



# **MBS Review Advisory Committee**

## **Genetic Counselling**

Final Report

November 2022

## **IMPORTANT NOTES**

1. This report does not constitute the final position on these items, which is subject to:
  - consideration by the Minister for Health and Aged Care, and
  - the Government.
2. Following consultation with stakeholders, the working group developed the views and recommendations in this report for consideration by the Medicare Benefits Schedule Review Advisory Committee (MRAC).
3. Should MRAC have any eliminations, amendments or commentary from the report presented by the working group, they will be captured in boxed comments in the body of the report, as follows:

[Working Group] Recommendation [#] – MRAC advice and rationale

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## Summary

Genetic counselling is recognised as an integral part of supporting patients and their biological relatives when under investigation for medical conditions where there is an established genetic risk factor. Currently, most government-funded professional genetic counselling services in Australia are provided by activity-based or block-funded clinical genetics services operating within metropolitan tertiary public hospitals. The proposal from the Human Genetics Society of Australasia (HGSA) seeks to increase access to clinical genetic services and professional genetic counselling through the addition of new genetic counselling consultation items on the Medicare Benefits Schedule (MBS).

### Medicare Benefits Schedule Continuous Review

The MBS Continuous Review involves the ongoing review of Medicare items and services by experts and is supported by the MBS Review Advisory Committee (MRAC). The Committee's role is to provide independent clinical, professional and consumer advice to Government about:

- opportunities to improve patient outcomes in instances where a health technology assessment by the Medical Services Advisory Committee is not appropriate
- the safety and efficacy of existing MBS items
- implemented changes to the MBS, to monitor benefits and address unintended consequences.

The Genetic Counselling Working Group (GCWG) was established as a subgroup of the MRAC to review and advise on the HGSA proposal.

### GCWG assessment of main issues

The GCWG considered the proposal in line with the PICO framework (population, intervention, comparator, outcomes):

- Population: people who require genetic counselling
- Intervention: an MBS item for genetic counselling
- Comparator: public genetics service that offer comprehensive testing, diagnosis, and counselling at, usually, large healthcare centres or hospitals that are funded by states or territories
- Outcomes: unclear and not well identified.

After reviewing the proposal and through committee meetings, the GCWG considered that the evidence presented indicated a need for increased access to genetic counselling services. The current limited availability of qualified genetic counsellors is a contributor to long waiting times for patients in public clinics (reported as being one week for pregnant women, four weeks for urgent matters and up to nine months for non-urgent matters). These are anticipated to increase even further as the availability of genetic testing expands.

However:

- The proposal's population was not well defined. The GCWG noted that identifying a priority population that would most benefit from genetic counselling would strengthen the proposal. This would require expert input from genetic counsellors, clinical geneticists, and other specialists. It may also be beneficial to link potential genetic counselling MBS items to the existing eighteen MBS items that recommend genetic counselling in their accompanying explanatory notes, noting that a review of these items could first be undertaken to ensure they represent current best practice and high value care for patients.
- The proposed model is based on a human resource-intensive activity and it is difficult to envisage how it can be provided without significant costs to the patient, which is not the case with the current public model. The GCWG noted that listing genetic counselling MBS items may not improve access for patients and families who may not be able to afford out-of-pocket costs associated with private services.
- Creating MBS items may incentivise the establishment of private genetic counselling clinics, leading to fewer available genetic counsellors in the public sector and driving inequity of access. This may then risk a disconnect between private clinics who choose to operate outside of current healthcare referral patterns and processes, and primary health care and specialists.
- A multidisciplinary team- (MDT-) based approach is a more preferred model to ensure safe and effective transition of patients between care. However, an MDT model was not presented in the HGSA proposal. It was also noted that there is a paucity of geneticists in the private sector to adequately support an MDT model.
- The proposal did not distinguish between genetic counselling for prognostic versus predictive testing and did not define 'complex' genetic counselling.
- If MBS items were created, genetic counselling may end up being provided as an add-on service, potentially involving inappropriate referrals and leading to 'low-value' counselling, where the patient does not receive any additional valuable advice beyond what they could have received from a general practitioner (GP) or non-GP specialist.
- The financial impact to the MBS is highly uncertain.
- There is a shortage of genetic counsellors and waiting times are 'long', but there are no data available to show the length of waiting times and to what extent having an MBS item will alleviate these problems. There are also no data to predict how the demand for genetic counselling will increase over time.
- More targeted funding of current public sector models could be considered to address unmet need and reduce waiting times.

## Recommendations and actions

The GCWG considered that agreement to create new MBS items and subsequent implementation of MBS items requires a more strategic approach that involves whole-of-system thinking. The original HGSA proposal did not provide this level of detail for implementation.

Therefore, the GCWG does not support the HGSA's proposal for new MBS items for genetic counselling at this time.

The GCWG recommends that a more strategic approach be pursued prior to the creation of MBS items for genetic counselling. This approach may include, but is not limited to, the following actions:

- investigate further the opportunities to revise the funding arrangements for genetic counselling services between the Commonwealth and states and territories.
- clarify the circumstances when genetic counselling should be reimbursed on the MBS
- gather additional evidence that demonstrates how MBS items for genetic counselling could improve health outcomes equitably.

## Acronyms

GCWG	Genetic Counselling Working Group
GP	general practitioner
HGSA	Human Genetics Society of Australasia
IT	information technology
MBS	Medicare Benefits Schedule
MDT	multidisciplinary team
MRAC	MBS Review Advisory Committee
PICO	population, intervention, comparator, outcomes

# Preamble

## Medicare Benefits Schedule Continuous Review

The Medicare Benefits Schedule (MBS) is a list of health professional services (items) that the Australian Government subsidises for health consumers. MBS items provide patient benefits for a wide range of health services including consultations, diagnostic tests, therapies, and operations.

The MBS Continuous Review builds on the work of the MBS Review Taskforce (the Taskforce). From 2015 to 2020, the Taskforce provided the first extensive, line-by-line review of the MBS since its inception in 1984.

In October 2020, the Australian Government committed to establishing a continuous review framework for the MBS, consistent with recommendations from the MBS Review Taskforce Final Report.

Established in 2021, the MBS Continuous Review allows for ongoing rigorous and comprehensive reviews of Medicare items and services by experts, on a continuous basis, to ensure that the MBS works for patients and supports health professionals to provide high-quality care.

## Medicare Benefits Schedule Review Advisory Committee

The MBS Continuous Review is supported by the MBS Review Advisory Committee (MRAC). The Committee's role is to provide independent clinical, professional and consumer advice to Government on:

- opportunities to improve patient outcomes in instances where a health technology assessment by the Medical Services Advisory Committee is not appropriate
- the safety and efficacy of existing MBS items

implemented changes to the MBS, to monitor benefits and address unintended consequences.

MRAC comprises practising clinicians, academics, health system experts and consumer representatives. The current MRAC membership is listed in Table 1.



**Table 1 MBS Review Advisory Committee members, November 2022**

<b>Member</b>	<b>Speciality</b>
<b>Conjoint Professor Anne Duggan (Chair)</b>	Policy and Clinical Advisor / Gastroenterology
<b>Ms Jo Watson (Deputy Chair)</b>	Consumer Representative
<b>Dr Jason Agostino</b>	Indigenous Health
<b>Dr Matt Andrews</b>	Radiology
<b>Professor John Atherton</b>	Cardiology
<b>Professor Wendy Brown</b>	General Surgeon – Upper Gastrointestinal and Bariatric Surgery
<b>Professor Adam Elshaug</b>	Health Services / Systems Research
<b>Ms Margaret Foulds</b>	Psychology
<b>Associate Professor Sally Green</b>	Health Services / Systems Research
<b>Dr Chris Helms</b>	Nurse Practitioner
<b>Professor Harriet Hiscock</b>	Paediatrics
<b>Professor Anthony Lawler</b>	Health Services Administration / Emergency Medicine
<b>Ms Alison Marcus</b>	Consumer Representative
<b>Associate Professor Elizabeth Marles</b>	General Practice / Indigenous Health
<b>Dr Sue Masel</b>	Rural General Practice
<b>Professor Christobel Saunders</b>	General Surgeon – Breast Cancer and Reconstructive Surgery
<b>Associate Professor Ken Sikaris</b>	Pathology
<b>Ms Robyn Stephen</b>	Paediatric Speech Pathology
<b>Associate Professor Angus Turner</b>	Ophthalmology / Rural and Remote Medicine
<b>Professor Christopher Vertullo</b>	Orthopaedic Surgery

## **MBS Continuous Review Guiding Principles**

The following principles guide the deliberations and recommendations of the MBS Continuous Review:

- a) The MBS:
  - is structured to support coordinated care through the health system by:
    - recognising the central role of General Practice in coordinating care; and
    - facilitating communication through General Practice to enable holistic coordinated care.
  - is designed to provide sustainable, high value, evidence-based and appropriate care to the Australian community.

- Item descriptors and explanatory notes are designed to ensure clarity, consistency, and appropriate use by health professionals.
  - promotes equity according to patient need.
  - ensures accountability to the patient and to the Australian community (taxpayer).
  - is continuously evaluated and revised to provide high value health care to the Australian community.
- b) Service providers of the MBS:
- understand the purpose and requirements of the MBS.
  - utilise the MBS for evidence-based care.
  - ensure patients are informed of the benefits, risks, and harms of services and are engaged through shared decision making.
  - utilise decision support tools, Patient Reported Outcome and Experience Measures where available and appropriate.
- c) consumers of the MBS:
- are encouraged to become partners in their own care to the extent they choose.
  - are encouraged to participate in MBS reviews so patient health care needs can be prioritised in design and implementation of MBS items.

The MRAC and its working groups recognise that General Practice is a specialty in its own right. Usage of the term 'General Practice' both within this report and in the MBS itself does not imply that it is not a specialty.

The MRAC notes that the MBS is one of several available approaches to funding health services. The MRAC and its working groups apply a whole-of-healthcare-system approach to its reviews.

### **Government consideration**

If the Australian Government agrees to the implementation of recommendations, this will be communicated through Government announcement.

Information will also be made available on the Department of Health and Aged Care website, including MBS Online, and departmental newsletters.

## Genetic Counselling Working Group

The Genetic Counselling Working Group (GCWG) was established as a subgroup of the MRAC to review and advise the Committee on the Human Genetics Society of Australasia (HGSA) proposal seeking to address the current and increasing need for professional genetic counselling services.

To help consider the proposal, the GCWG invited presentations from the HGSA and from health professionals working in public and private settings.

The GCWG met on five occasions: Friday 25 March 2022, Wednesday 27 April 2022, Tuesday 14 June 2022, Tuesday 26 July 2022 and Tuesday 25 October 2022.

# Summary of the Human Genetics Society of Australasia's proposal

Genetic counselling is a communication process to help people and their families understand, make decisions about, and adapt to their genetic health risks. The definition of genetic counselling developed by the Genetic Counselling Definition Task Force of the National Society of Genetic Counsellors in the United States outlines that genetic counselling is the process of helping people understand and adapt to the medical, psychological, and familial implications of genetic contributions to disease. This process integrates the following:

- interpretation of family and medical histories to assess the chance of disease occurrence or recurrence
- education about inheritance, testing, management, prevention, resources, and research
- counselling to promote informed choices and adaptation to the risk or condition.

Genetic counselling is recognised as an integral part of supporting patients and their biological relatives when under investigation for medical conditions where there is an established genetic risk factor.

Most government-funded professional genetic counselling services are provided by activity-based or block-funded clinical genetics services operating within metropolitan tertiary public hospitals. These services are unable to meet current demand, resulting in increasing waitlists and barriers to accessing clinical genetic services and professional genetic counselling in the public setting.

With the role of genetic testing in clinical practice increasing, mainstream primary care and specialist healthcare providers are bearing the responsibility for facilitating genetic testing and providing genetic counselling. The lack of referral opportunities for patients to receive reimbursed professional genetic counselling outside of activity-based or block funded clinical genetics services does not support the needs of patients and their managing clinicians where genetic testing is being considered by a mainstream primary care or speciality medical practitioner.

The proposal from the Human Genetics Society of Australasia (HGSA) seeks to address the current and increasing need for professional genetic counselling services. The proposed item descriptor for genetic counselling consultations and associated MBS fee are in Table 2.

**Table 2 Proposed MBS item for genetic counselling**

<b>Category 1, Group AXX</b>
<p>Professional attendance by a genetic counsellor in the consulting rooms or health service of the genetic counsellor or by video conference or by telephone following referral of the patient to the genetic counsellor by a medical practitioner OR is a professional attendance for a biological relative of a patient confirmed as harbouring a pathogenic variant responsible for a heritable medical condition, if the attendance is undertaken:</p> <ul style="list-style-type: none"><li>(a) when a genetic/genomic medical condition has been diagnosed or is suspected in a patient or their biological relative; and/or</li><li>(b) when genetic/genomic testing in a patient or their biological relatives is being considered; or</li><li>(c) to deliver and/or discuss the result of genetic/genomic testing in a patient or their biological relatives; and</li><li>(d) includes an assessment of patient or family medical history to determine risk of genetic medical conditions; and</li><li>(e) includes an assessment of eligibility for genetic testing and advice about how to access testing; and</li><li>(f) includes discussion and facilitates understanding of the features, natural history, means of diagnosis, and inheritance pattern of genetic medical conditions; and</li><li>(g) includes non-directive counselling; and</li><li>(h) where relevant and appropriate:<ul style="list-style-type: none"><li>i. facilitates consideration and collection of informed consent for genetic/genomic tests and other diagnostic studies for the genetic medical condition under investigation; and</li><li>ii. facilitates adaptation to the results of genetic/genomic testing; and</li><li>iii. includes discussion of risk management strategies, treatments, and reproductive options for the genetic medical condition.</li></ul></li></ul> <p>(See explanatory note)</p> <p>Fee: \$236.82 Benefit: 75% = \$177.61 85% = \$201.29</p>

The proposal also recommends MBS item numbers for telehealth consulting by genetic counsellors, and genetic counsellors' participation on a multidisciplinary team case conference.

## Consultation and feedback review process

Consultation with relevant and interested organisations, peak bodies, and consumers is considered essential in the formulation of advice to government on recommended changes to MBS items. The MRAC and its working groups seek feedback on their understanding of the existing model of care and issues of consideration, with particular emphasis on any (as yet) unidentified consequences that may result from proposed changes.

All feedback provided via consultation processes is considered.

### Targeted consultation

Sixty-seven relevant stakeholders were approached to provide feedback on the GCWG findings report, during a four-week targeted consultation process closing 15 July 2022. The GCWG considered all feedback received at its fourth meeting on 26 July 2022 and amended the report as necessary.

The GCWG final draft report was presented to the MRAC at its meeting on 5 August 2022. The MRAC provided further comments and endorsed the report for public consultation.

### Public consultation

The GCWG draft final report was published on the Department of Health and Aged Care Consultation Hub for a six-week public consultation between 26 August 2022 and 7 October 2022.

The primary objective of this process was to test the robustness of the GCWG's findings and recommendation.

A total of forty submissions was received during this period. Submissions were received from relevant peak bodies and their individual members.

The GCWG considered all feedback at its fourth meeting on 25 October 2022 and made its final recommendation.

# General response to the proposal

The GCWG considered the HGSA proposal in line with the PICO framework (population, intervention, comparator, outcomes).

## Population

The GCWG agreed that the evidence presented indicated a need for increased access to genetic counselling services. The current limited availability of qualified genetic counsellors is a contributor to long waiting times for patients (reported as being one week for pregnant women, four weeks for urgent matters, and up to nine months for non-urgent matters) in public clinics, which are anticipated to increase even further as the availability of genetic testing expands.

Patients are currently triaged according to need and the service is provided in conjunction with a geneticist when required, to enable test ordering at the time of consultation. Most state and territory services are large and provide access to a range of subspecialist geneticists and genetic counsellors. These services are usually for a large geographical population and provide outreach either physically or via telehealth. Services are based within hospital or health districts and may provide consultative services to other departments and inpatients (e.g. after birth).

The GCWG noted that many conditions are associated with a genetic predisposition. It noted, for example, that coeliac disease, which affects 1 in 100 people, has a recognised genetic predisposition. The GCWG was unable to satisfactorily define the full cohort of patients who should be referred to a genetic counselling service. For many conditions, such as hemochromatosis, a GP or non-GP specialist is qualified to provide genetic counselling.

There are currently eighteen MBS items for genetic testing that recommend genetic counselling be provided to the patient by the specialist treating practitioner, a genetic counselling service or a clinical geneticist on referral. This recommendation is contained within the explanatory note of these MBS items, but is not claiming requirement for benefits to be payable.

The test-related risks of patients and families not accessing appropriate genetic counselling include:

- an incorrect test being ordered
- lack of follow up from an initiating clinician
- where relevant, family members not realising a test result impacts them.

The non-test related risks for patients and families not being able to access genetic counselling include:

- inadequate informed consent (before testing)
- misinterpretation of genetic testing results
- incorrect advice.

The GCWG noted that genetic counselling is amenable to telehealth, as it does not usually require a physical exam (although there may be exceptions).

## Intervention

The HGSA model included a clinical management algorithm (Figure 1 in the proposal). It was noted that several key aspects of the algorithm require clarification:

- 'patient under investigation for medical condition that may have a genetic cause'. The term 'medical conditions' should be defined.
- Medical practitioner refers patient to HGSA-registered counsellor. The type of medical practitioner should be clarified (e.g. GP, non-GP specialist, or both).
- The mechanism of arranging tests before 'post-test genetic counselling' should be clarified.

Although the proposed MBS item numbers may help to address the genetic counselling aspect of the unmet need, it was noted that it did not articulate how it would address the need for more comprehensive genetic testing and counselling services, as currently provided by large public health centres. Other concerns raised were:

- The likelihood that the MBS fee would not be sufficient to cover all costs given the time outside of the actual attendance involved in preparing for counselling (e.g. acquiring relevant history, results and correspondence) as well as overheads including IT services for communications with other clinicians. It was noted that there is a paucity of data to estimate the amounts involved.
- Workforce issues in relation to the number of trained genetic counsellors available and geneticists in the private sector to support the model.
- The implications for workforce shift to the private sector and further adversely affecting the capacity of the public sector to provide services.
- The capacity of the proposal to provide services equitably across the country.
- The logistics of a single practitioner being able to provide expertise across the spectrum of genetic conditions.
- The lack of a detailed description MDT model in the proposal.
- Mechanism(s) to prevent scope creep into low-value care (e.g. where the patient does not receive any additional valuable advice beyond what they could have received from a GP or non-GP specialist).
- The paucity of data to inform costing of the initiative.

These and other risks are further addressed in [Assessment of main issues](#).

## Comparators

The GCWG also considered the pros and cons of any other options to increase access and equity of access to genetic counselling services. They noted the option to maintain the status quo and increase funding to states and territories to meet increasing demands in the public system. This option has the advantages of:

- increasing access by increasing funding to grow the available workforce both for direct patient care and support services



- ensuring equity of access based on need through maintaining a triaged approach (as in the current model), ensuring high-value care through triage and role delineation for services according to population need
- providing improved outreach services through increased resources achieves a more sustainable model of care through integration with the public hospital system
- providing an integrated service to allow both counselling, geneticist review and test ordering at a single visit
- promoting multidisciplinary care
- promoting appropriate communication between non-GP specialists and GPs through existing infrastructure
- maintaining no direct cost implications for consumers.

Other limited options considered were:

- increasing the MBS rebate for genetic testing to include the cost of genetic counselling and make it a requirement of the testing process
- continued provision of non-MBS funded professional genetic counselling services in the private sector as currently occurs to a limited extent.

## Outcomes

The outcomes of the submitted proposal are uncertain. In particular, there are no available data to show current waiting times and usage of genetic counselling services. Without this base information, it is difficult to quantify the current usage of genetic counselling services. Therefore, it is also not possible to predict the increase in demand and the extent to which new MBS item numbers will alleviate current and future capacity issues. Additionally, there are no available data to quantify the flow-on savings in the health system when a genetic counsellor has provided effective intervention.

These and other outcomes are further addressed in [Assessment of main issues](#).

## Assessment of main issues

This proposal has several limitations that restrict its ability to meet the need of more genetics services:

- It only addresses a single component – counselling.
- It does not address the need for integration with a clinical geneticist.
- It risks the professional isolation of genetic counsellors who choose to practice privately without access to medical specialists.
- It is not amenable to the triaged approach that the current model has, to ensure high-value care.
- There are no available data to provide information on usage, cost, and demand for current genetic counselling services.

### Equity of access may decrease, not increase

The proposed model is based on a human resource-intensive activity and it is difficult to envisage how it can be provided without costs to the patient, which is not the case with the current public model.

The MBS was established to create equity of access to the most important health services. It is a funding mechanism to reimburse patients for clinically necessary services.

The GCWG raised concerns that MBS rebates are not enough to sustain a private genetic counselling practice. In a private practice, the income from face-to-face consultation would be required to cover the non-face-to-face tasks that are not normally covered by the MBS, such as:

- research concerning patient history, previous investigations and so on to inform the counselling that is required
- overheads such as a room and/or secretarial support to administer billing and communicate to other clinicians
- insurance
- possibly, in the future, uploading data to My Health Record or a registry.

Therefore, the GCWG noted the proposed fee (\$236.82) could result in large out-of-pocket costs to patients, thus increasing inequity of access. Any increase in costs of genetic counselling limits the service to those who can afford to pay. However, the GCWG accepted that out-of-pocket costs to patients may be unavoidable. The GCWG also noted that creating MBS items for genetic counselling may not improve access to genetic counsellors for all consumers.

However, genetic counsellors note that their profession is not equipment-intensive, allowing them to operate at slightly lower costs than, for example, an interventionalist.

In addition, there are variable levels of health literacy and therefore variation in the amount of work the genetic counsellor will need to do to educate patients so that they

can participate in discussions and make decisions about their health care. Often, patients with very low health literacy are also the same patients who are most at risk and unable to pay for services.

## Impacts on other aspects of the healthcare system

### Services shifted from the public to the private sector

Under the current public sector service model, genetics services offer testing, diagnosis, and counselling at, usually, large healthcare centres or hospitals. A strength of the public model is a triaged system that ensures patients and families with the highest need are provided with counselling services first.

Creating MBS items may incentivise the establishment of private genetic counselling clinics, leading to fewer available genetic counsellors in the public sector, if the genetic counselling workforce is not also increased. This is likely to drive inequity of access, with financial and geographical barriers worsening (see [Equity of access may decrease, not increase](#)).

### Possible disconnect within the healthcare pathway

Private genetic counselling services may be at risk of operating outside current healthcare referral patterns and processes, leading to a lack of coordination between private clinics, and primary health care and specialists. The GCWG queried how information will be effectively coordinated throughout a patient's healthcare journey, as inadequate communication may result in patients falling through the gaps. Ideally, this would be done through electronic healthcare records, but the GCWG acknowledged that these are not yet sufficiently well established in Australia.

The GCWG stressed the importance of the role of GPs and non-GP specialists in genetic counselling. Referral to a genetic counsellor should involve a GP or non-GP specialist as the coordinating point of care. An MDT-based approach, with genetic counsellors working alongside clinical geneticists, GPs, and non-GP specialists, would be required to improve the transition of patients between care. Genetic counsellors in private practice report that they are currently working within MDTs and find this is highly effective. These genetic counsellors consider communication with specialists and other healthcare professionals a part of their role. The GCWG acknowledged this, but also queried if this could be maintained as the number of genetics counsellors and the demand for their services increased.

The GCWG noted that the original proposal did not detail how genetic counselling could be delivered as part of an MDT and considered that further work and consultation are required to determine how this could be achieved.

### Low-value genetic counselling

The GCWG was concerned that if MBS items were created, genetic counselling may end up being provided as an add-on service, potentially involving inappropriate referrals and leading to 'low-value' counselling, where the patient does not receive any additional valuable advice beyond that they could have received from a GP or non-GP specialist.

The GCWG also expressed concern that, in private practice, patients may pressure their doctor for a referral to genetic counsellors when there is no family history, or symptoms or signs to indicate a need for genetic counselling and/or testing.

The breadth of genetic counselling needs to be noted and the risk that a single counsellor in solo practice may be required to address a wide range of conditions. However, many genetic counsellors specialise in a particular area and would refer patients elsewhere if they are not able to offer the support that a particular patient or family required. The GCWG was concerned that this may lead to patients be referred multiple times within the sector to be linked with a counsellor that has the appropriate knowledge base for the patient's specific needs.

### **Uncertain financial impact to the MBS**

The GCWG noted that the financial impact was highly uncertain. Advertising genetic counselling services could provide a competitive advantage for pathology and large medical centres, in addition to public hospitals, and this may lead to a rapid growth in this service. Genetic counselling currently provided by GPs (e.g. taking up prenatal testing) may be shifted to genetic counsellors.

The potential for cost-shifting should be quantified and included as part of the financial evaluation.

Listing genetic counselling services on the MBS would allow for uncapped services. This carries the risk of reduced funding of other programs, including public genetics services.

This risk is inherent to all MBS listings therefore, it is important that MBS items aim to reduce unwarranted clinical variation and low-value care.

## Information gaps and barriers to implementation

The GCWG highlighted the following information gaps.

- The GCWG accepts that there is a shortage of genetic counsellors and that waiting times are 'long', but there are no data available to show the length of waiting times and to what extent having an MBS item will alleviate these problems. There are also no data to predict how the demand for genetic counselling will increase over time.
- The HGSA proposal did not include a clinical management pathway to visit a genetic counsellor and the flow-on effects. It is not clear how a referral pathway and record sharing would work between the public and private sector. It is also not clear how genetic counselling would be integrated into an MDT framework.
- The GCWG noted that having a reliable 'gatekeeper' to reduce leakage and prevent low-value genetic counselling services in the private sector will be challenging. It may be resolved through a carefully worded MBS item descriptor and a detailed Explanatory Note. MBS utilisation data reveals who and where an MBS item is used but does not reveal information about appropriate use and if health outcomes improved.
- The GCWG considered that the MBS item and fee proposed by HGSA may be suitable to break down to multiple MBS items, for example, initial appointment, follow-up appointment and so on. The fee might be too low in that it results in large out-of-pocket costs for patients and families. However, the GCWG considered that out-of-pocket costs may be inevitable. The GCWG also noted that, due to the out-of-pocket costs, access to genetic counselling may not improve for some patients and families.
- It needs to be clear who could request the genetic testing. For simpler conditions, such as haemochromatosis, a GP would be appropriate for requesting genetic testing. However, for more complex conditions, the GCWG proposed that a non-GP specialist may be most appropriate. This means that GPs will need to refer a patient or family to a non-GP specialist before they can access genetic testing. Complex conditions are those that require detailed evaluation of the phenotype, and consideration of secondary (non-genetic) causes (i.e., phenocopies), such as, cardiomyopathies and arrhythmogenic disorders.
- An evaluation of how increased genetic counselling may lead to more appropriate use of resources, to assess its cost-effectiveness, would be helpful (for example, increased genetic counselling could lead to fewer unnecessary colonoscopies). The GCWG considered that audit data from mandatory quality assurance processes (e.g. to comply with the Primary Care Standards) could be used to demonstrate the value of genetic counsellors and how their services improve health outcomes.

## GCWG consideration

After considering MRAC and consultation feedback, the GCWG considered that:

- The proposal's population was not well defined. The GCWG noted that identifying a priority population that would most benefit from genetic counselling would strengthen the proposal. The GCWG considered that this would require expert input from genetic counsellors, clinical geneticists, and other specialists.
- In relation to the previous point, it would be beneficial for decision-making if the proposal identified a model to link potential genetic counselling MBS items to the existing eighteen MBS items that recommend genetic counselling in the explanatory notes, noting that a review of these items could first be undertaken to ensure they represent current best practice and high value care for patients.
- The proposal would benefit from a definition of 'complex conditions'.
- The proposal did not address inequity and possible out-of-pocket costs to patients, and how these could be minimised. Creation of MBS items would allow genetic counsellors to move from a triaged public service to private services, at possible larger costs to patients. The GCWG considered that the proposal would benefit from a model of how the genetic counselling services could be embedded in private services, while still providing high-value and cost-effective care to those who need it most.
- The proposal did not identify a model for genetic counsellors to remain embedded in MDTs if they were established in a private practice.
- The proposal did not distinguish between genetic counselling for prognostic versus predictive testing. The GCWG considered this to be an important distinction.
- An alternative solution could be to increase funding for state and territory public genetic counselling services, to address the shortage of genetic counsellors and long waiting times.

## Recommendations and actions

The GCWG considers that agreement to create new MBS items and subsequent implementation of MBS items requires a more strategic approach that involves whole-of-system thinking. The original HGSA proposal did not provide this level of detail for implementation.

Therefore, the GCWG does not support the HGSA's proposal for new MBS items for genetic counselling at this time.

The GCWG recommends that a more strategic approach be pursued prior to the creation of MBS items for genetic counselling.

The Department advised that broader work is ongoing towards harnessing the potential of genomic and genetic medicine in an efficient, effective, ethical and equitable way for all Australians. This will include further consultations with research and clinical communities and state and territory governments. Future consideration of the HGSA's proposal may be more appropriately considered in the context of this broader work.

### **Investigate the funding arrangements with states and territories**

The GCWG recommends that the relationship and funding arrangements between states/territories and the Australian Government, as set out in the 2020–25 National Health Reform Agreement, be further investigated to explore the most appropriate source/s of increased, dedicated funding for genetic counselling services. The primary care sector may be another important stakeholder to include in such discussions. The GCWG acknowledges the challenges around these relationships and arrangements, and the difficulties in providing additional funding to states and territories.

### **Clarify the circumstances when genetic counselling should be reimbursed on the MBS**

The GCWG recommends that clarification be sought about which current genetic tests should be associated with a genetic counselling consultation. This may include more discussion to clarify the MBS item descriptors and accompanying explanatory notes.

The GCWG also considers that MBS reimbursement may include details about how an MDT may be used. It is likely that a clinician would lead an MDT, and the team would include genetic counsellors, clinical geneticists, and specialists. The GCWG noted that patients are usually not involved in MDT discussions, so clarity about how this would work for genetic counselling is needed.

The current MBS items for MDT arrangements provide MBS benefits for allied health practitioners who are invited to partake in a multidisciplinary case conference by the patient's treating medical practitioner.

However, in contrast to existing MDT arrangements, which the GCWG noted typically involve a case conference between medical and allied health practitioners in the absence of the patient, it is envisaged the adoption of this model for genetic counselling would typically involve the patient.

In its advice to the GCWG, the Department alternatively advised a model akin to the Better Access initiative, under which eligible patients can receive up to ten individual and ten group allied mental health services each year where they have received a mental health plan from their GP, may be appropriate.

Under either the MDT or Better Access initiative models, the initiating clinician would be primarily responsible for discerning when they can directly provide appropriate genetic counselling for their patient (for example, in the case of a well-understood condition with a simple inheritance pattern) or if the assistance of a genetic counsellor is required.

The GCWG considers further clarity about how the adoption of similar models would work for genetic counselling is needed.

### **Gather additional evidence that demonstrates how MBS items for genetic counselling would improve health outcomes equitably**

The GCWG noted multiple claims in the original proposal and consultation feedback that MBS items for genetic counselling would improve health outcomes, but none included data to back the claims. The GCWG considered that quality assurance processes already in place can be used to demonstrate the value of genetic counselling and principles of high-value care, and that this would be valuable information for the MRAC and the Government to consider when implementing MBS items. The GCWG also recommended approaching states and territories for public hospital data.