

HUMAN GENETICS SOCIETY OF AUSTRALASIA

ARBN. 076 130 937 (Incorporated Under the Associations Incorporation Act)

The liability of members is limited

Regulation for Genetic Counsellors in Australia and New Zealand

Genetic counsellors as health professionals:

Genetic counsellors are allied health professionals who have specialized education in genetics, counselling, and health communication. Most are employed in clinical roles in public hospitals although many more are entering private practice and undertaking roles in management, administration, education, industry, research, laboratory, and policy.

The HGSA has endorsed the Australasian Society of Genetic Counsellors (ASGC) definitions of genetic counselling as a process and genetic counsellors as a profession <u>HERE</u>.

Genetics is increasingly being recognised as a vital component of many aspects of healthcare, and genetic counsellors' specialised skillset contributes to the safe implementation of genetic technologies to improve patient outcomes (Yashar & Peterson, 2013). Ongoing advances in genetic technologies are resulting in vast amounts of information being available to clinicians, patients, and their families, contributing to the rapid expansion of the profession (Barlow-Stewart, Dunlop, Fleischer, Shalhoub, & Williams, 2017; Ormond et al., 2018). Employment of genetic counsellors is projected to grow much higher than the average for all occupations (Careercast, 2018). With increasing demand, it is inevitable that the profession will continue to expand (Yashar & Peterson, 2013), and there are global efforts to regulate the profession of genetic counselling.

There is currently no legislative or statutory protection in Australia or New Zealand for the title of genetic counsellor.

Anyone in Australia or New Zealand can currently claim to be providing genetic counselling regardless of qualifications and without fear of reproach. The increasing availability of and demand for genomic information, significantly increases the likelihood of harm to the public from unqualified healthcare providers offering services in a complex and rapidly changing field.

HGSA as a professional organisation for genetic counsellors:

The Human Genetic Society of Australasia (HGSA) was formed in 1977, and is now a society of over 1300 professionals from clinical, laboratory and academic specialties in Human Genetics. Genetic counsellors comprise the largest professional group in the HGSA. In 1993, the Australasian Society of Genetic Counsellors (ASGC) was formed as a Special Interest Group within the HGSA. In 1989 the HGSA appointed a Board of Censors for Genetic Counselling (the BOC) to certify genetic counsellors in Australia and New Zealand. In 1990, the HGSA ratified the first Guidelines for Training and Certification in Genetic Counselling, to be administered by the BOC.

Graduates of an accredited tertiary Master of Genetic Counselling course can apply to become a Member of the HGSA (MHGSA). MHGSA genetic counsellors can undertake further training and clinical practice to be granted Fellow of the HGSA (FHGSA) Clinical Certification.

In 2019 there were only an estimated 202 genetic counsellors working in fully clinical roles in Australia and New Zealand, 85 of whom held FHGSA Clinical Certification (ASGC membership data 2019). In 2023 it is now estimated

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that 305 genetic counsellors work in clinical practice roles in Australia and New Zealand, with 162 holding FHGSA Clinical Certification (HGSA data, 2023)

The HGSA and the ASGC identified regulation of the genetic counselling profession as a priority. Since the 1990's, State, Territories and Commonwealth agencies have acknowledged the need to protect the public from harm through appropriately qualified and trained genetic counsellors. However, attempts to engage with State, Territories, and Commonwealth agencies to achieve this have met with little success.

Genetic counsellor regulation in Australia:

The <u>Australian Law Reform Commissions Report 96</u> 'Essentially Yours: The Protection of Human Genetic Information in Australia' recommended that the Commonwealth, States and Territories examine options for recognition of genetic counselling as a health profession, including registration. It also cites the public need for access to expert genetic counsellors, as well as the need to protect the public from unqualified individuals claiming to be genetic counsellors.

The <u>Australian National Health Workforce Innovation and Reform Strategic Framework for Action</u> 2011-2015 notes the logic in shifting health service costs from higher paid medical practitioners to more modestly paid allied health professionals where it is appropriate, safe and practical to do so.

The <u>National Health Genomics Policy Framework and Implementation Plan 2018-2021</u> identifies the need for a specialist genomics workforce as an issue of strategic importance and critical to successful implementation of genomic medicine into the national health system. It also notes the self-regulatory arrangements for genetic counsellors through the <u>National Alliance</u> of <u>Self Regulating Health Professions</u> (NASRHP).

After July 2010, regulation in Australia through the <u>National Registration and Accreditation Scheme</u> (NRAS) was confined to those health professions that were already or partially registered. Genetic counsellors were denied regulation under NRAS as administered by the <u>Australian Health</u> <u>Practitioner Regulation Agency (AHPRA)</u>, and sought an alternative pathway through the <u>National Alliance of Self Regulating Health Professions (NASRHP)</u>.

Genetic counsellor regulation under NASRHP:

NASRHP is the national peak body representing self-regulating health professionals in Australia and is supported by the Australian Department of Health. NASRHP provides a quality framework and benchmarked standards for practitioner regulation that are aligned with AHPRA standards and satisfy the National Code of Conduct for health care workers.

In March 2020, the HGSA Board of Censors for Genetic Counselling was granted full NASRHP membership for the regulation of genetic counsellors in Australia.

Genetic counsellor regulation in New Zealand:

Genetic counsellors have been employed in New Zealand since 1995. The national public Genetic Health Service New Zealand (GHSNZ) employs genetic counsellors in Auckland, Wellington, and Christchurch, and requires them to be active members of the HGSA and ASGC. However, there is a growing private sector in NZ. In 2008, genetic

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counsellors sought regulation under the Health Practitioners Competence Assurance Act but were denied due to the small size of the profession.

HGSA as the Regulatory Body for Genetic Counsellors:

Under NASRHP requirements, the Guidelines for Training and Certification in Genetic Counselling have been restructured into 11 HGSA Policies aligned with the NASRHP Standards for administration by the BOC. A transitional period was in place from March 2019-March 2023 to support genetic counsellors engaging with the regulatory process.

The HGSA publishes an <u>online register</u> of genetic counsellors who are engaged in the regulatory process, which includes active participation in or completion of certification and continuing professional development (CPD). Genetic counsellors who do not participate in the regulatory process will not appear on this list. Genetic counsellors may have their registration lapse, expire, or terminate if they do not submit annual registration requirements, or for a breach of the HGSA Code of Ethics or Scope of Practice for Genetic Counsellors. The HGSA Register of Genetic Counsellors includes:

- ACTIVE genetic counsellors who are qualified to practice in any area of practice
- PROVISIONAL genetic counsellors undertaking further training specific to clinical practice, and
- REGISTERED genetic counsellors who have achieved FHGSA certification for clinical practice.

Enforcement of regulation for genetic counsellors:

To meet NASRHP standards, the HGSA has established a process through the <u>Professional Concerns and Complaints Committee (PCCC)</u> for receiving, overseeing, managing and resolving complaints about unethical and/or unprofessional practice against MHGSA or FHGSA genetic counsellors. Suspension or termination of HGSA registration will be reported to the relevant regulatory bodies, published on the HGSA Register that is available to the public, and otherwise released or published as required or directed by law.

The HGSA does not have jurisdiction over complaints of a genetic counsellor who is not an MHGSA or FHGSA Genetic Counsellor, the PCCC can suggest alternative avenues including referral of the complainant to the Health Complaints Commissioner, the Australian Competition and Consumer Commissioner or the Patient/Consumer Liaison Officer at the genetic counsellor's place of employment.

Genetic counsellor regulation under the HGSA is not mandatory and remains voluntary. Statutory and legislative protection of the regulatory process is necessary to ensure safe access to genetic services that meet the needs of the public and of the health system.

HGSA genetic counsellors are currently recognised as a "self-regulating" professional group under NASRHP. Self-regulation is a voluntary process, as the HGSA does not yet have statutory powers to license members. Although members of a voluntary regulatory system may be expelled for misconduct and serious breaches of the code of ethics, expelled practitioners cannot be prevented from practising, which is not in the best interests of the public.

Employers may choose to uphold a voluntary regulatory system through their policies, formal job descriptions and advertised position descriptions. Indirect title protection will occur if regulation is taken into account in employer Job Description Form (JDF) and position descriptions, enterprise bargaining agreements (EBA) and pay scales.



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Co-regulation, in partnership with government, has been achieved by other NASRHP professions. The key difference between co-regulation and self-regulation is that some regulatory functions may be carried out under delegation from government or recognised by government for access to some authority, benefit or entitlement, for example, Medicare provider numbers for services.

The HGSA will continue to pursue statutory and legislative endorsement of regulation by Commonwealth and State governments to ensure safe access to genetic counselling services, including:

- Statutory/legislative endorsement of regulation by Commonwealth, State, and Territory governments
- National title/career structures and title protection for genetic counsellors
- Models of funding for genetic counselling (including ABF, Medicare, private insurance)