Human Genetics Society of Australasia
ARBN 076 130 937 (Incorporated Under the Associations Incorporation Act)
The liability of members is limited
... making sense of your genes

9th July 2021
IHPA Secretariat
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Dear IHPA Secretariat,

RE: Independent Hospital Pricing Authority (IHPA) Consultation Paper on the Pricing Framework for Australian Public Hospital Services 2022-23

The Human Genetics Society of Australasia (HGSA) was formed in 1977 to provide a forum for the various disciplines represented under the title of Human Genetics and is the leading professional body for health professionals working in the fields of genetics and genomics. Our members include clinical geneticists, genetic counsellors, diagnostic scientists, researchers and academics.

We welcome the opportunity to provide a response to the consultation paper. We are specifically responding to the question "***What evidence is there to support increased costs for genetic services…?"***

Capturing cost of testing in determining NEP for genetic services

Genetic health professionals report uncertainty about how their local jurisdictions derive the costings reported to IHPA. Interpretation of codes is inconsistent and therefore data supplied to IHPA is unreliable.

Previous HGSA submissions to IHPA, going back to 2012, have questioned how costs for genetic and genomic testing are captured in the data provided to IHPA. We feel this is still not captured in a consistent manner by the reporting entities. The laboratory costs are not easy to incorporate into the overall costing and we feel these are often "lost" especially for tests referred overseas/interstate?.

There are increasing opportunities for Australian patients and families to benefit from genomic testing as evidenced by a number of published studies[1,2,3], yet many health professionals convey constraints in ordering the genetic and genomic tests that they feel are appropriate to deliver the necessary standard of health care for their patients. This means that equitable access to appropriate genetic/genomic tests, information and counselling is limited.

Therefore, even if existing testing were captured consistently, these rates would under-represent the appropriate level of service if cost effectiveness and clinical utility were applied to all patients. Genetic and genomic testing remains poorly covered by Medicare and the testing currently funded through Australian Genomics flagship programs needs to be made sustainably accessible via Activity Based Funding (ABF) of clinical genetics services.

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Underestimated cost of genetic services due to complexity and non-consultation time

By their nature genetic conditions are rare and thus have added complexity related to the consultation. In most cases this will require a review of the literature relating to the suspected condition and extensive investigation of testing options unique for each family. Appropriate informed consent for testing and subsequent interpretation of results adds to the administrative burden.

The family implications of making a diagnosis also have wide reaching impact on genetic services which are not captured by standard non-admitted activity reporting. The true time spent on each family accessing genetic services has been estimated at 7.5hrs of clinical geneticist time and a further 6.25hrs of genetic counsellor time per patient[5].

Overall underfunding of genetic services caused by these issues has an obvious effect on service delivery, but there is also an effect on recruitment and training making it difficult to attract providers into this expanding area of practice.

Data capture for genetic counsellor services

The increasingly important role of genetic counsellors in delivering clinical genetics services has been highlighted in a 2017 report to NSW Health[4]. In previous correspondence from HGSA to IHPA in 2020, we suggested establishing a new Tier 2 class 40 service category for genetic counsellor services. At that time, we noted some jurisdictions were using the 40.53 classification General medicine to capture genetic counselling allied health services. This clearly underestimates the complexity of genetic counselling and the extensive work required outside of the face to face consultation. For example, we know from the 2017 AGHA Professional Status Survey of Genetic Counsellors and Clinical Geneticists[5] that much of the preparative work for genetic and genomic testing was performed by genetic counsellors.

The inconsistency in recording of genetic counsellor activities across different services makes it hard to provide evidence of how a new classification would replace existing activity estimates and/or capture something currently invisible.

If we are to be successful in mainstreaming genomics into other clinical services, we will need to fund the appropriate use of genetic counsellors in multidisciplinary teams, primary care and through allied health referrals to specialist genetic counselling services.

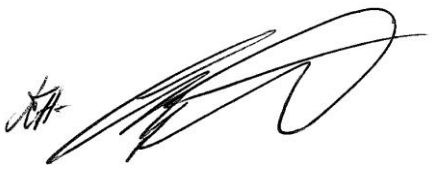
Recommendations

IHPA should urgently undertake onsite visits to genetic services in a number of different jurisdictions to better understand the effectiveness and accuracy of data capture for their activity. We note this was planned as part of the Australian non-admitted care costing study which was suspended due to the impact of COVID-19.

A new Tier 2 class 40 service category should be established for genetic counselling.

We would welcome further discussion and collaboration with IHPA to progress these recommendations.

Yours sincerely,



Dr Kevin Carpenter, CEO HGSA

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