AUSTRALIAN DATA STRATEGY CONSULTATION 2021

Response to the Initial Consultation Questions

Population Health Research Network

August 2021

ABOUT THE PHRN

The Population Health Research Network (PHRN) is a national data linkage infrastructure network. The PHRN commenced in 2009 and is funded by the Australian Government's National Collaborative Research Infrastructure Strategy (NCRIS), with support from state and territory government agencies and academic partners. The University of Western Australia is lead agent for the PHRN. The PHRN's primary purpose is to build and support the operation of collaborative, nationwide data linkage infrastructure capable of securely and safely linking data collections from a wide range of sources including within and between jurisdictions and across sectors and providing access to linked data[1].

Our Roles

- We are a respected, independent and trusted broker, valued for bringing governments, organisations, individuals and data together securely.
- We collaborate to enhance and maintain significant, innovative research infrastructure to improve the nation's data linkage capability.
- We facilitate and grow the use of linked data in the areas of health and human services.
- We advocate for an improved authorising environment for better access, use and sharing of data.
- We support the whole of government focus on accessing, sharing and using data for the national good.

Our Vision

Linking life data to improve the wellbeing of all Australians

Our Mission

To lead and enable the linking of data for world class, action-oriented research

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[1] Flack, F. and Smith, M. (2019) "The Population Health Research Network - Population Data Centre Profile", *International Journal of Population Data Science*, 4(2). doi: 10.23889/ijpds.v4i2.1130.

PHRN RESPONSE TO THE INITIAL CONSULTATION

Executive Summary

The PHRN are very supportive of the development of an Australian Data Strategy. The vision described in the Draft Framework is high level and the structure of the strategy could be improved. In particular, it would be helpful to be more specific about what data and organisations will be covered by the Strategy, and about the consolidated vision for Australian data and how it might be achieved. In order for Australia to become a leading digital economy by 2030, a clearer vision and a more detailed strategy will be required. This should leverage the significant integrated data, systems and workforce assets that Australia already has.

Scope of the outline Australian Data Strategy

1. To what extent do you agree that the outline of the Australian Data Strategy covers the right issues?

The proposed principles are very high level. The *Opportunity and Vision* section indicates that data is important but does not include a section on vision for the future. The *Data Now* section should provide useful baseline information. It needs to recognise the significant integrated data, systems and workforce assets that Australia already has as well as funded plans to further develop these assets. There also needs to be some assessment of the current and planned situation relative to international trends and opportunities and the overall vision (gap analysis). *Creating Value for the Future* is where the strategy could be articulated. However the section seems to focus on the risks and process (trust, security, management), rather than strategy. The next section is titled *Current Data Initiatives* which could perhaps be part of the *Data Now* section. There is a separate section on *State and Territory Data Strategies*, but not on strategies related to industry, not for profit organisations and research institutions. It will be important to clearly articulate whether the strategy will be an Australian **national** data strategy or a data strategy for the Australian Government.

2. What key areas or issues are missing? Why are they key issues?

The key areas missing from this framework are in the vision and strategy areas, and in concrete actions that will be undertaken. A strategy would usually include clear goals with a plan of action to achieve the goals. The strategy shell provided in the discussion paper does not appear to include a section to describe the goals of the Australian Data Strategy. This will be essential for an action plan to be developed and for the success of the strategy to be measured.

Specific issues

3. Are the issues below considered important to your organisation; and if so why?

While the issues listed are of great importance to data in Australia, and to PHRN, they are being addressed in various Government forums and by legislation (see the Office of the National Data Commissioner). An Australian Data Strategy may address these issues, but the opportunity for a higher level vision and more concrete actions should be taken.

All of the listed issues could be consolidated into a smaller number of categories which may be more relevant for a national data strategy. For example, the UK National Data Strategy describes "four pillars": data foundations, data skills, data availability and responsible data which all of the issues listed could easily be mapped against.

a. Ethical and transparent use of data

PHRN is strongly committed to the ethical and transparent use of data. We note that approvals have become a significant and costly barrier to many types of research. This is especially the case when national data is being considered.

b. Data security

The security of data is critical when dealing with the personal records of citizens. Currently in the health/human services area, approval for analysis is generally obtained on a project by project basis to meet ethical and privacy requirements and this is likely to continue. Data mining is rare. In other words, a one size approach may not fit all circumstances.

c. Data privacy

The PHRN agrees that it is essential for all activities to align with the relevant privacy and other laws. In our experience this is a specialised area and ongoing access to expert advice is needed.

There may be concerns about use of personal data and these need to be addressed. Based on our experience, active consumer and community participation in the development, implementation and oversight of the Data Strategy will be essential to building and maintaining community trust and reaching successful outcomes. Engaging with consumer groups such as the Consumers' Health Forum of Australia should be an important part of the Data Strategy.

d. Data innovation

Innovation is key to any long term strategy, and PHRN is fully supportive of and interested in data innovation at a national level.

e. Accessible data/open data

PHRN endorses the FAIR principles of data (Findable, Accessible, Interoperable, and Reusable), and implements the principles where possible. However, public administrative data cannot always be "open", and use if often restricted to ensure public safety and privacy.

f. Data sharing for improved services

Access to data for research in Australia, particularly for population level research without consent, can be a long and complex process. The difficulties and consequences of these long processes have been highlighted over many years in a range of government reports and research publications[2]. These issues were addressed in the Productivity Commission Report on Data Availability and Use[3]. The recommendations from the report were accepted by the Australian Government and part of the response was the establishment of the Office of the Data Commissioner and the drafting of Commonwealth data sharing and release legislation[4]. The Office of the Data Commissioner released a discussion paper on 3 September 2019 which indicates the Office's current thinking on how the legislation will be framed[5].

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[2] Mitchell RJ, Cameron CM, Bambach MR. Data linkage for injury surveillance and research in Australia: perils, pitfalls and potential. Aust N Z J Public Health. 2014;38(3):275-80. Moore HC, Guiver T, Woollacott A, de Klerk N, Gidding HF. Establishing a Process for Conducting Cross-Jurisdictional Record Linkage in Australia. Australian & New Zealand Journal of Public Health. 2016;40(2):159-64. Andrew NE, Sundararajan V, Thrift AG, Kilkenny MF, Katzenellenbogen J, Flack F, et al. Addressing the challenges of cross-jurisdictional data linkage between a national clinical quality registry and government-held health data. Aust N Z J Public Health. 2016;40(5):436-42.

[3] Australian Government Productivity Commission. Productivity Commission Inquiry Report; Data availability and use: Overview and Recommendations. Canberra: Productivity Commission; 2017.

[4] The Australian Government's response to the Productivity Commission Data Availability and Use Inquiry. In: Cabinet DotPMa, editor.: Commonwealth of Australia; 2018.

[5] Commonwealth of Australia, Department of the Prime Minister and Cabinet, Data Sharing and Release Legislative Reforms Discussion Paper. 2019.

We reviewed the discussion paper and the Best Practice Guide for Applying Safe Data Sharing Principles to better understand whether the proposed data sharing framework would address the complaints of the research community[6].

In our experience, a cross agency analytical capacity is very important. We agree that for this to work, there needs to be more standardised data management practice including metadata management. Data quality and information assets registers are also issues. We note that there are already some national initiatives in this area that could be leveraged.

Next steps

4. What are the top three outcomes from the Australian Data Strategy you would like to see by 2025?
   - Improve Data Availability
   - Improve Data Quality and Consistency
   - Promote Innovation in Data Collection and Use
   - Empower Australians in Data Use

5. Do you have any other comments on the Australian Data Strategy?

Consideration should be given to including greater emphasis on research organisations. In health in particular, research institute and university based researchers are important users and generators of data and often have strong knowledge transfer links to government e.g. the Developmental Pathways Project in Western Australia. Research using linked population health/human services data has already demonstrated/continues to demonstrate important insights into key areas of society.

PHRN has expertise in these areas and can assist in the ongoing discussions.

6. How should the Government keep talking about data issues?

The Government should ensure active, ongoing consumer and community engagement, with simple, clear messaging. Ongoing engagement with those that generate data as well as those that use it, across all sectors, will also be important.

7. How do you see your organisation interacting with the Australian Data Strategy? What guidance is important to you to help you achieve the actions set out in the Strategy?

Australian Government agencies such as the Australian Bureau of Statistics, the Commonwealth Scientific and Industrial Research Organisation and the Australian Institute of Health and Welfare along with a range of data-related national research infrastructures funded by the Department of Education, Skills and Employment (e.g. PHRN; the Australian Research Data Commons; the National Computational Infrastructure; the Pawsey Supercomputing Infrastructure) should be approached to contribute to the Data Strategy.

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[6] Commonwealth of Australia, Department of the Prime Minister and Cabinet, Best Practice Guide for Applying Safe Data Sharing Principles. 15 March 2019.