

National Health Information Strategy – Framework

Preface

Evidence is the foundation of good health care, and the basis of improvements in personal and population health into the future. Timely and accurate health information - including data - is a critical part of this evidence base and needs to be sustained, grown and nurtured.

Technology, analytics and the democratisation of data are changing rapidly in Australia and around the world bringing expectations for data availability, alongside enhanced need for trust at all levels, particularly from the public in terms of how and why their data are accessed and by whom. There are also new forms of data collection emerging digitally, highly detailed, and sometimes available almost instantly in raw form. However, despite these changes and emerging trends, we currently do not fully harness the power of existing data for research, policy, planning and personal purposes. We have an opportunity now to ensure Australia has a national health information system that can adapt and thrive in this environment.

The Australian Health Ministers' Advisory Council (AHMAC) has tasked, via its Health Services Principal Committee and the Australian Institute of Health and Welfare (AIHW), an Independent Expert Panel to oversee development of a National Health Information Strategy (NHIS). More information can be found on the [AIHW's website](#)¹.

The NHIS must deliver a coordinated national health information system that is unified in purpose and addresses intersecting aspects of health and wellbeing, including the social determinants of health, over the life course of individuals. This involves bringing together data from other sectors such as Aged Care, Disability, Education, Welfare, Justice, Housing, and Employment, as well as bringing together and integrating comprehensive data and information from private and public sources.

The NHIS must ensure a focus on the needs of consumers, carers and communities whilst continuing to serve the needs of managers and funders. It must also address areas of disadvantage and inequalities to ensure that overall health benefits and improved health outcomes are achieved for all Australians.

The challenges of disparate legislative, regulatory, and technical arrangements must be overcome to ensure that health data are high-quality, and shared and used in timely way for the benefit of all.

As governance is an overarching issue, it has not been included in the principles. However, the NHIS will need to provide a governance framework for managing health information in Australia.

¹ National Health Information Strategy Independent Expert Panel: <https://www.aihw.gov.au/our-services/committees/national-health-information-strategy-independent-e>

Context

- This **draft** document has been compiled based on feedback from previous consultation workshops where there has been overall in principle agreement to the content and the approach taken and direction of the work have been supported.
- The document is intended for AHMAC (the Australian Health Ministers Advisory Council), whose charter is to provide effective and efficient support to the Council of Australian Governments (COAG) Health Council by:
 - Advising on strategic issues relating to the coordination of health services across the nation and, where appropriate, with New Zealand.
 - Operating as a national forum for planning, information sharing and innovation.
- The focus for this consultation is on the sections:
 - Principles
 - The Current State
 - Where do we want to be; and
 - How to make this happen (Priority action areas).

Vision

Meeting the information needs of all who use, work in and manage Australia's health system to ensure better health outcomes for all Australians.

The Strategy at a Glance

The underlying principles of the National Health Information Strategy



Principles

A trusted and transparent environment

The NHIS will ensure that the community can trust, feel confident in and accept Australia's approaches to management and use of health data and information (i.e a social licence). It will demonstrate public good and benefits, and be transparent about respectful and appropriate processes for consent, governance, security, privacy, and ethical and responsible use of data. The general public will be able to understand what data are collected and how they are used and can be accessed, and the benefits that are delivered to the community. The current approach of 'custodianship' (with its connotation of locking data away) will be transformed into 'stewardship' to allow data and information to be readily and willingly shared for public good. Assurance of privacy and confidentiality will remain paramount.

Data are used to drive better services and better health outcomes

The NHIS must ensure that data are used to improve policies and practices for better health and wellbeing of all Australians and their communities, as well as to facilitate the efficiency and effectiveness of the Australian health system. It will also ensure improved clinical and consumer outcomes and experiences. The data being collected and collated need to be safely and securely shared, accessed and analysed to enable and create actionable information to improve the health and wellbeing of all in society. It is a strategy for everyone – individuals, communities, consumers, clinicians, public, private and allied health professionals, service providers, researchers, health informaticians, policy makers, legislators, system managers, private health sector and industry.

Data are fit for purpose

The NHIS will optimise the quality and utility of data for all who are served by, work in and manage Australia's health system, including vulnerable and disadvantaged populations. It will focus on appropriate documentation, harmonisation, standardisation, timeliness, connectedness and linkage of data with detail relevant to communities and population groups.

Data are accessible

The NHIS will ensure data stewardship that delivers equitable, timely and uniform access to national health information assets (both public and private), and relevant data from other sectors and domains. The system will be easy to navigate, with data and information easy to find. Policies, processes and practices covering access to data and the release of information will be publicly available, clear and transparent.

The health workforce is data-enabled

The NHIS will enhance data literacy and capability in data management and data analytics across Australia's health workforce (from front line staff to Board level). It will ensure the workforce has appropriate skills and experience in data technology, research and analytical methods to effectively participate in the creation and use of national health information assets and infrastructure effectively.

Health information infrastructure is agile and innovative

The NHIS will establish a national approach that is coordinated, secure, efficient, effective and sustainable and harnesses new sources of data and advances in technology for greater

productivity. The system will be future-focussed and adaptable. It will apply best practice principles of continuous review for improvement.

Data support improvements in Aboriginal and Torres Strait Islander Peoples Health

The NHIS will deliver health information which is relevant and accessible to Aboriginal and Torres Strait Islander peoples and communities and will support improvements in health outcomes, healthcare and wellbeing. It must also include clear mechanisms for involvement in data governance.

DRAFT

The Current State

Achievements

Australia's health information system achieves some of the best outcomes in the world from strong foundations in clinical practice, education, training and research, supported by an evolving national health information infrastructure. This includes:

- The [National Health Information Agreement](#)² (an agreement between agencies of the Australian Government and state/territory governments)
- The associated nationally agreed [National Health Data Dictionary](#)³ housed in the Metadata Online Repository (METeOR)
- National Minimum Data Sets which support national administrative data collections and reports
- The Australian Bureau of Statistics' series of national health surveys
- Information supports for activity-based funding for public hospitals and other health services
- Information supports for monitoring and improving the safety and quality of health care services, locally and nationally
- Data sharing and access arrangements under new policy and legislation governing data use introduced across Australian governments
- The National Digital Health Strategy, that focusses on health information for individuals and their health services, as well as on the digitisation of health records and information
- Health sector performance reporting through the [Australian Health Performance Framework](#)⁴.

More recently, there has been work towards creating more enduring linked data assets. In addition, steps have been made towards use of My Health Record information for research and public health purposes.

This legacy is important, but we can do better.

Limitations

The absence of a national strategy or framework

The absence of a national strategy or framework for the management of national health data and information in Australia has led to an environment of territoriality and competitive short-term thinking about data use and sharing. This has been a barrier to collaboration (including with the clinical and research communities and the private sector) and has resulted in missed opportunities and limited strategic investment.

Trust and risk management deficits across all levels

In parallel, there is often a lack of trust among the public and consumers (and in particular in disadvantaged populations and groups) and a general lack of confidence and understanding

² National Health Information Agreement: <https://meteor.aihw.gov.au/content/index.phtml/itemId/182135>

³ National Health Data Dictionary: <https://meteor.aihw.gov.au/content/index.phtml/itemId/268110>

⁴ Australian Health Performance Framework: <https://www.aihw.gov.au/reports-data/indicators/australias-health-performance-framework>

regarding the collection, storage, security, safety, risk management, use and benefits of health data and information.

Uncertainty about ownership and control

Uncertainty about ownership and control of health data and information is coupled with the absence of policies, agreements and systems. Consequently, there is insufficient cooperation, common purpose and collaboration in the use of data and information. Resolution may require legislative change.

Data are not widely recognised as a valuable resource

Data are not recognised and valued as a resource. Data quality is inadequate in its timeliness and granularity, and data are widely underutilised (particularly linked data). There are limited data standards that are agreed and widely applied to ensure data are collected in a consistent manner and allows for international, national and jurisdictional comparison.

Widespread fragmentation of data

Data across the health system exist in a plethora of separate collections that are not readily or willingly shared (including from outsourced service providers and the private sector). There are significant data gaps as well as inefficiencies created by double handling of data. Relevant data from outside the health sector are underutilised.

Limited capacity and capability in the health workforce

The health workforce (from front line staff to Board level) is not uniformly sufficiently skilled and prepared to participate in and make best use of a national health data and information system. There are mixed levels of data literacy and training in data handling and analysis, and insufficient capability to use 'big' and linked data. There are no systems to credential data users for efficient data use.

Gaps in Aboriginal and Torres Strait Islander Peoples health information

Aboriginal and Torres Strait Islander peoples health information is insufficient to inform and support marked improvements in health outcomes. Completeness of identification of Aboriginal and Torres Strait Islander peoples in key data collections needs to be improved.

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

Governance of national health information

There is clear and nationally unified governance with clarity about decision-makers, decision-making and approaches to investment.

This strategy is used to guide the development and maintenance of 4 - 5 year investment plans for managing and improving the health information system.

Legislative barriers are removed to support the NHIS principles.

There is readily accessible information on the national health information system and the data assets that it encompasses.

Transparent and appropriate processes are in place for consent, governance, security, privacy, and the ethical and responsible use of health data and information.

There is sustainable funding to support the implementation of the NHIS.

A trusted and transparent environment

There is public confidence and trust regarding the collection, management and use of health information and infrastructure.

A public communication strategy is in place to support public, consumers, providers and users' understanding of the benefits of the NHIS.

Data literacy for health consumers and communities has improved.

Real-life examples of how the use of data can improve health outcomes for all Australians are available for health professionals to explain the importance of data collection to patients.

Data are used to drive better services and better health outcomes

Data and information can be used to improve policies, practices and research activities for improved health outcomes for all Australians.

Health information can be appropriately utilised across the health sector and other sectors to ensure that the information addresses key social determinants of health and wellbeing as well as health sector drivers.

Data are fit for purpose

The quality and utility of data is optimised for all who use, work in and manage the health system.

The value of information is linked to the data collected.

Different stakeholders in the health sector agree that the quality and timeliness of relevant data are at an acceptable level for their purposes.

Data sources are comprehensive, timely, enduring, appropriately person-centred and standardised, and include the government, private and non-government sectors. Data are drawn from sectors other than health as required.

Appropriate data sets are available and are comparable internationally, nationally and at sub-national levels.

There is consistency of data standards, definitions, terminologies and metadata as well as improved interoperability.

Data are accessible

The transition from a concept of data 'custodianship' to one of 'stewardship' of data has been achieved and sharing and use approval arrangements are in place for health information and data assets.

Data sharing and use (particularly collaborative use) is increased, and is supported by agreements involving all stakeholders across government, clinical, non-government, consumers and private sectors.

The health workforce is data-enabled

Appropriate data literacy levels have been achieved across the health sector and through the varying roles and levels of the workforce.

There is a high level of competence in the data analytics workforce that supports health and health research.

Training and accreditation systems are in place to support efficient and effective analysis of existing and emerging data sources and translation to improved policies and practices.

The role of those working with health data and information is recognised and acknowledged and appropriate career paths established.

All involved in the health sector/workforce have the appropriate skills to use the data and information to implement change.

Health information infrastructure is agile and innovative

Data access and use is facilitated by a coordinated and seamless technical system that is accessible remotely and easy to navigate.

The health data and information system is future-focussed and adaptable.

New computational and analytical approaches are used to understand the full spectrum of health determinants and support research, evaluation and policy.

Health data and information is clearly contributing to improved outcomes and productivity.

Data and information are being used to inform regional and local health needs.

Data support improvements in Aboriginal and Torres Strait Islander Peoples health

There is Aboriginal and Torres Strait Islander peoples leadership and governance for the design and collection of information on Aboriginal and Torres Strait Islander peoples health issues.

Aboriginal and Torres Strait Islander communities are able to have access to and understand how their health data is used.

Aboriginal and Torres Strait Islander perspectives and key information needs for Aboriginal and Torres Strait Islanders are considered and reflected in data collections, in addition to a "health gap" focus. The importance of cultural determinants, connection to culture and land and cultural safety in health services underpins the data.

Aboriginal and Torres Strait Islander peoples numbers are more accurately reflected in relevant health data sets.

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

Governance of national health information

- Prepare a comprehensive view of future health and wellbeing information needs and technical and governance infrastructures.
- Undertake a gap analysis through a stocktake of current health data assets and technical infrastructures against the needs assessment.
- Undertake a gap analysis of existing Commonwealth, state and territory legislation relevant to health information management, with a view to planning harmonisation or change as appropriate.
- Investigate the roles of ethics committees and others in approval requirements for establishment and use of national health data assets, with a view to rationalisation.
- Enhance the National Health Information Agreement in order to improve the coordination, streamlining and sharing of data, and to clarify roles and responsibilities.
- Establish an independent oversight mechanism of the national health information arrangements.

A trusted and transparent environment

- Build public trust in health information assets and infrastructure by communicating effectively to demonstrate the public good and benefits, and the existence and efficacy of respectful, appropriate and transparent processes for consent, governance, security, privacy, and ethical and responsible use.
- Build health sector-specific initiatives based on principles for community trust in government use of data being developed by the Office of the National Data Commissioner and the Australian Digital and Data Council.
- Build community support for the secondary use of My Health Record data.
- Engage with consumers and clinicians to demonstrate the value of data to gain their trust in the use of health data and information.
- Encourage individuals to be engaged with their own health data (in alignment with the National Digital Health Strategy).
- Ensure that the community is well informed as to how effective data collection and use has improved the health of Australians.
- Provide reliable information on public and private health services, such as costs, availability and track-record, to support consumer choice and decision making.
- Use data champions and champions of the NHIS.
- Establish a library of online resources, containing plain-English and real-world stories, to assist health professionals to promote to patients how data has and can be used to improve health outcomes for Australians.

Data are used to drive better services and better health outcomes

- Enhance mechanisms to shape data analysis to guide policy development.
- Return data and analyses to health service and system providers (clinicians, primary health services etc) to provide a better understanding of service performance, and to support local planning and funding decisions.

- Enhance mechanisms to ensure timely feedback of outcomes information to inform health care safety and quality, clinical and personalised health care.
- Enhance mechanisms to drive improvements in innovation and research.
- Establish initiatives to explore best uses of 'raw', uncurated data such as from electronic medical records.
- Use health information to inform policies and programs in other sectors, such as education and housing, to improve community health and wellbeing.

Data are fit for purpose

- There is robust discussion amongst stakeholders on issues relating to quality, timeliness and utility of data for their requirements.
- Develop implementation plans for improvement of data quality.
- Ensure the benefits of data reuse are visible and meaningful.
- Ensure the right data are collected and are of the appropriate quality to answer the key health questions about health outcomes for Australians and/or Australia's health system (data integrity).
- Investigate needs and options for national individual health identifier(s) that would support activities such as data integration.
- Establish agreed clinical data models and terminologies for use across health professions and sectors.

Data are accessible

- Prepare transparent information about the existence of and access arrangements for national health data assets.
- 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.
- Develop the capacity for rapid release of data and analyses, subject to pre-determined criteria, in urgent and emergency care scenarios (e.g. infectious disease outbreaks and suicide clusters) to enable clinicians and service providers to respond more effectively.
- Incorporate data sharing and access agreements into relevant national documents, including for approving establishment and use of national health information assets and infrastructures.
- Create a directory and mapping of data repositories.
- Engage with the private and non-government sectors for effective collaboration and sharing of data.
- Develop comprehensive governance and security protocols for managing data access.

The health workforce is data-enabled

- Identify the gaps in skills and literacy throughout all levels of the health workforce, to inform data and information management training.
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- Liaise with the education sector and other relevant sectors regarding enhancing health data literacy content in health professional curricula.

- Investigate the establishment of a national accreditation system for data analytics
- Build health system capacity in health data science and data analytics through continuing professional development programs.
- Implement strategies to bridge the gap between information workers and researchers, and policy makers and practitioners, to strengthen the health system's ability to use and action evidence.
- Train health and care workers in point-of-care data capture, and in accessing and using information, to improve health care delivery and outcomes
- Collect and analyse information on the capability and performance of health care workers to support professional development and performance improvement
- Train policy makers and administrators in engaging with research, and the evaluation and use of evidence to inform policy, planning and decisions about health services and finances.
- Support the existing health information and data workforce and encourage participation in tertiary education programs related to health information and health data.

Health information infrastructure is agile and innovative

- Establish a national plan for coordinated remote, secure data access arrangements.
- Investigate the implementation of ICD-11 (International Classification of Diseases 11th Revision) and its relationship with clinical terminologies, including SNOMED.
- Create data dictionaries for sectors such as Aged Care, Disability, Education, Welfare, Justice, Housing and Employment that have a level of interoperability with the more established health metadata.
- Establish a process for harmonising and aggregating electronic medical record data from Australian hospitals so these can be used for secondary purposes.
- Promote research to support the safe and effective deployment of artificial intelligence and machine learning in the Australian health system.
- Investigate opportunities to improve the interoperability of health data systems, including technology solutions for greater operational efficiency and lower costs of data access.
- Investigate opportunities to use artificial intelligence, synthetic data sets, and other options to enable modelling to test data quality and privacy issues have been fully explored.

Data support improvements in Aboriginal and Torres Strait Islander Peoples Health

- Aboriginal and Torres Strait Islander peoples are under-identified to a varying degree in most administrative data collections. In addition, the Aboriginal and Torres Strait Islander peoples samples in national surveys are not enough to give robust estimates. This impacts on the accuracy of the estimates for Aboriginal and Torres Strait Islander peoples. A concerted effort is made to address this issue.
- Make data accessible to Indigenous communities and build a two-way exchange for capacity building.
- In data analysis, ensure a focus on the distinction between health outcomes and changes in Indigenous identification.
- Take steps to ensure the opportunities for Aboriginal and Torres Strait Islander peoples involvement in governance of data are identified and actioned.