

Submission

2016 National Research Infrastructure Roadmap Capability Issues Paper

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Australian Government

Australian Institute of
Health and Welfare

*Authoritative information and statistics
to promote better health and wellbeing*

Dr Alan Finkel AO
Australia's Chief Scientist
c/- Department of Education and Training

Dear Dr Finkel

Issues paper: National Research Infrastructure Capabilities

The Australian Institute of Health and Welfare (AIHW) welcomes the opportunity to comment on the Chief Scientist's issues paper on national research infrastructure capabilities. We broadly support the capability focus areas highlighted in the paper, but wish to make some specific commentary on emerging and/or desirable capability needs as outlined in the attached submission.

The AIHW is a major national agency set up by the Australian Government in 1987. It is an independent corporate Commonwealth entity within the Health portfolio. Our mission is to provide authoritative information and statistics to promote better health and wellbeing.

We provide timely, reliable and relevant information and statistics on hospitals and other health services, aged care, child care, services for people with disabilities, housing assistance, youth justice and other community services. We collect data and manage national data collections in these areas, producing over 150 information products each year.

Our work is frequently referenced by the media. We also provide information to other government bodies and cross-jurisdictional councils, to external researchers and also directly back to data providers. We report in formats that suit their purposes and allow them to place their service provision in a wider context.

We also develop, maintain and promote data standards to ensure that data collected are nationally consistent. In all these activities, we enable governments and the community to make better informed decisions to improve the health and wellbeing of Australians.

We trust that you find this information useful to the development of your roadmap. Any specific queries about the information I have provided or requests for additional data from the AIHW, can be directed to Geoff Neideck, Head, Data Strategies and Information Technology Group, on (02) 6244 1163.

Yours sincerely

Barry Sandison
Director (CEO)
Australian Institute of Health and Welfare

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Introduction

In July 2016, Australia's Chief Scientist, Dr Alan Finkel, called for submissions on the National Research Infrastructure Capabilities Issues Paper (July 2016) in order to inform development of the 2016 National Research Infrastructure Roadmap.

The Australian Institute of Health and Welfare (AIHW) has extensive experience handling health and welfare data and has managed national data collections in these areas for nearly 3 decades. We work closely with stakeholders using data linkage and other analysis methods to explore fundamental policy questions.

This submission provides specific commentary on emerging and/or desirable capability needs, to enhance national health and medical data capability, with a particular focus on:

- big health data
- indigenous research platforms
- managing and leveraging research data insights through the development of geospatial systems and data linkage infrastructure.

Through this submission we wish to highlight how existing capabilities can be brought together and enhanced to support broader national research infrastructure development. It is AIHW's view that the development of this roadmap comes at an opportune time for identifying and addressing capability and infrastructure gaps relevant to the analysis of health and welfare issues.

Questions under 'Health and Medical Sciences'

Question 15 - 17: Are the identified emerging directions and research infrastructure capabilities for Health and Medical Sciences right? Are there any missing or additional needed?

Are there any international research infrastructure collaborations or emerging projects that Australia should engage in over the next ten years and beyond?

Is there anything else that needs to be included or considered in the 2016 Roadmap for the Health and Medical Sciences capability area?

The AIHW believes the emerging directions identified in the issues papers broadly cover the research infrastructure capabilities that are needed for Health and Medical Sciences research. Appropriate levels of access to a broad range of high quality linked data at the person level will be essential to answer questions in the fields of genomics, proteomics and other large scale analytical technologies ('omics) and health/human services research. While we note a strong, and appropriate, focus on health and medical data in the issues paper points to a large and complex sector with much potential for investigation – we also point to the significant potential within the welfare sector. In particular the interface between health and community services and data infrastructure that supports pathways and outcomes analysis is expected to become a core avenue to be pursued underneath these national research activities. This is becoming an issue of increasing focus, with recent publications such as Australia's Health (AIHW 2016c) highlighting how social determinants should be considered a key factor in health outcomes.

The AIHW has developed substantial capability in the collection, collation, governance and use of national health and medical data assets and has identified a need for a substantial

further expansion in capabilities in this area. There have been strong gains realised from linking data sources to create new insights that could not be achieved from a single source (see for example, Mathews et al 2013) and enhanced capabilities are now required to support the increased variety, volume and velocity of current and future health data needs. A more detailed discussion of how health data systems can be managed and leveraged to realise value through research data insights is provided in response to questions under 'underpinning research infrastructure'.

Along with improved data linkage/sharing infrastructure and protocols to extend health data assets, we also expect that eHealth developments will greatly increase data availability. This will cover a range of aspects of health, services delivery and other data about people that will provide important opportunities to inform our understanding of the health and welfare of Australians. As the variety of data available in big health data assets increases, one critical and core component of Australia's national information infrastructure will be tools to ensure the consistency and visibility of data standards and metadata. Metadata repository and management systems, such as AIHW's METeOR <<http://meteor.aihw.gov.au>>, are used to

- ensure the comparability of the data reported from different sources (wherever possible),
- improve the accuracy of the data, and
- support the correct interpretation of data.

Metadata registry systems will need to be enhanced to support expanded functionality to meet technical interoperability standards in eHealth initiatives, and include support for sharing of genomic data and personal monitoring device data (for example). This will optimise the value that can be obtained from big health data, by aligning definitions with that used in other research which improves the information base for decision making.

Indigenous research platforms

The AIHW broadly supports the emerging directions highlighted in this issues paper and in particular the need for a national linkage and data clearinghouse for Indigenous health. This is similar to and would extend on work by the AIHW, in collaboration with the Australian Institute for Family Studies, in maintaining the Closing the Gap Clearinghouse between 2008 and 2014. There will be a need to co-ordinate development of this new clearinghouse as there is the potential for duplication of effort in establishing any such facility. The AIHW already undertakes a range of functions, such as maintaining data resources, reporting and undertaking complex modelling work, that would fit within the suggested 'indigenous research platform' framework and co-ordination of already existing artefacts under this platform would be an essential capability in moving this agenda forward.

Further details regarding AIHW's functions and developments relating to 'indigenous research platforms' have been provided in Attachment 1.

Questions under 'Underpinning Research Infrastructure'

Question 30-32: Are the identified emerging directions and research infrastructure capabilities for Underpinning Research Infrastructure right? Are there any missing or additional needed?

*Are there any international research infrastructure collaborations or emerging projects that Australia should engage in over the next ten years and beyond?
Is there anything else that needs to be included or considered in the 2016 Roadmap for the Underpinning Research Infrastructure capability area?*

The AIHW strongly supports developing new capabilities and infrastructure for managing and leveraging research data insights. As highlighted in section 5.3.5 of the issues paper, we agree that investment which *“builds on and substantially extend(s) the existing PHRN infrastructure”* is the key pillar in *“creating a national health and medical big data capability”* to enable research data insights and realise value from substantial existing data assets. The issues paper has highlighted the broad emerging directions and research infrastructure capabilities well and the key step going forward will be to manage the evolution of current capabilities in a co-ordinated manner and with an over-arching vision to realise appropriate future infrastructure outcomes. Co-ordinated enhancement of this infrastructure should be included in the 2016 roadmap to manage and maintain data sources in an enduring manner commensurate with emerging international initiatives to support reproducible research. Partnerships with international health organisations, for example the World Health Organisation and the Canadian Institute for Health Information will be central to this development.

As an accredited Commonwealth integrating authority and the national linkage node within the Population Health Research Network (PHRN), the AIHW has been involved in the establishment of robust data linkage models that ensure the safety, privacy and security of data used in integration projects. The evolution of aspects of a regularised data systems approach to data linkage to enable data sharing and use have resulted in the development of a number of pieces of supporting infrastructure to manage metadata standards, data transport and consistency and arrangements within a data system. The key research infrastructure capability need going forward is now to take the current system and systematically enhance this, in a co-ordinated way, into a comprehensive and fully realised national data system to support data availability and use.

Data sharing activities occupy a wide spectrum, fulfilling a variety of needs and occur on a wide variety of data types. The infrastructure needed will therefore vary depending on the type of data being shared and the purpose to which the shared data resource will be put. For example, in policy development an initial, but approximate result may be appropriate provided this can be produced in a very timely fashion, whereas in an epidemiological research, completeness and accuracy of the shared data may be paramount. Ideally a data system to enable data availability and use should be able to meet a variety of needs successfully in a flexible and cost effective manner.

The benefits to improved data sharing and from improved data sharing infrastructure for managing and leveraging data insights will be high. This is clearly recognised in the Australian Government Public Data Policy Statement (Department of the Prime Minister and Cabinet 2015), which states data is a key

‘strategic national resource that holds considerable value for growing the economy, improving service delivery and transforming policy outcomes for the Nation’.

The Australian Government has also committed to the improved use of public data and to release non-sensitive data by default. Our opportunity is now to invest in and leverage our current data infrastructure to design a data sharing system that will allow us to realise these gains in the most efficient and effective way.

What could a data system to enhance data sharing and realise data insights look like?

Under a flexible data system data sharing activities can adopt a fit for purpose method depending on the needs of the data activity and the purpose to which the data will be applied, however the data system should be designed so that it can facilitate all types of data sharing activities effectively. Along with investment in pre-enabling data to increase speed of availability and use, a data systems approach will improve security and probity of data across the data system (see for example, Trutwein et al 2006) this is because the use and transfer of identifiable information is minimised when brought together by a small number of central data linkage agencies. Under a working data system the identifiers flow less frequently, as they are not required to be transferred in every single linkage project but the sharing and availability of data will increase as de-identified data flows are used to bring together combined data resources.

Along with streamlining legislative arrangements for data sharing, two key pieces of infrastructure development needed to enable effective data sharing activities are:

- A national master linkage key. This is the central pointer that is used to pre-‘enable’ or pre-link data on the source dataset ready for sharing. A national key would contain pointers to the existing master linkage keys in each state and territory unlocking their already existing data system for the management of state and territory data. Note that a trial is already in place, between NSW, Victoria, Health and the AIHW which is developing this key based on MBS and hospitals data.
- Curation of enabled source datasets. This could be done either centrally, at source or under a hybrid approach where integrating authorities with experience in data sharing activities can advise and support on the best approach for a specific dataset.

Subsequent development of the data system would then rely on this infrastructure in the gathering of data into enduring linked datasets and any roll-out of resources, applications and software to support this data system.

This type of infrastructure is an evolution of the current internationally unique national collaborative data linkage infrastructure and would leverage off already developed infrastructure components as the most efficient way forward. Key learnings from investigations into instigating a data systems approach to sharing data are as follows.

- Investment is necessary to pre-‘enable’ data resources for sharing efficiently and on a regular basis, particularly with regards to establishing the metadata, common definition and standards. This investment does not have to be onerous; however, provided relevant information can be retained after linkage is performed using each dataset. Essentially this infrastructure preparation can be viewed as a data ‘curation’ function which can be supported either through a central agency (or a small number of agencies) or done collaboratively through shared resources and recording portals and with open supporting infrastructure and software. For example, data can be
 - geocoded (if possible) to become geospatially enabled
 - pre-linked (linkage enabled) by incorporating a linkage key or standardising for use in a linkage engine
 - standardised (sharing enabled) so that the data is cleaned and uses common definitions where necessary. Raw source datasets are often not in standardised

formats, without standardised metadata, and require substantial preparation for use as analytics resources.

- Agreement and collaboration with data custodians is central to producing an ongoing data resource. Each data custodian must be comfortable with the provisions under which data will be shared and the governance arrangements under which it will be collected, stored and used. High level directives and legislative changes could potentially have a big impact on the way in which these processes occur.
- To pre-enable data sharing activities it must be recognised that identifier data will be transferred at some point between contributing data custodians across the data system in order to link records and produce keys or pointers lining up records belonging to the same individual or entity. This can be done in a number of ways for privacy, efficiency and effectiveness. Privacy preserving linkage methods can be applied within this data system, however these will not be fit for all purposes as they do not achieve as high quality results as linkage methods which rely on the transfer of personal identifiers to a secure environment, such as in an accredited integrating authority.
- A flexible approach to data sharing will be critical to developing a useable data system. Different types of data and different uses of data will require different levels of protection, handling and curation. This continuum could extend from open-by-default and non-sensitive data that is not required to be of high quality on one end to highly sensitive unit record level data that requires high levels of curation and accuracy at the other. A light touch approach is possible here where each dataset is used differently, in a fit for purpose and resource appropriate way, however for this data system to be flexible enough for all purposes it should also have the capability to handle the most sensitive and highly curated datasets.
- Interoperability issues can be addressed with machine readable formats, data transmission checks and agreed data standards. The AIHW has developed the VALIDATA system that enables custodians to develop their data submissions in a consistent way in collaboration with the source agency to address these issues.
- A systematic approach to metadata development allows external comprehension of the data and enables appropriate usage. Where possible this should be made compatible with commensurate data items in other datasets to enable comparability. The AIHW has developed the METeOR system that enables collaboration in metadata development.
- Ongoing and regularised usage of data resources builds up key knowledge and skills in their use allowing additional value to be unlocked.

Adopting a full data systems approach to data sharing activities would build on existing, and establish new, infrastructure and experience but may initially require investment decisions by data custodians in preparing data for linking and establishing arrangements within an overarching data sharing environment. When a data systems approach is applied it enables more effective and efficient use of high value resources, particularly when they are accessed regularly. In cases where this investment is not warranted the datasets can still be linked or brought together on a once-off basis but additional resources will be required in data preparation and understanding before appropriately reliable outputs can be produced. Efficient data sharing can from this perspective be viewed as a value proposition related to the fitness for purpose of the shared data resource as many questions can be assessed at an approximate level and still provide appropriate results. However where a dataset has been shared, or linked at least once, infrastructure to store the intelligence gained through this

process should be developed to prepare and pre-enable the source data for possible future sharing, research and analysis activities.

A data systems infrastructure incorporating new and enhanced capabilities and building on current PHRN infrastructure would allow more effective development of our national health and medical data capability and support for big health data assets. This can therefore be considered a key capability to enable leveraging and managing of research data insights.

Geospatial systems

The AIHW strongly supports the paper's classification of geospatial systems as a key area requiring increased capability to underpin research infrastructure, and has identified this as a key strategic priority for further development. As has been highlighted above, additional capabilities to support to support data curation and development will be required to linkage-enable, sharing-enable and geospatially enable data. This submission has already discussed how to support linkage and sharing curation needs going forward and will now address additional research infrastructure requirements to support geospatial systems.

In health, geospatial analysis is essential for analysing and mapping:

- health outcomes
- locations of health services
- areas of health "need" – which can be a function of a combination of socio-economic and behavioural determinants, demography, and health status
- access to services – for example, through drive time analyses.

The outcomes of these analyses can be integrated to identify 'hot spots' – for example, areas less well-serviced than others in relation to access to health services, or areas where health outcomes may be correlated with particular levels of access to services, or socioeconomic factors. Such analyses are critical for public health responses to emerging situations as well as in addressing service gaps.

To inform these analyses, some types of geospatial capacity are particularly important, including:

- the capacity to map locations of health services and health outcomes (for example, residence of patients) at a local scale through geocoding or other means
- up to date and accurate geospatial data that can inform analyses of access (for example, road and transport networks) and algorithms to inform analyses
- in the case of area-based statistical data (for example, much health data), capacity to analyse those datasets in parallel with other spatial data (for example, locations of places of residence) so that area-based data can be weighted spatially to facilitate further analyses
- sufficient computing infrastructure and processing capacity to handle the analyses required
- methods to communicate spatial outputs (for example, maps) in both hardcopy (print) and online (interactive) formats.

Section 10.1 of the issues paper notes that emerging directions in geospatial systems include remote sensing and other forms of data from planes, satellite and global positioning systems, as well as high performance computing and software.

- The paper could more specifically mention emerging directions such as ensuring investments in making data sets geospatial enabled through geocoding of data sets to the lowest possible level of geography which can then allow aggregation to relevant levels (important to being able to map health services, patients and outcomes); and spatial datasets (for example, road and transport networks) and software which can facilitate analyses of travel times.
- The paper could more specifically mention the value in effective communication and presentation of spatial outputs to stakeholders, and the need for software and hardware systems to support this.

Section 10.2 of the issues paper identifies that geospatial data and data models are well developed and used by a number of disciplines, and that geospatial data tends to require large storage volumes and fast processes, especially for remotely sensed data. It notes projects such as National Positioning Infrastructure and Australian Data Cube.

- As well as the need for storage volume and processing capacity, the paper could mention the need for effective management of data privacy and access. This is particularly important in the health area.

We also note that the table on page 20, relating to Health and medical science, could more explicitly recognise that “national health and medical big data capability” could include linking of health data with other datasets such as geospatial datasets.

As outlined in the paper building geospatial capabilities in Australia is highly important for research infrastructure.

Summary

This submission has highlighted a number of areas in which the emerging capabilities should be further developed in a co-ordinated manner as part of the emerging capability needs highlighted in the National Research Infrastructure Capability Issues paper (July 2016). The AIHW provides several key components of national data infrastructure for managing and leveraging research data insights into health and welfare issues and we strongly support an over-arching vision for development of further capabilities in this field.

Overall the effective re-use of data and the metadata that can be developed through sharing activities will be paramount in establishing ongoing national research infrastructure to manage and leverage research data insights as the majority of efficiency gains and improved outcomes come from the principles of:

- preparing data once and then using often
- recognising high value data sources and investing in their ongoing development so they are enabled for regularised usage across the data systems at an appropriate level, that is, either an authoritative and highly reliable source or a quickly accessible source of approximate information
- turning disparate data sources into enabled platforms supporting research and development
- developing systems and preparing/enabling data and platforms to work in an interoperable manner with and within these systems to meet research needs.

Where data is available, health data sharing activities to enable and leverage research outcomes have generally been able to occur under current legislation, practices and

infrastructure but the challenge has been to increase the speed, flexibility and utility of these processes in line with emerging big health data needs.

There is an opportunity to now further invest in enabling a data system to continue to improve the practice of sharing data and usage, and there remains much work to be done to develop the infrastructure to realise this vision including:

- improved consistency of data sharing methods, processes and outputs
- updates, particularly with regards to harmonisation and streamlining of privacy legislation together with the various confidentiality and secrecy provisions
- considering community services related data sets, including their interface with the health and medical sector
- investment in 'enabling' and curation of data – many barriers in bringing together (and usage) are up front from not being prepared and due to lack of investment in data assets. The AIHW has highlight 3 areas of particular interest for infrastructure development here, geospatial enabling, linkage enabling and sharing enabling.
- social license for data sharing activities.

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Attachment 1: AIHW capabilities to support indigenous research platform development

The AIHW undertakes a range of functions that would enable it to play a central role in the proposal to establish an 'Indigenous research platform' framework. As well as being an accredited Commonwealth Integrating Authority and part of the PHRN, with access to a range of relevant national data collections and data linkage infrastructure, the AIHW has an established track record and extensive work program relevant to Indigenous health research and social determinants of health and to improving the quality and comprehensiveness of data relevant to Aboriginal and Torres Strait Islander people. This work program is undertaken in collaboration Aboriginal and Torres Strait Islander organisations and with other national, state and territory agencies and with international collaborators. The AIHW contributes significantly to the growing body of knowledge on Indigenous health and wellbeing. The annual report by the Prime Minister on "closing of the gap" and the regular report by the Productivity Commission on Indigenous disadvantage rely heavily on data and analyses from the AIHW.

We undertake comprehensive reporting on Indigenous health and welfare, including national and jurisdictional reporting against the Aboriginal and Torres Strait Islander Health Performance Framework (AIHW 2015a), and our biennial series *The health and welfare of Australia's Aboriginal and Torres Strait Islander people* (AIHW 2015b). We also undertake regular reporting on specific issues of interest, such as hearing and oral health services for Northern Territory Indigenous children, eye health, cardiac care, and general health checks.

Our data linkage work program includes the development of an Enhanced Mortality Database for improving estimates of Indigenous mortality and life expectancy by linking death registration data with hospitals, residential aged care and perinatal data (AIHW 2012). This enhanced data base provides time series reliable adjustments to overcome under-registration of Indigenous deaths to enable robust estimates of Indigenous mortality and life expectancy. Work is also progressing on a project linking perinatal, birth and death data to look at cohort survival rates and understand the determinants of outcomes for babies born to Indigenous and non-Indigenous mothers. We have worked in collaboration with the Australian Bureau of Statistics to produce best-practice guidelines for data linkage activities relating to Aboriginal and Torres Strait Islander people (AIHW and ABS 2012), as well as preparing reports documenting the use of linked data relating to Indigenous Australians (AIHW 2013a, 2013b). We have also worked in collaboration with the NSW Native Title Services Corporation in validating our Indigenous mortality linkage results.

The AIHW maintains data collections relating to Indigenous primary health care services and undertake annual reporting against National Key Performance Indicators for Indigenous Primary Health Care services (AIHW 2015c, AIHW 2016a). We have a strong long-term relationship with these individual service providers and the peak body National Aboriginal Community Controlled Health Organisations. We provide all Indigenous specific primary health care services with individual service reports and work with them to improve the quality of their data.

As well as health-related data collections such as national mortality and hospitals data, the AIHW maintains a range of other relevant data collections including those on Child Protection, Youth Justice, Disability Services, Specialised Homelessness Services and public housing. We analyse all these data collections to report on outcomes for Indigenous

Australians and work with relevant states and territories to improve the quality of the Indigenous identification in these data sets.

The AIHW has a strong track record of undertaking complex modelling work to extend the usefulness of existing data and fill research gaps – for example, we recently published the national results of the Australian Burden of Disease Study 2011 (AIHW 2016b) and are about to release results for Aboriginal and Torres Strait Islander people. We have also undertaken modelling to explore the impact of health risk factors and the social determinants of health and their contribution to the gap in health outcomes between Indigenous and non-Indigenous Australians (AIHW 2014).

We also are increasing our capabilities in geospatial analysis, having produced a number of reports examining the distribution of health services in relation to the Indigenous population, and have developed an Access Relative to Need Index which has received considerable interest (AIHW 2014). This work resulted in the identification of 38 areas in Australia where service gaps exist despite the high need for services in these areas.

The AIHW is experienced in work relating to Indigenous identification and improving identification of Aboriginal and Torres Strait Islander people in key health data sets. We prepared the National Best Practice Guidelines for collecting Indigenous Status in health data sets (AIHW 2010) and maintain the Data Improvement Service Centre which provides advice and resources on collecting information on Indigenous status. The AIHW has undertaken a series of audits of hospital records to establish the level of under-identification of Indigenous people, which has resulted in adjustment factors that can be used at various levels to more accurately estimate the number of hospitalisations of Indigenous people. We have also produced reports on Indigenous identification within community health and housing data collections. The Australian Indigenous Statistical and Technical Advisory Group will oversee an innovative future work program relating to Indigenous identification and data quality and using modelling and actuarial methods to improve the evidence relating to Indigenous health and welfare, having regard to the principles of Indigenous data sovereignty.

The AIHW, in collaboration with the Australian Institute for Family Studies, maintained the Closing the Gap Clearinghouse between 2008 and 2014. This required forming and maintaining links to the external research community and other relevant stakeholders, to produce an extensive collection of papers and summaries of what works to overcome Indigenous disadvantage.

The AIHW has well-established links to national forums for Indigenous health data including the National Advisory Group on Aboriginal and Torres Strait Islander Health Information and Data (NAGATSIHID), the National Aboriginal and Torres Strait Islander Health Standing Committee (NATSIHSC) and the National Indigenous Reform Agreement Performance Information Management Group (NIRA PIMG). We are also a member of the International Group for Indigenous Health Measurement (IGIHM), a forum for sharing information and knowledge regarding the collection, analysis and reporting of health information for Indigenous populations from a variety of nations.

The new Indigenous Research Platform would build on all this current activity. The AIHW would be the data and linkage hub. The AIHW is well positioned to build on existing Indigenous partnerships to develop the overall framework and governance structures.