

Health information in Australia: an evolving landscape with an integrated future

A decorative graphic in the bottom half of the page. It features a dark grey diamond shape containing the white number '10'. To the left of the diamond is a purple trapezoidal shape, and to the right is a large grey triangular shape. The background is white.

10

Health information in Australia: an evolving landscape with an integrated future

The profile – and value – of health data and information in Australia was brought into the spotlight during the response to COVID-19. This emergency action enabled innovative approaches to be taken in respect to both timeliness and the use of novel data sources.

Maintaining these approaches and the benefits they provided to the health information landscape outside of the emergency context may be a challenge. Emulating that innovation in the longer term is an exciting opportunity for the health information and health service sectors to meet the needs of the Australian population into the future.

This article describes the health information landscape in Australia. It explores ways that data on the health of Australians and the Australian health system are currently generated, collected, transformed, transmitted and translated into actionable information. It comments on inconsistencies in and barriers to collecting and using that information, and on opportunities to innovate and enhance the landscape.

The article takes a system-wide perspective on data and information gaps, and on advances to fill those gaps.

Key messages

The Australian health information landscape is changing in response to internal and external pressures. This article:

- focuses on the totality of that landscape as it currently stands: how and where health data and information are generated and used, where there are systemic gaps or barriers, and where opportunities exist to resolve those gaps at a system level
- presents a vision for an interoperable future: one where health data form part of a connected health system in which digital information is well managed, accessible, shareable and translatable between systems within the health sector and across portfolios
- draws on lessons and innovations from the ongoing COVID-19 pandemic under 3 broad themes: governance and infrastructure, insights and expertise, and timeliness and utility.

Health information landscape

The health information landscape comprises health-related data generated through:

- interactions between patients, clinicians and the health system, collected as clinical, administrative and payment records
- cross-sectional, longitudinal, local and national surveys
- clinical trials and other research
- cross-sectoral data from, for example, disability, education and aged care services
- consumer transactional sources, such as banking and supermarket data
- user-generated data, such as from apps and wearables
- emerging data sets, including genomic data and surveillance monitoring systems.

Collection entities

Multiple entities are involved in collecting health-related data. Primary collection entities include:

- health services, individual consumers, health professionals, private health insurers and governments who are predominantly involved in the collection of clinical, administrative and payment records, for clinical care and resource planning
- statistical agencies, universities and non-government organisations who are predominantly involved in the collection of data through surveys, clinical trials and other research for population health insights, clinical care and policy development.

Australian, state and territory health departments, primary health networks, medical software vendors, statistical agencies, universities and non-government organisations may draw on information sourced from primary collection entities, combined with other health-related data (cross-sectoral, user-generated, consumer transactional), to undertake analytics for population health insights, resource planning and policy development.

The complex interaction between collection entities, data sources and data uses are described further in the following sections.

Data sources

Clinical, administrative and payment records

Clinical information, such as that generated during health care encounters or through clinical trials, is primarily used in individual patient management. It may also be collated and stored in condition-specific clinical registries that support research on the effectiveness of existing and emerging treatments. Data collection and reporting mechanisms – such as those for many services provided by hospitals,

and the administrative data generated by the Medicare Benefits Schedule (MBS), the Pharmaceutical Benefits Scheme (PBS) and private health insurance (PHI) – provide some understanding of health service function and usage.

- For example, information on demographics, diagnoses and procedures are collected during a hospital stay, while data on service provider and intervention or medication data are collected as part of the MBS, PBS or PHI billing process. The information these sources provide helps in understanding population health status, disease prevalence, the need for and access to health services, and the operation and resourcing (including funding) of the health system.

There are multiple points of interpretation and transformation as clinical data move, firstly, from a patient to a health professional or health service; then to a record in a clinical information or patient management system; and, finally, to extraction for a range of uses. Each of these points is shaped by data sharing agreements, legislation and technical requirements.

Surveys

Some information on the health of Australians cannot be derived from the administrative systems of health services. Both cross-sectional and longitudinal surveys are used to gain population-level insights on health status, and service use and experiences – including changes over time.

Cross-sectional surveys run by the Australian Bureau of Statistics – including the National Health Survey and Patient Experience Survey (from the Multipurpose Household Survey) – collect targeted information from participants about their diagnosed conditions, and their preferences, experiences, and barriers encountered in using health services. Some outcome information such as self-reported health status is also collected.

Longitudinal surveys such as the Sax Institute's 45 and Up Study and the Australian Longitudinal Study on Women's Health provide information that enables a better understanding of how lifestyle, actions and events can affect health and wellbeing over time.

Surveillance systems

National health monitoring and surveillance systems offer a very specific set of health-related data on population health in Australia. For example, the Communicable Disease Network Australia, which operates under the Australian Health Protection Principal Committee, facilitates the delivery of data on notifiable diseases to the National Notifiable Diseases Surveillance System. This data delivery mechanism has been and remains essential to the Australian Government's response to COVID-19; it also helps in developing a series of national guidelines for the prevention, control and public health management of COVID-19.

The National Ambulance Surveillance System (NASS) is another example, and an emerging source of population health data. This novel system recently contributed to data collection for intentional self-harm (including suicidal behaviours with self-injurious intent), mental health, and alcohol and other drug-related ambulance attendance services. For more information, see Box 10.7.

Other data sources

Cross-sectoral data (for example, on mental health, disability, and aged care services), new consumer sources (such as banking and supermarket data) and emerging data sets (including genomic data, electronic health records and enduring multi-source linked data sets) also contribute to an understanding of the health and wellbeing of the Australian population. The collection, sharing and use of these data as part of the health information landscape is developing.

How is information on the health system and the health of Australians used?

The health information landscape in Australia comprises data collected from and about health care practice, health status and the health system. The data are used to:

- provide clinical care
- generate population health insights
- undertake resource planning
- develop policy.

Providing clinical care

Information from Australia's health system influences the provision of clinical care. For example, data generated at the point of clinical care and through clinical research support quality improvement in clinical care standards, such as those developed by the Australian Commission for Safety and Quality in Health Care. The measures for each standard define the data required to report on quality of care and adherence to the recommended approach, and as such are an important component of the health information landscape (ACSQHC 2022).

Another example is the use of population-level data and associated research in developing the clinical decision support systems (CDSSs) used in a wide range of clinical contexts. CDSSs include tools used by clinicians as well as tools that assist shared decision-making between clinicians and patients. Use of data in this context enables a consistent and evidence-based approach to clinical decision support (AHHA 2014). Many CDSSs are regulated by the Therapeutic Goods Administration; this regulation includes requirements for assurance of quality and consistency of data that they use (TGA 2021).

Population health insights

The collection and processing of population-level data (monitoring) provide a strong evidence base for the health system and the health status of people who use it. Information used for statistical analysis can be collected from surveys, administrative data sets, extracts from clinical information systems and clinical registries. Population health insights can be used at the point of clinical care, providing the basis for real-time risk assessments and benchmarking information to guide treatment decisions.

Measuring health status at a population level involves analysing trends and patterns in risk factors, disease frequency and impact, and condition- or population-specific health service use. When used to its full potential and linked to cross-sectoral data, information from and about Australia's health system contributes to a better understanding of:

- the determinants of health: the links between a person's behaviours and circumstances and their lifetime risks and health outcomes
- the health status of a person: their health conditions, functioning ability and general wellbeing
- the health system (including health service provision, funding and planning): the system's effectiveness, efficiency and appropriateness; its safety and accessibility; and the sustainability of health care
- the broader area of societal impacts (contextual information): the changing demographics of the Australian population, the advancements in research, the economic circumstances affecting workforce and infrastructure, and the expansion and improvements in the collection of data (AIHW 2020).

Resource planning and policy development

Outputs from statistical analysis allow people with oversight of the health system:

- to develop evidence-based policy
- to plan effective resourcing of the health system, resolving gaps in adequate care.

This process relies on interpreting data extracted and compiled from disparate systems to produce meaningful insights. Generating actionable information from health data in this way ultimately contributes to better health and wellbeing outcomes for the Australian population.

Role of COVID-19 in shaping the current health information landscape

Health data have been critical in managing the response to the COVID-19 pandemic, by:

- reporting on case numbers, and on admissions to hospitals and intensive care units
- epidemiological modelling of outbreaks, and the effectiveness of COVID-safe measures
- recording the use of, and anticipating the need for, personal protective equipment (PPE), vaccines and testing kits.

The pandemic propelled health and health information (as a whole-of-population and cross-sectoral issue) into the spotlight, exposing it to greater public scrutiny. The higher visibility of data informing the emergency response to the pandemic – their timeliness, accessibility, utility and governance – exposed gaps in:

- health system information: the number of hospital beds, the supply and stockpile of medical equipment and PPE, the size of the health workforce, protocols and plans for outbreak management in residential facilities
- communication: between governments, service providers, sectors and with the Australian public
- supports for populations at risk: people experiencing disability, frailty, family violence, economic disadvantage, social isolation and marginalisation.

The pandemic response highlighted inequalities in access to services and in health outcomes. But it also created an environment in which standard data governance processes and resourcing restrictions had to be suspended to rectify immediate data and information deficits. This ‘opened the door’ to innovation and to transformation of the health information landscape.

Current challenges and emerging opportunities in the evolving health information landscape

Beyond the pandemic emergency, drawing value from the growing volume of information generated by the whole health system and technological advancements in how that information is managed is an ongoing challenge. But the situation also presents many opportunities for the evolving health information landscape.

Health providers, consumers and funders expect health information to be accessible, timely, relevant, accurate and actionable; such information could enable evidence-based decisions to be made in 'near real time' at clinical, service and policy planning levels. The benefits of (and requirements for) health data and information in evidence-based decision-making are documented at the national level:

- in frameworks and strategies specific to health conditions, population groups, population sectors and health services (such as the Aboriginal and Torres Strait Islander Health Performance Framework and the National Preventive Health Strategy 2021–2030)
- in clinical guidelines (such as the Australian Commission for Safety and Quality in Health Care's Clinical Care Standards).

These expectations of health data place increasing pressure on data administrators and data systems and, in many cases, are outpacing developments in the technical capacity and governance of systems that support data sharing and analysis. All these factors, in combination, underscore:

- the importance of accessibility and timeliness of data
- the value of technical expertise and data integration to produce meaningful insights
- the critical nature of enabling governance and infrastructure.

These are all areas of recent and ongoing development in the Australian health information landscape.

Gaps in health information: we cannot understand what we cannot see

The health sector is rich with data. Every clinical encounter, every service transaction and every purchase of goods or therapeutics is captured to record the event for clinical, administrative and billing purposes.

These data sources are comprehensive in terms of their primary administrative purpose. However, their uses beyond those purposes are limited. For example, MBS

and PBS data do not capture diagnosis or outcome information. So, while the types of services and medications Australians are receiving are well documented, the reason for them and their efficacy are not always known.

Funding and administrative arrangements for these services often prioritise data sharing for these established collections. This means that some parts of Australia's health system are reported on more and have greater visibility than others. Service activity and potential demand are less visible in parts of the system that have greater variation in administration and funding arrangements – for instance, private primary care providers, ambulance services, mental health care services and community outreach services provided by non-government organisations, charities and not-for-profit organisations.

For example, the capacity for detailed reporting on activity for hospital admitted patient care results in more focus on the performance of the hospital system, with the role and functioning of emergency departments being less visible, while the collection of detailed MBS data acts as a partial proxy for primary care.

Similarly, routine collection of demographic information (such as age, sex, geographic location and country of birth) are often used as the default descriptors of diversity. This approach limits the potential value of demographic analysis in understanding the spectrum of the population's health status and service use. It often leads to deficit-based reporting.

For example, where sex becomes a proxy for gender, and country of birth the proxy for cultural and linguistic diversity, the experience of health and the health system among those populations is lost and potentially misrepresented. Binary comparisons between people living in urban and regional areas or between Aboriginal and Torres Strait Islander people and non-Indigenous Australians emphasise the measuring of difference, rather than describing experience and diversity within these populations.

Gaps in information in crucial areas of the health system can limit the capacity for population health monitoring, research, planning and policy development. They can also create an imbalance in understanding the health system as a whole. Gaps can occur due to circumstances at multiple stages in the data life-cycle. For example:

- data can be missing because they are not recorded at the point of care, during a service interaction or included in a survey
- collected data could be unavailable because they are never extracted, transferred or shared in a meaningful or consistent way, or because governance arrangements preclude extraction and sharing

- collected data that are subsequently extracted may not be used, as they are not in a suitable format (with appropriate quality, granularity and completeness) for statistical analysis or for translation to actionable information.

Data gaps vary in their breadth and depth. Some are whole-of-sector gaps and some relate to specific data items. Gaps can be resolved by developing new data collections or by adding new items to existing collections (data development). Sometimes a gap exists because it is not appropriate or practical to collect some data in certain settings. For example, it may not be appropriate to collect comprehensive demographic information in an emergency care setting. Data integration (linkage) can help to enhance existing collections without needing to collect more data.

Data development

The aim of data development is to improve the coverage, quality, relevance and consistency of information. Developing new collections or improving the quality of data already collected means that data can be collected and interpreted more efficiently and accurately, helping to resolve data gaps. Data development includes:

- identifying what data are required
- establishing what data are already collected
- deciding how feasible it is to obtain the data
- determining the mechanisms for using those data appropriately.

Developing or adopting data standards in consultation with stakeholders to enable uniform data collection and reporting is a crucial component of data development.

Box 10.1 describes a holistic data development approach to resolve information gaps in primary health care.

Box 10.1: Developing a primary health care information system

Primary health care is a vital component of Australia's health care system and is often the first point of contact individuals have with the health system. It encompasses a broad range of professions and services. Despite this, there are limited data available to understand how people use primary health care, the conditions managed, the health and wellbeing outcomes, and links between primary and tertiary (hospital) health care and other sectors such as disability and aged care. This makes it difficult to assess the positive impact of the primary health care sector on the health of Australians or to identify where improvements are needed.

continued

Box 10.1 (continued): Developing a primary health care information system

Projects that collect and analyse data from primary care settings show the usefulness of data from the primary health care sector. Examples of projects that have made important gains in overcoming the challenges in extraction, compilation and analysis of general practice data include:

- the Australian Centre for Health Innovation's collaborative project which reported on the impact of COVID-19 on general practice through a suite of impact measures (Thomas et al. 2022)
- the NSW Ministry of Health's Lumos program which links de-identified data from general practice to other NSW health service data to better understand patient experiences of the health system as a whole (NSW Health 2021)
- NPS MedicineWise's MedicineInsight which uses insights gleaned from de-identified general practice data to support quality improvement in primary care and the post-market surveillance of medicines (NPS MedicineWise 2022).

Building on the myriad of efforts to resolve the known gaps in primary health care information, the AIHW is leading the development of a Primary Health Care Information System. This system will encompass the governance, standards, infrastructure, collection, analysis and reporting of primary health care data within Australia. One component of this system is a Primary Health Care Data Collection. This work will complement existing systems and data collections such as the MBS and the My Health Record.

To achieve this, the AIHW's 2022 work program for the development of primary health care includes:

- a Primary Health Care Data Governance Roadmap and Framework, inclusive of Indigenous Data Governance, privacy and consent
- a core data model and standards to support the quality, consistency, interoperability and validation of primary health care data for research and population health
- protocols for the secure transfer and linkage of general practice data and methods to assess their quality, variability and use
- data capacity and capability building in the allied health sector, including a set of common core data items for analytics and reporting, aligned with the overall approach to standardisation of primary health care data
- appropriate infrastructure and governance protocols for the primary health care data collection: how data are collected, stored, analysed and reported and who has access to the collection.

Insights from integrated data

Data integration (also known as data linkage) is increasingly being used to resolve knowledge gaps across the health information system. Data integration helps to reduce the need for resource-intensive comprehensive data collection in all settings, by enabling data from one collection to supplement data in another. It is also used to derive system-level insights on the patient journey, such as:

- before, during and after hospitalisations
- intersection issues, such as the coordination of care between general practice and hospitals and between the health, aged care and disability sectors.

Demand for accessible and large-scale linked data assets to answer complex cross-sector, and cross-jurisdiction health questions is growing. To meet this demand, several enduring linked data assets have emerged in Australia, including the National Integrated Health Services Information Analysis Asset (NIHSI AA) and the Multi-Agency Data Integration Project (MADIP). Enduring linkages have proven more efficient than project-specific linkages as they can be reused for multiple analyses and reporting outputs and added to (both new years of data and new data sources) over time. Box 10.2 provides an example of how meaningful insights from linked data are informing the COVID-19 vaccination roll-out.

Box 10.2: Insights into COVID-19 vaccinations: linking the Australian Immunisation Register to the Multi-Agency Data Integration Project

Linking the Australian Immunisation Register (AIR) to the MADIP is an example of how timely linkage can increase the usefulness of data by forming new insights.

Australia's COVID-19 vaccination roll-out is a national priority that aims to ensure all Australians who want to be vaccinated can be. Enhanced de-identified information from weekly integration of AIR data with the MADIP supports detailed and targeted analysis to understand and foster progress of the roll-out. The integrated data will offer further insights, including identifying priority cohorts (such as people with disability or chronic health conditions), without additional data collection. Individuals need to provide their information once only and it can be used for multiple purposes.

The integrated data set allows for deeper analysis of vaccination trends by occupation and industry, and by different groups, such as young adults or people from culturally and linguistically diverse backgrounds.

Early analysis identified languages and geographic areas that could be used for more focused communications to support vaccine uptake. The use of existing data is carefully managed to protect people's privacy while supporting important policy and real-life outcomes. The integrated MADIP and AIR data, and the associated work to connect the MADIP to the Business Longitudinal Analysis Data Environment and other integrated data assets, continues to support more comprehensive social and economic analyses for the COVID-19 response, as well as longer term research requirements.

Enduring linked data collections benefit from validation, analysis and reporting tools that support the automation of otherwise cumbersome and time-consuming processes and allow for a broader range of analysis techniques and outputs. Machine learning and associated artificial intelligence tools, including natural language processing (NLP) and robotic process automation offer large efficiency gains. Take-up of these tools across the health care sector has been slow, however. This is due to sensitivities around using person-centred data, and a wish to derive insights that are certain and not contestable – not easy to demonstrate with complex computing algorithms. Nonetheless, the AIHW is exploring the use of machine learning and NLP tools for a range of projects to fill information gaps and improve timeliness and efficiency of analysis.

Box 10.3 summarises recent findings for the AIHW's use of the NIHSI AA, demonstrating both the reuse of an enduring linked data asset, and the use of machine learning tools to support analytics and insights.

Box 10.3: Population health insights

Treatment patterns and condition incidence using linked data: incidence of cardiovascular diseases

Acute coronary syndrome (ACS), a subset of coronary heart disease (CHD), refers to acute myocardial infarction (commonly known as a heart attack) and unstable angina.

Counting new cases (incidence) of ACS events is important to understand disease patterns and trends, treatment outcomes and the effectiveness of public health interventions. The current method for estimating the incidence of ACS uses unlinked hospitalisation and deaths data. This method cannot, however, differentiate between initial ACS hospitalisations on the one hand and transfers or readmissions for subsequent treatment of the same ACS event in the same person.

Using this method, hospitalisations where the patient was transferred to another hospital are excluded to minimise the potential for double-counting.

Using linked hospitalisation and deaths data from the NIHSI AA from 2011 to 2018, the AIHW examined all hospitalisations (including transfers and readmissions) and deaths associated with an ACS event. It then used this information to assess the impact of hospital transfers, readmissions and clinical coding on estimating ACS incidence.

It is expected that the results of this study will be published in September 2022. They will help to improve the accuracy of the method used to estimate the incidence of ACS events from unlinked data for national CHD surveillance.

continued

Box 10.3 (continued): Population health insights

Machine learning to predict disease cases: predicting early dementia using Medicare claims

People living with dementia in Australia can be identified from information recorded in data for hospitalisations, prescription medications, residential aged care and death certificates. These sources better capture people at later stages of the disease, however. This means that people with early dementia are under-represented in population health analyses. The majority of health care interactions in the early stages of dementia occur in primary and secondary care settings where diagnosis and other dementia-specific information is lacking.

To better identify people with early dementia, the AIHW used 2 simple machine-learning techniques on linked Medicare data, and linked data for other health services and aged care services from the NIHSI AA, to train algorithms to recognise cases of early dementia in Medicare claims data.

This study explored Medicare claims data for the period 2009–2017. It found that both machine-learning techniques identified around 30,000 possible cases of early dementia in the data that were not identifiable in other health data sets. Around 25,000 of these were true cases (85% precision), representing 80% of all known early dementia cases, based on prescription data. The best predictor of early dementia was geriatrician-specific Medicare item claims, followed by claims for magnetic resonance imaging (MRI), computerised tomography (CT) scans and chemical pathology tests.

These findings suggest that, while it is feasible to use Medicare claims data to identify most people with early dementia, some information on primary and secondary care service use is potentially missing from the algorithm that could help to identify the remaining 20% of known early dementia cases.

In the future, statistical approaches such as these – which help to identify likely cases of dementia in data sources without dementia diagnosis information – may help to improve the accuracy of national dementia prevalence estimates and substantially improve knowledge and understanding of people living with early-stage dementia.

For more information, see the 2021 AIHW study *Predicting early dementia using Medicare claims: a feasibility study using the National Integrated Health Services Information Analysis Asset*, at <https://www.aihw.gov.au/reports/dementia/predicting-early-dementia-using-medicare-claims/contents/summary>.

Factors that contribute to data gaps are many and complex. Data integration, analysis and development projects, such as those described earlier, have improved the enumeration of health conditions, and the understanding of both health service use and barriers to its use. They have also identified risk factors for poor outcomes and contributed to the development of targeted interventions. These studies offer important (often groundbreaking) means to resolve gaps in data and information for a particular disease, population group or service area. However, many are discrete pieces of work; they could be scalable or their methods and approaches adapted more broadly, but generally their immediate application is limited.

In contrast, a focus on the following 3 areas could resolve multiple important and longstanding issues, and have a broad and sustained effect across the health system:

- data governance: implementing improvements that ensure a balance between privacy and accessibility, founded on principles of community trust, accountability and consent
- interoperability: harnessing technical developments to enable information sharing and use between different parts of the health system, and at the interface with other sectors, to improve clinical care and health outcomes
- workforce: developing digital literacy and capacity among health professionals and building a capable and well-utilised workforce of health information managers, information system developers and data scientists.

Data governance

Information about an individual's health problems and treatments is highly personal and many Australians are justifiably sensitive about who has access to that information. The legislative and regulatory environment around health information is vast, with slight variations between the states and territories. All health organisations must comply with the *Privacy Act 1988* (Cwlth) and the Australian Privacy Principles where any person can be identified; there are also specific provisions for health information to protect people's privacy throughout the data life-cycle.

Legally binding guidelines included in public health acts and in those issued by the National Health and Medical Research Council and approved by Australia's Privacy Commissioner guide appropriate use of health information. Some population health monitoring uses, including research and data linkage activities not authorised by specific legislation, must undergo a rigorous assessment and approvals process by a fully constituted Human Research Ethics Committee.

The Five Safes framework (see <https://www.aihw.gov.au/about-our-data/data-governance/the-five-safes-framework>) reinforces principles for managing the privacy and confidentiality of data:

- Safe projects – Is the use of the data appropriate?
- Safe people – Can the users be trusted to use it in an appropriate manner?
- Safe data – Is there a disclosure risk in the data itself?
- Safe settings – Does the access facility prevent unauthorised use?
- Safe output – Are the statistical results non-disclosive?

Public trust is also a major factor in the acceptability of using health information to guide research on the health of the population (Aitken et al. 2016). Consumers are engaged by developing a culture of 'digital citizenry' – one that provides opportunities for consumers to experience the collective and individual benefits of understandings gained from analysing population-level health data. As individuals realise the potential for their health information to help meet their own immediate and ongoing health care needs, they may increasingly support the use of their health information to make evidence-based decisions that also support the wellbeing of the population.

The Attorney-General's Department is currently reviewing the *Privacy Act 1988* to ensure consumers are empowered and protected, while ensuring that data retain usefulness for informed decision-making. Proposed reforms focus on the safe use of data in a digital environment with close reference to the Australian Competition and Consumer Commission's *Digital Platforms Inquiry* (see: <https://www.accc.gov.au/focus-areas/inquiries-finalised/digital-platforms-inquiry-0>).

Streamlining data governance

Developments in timeliness and data integration have prompted decision-makers to think about the best approaches to data governance. The longevity and efficacy of the Australian health information system requires an approach that supports safe and secure sharing of data to meet legislative requirements and to bolster community trust. Emphasising the safe and timely sharing of data to benefit the community while offering assurance of privacy protection and security has become more important than ever.

While legislated privacy protections and rigorous government frameworks remain firmly in place, there has been a shift toward streamlining release and approval processes to reduce duplication of effort; this has increased the timeliness and usefulness of data. These efforts may also bolster community trust by making it possible to not only use – but also show the worth of – health data where it was not previously permissible to do so – such as happened during the emergency response to COVID-19.

A notable example of this shift is the progress made toward creating a national linkage system, transforming the way enduring data linkages are handled. This approach aims to coordinate and streamline governance processes to increase the usefulness of linked data by de-duplicating approval and linkage activities while protecting privacy. The National Disability Data Asset (NDDA) is a project that is driving a national, streamlined approach to governance. (See Box 10.4 for more details on this project.)

Box 10.4: National Disability Data Asset – governance aspects

Through the NDDA pilot, governments have examined how to best link data to understand outcomes of people with disability – while protecting people’s privacy (NDDA 2022).

The pilot phase of the project was completed at the end of 2021. Lessons learnt are informing the design principles for the technical, operational and governance aspects of an enduring NDDA. In December 2021, the Australian Government announced plans to invest a further \$36.9 million in the next phase of the NDDA, with its design, governance and costs shared with states and territories. The Australian Bureau of Statistics and the AIHW are jointly responsible for working with Australian and state and territory governments on the next phase of technical implementation.

The pilot highlighted a great willingness by Australian and state and territory governments to share data. However, limitations of existing data governance arrangements and technical infrastructure pose substantial challenges.

Box 10.4 (continued): National Disability Data Asset – governance aspects

A key design principle for the NDDA is to build and govern a national ‘multi-purpose data system’ as the basis for any people-centred national data asset. The intent is to establish ‘context specific’ governance for the effective and trust-building use of portfolio-specific data (disability in the case of the NDDA).

To support this objective, the NDDA design is based on 7 building blocks. The first 3 constitute the foundations of a national approach to people-centred data for use, and re-use, across population groups and across human services:

- 1. data linkage and integration infrastructure:** to establish a national hub-and-spoke network, building on and evolving existing capabilities for people-centred data sharing across jurisdictions, while allowing jurisdictions to maintain and enhance their own person-centred data assets
- 2. National data system governance:** to institutionalise collaboration and joint governance between jurisdictions by establishing a National Data Integration and Infrastructure Board
- 3. Streamlined data sharing arrangements:** to facilitate more efficient sharing of data within existing legislation and within each jurisdiction’s obligations to data custodians.

The remaining 4 building blocks are to ensure that the enduring NDDA is adapted to deliver scaled insights:

- 1. Co-governance of the use of data by governments and the relevant community:** to build and maintain trust – in the NDDA case, people with experience of disability
- 2. Data development and a knowledge sharing platform:** to focus on improving data quality practices, and on sharing knowledge of how to use the data effectively – both across governments and with community organisations and researchers – while resolving priority data gaps to enrich insights
- 3. Centrally coordinated analysis:** to deliver this through a distributed team that is centrally coordinated, with members chosen from across Australia for their expertise in the given policy context
- 4. Sharing of insights with specific decision-makers and communities:** to share insights, via a range of useful formats, with governments, communities and researchers.

Further changes in governance relate specifically to community expectations of and response to the Australian Government’s COVID-19 monitoring and reporting – for example, streamlined approval processes, and encouraging release of key or preliminary findings before detailed reports are finalised.

Improving accessibility and timeliness

COVID-19 and the 2019–20 bushfire season in Australia showed that in times of crisis and uncertainty, accessible and well-timed information is key. The information needs of multiple levels of government, service providers and the public pressured the health information system to provide information that was timely and targeted. This required new mechanisms for sourcing data, and new ways to present information.

Examples of these innovations include:

- compiling summary statistics on mental health, suicide and crisis support based on novel data drawn from mental health telehealth services and crisis lines
- working with the Australian National University to undertake COVID-19-focused surveys on mental health, loneliness, alcohol and illicit drug consumption, and housing
- adding short focused reports and dashboards to the AIHW's core suite of products to highlight the COVID-19 period
- developing the Critical Health Resource Information System early in the pandemic (developed by the Australian and New Zealand Intensive Care Society [ANZICS], Ambulance Victoria and Telstra Purple) to capture and report on intensive care unit capacity and activity.

Examples of timely use of data are described in Box 10.5.

Box 10.5: Support for policy and planning: timely monitoring of system and service activity and capacity

Florence

At the start of the COVID-19 pandemic, it was clear there would be a need for active monitoring of health system capacity and activity as the virus progressed through the community. To help meet this need, the AIHW worked with the states and territories, the Australian Government and the ANZICS to set up new data sharing arrangements. The states and territories dedicated resources to provide daily data feeds from every public hospital as part of the data sharing system for hospital capacity and activity. It also involved working with a group set up by the ANZICS to obtain data from public and private intensive care units and using the AIHW's access to MBS and PBS data to include activity not related to hospitals.

These data sources are brought together in a set of digital dashboards known as Florence (in honour of Florence Nightingale).

Box 10.5 (continued): Support for policy and planning: timely monitoring of system and service activity and capacity

Florence represents an unprecedented collation and rapid sharing of data from across the health system. Data are uploaded each day and made instantly available to all levels of government in Australia, to assist with health system resourcing and the planning of public health measures in response to the crisis.

Mental health dashboards

Since April 2020, the AIHW has been assisting the Department of Health to curate, analyse and report on activity related to mental health during the COVID-19 pandemic. Data are reported via 2 dashboards. They include information obtained from the MBS, PBS, and crisis and support organisations (Lifeline, Kids Helpline, Beyond Blue), and through analysis of emerging research findings.

The AIHW has facilitated the sharing of detailed data on the use of mental health services with the New South Wales, Victorian and Queensland governments. Importantly, this involves a 2-way sharing of data with the Australian Government. There is a national version of the mental health COVID-19 reporting dashboard as well as a jurisdictional version that focuses on service activity in each of New South Wales, Victoria and Queensland (AIHW 2022).

The AIHW was able to accelerate planned work to design data requests from new sources, compile them and then provide these data to Australian, state and territory governments. These data supported decision-making for the potential mental health impact of COVID-19 and for the public health measures put in place to slow the pandemic's transmission, such as physical distancing and limitations on gathering.

These monitoring dashboards were provided to governments weekly in 2020, fortnightly in 2021 and now monthly in 2022.

Timely use of data does not mean that all data should be received and reported on with increasing rapidity. 'Timely' does not always mean 'immediately'. Each use of data has a specific purpose in bolstering the health system and the optimal timing for reporting on that data depends on its purpose. An example of varying frequency that affects reporting is the use of deaths data to inform rapid COVID-19 reporting. Preliminary cause of death data are used to show how the pandemic is developing day to day. This provisional reporting is necessarily revised once cause of death is finalised and reported on.

Highly cleansed, curated and slower cadence data sets such as the National Hospital Morbidity database play an important role in complex epidemiological modelling to anticipate population health outcomes based on historical information about the population.

Improved timeliness in the release of data and information in a range of formats that are accessible and relevant to a variety of audiences and for a variety of uses has been and should remain a focus of the Australian health information system.

Engaging with the community

Consumers are becoming more aware of the usefulness of data to monitor and improve the capacity of the health system, sparking an increase in data literacy. This increase coincides with increasing technical capacity for data sharing and evolving consumer expectations about access to and control over data – generating a new form of digital citizenry.

This appetite for data-driven information offers a great opportunity to learn about ways to effectively use data to support community wellbeing.

For example, community-led data visualisations have emerged that integrate publicly available Australian, state and territory government data and present them in a way that is meaningful to the broader community. Projects such as *bushfire.io* at <https://bushfire.io/> and *Covid-19 Near Me* at <https://covid19nearme.com.au/> are examples.

The interactive tools on websites such as these recognise that there is a heightened level of public engagement in the usefulness of timely, accessible data. These sites make government data accessible to the community in a way that not only resonates with users but also has (at times) been more responsive than government representation of that information.

Robust, transparent and increasingly dynamic privacy protection measures support developments in digital health and empower consumers by offering more access to and control over their own health information. Examples of these developments include the range of mHealth applications (mobile applications used to support health care) being developed by the Australian Digital Health Agency. Direct engagement with consumers is a positive force in ongoing work to improve the quality, quantity and availability of health information on a national level.

Looking to the future, the increasing diversity of data sources, the integration of big data sets and the use of artificial intelligence and machine learning to process those data sets emphasise the need for a more coordinated and streamlined approach to governance that will reduce barriers to data sharing while assuring the privacy of individuals and maintaining community trust.

Interoperability

For health data to be most useful it needs to be shared safely within and between clinical, statistical and policy and planning settings and use cases.

From a clinical perspective, transfer of clinical information between service providers and between different parts of the health system (for example, between primary care and hospitals) determines the accuracy and timeliness of communication between care providers and influences the quality of care, especially in shared care settings. It does this, for example, by:

- streamlining and improving the timeliness of access to health care users' data and information
- providing real-time support for improved clinical decision-making and decisions on patient safety
- providing digitally enabled patient screening and medication alerts.

Building on this, accurate transfer of information from clinical settings to analysis environments is fundamental to the compilation and development of insights for population health analysis and system resourcing.

Successful transfer of information relies on both technical and semantic interoperability:

- Technical interoperability is enabled through use of agreed data exchange specifications to encourage consistency in data structure and format to simplify system interactions and integrations.
- Semantic interoperability can be described as 'the capability of 2 or more systems to communicate and exchange information, and for each system to be able to interpret the meaning of received information and to use it seamlessly with other data held by that system' (Rowland 2020:29).

Technical and semantic interoperability each support the transfer of data between systems and the capacity to access that data beyond their original setting.

Traditionally, service providers, clinicians and academics in both public and private sectors collect data for specific purposes, with limited integration with other health data systems or across different sectors. Data sharing for multiple purposes is a major shift from paper-based clinical and administrative notes generated for use within one health care environment (for example, a hospital department or a general practice). Improving the portability of that data increases its availability for a wider range of uses, including transitions between care providers and any activity that involves extraction and use of data outside of its original environment.

Momentum generated by the COVID-19 pandemic allowed data to flow more easily between entities to meet an acute need for a more complete picture of the Australian health system. However, the national response to solving a shared problem has also highlighted the need for better communication across the health system in non-emergency situations – essentially a need for better interoperability to increase capacity for data sharing.

A coordinated, whole-of-system approach to managing health information that is complete and comparable requires communication between information systems and a common understanding about the meaning of that information as it moves between systems.

As well as appropriate governance arrangements, a key driver in resolving data gaps is the technical capacity to share information between systems. Inconsistencies in data definitions, coding, classifications and standards – as well as inconsistent quality across input data sources – create a challenge at each stage of the data life-cycle. This affects the safe and accurate transfer, storage, meaningful use and appropriate sharing of the data.

Effective interoperable systems resolve this challenge by standardising input, output or the automation of processes for consistent transformation from one format to another. Interoperable systems lead to improved:

- quality of care – facilitating access not only to timely and accurate information but also information sharing between clinicians and clinical decision support
- quality of data generated about that care – implementing the use of standard forms, definitions and meanings
- capacity for that data to traverse the health system – following the care pathway from one setting to another through compatible system interfaces.

The need for interoperability of health information is emphasised in the *National Health Reform Agreement – Addendum 2020–25*, the *Australian Digital Health Strategy* and the *National Healthcare Interoperability Plan* (in development).

The AIHW's Metadata Online Registry (METeOR) is Australia's repository for national metadata standards for health, housing and community services statistics and is one example of infrastructure that supports semantic interoperability. Metadata endorsed for use within an organisation or across Australia are referred to as data standards and describe the expected meaning and acceptable representation of data for use in a defined context. These consistent definitions facilitate a shared understanding of terminology in data collections – a major enabler of interoperability.

Workforce

An appropriately skilled and diverse workforce is crucial to realising the full value of emerging developments in Australia's health information landscape, and to meeting increasing needs for 'useful' health data.

This workforce – comprising clinical, administrative, information management and data science professionals – must keep pace with technological developments and be situated within and reflect the complex political economy of the health system. This is inherently a multi-sectoral collaboration, involving engagement by public and private sectors and many different disciplines, including:

- 'up-skilled' clinicians and other professions involved in collecting clinical information in digital environments
- a health information management workforce skilled in the development of standards to convert that clinical information to meaningful data for use by analysts
- analysts skilled in the quantitative analysis of large, complex data sets, as well as people with the right 'soft' skills and emotional intelligence to understand the narrative behind the data.

Accurate and accessible communication of health information for easy consumption by individuals, their advocates, program managers and policy-makers is an essential component in transforming health data to health information and knowledge.

Digital literacy

Digital health is an umbrella term referring to a range of technologies that can be used to treat patients and collect and share a person's health information. These include mobile health and applications, electronic health records, telehealth and telemedicine, wearable devices, robotics and artificial intelligence (see 'Digital health' at <https://www.aihw.gov.au/reports/australias-health/digital-health>).

Digital health is transforming health information in terms of the environments it is collected in, the format it is stored in and the capacity to share and integrate information from a range of sources.

The clinical workforce plays an important role in the health information landscape, by undertaking primary data entry in the form of clinical notes, diagnostic reports, screening tests, prescriptions and referrals. Digital literacy and capacity among this workforce are therefore important to encourage the use of digital health systems, and the quality of the data and information they contain.

The National Digital Health Workforce and Education Roadmap, developed by the Australian Digital Health Agency, identified the use of digital platforms by the health workforce as an area for development. It does acknowledge, though, that the technical capacity for implementing digital tools is developing faster than the capacity to use them.

This roadmap focuses on key activities needed to build a digitally capable health workforce, including:

- embedding safe, ethical and effective use of systems of records
- integrating new technologies and ways of working
- transforming digital health data (ADHA 2020).

Digital technologies are intended to improve health care and the experience of clinicians and patients by:

- making health information more readily available at the point of care and more easily transferred between care settings
- reducing the duplication or loss of information across settings and care teams.

It is important to understand the need for well-developed digital literacy among clinicians and other health professionals, and the effect that digital technologies have had on clinical practice. Access to information about the health workforce represents a substantial health information gap (Box 10.6).

Box 10.6: Data on Australia's health workforce

The size, utilisation and capacity of the health information workforce are important elements of the health information landscape.

A substantial gap in the health sector, more broadly, is the limited data on its clinical workforce. This information is critical for service planning and delivery, recruitment and retention and, as highlighted during the Australian response to the COVID-19 pandemic, for resolving potential capacity issues in times of crisis and health emergencies.

Agencies that register health professionals, such as the Australian Health Practitioner Regulation Agency or self-regulated bodies, are sources of information on the number of health professionals permitted to work in the Australian health sector as well as on some of their demographic and employment characteristics.

What these registers do not provide, however, is complete information on aspects such as the setting (or the number of settings) in which an individual health professional works or their scope of practice. Some of this information is collected in survey form by professional bodies, such as the Workforce Survey run by the Australian Primary Health Care Nurses Association or the Commonwealth Fund International Survey of Primary Care Physicians. These surveys provide information on the qualifications and scope of practice of health professionals, their digital literacy and their experience of the health system; they also highlight settings and circumstances in which there may be opportunities to improve workforce utilisation, recruitment and retention (APNA 2022; Doty et al. 2019).

Collating comprehensive national health workforce information within professions, settings or sectors is an area of emerging work.

Health information management

Work to convert clinical data into meaningful information for analysis is managed differently across the health sector. In hospitals, this work relies on the highly skilled Health Information Management workforce, which:

- develops and implements classifications and coding standards
- codifies clinical notes for statistical analysis based on those standards
- ensures, in conjunction with data scientists, the quality of codified data (Henderson 2015; Shephard 2019).

This work is a key foundation of the national health information landscape, particularly for data that flow from the clinical information systems through to the national collections. While this hospital workforce is well established to collect data on admitted patient care, there is generally no equivalent workforce overseeing data from other sectors, such as those for primary health care, ambulance and emergency departments (Box 10.7).

In general practice, clinical information is transformed into statistical outputs for analysis via complex mapping algorithms built into a range of independent extraction tools. Patient interactions with allied health are rarely codified or used for routine analysis. Variability in the mapping of clinical terms for use in statistical analysis is a potential barrier to the quality, consistency and comparability of data both within and beyond the primary care sector, as data are increasingly brought together through data integration (Youens et al. 2020).

The importance of health sector data – and the mismatch in collection, transformation and reporting and in the subsequent quality and utility of the data – highlight the value obtained by investing in the data workforce and in systems to support standardisation. A highly skilled whole-of-sector health information workforce could secure the future of the health information landscape in Australia. It would guide the implementation of data standards to support interoperability and influence the effective use of emerging data interpretation techniques, such as natural language processing. Health information management processes at the clinical interface would feed through to data transformation and coding to improve analysis of structured coded data and to translate that analysis into information and knowledge that can be acted upon.

Box 10.7: Coding ambulance data

The suicide and self-harm monitoring component of the NASS (a public health monitoring system) was established in 2020. It provides timely and comprehensive data on intentional self-harm (including suicidal behaviours) in the community and builds upon previous work in ambulance surveillance (alcohol and other drugs). Data for the NASS are compiled by Turning Point, in partnership with the Monash University, and are sourced from paramedic electronic patient care records provided by Australian, state and territory ambulance services. As part of the National Suicide and Self-harm Monitoring Project, the AIHW contracted Turning Point, through the Monash University, to develop the NASS for attendances related to self-harm.

continued

Box 10.7 (continued): Coding ambulance data

Information is obtained and coded through manual scrutiny of de-identified electronic patient care records (ePCRs), including paramedic clinical assessment; patient self-report; information from third parties; and other evidence at the scene, such as written statements of intent (including social media, text messages and written notes) recorded by paramedics. Intent of self-harm behaviours derived from the ePCR may be from either stated or physical evidence, or where there is evidence but the patient may have denied the behavioural intent (Lubman et al. 2020).

Ambulance attendances related to self-harm are included if the self-harm occurred in the preceding 24 hours or during the ambulance attendance. There are 4 categories of ambulance attendances for self-harm, defined and coded as:

1. self-injury (non-fatal intentional injury without suicidal intent)
2. suicidal ideation (thinking about killing oneself without acting on the thoughts)
3. suicide attempt (non-fatal intentional injury with suicidal intent, regardless of likelihood of lethality)
4. suicide (fatal intentional injury with suicidal intent).

It is important to note that suicide, suicide attempt and suicidal ideation are considered to be mutually exclusive; however, self-injury could be simultaneously coded with any other self-harm category.

The number of attendances related to suicide is under-represented as ambulances do not attend all deaths. Furthermore, when they do attend, there may be insufficient information to determine suicidal intent at the scene.

Methods of suicide, suicide attempt or suicidal ideation are coded – as are methods of self-injury and categories of suicidal ideation preparation (planned, unplanned and unknown if planned) – using a modified International Statistical Classification of Diseases and Related Health Problems, 10th Revision (ICD-10) coding framework.

For data on ambulance attendance for suicide and self-harm, see <https://www.aihw.gov.au/suicide-self-harm-monitoring/data/ambulance-attendances/ambulance-attendances-for-suicidal-behaviours>.

For more information on the topic, see <https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0236344>.

Data science

Machine learning and associated artificial intelligence tools, including NLP and robotic process automation offer large efficiency gains in analytics and insights generation (AIHW 2021a). Take-up of these tools in the health care and health information sector has been slower than in other areas due to sensitivities in using person-centred data and a desire for certainty and transparency that favours more traditional and established methods of analysis and interpretation.

Data scientists with the skills to perform safe and accurate analysis of big data sets using artificial intelligence and machine learning techniques are becoming increasingly essential. Directing effort and resources towards growing capabilities in this area will support expanded use of large linked data sets for predictive modelling, forecasts, projections and/or the formulation of preliminary estimates.

Shaping the future of health information in Australia

The COVID-19 pandemic created momentum and fostered innovation to resolve immediate and critical gaps in the health information landscape during a period of national emergency. Great opportunities and equivalent challenges for the governance and use of health information in Australia also emerged through that emergency, in the:

- increased realisation of the importance and value of health data and information
- need for timely (including real time), granular, local and linked data
- connection between digital and statistical information within the sector
- increased recognition of the important intersections between segments of the health sector, and between the health sector and others (aged care, disability, for example) (AIHW 2021a).

The COVID-19 emergency also highlighted the benefit of a coordinated national approach to meet these challenges and opportunities. This will be increasingly important to ensure:

- further development in governance and in building community trust
- completeness of information from the whole health system
- sufficient workforce capacity
- technical infrastructure for the future.

Australian governments and health information agencies such as AIHW have a role to play in working collaboratively to meet these challenges and opportunities – harnessing the momentum and innovation generated by the COVID-19 pandemic to secure a more sustainable and effective health information system as a foundation for a healthier Australia.

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