National Health Information Strategy Consultation

Response to the Draft Framework

Population Health Research Network

3 April 2020

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. The Population Health Research Network - Population Data Centre Profile. International Journal of Population Data Science. 2019. DOI https://doi.org/10.23889/ijpds.v4i2.1130

PHRN RESPONSE TO THE DRAFT FRAMEWORK

Introduction

The PHRN are very supportive of the development of a national vision for health and wellbeing data in Australia. The vision described in the Draft Framework is high level and the scope of the Framework is unclear. In particular, it would be helpful to be more specific about what data and organisations will be covered by the Framework. In order to make a real difference to the data environment in Australia a more detailed vision for what data is collected and how it's collected, linked and accessed is required.

PHRN Response

Principles

The proposed principles are very high level.

There is significant duplication in the Australian information system e.g. collection of hospital admissions data by numerous agencies, which is expensive, inefficient and provides different versions of the truth. the 'collect once, use often' principle could address this issue.

The Current State

This section fails to recognise the internationally significant national data linkage infrastructure in Australia. No other equivalent country (e.g.UK, Canada, Germany) has such a comprehensive and cross-jurisdictional data linkage system. Every jurisdiction in Australia has a data linkage unit which routinely links administrative data and can conduct ad hoc linkages to other data sources. In addition, Australia has the unique capacity to conduct cross-jurisdictional linkages and has national, secure, remote access facilities.

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

The Draft Framework includes eight focus areas and over 50 proposed actions. If the National Health Information Strategy delivered on them all, things would arguably be better but Australia may still not have a robust national health information system. It may be helpful to identify the five most important things that would make a real difference across the system and focus on them.

The PHRN does not recommend undertaking the proposed gap analysis of the Commonwealth, state and territory legislation. The legislative environment for data sharing in Australia is very complex. To conduct this analysis to the necessary level of detail a large number of data use scenarios would need to be developed and used by many lawyers to review hundreds of pieces of legislation. This would be an extremely time consuming and expensive task which would result in a long list of legislative changes that would take many years to implement. A more pragmatic approach would be to develop guidelines to assist legislators to incorporate appropriate provisions whenever legislation is reviewed or new legislation developed. Please see the attached guidelines developed for the Population Health Research Network as an example. The possibility of incorporating clauses in existing or new data sharing legislation which take precedence over other legislation should also be investigated. This would be a much simpler approach than amending all existing legislation.

The collection, use and disclosure of health information in Australia is already highly regulated. The PHRN suggested the proposal to *“Establish an independent oversight mechanism of the national health information arrangements”* is carefully considered to ensure that it doesn’t just add another layer of bureaucracy which inhibits data sharing.

The PHRN strongly supports real and comprehensive community and consumer involvement in the National Health Information Strategy. The Draft Framework includes a focus on good communication and building the trust of the community. We suggest that the Framework should also include a requirement to understand what the community want their data to be used for. The current wording seems to focus on one way communication and keeping the community informed.

The PHRN has spent the last ten years improving access to linked (integrated) data across Australia. We recommend that the PHRN is an important partner in the proposal to “*Develop plans for national health and related data integration, including administrative data from health and non-health sectors and data from clinical registries, clinical trials and nationally significant research studies*”.