



... making sense of your genes

Human Genetics Society of Australasia Limited

Genetic experts call for more frontline staff to combat long waits for support

NATIONAL: Human Genetics Society of Australasia Ltd (HGSA) is calling on all major parties and community independents to commit to expanding access to genetic health services and genetic risk assessments for Australians through the Medicare Benefits Schedule (MBS) as part of the 2025 Federal Election.

Genetic and genomic testing is important in guiding decision making and treatment pathways for people with common conditions, including cancer and heart disease. In addition, rare diseases affect 8% of people in Australia and are often devastating for patients and their families. Over 80% of these conditions are caused by genetic variations. Genetic health services are crucial for diagnosis, management, and providing support to families affected by rare disease.

At present, no MBS item number exists to allow for professional genetic counsellor risk assessments in community settings. Due to this and an overburdened public healthcare system, the wait to access genetic counsellors can be up to 36 months.

HGSA is the professional membership organisation representing the human genetics workforce including genetic counsellors, clinical geneticists, laboratory professionals, academics and researchers.

Genetic risk assessments are a pivotal part of modern genomic medicine, and can support an improved understanding of an individual's genetic make-up. This includes:

- individuals learning if that they are a carrier of a genetic variant which may increase their chance of developing certain health concerns;
- Informing other family members of this increased chance to enable their assessments to be completed also;
- Assisting couples to learn if they have an increased chance of having a child with a severe health condition.

All of these genetic risk assessments aim to provide information so individuals, couples and families can make informed decisions about their personal and future healthcare.

Specialist allied health professionals known as genetic counsellors, combine genetics knowledge with health communication and counselling skills to support people and families to understand the implications of their genetic assessments and test results. Seeing a genetic counsellor helps people incorporate the information into their healthcare and life plans.

Cost benefit analysis provided to Government shows that for every dollar spent on genetic counselling, there is a 250% return on investment which can provide additional benefits to the Australian population.

Genetic counsellors work in all areas of health, including clinical, research, academic, education, policy, industry and laboratory settings. They are key conduits to enable individuals and families to



access genomic services which can be of benefit to them through some of the most consequential health decisions they will make.

At a projected cost of only \$10 million per year, an MBS item number would improve the reach and benefit of professional genetic counselling for families of those receiving genetic diagnoses, individuals concerned with their own genetic risk and couples planning their families.

HGSA's proposal of an MBS item number for genetic counsellors aligns with multiple recent health announcements by the Australian Government, including the \$573 million proposed for women's health, and the \$8.5 billion announced for strengthening Medicare by increasing bulk billing services.

Quotes attributable to HGSA President Associate Professor Yemima Berman

"No family should be expected to make complex and difficult decisions about genetic testing, results, or management without timely access to expert advice."

"More equitable access to genetic counselling would support the delivery of genomic health initiatives, which support women and families, and can be delivered in primary care settings alongside general practitioners and other health care practitioners."

"It is no secret that genomics services in Public Hospitals are overstretched, with wait times extending up to 3 years in some services. Delaying action in addressing service delivery issues until after the establishment of Genomics Australia, risks increasing inequity and uncertainty about the future of genetic services in Australia."

"By supporting the HGSA's proposal for an MBS item number for genetic counsellors, all sides of politics will play a vital role to improve access to genomic health services for all Australians."

Media contact:

Mathew Langdon, Mathew.langdon@londonagency.com.au, 0400 645 779