8th July 2022

IHPA Secretariat
submissions.ihpa@ihpa.gov.au

Dear IHPA Secreteriat,

RE: Consultation Paper on the Pricing Framework for Australian Public Hospital Services 2023–24

I write on behalf of the Australian Genomics Health Alliance (Australian Genomics), 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.

A key priority for Australian Genomics is to support resolution of complex issues to funding of public genetic services across Australia. Through engagement with genetics services, other health professionals delivering genetic health care, and senior health managers in each jurisdiction, Australian Genomics continues to raise awareness and to support action and collaboration with key stakeholders to bring about change.

We thank you for your engagement with Australian Genomics and the opportunity to provide a response to the 2023-24 consultation paper.

In response to the consultation question *"Are there any adjustments IHPA should prioritise investigating to inform the development of NEP23?"*:

In 2021, Australian Genomics provided evidence to support the increasing costs of genetic services (including genetic/genomic testing) in response to the IHPA Pricing Framework 2022-23 consultation paper. Our response highlighted the need to capture the rapidly increasing demand for genetic services more accurately and systematically, the variability within genetic services, the time spent on each patient and the different types of genetic tests used across all services. Our recommendations included standardised data collection of genetic service provision across jurisdictions and support for reinstating delayed costing studies to capture service activity more accurately.

We are therefore reassured by IHPA's continued commitment to investigate feasible ways to recommence costing studies outlined in this year's consultation paper, to explore better classification of genetic services within the existing Tier 2 non-admitted classification system, and to devise a new system. We also support IHPA's plans to use existing electronic medical data systems to enable better data linkage and capture of service activities that are likely recorded across multiple databases, potentially leading to improved costing assessment whilst decreasing the burden of costing studies.

Following our response to the 2022-23 consultation paper, we had further engagement and advice from IHPA, including clarification that the 20.08 code is currently the most appropriate Tier 2 Non-Admitted Services code for Genetic Counsellors, in addition to Clinical Geneticists and other medical professionals providing services related to hereditary and/or genetic disorders. For particular states where services were using alternative codes for genetic counsellors (e.g. 40.53 in WA), this advice has been fed back through senior health managers and has led to more appropriate coding. We would welcome further refinements to the Tier-2 Non-Admitted Services Classification for 2023-2024 to capture the wide variety of patients accessing genetic services, their reason for referral or attendance, the amount of time required for service provision (including pre- and post-consultation) and investigations performed (including but not limited to genetic testing). In combination, the existing divisions within genetic services and different appointment types might adequately capture the additional information required and could inform refinements to the Tier 2 system. For example, services are generally divided between sub-specialties: Cancer, Paediatrics, Prenatal/Reproductive and General/Adults. Appointment types can differ based on reason for attendance and urgency, including (but not limited to) 'diagnostic' appointments for individuals affected by a suspected genetic disorder and 'predictive' appointments for individuals where there is a genetic disorder in the family with a known underlying mutation. As outlined in a submission to IHPA by Genetic Health Queensland and South Australian Clinical Genetics Service in 2012, there are different types of consultation (e.g. face to face, telehealth, letter) which could also impact the cost of service provision.

As with the refinements for the current Tier 2 system, we would support the same considerations for adjustments in the development of NEP23. In addition, other adjustments could be considered to reflect more time and/or costs involved with particular types of genetic services, such as whether the patient has a rare disease, lives in a regional/remote area, or has a genomic test requested. Given the increasing number of other specialties providing genetic counselling and requesting genetic testing for their patients, it would be important to consider how adjustments might also apply in other contexts, including specialist multidisciplinary clinics (e.g. cardiac and renal genetics clinics).

As noted in our response to the IHPA consultation paper for 2022-23, significant pre- and post-consultation work is performed by Genetic Counsellors and Clinical Geneticists for each patient and this is not adequately captured in the ABF price for non-admitted service events. Work performed outside of face-to-face appointments can include workup and validation of family history, pre-clinic contact with the patient, multidisciplinary and laboratory case discussions, summary notes and clinical letters, reviewing medical literature, , expert consultation for rare diseases and post consultation results follow up and disclosure, with overlap of these tasks between genetic counsellors and clinical geneticists depending on the case. A 2017 survey by Australian Genomics reported that delivering services relating to genomic testing added approximately 2.25 hours extra in total workload per patient for genetic counsellors, and approximately 1.5 hours per patient for clinical geneticists, compared to genetic testing. The greatest addition is in time taken for tasks relating to testing for both clinical genetic counsellors (3.8 times as long) and clinical geneticists (2.8 times as long).

Many service events will have contributions from clinical geneticists and genetic counsellors, and the proportion of input from each is variable depending on the complexities that have already been raised. We think this would be an important consideration in any changes made to the current or new system,

and hope that findings of future costing studies will also better inform the breakdown of time involved in the breadth of genetic services provided, and whether a specific 'genetic counselling' code is warranted as has been recommended in the past. Given the downstream economic benefits of access to genetic services and early genomic testing, adequate costing and funding of these services is imperative.

Australian Genomics would also like to acknowledge the uncertainty around the collection of genetic service data across hospitals and jurisdictions, and whether the increasing number of Medicare-funded genetic tests are being requested for public patients and reported to IHPA.

In response to the consultation question "*Are there any specific considerations IHPA should take into account for assessing COVID-19 impacts on the 2020–21 data in the development of NEP23?*":

Throughout the COVID-19 pandemic, all hospitals have become more resource-intensive to deal with PPE requirements, space and social distancing requirements (e.g. operating theatres required greater time between patients to allow for "deep cleaning"), and there was increased sick leave for staff (especially those who were infected with COVID). Some services were increased (e.g. ICU) but most outpatient services decreased or moved to a telemedicine basis, which included genetics. Therefore, services such as genetics with decreased throughput saw an increase in cost per case, which might not be reflective of business as usual in 2022/23, thus impacting the pricing model.

Rapid whole genome sequencing for critically ill paediatric patients:

Australian Genomics commends IHPA for shortlisting 'rapid whole genome sequencing for critically ill paediatric patients' for consideration of classification development in 2022. Australian Genomics would like to remain engaged in this process, and we have noted it is not listed in the recently-released National Coding Advice – Coding Rules for ICD-10-AM/ACHI/ACS (Twelfth Edition) nor in mentions of new submissions to IHPA. Would this be captured in the new intervention codes to enable the classification to keep pace with new health technology and other emerging concepts that require classification prior to the release of a new edition? As further information becomes available, Australian Genomics would like to share details and progress through its national clinical and diagnostic networks.

Australian Genomics representatives would welcome the opportunity over the coming year to engage further with IHPA on these and other emerging matters in relation to genomic testing.

Sincerely,

Tiffany Boughtwood
Managing Director
Australian Genomics