



Mr Steven Issa,
Chief Digital Officer,
Australian Digital Health Agency

13 December, 2021

Dear Steven,

RE: Australian Digital Health Agency Draft National Health Interoperability Plan Consultation

I am pleased to provide a submission to the consultation on the Draft National Health Interoperability Plan, 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.

To facilitate review, we have responded to the questions posed in the consultation response template.

Interoperability Principles

1. Do you support the Interoperability Principles in section 3.1, or should some principles be amended, added or removed?

- Australian Genomics supports the proposed Interoperability Principles, and agree these principles will be critical to progress maturity of the digital health sector. These principles further apply to interoperability in research settings, and alignment of principles and approaches to interoperability across health and research digital environments will be important in furthering innovation and responsiveness in the health system.
- We do note that the Principles address information sharing in relation to patient *choice*, but something that appears to be missing is patient *expectations*, which is independent of patient choices – one would not expect record of their access to mental health services be available to other healthcare or allied health services, for example.
- The National Health Interoperability Priorities, too, are solid foundational elements to progress the principles.

Implementation Actions

2. Are there any key actions missing to promote the objectives of this Plan? (A consolidated list of actions can be found in section 10)



- Action 4.3 - Jurisdictions, the Department of Health, and Services Australia will adopt and use national healthcare identifiers in future digital health initiatives involving health information sharing – would it be possible to address the feasibility of use of healthcare identifiers in research, clinical trials and cohort studies to improve the seamlessness of patient/participant engagement with translational research and health?
- Further to the research intersection with clinical management, guidance on whether/in what circumstances research information should be included in the healthcare record would also be welcomed.

3. *Would you like to see any changes to the scope or timeframe of the proposed actions?*

- The proposed actions outline an ambitious goal of mature interoperability over five years. The Plan considers interoperability across all sectors: from acute care, primary care, through to health and human services. Health genomics is a pan-disciplinary technology that is applied across health sectors – and the life course, and genomic information management is therefore a key exemplar for the need for system interoperability.
- There are foundational elements required to progress the maturation of the digital health ecosystem as described, and slow adoption by some services / jurisdictions could be an implementation risk to the broader Plan. For example, it is noted that many services are still reliant on paper records rather than digital storage of healthcare records. Strong endorsement, and incentivisation, by jurisdictions will be critical to progress the Plan – and it is noted endorsement by the Health Chief Executives Forum will be sought in 2022.
- Australian Genomics would welcome the consideration of extending the scope to include interoperability with research datasets: clinical genomics involves significant intersections with research, and progressing clinical genomics will require interoperability with research environments. We acknowledge that research is mentioned in the plan, under “Initiatives” but not prior – but is an element missing across the rest of the plan.

4. *Are there any actions that your organisation would like to be involved in progressing, and what would that involve?*

Actions 5.6, 6.3, 6.7, 6.9 and 7.3:

- Australian Genomics would like to work with the Agency and Governments to progress alignment of digital health interoperability with strategies for optimisation of research data interoperability – particularly in the realm of genomics. This would involve coordination of recommendations from the NAGIM Blueprint Implementation (see Q6 below); support of adoption of common standards across digital health implementations and those of translational research initiatives; and engagement with key stakeholders including ARDC/HeSANDA project; AAF; and genomic research data initiatives nationally.
- Australian Genomics has worked nationally and internationally to progress standards of clinical and research consent, including models of granular, dynamic consent (see Q6 below). We would value the opportunity to contribute to actions to develop standards and approaches to consent-based information exchange, informed by work of international consortia like the GA4GH. This may involve participation in working groups progressing these items; preparation of reports / summaries; and / or engaging with our national clinical, diagnostic, and research network to garner expert opinion.
- Australian Genomics could provide valuable contribution to the ‘accessing genomic data across IT systems’ initiative, from our work nationally across the clinical, diagnostic and research genomic spectrum; through to our activities under the NAGIM Blueprint Implementation.
- It will be important to ensuring the inclusion and implementation of terminologies considered those used in clinical genomics (e.g. HPO for rare diseases, and MONDO terms for clinical variant

interpretation repositories), as well as efforts around “national minimum datasets” considers minimum clinical phenotype sets to support clinical genomic testing.

Interoperability Initiatives

5. Which, if any, of the implementation initiatives in section 7.4 would you like prioritised for delivery and why?

- Information Sharing - Accessing genomic data across IT systems: this aligns well with the NAGIM Blueprint Implementation activity of Australian Genomics, and responds to a key need identified by our community of practice.
- Digital Models of Care – Managing patient information sharing and access consent: as noted above, Australian Genomics has progressed optimised approaches to clinical and research consent, and have championed the use of digital platforms to improve an individual’s dynamic and granular choices around data sharing and use.
- Standards – Developing genomics data standards: Developing nationally agreed standards for data collection, storage and sharing of genomic data is a core deliverable of Australian Genomics.

General feedback

6. Is your organisation leading any activities that should be identified in the final Plan?

- Progressing the National Approach to Genomic Information Management (NAGIM) Blueprint Implementation – recommendations to Governments Q1/Q2 2022.
- The emphasis in the Plan about individual autonomy around health data sharing and access – the ‘consent-based information exchange’ and a ‘national approach to individual consent’: Australian Genomics has progressed concepts of dynamic consent in Australia and developed the web app CTRL (Control) as a means to support an individual’s granular, dynamic data use preferences.
- It was pleasing to see reference to the activities of CSIRO / Australian eHealth Research Centre, noting that Dr Alejandro Metke Jimenez is progressing work around phenotype data capture and standardisation with Australian Genomics.
- Noting the Agency-led ‘electronic requesting’ initiative cited: Australian Genomics is progressing a project exploring the feasibility and core requirements for electronic test request, including the phenotype data capture requirements to inform interpretation of genomic data.
- Not an Australian Genomics-led initiative, but the activities of the Australian Research Data Commons and the Health Studies Australian National Data Asset (HeSANDA) program may have bearing on the Plan.
- Standards around the management of genomic and health data have been collaboratively developed by the global standards setting organisation the Global Alliance for Genomics and Health. Australian Genomics is a driver project of the GA4GH, and has contributed to the development and uptake of many GA4GH standards. Adoption of these standards will be important to ensure Australia remains part of the global health data ecosystem.

7. Do you have any additional feedback on the Plan?

- The Plan sets out an aspirational vision for an interoperable national healthcare system, which would drive efficiencies and benefits for individuals, healthcare providers, HCP organisations, funders and regulators – and, potentially, researchers (especially noted 2.2 – Purpose and Scope of the Plan – intended users). While intersections and outcomes for the research community are not emphasised in this plan, we see considerable potential to harmonise digital health system interoperability, with that of the research domain.



- As Australia shifts policy and practice to more effectively respond to healthcare innovation, as described in the Zimmerman Report Nov 2021, the efficiency of interfaces between research and clinical practice will become more critical. We will need to proactively align standards and practices between digital healthcare and research environments to support this interoperability.

Thank you again for the opportunity to respond to the draft National Health Interoperability Plan, and acknowledge that it describes an ambitious, aspirational future for Australian healthcare. We look forward to continuing to engage with the Agency as these activities progress.

Best regards

A handwritten signature in blue ink, appearing to read 'TB'.

Tiffany Boughtwood
Managing Director, Australian Genomics