



Australian Academy
of Health and
Medical Sciences

Feedback on the Australian Data Strategy: The Australian Government's whole-of-economy vision for data

SUBMISSION BY THE AUSTRALIAN ACADEMY OF HEALTH AND MEDICAL SCIENCES

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The Australian Academy of Health and Medical Sciences

PO BOX 6114, WOOLLOONGABBA, QLD 4102

www.aahms.org | Ph +61 7 3102 7220 | ceo@aahms.org

ABN: 55 167 124 067

About the Academy

The Australian Academy of Health and Medical Sciences is the impartial, authoritative, cross-sector voice of health and medical science in Australia. We advance health and medical research in Australia and its translation into benefits for all, by fostering leadership within our sector, providing expert advice to decision makers, and engaging patients and the public.

The Academy is an independent, interdisciplinary body of 448 Fellows – elected by their peers for their outstanding achievements and exceptional contributions to health and medical science in Australia. Collectively, our Fellows represent an independent voice, through which we engage with the community, industry and governments.

Key messages

In health and medicine, patient and public data offer important opportunities to advance our understanding of health and disease, and to develop better approaches to prevention and treatments. Australia needs to create an environment in which safe and secure use of patient and public data for legitimate research purposes is balanced with the rights and interests of individuals.

- The Academy supports any efforts to harmonise Australia's data policy, governance and infrastructure to ensure consistency and reliability. This will enhance efforts to achieve other goals described in the Strategy, particularly those aiming to improve the efficiency and effectiveness of the data ecosystem.
- The use of data must be done in an open and transparent environment. This requires regular ongoing monitoring of public perceptions and concerns to ensure that the use of sensitive data continues to be justified and that there is a legitimate basis for believing that a social licence for doing so exists. Insights from monitoring should be used to ensure that the public remains educated in how their data are being used – for instance to identify and address gaps in understanding – and to ensure that policy is developed in line with public expectations.
- The Academy supports the Australian Government's vision to make better use of data sharing between the public and private sectors for legitimate research purposes, but the Strategy should more strongly encourage and promote openness, transparency and security to ensure the use of data for public good can be maximised.
- We strongly advocate for the FAIR (Findable, Accessible, Interoperable and Reusable) and CARE (Collective benefit, Authority to Control, Responsibility, Ethics) principles to be explicitly stated in the Australian Data Strategy to ensure these values are properly embedded into data infrastructure, policies and governance.
- The Strategy should support and advance existing efforts to put research and data pertaining to Aboriginal and Torres Strait Islander peoples in the hands of Aboriginal and Torres Strait Islander peoples. In addition, the Australian Government should partner and collaborate with First Nations peoples to help expedite First Nations goals and self-determined interests to mitigate the impact of current data gaps on health equity.
- The Academy supports additional investment into the development of training programs and workforce incentives that grow and retain an Australian workforce with the necessary skills to implement the Australian Data Strategy. In addition, the Strategy should include a commitment from the Australian Government to investigate and address challenges associated with attracting and retaining international talent to fill the current data skills gap in our local workforce.
- We support the development of national policies that promote the harmonisation and streamlining of health data collection, linkage and sharing within existing data infrastructure. We urge that health and medical researchers are formally and actively engaged in the design and governance of new national data policies and data assets to ensure that these deliver maximal value for health-enhancing research.
- The Strategy should address in greater depth how data biases will be managed and mitigated.
- The Strategy is an opportunity for the Australian Government to identify leaders across the health and medical research sector that it will collaborate with to ensure the Strategy can be implemented nationally.

Introduction

The Australian Academy of Health and Medical Sciences (the Academy, or AAHMS) welcomes the Australian Government's work to develop an Australian Data Strategy (the Strategy) and the opportunity to provide feedback on its content.¹ In partnership with the other four Learned Academies (the Australian Academy of Science, Australian Academy of Technology and Engineering, Academy of Social Sciences in Australia, and Australian Academy of the Humanities), the Australian Council of Learned Academies (ACOLA), and the Australian Research Data Commons (ARDC), AAHMS recently conducted a major policy study entitled, *'Australia's Data-Enabled Research Future'*, to scan the national datasets and infrastructure needed to ensure data can be used appropriately and for maximum benefit across the full diversity of research domains in Australia. To complete this study, AAHMS convened a series of roundtables with health and medical researchers and other key stakeholders to identify opportunities, gaps, and priorities relating to Australia's data infrastructure, assets, policies and skills. The report was published in June 2022 and is available from: <https://aahms.org/policy/australias-data-enabled-research-future/>. This submission draws on the findings of that report.

We welcome the vision set out in the Australian Data Strategy for Australia to become a modern data-driven society. We acknowledge that the Strategy covers Australia's entire data ecosystem and support a coordinated approach. Our submission addresses challenges and opportunities specific to health and medicine, and in particular to health and medical research and innovation. Investment in health and medical research data infrastructure could generate considerable returns. It is estimated that more effective use of routinely collected data could deliver savings to national healthcare expenditure of around 8% per year, translating to more than \$11 billion annually in Australia.² New knowledge generated by this sector informs policy decisions, benefitting not only public health, but our society and economy.

The Strategy notes the research sector as a critical stakeholder for the generation, collection and analysis of data to cultivate knowledge and drive innovation.

Following discussions with health and medical researchers for the *'Australia's Data-Enabled Research Future'* policy study as noted above, the Academy has identified several gaps and opportunities in Australia's data infrastructure that require further consideration.³ Our submission identifies these in relation to the three key themes of the Strategy: maximising the value of data, trust and protection, and enabling data use.

Maximising the value of data

Health and medical research underpins important advances in health and medicine – across fields and disciplines; for instance, from tracking infectious diseases, to monitoring the quality of patient care, or trialling innovative medical devices. The Strategy recognises the value of data, of sharing data and of building partnerships, and it acknowledges the potential for job creation enabled by a successful data ecosystem.

There are several barriers preventing Australia from realising the full potential of routinely collected data. One of the biggest barriers is that Australia's health data landscape is fragmented. Data at the federal and state or territory level are subject to different policy and legislative environments. In addition, complex and inconsistent governance, ethics and regulatory frameworks make it challenging for researchers to know what to expect and plan for. Meanwhile, public and private sectors also have differing regulations and data agendas.

Such fragmentation will make it a challenge to achieve the goals described in the Strategy, for instance in relation to collaboration and partnerships. Furthermore, efforts to support data sharing across governments and public and private sectors often have not considered research use of the data as a primary purpose. We urge that health and medical researchers are formally and actively engaged in the design and governance of new national data policies and data assets to ensure these deliver maximal value for health-enhancing research.

Coordination of public and private data can potentially deliver benefits to health and medical research, and in turn, the Australian public. Australian health data assets do not cover all aspects of health, consequently there can be benefits to incorporating data from outside the health sector. For example, lifestyle factors, weather patterns and housing trends are all relevant to health and health research. In addition to publicly held data, private sector data sharing can help to develop a more complete data picture for use in health and medical research. Some of the highest value private data collections that could benefit health and medical research include private hospital data, general practice data, aged care data, health insurance data, food purchases, patterns of transport, social media and more. At present, there does not appear to be clear incentives for the private sector to share data for use in research or link data with government assets.

The Academy supports the use of private sector data for legitimate research purposes and suggests the Government expand its strategy to ensure openness, transparency and security to maximise the use of private sector data for public good.

Trust and protection

The Academy supports the Strategy's priority of trust and protection in data infrastructure and use. The safety and security of an individual's data through its entire lifecycle is crucial to the ethical use of data and therefore to maintaining public trust. The Academy suggests the Strategy integrates the concept of 'social licence' and public dialogue within these priorities. Social licence refers to the informal permissions given by the public to organisations when performing particular activities.⁴ Organisations and institutions that are trusted by the public are more likely to have the social licence to engage in certain activities, such as the collection and use of health data. In combination with this discourse, monitoring public perceptions and concerns over time is crucial to ensuring that organisations engaging in the use of sensitive data maintain their social licence, whilst the public remain educated in, and supportive of, the use of their data. Importantly, it also means that policy can be developed in line with public expectations.

FAIR and CARE Guiding Principles for Research Data Management

Although the Strategy supports the accessibility, reusability and interoperability of data, we would urge the explicit inclusion of the FAIR (Findable, Accessible, Interoperable and Reusable) and CARE (Collective benefit, Authority to Control, Responsibility, Ethics) principles, to ensure these values are properly embedded into data infrastructure, policies and governance. By using these principles, Australian data usage can be held to a standard that can be easily communicated internationally and to the general population. The FAIR guiding principles for research data management and stewardship were published in 2016. Although these principles have been supported by the National Health and Medical Research Council (NHMRC) and other key data leaders, such as the Australian Research Data Commons, currently there is no national research data policy promoting the FAIR principles.^{5,6} The Strategy is an excellent opportunity to address this gap.

Additionally, the CARE principles for Indigenous Data Governance were developed in 2018 by international Indigenous data representatives, including Aboriginal and Torres Strait Islander researchers, to complement the FAIR principles. The CARE principles address a gap to ensure data sovereignty for Indigenous peoples worldwide and should be incorporated alongside the FAIR principles at a national level.⁷

Historically, data practices have not served Aboriginal and Torres Strait Islander peoples and have been seen as obstructive of Indigenous goals rather than assisting in their progress.⁸ The Strategy currently details some benefits of data usage for Aboriginal and Torres Strait Islander peoples and promotes a strengths-based approach for future reporting. However, the Strategy does not sufficiently acknowledge the data contributions of Australia's First Nations peoples, or a plan to work with this group to ensure their data sovereignty rights are protected.

More can be done in this section of the Strategy to highlight the specific needs and goals of Aboriginal and Torres Strait Islander peoples and communities. The Academy suggests the Strategy should support and advance existing efforts to put research and data pertaining to Aboriginal and Torres Strait Islander peoples in the hands of Aboriginal and Torres Strait Islander peoples. In addition, the Australian Government should partner and collaborate with First Nations peoples to help expedite First Nations goals and self-determined interests to mitigate the impact of current data gaps on health equity.

Enabling data use

The Academy supports the inclusion of data management mechanisms, cross-sector communication, and international collaboration in the Strategy. We also welcome the Government's investment in building data capabilities, including the development of an appropriately skilled workforce. We would like to see the Strategy more explicitly lay out the necessary skills required to build such a workforce. Throughout the Academy's discussions with the health and medical research sector, it was clear that multidisciplinary and interdisciplinary teams with a range of skills would be necessary for data collection, analysis, interpretation and the development of data-informed policy. Some of these key data skills include:

- Data/analysis communication skills
- Ability to work across traditional discipline silos
- Ability to integrate different stages of the data pipeline
- Understanding of both qualitative and quantitative data
- Cross-sector data understanding
- Ability to understand and address cultural sensitivities within data collection, use, analysis and interpretation
- Ability to understand key statistical issues in the use of data, including sampling biases and clear analysis planning around well-defined goals
- Skills in using data to inform policy and communicating with policymakers
- Skills in dynamic systems modelling
- Skills in modern computation, including machine learning and artificial intelligence (AI)

The Academy supports additional investment into the development of training programs and workforce incentives that grow and retain an Australian workforce with the necessary skills to implement the Australian Data Strategy. In addition, Australia should aim to attract and

retain international talent to supplement our expertise and fill identified skills gaps. The health and medical research sector report strong demand for international researchers with data skills. At present, Australia is not attracting a large enough cohort, which is leading to a skills deficiency for many research teams. The Australian Government should investigate this issue with a view to developing a solution in consultation with the research and innovation sector.

The Strategy also details current efforts by the Australian Government to enable the use of government data. The government has several data sets such as the National Integrated Health Services Information (NIHSI) Analysis Asset (AA) and products from the state-based data linkage units, but these are often not available to researchers outside government. However, from discussions with health and medical researchers we believe that although these data assets are good individually, they are often fragmented and inconsistent, making data linkage and comparative analyses hard. In addition, they report many barriers to accessing government data assets for researchers outside of government agencies. It is in navigating these jurisdictional requirements that researchers frequently waste time and resources, resulting in delays in producing and releasing the most up-to-date, unbiased research.

One concept recommended by researchers is a national level 'Plug and Play' data asset, comprising a national population spine of linked administrative state and territory and Commonwealth datasets, with the facility for rapidly linking in other datasets with high research value, such as clinical registries, clinical trials and cohort studies. This would add rich clinical detail to administrative data and enable cost-effective long-term follow-up of outcomes. While ambitious, this kind of infrastructure could bring about a step change in the use of data and the associated benefits. It could also be scaled up or down to meet needs within and outside of health and medical research. By prioritising better integration, data sharing and more comprehensive data assets through such a mechanism, Australia could deliver improvements in research efficiency and effectiveness that would enable us to become a world leader in the use of health system data for research purposes – and therefore accelerate access to the associated benefits. Better quality research and faster outputs have the potential to be translated into effective policy and practice. The Academy supports the development of national policies that promote the harmonisation and streamlining of health data collection, linkage and sharing within existing data infrastructure.

Data biases

Despite being a relatively new field, health data science has unsurprisingly been shaped by the social forces impacting the individuals and communities that data sets are built from. This leads to biases in data. The Strategy should expand its acknowledgement of, and management plan for, types of biases in data. In defining useful data, the Strategy details that data must be free from bias, however, there is little detail as to how data biases will be identified and managed across government data assets. In addition, there are limited recommendations for managing data biases across private data assets outside non-discriminatory AI for businesses. The Academy is aware that data bias can present in many ways, which impact the analysis and interpretation of data, such as:

- Under-reporting and poor data quality, such as for Aboriginal and Torres Strait Islander status and languages spoken.
- Under-representation of certain groups in some data collections, such as people who may not have access to digital devices.

- Non-inclusion of data from the private health sector.
- Inappropriate data sets being used to train machine learning/AI algorithms, such that they perpetuate biases in past or current practices.⁹

The Strategy should consider in greater depth how data biases will be managed and mitigated in the future.

For further information on this submission, please contact the Academy's Policy Manager, Lanika Mylvaganam, via policy@ahms.org.

This response was developed through contributions from AAHMS Fellows and Associate Members and was approved for submission via the AAHMS Executive. We would like to thank the Academy's Fellows and Associate Members and who contributed to this response.

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