# Consultation response on the National Health Information Strategy Framework

FROM THE AUSTRALIAN ACADEMY OF SCIENCE AND
THE AUSTRALIAN ACADEMY OF HEALTH AND MEDICAL SCIENCES

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*The Australian Academy of Science and the Australian Academy of Health and Medical Sciences welcome the opportunity to comment on the National Health Information Strategy Framework. The Academies are submitting a joint response to this consultation since the topic builds on our previous joint work in 2019, as detailed below. We are grateful for the additional input received from Fellows to inform this response.*

## Principles

*When you look at the achievements listed in the draft Framework, are there any other essential elements of the health information system that should be listed as achievements that are starting points for future arrangements?*

We will first comment on the principles listed. The Academies developed a joint position on the use of data for health and medical research purposes in 2019, publishing a joint statement on 'Improving accessibility and linkage of data to achieve better health outcomes for all Australians', which was informed by a roundtable of Fellows and other relevant experts.[1] We identified the following priorities for action, which we are pleased to see reflected in aspects of the NHIS principles, particularly regarding data access and linkage:

- Resolve regulatory barriers limiting timely access to existing population and health data collected at state and national levels.
- Enhance medical and community understanding of and protocols for safe and ethical collection, storage, synthesis and analysis of health data.
- At Commonwealth level build upon successful State-based linkage programs such as the Public Health Research Network.
- Develop new approaches to accessing and utilising data from novel sources, including the Internet of Things, social media and wearables.
- Ensure continued engagement with and respect for Indigenous data sovereignty.
- Further improve the quality and reliability of health and medical data collections.
- Bolster efforts to generate a data-skilled clinical and research workforce through expanded professional and post-graduate training programs.

There is a need to foster and develop an academic disciplinary base for the research methodologies that are critically necessary for data to be transformed into evidence. Fostering specialised research skills will help in the processing of high-quality data, and help facilitate better data management, coordination and linkage.

Regarding the principle for 'a trusted and transparent environment', this should also be considered in the context of emerging technologies – for example, there is a lack of 'explainability' in the adoption of deep machine learning and artificial intelligence (AI) technologies. Governance, social license and stewardship need to be cognisant of these challenges.

Turning to the list of achievements, Australia has an opportunity to drive improvements in health and healthcare through the appropriate use of data – we need to create an environment in which the safe and secure use of patient data for legitimate research purposes is balanced with the rights and interests of individuals. This should be an important focus for the Strategy and we agree with the statement in the consultation document that Australia can do better.

## The Current State

*When you look at the limitations listed in the draft Framework, are there any key limitations from a national perspective that are missing?*

We agree that the limitations raised must be addressed. There is an urgent need to improve data access and linkage if we are to unleash its potential to improve health for all Australians. It is important that the use of

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[1] More information: https://aahms.org/wp-content/uploads/2019/07/linkage-data-for-better-health-outcomes_FINAL-1.pdf

data is appropriately regulated in a way that is proportionate and streamlined, while still allowing valuable research to proceed. The limitations identified place an administrative burden on researchers and can cause serious delays to medical research and therefore the promise of those studies to benefit patients and society.

The lack of a substantial academic base in the disciplines of biostatistics and epidemiology is a serious limitation. The health sector requires a type of data science expertise that helps produce scientific evidence, rather than solely focusing on the technical computing skills and tools. These technical abilities cannot be sufficiently met by upskilling the healthcare workforce alone, but requires a concerted effort to foster academic expertise in the data sciences, equipped to cater for health sector needs.

Inconsistent application of standards and terminologies may affect the efficiency and timeliness of sharing data. Standardisation and harmonisation of system platforms are a fundamental technical requirement for a national mission. The draft framework rightly identifies critical issues such as fragmentation of systems, and different platforms within and between states – these have impacted on the use of electronic health records and they also affect data sharing and linkage. This problem needs to be resolved at the COAG level.

Health data are often not compliant with the FAIR principles – that is, they are not Findable, Accessible, Interoperable and Reusable.[2] Although a reasonable amount is human readable, it is not machine actionable because data repositories have been set up at local sites and optimised for use-cases specific to each institution storing the data.

These kinds of data are also sensitive and our 2019 statement stressed the importance of continued engagement with and respect for Indigenous data sovereignty.[3] Principles such as the CARE Principles for Indigenous Data Governance (Collective Benefit, Authority to Control, Responsibility and Ethics) are valuable here.[4]

The Framework needs to address issues related to the cost of accessing data and of data analysis. Even after the identified on the consultation have been cleared, which can be time-consuming and fragmented, this issue can still be self-limiting.

*From your perspective, what are the top three key limitations that are creating barriers to successful use of health information in Australia?*

The limitations identified must all be addressed to deliver the kind of efficient and effective applications of health data for research purposes that bring benefits to patients and society.

## Where do we want to be; what opportunities should we grasp?

*From your perspective, what are the three key opportunities to address the limitations and barriers to successful collection, collation and use of health data and information in Australia?*

Australia has an opportunity to drive genuine improvements in health through the appropriate use of data – especially given the composition of our population and the structure of our health system.

Technological advances through AI and ICT offer powerful tools to analyse and predict health events. AI-driven technologies are currently being used in the analysis, prediction and modelling of the COVID-19 outbreak. For instance, the Canadian AI start-up Bluedot was one of the first to identify the outbreak in Wuhan, China,  in late December 2019 and has, through flightpaths data, been able to predict paths of transmission.[5] In the context of this disease outbreak, Australia is currently relying on international data

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[2] More information: https://www.nature.com/articles/sdata201618

[3] More information: https://aahms.org/wp-content/uploads/2019/07/linkage-data-for-better-health-outcomes_FINAL-1.pdf

[4] More information: https://www.gida-global.org/care

[5] McCall, B (2020). COVID-19 and artificial intelligence: protecting health-care workers and curbing the spread. *The Lancet*, Volume 2, Issue 4, Pe166-E167.

collection and analysis of epidemiological data collection. There is an opportunity for Australia to develop its own data infrastructure that will enable AI and ICT technology to thrive.

As noted above, to deliver on this potential, we need to create an environment in which the safe and secure use of patient data for legitimate research purposes is balanced with the rights and interests of individuals. We agree that the opportunities identified will help to deliver this and would again support the need to address them collectively.

*When you look at the opportunities listed in the draft Framework, are there any missing?*

Opportunities to improve health also arise when data are combined beyond health – for instance, those from other domains such as societal data (e.g. from social services, aged care, justice services) and environmental data. The framework should ideally include reference to datasets from these other domains, and how they are organised and referenced. It may also be helpful to include reference to national datasets held by others, e.g. universities and the Specialist Colleges – all of which will be critical if we are to effectively use data to improve the evidence-base for improved healthcare and social services.

Further to our comments above, other opportunities include making health data collection comply with the FAIR principles, to help make data findable, accessible, interoperable or reusable or the CARE principles that relate to Indigenous data governance.

Disease and patient registries can be a powerful means of tracking disease epidemiology and treatment outcomes. Registries in Australia are usually established in an *ad hoc* manner, driven by individuals, research groups or professional societies. They are funded in a variety of ways, often operating in parallel. Other countries have long had national patient registries, which can be a crucial source of informative health data and the Strategy could consider opportunities to improve the use of such resources in Australia.[6]

It is also worth thinking about the role of commercial interests in this endeavour. There are of course separate considerations for this sector, but nevertheless it plays an important role in the development of new drugs, devices and innovative digital technologies, which are valuable to developing the evidence-base and improving healthcare overall. This does not seem to have been incorporated in the draft Framework.

## How to make this happen - Priority areas for investment and implementation steps

*When you look at the priority areas for investment/implementation listed in the draft Framework, are there any missing?*

There is a critical need to build a data science workforce that is able to meet the needs of the healthcare sector. Cross-investment between the health and education sectors can play an important role in developing the data science competence needed within the workforce to analyse data to the quality standards required by the Australian health sector.

## Summary questions

*When you look at the suggested approach to governance of health information in the draft Framework is there anything missing or wrong?*

The framework offers a comprehensive overview and targets, but we would highlight the following additional considerations:

- More specific short- and medium-term goals and targets may help in navigating the implementing of the framework in the complex Federal and State systems. It will be important to develop clarity about how the jurisdictions will be in a position to guide the draft framework and its delivery.

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[6] For example, see: Canadian Medical Association or its licensors (2014). Sweden's health data goldmine. *CMAJ,* June 10, 2014, 186(9).

- Community buy in and co-ownership of trust will be key to successful implementation of the data collection strategies that are required to sustain high quality data input. The recent community scepticism towards *My Health Record* is an example of how the social dimension needs to remain a keystone of health data collection.
- The framework could do more to acknowledge the key role of the States and Territories as well as key Government agencies such as the Therapeutic Goods Administration (TGA) – not only in terms of their need for data, but in relation to the data they hold.

### *Are you aware of other strategies for health information in Australia or elsewhere that could inform this strategy?*

The Australian Research Data Commons has developed a project on health data.[7]

### *Do you have 1-2 high profile examples where data has made a clear contribution to a successful health outcome that you are willing to share?*

There are many good examples of how data have made a significant contribution to improved health outcomes. The below examples highlight the importance of how longitudinal population data are contributing to our understanding of disease patterns and healthcare:

- The Australian Longitudinal Study on Women's Health (ALSWH) which was launched in 1996 and is a long-running population-based survey and cohort study of over 57,000 women in the age group 18-23, 45-50 and 70-75.[8] The study has helped to inform Government policy on several issues of which some include physical activity, mental health and sexual and reproductive health.
- The 45 and Up study is a cohort study involving 250,000 men and women in New South Wales.[9] This longitudinal study investigates health ageing in a population of individuals aged 45 years and over. The study has offered significant insight into conditions commonly linked to the ageing process such as cancer risk, cardiovascular disease, diabetes and mental health.
- The Hunter Community Study is another population-based cohort study that assesses the impact of ageing on health, well-being, social-functioning and economic consequences.[10]

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[7] For more information: https://ardc.edu.au/project/federated-secure-environment-for-health-data/

[8] For more information: https://www.alswh.org.au/

[9] For more information: https://www.saxinstitute.org.au/our-work/45-up-study/

[10] McEnvoy, M (2010). Cohort Profile: The Hunter Community Study. *International Journal of Epidemiology*, Volume 39, Issue 6, December 2010, Pages 1452–1463.