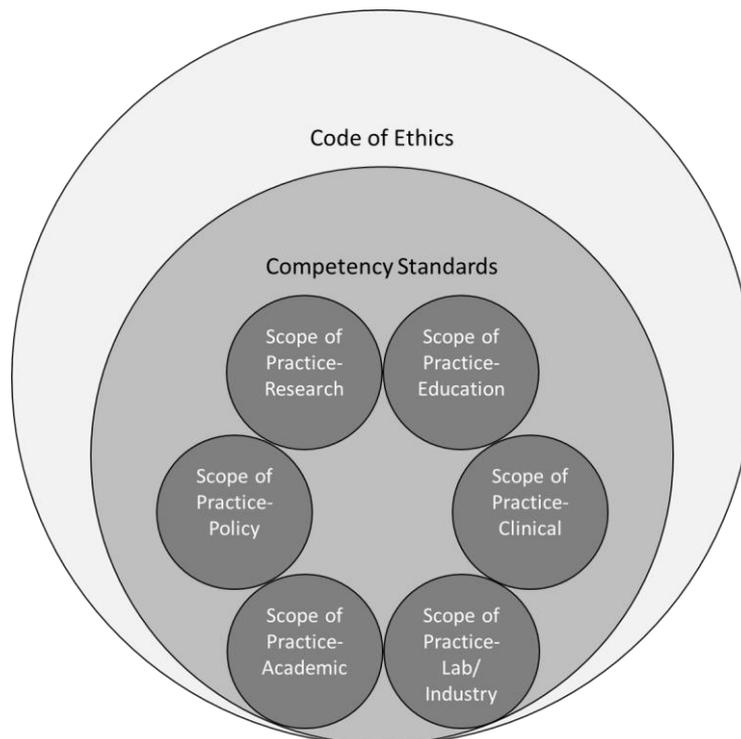
The four sections of this document aim to clarify the most important ethical considerations for genetic counsellors and their relationships with clients, colleagues, and society.

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<sup>1</sup> Australian Health Ministers' Advisory Council. (2014). *A National Code of Conduct for health care workers* <https://www.coaghealthcouncil.gov.au/NationalCodeOfConductForHealthCareWorkers>

<sup>2</sup> New Zealand Ministry of Health. (2018). *Articles of the Code of Practice for Health Workers* . <https://www.health.govt.nz/our-work/who-code-nz/code-practice-health-workers>

**Figure: Code of Ethics, Competency Standards, and Scope of Practice**



This figure shows the relationship between these three documents as defined below (taken from the definitions in the [National Alliance of Self Regulating Health Professions \(NASRHP\) Self Regulating Health Profession Peak Bodies Membership Standards, 2016](#)).

A **Code of Ethics** expresses the overarching values and responsibilities which are integral to and characterise the profession, assist practitioners (collectively and individually) to act in ethically accountable ways in the pursuit of the profession’s aims, and by which practitioners are held accountable for ethical practice.

**Competency Standards** are standards for professional practice that set out what individuals should know, understand and be able to do, in order to practice safely and effectively. See the [HGSA Competency Standards for Genetic Counsellors](#).

A **Scope of Practice** describes the area or areas of the profession in which a practitioner has the particular knowledge, skills, and experience to practise lawfully, safely, and effectively, in a way that meets professional standards and does not pose any danger to the public or themselves. See the [HGSA Scope of Practice for Genetic Counsellors Policy](#).

## 1. Genetic Counsellors' Personal Responsibilities

To achieve and maintain best practice, genetic counsellors will:

- 1.1. Be accountable and keep up to date with current standards of practice, continue education and training, and engage in continuing professional development. See the HGSA [Continuing Professional Development Policy for Genetic Counsellors](#).
- 1.2. Maintain respect for their clients, colleagues, society, and themselves by being involved in practices that are legally permitted and ethically defensible, and meet the standards set out in this code.
- 1.3. Maintain truthfulness in their practice by being transparent to clients, colleagues, and the wider community about the limits of their own training, knowledge, expertise, or experience and therefore competence. See the HGSA [Scope of Practice](#) and [Competency Standards](#) for Genetic Counsellors.
- 1.4. Avoid relationships and activities that interfere with professional integrity.
- 1.5. Identify personal interests and manage actual and perceived conflicts of interest transparently.
- 1.6. Engage in regular supervision that encourages self-reflection and continued development of personal practice. See the HGSA [Supervision Policy for Genetic Counsellors](#).
- 1.7. Practice self-care and reflection on the impact of physical and emotional health on their professional performance, wellbeing, and individual competency to practice, and support colleagues to do the same. See the HGSA [Scope of Practice](#) and [Competency Standards](#) for Genetic Counsellors.
- 1.8. Acknowledge the role personal beliefs, values and world views might assume in all interactions with colleagues, clients and communities as a genetic counsellor.

## 2. Genetic Counsellors' Responsibilities to their Clients

The interests and wellbeing of the client are of primary importance. Genetic counsellors will:

- 2.1. Develop and maintain the necessary skills to deliver non-discriminatory, respectful, empathetic, and culturally safe genetic counselling for all clients.
- 2.2. Elicit, listen, assess and respond to clients' needs, values, and preferences in order to provide client-centred care.
- 2.3. Respect clients' rights to self-determination.
- 2.4. Recognise that individual clients do not exist in isolation and that genetic counsellors may need to balance competing needs, for example, within families, organisations or between stakeholder groups.
- 2.5. Recognise that their own biases, experiences, values, culture, and beliefs will influence their work to varying degrees, and proactively recognise and manage any (perceived or actual) conflicts that might arise if clients hold different beliefs, values and world views.
- 2.6. Be open, transparent, and clearly communicate their professional role and boundaries of their scope of practice to clients, including where they may hold dual roles or qualifications. See the HGSA [Scope of Practice for Genetic Counsellors Policy](#).

- 2.7 Use a collaborative and client-centred approach with each client to explore and support their informed decision-making, including documenting preferences and informed consent.
- 2.8 Advocate for and make every effort to ensure access to qualified healthcare interpreters and translated written materials as appropriate.
- 2.9 Respect and protect client privacy and confidentiality, considering appropriate legal and organisational requirements for collecting, keeping, and disclosing of client information and client records.
- 2.10 Provide services within their individual scope of practice, and refer clients as needed to appropriately qualified professionals (see the HGSA [Scope of Practice for Genetic Counsellors](#)).
- 2.11 Advocate for client-centred care and client preferences within the healthcare system as appropriate.
- 2.12 Abstain from the exploitation of clients for personal, professional, or institutional advantage, profit, or interest.

### **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 interdisciplinary and interprofessional relationships, genetic counsellors will:

- 3.1 Provide a safe and supportive environment for colleagues regardless of gender, religion, sexuality, pregnancy status, disability etc; valuing and acknowledging the contribution to work regardless of experience level; ensuring fair and equitable access to opportunities etc.
- 3.2 Promote diversity within the profession, and equity of access to genetic counsellor education, training, and regulation for all people choosing this profession.
- 3.3 Collaborate with colleagues and other professionals as needed to provide comprehensive service to each client.
- 3.4 Respect and work with colleagues, with acknowledgement that they contribute different knowledge, levels of competence, experience and perspectives.
- 3.5 Encourage and support ethical decision-making and behaviour of colleagues.
- 3.6 Maintain a peer support network based on the principles of confidentiality and trust.
- 3.7 When appropriate, provide and support the mentoring, supervision and education of colleagues, students, and other health professionals.
- 3.8 Report breaches of ethical standards, competent practice, and/or practice out of scope to the necessary governing bodies. Refer to the HGSA [Code of Ethics \(COE\)](#), [Competency Standards](#), and [Scope of Practice \(SOP\)](#) for Genetic Counsellors. The HGSA manages breaches through the [Genetic Counsellor Professional Concerns and Complaints Committee \(PCCC\)](#).
- 3.9 Take responsibility and credit only for work they have performed and to which they have contributed, and appropriately acknowledge the work and contributions of others.
- 3.10 Maintain relationships with, and participate in, relevant professional communities.
- 3.11 Contribute to the ongoing development of the genetic counselling profession.

#### 4. Genetic Counsellors' Responsibilities to Society

A complex interplay between social, political, and economic factors and medical and scientific discovery directs the development and delivery 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 ethical implications associated with the use of genetic technologies. Therefore, genetic counsellors will:

- 4.1 Promote the equality of all individuals regardless of age, sex, gender identity, sexual orientation, class, race, ability, ethnicity etc.
- 4.2 Advocate for equity of access to healthcare and health education, in particular genetics services, with an understanding of the barriers that prevent access.
- 4.3 Advocate for individual rights with respect to medical services and prevention of discrimination.
- 4.4 Actively manage the risk of professional and personal liability through awareness of and adherence to local, state, and federal laws and regulations.
- 4.5 Strive to be critically aware of the potential political, economic, and social challenges associated with the development and application of genetic technologies.
- 4.6 Serve as a source of authentic, reliable, balanced information and expert opinion on issues related to human medical genetics appropriate.
- 4.7 Strive to promote public understanding of human genetics through education, communication, and rational debate of technological and scientific advances, and their potential impact on society.
- 4.8 Engage with stakeholders for genetic services (including communities, consumers and potential beneficiaries) to determine and deliver appropriate care and resources.

## Review Process

The HGSA [Code of Ethics \(COE\)](#), [Competency Standards](#), and [Scope of Practice \(SoP\)](#) for Genetic Counsellors will be reviewed together every three years, or sooner if necessary, to maintain consistency with current evidence-based best-practice guidelines. A working group will be formed by the HGSA [Board of Censors \(BoC\) for Genetic Counselling](#) Chairperson no later than six months before the end of the third year. The size and membership requirements of the working group will be determined by the BoC Chairperson.

The working group shall include, but not be limited to:

- The members of the Board of Censors. The Chair of the Board of Censors will act as the Chair of the working group.
- A genetic counsellor and/or academic member with an interest in the process of genetic counselling, and with training in medical ethics and/or law.
- A member of the HGSA [Education, Ethics and Social Issues Committee \(EESIC\)](#),
- A member of the [Australasian Society of Genetic Counsellors \(ASGC\) Executive](#).
- A Master of Genetic Counselling course convener/academic genetic counsellor.
- Any other member representation deemed necessary for a thorough review, including additional legal or medical ethics experts. Representation from diverse areas of genetic counselling practice is necessary to ensure that the documents remain inclusive and applicable to all practicing genetic counsellors.

Any genetic counsellor members must be practising genetic counsellors in good standing on the HGSA [Register of Genetic Counsellors](#) with at least two years of professional experience in a genetic counselling role.

The working group will review the documents in light of the current and developing trends in the practice of genetic counselling and benchmark them internationally and against other allied health professions. A draft of the revised documents 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 and ratified by the HGSA Council. Final ratified versions of the revised documents are posted on the [HGSA website](#).

## Glossary

### *Accountability*

Readiness or willingness to take responsibility and give an explanation or justification to stakeholders for one's judgments, intentions and actions.

### *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*

Any individual or organisation receiving services from a genetic counsellor, including patients and their families, the general public, students, other health care providers, and government/non-governmental agencies or departments

### *Colleague(s)*

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.

### *Cultural safety*

“An environment that is safe for people: where there is no assault, challenge or denial of their identity, of who they are and what they need. It is about shared respect, shared meaning, shared knowledge and experience, of learning, living and working together with dignity and truly listening.”<sup>3</sup>

### *Dignity*

The right of a person to be valued and respected for their own sake, and to be treated ethically.

### *Equality*

Where a group of individuals has equivalent value, worth, and importance, despite their individual differences.

### *Equity*

The absence of avoidable or remediable differences or disparities among groups of people.

### *Human Genetics Society of Australasia*

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

### *Competence*

Possession of sufficient required skill, knowledge, and/or capacity to perform a particular activity (e.g. competence to give informed consent, competence to practice as a genetic counsellor).

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<sup>3</sup> Williams R. (1999). Cultural safety--what does it mean for our work practice?. *Australian and New Zealand Journal of Public Health*, 23(2), 213–214. <https://doi.org/10.1111/j.1467-842x.1999.tb01240.x>

### *Consent*

Consent relies on the client being able to make an informed decision. In order for consent to be valid, it should be provided freely, without coercion, it should be relevant to the decision to be made and with adequate information communicated and documented, and given a reasonable opportunity to make the decision. Consent should be given by a competent adult with decision-making capacity, or in the context of substitute decision-making, by a designated substitute decision-maker.

### *Genetics/Genomics*

For the purpose of this document, the term '*genomic*' is inclusive of single genes (genetics), multiple genes (genomics) and the interactions between genes and environmental or non-genetic factors that have health implications.<sup>4</sup> These terms may be used interchangeably in this document.

### *Informed decision-making*

A process designed to provide clients with accurate and unbiased information in a format that enables understanding of the nature of the condition being addressed, the benefits, risks, limitations, alternatives and uncertainties of the service being offered, so that they can make decisions about their care or treatment. In addition, clients should be given time, space, and support to come to a decision that best aligns with their values and preferences.

### *Interpreter*

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

### *Practice/Practising genetic counsellor*

"...indicates that an individual [genetic counsellor] is drawing on their relevant professional skills and knowledge in the course of their work to contribute to safe and effective delivery of services within the profession... It is not restricted to the provision of direct clinical care and may also include working in a direct non-clinical relationship with clients; working in management, administration, education, research, advisory, regulatory or policy development roles, for example. This work can be of a paid or formal volunteer nature on a full or part-time basis."<sup>5</sup>

### *Privacy*

In the context of genetic counselling, privacy rights involve the protection of confidentiality and freedom of clients to choose to whom and when their private information may be disclosed. These privacy rights may not always be absolute and can be subject to different levels of protection, depending on the jurisdiction and institution the genetic counsellor is practising within.

### *Professionals*

Groups of individuals who have recognised skill pertaining to their profession, adherence to a certain standard of practice, and a recognised training program to achieve their skill.

### *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](#).

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<sup>4</sup> Commonwealth of Australia Department of Health. National Health Genomics Policy Framework. 2017.

<sup>5</sup> National Alliance of Self Regulating Health Professions (NASRHP); Self Regulating Health Profession Peak Bodies Membership Standards; 2/12/2016

*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 genetic counsellor. See the HGSA [Supervision Policy for Genetic Counsellors](#).

*Veracity*

Comprehensive, accurate, transparent, and objective transmission of information.

## Review History

- Originally adapted with permission from the National Society of Genetic Counselors, Inc. Code of Ethics, USA (1992).
- Revised in 2007 with reference to the National Society of Genetic Counselors, Inc. Code of Ethics, USA (2006) and issues of relevance to local circumstances.
- Revised in 2018 with reference to the National Society of Genetic Counselors, Inc. Code of Ethics, USA (2018), codes of ethics of other allied health professions (Australian Association of Social Workers (2010), Australian Psychological Society (2007), Dietitians Association of Australia (2004)) and issues of relevance to local circumstances including self-regulation of the profession of genetic counselling.
- Reviewed and revised in 2020, in consultation with the Inclusivity working group of the HGSA Implementation Committee for Genetic Counsellor Regulation and BOC working group as outlined in the Review Process above.

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