



AUSTRALIAN MEDICAL  
ASSOCIATION

ABN 37 008 426 793

T | 61 2 6270 5400

F | 61 2 6270 5499

E | [info@ama.com.au](mailto:info@ama.com.au)

W | [www.ama.com.au](http://www.ama.com.au)

42 Macquarie St Barton ACT 2600

PO Box 6090 Kingston ACT 2604

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## **AMA submission – draft National Health Genomics Policy Implementation Plan**

**[genomics@health.gov.au](mailto:genomics@health.gov.au)**

The AMA commends the *National Health Genomics Policy Framework 2018-2021* endorsed by the Council of Australian Governments in November 2017. The AMA also acknowledges the Federal Government's strong leadership role in the development, and now implementation, of the Framework.

The Framework provides essential national guidance for governments to address the significant issues and challenges arising from the rapidly developing field of health genomics, and to harness its potential to improve clinical practice and outcomes for patients.

Overall, the AMA considers the draft Implementation Plan represents a good first step in moving forward. The AMA agrees the areas identified for action are priorities and should be achievable in the timeframes predicted.

In particular, we are pleased to see the actions proposed relating to workforce development which was identified as a key issue in the AMA's submission of March 2017. It is important that the initial workforce mapping project leads to concrete actions to support genomic workforce capabilities and supply.

However we raise the following two key concerns.

Firstly, a major weakness of the draft Implementation Plan is the government/jurisdictional focus on clinical services which are likely to eventually be community based.

As pointed out in our previous submission, limiting planning and implementation to the policies and activities of public hospitals, ignores the capacity in the private sector, including primary health care, to contribute to, and complement, public health services.

Australia's health system is built on a complementary system of public and private services. There is potential to increase efficiencies, and reduce waiting lists, by better utilising capacity in the private sector. This may require upskilling of the medical workforce in this new area of genomics, but will result in dramatic improvements in access for patients.

The AMA therefore recommends that the Governance section of the draft Implementation Plan includes the establishment of an advisory group to AHMAC with representation from a broad range of stakeholders. Membership should include representatives from the private sector, public sector, clinicians and laboratory practitioners, implementation experts, as well as patients and consumers.

Private sector representatives should include general practitioners and private sector genomic practitioners (those interacting with patients and those working within laboratories) to ensure that the potential synergies and opportunities to work with the private sector are not missed.

The expertise provided by a stakeholder group of this kind will help develop well considered approaches to achieving the Framework's strategic priorities, for example, the priority areas for action: 3.4 'better understanding the role of the private industry, and opportunities for partnerships to support the development and sustainable application of genomic knowledge'; and 3.5 'collaborate across governments and stakeholders to maximise investments and reduce duplication of resources and efforts'.

Advice from a wide range of stakeholders, including the AMA, will also be essential in deciding how to proceed with complex issues such as national genomic data collection, storage and sharing.

Secondly, and as flagged above, the AMA has concerns about strategic priority area 5 and the development of 'nationally agreed standards for data collection, safe storage, data sharing, custodianship, analysis, reporting and privacy requirements'.

In considering options for how genomics data might be dealt with, it will be important to ensure that the risks and benefits are carefully considered given the potentially sensitive nature of an individual patient's genomics information.

In particular, if the option of integrating genomics data into the My Health Record (MHR) is explored, the protocols will need to align with the MHR data storage, use and disclosure protocols.

At the least, the framework governing the secondary use of MHR data must be finalised and details well known before any consideration of integration is pursued.

The AMA is extremely cautious about the secondary use and disclosure of health data as articulated in a recent [submission](#) on this issue. Our position recognises the sensitivity of health data and the technical difficulty of de-identifying it in a way that removes the risk the data, in a new environment, becomes re-identifiable.

Any disclosure for secondary purposes must only occur in a controlled environment that removes virtually all risk that individuals can be re-identified.

The AMA also opposes the release of MHR data in a way that permits it to be downloaded by an off-shore entity/researcher.

We have a strong view that consumer consent to share sensitive health data for the purpose of health care delivery must be separate from the consent process to disclose their health data for secondary purposes.

The AMA looks forward to further engagement in the implementation of a national health genomics policy.

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**Contact**

Georgia Morris  
Senior Policy Advisor  
Medical Practice Section  
Ph: (02) 6270 5466  
gmmorris@ama.com.au