Co-Chairs
Primary Health Reform Steering Group

27th July 2021

Dear Dr Hambleton and Dr Jammal,

Thank you for the opportunity to provide a response to the consultation on Primary Health Reform Draft Recommendations, which we submit on behalf of Australian Genomics.

Australian Genomics is an Australian Government initiative supporting genomic research and its translation into clinical practice. Through broad engagement and a national collaborative approach, it achieves two key objectives: to improve 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.

Overall, we find the recommendations comprehensive and address wide-ranging and well-known issues, indicating that this work is on a path to achieve the Government's Primary Health Reform. Here we address recommendations specifically relating to health genomics and its delivery through primary health care.

Recommendation 1 (One system focus): Reshape Australia's health care system to enable one integrated system, including reorientation of secondary and tertiary systems to support primary health care to keep people well and out of hospital

For the primary health care system of the future, an integrated system will be essential. For example, for a person's genetic information to maximally inform their health and wellbeing, it will need to be information that is available across the spectrum of health care. Pharmacogenomic information will need to be available to clinical teams treating patients in emergency and surgery situations, as well as at the GP and pharmacy. Information from a person's genetic history will impact upon advice given to couples about reproductive decisions at the GP, for IVF, at the obstetrician, and in the hospital.

Another issue is that health consumers consistently report frustration, time-wasting and confusion that arises from needing to be the conduit for information between all health professionals involved

in their healthcare, and for a child affected by a genetic condition the number of different health care specialties involved in their care can be extensive.
The need to share genomic information has been spotlighted by the recently published National Approach to Genomic Information Management Blueprint, which has now progressed to piloting and prototyping. Information management systems will support complex data integration and sharing systems, and the knowledge arising from this work is potentially translatable across disciplines of healthcare delivery.

Recommendation 7 (Comprehensive preventive care): Bolster expanded delivery of comprehensive preventive care through appropriate resourcing and support
In our responses to two National Preventative Health Strategy consultations (September 2020 and April 2021), we provided a detailed evaluation of current evidence and forecasted opportunities where health genomics can play a significant role in a health system committed to preventative care. Examples include:

- Reproductive carrier screening for X-linked and recessive genetic conditions.
- Newborn genomic screening, both in the context of expanding on the current "heel prick" metabolic tests to include genomic testing, and "whole of life genomics", where genomic data obtained after birth is available for reinterrogation as different health questions related arise at different stages of life.
- Rapid genomic testing to diagnose and alter the management of monogenic disorders.
- The great potential for pharmacogenomic information, made adequately available across health care delivery systems, to reduce adverse events and save health system dollars through reduction in hospitalisations due to adverse drug events.
- The emerging potential for Polygenic Risk Scores to identify at risk populations for developing complex conditions with an underlying genetic basis, and to stratify the population for surveillance and screening.

As these services begin to be mainstreamed, they will increasingly be appropriately delivered in the primary health care setting.
The initial Primary Health Care workshop held in December 2020 included a presentation on genomics and diagnostics by Prof Edwin Kirk. This indicated that health genomics is at the forefront of primary health reform, and we support this as a continued focus as the Implementation Plan is developed.

Recommendation 8 (Improved access for people with poor access or at risk of poorer health outcomes): Support people to access equitable, sustainable and coordinated care that meets their needs
Clinical genetics services in parts of the country such as Queensland have been finding solutions to equitable access to health care for some time; for example, through regular, remote clinics and the widespread use of telehealth services. These services could be used as exemplars and expanded

upon, with access to improved national digital infrastructure, which also aligns with Recommendation 15.

Recommendation 11 (Allied health workforce): Support and expand the role of the allied health workforce in a well integrated and coordinated primary health care system underpinned by continuity of care

Recently, Australian Genomics responded to the Independent Hospital Pricing Authority's annual pricing framework consultation for the year 2022-2023. Our response highlighted the confusion about the recording of genetic counselling service events (an allied health) for Activity Based Funding, meaning that genetics services are likely going underfunded, and that we do not have correct costing data. This is likely to be true across other allied health services, and we encourage collaboration across jurisdictional and Commonwealth government stakeholder entities to review funding for allied health services, to promote sustainability and expansion.

Recommendation 15 (Digital infrastructure): Develop digital infrastructure and clinical systems to better support providers to deliver safe and effective care

Australian Genomics has been tasked with leading the Implementation Plan of the National Approach to Genomic Information Management (NAGIM) Blueprint. The Blueprint, led by Queensland Health and Queensland Genomics, will pilot integrated digital health infrastructure, taking into account all of the privacy, regulatory, legal and jurisdictional issues, and could serve as foundational work to inform broader digital infrastructure development.

Recommendation 17 (Data): Support a culture of continuous quality improvement with primary health care data collection, use and linkage

A federated approach to linking health data, electronic medical and other health records, a wide range of test results (including genomic data) and other information such as environmental and socio-economic datasets is a key component to realising primary health reforms. Having a federated approach to data sharing would be of immense benefit. This recommendation has synergies with strategic priorities of the Australian Digital Health Agency National Digital Health Strategy, and the Office of the National Data Commissioner's Data Availability and Transparency Bill being introduced to parliament. The National Approach to Genomic Information Management Blueprint considers many of these issues and the principles may be adaptable to sharing other kinds of health data across jurisdictions.

Recommendation 18 (Research): Empower and enable contextually relevant, translational and rapid research and evaluation in primary health care, addressing questions directly relevant to service delivery in localised context

Australian Genomics administers the MRFF Australian Reproductive Carrier Screening Project (Mackenzie's Mission). Covering all States and Territories, 549 GPs from 201 clinics have been engaged in the research as the primary interface for recruiting couples to have reproductive carrier

screening through the study. This involves GPs in research, as well as educational and evaluation activities. This is a significant, national exemplar of primary care involvement and delivery of translational research, piloting the systems and preparing the workforce for emerging services that will primarily be the responsibility of primary care. Supporting GPs to be involved in research like this will have rich outcomes across the sector.

Recommendation 20 (Implementation)
Ensure there is an Implementation Action Plan developed over the short, medium and long-term horizons
Ensure consumers, communities, service providers and peak organisations are engaged throughout implementation, evaluation and refinement of primary health care reform
We would welcome the opportunity to remain involved in Primary Health Reform as this work progresses toward development of an Implementation Plan and can continue to contribute by communicating the evidence and role for health genomics in the future of primary healthcare.

With kind regards,

MHaas

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