



HUMAN GENETICS SOCIETY OF AUSTRALASIA

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Submission to the Commonwealth Department of Health MBS Review Advisory Committee: Provision of Services by FHGSA Registered Clinical Genetic Counsellors

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Executive 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 (NHMRC 2010). The majority of 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 increasing role of genetic testing in clinical practice the responsibility for facilitating genetic testing and providing genetic counselling is increasingly being borne by mainstream primary care and specialist healthcare providers. 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 Human Genetics Society of Australasia (HGSA) is seeking the creation of MBS items for services provided by professional genetic counsellors in order to address the current and increasing need for professional genetic counselling services. The proposed item descriptor for genetic counselling consultations and associated MBS fee is provided below. Information on the role of genetic counselling, responses to questions provided by the Department of Health, and details on the calculation of the proposed MBS fees is provided below. It is hoped this is supportive of the MBS Review Advisory Committee (MRAC) making a recommendation for the creation of MBS items accessible to genetic counsellors.

Category 1, Group AXX
<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">(a) when a genetic/genomic medical condition has been diagnosed or is suspected in a patient or their biological relative; and/or(b) when genetic/genomic testing in a patient or their biological relatives is being considered; or(c) to deliver and/or discuss the result of genetic/genomic testing in a patient or their biological relatives; and(d) includes an assessment of patient or family medical history to determine risk of genetic medical conditions; and(e) includes an assessment of eligibility for genetic testing and advice about how to access testing; and(f) includes discussion and facilitates understanding of the features, natural history, means of diagnosis, and inheritance pattern of genetic medical conditions; and(g) includes non-directive counselling; and(h) where relevant and appropriate:<ul style="list-style-type: none">i. facilitates consideration and collection of informed consent for genetic/genomic tests and other diagnostic studies for the genetic medical condition under investigation; andii. facilitates adaptation to the results of genetic/genomic testing; andiii. includes discussion of risk management strategies, treatments, and reproductive options for the genetic medical condition. <p>(See explanatory note)</p> <p>Fee: \$236.82 Benefit: 75% = \$177.61 85% = \$201.29</p>

There has been overwhelming support from a diverse range of stakeholders including: professional societies; consumer groups; and government funded research alliances for the development of MBS item numbers for genetic counsellors. Copies of the letters received to date are included as an Appendix to this document.



Submission to the Commonwealth Department of Health MBS Review Advisory Committee:
Provision of Services by FHGSA Registered Clinical Genetic Counsellors

Background

In July 2021 the Human Genetics Society of Australasia (HGSA) submitted Application 1687 “Provision of Genetic Counselling Services and Request for Genetic Testing by HGSA Registered Genetic Counsellors” to the Medicare Services Advisory Committee (MSAC), seeking the creation of MBS items for services provided by genetic counsellors. After review of the MSAC Application Form, the Department of Health advised that the creation of MBS items for genetic counsellors’ services was more suitable for consideration by the MBS Review Advisory Committee (MRAC) rather than by MSAC on the basis that a Health Technology Assessment framework was not required for the assessment of genetic counsellors’ services. The Department of Health also provided the HGSA with a list of questions considered relevant to supporting MRAC in making a recommendation to list services provided by suitably qualified and regulated genetic counsellors on the MBS.

The HGSA provides background information on genetic counsellors and responses to the questions provided by the Department of Health to support MRAC’s deliberation in this document. It is hoped that the information herein is supportive of MRAC making a recommendation for the creation of MBS items accessible to genetic counsellors.

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. The National Health and Medical Research Council (NHMRC) acknowledge the important role that genetic counselling plays in patient care and recommend that genetic counselling is provided in the following circumstances: before and after predictive genetic tests; following a positive genetic carrier test; following an abnormal result on a prenatal diagnostic or screening test; and when test results are likely to provide uncertain results and/or to have significant implications for the patient and their family (NHMRC 2010).

The NHMRC publication Medical Genetic Testing: Information for health professionals (NHMRC 2010) equates the term “professional genetic counselling” to the service provided by an FHGSA certified genetic counsellor. For the purposes of this document, we are using the same terminology, to distinguish the services of a Registered FHGSA certified clinical genetic counsellor from genetic counselling that may be performed by other healthcare providers.

As with other healthcare services, clinical genetic services are provided in a blended system with services rendered in public and private healthcare settings. When treated in the public setting patients may access genetic testing and professional genetic counselling at no cost when these services are provided by public clinical genetics services employing allied health genetic counsellors. When treated in the private setting patients can access government funded genetic testing through the MBS, however there are no MBS items supporting professional genetic counselling provided by allied health genetic counsellors. Subsequently, patients treated in the private setting either receive genetic counselling by their managing clinician who may or may not have specialised training in genetic counselling, pay for consultations with an allied health genetic counsellor as an out of pocket expense, or forgo genetic counselling altogether. The creation of MBS items accessible to allied health genetic counsellors will ensure equity in access to health care services supporting patients and their biological relatives under investigation for medical conditions with an established genetic risk factor, regardless of whether they are being managed in the public or private setting.

Issue: the current funding model is unsustainable and does not support best practice

The majority of government funded professional genetic counselling services are provided by activity-based or block funded clinical genetics services operating within metropolitan tertiary public hospitals. Several members of the HGSA who work in public clinical genetics services report that their clinic is operating at capacity and unable to meet the current demand for services.

The capacity constraints of publicly funded clinical genetics services have reduced access for patients who would have previously been able to access professional genetic counselling, indeed many patients are denied an appointment altogether as they do not meet the triage and eligibility criteria now having to be applied in public hospital clinical genetic services.

The demand for genetic testing and genetic counselling is anticipated to increase in the future as a wider range of genetic tests are incorporated into mainstream clinical practice. The importance of patient access to professional genetic counselling and adaptation of multidisciplinary care in response to the increasing role of genetic testing in mainstream clinical practice is reflected in the following statement from the Australian Medical Association (AMA 2020):

“Genetic testing and associated counselling in health care requires a multidisciplinary approach with a range of health professionals and community support groups. There should be a sufficient health care workforce to support the use of genetic testing in mainstream health care as well as appropriate infrastructure to ensure that individuals have access to genetic testing, relevant health care professionals, pathology services, specialist genetic services and counselling services regardless of where they live.” (Item 6.2, p.5)

With the increasing role of genetic testing in clinical practice the responsibility for facilitating genetic testing and providing genetic counselling is increasingly being borne by mainstream primary care and specialist healthcare providers without specific or specialised training in clinical genetics or genetic counselling. In a national survey, medical specialists identified their need for ‘support from genetic services’ and education with respect to counselling issues (Nisselle et al. 2021). Clinicians leading Melbourne Genomics projects to implement genomics into mainstream clinical care, highlighted the need for genetic counsellors to work with them (unpublished evaluation data). The lack of referral opportunities for patients to receive reimbursed professional genetic counselling due to the lack of MBS items for services provided by genetic counsellors does not support the needs of patients and their managing clinicians during clinical investigations where genetic testing is being considered.

Clinical scenarios where professional genetic counselling is recommended are outlined in the National Pathology Accreditation Advisory Council requirements for medical testing of human nucleic acids (NPAAC 2013). The NPAAC classify Level 2 genetic tests as those requiring specialist knowledge, and associated with complex interpretive, ethical, or consent issues (typically predictive genetic tests in an unaffected individual). Under the NPAAC requirements, all Level 2 genetic tests require professional genetic counselling to precede and accompany the test.

Examples of Level 2 genetic tests currently funded through the MBS which explicitly specify that testing be accompanied by genetic counselling are MBS items 73297, 73300, 73305, 73334, 73339, 73340. Pathology services note PN.0.23 outlined in the MBS Book Operating from 1 November 2021 states that “prior to ordering these tests (73297, 73300, 73305, 73334, 73339 and 73340) the ordering practitioner should ensure the patient (or approximate proxy) has given informed consent. Testing should only be performed after genetic counselling. Appropriate genetic counselling should be provided to the patient either by the specialist treating practitioner, a genetic counselling service or a clinical geneticist on referral. Further counselling may be necessary upon receipt of the test results.”

For patients being managed in the private setting and accessing genetic testing funded through the MBS, the current lack of MBS items for professional genetic counselling means treating practitioners can only refer a patient to professional genetic counselling services funded through public hospitals. However, public services are unable to meet demand for genetic counsellors' services resulting in clinicians having limited referral pathways to reimbursed professional genetic counselling services in broader clinical practice despite such referrals being endorsed by the MBS.

In order to address the current and increasing need for professional genetic counselling services it is important to establish a universal funding model enabling patient access to consultations with a genetic counsellor outside existing clinical genetic services operating in public hospitals.

Proposal: The creation of MBS items for services provided by genetic counsellors

The HGSA submitted an application to MSAC seeking the creation of MBS items for services provided by professional genetic counsellors. The creation of MBS items is anticipated to enhance patient access to professional genetic counselling by:

- Providing a universal funding mechanism for consultations with genetic counsellors that are unable to be provided by clinical genetic services in public hospitals:
 - Creation of MBS items for professional genetic counselling will allow FHGSA Registered Clinical Genetic Counsellors to provide reimbursed consultations to patients treated outside of a public clinical genetics service who would otherwise forgo genetic counselling or pay for consultations as an out of pocket expense.
 - Having MBS items for professional genetic counselling provided by FHGSA Registered Clinical Genetic Counsellors will give General Practitioners and medical specialists (e.g. oncologists and cardiologists) a clear referral pathway for their patients to access reimbursed services from a Registered FHGSA certified clinical genetic counsellor when genetic testing is being ordered outside the setting of a speciality clinical genetic service.
- Facilitating patient access to reimbursed services from a Registered FHGSA certified clinical genetic counsellor in a wider range of geographical settings.
 - Clinical genetic services funded by public hospitals tend to be located within tertiary hospitals in major metropolitan centres. Even with the availability of telehealth and outreach clinics, this can make it impractical or inequitable for patients residing outside of major metropolitan centres to access genetic counsellors' services.
 - Creation of MBS items will establish a mechanism for patients in a wider range of locations to access reimbursed services from a Registered FHGSA certified clinical genetic counsellor.
- Improving equity of patient access to services from a genetic counsellor if they are being managed by clinicians who are not working in public hospitals.
- Removing a barrier to Registered FHGSA certified clinical genetic counsellors entering private practice by establishing a universal funding mechanism for the delivery of professional genetic counselling services in the private setting.

The HGSA considers the MBS listing of services provided by genetic counsellors to be a mechanism to improve equity of access to genetic counsellors' services rather than a cost shifting mechanism. Public services will continue to deliver professional genetic counselling services to public patients at capacity. The intent of MBS listing is to ensure that patients receiving services in the private setting have access to reimbursed services provided by genetic counsellors that have the same level of education, clinical training, and requirements for continuing professional development as qualified and regulated genetic counsellors providing services in the public setting.

Genetic counselling as a process

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 Counseling Definition Task Force of the National Society of Genetic Counselors (Resta et al. 2006) 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 may be delivered by medical practitioners such as General Practitioners, specialists with expertise in the genetics of their area of specialty (e.g. medical oncologist with expertise in the genetics of cancer), and clinical geneticists. Genetic counselling provided by medical practitioners is reimbursable through MBS items supporting patient consultations such as:

- General Practitioner consultations lasting at least 40 minutes: MBS item 44
- Specialist consultations: MBS items 104 (first attendance), 105 (after first attendance)
- Consultant Physician attendances (less complex conditions): MBS items 110 (first attendance), 117 (after first attendance), 119 (minor attendance after first attendance)
- Consultant Physician attendances to patient with at least 2 morbidities (complex conditions): MBS items 132 (first attendance of at least 45 minutes), 133 (after first attendance of at least 20 minutes).

Genetic counsellors as health professionals

Genetic counsellors are allied health professionals with specific education, training, and certification in genetic counselling. As such, and for the purposes of this submission, the act of genetic counselling may be performed by medical practitioners (currently reimbursable through the MBS) or specifically trained allied health genetic counsellors (not currently reimbursable through the MBS).

In both Australia and New Zealand, the HGSA is the only organisation that administers training, certification, and regulation of allied health genetic counsellors. Allied Health Professions Australia (AHPA) recognises genetic counsellors as autonomous allied health professionals with tertiary university qualifications, working in direct patient care, under a national professional organisation, with a code of ethics/conduct, competency standards and assessment procedures, core scope of practice, and regulatory mechanisms.

The HGSA Board of Censors for Genetic Counselling is a member of National Alliance of Self Regulating Health Professions (NASRHP) for the purposes of the regulation of genetic counsellors. As such, the regulatory process for genetic counsellors under the HGSA meets NASRHP's benchmarked standards, which have been aligned with AHPRA standards, and satisfy the National Code of Conduct for health care workers. This regulatory framework aligns HGSA genetic counsellors with other self-regulating allied health professions recognised under the *Health Insurance (Allied Health Services) Determination 2014* and eligible to provide services reimbursed through the MBS, namely Audiologists, Dietitians, Exercise Physiologists, and Social Workers.

The HGSA grants the title Member of the Human Genetics Society of Australasia (MHGSA Genetic Counselling) in recognition that a genetic counsellor meets the minimum tertiary educational requirements to practice as a genetic counsellor. The HGSA grants the title Fellow of the Human Genetics Society of Australasia (FHGSA Genetic Counselling) to tertiary qualified genetic counsellors who have completed additional practice and training requirements and have achieved certification by the HGSA Board of Censors for Genetic Counselling.

The process of FHGSA certification in clinical genetic counselling is through supervised practice and a portfolio of work undertaken after graduation from a relevant tertiary course, and while working in clinical practice. Comparable certification pathways for genetic counsellors exist through professional boards in the UK (the Genetic Counsellor Registration Board, GCRB), USA (the American Board of Genetic Counselling, ABGC), Canada (the Canadian Board of Genetic Counsellors, CBGC), and South Africa (Health Professions Council of South Africa, HPCSA). Genetic counsellors as a profession continue to develop internationally and, despite differences in how long the profession has been established, genetic counsellors practicing overseas face similar professional challenges to those practicing locally including: regulation and formal recognition of regulatory processes; title protection and recognition; and funding models for genetic counsellors.

The HGSA maintains a Register¹ of genetic counsellors. MHGSA genetic counsellors who are undertaking certification through the HGSA are granted Provisional Registration status. Those who have achieved FHGSA certification in clinical genetic counselling through the HGSA are granted Registered status. All genetic counsellors on the Register must meet annual requirements including continuing practice and professional development. This regulatory process is currently voluntary for individuals choosing to undertake the minimum qualification, specialist practice training, and regulatory requirements.

The HGSA acknowledges that some people without appropriate allied health (i.e. genetic counselling) or medical qualifications claim to offer 'genetic counselling.' The HGSA does not endorse this practice. Thus, in order to support the quality of care funded through the MBS it is proposed that only FHGSA Registered Clinical Genetic Counsellors would be eligible to provide services funded through the MBS (refer to the explanatory note for the proposed MBS items for details on this matter).

It is foreseeable that with the availability of MBS items supporting professional genetic counselling consultations by FHGSA Registered Clinical Genetic Counsellors through the MBS that there could be an increase in the number of suitably qualified allied health professionals who seek to become FHGSA Registered Clinical Genetic Counsellors and, subsequently, would deliver services within the established regulatory framework for genetic counsellors.

Private sector service settings for genetic counsellors

Genetic counsellors working in the private sector currently practice in a number of different settings:

- In private clinical genetics services working with a private clinical geneticist. In this setting the cost of consultation with a genetic counsellor may be incorporated as part of MBS item(s) billed by the clinical geneticist for the patient consultation. The HGSA understands that there are a number of private clinical genetics clinics who do not have access to a genetic counsellor embedded within the service. The lack of MBS items for a genetic counsellor to deliver professional genetic counselling may be a driver of this practice and MBS listing of genetic counselling provided by FHGSA Registered Clinical Genetic Counsellors is anticipated to facilitate a more collaborative and holistic approach to managing patients.
- In private specialist clinics working in with a non-genetics medical area, e.g. oncology, cardiology, neurology, ultrasound, IVF or fertility clinic. In this setting the cost of consultation with a genetic counsellor may be incorporated as part of the MBS item(s) billed by the specialist for patient consultations or procedure, and/or have to be met by the patient as an additional out of pocket expense.
- Embedded in private diagnostic laboratories. Not all private laboratories will offer access to a genetic counsellor for patients but, where it is, the cost of this service may be included as part of the total test cost charged by the pathology laboratory for genetic tests (which may or may not be MBS reimbursed).

¹ <https://www.hgsa.org.au/resources/genetic-counselling/register-of-genetic-counsellors>

Currently, private diagnostic laboratories typically only offer short consultations with genetic counsellors (15-20 minutes), often limited to post-test counselling.

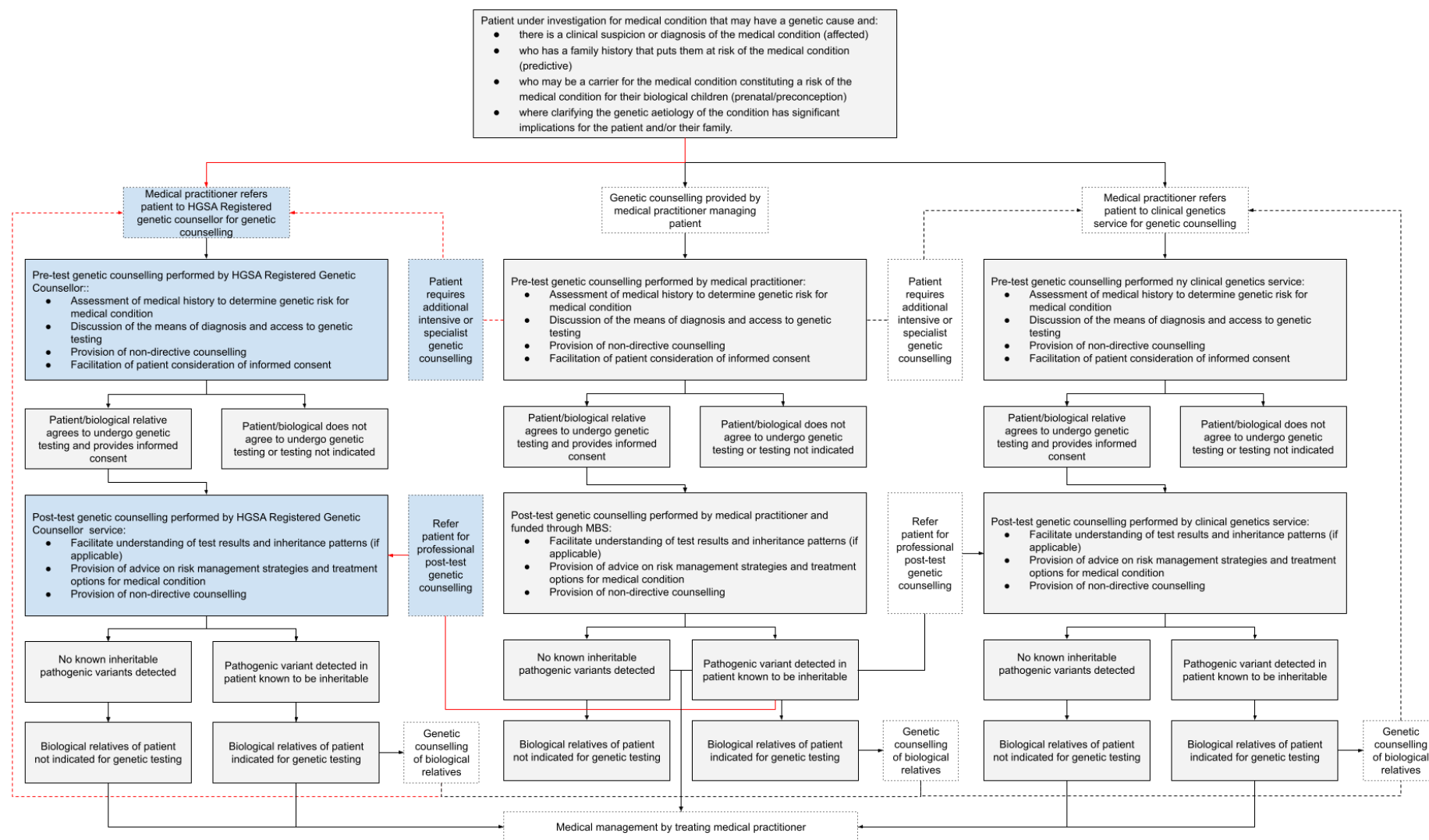
- Independent private practice. There are no MBS rebates for this setting and patients must pay for these consultations entirely as out of pocket expenses. Independent genetic counsellors give advice on patients' eligibility/suitability to receive genetic testing, provide information and education to patients, support the provision of informed consent, deliver results of genetic tests, and provide non-directive counselling to patients assisting them to make decisions about, and understand the results of, genetic testing. This is done in liaison with diagnostic clinicians (e.g. General Practitioners, oncologists, clinical geneticists, or cardiac specialists), who are responsible for the medical management of the patient, and who generally make a referral to the private genetic counsellor.

Clinical pathways for access to genetic counsellors

An algorithm representing the clinical pathways for the referral of patients or their biological relatives to genetic counselling provided by FHGSA Registered Clinical Genetic Counsellors under a scenario where MBS items are made available is provided in Figure 1. It is not proposed that genetic counselling provided by FHGSA Registered Clinical Genetic Counsellors through the MBS would be used instead of genetic counselling provided through clinical genetic services within public hospitals; these consultations would continue to be funded through State and Territory governments through existing funding mechanisms. Rather, it is proposed that the availability of genetic counselling by FHGSA Registered Clinical Genetic Counsellors on the MBS would:

- Provide a referral pathway for medical practitioners operating in private practice. It is expected that not all patients will be referred to a Registered FHGSA certified clinical genetic counsellor for professional genetic counselling, and that some patients will continue to receive genetic counselling from their managing practitioner or referred to a clinical genetic service within a public hospital.
- Provide a pathway for medical practitioners and clinical genetics services to refer biological relatives of patients identified with a pathogenic variant known to be inheritable and indicated for cascade testing.

Figure 1: Clinical management algorithm depicting referral pathways with the availability of MBS items for professional genetic counselling provided by FHGSA Registered Clinical Genetic Counsellors (highlighted in blue)



Clinical examples of referral pathways for access to genetic counsellors

Clinical examples assisting MRAC to contextualise the role of genetic counsellors in broader clinical practice are provided below. **These examples are non-exhaustive.** Genetic counsellors are trained to support patients and their biological relatives under investigation for an extensive range of medical conditions with an established genetic component.

Reproductive genetic testing

The Royal Australian and New Zealand College of Obstetrics and Gynaecologists (RANZCOG) recommend that all couples intending to have children and identified with a family history of a specific inherited disorder should be offered referral to a genetic counselling service for information about carrier screening and prenatal diagnosis/pre-implantation genetic diagnosis testing (PGT) for the condition.²

- Following on from Mackenzie's Mission, the MRFF-funded pilot of population reproductive carrier screening, MSAC Applications 1637³ and 1573⁴ for reproductive carrier screening recommend that pre-test and post-test genetic counselling be performed. In these documents it is estimated that 58,608 couples would be tested each year, with an anticipated 1-2% of those (586 – 1,172 couples) identified as "increased risk."
- The recent MBS listing of PGT should also be accompanied by genetic counselling. Based on information outlined in the Public Summary Document for MSAC Application 1165.1⁵ it is estimated that up to 1,600 PGT services will be performed each year.

The provision of genetic counselling to the additional high risk reproductive couples identified through carrier screening, cascade testing for their relatives, and those high risk couples electing to pursue PGT, cannot be delivered exclusively through public clinical genetic services as these services are unable to meet existing demand. Creation of MBS items for genetic counselling by FHGSA Registered Clinical Genetic Counsellors will provide primary and specialist healthcare providers a clear referral pathway for those patients who they determine warrant professional genetic counselling when genetic testing is being offered as per the RANZCOG position statement on genetic screening.

Cancer genetic testing

Recommendations for the management of early breast cancer published by Cancer Australia recommend that clinicians "offer genetic counselling to women diagnosed with breast cancer who are considered at high risk of a mutation in a breast cancer predisposition gene [e.g. BRCA1 and BRCA2] at the time of diagnosis. If possible, also offer women genetic testing shortly after their breast cancer diagnosis to inform decision-making."⁶ Cancer Australia also recommends that all women who have had a diagnosis of invasive epithelial ovarian, fallopian tube or primary peritoneal cancer should be offered assessment of their genetic risk, regardless of their age or family history.⁷

² [https://ranzco.edu.au/RANZCOG_SITE/media/RANZCOG-MEDIA/Women%27s%20Health/Statement%20and%20guidelines/Clinical-Obstetrics/Genetic-carrier-screening\(C-Obs-63\)New-March-2019_1.pdf?ext=.pdf](https://ranzco.edu.au/RANZCOG_SITE/media/RANZCOG-MEDIA/Women%27s%20Health/Statement%20and%20guidelines/Clinical-Obstetrics/Genetic-carrier-screening(C-Obs-63)New-March-2019_1.pdf?ext=.pdf)

³ [http://www.msac.gov.au/internet/msac/publishing.nsf/Content/58B9ED94DEC5BCDECA2586D500054D7E/\\$File/1637%20Redacted%20Application%20Form.pdf](http://www.msac.gov.au/internet/msac/publishing.nsf/Content/58B9ED94DEC5BCDECA2586D500054D7E/$File/1637%20Redacted%20Application%20Form.pdf)

⁴ [http://www.msac.gov.au/internet/msac/publishing.nsf/Content/4EF0E3C5A7CC9D05CA2584240009557E/\\$File/1573%20-%20Final%20PSD_Jul2020.pdf](http://www.msac.gov.au/internet/msac/publishing.nsf/Content/4EF0E3C5A7CC9D05CA2584240009557E/$File/1573%20-%20Final%20PSD_Jul2020.pdf)

⁵ [http://www.msac.gov.au/internet/msac/publishing.nsf/Content/17BAA5247F22729DCA25801000123C2C/\\$File/1165.1-FinalPSD-accessible.pdf](http://www.msac.gov.au/internet/msac/publishing.nsf/Content/17BAA5247F22729DCA25801000123C2C/$File/1165.1-FinalPSD-accessible.pdf)

⁶ https://www.canceraustralia.gov.au/sites/default/files/__migrated_guidelines/guideline_17.pdf

⁷ <https://www.canceraustralia.gov.au/resources/position-statements/genetic-testing-women-diagnosed-ovarian-cancer/recommendations>

Existing oncology and public clinical genetic services do not have the capacity to provide the additional genetic counselling services needed for timely testing to inform treatment, the additional genetic counselling for high risk gene carriers identified, and cascade testing for their relatives. Despite the Cancer Australia recommendations, and an intensive nationwide training program to support mainstream genetic testing⁸ for women with high grade epithelial non-mucinous ovarian cancer, only 58% of oncology healthcare professionals reported either 'always' or 'nearly always' having ordered BRCA testing for eligible patients (Gleeson et. al., 2020). Anecdotally, a significant number of eligible patients continue to be referred to public genetic services for genetic counselling and the offer of testing. Creation of MBS items for genetic counselling by FHGSA Registered Clinical Genetic Counsellors will provide treating specialists (surgeons, medical and radiation oncologists) with a clear referral pathway, for those patients who they determine warrant professional genetic counselling, when genetic testing is being performed as part of the clinical investigations informing the diagnosis and treatment of cancer patients.

Cascade testing in biological relatives of patients with confirmed pathogenic variant

Achieving the full benefit of genetic testing requires biological relatives of patients identified with a heritable pathogenic variant to avail themselves of cascade testing. Cascade testing usually involves the conduct of genetic testing in biological relatives of patients confirmed as harbouring a pathogenic variant responsible for a heritable medical condition (predictive genetic testing, classified as a Level 2 test by the NPAAC requiring pre-test and post-test professional genetic counselling).

For example, if a patient is confirmed as carrying a variant conferring familial hypercholesterolaemia (FH) then their biological relatives (first or second degree) are indicated for cascade testing to determine if they also carry that variant. The Cardiac Society of Australia and New Zealand (CSANZ) recommend that individuals in whom predictive testing for FH is required should be offered genetic counselling prior to consenting for genetic testing.⁹ Creation of MBS items for genetic counselling by FHGSA Registered Clinical Genetic Counsellors provides primary and specialist healthcare providers with a clear referral pathway for patients indicated to receive genetic counselling as per the CSANZ guidelines for the diagnosis and management of FH.

There are many medical conditions where cascade testing of biological relatives is indicated, thus the requirement for professional genetic counselling in the context of cascade testing is broader than the example of FH provided.

A significant number of biological relatives of patients with a confirmed pathogenic variant will not pursue cascade testing for a variety of heritable conditions (Srinivasan et al. 2020). The current waitlists for public genetic services for predictive cascade testing are a barrier for biological relatives indicated for cascade testing being able to access professional genetic counselling and genetic testing in broader clinical practice. Seeing a medical provider for a referral to genetic services also presents a barrier to cascade testing when ~50% of relatives will not require medical intervention based on their test result. Biological relatives indicated for cascade testing are often asymptomatic and, thus, will often not require diagnostic medical examinations. Because diagnostic examinations are usually not required for cascade testing it is common practice for cascade testing of biological relatives to be coordinated and facilitated by genetic counsellors with minimal involvement from a medical practitioner in clinical genetic services operating in the public setting.

⁸ Originally described as "An 'oncogenetic' model of...testing, whereby testing in patients with cancer can be performed through the cancer team, with support as required from genetics." (Rahman et. al., 2014), the "mainstream" model of genetic testing is now commonly used to describe genetic testing delivered by a treating healthcare provider who is not a genetic counsellor or clinical geneticist.

⁹ https://www.csanz.edu.au/wp-content/uploads/2017/07/Familial-Hypercholesterolaemia_ratified_-25-Nov-2016.pdf

In order to improve access to cascade testing in broader clinical practice the HGSA proposes that biological relatives of patients confirmed as harbouring a pathogenic variant responsible for a heritable medical condition would be eligible to access professional genetic counselling funded through the MBS without a referral. The genetic counsellor would facilitate cascade genetic testing when indicated, as well as refer patients back to a medical practitioner for appropriate management and follow-up when a positive test result is reported. The delivery of professional genetic counselling in biological relatives of patients who are indicated for cascade testing without the need for additional referral would be facilitated by the proposed MBS item descriptors.

Responses to questions from Department of Health

An external briefing paper provided to the HGSA ahead of a meeting with the Department of Health conducted 8th October 2021 outlined several questions which may be raised by MRAC as part of its consideration to recommend that genetic counselling provided by FHGSA Registered Clinical Genetic Counsellors be listed on the MBS. Responses to these questions are provided below.

How many genetic counsellors have achieved status of clinical Fellow of the Human Genetics Society of Australia (FHGSA) Certification in genetic counselling?

How many genetic counsellors have registered status on the HGSA Register of Genetic Counsellors?

Information from the HGSA Register of Genetic Counsellors indicates that there are currently:

- 129 genetic counsellors working in clinical practice who have completed FHGSA Certification in Clinical Genetic Counselling and meet the annual requirements for registration (continuing education, continuing practice, and mandatory declarations).
- 90 genetic counsellors that have been granted the title of MHGSA and are currently undertaking the supervised clinical training that is required for FHGSA certification.

Considered together, it is anticipated that there will be in excess of 200 HGSA Registered genetic counsellors that will be able to provide professional genetic counselling within the next 5 years.

Given that a defined tertiary qualification, clinical training, and certification pathway for genetic counsellors has been established by the HGSA, there is sustainable workforce 'pipeline' that will expand the number of FHGSA Registered Clinical Genetic Counsellors to meet the anticipated growing demand for genetic counselling services over time. Notably, there has been a substantial increase in the number of enrolments into HGSA-accredited courses providing tertiary qualification in genetic counselling. There are currently two accredited courses (University of Technology Sydney and University of Melbourne), with approximately 90 students enrolled and approximately 45 students graduating per year combined.

What are the locations and distribution of where genetic counsellors privately practice?

The HGSA listing of clinical genetic services¹⁰ indicate that there are at least 25 private clinical genetic services operating across Australia (NSW, QLD, TAS, VIC, and WA). The inclusion of private genetic services in the HGSA register is 'opt in', and the HGSA are aware of other services that are not listed and so there would be more than 25 private clinical genetic services currently operating in Australia.

The HGSA understands that some private genetic services provide services to patients interstate via telehealth/online consultations. These telehealth/online consultations are an effective mechanism allowing private genetic services to serve patients that reside outside of major metropolitan centres who may otherwise face logistical constraints in accessing genetic services, including genetic counselling.

¹⁰ <https://www.hgsa.org.au/resources/clinical-genetic-services-2>

The HGSA hold records of 33 genetic counsellors who self-reported as working primarily in the private sector. However, genetic counsellors, like many other health professionals, often work across both the public and private systems. The HGSA are aware that there are additional genetic counsellors providing services in the private sector, who are not FHGSA certified, HGSA Registered, or members of the HGSA and therefore aren't accounted for using HGSA records. Under the proposed MBS item descriptors non-FHGSA genetic counsellors would not be eligible to provide genetic counselling consultations funded through the MBS.

It is foreseeable that the availability of MBS items supporting the provision of genetic counselling by FHGSA Registered Clinical Genetic Counsellors would result in an increase in the number of registered providers offering services in private practice, and potentially an increase in the distribution of practitioners across various clinical settings and geographical locations.

What is the total number of services that genetic counsellors provided/ is the total number of patients that genetic counsellors treated each year for the previous five years and projected for the next 5 years?

Genetic counselling provided as part of an episode of care within a clinical genetics service in public hospitals is not currently funded on a 'fee for service' basis as per the provision of services funded through the MBS. Further, different funding models for the provision of genetic services are in place and may be applied in different ways across the States and Territories of Australia.

Genetic counselling services provided in the private setting are funded through a wide range of sources, including direct out of pocket expenses by the patient. There is no requirement for genetic counsellors (or any other healthcare professional) operating in the private setting to collate and report data on the number of services they provide.

Due to the wide range of funding models for genetic counselling that are in place in Australia, as well as the lack of formal mechanisms that capture and report the number of services that genetic counsellors provide each year, a robust response to the questions on the number of services rendered and patients treated cannot be provided.

Notwithstanding the limitations described above, an estimate of the number of services provided by genetic counsellors and the number of patients that genetic counsellors treated each year for the previous five years is provided below. It is acknowledged that these estimates rely on simplifying assumptions. Nonetheless, it is considered that these estimates would represent the upper limit of the number of services genetic counsellors provided in the private setting each year as it assumes that all genetic counsellors operating in the private setting currently have done so for the last 5 years, and on a full-time (1.0 FTE) basis. In broader clinical practice it is anticipated that most genetic counsellors operating in private practice would not be working in a full-time capacity and/or would be splitting time working across the public and private settings.

Input	ID	2016	2017	2018	2019	2020
# HGSA Registered genetic counsellors offering private services ^a	A	33	33	33	33	33
Hours worked per year ^b	B	1,748	1,748	1,748	1,748	1,748
Average time of activity per patient (hours) ^c	C	7.4	7.4	7.4	7.4	7.4
Estimated number of services provided per year ^d	D	7,795	7,795	7,795	7,795	7,795

Source: 'MBS Fee' tab of Genetic Counselling MBS FEE and Services Provided Workbook

a: HGSA membership details; b: Based on 1.0 FTE, minus paid leave and sick leave; c: Weighted average time for genetic testing and whole exome testing reported in AHGA survey; d: $A \times (B/C)$

An estimate of the number of services provided by professional genetic counsellors in the event of funding is through the MBS is provided in the table below. These estimates rely on the following simplifying assumptions: 2023 will be the first full year of MBS listing; there will be an increase in the current number of genetic counsellors who complete clinical training requirements and achieve FHGSA certification between 2023-2025 as a result of recent increases in enrolment in tertiary genetic counselling courses; and the current percentage of certified genetic counsellors offering private services will remain consistent over time.

Input	ID	2023	2024	2025	2026	2027
# Genetic counsellors who have completed FHGSA certification at 2023 ^a	A	219	-	-	-	-
# New genetic counsellors completing FHGSA certification throughout the year ^b	C	15	20	25	30	30
# Total genetic counsellors who have completed FHGSA certification	D	15	20	25	30	30
% Genetic counsellors offering private services ^c	E	219	234	254	279	309
# HGSA Registered genetic counsellors offering private services ^c	F	26%	26%	26%	26%	26%
Hours worked per year	G	57	61	66	73	80
Average time of activity per patient (hours) ^c	H	1,748	1,748	1,748	1,748	1,748
Estimated number of services provided per year ^d	I	7.4	7.4	7.4	7.4	7.4
Estimated number of services provided per year ^d	I	13,450	14,371	15,600	17,135	18,978
# Services rendered per patient	J	2	2	2	2	2
# Patients receiving genetic counselling per year ^e	K	6,725	7,186	7,800	8,568	9,489

Source: 'Utilisation Estimates' tab of Genetic Counselling MBS FEE and Services Provided Workbook

a: 129 current FHGSA + 90 MHSGA currently undertaking training towards FHGSA; b: Estimate based on internal HGSA certification and enrolment data on; Based on current estimate of 33/129 FHGSA genetic counsellors offering private services; d: $F \times (G/H)$; e: I/J

What is the current gap in the delivery of genetic services? What are wait times? How many referred patients are not offered an appointment?

Metrics used to assess the delivery of clinical genetics services are inconsistent. The data reported by individual genetic clinics to their local hospital, health service, and state health departments vary, and a national dataset does not currently exist. The HGSA is actively working to develop surveys to build a consistent longitudinal dataset reflecting the genetics/genomics workforce and service delivery over time. However, there are some published data reflecting changes to referral patterns for individual services:

- The "Angelina Jolie effect" is used to describe the influx of referrals seen by cancer genetics clinics around the world in response to the actor's public statement about their genetic testing, BRCA1 carrier status, and prophylactic surgeries in May 2013. Genetic Services of WA, the single statewide public service for Western Australia experienced a near quadrupling of monthly referrals compared to the average in the months following the announcement and, although the spike in referrals decreased over time, the monthly average remained nearly double (Freedman et al. 2017). The service published increasing wait times to see a genetic counsellor (from 4-6 weeks up to 11-12 months) and to see a clinical geneticist (from 4 weeks up to 6-7 months).

- Monash Genetics in Victoria published an increasing trend in referrals from 2015 to 2018, with an overall 58% increase in patient referrals to the general genetics service over that time period (Fennell et al. 2020). They also noted an increase in review appointments for patients along with increasing complexity of genomic testing requiring multiple appointments, reflected in a reduced capacity for the service to see new patients.

Discussions among the clinical geneticist and genetic counselling community are consistent in acknowledging that clinical genetic services across Australia are seeing an upward trend in referrals. This is reflected in the results of survey of genetic counsellors and clinical geneticists where respondents report working in clinics with long wait lists (Nisselle 2018).

More recently, there are reports of decreasing capacity of genetic services to provide appointments due to the impacts of COVID-19. The number of genetic counselling positions in public genetic services have not increased in proportion to rising referral rates resulting in increased waitlists. The increasingly strict eligibility criteria, referral triage processes, and waitlist management processes introduce barriers and inequities in access to genetic counsellors' services.

What is the average cost to the patient for provision of genetic counselling services?

In the private setting genetic counsellors provide services to patients under a range of arrangements.

Some private pathology laboratories provide session(s) with a genetic counsellor as part of the overall fee. Often this is limited to a 15-20 minute telephone or online consultation and may be limited to post-test counselling. The costs to the patient for privately funded reproductive carrier screening, which may or may not include post-test genetic counselling ranges from \$350 - \$790. Although we lack the information to inform it, if a significant assumption is made that the lower range does not include professional genetic counselling, this suggests a cost for professional genetic counselling of up to \$440.

For some patients, referral to a genetic counsellor for pre-testing counselling is indicated to support best practice. Post-test genetic counselling with the patient and potentially their biological relatives may also be indicated based on the results of testing and the nature of the genetic variant identified. For patients referred to a genetic counsellor operating in a private capacity, fees are typically charged on a 'pre-test' and 'post-test' basis. Given the wide range in case complexity genetic counsellors in private practice often charge based on an hourly rates in the range of:

- Pre-test setting: \$200 - \$360 per hour
- Post-test setting: \$150 - \$360 per hour

Due to the wide range in complexity in the clinical conditions and family history involved it is not possible to provide a robust estimate of the 'average' cost to the patient for the provision of genetic counselling services.

Consistent with other healthcare professionals operating in a private setting, genetic counsellors are able to set their fee structure independently and the HGSA does not collate, and has no authority to specify, the fees charged by genetic counsellors. There is no requirement in the private setting to report on fees for genetic counsellors' services, and publication of fees is uncommon for private genetic services. However, the HGSA have provided a range based on those fees charged by genetic counsellors operating in a private capacity that are publicly available. These have been provided to give MRAC insight into the indicative costs to patients accessing genetic counselling provided by professional genetic counsellors operating in a private setting.

MBS item descriptors and fees

Proposed MBS item descriptors

The HGSA is proposing MBS items for the provision of consultations by a genetic counsellor under two scenarios:

- Scenario 1: The proposed MBS descriptor supports the provision of services required when a patient or biological relative is being considered for genetic testing, and when professional genetic counselling may be delivered as a telehealth consultation without the requirement for a co-claimable telehealth item
 - This scenario offers the greatest flexibility for patients to access genetic counselling sessions as telehealth consultations and is anticipated regardless of their location. This scenario is preferred by the HGSA and is not proposed to incur additional costs to the MBS.
- Scenario 2: The proposed MBS descriptor supports the provision of services required when a patient or biological relative is being considered for genetic testing, and when professional genetic counselling provided as a telehealth consultation is facilitated through the use of a co-claimable telehealth item.
 - This scenario is based on the current arrangements for MBS consultation items to be eligible to be provided as telehealth consultations only when patients meet specific criteria. This scenario requires the use of a co-claimable item and would incur additional costs to the MBS.

The HGSA are proposing a single MBS item descriptor and fee for consultations with a genetic counsellor. While the average number of appointments for patients is expected to be two (one pre-test and one post-test), there will be exceptions. A patient may decline, not warrant, or not be eligible for genetic testing, in which case they will not progress to a post-test appointment. However, they will still require pre-appointment preparation, and post-appointment follow-up similar to if a result had been delivered (risk calculation, risk management recommendations, adaptive counselling, documentation, and correspondence).

The amount of preparation for a post-test result appointment will also vary depending on the complexity of the result interpretation, delivery and follow-up time will vary by individual and family counselling needs, and neither of these is necessarily dependent on whether the result is positive or negative. As the time required is not necessarily dependent on an appointment being a first or follow-up appointment or the type of result being delivered (positive, negative, uncertain/inconclusive) a single MBS item and fee is considered to be supportive of genetic counsellors providing best clinical practice services. The proposed MBS fee is based on the average time required for the patient consultation plus associated patient-related activities (see the Rationale for proposed MBS fees below).

An MBS item descriptor facilitating the attendance of a genetic counsellor at multidisciplinary team meetings is also proposed. This item will facilitate the multidisciplinary management of patients with complex conditions as per the recommendations of multiple peak clinical organisations outlined above.

The proposed item descriptors for genetic counselling consultations are provided below.

Scenario 1: Genetic counselling able to be delivered as a telehealth consultation without co-claimable telehealth item

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

This MBS item descriptor includes telehealth consultations with associated wording based on existing MBS items for professional attendances by videoconference (e.g. MBS item 112). Physical examination is generally not a routine part of genetic counsellors' services and, therefore, an equivalent genetic counselling service can be provided by telehealth without incurring additional cost or loading. Access to telehealth consultations is anticipated to increase accessibility to genetic counselling services for regional or remote patients, or those undergoing treatment. The delivery of genetic counselling through telehealth has been a necessity of providing services during COVID-19 and is an established method of delivering genetic counselling in Australian clinical practice.

Scenario 2: Genetic counselling delivered as a telehealth consultation through co-claimable telehealth item

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

Category 1, Group AXX
<p>Professional attendance on a patient by a genetic counsellor if:</p> <ul style="list-style-type: none"> (a) the attendance is by video conference or by telephone; and (b) the attendance is for a service provided with item XXXX (genetic counselling MBS item) I the patient is not an admitted patient; and (d) the patient: <ul style="list-style-type: none"> (i) is located both: <ul style="list-style-type: none"> (A) within a telehealth eligible area; and (B) at the time of the attendance-at least 15 kms by road from the genetic counsellor's consulting rooms or health service; or (ii) is a patient of: <ul style="list-style-type: none"> (A) an Aboriginal Medical Service; or (B) an Aboriginal Community Controlled Health Service; for which a direction made under subsection 19(2) of the Act applies <p>(See explanatory note)</p> <p>Derived Fee: 50% of the fee for the associated item. Benefit: 85% of derived fee</p>

The MBS item descriptors outlined above facilitate the provision of professional genetic counselling as a telehealth consultation through the use of a co-claimable MBS item. This approach is consistent with the MBS funding arrangements for other telehealth consultations through MBS item 112.

The HGSA preferred MBS listing scenario is for professional genetic counselling consultations to be eligible to be delivered as telehealth services without a requirement for a separate co-claimable MBS item (Scenario 1). However, the Scenario 2 would be accepted should MRAC or the Department of Health consider that current MBS funding arrangements for professional attendances via telehealth through a separate co-claimable item be more appropriate.

Multidisciplinary care item

MBS items facilitating genetic counsellor participation in multidisciplinary care/case conference meetings are proposed. The wording of this item has been developed in consideration of existing MBS items attendance at multidisciplinary case conferences (e.g. MBS items 825, 826 and 828).

Category 1, Group AXX
Professional attendance by a genetic counsellor in the practice of the genetic counsellor's specialty, as a member of a multidisciplinary case conference team of at least 2 other formal care providers of different disciplines, to participate in a community case conference (other than to organise and coordinate the conference) of less than 15 minutes/at least 15 minutes but less than 30 minutes/at least 30 minutes but less than 45 minutes/at least 45 minutes, with the multidisciplinary case conference team
(See explanatory note)
Fee: \$16.02 [<15 minutes]; \$32.04 [≥15 minutes - < 30 minutes]; \$48.06 [≥30 minutes - < 45 minutes]; \$64.09 [≥ 45 minutes]
Benefit: 75% \$12.02 [<15 minutes]; \$24.03 [≥15 minutes - < 30 minutes]; \$36.05 [≥30 minutes - < 45 minutes]; \$48.06 [≥ 45 minutes]
Benefit: 85% \$13.62 [<15 minutes]; \$27.24 [≥15 minutes - < 30 minutes]; \$40.85 [≥30 minutes - < 45 minutes]; \$54.47 [≥ 45 minutes]

Proposed explanatory note

In order to ensure only genetic counsellors with appropriate training and certification are able to provide professional genetic counselling consultations eligible for MBS funding an explanatory note is proposed.

Who can provide

The items for professional services (XXXX) are available for use by genetic counsellors in the provision of services to a patient or their biological relatives following referral of the patient to the genetic counsellor by a referring medical practitioner. Genetic counsellors must:

- have achieved status as a Fellow of the Human Genetics Society of Australasia (FHGSA) with Certification in Clinical Genetic Counselling; and
- have current Registered status on the HGSA Register of Genetic Counsellors; and
- be registered with the Department of Human Services to provide these services.

Rationale for proposed MBS fees

The methodology used to calculate the proposed MBS fees is outlined in full in the 'MBS Fee' tab of the Genetic Counselling MBS Fee and Services Provided Excel workbook that accompanied this document.

The HGSA has derived the MBS fees for genetic counsellors' services based on two key considerations:

- The time required to undertake genetic counselling on patients undergoing genetic/genomic testing.
 - As per the guidance on establishing an MBS fee provided in the MSAC Guidelines, this accounts for the time that genetic counsellors are required to dedicate before and after the consultation (patient-related activities), as well the delivery of the consultation itself (face-to-face or telehealth consultation with patient).
- Salary bands for genetic counsellors established in public health awards applied in the public healthcare system in the following jurisdictions: ACT, NSW, SA, TAS, VIC, WA, QLD.
 - To account for variation in the salary of genetic counsellors across Australia, as well as variation in salaries for genetic counsellors with increasing levels of experience and responsibility, the HGSA have based the proposed MBS fee on an 'average' salary genetic counsellor.

Proposed MBS fees for professional attendance by a genetic counsellor, and the inputs used to derive them, are provided below.

MBS fee input: time required to undertake genetic counselling

A survey of healthcare professionals working in clinical genetics was undertaken by the Australian Genomic Health Alliance (AGHA) between February and April 2017 (Nisselle 2018). A total of 354 responses were available for analysis, with 271 (77%) being from genetic counsellors. Results of the analysis of data relating to the average time spent per patient as reported by genetic counsellors responding to the survey are presented below.

	Average minutes spent per patient (±SD): Genetic Test	Average minutes spent per patient (±SD): Whole exome/genome sequencing
Pre-test	116 (± 27)	125 (± 26)
Test	57 (± 29)	219 (± 27)
Post-test	96 (± 26)	133 (± 27)
Administration	32 (± 28)	19 (± 21)
Other	71 (± 35)	23 (± 21)
Total	372 (± 28), ~6.25 hours	519 (± 24), ~8.5 hours

Source: Table D-2 (p. 54) of AGHA survey report

Based on the time spent per patient across genetic test and whole exome/genome sequencing outlined above a 'weighted average' time spent per patient was calculated based on 48.6% of genetic counsellors doing whole exome/genome sequencing work.

	Average minutes spent per patient (±SD): Genetic Test	Average minutes spent per patient (±SD): Whole exome/genome sequencing
Total	372 (± 28), ~6.25 hours	519 (± 24), ~8.5 hours
Proportion workload	51.4%	48.6%
Weighted average time per patient	443, ~7.4 hours	

The weighted average time per patient incorporates all activities associated with pre-test and post-test genetic counselling. Not all patients will require or not seek post-test genetic counselling (e.g. patient assessed as not being a candidate for genetic testing during pre-test genetic counselling consultation).

In order to ensure the proposed MBS fee reasonably reflects the services actually rendered the MBS fee for a single genetic counselling consultation is based on a simplifying assumption that each patient will receive 2 genetic counselling consultations (pre-test and post-test), with the corresponding MBS fee based on 221.5 minutes (~3.7 hours) of activity (443 minutes/2).

The average time spent per patient reported by genetic counsellors responding to the AGHA survey is consistent with the results of a real-time workflow study of 16 genetic counsellors in the US working in prenatal, cancer, adult, and paediatric genetics (Attard et al. 2019). In this study, the mean total time to perform a genetic counselling consultation was 3.8 hours/patient. Assuming each patient receives 2 genetic counselling consultations, the mean time required to perform pre-test and post-test genetic counselling based on the workflow study reported by (Attard et al. 2019) would be 7.6 hours/patient, an estimate highly consistent with the AGHA survey results of 7.4 hours/patient.

The HGSA considers that the consistency in the estimated time required to conduct a genetic counselling consultation reported by the AGHA survey and (Attard et al. 2019) study, results in the MBS fees being based on robust and reliable estimates of the time required to prepare for, deliver, and perform follow-up activities associated with genetic counselling consultations.

MBS fee input: salary bands for genetic counsellors

The annual salary for genetic counsellors awarded the title of FHGSA that would be eligible to access the proposed MBS items were used to derive the proposed MBS fee. These salary bands have been averaged to account for variation in the awards and associated salaries applied across Australia.

Annual salaries were used as the basis to calculate an equivalent hourly rate for genetic counsellors awarded the title of FHGSA. This calculation was based on there being 1,787 hours worked/year: (52 weeks/year*38 working hours/week) - 152 hours annual leave - 76 hours sick leave = 1,784 hours worked/year.

The position classifications, average annual wage, and derived hourly rates used as inputs in the derivation of the proposed MBS fee are provided below.

Position	Average wage across Australia	Hourly rate
Genetic Counsellor: Level 2	\$96,565	\$55.24
Senior Genetic Counsellor: Level 3	\$106,292	\$60.81
Senior Genetic Counsellor: Level 4	\$115,245	\$65.93
Manager: Level 5	\$129,982	\$74.36

MBS fee calculation

The hourly rate for genetic counsellors working across pay scales was multiplied by the time required to perform all activities associated with the delivery of a genetic counselling consultation based on the results of the AHGA survey (3.7 hours). The final proposed MBS fee for a genetic counselling consultation of \$236.82 represents the average of the total fees calculated for each pay scale.

Position	Hourly rate	Fee for pre-test and post-test genetic counselling (443 minutes, ~7.4 hours)	Average fee for pre-test and post-test genetic counselling (443 minutes, ~7.4 hours)	Average fee for pre-test genetic counselling (221.5 minutes, ~3.7 hours)	Average fee for post-test genetic counselling (221.5 minutes, ~3.7 hours)
Genetic Counsellor: Level 2	\$55.24	\$408.29	\$473.63	\$236.82	\$236.82
Senior Genetic Counsellor: Level 3	\$60.81	\$449.41			
Senior Genetic Counsellor: Level 4	\$65.93	\$487.26			
Manager: Level 5	\$74.36	\$549.57			

The proposed MBS fees for the attendance of a genetic counsellor at a multidisciplinary case conference meeting is based on the equivalent hourly fee applicable for the MBS item for a genetic counselling consultation adjusted for the duration of the multidisciplinary meeting, e.g. \$236.82/3.7 hour genetic counselling consultation = \$64.09 hour → MBS fee for attendance at multidisciplinary meeting <15 minutes fee based on 15 minutes (0.25 hours) calculated as \$64.09*0.25 = \$16.02.

It should be noted that this fee is an underestimate of the total cost of providing the service. As per the guidelines for preparing assessments for the Medical Services Advisory Committee, this fee accounts for the costs of the time taken for the provider to perform the service (before, during and after the service). However, it does not account for non-salary costs incurred by private practitioners such as rent of consulting rooms, compulsory superannuation contributions, and professional and medical indemnity insurances. Accounting for additional non-salary costs based on 1.3 X the average hourly wage across Australia would result in an MBS fee of \$307.86 in place of the proposed fee of \$236.82.

Benchmarking - MBS fees for genetic counselling

The MSAC Guidelines outline that “genetic counselling cannot be funded separately via the MBS. Consequently, it is suggested that genetic counselling be captured within an appropriate consultation item claimed by the professional responsible for the care of the patient (usually the professional requesting the test)” (p. 45). It is reasonable to expect that straightforward cases could have genetic counselling incorporated into a shorter consultation or along with other clinical content where a provider has the knowledge, skills, and confidence to do so. It is primarily those requiring more intensive professional genetic counselling (and therefore more time investment) that we project would be managed by Registered FHGSA clinical genetic counsellors. It would not be practicable to include genetic counselling for these sorts of cases as a portion of a shorter consultation or the limited consultation time available for an appointment requiring other clinical content.

A comparison of the proposed MBS fee for genetic counselling with the MBS items and associated fees used as a proxy for genetic counselling that were applied in previous MSAC deliberations is provided below. Due to the lack of MBS items for genetic counselling, precedent MSAC assessment have relied on fees for extended initial consultations (at least 45 minutes) and subsequent consultation (at least 20 minutes) provided by consulting clinicians as a proxy for the cost of genetic counselling.

Parameter	MBS fee	Time period covered by MBS fee(s)	MBS fee/hour
HGSA Proposed MBS fee	\$236.82	3.7 hours	\$64.09/hour
MBS items applied for genetic counselling, MSAC Application 1161.1 Pre-implantation genetic diagnosis	\$278.75, Item 132 for initial consultation (≥ 45 minutes) \$139.55, Item 133 for subsequent visits (≥ 20 minutes)	Item 132: 0.75 hours (≥ 45 minutes)	Item 132: \$371.67/hour
MBS items applied for genetic counselling, MSAC Application 1216.1 Cystic fibrosis transmembrane regulator (CFTR) testing	\$278.75, Item 132 for initial consultation (≥ 45 minutes) \$139.55, Item 133 for subsequent visits (≥ 20 minutes)	Item 33: 0.33 hours (≥ 20 minutes)	Item 133: \$419.07/hour

Benchmarking – MBS fees for allied health consultations

The MSAC Guidelines outline that “a comparison of MBS item fees of similar services may provide some context for the proposed fee.” To that end, a comparison of the MBS fees in terms of cost/hour for genetic counselling services provided by allied health genetic counsellors with other services provided by allied health professionals is provided below. The HGSA consider that it is important for MRAC to consider the equivalent cost/hour for allied health services on the basis that the complexity of activities associated with genetic counselling differ substantially from other allied health professionals funded which are funded at levels of consultations lasting at least 20 minutes the MBS.

Parameter	MBS fee	Time period covered by MBS fee(s)	MBS fee, \$/hour
Proposed MBS fee for genetic counselling provided by allied health professional	\$236.82	3.7 hours	\$64.09
Allied health services of at least 20 minutes (diabetes education/audiology/exercise physiology/dietetics/mental health service/occupational therapy/physiotherapy/podiatry/chiropractic/osteopathy/psychology/speech pathology)	\$64.80	0.33 hours (20 minutes)	\$194.40

Concluding statement

Clinical genetics services operating in public hospitals are operating at capacity and current demand for their services is exceeding their delivery capacity. With genetic testing playing an ever-increasing role in mainstream clinical practice the current scenario whereby patients are unable to access genetic counsellors' services through the MBS is not supportive of best clinical practice and is not sustainable.

The HGSA has invested the time and resources to establish a framework for training, certifying and regulating genetic counsellors as allied health professionals. The standards established by the HGSA are consistent with other allied health professionals who are able to provide services reimbursed through the MBS.

As part of completing the MSAC Application Form to have professional genetic counselling services listed on the MBS, the HGSA obtained letters of support from a diverse range of stakeholders including: professional societies; consumer groups; and government funded research alliances. Copies of these letters of support are included as an Appendix to this document. There was overwhelming support for the HGSA proposal to have MBS items created for genetic counsellors.

The proposed MBS item descriptors have been rigorously reviewed by genetic counsellors practicing in a range of clinical settings. There is broad consensus among these genetic counsellors that the proposed MBS items descriptors are supportive of the provision of 'best standard' care to patients.

The MBS fee has been developed based on the current remuneration for genetic counsellors in the public health care setting and the time required to deliver 'best standard' genetic counselling to patients. Availability of MBS item for genetic counsellors at the proposed MBS fee will mitigate the potential for, and magnitude of, out of pocket expenses incurred by patients who receive professional genetic counselling from a genetic counsellor outside of public clinical genetics services funded by State and Territory governments.

The HGSA requests that MRAC make a recommendation to create MBS items for professional genetic counselling as proposed under Scenario 1 in this document. The HGSA has provided responses to all questions provided by the Department of Health, as well as additional contextualising information on the clinical setting where genetic counsellors are supporting clinicians and patients in current clinical practice.

It is understood the MRAC is a newly convened committee and that the processes for MRAC decision-making are being finalised. As such, the HGSA will work in good faith to provide any additional information to assist MRAC in its consideration of the request to create MBS items for professional genetic counselling.

Further consideration: Genetic test requests by genetic counsellors

Genetic tests deemed clinically relevant based on patient medical history and/or results of previous genetic testing may only be ordered by a medical provider, usually the managing general practitioner or medical specialist. It is widely recognised within the genetic counselling profession and by our laboratory, medical and other healthcare colleagues, that there are circumstances where requests for genetic testing may be reasonably made by a genetic counsellor, i.e. when a definitive diagnosis of a condition is made by the patient's managing clinician who makes a referral to a genetic counsellor for the purposes of facilitating informed consent and testing and/or when follow-on genetic testing is indicated for biological relatives of a patient with a confirmed pathogenic variant. Indeed, laboratories are increasingly employing genetic counsellors to act as gatekeepers for genetic test requests. Studies assessing the impact that genetic counsellor review of ordered genetic tests have reported a change in genetic tests ordered after genetic counsellor review, including cancelling tests on the basis of not being clinically appropriate for the patient (Riley et al. 2015, Haidle et al. 2017). The cancellation or amendment of genetic tests order by clinicians after genetic counsellor review resulted in net cost savings to laboratories.

The HGSA is requesting advice from the Department of Health regarding the process to enable Registered FHGSA clinical genetic counsellors to request genetic tests funded through the MBS. The HGSA considers the matter of genetic counsellors being eligible to request genetic testing to be a separate policy-related issue to the request for MBS listing of genetic counselling consultations and does not want the matter of genetic test requests by genetic counsellors to delay the assessment of the request for MBS listing of genetic counselling consultations. The HGSA will work with the Department of Health, and any other key stakeholders, to provide any further necessary information to assist the Department's consideration of facilitating genetic tests requests by genetic counsellors.

Submitted by:

The Human Genetics Society of Australasia, Implementation Committee for Genetic Counsellor Regulation, Funding Models Workstream and MSAC Application Working Group.

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<https://www.health.nsw.gov.au/workforce/alliedhealth/Documents/gsw-final-report.pdf>

Attachments

Copies of all references and other relevant publications have been included as separate attachments to this submission.

For transparency with regard to the calculations included in this submission, the Excel workbook *Genetic Counselling MBS Fee and Services Provided Calculations.xlsx* is also included as a separate attachment.

Letters of support received to date from stakeholders (including professional societies and consumer groups) are attached in the following appendix.

Appendix: Letters of clinical and consumer support

Letters received to date from the following stakeholders (including professional societies and consumer groups) are attached:

Allied Health Professions Australia (AHPA)
Australasian Association of Clinical Geneticists (AACG)
Australasian Society of Diagnostic Genomics (ASDG)
Australasian Society of Genetic Counsellors (ASGC)
Australian Genomics
Australian Patient Organisation Network (APON), Centre for Community Driven Research
Breast Cancer Network Australia (BCNA)
Breast Surgeons of Australia & New Zealand (BreastSurgANZ)
Centre for Genetics Education
Cystic Fibrosis Australia
Fragile X Association Australia (FXAA)
Genetic Alliance Australia
Genetic Support Network Victoria (GSNV)
Genetic, Undiagnosed and Rare Disease Collaborative (GUARD)
Industry Genomics Network Alliance (InGeNA)
Lung Foundation Australia
Melbourne Genomics Health Alliance Community Advisory Group
National Alliance of Self Regulating Health Professions (NASRHP)
Pink Hope
Rare Voices Australia (RVA has over 90 partner consumer organisations)
Red Nose Australia
Royal Australian and New Zealand College of Obstetricians and Gynaecologists (RANZCOG)
Royal College of Pathologists of Australasia (RCPA)
SCN2A Australia
Syndromes Without A Name (SWAN)
Through the Unexpected
Tuberous Sclerosis Australia
UsherKids Australia



12 July 2021

Professor Robyn Ward, Chair

Medical Services Advisory Committee (MSAC)

RE: Genetic Counsellors of the Human Genetics Society of Australasia (HGSA) application

Dear Professor Ward

We are writing to express support for the Genetic Counsellors of the Human Genetics Society of Australasia (HGSA) application to open a dialogue about Medicare Provider numbers for genetic counsellors, and Medicare Benefits Scheme (MBS) items for services provided by genetic counsellors.

HGSA is a full member of Allied Health Professions Australia (AHPA) which is the peak body for allied health professions in Australia. In that capacity we support the provision of services by appropriately trained, qualified, and regulated genetic counsellors as a clinically relevant and necessary part of the management of many patients and families affected by genetic/genomic conditions. This area of practice is only going to grow and currently there are insufficient provisions anywhere to support the work of genetic counsellors.

The value of allied health professionals in primary care has been highlighted in the Draft Primary Care 10 Year Plan and genetic counsellors need to be incorporated into this future.

We support this application in principle, and its acceptance by MSAC for consideration and entry into the MSAC process. We would also welcome contact from the Department during the consultation process.

Your Sincerely

Claire Hewat, CEO



PO Box 6012
Alexandria
NSW 2015
T +61 2 9669 6602
E executive@aacg.org.au

Professor Robyn Ward, Chair
Medical Services Advisory Committee (MSAC) Secretariat
Australian Government Department of Health
MDP 960
GPO Box 9848
Canberra ACT 2601
hta@health.gov.au

22 July 2021

Dear Professor Ward,

We are writing to express support for the Genetic Counsellors of the Human Genetics Society of Australasia (HGSA) application to open a dialogue about Medicare Provider numbers for genetic counsellors, and Medicare Benefits Scheme (MBS) items for services provided by genetic counsellors.

There are currently no Medicare or Private Health Insurance rebates for genetic counsellors' services, and the Activity Based Funding (ABF) of genetic services in public hospitals is not sufficient to meet the growing demand for genetic counselling. With the rapid developments in the field of genetics/genomics and increasing integration of genetic/genomic testing into all areas of healthcare, the provision of genetic counselling is increasingly being borne by specialists, GPs, and nursing staff. Genetic counsellors are crucial enablers of this mainstreaming of genetic testing and advice by non-genetic health professionals.

As a professional body representing Clinical Geneticists, we support the provision of services by appropriately trained, qualified, and regulated genetic counsellors as a clinically relevant and necessary part of the management of many patients and families affected by genetic/genomic conditions. We support this application in principle, and its acceptance by MSAC for consideration and entry into the MSAC process. We would also welcome contact from the Department during the consultation process.

Kind regards,

Mimi Berman
Clinical Associate Professor
Head, Department of Clinical Genetics
Royal North Shore Hospital
President Australasian Association of Clinical Geneticists

EXECUTIVE OF THE AACG

PRESIDENT
A/Prof Yemima Berman
Royal North Shore Hospital

IMMEDIATE PAST PRESIDENT
A/Prof Michael Gabbett
Queensland University of Technology

TREASURER
Dr Ingrid Sinnerbrink
Nepean Hospital

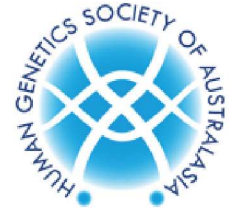
RACP REPRESENTATIVE
Dr Jason Pinner
Sydney Children's Hospital

DEPUTY PRESIDENT
Dr Jason Pinner
Sydney Children's Hospital

SECRETARY
Dr Gemma Poke
Genetic Health Service NZ

NZ REPRESENTATIVE
Dr Rachel Stapleton
Genetic Health Service NZ

TRAINEE REPRESENTATIVE
Dr Gunjan Garg
Royal North Shore Hospital



Australasian Society of Diagnostic Genomics

A special interest group of the HGSA

Professor Robyn Ward, Chair
Medical Services Advisory Committee (MSAC)

18th July 2021

Dear Professor Ward,

The Australasian Society of Diagnostic Genomics represents scientists and pathologists in the field of diagnostic genomics and genetics. The field of diagnostic genomics is rapidly expanding with uptake of genetic and genomic testing increasing due to decreased cost, increased clinical and personal utility, and the increased potential to inform targeted treatments and therapies. Genetic counselling is a critical and necessary component of the genetic and genomic testing cycle, both before and after testing. Before testing it ensures that testing is appropriate, patient's and families have considered possible outcomes of testing and have provided informed consent. Following testing it ensures that results are interpreted correctly, the familial implications are communicated and appropriate referrals for ongoing treatment and monitoring are made.

The NPAAC Requirements for Medical Testing of Human Nucleic Acids (Second Edition 2013) states that for a level 2 DNA test (i.e. the test has the potential to lead to complex clinical issues) "specialised knowledge is needed for the DNA test to be requested, and for which professional genetic counselling should precede and accompany the test."

The Increase in "mainstreaming" of genetic and genomic services has meant an increased demand for genetic/genomic testing and therefore an increased demand for genetic counselling. Ordering clinicians are often time poor or insufficiently experienced in the requesting and result return for genomic tests. This may result in insufficient time dedicated to the important need for genetic counselling and informed consent. Genetic counsellors are highly skilled, Masters qualified health professionals, trained specifically to consider the psychosocial and familial aspects of genomic testing. This is a clinically relevant facet which may be missed by some treating clinicians.

The role of genetic counsellors in the testing cycle is not to replace the care of treating clinicians, but rather to support medically trained health professionals as well as patients. This support will both benefit the health system by reducing the counselling demand on specialist clinicians and improve care by putting a dedicated focus on patient pre- and post-test support. To facilitate these benefits, dedicated funding models to support the services of genetic counsellors during routine genetic and genomic test ordering and result delivery are essential. We also note that the fee structure should be commensurate with the skill level of genetic counselling being at Masters level qualification, often with further professional qualifications such as Fellows of the Human Genetics Society of Australasia.

For these reasons the ASDG Executive Committee will fully support any application to MSAC or other government agencies that will lead to sustainable funding for genetic counselling services.

Regards,

Ben Lundie
ASDG - Chair
(on behalf of the ASDG Executive Committee)

19 July 2021

Professor Robyn Ward, Chair
Medical Services Advisory Committee (MSAC)

Dear Prof Ward,

RE: Genetic Counsellors of the Human Genetics Society of Australasia (HGSA) application

I represent the Australasian Society of Genetic Counsellors (ASGC). We are a group of allied health professionals who provide genetic counseling in both clinical and research setting for genetic diseases, across all disciplines of medicine, in all states and territories.

Genetic Counsellors are highly trained allied health care professionals with a wide scope of practice. Genetic Counsellors provide essential care to those affected by genetic disease including those making use of genetic/genomic technologies. The services provided by professional Genetic Counsellors are clinically relevant and necessary in the management of genetic/ genomic conditions.

We encourage and support an MSAC/government consideration of the HGSA's application. There are currently no Medicare or Private Health Insurance rebates for genetic counsellors' services, and the Activity Based Funding (ABF) of genetic services in public hospitals is not sufficient to meet the growing demand for genetic counselling. With the rapid developments in the field of genetics/genomics and increasing integration of genetic/genomic testing into all areas of healthcare, the provision of genetic counselling is increasingly being borne by specialists, GPs, and nursing staff. An MSAC consideration of providers numbers and Medicare benefits scheme items for services is the critical next step to ensure equal access to Genetic Counsellors by all Australians who need them.

We are in support of the proposed fees, which are benchmarked against other allied health item numbers. We understand advice on this is also being sought from the Department.

In summary, we support the HGSA application to MSAC and believe it is a critical next step for ensuring equal access to Genetic Counsellors by all Australians.

Please don't hesitate to contact me if you require further information.

Kind regards



Laura Yeates
Chair, Australasian Society of Genetic Counsellors

Professor Robyn Ward, Chair
Medical Services Advisory Committee (MSAC)
E: hta@health.gov.au

Tuesday 20 July 2021

Dear Professor Ward,

RE: Medical Services Advisory Committee consideration for Medicare Provider numbers for genetic counsellors, and public funding for services provided by genetic counsellors.

Australian Genomics is an Australian Government initiative supporting genomic research and its translation into clinical practice. Through broad engagement and a national collaborative approach, we achieve two key objectives: to improve the efficiency, reach and timeliness of genomic research projects, and to support Commonwealth State and Territory Health Departments in the implementation of genomics research outcomes by refining and communicating evidence to inform policy development. Australian Genomics engages with current and emerging government policy and priorities to identify gaps and opportunities, to support policy and action for integrating genomic technologies into the health system. By interfacing with consumers, Governments, industry and global genomics initiatives, Australian Genomics drives change and growth in the sector.

In this capacity, Australian Genomics has evaluated the genomic workforce in Australia. There is extensive evidence that genetic counselling services ensure the safety and quality of genomic testing, and equity of access to genetic counselling is critical for patient care and support (as noted in Pillar 2 of National Strategic Action Plan for Rare Diseases).

It is also noted that demand for genetic services is increasing:

- A NSW-led report on genetic counselling services in 2017 noted an increase in wait times for appointments to up to two years, depending on geographic location and urgency of the test¹;
- Approximately 1700 genetic and genomic germline and somatic diagnostic tests were undertaken in the 2016 financial year². By 2019, the number of tests performed by public laboratories had grown to 4000 (personal communication).
- Genetics services partnered with Australian Genomics have reported increase in genetic / genomic test referrals from 22% to 60% since the 2015/2016 financial year.
- As carrier testing becomes publicly funded, the application of genetic / genomic testing will move beyond diagnostic applications in affected people, towards large-scale programs accessible by asymptomatic members of the public. Commensurate with this, we envisage even greater demand for genetic counselling services.

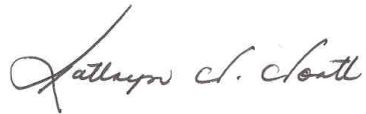
¹[The changing landscape of the genetic counselling workforce \(2017\)](#)

² Australian Health Genetics / Genomics Survey 2017

Compounding these capacity challenges, the current Activity Based Funding model for genetic services fails to correctly or adequately fund genetic counselling – and has led to discrepancies in management across States and Territories.

In this context, Australian Genomics supports the Genetic Counsellors of the Human Genetics Society of Australasia (HGSA) engaging with the Medicare Services Advisory Committee about Medicare Provider numbers for genetic counsellors, and Medicare Benefits Scheme (MBS) items for services provided by genetic counsellors. We support this application in principle, and its acceptance by MSAC for consideration and evaluation for public funding, and would welcome contact from the Department during the consultation process.

Sincerely,

A handwritten signature in black ink, appearing to read "Kathryn North", written in a cursive style.

Professor Kathryn North AC
Lead, Australian Genomics

Professor Robyn Ward, Chair
Medical Services Advisory Committee (MSAC)
Australian Government Department of Health
MDP 960
GPO Box 9848
Canberra ACT 2601

18 July 2021

Dear Professor Ward,

RE: Genetic Counsellors of the Human Genetics Society of Australasia (HGSA) application to open a dialogue about Medicare Provider numbers for genetic counsellors, and Medicare Benefits Scheme (MBS) items for services provided by genetic counsellors.

As background, the Centre for Community-Driven Research (CCDR) is a non-profit organisation developing a repository of patient experience data to provide a systematic approach to inform decisions about health (PEEK program). CCDR also host the Australian Patient Organisation Network (APON). With 135 members APON is the largest group of patient organisations in Australia and the professional body for patient organisations. CCDR also received funding from the Federal Department of Health to implement a community-based telehealth nurse service across 10 disease areas, most of which are rare and genetic conditions. I also work as a rare, genetic and complex condition telehealth nurse within this service which is called Patient Pathways.

As a rare, genetic and complex condition telehealth nurse, most of the patients that come through the clinic have a need to access a genetic counsellor. My role however is often explaining to patients and families that, while the recommendation on their genetic test says that referral to a genetic counsellor is needed, in most cases, it is not likely that they will be able to access one in a timely manner. In my work liaising with health professionals, I completely understand the pressure that clinical genetics centres are under and the need to triage access to genetic counsellors to those most in need – and try to support colleagues by explaining this to with patients and families within the telehealth clinic. However, that doesn't remove their need to access a genetic counsellor, it simply alleviates some of their anxiety when they are unable to do so.

From my current work, and also previous worked as Head of Research as Cancer Council NSW and Head of Policy and Strategy at the Kinghorn Cancer Centre, I support the provision of services by appropriately qualified and regulated genetic counsellors as a clinically relevant and necessary part of the management of many patients and families affected by genetic/genomic conditions.

Should you require additional consultation with the patients and patient organisations on this matter, we would be very happy to help and facilitate this through data collected in our PEEK repository, APON and Patient Pathways, and would welcome contact from the Department during the consultation process (holliday@cc-dr.org 0424 756 434)

Kind regards,



Kate Holliday
PhD MHSc MHP Grad Dip Nutr BN(RN)
Chief Executive, Centre for Community-Driven Research (CCDR)
Genetic, Rare + Complex Conditions Telehealth Nurse, Patient Pathways

Centre for Community-Driven Research
www.cc-dr.org
www.pathwaysportal.org
39 Helena Street
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ABN 44 161 440 615

Professor Robyn Ward, Chair
Medical Services Advisory Committee (MSAC)



15/10/2021

Dear Professor Ward

About Breast Cancer Network Australia

Breast Cancer Network Australia (BCNA) is the peak national organisation for Australians personally affected by breast cancer. We support, inform, represent and connect people whose lives have been affected by breast cancer. We work to ensure that Australians diagnosed with breast cancer receive the very best care, treatment and support. BCNA represents more than 150,000 individual members.

BCNA has a strict policy, endorsed by our Board, governing how we work with pharmaceutical and biomedical companies. We do not accept funding from pharmaceutical and biomedical companies, and there is no financial benefit to BCNA when we provide letters and submissions of support for new breast cancer treatments. Our *Working with pharmaceutical and biomedical companies* policy can be viewed on our website, www.bcna.org.au.

We are writing to express support for the Genetic Counsellors of the Human Genetics Society of Australasia (HGSA) application to open a dialogue about Medicare Provider numbers for genetic counsellors, and Medicare Benefits Scheme (MBS) items for services provided by genetic counsellors.

As a consumer group representing people who may benefit from the services of genetic counsellors, we support the provision of services by appropriately trained, qualified, and regulated genetic counsellors as a clinically relevant and necessary part of the management of many patients and families affected by genetic/genomic conditions, and those with a strong family history of breast and other cancers which might have a genetic basis.

Some people inherit changes in certain genes that can increase their risk of breast and other cancers. Genetic counselling is a service that can assist in reviewing family history in detail to determine how likely it is that a person is at risk of an inherited change in genes such as BRCA1 and BRCA2, which greatly increases the risk of developing breast cancer. Genetic counsellors can also give further information about the risks and benefits of genetic testing.

Genetic testing can test for the presence of mutations or significant variants in the BRCA genes and other breast cancer susceptibility genes. If a mutation is found, steps can be taken to reduce the risk of breast or other cancer developing, or it may inform the treatment plan of someone already diagnosed with cancer. If a gene mutation is not found, this can be either greatly reassuring or very confusing for the patient and may assist with further treatment and surveillance decision-making.

SUPPORTING AUSTRALIANS AFFECTED BY BREAST CANCER

293 Camberwell Road Camberwell VIC 3124

1800 500 258 (03) 9805 2500 beacon@bcna.org.au bcna.org.au ABN 16 087 937 531

BCNA recognises that genetic counsellors are uniquely skilled professionals, who have advanced training in both medical genetics and counselling; genetic counsellors are able to both interpret genetic test results and provide guidance and support for families navigating challenging situations.

BCNA has consulted with its consumer base on genetic counselling. The largest barriers to this important service are cost and access, as the MBS does not currently cover genetic counselling by HGSA certified genetic counsellors. Some breast cancer patients choose to self-fund genetic counselling services and have reported positive experiences that have benefitted their overall breast cancer journey.

'The assistance of an informed genetic counsellor working with clinical geneticists at a Family Cancer Centre helped me make an informed decision about proceeding with genetic testing. The counsellor was able to guide me through discussions about risk, genetic testing pros and cons. and implications for other family members. Following testing the counsellor assisted in interpreting results and together with a medical geneticist, provided information about management and surveillance.'

Gerda Evans, BCNA Consumer Representative

A 2014 study on risk-reducing breast cancer surgery found that factors such as cancer-related distress and perceptions about the risk of cancer were found to impact people's decisions about whether to have a risk-reducing surgery¹. As such, the importance of genetic counselling was highlighted to help patients understand more about their actual risk of developing cancer and to assist with informed decision-making.

BCNA also notes the evidenced psycho-social benefit of genetic counselling in assisting patients to deal with emotional concerns relating to risk and cancer in them and their families.

We therefore support this application in principle, and its acceptance by MSAC for consideration and entry into the MSAC process. We would also welcome contact from the Department during the consultation process.

For further information, please contact us at kpilatti@bcna.org.au or vdurston@bcna.org.au.

Kind regards,



Kirsten Pilatti
Chief Executive Officer



Vicki Durston
Director, Policy, Advocacy & Member Support

¹ <https://onlinelibrary.wiley.com/doi/abs/10.1002/pon.3560>

21 July 2021

Professor Robyn Ward, Chair
Medical Services Advisory Committee

via email: projectofficer@hgsa.org.au

Dear Professor Ward,

I am writing to express BreastSurgANZ support for the Genetic Counsellors of the Human Genetics Society of Australasia (HGSA) application to open a dialogue about Medicare Provider numbers for genetic counsellors, and Medicare Benefits Scheme (MBS) items for services provided by genetic counsellors.

As a professional organisation that may be impacted by this application we support the provision of services by appropriately trained, qualified, and regulated genetic counsellors as a clinically relevant and necessary part of the management of many patients and families affected by genetic/genomic conditions.

BreastSurgANZ supports this application in principle, and its acceptance by MSAC for consideration and entry into the MSAC process. We would also welcome contact from the Department during the consultation process.

Yours sincerely,

Melanie Walker

Melanie Walker
President, BreastSurgANZ

Professor Robyn Ward, Chair
Medical Services Advisory Committee (MSAC)

23.7.21

Dear Professor Ward,

We are writing to express support for the Genetic Counsellors of the Human Genetics Society of Australasia (HGSA) application to open a dialogue about Medicare Provider numbers for genetic counsellors, and Medicare Benefits Scheme (MBS) items for services provided by genetic counsellors.

As a representative of the Centre for Genetics Education, the peak public health genomics education service within NSW Health, I wholeheartedly support the provision of services by appropriately trained, qualified, and regulated genetic counsellors as a clinically relevant and necessary part of the management of many patients and families affected by genetic/genomic conditions.

With the ongoing advances in genomic testing and the progressive decrease in costs of obtaining test results, it is clear to see that demand for genomic testing is set to increase over the coming decade. Genetic counsellors are skilled at ensuring informed consent is obtained prior to genetic testing and that testing is arranged only when appropriate. It is vital that the correct test is ordered at the right time for the patient and appropriately trained genetic counsellors are suitably positioned to arrange testing and help support other professionals in this regard within a variety of settings and specialties. Once results are obtained, genetic counsellors have the necessary training and experience to help interpret and explain results to patients in a comprehensible way.

Consequently, I support this application in principle, and its acceptance by MSAC for consideration and entry into the MSAC process. We would also welcome contact from the Department during the consultation process.

Yours sincerely,



Edwina Middleton
Program Lead for Cancer and Genomics Education
Centre for Genetics Education, NSW Health



Professor Robyn Ward
Chair
Medical Services Advisory Committee (MSAC)

7 July 2021

Dear Professor Ward,

Cystic Fibrosis Australia (CFA) is writing to confirm our support for the Genetic Counsellors of the Human Genetics Society of Australasia's (HGSA). They are applying for Medicare Provider numbers for genetic counsellors, and Medicare Benefits Scheme (MBS) items for services provided by genetic counsellors. We believe that this is a worthy and practical request given their contribution.

Cystic fibrosis (CF) is an inheritable genetic disease that results in a thick mucus building up in various organs, including the lungs, pancreas, liver, and intestines. It is caused by mutations in the CFTR (cystic fibrosis transmembrane conductance regulator) gene.

There is currently no cure for CF, but various therapies are available to help manage symptoms and extend the life expectancy of patients.

Our community relies on the skills and knowledge of genetic counsellors as they navigate the complex field of genetics and IVF. The Human Genetics Society of Australasia is a professional organisation whose rigorous professional standards are a source of comfort and security to our community. We rely on their oversight and expertise.

CFA supports the provision of services by appropriately trained, qualified, and regulated genetic counsellors as a clinically relevant and necessary resource for many patients and families affected by genetic conditions.

CFA supports this application wholeheartedly, and its acceptance by MSAC for consideration and entry into the MSAC process. We would also welcome contact from the Department during the consultation process.

Kind regards

A handwritten signature in black ink, appearing to read "Nettie Burke", written in a cursive style.

Nettie Burke
CEO
Cystic Fibrosis Australia
0404 034 294
nettieb@cfa.org.au



22 July 2021

Professor Robyn Ward, Chair
Medical Services Advisory Committee (MSAC)
Department of Health

Dear Professor Ward,

I am writing on behalf of Fragile X Association of Australia to express support for the Genetic Counsellors of the Human Genetics Society of Australasia (HGSA) application to open a dialogue about Medicare Provider numbers for genetic counsellors, and Medicare Benefits Scheme (MBS) items for services provided by genetic counsellors.

As the authorised representative of an organisation with a member base that may be impacted by this application, I support the provision of services by appropriately trained, qualified, and regulated genetic counsellors as a clinically relevant and necessary part of the management of many patients and families affected by genetic/genomic conditions.

Genetic counsellors play a critical role in the pathway to diagnosis and clinical management of individuals affected by or at risk of Fragile X-associated disorders, in many instances across a span of time.

Fragile X Association of Australia supports this application in principle, and its acceptance by MSAC for consideration and entry into the MSAC process.

We would also welcome contact from the Department during the consultation process.

Kind regards,

A handwritten signature in black ink that reads "Wendy Bruce". The signature is fluid and cursive, with the first name "Wendy" and last name "Bruce" clearly distinguishable.

Wendy Bruce
Executive Director
Fragile X Association of Australia Inc
wendy@fragilex.org.au
02 9907 2366



C/- Garvan Institute of Medical Research
Level 6, Room 6.39
384 Victoria Street
Darlinghurst NSW 2010

Phone: **+61 2 9295 8359**
Fax: **+61 2 9295 8181**

Email: director@geneticalliance.org.au

Professor Robyn Ward, Chair
Medical Services Advisory Committee (MSAC)

16 July 2021

Dear Professor Ward,

We are writing to express support for the Genetic Counsellors of the Human Genetics Society of Australasia (HGSA) application for Medicare Provider numbers for genetic counsellors, and Medicare Benefits Scheme (MBS) items for services provided by genetic counsellors.

Genetic Alliance Australia provides support and information for those affected directly and indirectly by rare genetic conditions. We engage with individuals, families and members of the community to provide this service to better equip them with information in their health and life journey. We provide support groups with information and education so that they can provide informed service to their members and to network on matters of mutual concern. As a peak body we provide representation at state, federal and research activities.

As a peak body for rare genetic conditions, we support the provision of services by appropriately trained, qualified, and regulated genetic counsellors. As the science of genomics is expanding from research into health care delivery, genetic counsellors have become a vital and necessary part of contemporary health care management. In 2015, a survey entitled "Australian patients and families' perspectives on genome sequencing" was conducted by Genetic Alliance Australia in order to inform the development of a Genome Sequencing Patient Charter. The response to the survey was very strong, 413 people living or caring for people living with a genetic disease responded to the survey.

The Perspectives Survey showed that people who have a genetic disorder, or their carers /relatives have a strong desire to find a diagnosis. There are high expectations that genome sequencing will provide either a diagnosis or deeper insight into their illness. Clear and concise communication and information is important to ensure patient are accurately informed of the risk and benefits before their genome is sequenced or genetic testing conducted. Healthcare providers, have a responsibility to ensure that the reality and expectation of genome sequencing are appropriately communicated and the risks and benefits clearly outlined. It must also be recognised that genomic technologies and medicine are still evolving and may change as technology improves and insights from data analysis improves. Data privacy and security, the impact on life insurance and responsibility of researchers were also commented on.

- Patients want full disclosure of risks and benefits of genome sequencing:
 - 82% what information can be revealed,
 - 73% who can access the data,
 - 63% understanding of genetics and genome sequencing,
 - 67% implications for health insurance,
 - 71% information about accuracy and potential for misdiagnosis,

Funded by:

NSW HEALTH

- 84% how much will it cost
- When patients are seeking information about Genome Sequencing, they consider the following as the main sources of information:
 - Medical specialist 58%,
 - genetic counsellor 49%,
 - Genetic Clinics 43%,
 - GP 42%,
 - support groups 34%

Genetic counsellors have distinct qualifications, skills, experience, and expertise to support individuals and families with genetic conditions. As allied health professionals they provide critical service to patients, including:

- enabling the genetic and genomic information to be explained in plain language
- to provide information and support to individuals and families attempting to comprehend and adjust to a genetic condition
- Applying genomic information to overall future healthcare for an individual and family.
- Providing practical and psychosocial support for those with, and at risk from, genetic disease.
- Navigating the ethical challenges surrounding the disclosure and sharing of genetic information.
- Interpreting and explaining complex, incidental or uncertain genomic information.
- Providing education for the wider healthcare workforce on the clinical application of genomics

These services are critical and especially important for people from disadvantaged or non-English speaking backgrounds, varying literacy levels, disabilities (blind, deaf, visually impaired) and as people who interpret and process data in different ways.

For patients and families affected by genetic/genomic conditions, the service provided by trained genetic counsellors is uniquely skilled: informed by genomic science and sensitive to the psychosocial needs of each client. This knowledge and skill is called upon in initial consultation, diagnosis and follow up, in some cases follow up may be in a yet unresearched, unknown future. In discussion with those who have engaged with genetic counselling services tell of being aware of options in health management, family planning and for many, conclusion of a diagnostic odyssey.

Genetic Alliance Australia supports this application in principle, and call for its acceptance by MSAC and entry into the MSAC process. We would also welcome contact from the Department during the consultation process.

Kind regards,
Jan Mumford



Executive Director
Genetic Alliance Australia

4 August 2021

Professor Robyn Ward, Chair
Medical Services Advisory Committee (MSAC)

Dear Professor Ward,

We are writing to express support for the Genetic Counsellors of the Human Genetics Society of Australasia (HGSA) application to open a dialogue about Medicare Provider numbers for genetic counsellors, and Medicare Benefits Scheme (MBS) items for services provided by genetic counsellors.

Genetic Counsellors provide critical support for individuals and families at times where they are at their most vulnerable. They provide a bridge between science to the reality of a future. At the time of interaction, that future is uncertain, overwhelming and almost always terrifying. This interface translates and delivers a pathway, a plan and a way forward. Access to genetic counsellors is needed by all in our community but not equitably available.

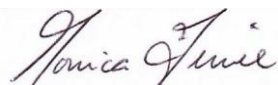
At the Genetic Support Network of Victoria (GSNV), we serve people living with genetic, undiagnosed and rare disease and support those who support them, including patient support organisations, carers, health professionals, researchers etc. We engage with those who are fortunate to have accessed a Genetic Counsellor and those who are not. We understand with clarity and experience, the difference this interaction can make, not just in the short term but to a family over many years. This service makes a huge difference.

We support the provision of services by appropriately trained, qualified, and regulated genetic counsellors as an integral part of the management of patients and families affected by genetic/genomic conditions and those who are seeking to make choices informed by genetic and genomic testing.

Genetic counsellors assist families and individuals to understand complex information and how it may impact their future, they explore choices, they bring objectivity and certainty into a time and space that is most uncertain. They are a source of care without judgment and bring invaluable tools and resources. The GSNV works closely with the genetic counselling profession and with the Masters of Genetic Counselling programs to bring the reality of genetic, undiagnosed and rare disease lived experience to increase the genetic counsellor understanding and resource kit ensuring individuals and families get what they most need.

We support this application in principle, and its acceptance by MSAC for consideration and entry into the MSAC process. We would also welcome contact from the Department during the consultation process.

Yours sincerely



Monica Ferrie
Chief Executive Officer
Genetic Support Network of Victoria
P: +61 403 909 748
E: monica.ferrie@vcgs.org.au



GUARD COLLABORATIVE AUSTRALIA

Professor Robyn Ward, Chair
Medical Services Advisory Committee (MSAC)

21 July 2021

Dear Professor Ward,

We are writing to express support for the Human Genetics Society of Australasia (HGSA) application for the timely introduction of Medicare Provider numbers and Medicare Benefits Scheme (MBS) items for services provided by genetic counsellors.

The Genetic Undiagnosed and Rare Disease (GUARD) Collaborative is a coalition of peak organisations; Genetic Support Network of Victoria, Genetic Alliance Australia (NSW) and Syndromes Without A Name (SWAN) Australia. Together we represent the voice of people living with genetic, undiagnosed and rare disease and those who support them. We strive for a fair, equitable and collaborative approach to health and wellbeing for all members of our population. We bring both personal and professional expertise and knowledge, to influence and improve outcomes for people with undiagnosed and rare genetic conditions.

Genetic counsellors have a unique set of expertise and provide critical, support and timely information to patients and consumers so they can make informed choices and decisions. They support the undiagnosed and rare disease community by:

- Communicating genetic and genomic information in plain language
- Providing information and support to individuals and families adjusting to diagnosis of a genetic condition (or lack of one)
- Providing practical support for those diagnosed or at risk from genetic disease
- Providing psychosocial support for those with or at risk of being affected from genetic disease.
- Identifying and navigating the ethical and personal challenges with regard to disclosure and sharing of genetic information with family and loved ones.
- Providing guidance and explanation of complex, incidental or uncertain genomic information.

GUARD supports the provision of services by trained, qualified, and regulated Genetic Counsellors. This discipline has evolved alongside the science of genomic technology, to provide the community with understanding of the personal impacts, health management and treatment choices available to them. We support the provision of Medicare funded item numbers for the services Genetic Counsellors provide to assist families and individuals to relieve health costs to a resource impacted community.

GUARD supports HGSA for initiating this application for needed services with MSAC and calls for MSAC to initiate the necessary process for provision of Item numbers. We would also welcome contact from the Department during the consultation process.

Kind regards

A handwritten signature in dark ink, appearing to read 'H. Renton', with a stylized, flowing script.

Heather Renton
CEO – SWAN Australia
On behalf of the GUARD Collaborative Australia

20 July 2021

Professor Robyn Ward, Chair
Medical Services Advisory Committee (MSAC)

Genetic Counsellors' application to the Medicare Services Advisory Committee (MSAC)

Dear Professor Ward,

InGeNA, the alliance for Australian genomics industry partners, is endorsing the Human Genetics Society of Australasia's request for in-principle support from the Medical Services Advisory Committee to open a dialogue about Medicare Provider numbers and Medicare Benefits Scheme items for services provided by genetic counsellors.

The alliance partners, working in collaboration with many patient and consumer bodies, believe genomics will bring long and far-reaching benefits to Australian health consumers.

Appropriate funding models are needed to facilitate and improve access to professional genetic counsellors, and enable support for patients and other healthcare providers, as the community is increasingly making use of genetic/genomic technologies and information.

An important first step is in-principle support to enter the Medical Services Advisory Committee assessment process.

Thank you for considering this request. We would like to make InGeNA available to discuss any aspect of the HGSA discussion regarding funding models for genetic counselling.

Yours sincerely,



David Bunker
Chair, InGeNA

8 July 2021

Professor Robyn Ward, Chair
Medical Services Advisory Committee (MSAC)

Dear Robyn,

I am writing to you in your capacity as Chair of the Medicare Services Advisory Committee. I understand that the genetic counsellors of the Human Genetics Society of Australasia (HGSA) are considering making an application to MSAC. As a respiratory paediatrician, I work very closely with genetic counsellors, and as such am writing to express support for their application to open a dialogue about Medicare Provider numbers for genetic counsellors, and Medicare Benefits Scheme items for services provided by genetic counsellors.

As lead for a recent Australian Genomics flagship for paediatric rare lung diseases (interstitial lung disease in childhood) I have witnessed first-hand the importance of the provision of services by appropriately trained, qualified, and regulated genetic counsellors as a clinically relevant and necessary part of the management of many patients and families affected by genetic/genomic conditions.

I strongly support this application in principle and its acceptance by MSAC for consideration for entry into the MSAC process. I would be very happy to be contacted by the Department during the consultation process if appropriate.

Yours faithfully,

A handwritten signature in black ink, appearing to read 'Adam Jaffe'.

Professor Adam Jaffe
Head, School of Women's & Children's Health
John Beveridge Professor of Paediatrics
UNSW Medicine

Prof Robyn Ward
Chair
Medical Services Advisory Committee (MSAC)

Wednesday 21 July 2021

Dear Professor Ward,

We are writing to express support for the Genetic Counsellors of the Human Genetics Society of Australasia (HGSA) application to open a dialogue about Medicare Provider numbers for genetic counsellors, and Medicare Benefits Scheme (MBS) items for services provided by genetic counsellors.

As the Melbourne Genomics Health Alliance Community Advisory Group (CAG), we provide a consumer perspective for those who access genetic and genomic services [now and in the future]. As genomic testing expands to the wider population the need for genetic counselling services will increase. We support the provision of services by appropriately trained, qualified, and regulated genetic counsellors as an integral part of managing and supporting patients and families affected by genetic conditions and who have to make important life decisions.

The CAG serves as a forum for the promotion of person-centred care in genomic medicine [and beyond]. We advocate for the interests of those who may benefit from genomic testing. Genetic counsellors play a key role in supporting people to make informed decisions about testing and in addressing questions and providing support once people have received their results, whether a diagnosis is made or not.

We wholeheartedly support the equitable availability of the provision of services by appropriately trained, qualified, and regulated genetic counsellors as an important part of the management of many patients and families affected by genetic conditions. This is so those patients and families are able to make balanced informed choices and decisions.

We support this application in principle, and its acceptance by MSAC for consideration and entry into the MSAC process. We would also welcome contact from the Department during the consultation process.

Kind regards,



Jane Bell

Chair

On behalf of:

Melbourne Genomics Community Advisory Group

Alliance members



Supported by



Professor Robyn Ward,

16/7/2021

Chair, Medical Services Advisory Committee (MSAC)

Dear Professor Ward,

We are writing to express support for the Genetic Counsellors of the Human Genetics Society of Australasia (HGSA) application to open a dialogue about Medicare Provider numbers for genetic counsellors, and Medicare Benefits Scheme (MBS) items for services provided by genetic counsellors.

HGSA is a member of the National Alliance of Self Regulating Health Professions. NASRHP supports the member organisations of self-regulating health professions. It provides a formal independent body administering a quality standards framework for these professions. These organisations must meet benchmark standards for regulation and accreditation of practitioners within that profession. NASRHP standards have been closely modelled on the AHPRA standards and are composed of the following eleven [standards](#)

The NASRHP support the provision of services by appropriately trained, qualified, and regulated genetic counsellors as a clinically relevant and necessary part of the management of many patients and families affected by genetic/genomic conditions.

We support this application in principle, and its acceptance by MSAC for consideration and entry into the MSAC process. We would also welcome contact from the Department during the consultation process.

Kind regards,

Anita Hobson-Powell

Chair, NASRHP



PO Box 725
Narrabeen, NSW 2101
T: 0415 582 837
E: sarah@pinkhope.org.au

Professor Robyn Ward, Chair
Medical Services Advisory Committee (MSAC)

14th July 2021

Dear Professor Ward,

We are writing to express support for the Genetic Counsellors of the Human Genetics Society of Australasia (HGSA) application to open a dialogue about Medicare Provider numbers for genetic counsellors, and Medicare Benefits Scheme (MBS) items for services provided by genetic counsellors.

As a health promotion charity that supports families with hereditary breast and ovarian cancer who use the services of genetic counsellors, we support the provision of services by appropriately trained, qualified, and regulated genetic counsellors as a and necessary part of the management of many patients and families affected by genetic/genomic conditions.

As someone that has used the services of genetic counsellors when undertaking genetic testing to find out I carry a BRCA1 mutation, I can vouch for the absolute need for this. Reducing wait times and costs for patients to have the services of a genetic counsellor would go a long way to improving the often overwhelming and stressful experience for those at high risk of cancer.

One of our community members Robyn Smith when asked for her views on this topic - *"From the time that I was told that my Mum carried a genetic mutation that predisposed our family to cancer in 2014, there was waiting. I waited to get an appointment with the Genetic Services in my State, I waited to get a telehealth appointment with a more experienced genetic counsellor, and I waited longingly for my results. This is not because the services are poor, it is because there are not enough services to deal with the demand. And we know that after Angeline Jolie came out with her mutation, this only got much, much worse*

Publicly provided Genetic Services do the best they can with the resources they have but being under resourced means that patients wait, and it is often an anxious time. Having an MBS item for genetic counselling services would mean that patients can be referred and see counsellors in a timelier manner and can access continuity of care with the same provider. Genetic Counsellors could provide so much more support if they were funded under the MBS. It would not be just the 'essentials', it would be the essentials and much more which would make the patient experience and outcomes much better.

As a human with a gene mutation, I have sought and paid for private health services for support, over and above what is publicly provided as I simply couldn't wait. I would gladly support an MBS item so that patients have timely access to genetic counsellors to support informed decision making and better patient outcomes. "

We support this application in principle, and its acceptance by MSAC for consideration and entry into the MSAC process. We would also welcome contact from the Department during the consultation process.

Kind regards,

A handwritten signature in blue ink, appearing to read 'Sarah', with a stylized, cursive script.

Sarah Powell

CEO, Pink Hope

Professor Robyn Ward, Chair
Medical Services Advisory Committee (MSAC)

16 July 2021

Dear Professor Ward,

I am writing on behalf of Rare Voices Australia (RVA) to express support for the Genetic Counsellors of the Human Genetics Society of Australasia (HGSA) application to open a dialogue about Medicare Provider numbers for genetic counsellors, and Medicare Benefits Scheme (MBS) items for services provided by genetic counsellors.

RVA is the national peak body for Australians living with a rare disease. RVA led the collaborative development of the National Strategic Action Plan for Rare Diseases (the Action Plan) and is now leading its collaborative implementation. In 2020, the Minister for Health launched the Action Plan with bipartisan support. The Action Plan provides guidance and direction around key goals and priorities of the rare disease sector in Australia, including a strong patient voice.

Rare diseases are estimated to affect two million Australians, and 80 per cent of rare diseases are of genetic origin. Therefore, advances in genomic medicine have been a game-changer for the detection and treatment of rare diseases. Many of the key priorities, actions and implementation steps in the Action Plan highlight the importance of genomic medicine and, in particular, the need for genetic counsellors:

Priority 1.3: Develop a national rare disease workforce strategy that responds to the current and future demands, including the impact of genomics.

Action 2.3.1: Ensure individuals and families known to have an increased chance of being carriers of genetic variants for rare diseases have equitable access to pre-conception genetic testing and counselling, which can provide them with information about becoming pregnant and pregnancy.

Implementation 2.4.1.2: Align with and build on the existing National Health Genomics Policy Framework for the systematic, equitable and timely delivery of genomic services, such as genetic testing (diagnostics) and gene therapies (treatments) and genetic counselling to Australians with, suspected of having, or with an increased chance of a rare disease¹.

'Advances in genetics and genomics provide opportunities to increase our understanding of disease, including prevention and treatment'^{2,6}. However, they also increase uncertainty and raise significant ethical, legal, social and economic implications. The Evidence Base for the Action Plan discusses the importance of education for individuals and families following genetic screening:

It has been well documented that with the growth in genomic testing, there has been a significant increase in demand for clinical geneticists and genetic

counsellors^{3,4}. A 2017 report commissioned by the New South Wales Ministry of Health articulated “the changing landscape” in which genetic counsellors are currently operating, noting that technological advancements have led to rapidly increasing potential to access genomic information, and this has led to a significant and widening gap between supply and demand of genetic counsellors and the services they offer^{5,6}.

In alignment with the Action Plan, RVA supports the provision of services by appropriately trained, qualified, and regulated genetic counsellors as a necessary part of the management of many patients and families affected by genetic/genomic conditions.

We support this application in principle and its acceptance by MSAC for consideration and entry into the MSAC process. We would also welcome contact from the Department of Health during the consultation process.

Kind regards,

Nicole Millis
CEO, Rare Voices Australia

References

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Professor Robyn Ward, Chair
Medical Services Advisory Committee (MSAC)

1st August 2021

Dear Professor Ward,

We are writing to express support for the Genetic Counsellors of the Human Genetics Society of Australasia (HGSA) application to open a dialogue about Medicare Provider numbers for genetic counsellors, and Medicare Benefits Scheme (MBS) items for services provided by genetic counsellors.

As a national organisation representing people who often use or may need the services of genetic counsellors, we support the provision of services by appropriately trained, qualified, and regulated genetic counsellors as a and necessary part of the management of many patients and families affected by genetic/genomic conditions.

Many people we see through our bereavement services are impacted by the devastating loss of babies due to genetic conditions. Many of these parents are desperate for answers and to understand how genetics can help them build their future families.

We support this application in principle, and its acceptance by MSAC for consideration and entry into the MSAC process. We would also welcome contact from the Department during the consultation process.

Kind regards

Bridget Sutherland
Director of Prevention and Advocacy
Red Nose Australia



**The Royal Australian
and New Zealand
College of Obstetricians
and Gynaecologists**
Excellence in Women's Health

5 August 2021

Medical Services Advisory Committee
Australian Department of Health

To whom it may concern,

Re: Letter of support | Australasian Society for Genetic Counsellors | access to the Medicare Benefits Schedule

On behalf of the Board and the Council of the Royal Australian and New Zealand College of Obstetricians and Gynaecologists (RANZCOG), the College is pleased to provide in principle support for the Australasian Society for Genetic Counsellors' application to the Medical Services Advisory Committee to explore the possibility of gaining access to the Medicare Benefits Schedule.

RANZCOG supports the provision of services by appropriately trained, qualified, and regulated genetic counsellors as a clinically relevant and necessary part of the management of many patients and families affected by genetic or genomic conditions. The College believes the services provided by professional genetic counsellors are clinical in nature and are necessary in the management of genetic and genomic conditions.

The College would welcome further discussion with the Australian Department of Health in relation to this application.

Your sincerely

Dr Vijay Roach
President

Cc Australasian Association of Clinical Geneticists executive@aacg.org.au

20 July 2021

Professor Robyn Ward, Chair
Medical Services Advisory Committee (MSAC)
Department of Health

Dear Professor Ward,

RE: Letter of Support – Genetic Counsellors of the Human Genetics Society of Australasia (HGSA) MSAC Application

We are writing to express support for the Genetic Counsellors of the Human Genetics Society of Australasia (HGSA) application to open a dialogue about Medicare Provider numbers for genetic counsellors, and Medicare Benefits Scheme (MBS) items for services provided by genetic counsellors.

As a professional body/organisation that may be impacted by this application, we support the provision of services by appropriately trained, qualified, and regulated genetic counsellors as a clinically relevant and necessary part of the management of many patients and families affected by genetic/genomic conditions.

We support this application in principle, and its acceptance by MSAC for consideration and entry into the MSAC process. We would also welcome contact from the Department during the consultation process.

Yours sincerely,



Dr Debra Graves
Chief Executive Officer
The Royal College of Pathologists of Australasia



Professor Robyn Ward, Chair
Medical Services Advisory Committee (MSAC)

July 21st, 2021

Dear Professor Ward,

We are writing to express support for the Genetic Counsellors of the Human Genetics Society of Australasia (HGSA) application to open a dialogue about Medicare Provider numbers for genetic counsellors, and Medicare Benefits Scheme (MBS) items for services provided by genetic counsellors.

As a consumer group representing people who use or may need the services of genetic counsellors, we support the provision of services by appropriately trained, qualified, and regulated genetic counsellors as a and necessary part of the management of many patients and families affected by genetic/genomic conditions.

With the evolution of rapid genomic testing many more families are being diagnosed with rare conditions such as SCN2A. Once diagnosed our families require immediate and ongoing support from a genetic counsellor. Access to a genetic counsellor is imperative to support families who are trying to digest not only complex information but very confronting information. Genetic counsellors are a pivotal care provider in the journey of our families and we rely on them heavily.

We support this application in principle, and its acceptance by MSAC for consideration and entry into the MSAC process. We would also welcome contact from the Department during the consultation process.

Kind regards,

Kris Pince



Syndromes Without A Name (SWAN) Australia

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PO Box 390, Fairfield, VIC 3078

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[linkedin.com/company/swanaustralia](https://www.linkedin.com/company/swanaustralia)

twitter.com/swanaus

Professor Robyn Ward
Chair
Medical Services Advisory Committee (MSAC)

19 July 2021

Dear Professor Ward,

We are writing to express support for the Human Genetics Society of Australasia (HGSA) application to open a dialogue about the introduction of Medicare Provider numbers and Medicare Benefits Scheme (MBS) items for services provided by genetic counsellors.

Syndromes Without A Name (SWAN) Australia is extremely grateful for genetic counsellors' support for our families. SWAN supports families caring for a child with an undiagnosed or rare genetic condition. As you can imagine, when you have a SWAN child, parents experience high rates of anxiety. They can be confused and frustrated that the medical profession cannot always give them a reason for their child's genetic condition or even identify it. Even when an answer is found for our SWAN children, the condition is generally so rare that not much information is known about the rare disease. Imagine how isolating our parents must feel. They often do not know where to turn to for support. What if families want to have more children? Who can give them credible information to support them to make informed choices and decisions? Usually, this trusted person is a professionally trained and qualified genetic counsellor. Many SWAN families utilise genetic counsellors to support them at the time of their diagnosis and post-diagnosis, or lack of diagnosis. There are very few professions that translate medical jargon into clear, understandable information for our families, and genetic counsellors are imperative in complementing the work of SWAN by providing information and support to our families. With an estimated 50 SWAN children born every week, our families would be lost without genetic counsellors' support.

SWAN strongly support genetic counsellors being able to charge for their services through a Medicare funded item number so that these highly trained, qualified and regulated professionals can continue to manage patients and consumers affected by genetic conditions. As genomic testing expands to the general population, so will the need for more professionally trained genetic counsellors.

We applaud the HGSA for commencing the dialogue with MSAC for consideration of their application. We would also welcome contact from the Department during the consultation process.

Kind regards

Heather Renton
Chief Executive Officer
Syndromes Without A Name (SWAN) Australia

Professor Robyn Ward, Chair
Medical Services Advisory Committee (MSAC)

Friday the 9th of September 2021

Dear Professor Ward,

On behalf of *Through the Unexpected*, I am writing to express support for the Genetic Counsellors of the Human Genetics Society of Australasia (HGSA) application to open a dialogue about Medicare Provider numbers for genetic counsellors, and Medicare Benefits Scheme (MBS) items for services provided by genetic counsellors.

Our health promotion charity aims to improve the experience of receiving a prenatal diagnosis of a congenital anomaly. Expectant parents who receive unexpected news about the health, development or genetics of their unborn baby experience shock, distress and a high incidence of PTSD and enduring mental health conditions. This experience is complicated by the lack of policies and guidelines to ensure equitable, patient centred care for parents moving through the unexpected. At a time when parents are in great need, they face barriers to services that can provide information, support and empowerment which can reduce both short and long term mental health challenges.

As an organisation, we support the provision of services by appropriately trained, qualified, and regulated genetic counsellors as a necessary part of the management of many patients and families moving through the unexpected.

Timely access to genetic counsellors, who can provide information and non-judgemental, non-directive support will improve the experience of receiving a prenatal diagnosis. At this time of stress and shock, the current time and session limited care does not adequately meet the needs of parents facing decisions about their pregnancy, understanding what a diagnosis may mean and grappling with new complex health information. Parents need more time to revisit information, to explore the meaning for their family and to understand tests and results, without this, informed consent remains challenged.

The availability of MBS items for genetic counsellors will improve access to support and reduce current inequities in accessing support. We support this application in principle, and its acceptance by MSAC for consideration and entry into the MSAC process. We would also welcome contact from the Department during the consultation process.

Kind regards,



Pieta Shakes
Executive Director



20 July 2021

Professor Robyn Ward

Chair, Medical Services Advisory Committee (MSAC)

Dear Professor Ward

May I firstly introduce myself as the General Manager at Tuberous Sclerosis Australia (TSA). TSA is the only charitable organisation in Australia supporting the 2,500+ people living with Tuberous Sclerosis Complex (TSC), a rare genetic condition that causes tumours to grow in various organs of the body.

I am writing on behalf of the staff and committee of TSA and the entire TSC Community in Australia to express support for the Genetic Counsellors of the Human Genetics Society of Australasia (HGSA) application to open a dialogue about Medicare Provider numbers for genetic counsellors, and Medicare Benefits Scheme (MBS) items for services provided by genetic counsellors.

Many of the people in our TSC community benefit from access to services of expert genetic counsellors. These counsellors provide support, answers and much needed counselling during the stressful and difficult time when our families are coming to terms with their diagnoses and interpreting what this may mean for their future.

In the words of our TSA Nurse, "it is about coming to terms with the implications of a genetic disease and you need comprehensive expert opinion to help understand the complexities of genetics."

As a patient organisation representing people who need the services of genetic counsellors, we strongly support the provision of those services by appropriately trained, qualified, and regulated genetic counsellors. It is a necessary and much-needed part of the management of many patients and families affected by TSC and other genetic/genomic conditions.

We support this application and its acceptance by MSAC for consideration and entry into the MSAC process. We welcome contact from the Department during the consultation process.

Kind regards

Jackie Gambrell

General Manager, TSA

Professor Robyn Ward, Chair
Medical Services Advisory Committee (MSAC)

29th October, 2021

Dear Professor Ward,

We are writing to express support for the Genetic Counsellors of the Human Genetics Society of Australasia (HGSA) application to open a dialogue about Medicare Provider numbers for genetic counsellors, and Medicare Benefits Scheme (MBS) items for services provided by genetic counsellors.

As a consumer group representing people who need the services of genetic counsellors, UsherKids Australia supports the provision of services by appropriately trained, qualified, and regulated genetic counsellors as a and necessary part of the management of many patients and families affected by genetic/genomic conditions.

Currently in Australia there is a huge disparity in the availability and access to genetic counselling for families of children with Usher syndrome. Having services provided by genetic counsellors funded through MBS would lead to more equitable outcomes and reduced health disparities for those that currently are unable to access services.

We support this application in principle, and its acceptance by MSAC for consideration and entry into the MSAC process. We would also welcome contact from the Department during the consultation process.

Kind regards,

Emily Shepard



Director
UsherKids Australia Ltd