ECONISIS

GENETIC COUNSELLING IN AUSTRALIA:

COST BENEFIT ANALYSIS OF MEDICARE LISTING

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EXECUTIVE SUMMARY

Introduction

- The Human Genetics Society of Australasia (HGSA) has made an application for a medical item number for genetic counselling.
- This has gone through the Medicare Review Advisory Committee (MRAC) and is currently with the Genomics and Health and Technology Assessment Policy Branch of the Federal Department of Health and Aged Care and the Minister for Health and Aged Care.
- 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.
- The main reasons people see a genetic counsellor are to be informed about potential genetic conditions when planning a family, to investigate family history of cancer or other health conditions.
- Econisis has modelled three different demand scenarios for genetic testing. This was based on data from AIHW Health Genetics/Genomics Survey 2017.[1]

Figure 1 Genetic Testing Scenarios

- Based on the Trend Scenario representing the medium series of need for genetic counselling, this indicates the potential for growth of 60% in annual demand for genetic counselling services by 2046.
- Econisis has applied a cost benefit analysis (CBA) methodology to assessing the benefits to the community of adding genetic counselling to the Medicare Benefits Schedule. A CBA is the most commonly used, and most comprehensive, of the economic evaluation techniques. CBAs are an effective impact analysis method as they allow long-term costs and benefits associated with an investment, converting future values into a present value for ease of comparison.
- It is estimated that adding genetic counselling to the Medicare Benefits Schedule would generate approximately $1.671b in benefits for patients, the community and the economy in present value terms at a 7% discount rate over 20 years for *all* genetic counselling activity. This includes:
  - $433.58m in Specialist Advice and Access benefits ($32.17m in year 1)
  - $425.08m in Delayed Treatment Economic and Social Impact savings ($31.54m in year 1), and

[1] AIHW (2019) Health Genomics Survey 2017. Accessed at https://www.health.gov.au/sites/default/files/documents/2022/03/national-stocktake-of-genetics-and-genomics-testing-and-activities-key-findings.pdf

- $813.17m in Premature Deaths Human Capital Value savings ($61.50m in year 1)

- This translates to a Benefit Cost Ratio (ratio of benefits to costs) of 2.53 at all discount rates. This means that that for every $1 spent on genetic counselling by the Government and the patient, over 20 years will generate $2.53 in benefits above and beyond that which would be secured in the absence of the Medicare funding.

Table 1 Results Summary Table

Summary	Nominal ($2024)	4%	7%	10%
Costs	$1,252.9	$847.2	$660.6	$532.8
Benefits	$3,171.0	$2,144.1	$1,671.8	$1,348.4
NPV	***$1,918.1***	***$1,297.0***	***$1,011.3***	***$815.6***
BCR	***2.53***	***2.53***	***2.53***	***2.53***

- Sensitivity testing was also undertaken to ensure that these results were robust to different assumptions and demand scenarios.
- In particular, if *Medicare coverage is 20% of total genetic counselling activity within Australia, this would equate to a Net Present Value of $202m over 20 years and a Benefit Cost Ratio of 2.53 at 7%.*
- Overall, including genetic counselling as a Medicare item would increase the number of users of the service and reduce wait times faster. This is expected to improve genetic advice and support access, reduce health-related impacts of treatment delay and even reduce premature deaths.
- The cost benefit analysis confirms that the proposed inclusion of genetic counselling as a Medicare item represent a value for money proposition for the Australia Government, resulting in significant economic and social benefits for patients, the health system, society and the economy.

1 INTRODUCTION

This section provides an overview of the background, purpose and scope of the report.

1.1 Background and Context

The Human Genetics Society of Australasia (HGSA) has made an application for a medical item number for genetic counselling. This has gone through the Medicare Review Advisory Committee (MRAC) and is currently with the Genomics and Health and Technology Assessment Policy Branch of the Federal Department of Health and Aged Care and the Minister for Health and Aged Care. To support this process, Econisis has prepared a cost benefit analysis to demonstrate the economic and social benefits of genetic counselling generally and the impact that access cost improvements through Medicare would have on the uptake of the service and its wider use.

1.2 About the HGSA

The Human Genetics Society of Australasia (HGSA) was formed in 1977 as an incorporated association in South Australia to provide a forum for the various disciplines collected under the title of Human Genetics. The Society contributes to all major debates and advocates for the safe, ethical and effective use of genetic information in healthcare. The HGSA is regularly called upon as the expert body to contribute to national and international initiatives that involve human genetics.[2]

The HGSA Strategic Plan 2023-2026 covers strategies and actions under 4 broad goals. The four goals are:

1. Deliver membership care, growth and engagement
2. Provide expert leadership, advice and advocacy
3. Promote inclusivity and cultural safety across the Society
4. Ensure the quality of Australasian genetic professionals through provision of educational opportunities and regulation of practices.

1.3 Report Purpose and Structure

Econisis was engaged to prepare a NSW compliant Cost Benefit Analysis and Economic Impact Assessment. This cost benefit analysis will estimate the impact of genetic counselling to support the HGSA's application for genetic counselling to be listed on the Medicare Benefits Schedule.

This report is comprised of the following key sections:

- **Introduction** - This section provides an overview of the report, its purpose and structure.
- **Background and Context of Genetic Counselling** – This section explains the role of genetic counsellors in health care, the benefits they provide, and describes the genetic counselling workforce in Australia and New Zealand.
- **Estimates of Demand for Genetic Counselling**– This section outlines the estimates of demand for genetic counselling through to 2046.
- **Cost Benefit Analysis -** This section provides the methodology, assumptions, and summary of the results of the CBA.
- **Conclusions and Findings –** This section summarises the findings and outcomes of the analysis.

[2] HGSA (2024) Our Society. Accessed at https://www.hgsa.org.au/Web/Web/About/Our-Society-2024.aspx?hkey=51a2c40c-11a4-4e18-b832-4a24d1f70a81

1.4 Glossary and Abbreviations

The following table outlines key terms and abbreviations used throughout this report.

Table 2 Glossary and Abbreviations

Term/Abbreviation	Definition
$m	Millions of dollars
ABS	Australian Bureau of Statistics
AIHW	Australian Institute of Health and Welfare
ASGC	Australasian Society of Genetic Counsellors
ATAP	Australian Transport Assessment and Planning
BCR	Benefit Cost Ratio
CBA	Cost Benefit Analysis
EIA	Economic Impact Assessment
EOI	Expression of Interest
FTE	Full Time Equivalent
GP	General Practitioner
GVA	Gross Value Added
HGSA	Human Genetics Society of Australasia
LGA	Local Government Area
MRAC	Medicare Review Advisory Committee
NPV	Net Present Value
NSW	New South Wales
RACGP	Royal Australian College of General Practitioners

1.5 Limitations

This report assessment has been undertaken for the specific purpose of informing the inclusion of genetic counselling as part of the Medicare Benefit Schedule by the Australian Government. All information, projections and estimates within this report relates specifically to this matter.

That these projections and estimates have been developed by Econisis in good faith based on data and information available at the time of the assessment and utilising information available. No independent validation of input data sets have been undertaken and all information included as inputs into the analysis are assumed to be correct and accurate.

Note that at the time of this report the latest Australian Health Genetics/ Genomics Survey was conducted in 2017. This was the third and latest surveys conducted for Royal College of Pathologists of Australasia, for the Australian Government Department of Health and released in 2018/19.

2 BACKGROUND AND CONTEXT OF GENETIC COUNSELLING

This section explains the role of genetic counsellors in health care, the benefits they provide, and describes the genetic counselling workforce in Australia and New Zealand.

2.1 What is Genetic Counselling?

Genetic counsellors interpret genetic test results, providing support and information about the results. Genetic tests can tell an individual whether they have inherited genetic conditions which may put them at a higher risk of developing a condition, and which they may pass on when they have children. Genetic testing is often done by people planning or already expecting to have a child, but it is also beneficial for any person to learn more about their genetics. Knowledge that they are at a higher risk of a certain condition can help the person take preventative measures to reduce their risk.

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.[3]

This process integrates the following:

- **Interpretation** of family and medical histories to assess the chance of disease occurrence or recurrence.
- **Education** about the natural history of the condition, inheritance pattern, testing, management, prevention, support resources and research.
- **Counselling** to promote informed choices in view of risk assessment, family goals, ethical and religious values.
- **Support** to encourage the best possible adjustment to the disorder in an affected family member and/or to the risk of recurrence of that disorder.[4]

The main reasons people see a genetic counsellor are to be informed about potential genetic conditions when planning for a family, to investigate family history of cancer or another genetic condition.

2.2 Policy Context

2.2.1 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."

2.2.2 National Health Genomics Policy Framework

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:

[3] ASGC (2024) Definition of Genetic Counselling. Accessed at https://asgc.org.au/ASGC/ASGC/About/Definition-of-Genetic-Counselling.aspx

[4] As above.

- 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.

2.2.3 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.

2.3 Genetic Counsellors in Australia and New Zealand

Australia has approximately 630 genetic counsellors, 493 of which are members of the HGSA.[5] In order to practice as a genetic counsellor, individuals must first attain a recognized Master's degree, then practice as an Associate. Following at least two years of supervised practice and successful passing of assessment set by the HGSA Board of Censors for Genetic Counselling, an individual can then be certified as a Fellow of the Human Genetics Society of Australasia (FHGSA). The HGSA is the regulatory body of the profession of Genetic Counsellors in accordance with the standards set by the National Alliance of Self-Regulating Health Professions.

Most genetic counsellors practice in public or private hospital settings, but roles in private ambulatory care, genomic diagnostic laboratories, industry, and in academia (teaching and research) are becoming increasingly common. Both public and private healthcare services are available in Australia and New Zealand. Genetic services are offered through the public health system in all states and territories. In the public system, genetic testing is paid for by the State Governments when the test is deemed clinically appropriate in accordance with relevant diagnostic evidence and/or national and international guidelines. When seeing a genetic counsellor in private practice the patient pays the full “out of pocket” cost of the consultation and (often) the test [6]

2.4 Trends in Genetic Testing

Many genetic tests are carried out each year in Australia for a multitude of reasons, including parentage tests, criminal proceedings, and health. The latter is the type of tests that genetic counsellors help their patients interpret. In 2016/17, 73 Australian laboratories conducted 660,150

[5] HGSA (2023) A census of the Australasian Professional Genetic Workforce 2022-2023. Accessed at https://hgsa.org.au/Web/Web/HP-Resources/Australasian-Professional-Genetic-Workforce-Census-Reports.aspx?hkey=017a67b0-87d0-4cf2-b655-84b2715642f9
[6] Ormond et al. (2018) Genetic counseling globally: where are we now? Accessed at https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5947883/

genetic/genomic tests. Around half of these laboratories are public, with 27% being private, and 16% being research labs.[7]

The data found that 1,181,923 tests were reported in that year. These comprised 660,150 genetic/genomic tests, 146,719 maternal serum screening test, 307,770 newborn bloodspot screening tests, and 67,284 biochemical genetic diagnostic testing. This was an increase of 22% from the number of genetic tests in 2011.

Data from the 2017 survey has formed the basis of genetic testing projection scenarios with adjustments to 2022/23.

Direct-to-consumer genetic testing is a new market in the last two decades which has skyrocketed in popularity. People use these tests to find out about their ancestry and/or health conditions. Although these results are delivered directly to the consumer, many consumers may seek a genetic counsellor to interpret the results professionally for them. This ease of access has massively changed the demand and landscape of genetic testing. This has and will continue to increase demand for genetic counsellors, putting pressure on the current workforce.

There are many Medicare Benefit Scheme funded genetic tests in Australia that attract different fees. There are tests for cancer risk, cardiac risk, deafness, undiagnosed childhood diseases, many of which attract an MBS rebate.

As of November 2023, 3 additional tests were added to the MBS relating to genetic tests for people planning pregnancy or already expecting. The three tests which are available for bulk-billing are for cystic fibrosis, spinal muscular atrophy, and fragile X syndrome.[8]

	prepair 3	*prepair* 500+	*prepair* 1000+
What is covered?	Cystic fibrosis (CF), fragile X syndrome (FXS), spinal muscular atrophy (SMA)	*prepair* 3 & additional 500+ gene test. Screens for a wider range of genetic conditions	*prepair* 3 & additional 1000+ gene test. The most comprehensive option that looks at over 1000 genes associated with 750 conditions
How much does it cost?	**Bulk billed** if Medicare eligible. *Non-Medicare $389*	$975/ couple if Medicare eligible for *prepair* 3. *Non-Medicare $1364*	$1500/ couple if Medicare eligible for *prepair* 3. *Non-Medicare $1889*
Who is tested?	**Biological female** usually screened first. Male reproductive partner only screened if female is a carrier for CF or SMA*	**Both biological parents** screened together (couple based test)*	**Both biological parents** screened together (couple based test)*
How long does it take?	2-3 weeks^	6-8 weeks^	6-8 weeks^

Figure 2 Example of Medicare Covered for Pregnancy Genetic Testing[9]

[7] RCPA (2019) Australian Health Genetics/Genomics Survey 2017 Report of Key Findings to Department of Health. Accessed at https://www.health.gov.au/sites/default/files/documents/2022/03/national-stocktake-of-genetics-and-genomics-testing-and-activities-key-findings.pdf

[8] Queensland Fertility Group (2023) New Medicare rebates for Genetic Carrier screening. Accessed at https://www.qfg.com.au/about-us/media-releases/new-medicare-rebates-for-genetic-carrier-screening#:~:text=Written%20by-,Queensland%20Fertility%20Group,along%20with%20their%20reproductive%20partners.

[9] VCGS (2023) Medicare rebates for genetic carrier screening. Accessed at https://www.vcgs.org.au/prepair-medicare/

New research has found that financial barriers are contributing to disparities in equal access for prenatal testing for common genetic conditions, such as Down syndrome. Led by Monash University, the study surveyed healthcare professionals providing Non-Invasive PreNatal Testing (NIPT) – including obstetricians, GPs, midwives, and genetic specialists – and found substantial variation in prenatal screening, with healthcare professionals reporting ongoing challenges in providing equitable access and pretest counselling. While most recommend NIPT to their pregnant patients, the findings show that out-of-pocket costs are the number one (94.1%) barrier to accessing the tests.

NIPT is not currently covered by Medicare, with patients required to pay $400–500 out of pocket to access the test. First offered in Australia in 2012, healthcare providers have reported concerns with the financial barriers to access NIPT – typically the most expensive prenatal screening test and the only one not subsidised by Medicare[10].

This highlights the sensitivity of patients to genetic related services to cost factors.

2.5 Challenges facing Genetic Counselling

A 2015 paper on the NSW genetic counselling field can be used to draw parallels with Australia and New Zealand as a whole. The paper identified several challenges facing genetic counsellors now and into the future: [11]

- ***The impact of new technologies –*** new technologies such as next generation DNA testing are making genetic testing more widely available, cheaper and faster. This makes the genetic counselling process more complex because there are more available tests with more complex results to interpret. This can lead to incidental findings and results of uncertain significance.
- ***Changing clinical paradigm to meet increasing demand –*** due to DNA testing becoming cheaper, demand is continuing to increase for professionals who can interpret those results. This increases pressure on the genetic counselling workforce. The paper concludes that “while employment settings are currently largely in the public sector, private sector employment opportunities could enable growth of the Australian genetic counsellor workforce.”
- ***Challenges related to building the workforce –*** such as limited places in the 2 available Master’s programs, limited clinical placement opportunities, and limited employment opportunities. There is also a lack of diversity in the profession, with 95% being women and an under-representation of ethnic and racial minorities.[12]

In a 2023 HGSA survey of 195 genetic counsellors in Australia and New Zealand, 95% thought that demand for genetic health professionals had increased in the past 5 years and 90% thought there was currently a shortage in the profession. 99% think demand will continue to increase in the next 5 years, with 63% thinking the genetics workforce will not meet this increase in demand.[13]

2.6 Benefits of Genetic Counselling

Genetic counselling outside of the public hospital system has the potential to:

- Support safe and effective implementation of MBS listed genetic testing through improved support of clinicians and patients.

[10] RACGP (2024) Cost a major factor for missed genetic testing during pregnancy accessed at https://www1.racgp.org.au/newsgp/clinical/cost-a-major-factor-for-missed-genetic-testing-dur citing Johnston, M et al Disparities in integrating non-invasive prenatal testing into antenatal healthcare in Australia: a survey of healthcare professionals, BMC Pregnancy and Childbirth accessed at https://bmcpregnancychildbirth.biomedcentral.com/articles/10.1186/s12884-024-06565-1
[11] Sax Institute (2015) The NSW Genetic Counselling Workforce. Accessed at https://www.saxinstitute.org.au/wp-content/uploads/The-NSW-Genetic-Counselling-Workforce_June2016.pdf
[12] Further discussion of the gender imbalance can be found at Badman, S (2021) Gender imbalance in the genetic counselling profession: an Australasian perspective.
[13] HGSA (2023) A census of the Australasian Professional Genetic Workforce 2022-2023. Accessed at https://hgsa.org.au/Web/Web/HP-Resources/Australasian-Professional-Genetic-Workforce-Census-Reports.aspx?hkey=017a67b0-87d0-4cf2-b655-84b2715642f9

- 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 of 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.

These benefits have been considered as part of the Cost Benefit Analysis.

2.7 Implications

Genetic testing is beneficial for people planning or expecting a child or looking to investigate their genetic risk of certain conditions such as cancer. Genetic counsellors are needed to interpret these genetic test results and provide support to people. Early detection of increased risk of conditions can be highly beneficial in preventing the conditions from developing.

Over recent decades genetic testing has become significantly more affordable and available, with developments such as direct to consumer genetic testing. Genetic counsellors are often needed to interpret these results.

Currently, there are 630 trained genetic counsellors across Australia and New Zealand, with entry to the profession requiring a Master's degree that is only offered at 2 Australian universities. There is currently a shortage in clinically practicing genetic counsellors due to a shortage of positions funded. It is estimated that a third of the genetic health professional workforce is on temporary contracts; and that of the 630 trained genetic counsellors, there are only around 400 working in clinical practice. Up to 45 new genetic counsellors graduate each year, but there are not 30 - 40 new positions. There is a sense of high demand and limited workforce, but there is capacity in the system.

Genetic counselling is publicly funded in New Zealand and widely available. In Australia, only certain genetic tests are funded by Medicare and genetic counselling is not included in the fee, despite being recommended in the item descriptor. If it were to be available through Medicare, more people would access the service and be able to find out if they have an inherited genetic risk for conditions such as cancer or find out which conditions they are likely to pass on to their future children.

This knowledge is highly beneficial in preventing and treating health conditions. It follows a preventative health model where people can prevent health issues from occurring rather than treating after the fact.

3 ESTIMATING DEMAND FOR GENETIC COUNSELLING

This section outlines the estimates of demand for genetic counselling through to 2046. These results are used to inform a cost benefit analysis of adding of a new genetic counselling consultation item on the Medicare Benefits Schedule.

This section includes:

- Overview of need modelling method and approach
- Outline of projections of demand for genetic testing scenarios
- Scenario testing of genetic counselling need in Australia.

3.1 Method and Approach

Econisis has adopted a dual approach to assessing demand for genetic testing and through that, genetic counselling services.

This has entailed the use of historical testing rates and growth rates for genetic and genomic testing in Australia and the application of these rates to the future population of Australia based on ABS population projections[14]. This has provided a "bottom up" basis for the projections of need.

This has then been compared with a "top down" approach which has examined long-term health condition data sets through the Australian Bureau of Statistics, by 10 year age groups and applied genetic shares of incidences by diagnostic group to provide an estimate of the total potential "unconstrained" demand for genetic testing and thereby counselling services in Australia.

Figure 3 Genetic Testing Scenarios

These two approaches in combination form the basis for three scenarios of *genetic testing need* namely:

- **Baseline Scenario** – maintenance of 2016/17 testing rates per population group forward with growth in line with projected population growth rates.
- **Trend Scenario** – continuation of growth rates of testing per population group
- **Growth Scenario** – transition of growth from trend scenario in 2022 to unconstrained testing in 2046.

These genetic testing scenarios form the basis of demand analysis for genetic counselling. Estimates of current genetic counselling capacity is assessed and used as the basis of counselling shares of

[14] ABS (2024) Population Projections, Australia Medium Series accessed at https://www.abs.gov.au/statistics/people/population/population-projections-australia

future genetic testing support, and this is applied to the three different genetic testing scenarios to provide estimates of genetic counselling demand in Australia into the future.

3.2 Genetic Testing Demand

Econisis has modelled three different demand scenarios for genetic testing.

The first 'Baseline' scenario applies the ratio of genetic tests to population in 2017 to the population as it grows to 2046. This results in a constant growth in genetic and genomic tests proportionate to population growth. This results in a demand for 973,247 tests in 2046.

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 results in a demand for 1,688,196 tests in 2046.

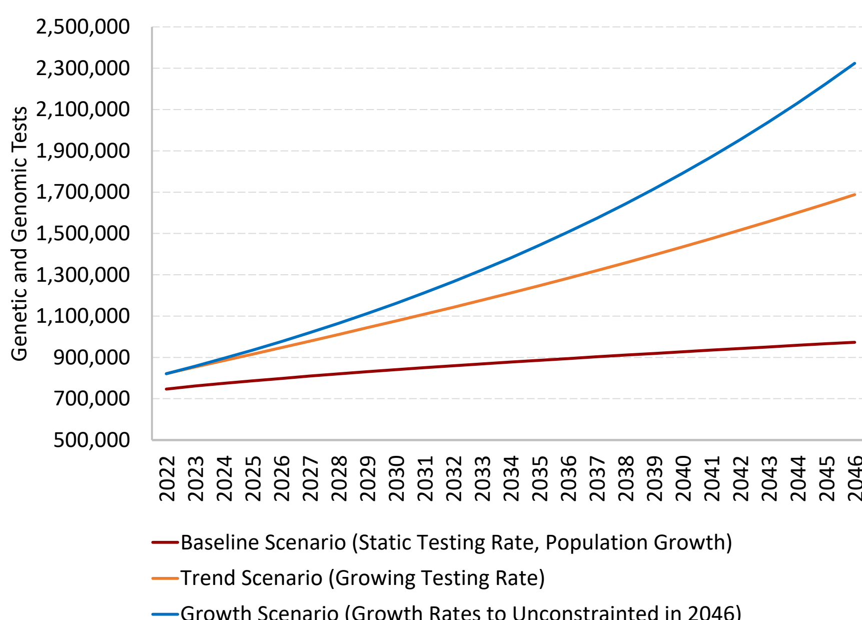

Figure 4 Estimated Demand for Genetic and Genomic Testing, 2022 to 2046

The 'Growth Scenario' is a scenario where every person with an underlying genetic condition gets tested and receives genetic counselling. The percentage of the population with chronic conditions was found for each age group. The proportion of each condition that is genetic was applied to this, which was then applied to the projected population of Australia in 2046. A growth rate was applied that would see the current testing numbers increase to this unconstrained demand. This results in a demand for 2,323,851 tests by 2046.

The Trend Scenario is likely the most accurate and defensible. Demand for genetic testing has increased significantly faster than population growth in the past two decades as technology has significantly improved and preventative health methods have become more popular. However, the Growth Scenario is also possible and represents an upside risk for demand.

Refer to Appendix A for further details on testing projections.

3.3 Genetic Counselling Demand

Not all genetic tests involve engaging a genetic counsellor to interpret the results. To estimate the share of tests that do, the number of tests done by genetic counsellors in Australia was estimated. The number of genetic counsellors in Australasia working in clinical practice was 432 in 2022.[15] This

[15] Kanga-Parabia et, al. (2024) Genetic counseling workforce diversity, inclusion, and capacity in Australia and New Zealand.

equated to approximately 346 FTEs, of which 93.9% worked in Australia. This resulted in an estimated 325 FTE genetic counsellors.

It was assumed that each of these counsellors saw 9 clients per week and worked 48 weeks per year. This is in line with industry expectations on genetic counsellor capacity. Applying these assumptions resulted in genetic counsellors seeing an estimated 140,192 client sessions.

Assuming that each genetic test results in a pre- and post-test meeting with a genetic counsellor, this means that 8.5% of genetic tests currently involve engaging a genetic counsellor.

Since it was assumed that 8.5% of genetic tests involve engaging a genetic counsellor, a share of 10% was applied to genetic testing demand to find genetic counselling demand. This was applied the three genetic testing need scenarios outlined above.

This resulted in a demand for genetic counselling of:

- 194,649 sessions in 2046 under the Baseline Scenario (+30% on 2022)
- 263,968 sessions in 2046 under the Trend Scenario (+60%) and
- 464,770 sessions in 2046 under the Growth Scenario (+183%)

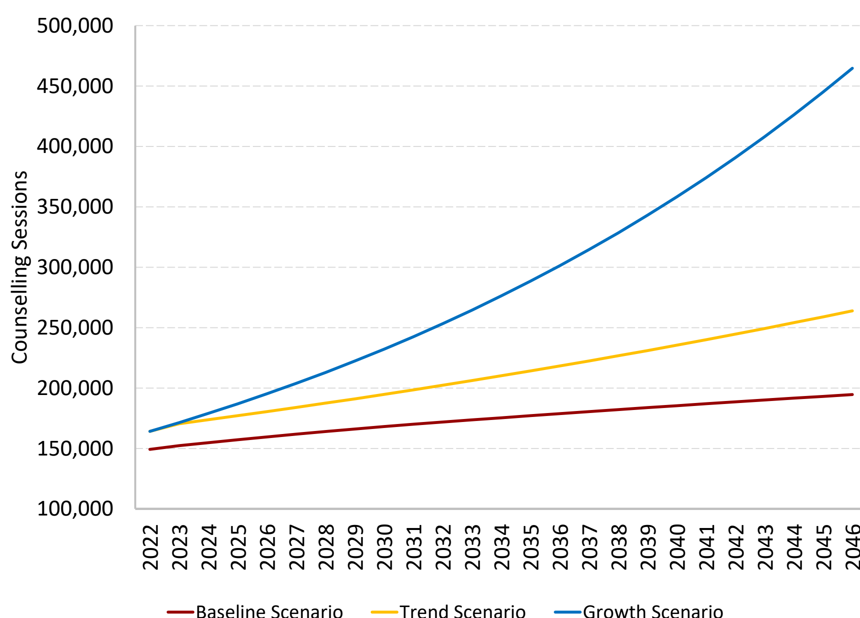

Figure 5 Estimated Demand for Genetic Counselling, 2022 to 2046

Based on the Trend Scenario representing the medium series of need for genetic counselling, this indicates the potential for growth of 60% in annual demand for genetic counselling services to 2046. This assumes that genetic counselling share of testing support is maintained at levels comparable to current services.

4 COST BENEFIT ANALYSIS

This section provides a summary of the methodology, assumptions, fiscal and financial costs, behavioural response-based benefits and results of the cost benefit analysis of the proposed scheduling of genetic counselling as a Medicare item. This includes:

- An outline of the method adopted with associated assumptions;
- A profiling of the assessed mix of behavioural responses and benefits;
- A summary of the results of the CBA for the core scenario (based on the Trend demand profile); and
- An examination of the results of sensitivity testing.

4.1 Method

Econisis has applied a cost benefit analysis (CBA) methodology to assessing the benefits to the community of adding genetic counselling to the Medicare Benefits Schedule. A CBA is the most commonly used, and most comprehensive, of the economic evaluation techniques. CBAs are an effective impact analysis method as they allow long-term costs and benefits associated with an investment, converting future values into a present value for ease of comparison.

The CBA steps include:

- Identify the quantifiable benefits that can be monetised
- Calculate the value (in monetary terms) of the quantified incremental benefits and capital costs in net present value (NPV) terms using the discount rates;
- Calculate the benefit cost ratio (BCR) – the total present value of all net benefits compared to the present value of capital costs to determine the ratio to which incremental net benefits exceed (or undershoot) incremental costs related with the upgrade; and
- Undertake a sensitivity testing assessment.

4.1.1 Discount Rates

Discounting is the reverse of adding (or compounding) interest. It reduces the monetary value of future costs and benefits back to a common time dimension – the base date. Discounting satisfies the view that people prefer immediate benefits over future benefits (social time preference), and it also enables the opportunity cost to be reflected (opportunity cost of capital).

Recognising the potential for multiple audiences for the business cases, a real discount rate of 4%, 7% and 10% has been applied. This complies with recommendations set by the Australian Government Department of Prime Minister and Cabinet Office of Impact Analysis CBA Guidance Note[16].

Modelling of quantifiable benefits and costs are developed over a 20-year timeframe (post initial year).

4.1.2 Comparison with the Base Case

For these assessments, the analysis is based on the net additional benefits and costs above and beyond the base case. NPVs and BCRs generated as part of the Cost Benefit Analysis are reflective of the net additional increase in economic and social benefits and costs from project.

[16] OIA (2023) Cost benefit Analysis accessed at https://oia.pmc.gov.au/resources/guidance-assessing-impacts/cost-benefit-analysis#:~:text=In%20impact%20analysis%2C%20CBA%20is,losses%20for%20all%20people%20affected.

4.2 Fee and Benefit Payable Costs

For the purpose of this assessment, the core scenario is based on the total cost of a counselling session in line with the proposed Medicare schedule fee of $276.70. This reflects the total cost to the economy and community and not the cost solely incurred by Government through the payment of the 75% or 85% benefit share (note 85% is covered by a sensitivity test).

This was then applied to the number of counselling sessions under the Trend demand scenario in the previous section. This resulted in costs of the service increasing from $49.02m in 2024/25 (in $2024) to $59.27m a year in 2035 and $71.67m a year in 2045.

These figures as well as the 85% benefit equivalent are outlined in the table below.

Table 3 Annual Fee and Benefit Payment (85%) Costs, Trend Scenario

	2025	2035	2045
Total Cost (Fees)	$49.02	$59.27	$71.67
Benefit Payment Only (85%)	$41.66	$50.38	$60.92

Note that this covers *all* genetic counselling services as per the demand scenario. The majority of demand is and will continue to be met by State-based public services. However, for the purposes of this assessment, the cost of all services has been included in the core scenario with a 20% scenario included as a sensitivity test.

4.3 Behavioural Responses and Benefits

Three behavioural responses to the project being implemented have been identified and assessed as part of the CBA. These represent different ways that patients/clients of genetic counselling, now and into the future will respond to the project compared to a base case.

These responses include:

- **Specialist Advice and Access** – it is assumed that the vast majority of patients (97.5%) would otherwise receive general advice and referrals from a GP or other generalist medical practitioner if genetic counselling services were not available through Medicare. This is effectively a proxy for a number of sub-responses to the scheduling of the service including:
  - **Travel cost savings** – patients would otherwise need to travel into inner metropolitan areas to access existing limited public funded genetic counselling support offered by each State, thereby incurring a travel-based cost impost in line with the Australian Transport Assessment Panel road transport travel costs parameters[17].
  - **Medical Specialist/Professional Advice** – it is regarded that the quality and applicability of counselling advice provided by a genetic counsellor would be superior to that of GP in the specific share of cases/sessions (i.e. 10%) allocated to genetic counselling. This is measured through a notional difference between GP and Specialist Medical Professional hourly remuneration rates as previous reflected in research undertaken by the Royal Australian College of General Practitioners (RACGP)[18]. This is used as a specialist medical professional productivity value proxy suitable. This has been applied to a 2-hour appointment duration to ensure conservative results.

  In this case, the Medical Specialist/Professional Advice as it was deemed more appropriate to apply at a national level. However, if a State or local based response was being analysed,

[17] ATAP (2024) Parameter Values – Road Transport accessed at https://www.atap.gov.au/parameter-values/index. Adjusted to 2024 dollars by CPI.
[18] RACP (2014) Does Remuneration Matter accessed at https://www.racgp.org.au/afp/2014/april/does-remuneration-matter. Adjusted to 2024 dollars by CPI.

travel cost savings proxies may be more appropriate or at least should be considered as part of this patient behavioural response.

- **Delayed or incomplete treatment -based response** – this represents a small minority of patients (2.4%) who, due to the lack of Medicare funded access to specialist genetic counselling support, will experience a delay in diagnosis and subsequent treatment or management of their genetic based medical conditions. This is in line with the results of the Patient Experiences Survey by the ABS in 2022/23 which highlighted that 10.5% of people delayed accessing medical specialists due to direct and indirect costs[19]. This rate increases based on socio-economic status and regional and remote residential status but has been applied consistently across Australia.

  Such delays and foregoing of treatment raises the potential for a deterioration in long-term health outcomes and be reflected in reduced capacity to contribute to and participate in the local economy and community. This value is reflected in a 5% reduction in the average worker productivity within Australia[20], applied only to the year of treatment to ensure the results are conservative.

- **Premature death-based response** – a very small minority of patients (0.1%) may forego treatment entirely due to the lack of accessible treatment in the local catchment and therefore experience a premature death. This is valued based on ATAP parameter values using human capital approach which values a human life lost at $3.4m (adjusted for inflation to $2023/24). Note that only part of this cost can be associated with non-treatment with other factors expected to contribute more significantly, such as environmental and lifestyle factors and genetic predisposition to being diagnosed. Based on this, a 5% attribution rate is applied specifically to account for the non-treatment linked to genetic counselling impacts.

4.3.1 Trend Demand Scenario

For the core scenario in this cost benefit analysis, the Trend demand scenario for genetic counselling has been applied. Sensitivity testing using Baseline and Growth Scenarios have been included for reference.

The costs and benefits are being assessed in the first instance based on 100% of genetic counselling demand being met, reflecting the total value of the sector.

4.4 CBA Results

4.4.1 Economic and Social Benefits

Based on this, it is estimated that adding genetic counselling to the Medicare Benefits Schedule will generate approximately $1.671b in benefits for patients, the community and the economy in present value terms at a 7% discount rate over 20 years. This includes:

- $433.58m in Specialist Advice and Access benefits ($32.17m in the year 1)
- $425.08m in Delayed Treatment economic and social impact savings ($31.54m in year 1), and
- $813.17m in Premature Deaths human capital value savings ($61.50m in year 1)

[19] ABS (2024) Patient Experiences 2022/23 accessed at https://www.abs.gov.au/statistics/health/health-services/patient-experiences/2022-23
[20] ID (2024) Economy ID – Worker Productivity Total Industries, Australia accessed at https://economy.id.com.au/

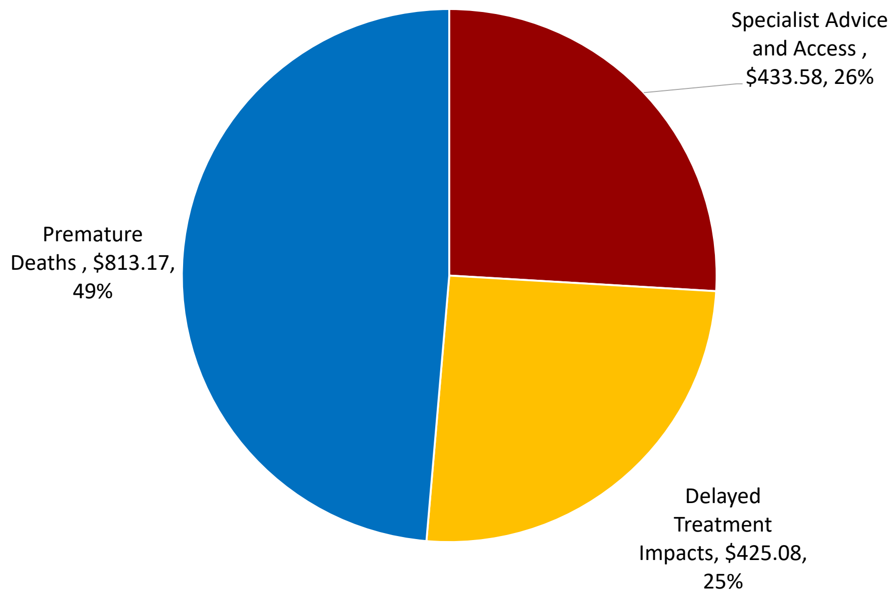

Figure 6 Present Value of Benefits ($m), by Benefit Type, 20 year assessment, 7% Discount Rate

4.4.2 Net Present Value and Benefit Cost Ratio

Comparing this to the present value Medicare Fee schedule costs, this results in a net present value (benefits minus costs) ranging from $1.297b at the 4% discount rate to $815.6m at the 10% discount rate. Any value above $0 means the present value for benefits exceeds that of costs.

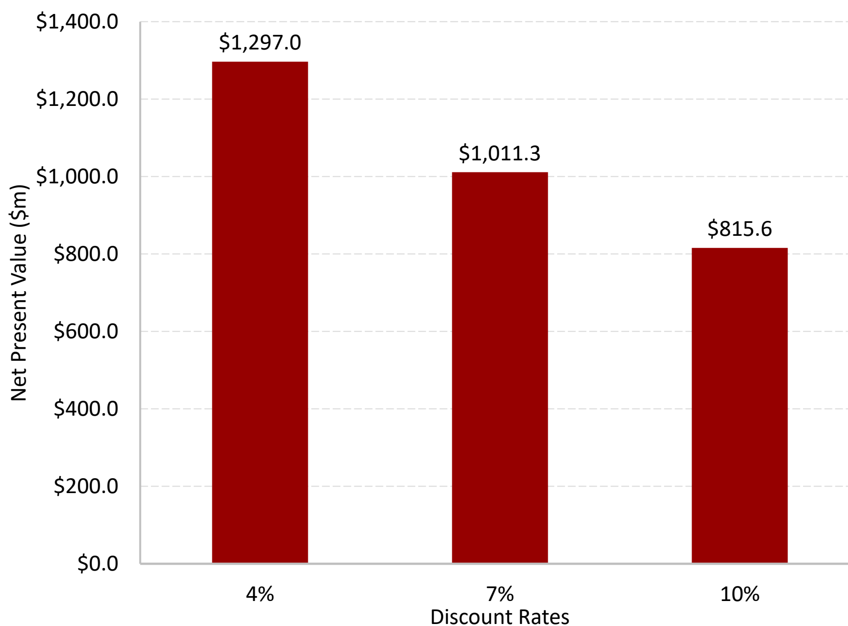

Figure 7 Net Present Value, by Discount Rate

This translates to a Benefit Cost Ratio (ratio of benefits to costs) of 2.53 at all discount rates. This means that that for every $1 spent on genetic counselling by the Government and the patient, over 20 years will generate $2.53 in benefits above and beyond that which would be secured in the absence of the Medicare funding.

Table 4 Results Summary Table

Summary ($m)	Nominal ($2024)	4%	7%	10%
Costs	$1,252.9	$847.2	$660.6	$532.8
Benefits	$3,171.0	$2,144.1	$1,671.8	$1,348.4
NPV	**$1,918.1**	**$1,297.0**	**$1,011.3**	**$815.6**
BCR	**2.53**	**2.53**	**2.53**	**2.53**

Again, any result above 1.0 means the present value of benefits exceeds costs. State and national Treasury departments typically seek BCRs that exceed 2.0 as this, along with the application of discount rates, provides further buffer regard the uncertainty of future benefits realising and supports the overall investment suitability and value for money of the project.

4.5 Sensitivity Analysis

4.5.1 Defining the Tests

A CBA methodology is required to test the sensitivity of the results to changes in key variables. In this instance, the following variables have been tested.

- Test 1 – application of core assumptions to Baseline counselling demand scenarios.
- Test 2 – application of core assumptions to Growth counselling demand scenarios.
- Test 3 – review of analysis excluding the Premature Deaths benefit
- Test 4 – costs based on 85% benefit payable of the total scheduled fee
- Test 5 – estimate based on 20% of services being delivered by private counselling funded by Medicare

As costs and benefits move proportionally in line with overall demand levels, focus has principally been afforded to analysing the size of the Net Present Value for all of the sensitivity tests in the first instance, with select analysis of discrete Benefit Cost Ratio impacts for Tests 3 and 4.

4.5.2 Net Present Value Impacts

Overall, the sensitivity tests 1 and 2 reflect the impact of more conservative and bullish genetic counselling demand on net present value estimates. The application of Baseline demand under Test 1 results in a 16.4% reduction in the NPV against the core scenario. However under the Growth demand scenario in Test 2, the NPV increases by 30.6%. This shows the broad range in which the net present value of the Medicare funding will be applied, based on the trajectory of growth of testing and therefore counselling demand.

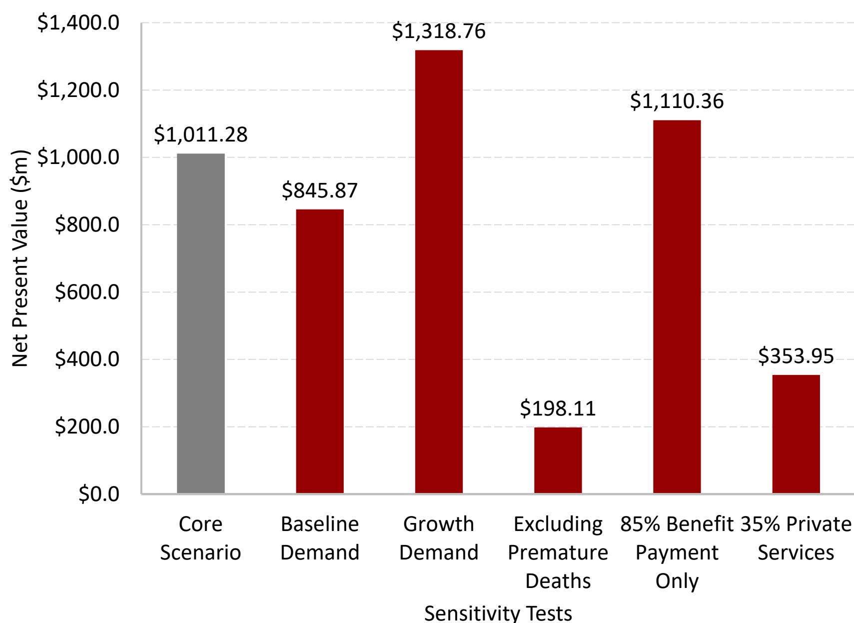

Figure 8 Net Present Values, Core Scenario and Sensitivity Tests, 7% Discount Rate

Test 3, in which premature deaths are excluded from the behavioural response based benefit profile, the Net Present Value falls by 80.4%. However it remains positive, meaning even if this benefit is excluded and only less severe impacts are considered, the value for money remains positive.

Test 4 demonstrates that if only the maximum payable benefit value of 85% of the total fee is applied as a proxy for the Australian Government's fiscal exposure, this increases the net present value by 9.8%.

Test 5 provides an estimate of the impact if only 35% of demand is considered, as a proxy for the private share of genetic counselling services. This revealed a cost of $17.16m in Year 1 and a Net Present Value over 20 years at 7% discount rate of $353.95m.

Overall, with the exception of Test 3 and 5, the results of the sensitivity testing on the net present value of the project are broadly consistent and show a high degree of resilience of the results to movements in the core assumptions of the analysis.

4.5.3 Benefit Cost Ratio Impacts

As highlighted above, changes in demand do not impact the Benefit Cost Ratio of the project as costs and benefits are both linked to the underlying demand profile. As such, the BCRs under Tests 1, 2 and 5 remain at 2.53 across all discount rates.

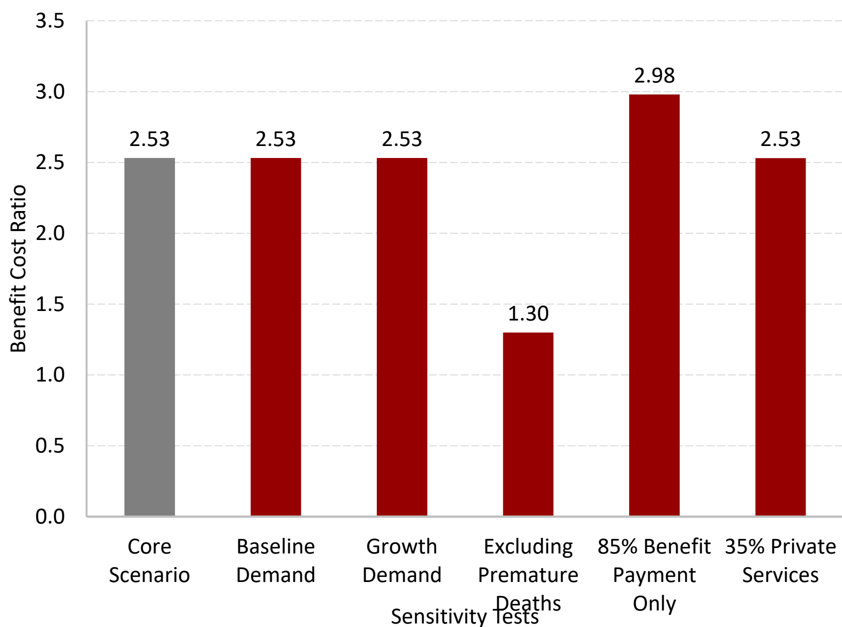

Figure 9 Benefit Cost Ratios, Core Scenario and Sensitivity Tests, 7% Discount Rate

However, for Test 3, the removal of premature death benefits and impacts has the effect of reducing the BCR to 1.30. This is an effective halving in the BCR, though it remains above 1.0, highlighting the resilience of the value for money.

In contrast, when the costs are adjusted to the 85% benefit payment threshold as a proxy for the Australian Government's fiscal exposure in line with investment principles, the BCR increases to 2.98. It should also be noted that if the 75% benefit payment threshold is applied, then the results would be even stronger.

This highlights the fact that if a fiscal, rather than whole of economy approach to costs is adopted a more escalated BCR is achieved. This reinforces the conservative and defensible nature of the Core Scenario in the CBA.

5 CONCLUSIONS

This section summarises the findings and conclusions of the report.

5.1 Summary of Findings

Econisis has estimated the future demand for genetic counselling through to 2046. Three scenarios were estimated. A baseline scenario maintained current testing rates applied to population growth, a trend scenario applied current growth rates of testing, and a growth scenario applied unconstrained growth based on population need for testing.

The estimated demand for genetic counselling is:

- 194,649 sessions in 2046 under the Baseline Scenario (+30% on 2022)
- 263,968 sessions in 2046 under the Trend Scenario (+60%) and
- 464,770 sessions in 2046 under the Growth Scenario (+183%)

The Trend Scenario was used to undertake a Cost Benefit Analysis of providing genetic counselling in the Medicare Benefits Schedule. It was estimated that funding *all* genetic counselling will generate approximately $1.671b in benefits for patients, the community and the economy in present value terms at a 7% discount rate over 20 years. This includes:

- $433.58m in Specialist Advice and Access benefits ($32.17m in the year 1)
- $425.08m in Delayed Treatment economic and social impact savings ($31.54m in year 1), and
- $813.17m in Premature Deaths human capital value savings ($61.50m in year 1)

This translates to a Benefit Cost Ratio (ratio of benefits to costs) of 2.53 at all discount rates. This means that that for every $1 spent on genetic counselling by the Government and the patient, over 20 years will generate $2.53 in benefits above and beyond that which would be secured in the absence of the Medicare funding.

Table 5 Results Summary Table

Summary ($m)	Nominal ($2024)	4%	7%	10%
Costs	$1,252.9	$847.2	$660.6	$532.8
Benefits	$3,171.0	$2,144.1	$1,671.8	$1,348.4
NPV	**$1,918.1**	**$1,297.0**	**$1,011.3**	**$815.6**
BCR	**2.53**	**2.53**	**2.53**	**2.53**

Sensitivity testing was also undertaken to ensure that these results were robust to different assumptions and demand scenarios.

In particular, if Medicare coverage is 20% of total genetic counselling activity within Australia, this would equate to a net present value at 7% of $202m over 20 years.

Overall, including genetic counselling as a Medicare item would increase the number of users of the service and reduce wait times faster. This is expected to improve genetic advice and support access, reduce health-related impacts of treatment delay and even reduce premature deaths.

The cost benefit analysis confirms that the proposed inclusion of genetic counselling as a Medicare item represent a value for money proposition for the Australia Government, resulting in significant economic and social benefits for patients, the health system, society and the economy.

APPENDIX A – GENETIC TESTING DEMAND SCENARIOS

Table 6 Projection Scenarios of Genetic Testing Demand, Australia, 2022 to 2046

Year	Baseline Scenario	Trend Scenario	Growth Scenario
2022	746,575	820,946	820,946
2023	761,565	853,487	857,321
2024	774,090	884,157	895,308
2025	786,237	915,250	934,978
2026	798,023	946,782	976,406
2027	809,371	978,657	1,019,669
2028	820,283	1,010,868	1,064,849
2029	830,759	1,043,409	1,112,031
2030	840,766	1,076,224	1,161,304
2031	850,328	1,109,334	1,212,760
2032	859,397	1,142,662	1,266,496
2033	868,321	1,176,665	1,322,612
2034	877,107	1,211,360	1,381,216
2035	885,763	1,246,770	1,442,415
2036	894,298	1,282,920	1,506,327
2037	902,711	1,319,818	1,573,070
2038	911,007	1,357,487	1,642,771
2039	919,192	1,395,946	1,715,560
2040	927,267	1,435,209	1,791,574
2041	935,229	1,475,287	1,870,957
2042	943,076	1,516,190	1,953,856
2043	950,804	1,557,924	2,040,429
2044	958,410	1,600,498	2,130,838
2045	965,893	1,643,920	2,225,253
2046	973,247	1,688,196	2,323,851

Table 7 Projection Scenarios of Genetic Counselling Session Demand, Australia, 2022 to 2046

Year	Baseline Scenario	Trend Scenario	Growth Scenario
2022	149,315	164,189	164,189
2023	152,313	170,546	171,464
2024	154,818	173,816	179,062
2025	157,247	177,149	186,996
2026	159,605	180,545	195,281
2027	161,874	184,007	203,934
2028	164,057	187,535	212,970
2029	166,152	191,131	222,406
2030	168,153	194,796	232,261
2031	170,066	198,531	242,552
2032	171,879	202,337	253,299
2033	173,664	206,217	264,522

Year	Baseline Scenario	Trend Scenario	Growth Scenario
2034	175,421	210,171	276,243
2035	177,153	214,201	288,483
2036	178,860	218,308	301,265
2037	180,542	222,493	314,614
2038	182,201	226,759	328,554
2039	183,838	231,107	343,112
2040	185,453	235,539	358,315
2041	187,046	240,055	374,191
2042	188,615	244,658	390,771
2043	190,161	249,349	408,086
2044	191,682	254,130	426,168
2045	193,179	259,002	445,051
2046	194,649	263,968	464,770

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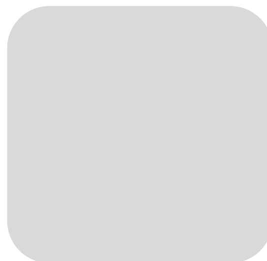

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