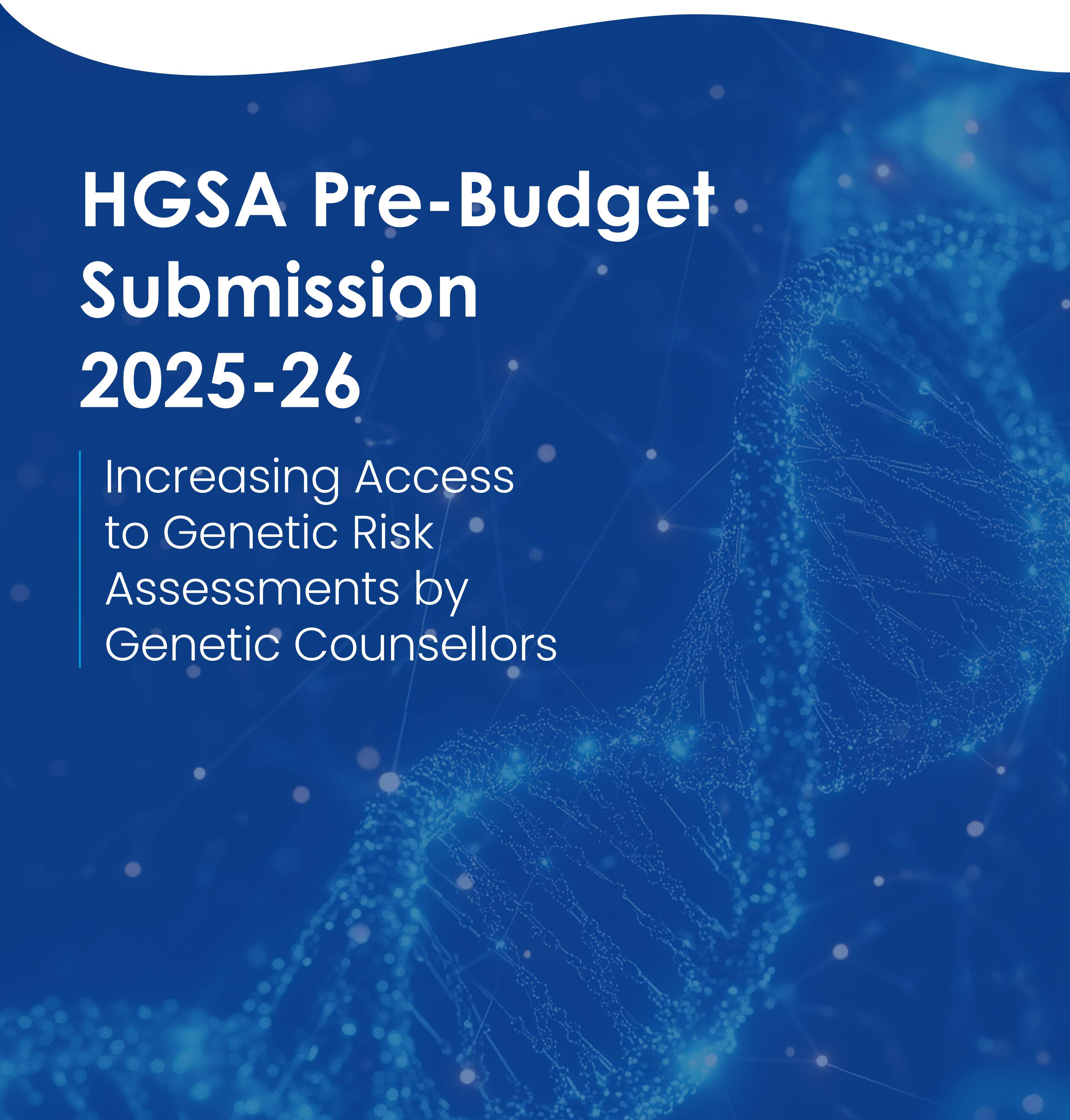
HUMAN GENETICS SOCIETY OF AUSTRALASIA

... making sense of your genes



HGSA Pre-Budget Submission 2025-26

Increasing Access to Genetic Risk Assessments by Genetic Counsellors

CONTENTS

1. EXECUTIVE SUMMARY

1.1 Proposal

The Human Genetics Society of Australasia (HGSA) seeks government commitment to establish access to affordable community based genetic risk assessments and support provided by Genetic Counsellors through the Medicare Benefits Schedule (MBS).

1.2 The HGSA is the peak professional body representing health and scientific professionals delivering genetic health services across Australia and Aotearoa New Zealand. The HGSA currently represents over 1400 members, including around 500 Genetic Counsellors.

> ***The HGSA's Vision is to support "equitable access to excellence in genetic health care across the lifespan".***

1.3 Genetic Counsellors are Masters degree qualified allied health professionals. Currently most genetic counselling occurs within clinical genetics services in tertiary level public hospitals. This network is already overwhelmed, with wait times up to 36 months. There are currently more genetic counsellors than funded positions, with up to 45 new genetic counsellors graduating each year.

Genetic testing is increasingly being performed in the community (outside the hospital setting) through general practitioners and other specialists. The introduction of a MBS item number for genetic counselling offers a community-based model of care, supporting patients and clinicians. Genetic counselling can also be delivered via telehealth, providing increased access for people living in rural and remote areas, where waiting times are often the longest.

1.4 Reason for Proposal

Genetic and genomic medicine has advanced significantly in the past decade and provides promise for earlier identification of health issues, targeted treatment options, and clarification of future health risks. With the continuing expansion of MBS funded genetic testing for large population groups, such as reproductive genetic carrier screening, cancer risk screening, and genetic testing to support precision medicine in cancer care, the demand for genetic counselling will continue to increase.

Increasing access to community based genetic counselling services will complement the Australian Government's commitment to genomic medicine through the Medical Research Future Fund (MRFF), the establishment of Genomics Australia, and the increased support for genetic testing through the MBS.

Ensuring that genetic counselling is readily accessible to support community based genetic testing is an integral component to the safe and appropriate uptake of genomic medicine and is consistent with the National Health Genomics Policy Framework.

1.5 Cost Effectiveness

Economic analysis has demonstrated that for every $1 invested in genetic counselling, there is $2.50 gained in health, social and economic benefits. This proposal seeks funding for up to 20% of genetic counselling services to be delivered through a MBS funded model with the cost over the forward estimates being up to $40 million (Table 1).

	2025-26	2026-27	2027-28	2028-29	4YR TOTAL
PROJECTED COST TO MBS	$9.80M	$9.99M	$10.18M	$10.38M	$40.36M

Table 1. Health economic analysis performed by Econisis

2. ISSUE

The Australian government has increased access to genetic testing through Medicare and, consistent with best practice, has often recommended or required that genetic counselling is provided either prior to testing or to support result interpretation.

Most genetic counsellors work within or in association with tertiary level public hospitals, as a member of a multidisciplinary clinical genetics service. This is an appropriate model of care for complex health concerns, and people with critical health needs that need to be addressed urgently.

Genetic testing included on the MBS is now being offered to healthy individuals without any prior health concerns, to determine if they or their family members have an increased risk of developing certain conditions. Reproductive genetic carrier screening, for example, is occurring in community settings via general practitioners and other medical specialists. However, there are very limited referral pathways to receive expert genetic advice following the receipt of an increased risk result. The options include being referred to a public hospital clinical genetics service (where wait lists may be up to 36 months); or seeking private genetic counselling with an associated out of pocket cost, which is not subsidised by Medicare or private health insurance.

2.1 Workforce

Australia has a stable workforce of genetic counsellors. While demand for services is high, this is due to the limited number of funded positions, not the limited number of genetic counsellors. There are up to 45 new graduates in genetic counselling each year, but there are not 45 new funded positions each year. Approximately one third of the 630 Australian trained genetic counsellors are not working in a clinical setting.[1] Across the genetics workforce, around one third of genetic health professionals are on temporary contracts; and one third are also working in more than one job (ie. two or more part time positions).[2]

Genetic counsellors are certified and regulated by the HGSA as a member of National Alliance of Self-Regulating Health Professions (NASRHP) which includes a detailed scope of practice, complaints framework and requirements on continuing professional development. In the past 12 months the HGSA has seen a record number of submissions for advanced credentialling (Fellowship of Human Genetics Society of Australasia qualification) from genetic counsellors, with almost 400 genetic counsellors now on the HGSA-Register.

[1] Kanga-Paraiba A. et al. Genetic counseling workforce diversity, inclusion and capacity in Australia and New Zealand. *Genetics in Medicine Open* 2024 (7 May 2024) https://doi.org/10.1016/j.gimo.2024.101848

[2] Kanga-Paraiba A. et al. Genetic counseling workforce diversity, inclusion and capacity in Australia and New Zealand. *Genetics in Medicine Open* 2024 (7 May 2024) https://doi.org/10.1016/j.gimo.2024.101848

2.2 Model of Care

A MBS item for genetic counselling is considered the most appropriate model of care to complement MBS listed genetic tests. Other Models considered included:

Model	Comment
Additional funding of hospital based genetics services	• Requires local negotiation and risks inequity of access due to varying arrangements across states and territories. • Many Clinical Genetics services consider referrals for population screening out of scope. • IHACPA review of genetics services has been delayed. • Genetics consultations are more expensive ($1066 per consultation) that the proposed genetic counselling MBS item.
Specialist Training Positions	More relevant to rare disease care than population screening, will not support GP or community implementation.
Rare Disease Centres	Important multidisciplinary clinics focussed on people with undiagnosed rare diseases, not healthy people in the community learning about genetic risk (eg WA RARE Care established at $10 million per centre).
Block Funding	Providers must meet certain requirements to be eligible for ongoing funding which is difficult for genetic counsellors to demonstrate when only seeing each individual once or twice.
Bundled Services	This approach can span across multiple providers in multiple settings and would require significant co-ordination and local negotiation.
Private Health Insurance	Drives further inequity as not everyone can afford private health insurance.

2.3 Benefits of Proposed Model

Genetic counselling outside of the public hospital system and embedded in the community has the potential to:

- Support safe and effective implementation of MBS listed genetic testing through improved support of clinicians and patients.
- Improve outcomes associated with genetic testing by guiding appropriate use of MBS listed tests and identifying family implications.
- Increase access to genetic counselling.
- Increase employment opportunities for genetic counsellors.
- Reduce pressure on hospital based genetic services.
- Provide a community based model of care, including integration with general practitioners and other specialists, keeping healthy people out of the hospital system.
- Support improved access across state and territory borders, including rural and remote settings, by delivering telehealth services, which are not linked to a state based system.

> ***“The most valuable thing for me with having genetic counselling was having someone who was able to explain everything to me in great detail and being able to tell me what the next steps were. Things I wasn’t able to google on my own. I found it really beneficial in my journey.”***
> *- Georgina Bellette*

3. POLICY CONTEXT

3.1 Genomics Australia

On Friday 15 November 2024, the Minister for Health and Aged Care announced the establishment of Genomics Australia from 1 July 2025. The Expert Advisory Group (EAG) for Genomics Australia recommended that Genomics Australia should deliver a cohesive national approach to the implementation of genomics into healthcare through coordination and collaboration with the aim of delivering better health outcomes for all Australians. The EAG also recommended that "A person-, family-, and community-centred approach will underpin all of Genomics Australia's activities."

3.2 National Health Genomics Policy Framework (2018-2021)

In addition to supporting the EAG objective for Genomics Australia, providing genetic counselling and genetic risk assessments in a community setting also aligns with key priorities in National Health Genomics Policy Framework:

Priority 1.1 Improve support for individuals and their families to make informed choices about genomic testing and take responsibility for those choices and related risks.

Priority 1.5 Identify barriers to equity of access and develop a national approach to address these, noting that access is multi-dimensional and includes location, cost, availability and appropriateness (including cultural acceptability). This includes, but is not limited to:

- exploring barriers to the uptake of genomic services including the potential for discrimination (life insurance, employment, lifestyle, access to services); and
- evaluating the delivery of genomic services in terms of being accessible, appropriate and culturally secure and responsive for Aboriginal and Torres Strait Islander peoples.

2.2 Build capacity for, and promote access to a skilled and literate genomics workforce through workforce strategies and planning at a national level.

3.3 National Preventative Health Strategy 2021-2030

The National Preventive Health Strategy aims to enhance the focus on preventive medicine to improve the health and wellbeing of all Australians at all stages of life. This strategy encourages greater integration of preventative medicine techniques, such as genetic information to reduce the overall burden of disease and reduce health inequities. The strategy emphasises that all sectors have a role of play in the implementation of preventative medicine, which includes governments, local health service providers, private providers and industry.

> ***Genetic risk assessments and genetic counselling in a community setting support the uptake and delivery of preventative health services.***

3. POLICY CONTEXT

3.4 Scope of Practice Review

The Australian Government's Strengthening Medicare Taskforce Report explored critical areas for government action to redesign primary care as the core of an effective, modern health system. In October 2024 the final report of the "Unleashing the Potential of our Health Workforce: Scope of Practice Review" was published with recommendations for how innovative workforce models can be developed, and supported to evolve and respond to changing community need.

The Scope of Practice Review articulates that barriers to health professionals working to full scope of practice contribute to workforce shortages, which are more profound in rural and remote settings. The key barrier to integrating genetic counsellors into community health services, including multidisciplinary teams, is the lack of a funding mechanism for their services, outside of user-pays all. Genetic counsellors currently working in community settings report that the cost is prohibitive for many individuals, particularly for those in rural and remote settings, and first-nation peoples.

The continued expansion of genetic testing via the MBS without the required support for individuals to act on these results, may lead to adverse medical outcomes and the risk that people make irreversible health decisions due to being ill informed, for example, risk reducing surgery or termination of pregnancy.

Integrating genetic counsellors into community care by enabling a funding model outside of the tertiary hospital setting, could help mitigate these risks by increasing access to services in the primary care setting for all people, regardless of where they live. This model could support clinicians and patients, and will also provide an appropriate and responsive care pathway for people with a future genetic risk, rather than waiting to be seen in the tertiary referral hospital setting, where critically ill patients will always be prioritised.

3.5 MRAC Submission

The HGSA made a submission to the MBS Review Advisory Committee (MRAC) in 2021. In November 2022, the final MRAC report agreed that there is a need for increased access to genetic risk assessments and genetic counselling.

The report also acknowledged the value of genetic counselling and the expectation that needs and demands will increase as genetic testing becomes more available. However, MRAC did not support the establishment of a Medicare Benefit for genetic counselling following this initial submission, and the HGSA was encouraged to work with the Department of Health and Aged Care to progress this initiative.

3.6 Response to MRAC Comments

HGSA has taken steps to address concerns raised by MRAC. HGSA has continued to consult widely with government, other professional bodies, and patient support groups to ensure this proposal addresses the needs of patients and clinicians, while incorporating feedback from MRAC.

MRAC raised concerns about "low value referrals". To ensure that genetic counselling is made available appropriately through the MBS, the HGSA supports limiting MBS funded genetic counselling services to services delivered following a referral from a health professional.

MRAC also noted the need to consider a whole of system response. HGSA supports the consideration of other models of care, however, increasing access to community based genetic counselling will need to be funded separately to hospital based genetic counselling services. The HGSA also commissioned health economic modelling (see Attachment 1) to understand the current and future demand for genetic counselling services and risk assessments. This work also clarifies the financial impact to the MBS.

4. ECONOMIC MODELLING

4.1 Economic Modelling: Demand, Cost and Forward Estimates

The demand for genetic testing is increasing. Health economic modelling has informed estimates of the likely growth of the uptake of genetic testing and the demand for genetic counsellors.

Econisis modelled Baseline, Trend and Growth scenarios. The 'Trend Scenario' applies the growth increase between 2011 to 2017 to continue to 2046. This assumes that the growth in genetic testing demand will continue to grow at the same rate. This scenario predicts a demand for 1,688,196 tests in 2046.

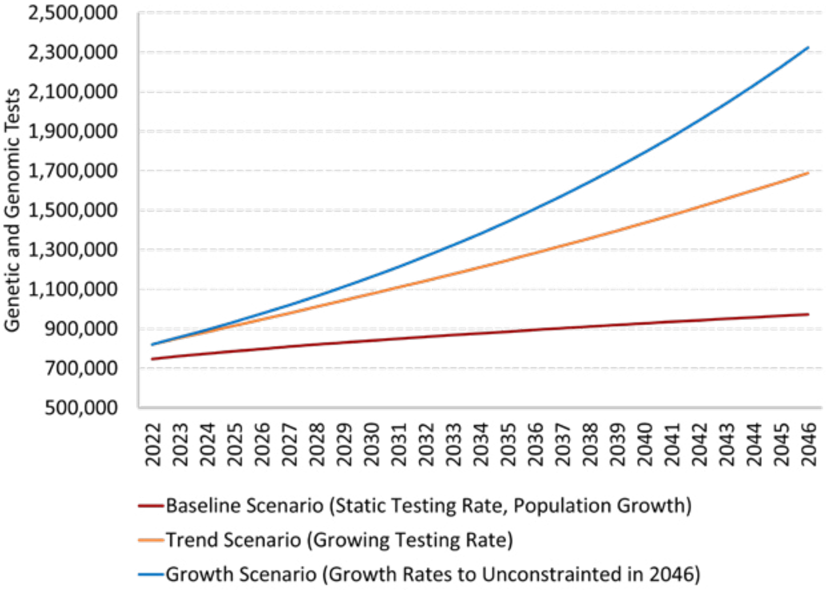


Figure 1. Estimated Demand for Genetic and Genomic Testing, 2022 to 2046

Not all genetic tests involve engaging a genetic counsellor to interpret the results. It is estimated that at present, 8.5% of genetic tests involve engaging a genetic counsellor. To ensure a conservative assessment, a share of 10% was applied to Trend scenario genetic testing demand to find genetic counselling demand.

This resulted in a demand for genetic counselling of 263,968 sessions in 2046 under the Trend Scenario (or 60% growth over the next 20+ years)

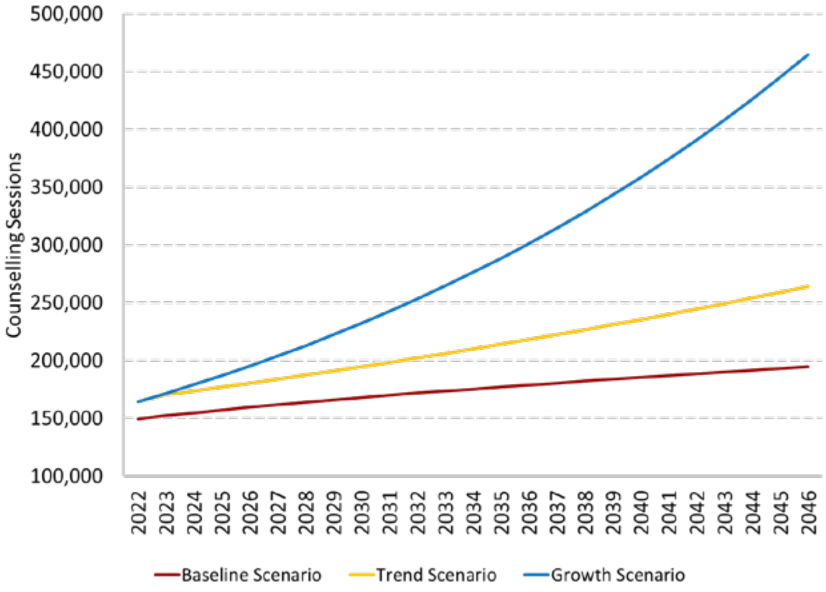


Figure 2. Estimated Demand for Genetic Counselling, 2022 to 2046

4. ECONOMIC MODELLING

Testing and counselling demand, based on the Trend Scenario, over the next 4 years is outlined in the table below. Additionally, cost estimates to the MBS have been provided based on an upper limit of a MBS item covering 20% of all genetic counselling sessions. This is as follows:

	2025-26	2026-27	2027-28	2028-29	4YR TOTAL
Estimated no. tests	915,250	946,782	978,657	1,010,868	3,851,551
Estimated genetic counselling demand*	177,149	180,545	184,007	187,535	729,236
Projected cost to MBS# Assumes 20% of all genetic counselling sessions are provided via MBS.	$9.80M	$9.99M	$10.18M	$10.38M	$40.36M

*Source, economic modelling by Econisis commissioned by HGSA. Figures are based on an assumption that genetic counsellors will only see around 10% of people who have a genetic test and of these, around 80% of cases will still be seen in the public health system.

#Unit price adjusted for increase in CPI 2021- 2024 = $276.70 per session (MRAC proposal was $236 per session).

Note that genetic counselling is likely to occur over one or two consultations. Each consultation is around 45 – 60 minutes patient contact but requires around 4 hours of genetic counsellor time for preparation, appointment and follow up.

Econisis has calculated that for every $1 spent on genetic counselling via the MBS there will be $2.53 in health, social and economic benefits gained over a 20-year period. Based on a 20% share of genetic counselling sessions linked to the proposed MBS item, this represents a net present value at 7% discount rate over 20 years of $202m. This is approximately one fifth of the present value of the benefits of the genetic counselling sector, estimated at over $1b over 20 years.

5. CONCLUSION

Establishing a MBS item number to support access to community based genetic counselling provides a cost effective strategy to support the safe implementation of preventative genomic health care in a community setting and improve the effectiveness of preventable genomic interventions.

> ***"We should be giving the genetic counsellors a separate Medicare number and just embedding them into the process so that we're making sure people have access to quality information in a timely fashion."***
> *- Carolyn Pearce*

> ***"[Genetic Counsellors] know the pathways, they know who to refer to, and they know who to be in touch with. Knowledge is power."***
> *- Carolyn Pearce*

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