13 July 2023

IHACPA Secretariat
submissions.ihacpa@ihacpa.gov.au

Dear IHACPA Secretariat,

RE: Consultation Paper on the Pricing Framework for Australian Public Hospital Services 2024–25

I write on behalf of 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 2024-25 consultation paper.

Continued need for data collection in the context of genetic service provision (relevant to Question 4 of Consultation Paper):

As outlined in previous consultation responses by Australian Genomics, in 2021 and 2022, there is an ongoing need to capture data on genetic service demand. Such data should

reflect the variability of genetic service provision in terms of time spent per patient, the type and cost of different genetic tests, tests utilised in the acute care setting and also genetic testing in non-genetic specialties (for example specialist endocrine, cardiac, oncology services). As outlined in previous correspondence, the purpose of such data capture is to ensure the adequate resourcing of genetic services across Australia.

Australian Genomics welcomes the 2023 commencement of the Australian Non-Admitted Patient Classification Project including use of health information available via jurisdictional electronic medical records (eMR). As outlined in the consultation papers, this should aid in the efficiency and accuracy of data collection. We recognize some of the challenges with health information collection including the use of different eMR systems across states and territories and also within health services in the same jurisdiction. In some cases, this may pose restrictions on how far back data collection can occur. As such, we recognize the need for further work on mapping and standardization of eMR systems across jurisdictions. Despite such challenges, we encourage this as an ongoing avenue to refine non-admitted care classification. Accurate collection of this data will aid in capturing the demand for genetic services and help inform adequate resourcing across Australia.

40.66 Genetic Counselling code (relevant to Question 4 of Consultation Paper):

In relation to the new 40.66 Genetic Counselling code, Australian Genomics welcomes its inclusion in Tier 2 Version 8.0. As outlined in our previous consultation response in 2022, we believe it is worthwhile to continue to collect data on use of the genetic counselling code in Australian jurisdictions, to reflect health practitioner time during the consultation and also pre and post consultation.

In terms of use and application of the new code, further advice may be required in contexts beyond that of genetics clinics. For example, in familial cancer clinics or metabolic clinics, genetic counsellors are employed for their specialist work alongside a specialist consultant physician. We believe that the efficient capture of such events may be possible through the eMR route as outlined above, although may face similar restrictions.

As outlined in section 3.4.1 of the consultation paper, we believe there is a benefit in continuing to collect data on the full range of patient-related activity, to ensure the pricing associated with this code is accurate. This is especially relevant as the field of genetic counselling continues to evolve. For example, we note that these health practitioners will

likely be involved in delivery of reproductive genetic carrier screening and other population level testing.

Virtual Care in the context of Genetic Service provision (relevant to Question 16 of Consultation Paper):

Virtual care is a broad and evolving space in health care. We believe this is an area that should be prioritised for genetics services, and data collection on how often care is being delivered in this format will be important for addressing equity of access for rural, remote and very remote patients.

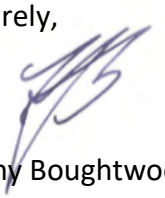
Rapid whole genome trio testing for critically ill paediatric patients:

We take this opportunity to comment on Acute Care Genomics – noting that there has been specific correspondence and engagement with IHACPA concerning this matter:

- We understand that rapid whole genome trio sequencing is unlikely to be considered for classification development in the admitted acute setting, in line with guidelines from IHACPA on the Assessment of New Health Technologies 2021-2022.
- We note that trio testing is the gold standard for rare disease patients, where sequencing of parental samples informs the de novo status of potentially disease-causing genetic variants.
- Rapid whole genome trio testing is currently available in some states, where interim funding arrangements have been put in place. For example, in some states this occurs via a case approval mechanism by State Health departments. In others, this testing is funded by the requesting inpatient-service team, as the state-wide genetic service is not funded for in-patient testing.
- The importance of State and Territory reporting on activity in this space is recognised. Specifically, collecting data on the frequency and mode of funding across States and Territories for rapid whole genome trio testing should occur to facilitate equitable access across Australia. Australian Genomics could support IHACPA in this data collection and aid in progressing discussions through our clinical networks.

Australian Genomics thanks you again for this opportunity to respond. Our representatives would welcome the opportunity over the coming year to engage further with IHACPA on these and other developing matters in relation to clinical genomic testing and services.

Sincerely,



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