HUMAN GENETICS SOCIETY OF AUSTRALASIA

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ARBN. 076 130 937 (Incorporated Under the Associations Incorporation Act)
The liability of members is limited

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Guideline

Title HGSA Code of Ethics

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The Human Genetics Society of Australasia (HGSA) is the peak body for a community of professionals and professions that practice in the field of human genetics and genomics in Australasia. Members work and train in a range of relevant disciplines and include clinicians; counsellors; educators; diagnostic and research scientists; academics; and policy-makers.

This Code of Ethics describes a practice framework for all members of the HGSA. It does not replace any ethical or legal obligations as mandated by the relevant jurisdictions, employers, and other professional bodies to which HGSA members belong.

HGSA members should ensure:

1. Improvement of health care and the advancement of science by:

- Providing and promoting leadership and expertise in clinical genetic and genomic services, education, training and related research;
- Promoting relevant professional standards and accreditation for clinicians, counsellors, trainees and researchers in genetics and genomics;
- Working towards the advancement of professional and consumer/community genetic and genomic knowledge and understanding, in order to enhance human health and wellbeing;
- Promoting relevant local, international and interdisciplinary collaborations to facilitate optimal outcomes, both domestically and internationally; and
- Promoting educational and ethical discourse to facilitate understanding and appropriate implementation of new technologies in genetics and genomics.

2. Respect and value of autonomy and equity by:

- Actively promoting and supporting decisions that are consistent with individual, group and cultural values, including through appropriate engagement and providing appropriate information;
- Advocating for equity of access to genetic and genomic counselling and testing;
- Actively facilitating provision of services based on clinical need without bias, stigma or discrimination;
 and
- Engaging with and respecting cultural and community practices, as outlined by the <u>Ethical Conduct in</u>
 Research with Aboriginal and Torres Strait Islander Peoples and Communities and the <u>Te Ara Tika</u>
 Guidelines for Maori Research Ethics

3. Professional integrity by:

- Promoting responsible, ethical and appropriately supervised practice for all clinicians, counsellors, trainees and researchers in genetics and genomics;
- Being trustworthy, responsible and of good standing;
- Behaving in a manner that is appropriate, honest and objective;
- Enhancing and maintaining professional knowledge and standards through ongoing education, training, and reflective practice;
- Maintaining professional accountability to relevant oversight bodies in the community at large;
- Respecting colleagues and collaborators and appropriately acknowledging individual input and intellectual property;
- · Maintaining cultural sensitivity towards others; and
- Treating everyone with respect and professionalism, irrespective of race, culture, gender, sexuality or religious beliefs.

4. Professional transparency by:

- Encouraging and informing public engagement and involvement with human genetic and genomic testing and research;
- Encouraging communication between family members about the possible implications of genetic or genomic testing and/or diagnosis, so that all relevant individuals are aware of their chances of developing or transmitting a genetic condition;
- Serving as a source of relevant and evidence-based genetic/genomic information for the community, including patient support groups;
- Promoting ethical research and reporting all research findings in a true, transparent, accurate and timely manner;

- Disclosing any real or perceived conflicts of interest in relation to personal, commercial, policy and/or research relationships that could influence a member's personal objectives when
 - working with patients/clients;
 - engaging in academic research or other activities;
 - publishing;
 - presenting work to colleagues, for example, at conferences such as the HGSA Annual Scientific
 Meeting; and
 - undertaking activities on behalf of the HGSA
- Actively acknowledging the potential ethical, political, social and legal implications of genetic and genomic technologies and their application; and
- Where appropriate, exploring and evaluating such technologies in order to anticipate and mitigate potential negative sequelae.

5. Protection of privacy by:

- Being aware of and respecting, within applicable legal limits, the confidential nature of genetic and genomic health information;
- Understanding the circumstances in clinical settings whereby disclosure of genetic information may be a consideration;
- Adhering to relevant privacy guidelines and legislation;
- Ensuring appropriate consent has been obtained before using potentially identifiable materials in publications or presentations; and

Protecting the privacy of research participants, as outlined by the <u>National Statement on Ethical Conduct in Human Research</u> and the <u>National Ethical Standards for Health and Disability Research and Quality Improvement</u>