

Aged Care Data: Explainer

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In this Explainer, we examine national digital health and aged care strategies released since 2023, in Australia, with the aim of understanding how they fit together^b. We highlight the gaps and identify how these might be addressed in the interest of advancing meaningful digital transformation of aged care.

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^b This explainer is intended for anyone interested in and/or likely to be impacted by the digital transformation of health and aged care in Australia.

The aged care data ecosystem

In February 2021, the **Royal Commission into Aged Care Quality and Safety** completed its investigation of the Australian Aged Care system and published its Final Report titled *Care, Dignity and Respect*¹. It called for reforms to address the problems that were leading to substandard care in this sector. Of relevance to this explainer, three of the gaps called out by the Royal Commission included:

- Fragmented and incomplete data, with notable data gaps in regular assessment of care needs, quality of life, and care quality
- Limited interoperability between systems and entities
- A lack of consistent data standards to support software development and the reuse of data.

The **Australian Government Department of Health and Aged Care (DOHAC)** took the lead in responding to the inquiry, working alongside two national organisations, the **Australian Institute of Health and Welfare (AIHW)** and the **Australian Digital Health Agency (ADHA)**, amongst others.

Between them, these institutions have since released a series of strategic planning documents. Understanding how these relate to one another is the initial objective of this explainer.

The first to be published of these data and digital reports was the AIHW report on stakeholder consultations to inform the development of **a draft National Aged Care Data Strategy**². Such a strategy document was identified by the Royal Commission as necessary to help improve data quality, comparability, and the usefulness of data collected across the sector. Importantly, this consultation report confirmed expectations for the data strategy to support better integration of aged care data systems with other health and social data systems.

In mid-2023, related to the work being undertaken by the AIHW on the aged care data strategy, the AIHW published version 1 of the **Aged Care National Minimum Data Set - NMDS V1**³. While the initial version is largely concerned with administrative data, subsequent annual releases (V2 in June 2024 and V3 in June 2025), will help ensure the data definitions inform care provision, operations, the workforce, and system reporting. Further, the expansion of the data set in this format allows data to be made consistently available for research and analysis. An accompanying technical report on the development of standardised aged care data makes the point that the NMDS will be impacted by regulatory or best practice data standardisation occurring in the broader digital health and care ecosystem. Over time, the NMDS will be shaped by the prevailing security, privacy, classification and data exchange standards^c, regulatory changes, and policy requirements.

For this reason alone, it is important to understand what are the factors that will or should be influencing how aged care data is defined and used in a modern health and aged care system.

Also in mid-2023, the AHDA published its **National Healthcare Interoperability Plan**, which sets out the steps to ensure cohesive, seamless data sharing across platforms, sectors, and hospitals⁴. This document promotes the adoption of national healthcare identifiers in future digital health initiatives, strengthened use of digital health standards, the use of procurement guidelines for future clinical systems (including for residential aged care), toolkits to support interoperability projects, including the use of the API gateway, education, and monitoring of digital health maturity. A **Supplement** to the Interoperability Plan provided more detail, including initiatives to assess data sharing between GP and aged care facility systems and uptake of national healthcare identifiers⁵.

In late 2023, the Department released its **Digital Health Blueprint**, which outlines the rationale for digital and data reforms to support the whole of the Australian Government's health-related needs⁶. Similarly, in early 2024, the ADHA officially released the **National Digital Health Strategy**, which is a strategy for the Australian Government to also support Australia's health-related needs⁷. The Blueprint and the Digital Health Strategy were accompanied, respectively, by an **Action Plan** and a **Delivery Roadmap**, each setting out priority actions and indicative timelines^{8,9}. These documents also share broad objectives of digitally empowering individuals and carers/clinicians, by improving the access and usefulness of data across the entire health sector.

These major digital health strategy documents were under development at the same time as the work by the Department, the AIHW, and the ADHA on the draft **Aged Care Data and Digital Strategy**, released in October 2023¹⁰. Whilst they issued complementary calls for changes to be made in the way data was used and shared by and with aged care providers, these documents provide little information on how the real 'under the bonnet' gaps in aged care data and digital technologies, currently hindering effective connected care, will be addressed. These are the issues relating to standardisation of data sets, data capture, and data sharing.

It is within this context, that the importance of the Aged Care Data and Digital Strategy becomes apparent. The October 2023 draft of the strategy lists a series of action areas, including those relating to enhanced data collection and use. It is understood that a final version of the strategy, due for release in 2024, may provide more information about how these action areas will be undertaken and by whom.

c For example SNOMED-CT and HL7 FHIR

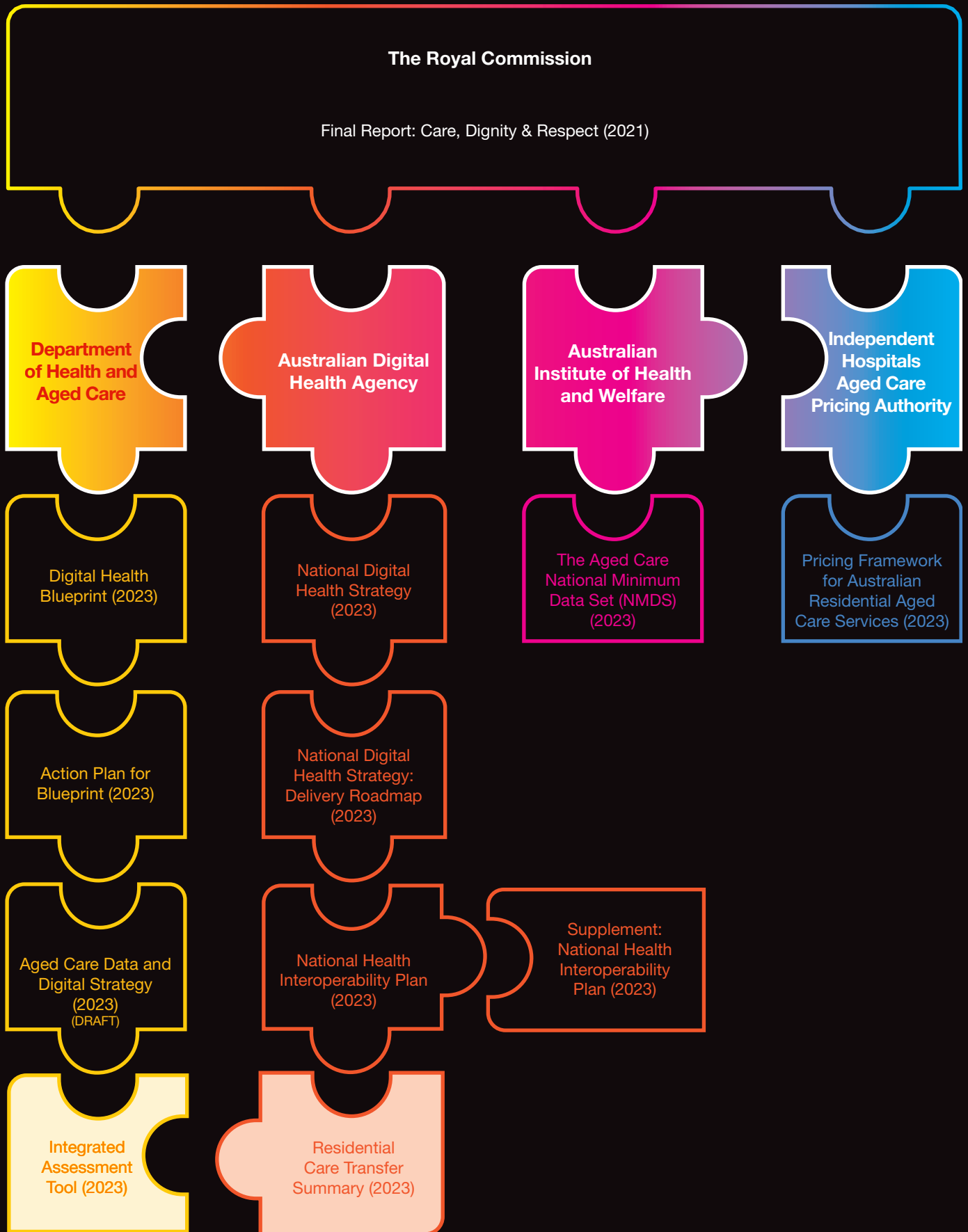


Figure 1: Major digital health strategy and related documents referencing aged care data published since the Royal Commission into Quality and Safety in Aged Care Report

New aged care data initiatives

The second objective of this explainer is to provide some suggestions for how to advance some of the data initiatives called for by the Royal Commission and referenced in the above-mentioned documents. To assist with our understanding of this complex area of data sets, data capture and data standards for data reuse, we look at three current initiatives: the role of the Aged Care National Minimum Data Set (NMDS); the Aged Care Transfer Summary (ACTS) and the Integrated Assessment Tool (IAT); and the Mandatory Quality Indicator (QI) Program.

The NMDS is a data set specification and sets out very clearly the metadata that needs to be collected and reported by each aged care provider, and how it should be recorded (Figure 2)³. The development of this minimum data set acts as one stepping-stone in a larger pathway towards data standardisation. The mandatory collection of data will feed into the AIHW National Aged Care Data Asset (NACDA), a repository of structured and coded, linked aged care data that is available for analytics and national reporting¹¹. The upgrading of Australia's national aged care data set, recommended by the Royal Commission, will ultimately allow data to be collected consistently, easily shared and re-used.

The NMDS V1 is being implemented in a stepwise manner with reporting to become mandatory by June 2024, and contains information related to people, assessments, services, and providers. The future development of the second volume of NMDS (V2) holds significant weight, as it is expected to include the metadata for clinical information pertinent to aged care. This is a tipping point opportunity for Australia to address the data needs called out by the Royal Commission and others - and a key message in this explainer. The data definitions and structuring included in NMDS V2 (or V3) will need to be consistent and evolve alongside the other national healthcare data activities listed as priorities in the National Digital Health Blueprint and Action Plan.

The **Integrated Assessment Tool (IAT)** is a new assessment instrument developed by the Department to assess an individual's needs for Australian Government subsidised aged care support¹². It was a recommendation of the Royal Commission to streamline how older people navigate access to the care system. To be commenced in July 2024, it will be used by Aged Care Assessment Teams across the country, via an online portal. The IAT has been developed using a range of verified assessment instruments building on the current National Aged Care Screening and Assessment Form, itself a largely administrative document, typically using secondary data. It is assumed that the IAT data will be reflected in a future version of the NMDS. Importantly, as this is an eligibility assessment instrument, there is an expectation that the NMDS will make explicit use of the data from the IAT and how it will be reused.

The **Aged Care Transfer Summary (ACTS)** is a new 'document' to better support an individual's transfer from residential aged care to hospital¹³. Again, addressing the Royal Commission recommendation to improve continuity and safety of care transfers, its aim is to replace the unreliable, paper-based care transfer document. The ACTS comprises three record types that become visible in an individual's My Health Record, including a residential care health summary (see Figure 3). Work is yet to get underway to build the specifications that will enable aged care vendors to upload data in a form that will enable that data to be reused by other clinical information systems. The current focus is on working with vendors to upload these components using PDFs into the My Health Record.

Aged Care episode - cessation reason, code N [N]

- 1: Entered residential aged care
- 2: Admitted to hospital
- 3: Returned to family, home or community (no aged care)
- 4: Commenced community-based, in-home or flexible aged care
- 5: Died while using aged care
- 10: Other

CODE 1: Entered residential aged care. This code is used where the aged care episode ends due to the person entering residential aged care. This includes people moving from one residential aged care service to another

Figure 2: Example of a data element in the Aged Care National Minimum Dataset (NMDS)

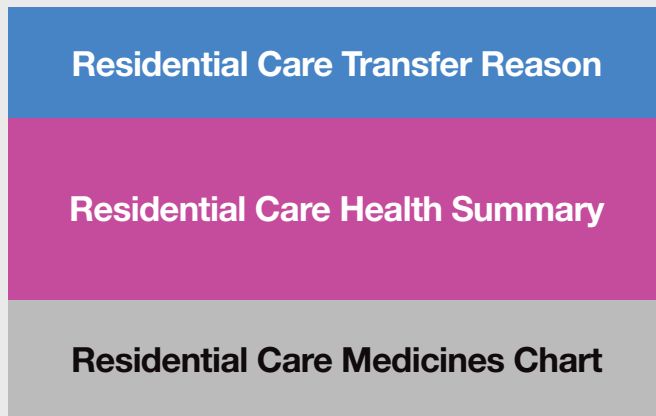


Figure 3: High level view of the three components to the Aged Care Transfer Summary

Few, if any, aged care clinical systems currently have the capacity to support the exchange of structured, standardised data, akin to that taking place in primary care. This gap is being addressed in part by the ADHA, who are developing new clinical information system conformance requirements for aged care vendors. However, to address Royal Commission imperatives for data interoperability, new system capability requirements must evolve in lockstep with policy decisions that sit with the Department. It is one thing to specify the data content for each of the three components to the ACTS, but it is quite a jump to form a national agreement on a standardised data set for specifying the functional needs of individuals in residential aged care. The government's current default position is to allow aged care providers to choose how they assess the functional and care needs of their residents. This presents several difficulties when it comes to formulating policy decisions around standardised reporting, using data that can be shared and reused by other stakeholders. Neither the AIHW nor the ADHA can mandate a truly national minimum data set of the standardised data definitions and formats required to support a truly interoperable ACTS until there is clear policy direction. This direction must come from the Department.

In explaining the aged care data ecosystem, the **Mandatory Quality Indicator (QI) Program** is another initiative that holds significant importance¹⁴. Currently, eleven quality indicators are collected from each aged care provider by the Department. This allows the monitoring of service quality, improves access to provider information, and facilitates evidence-based decisions by policy makers. Despite its nationwide implementation, a policy failure of sorts means the mandatory quality indicators have not been formally endorsed as metadata standards by a nominated authoritative body – known as a Registration Authority. The mandatory QI have been developed via a different mechanism and cannot be formally recognised as a national data set specification. For the time being at least, they cannot form part of the NMDS.

Closing out our understanding of the aged care data ecosystem, is the recommendation by the Royal Commission to establish the **Independent Hospitals and Aged Care Pricing Authority (IHACPA)** to determine sustainable and equitable unit prices for each level (casemix) of aged care need¹⁵. The NMDS V2 is again pertinent as it ought to provide the standardised data items that will facilitate a consistent approach for providers to report their costs. Similarly, a nationally mandated, evidence based comprehensive assessment data set specification would provide Australia with a sound basis upon which to both determine costs for care delivery and monitor outcomes using similarly aligned quality indicators. However, in the absence of data set specifications aligned to the major digital health reform documents listed here, the current new process of reporting costs and risk adjusting these using the Australian National Aged Care Classification (AN-ACC) casemix tool is still developing and may not deliver optimal outcomes in the medium term for Australian aged care reforms¹⁶.

Other national data standardisation initiatives

Whilst the Royal Commission was focused on improving the quality and use of data in aged care, similar reforms are being progressed across the broader health care ecosystem. Notably, work is underway to develop data models and exchange standards to ensure consistent data use across primary care⁶. A key deliverable will be an Australian Core Data for Interoperability (AUCDI) and an associated AU Core FHIR Implementation Guide by 2025¹⁷. Fast Healthcare Interoperability Resources (FHIR) is a new national data exchange standard being implemented in Australia under a Department-funded program called Sparked¹⁸.

The completion of the AUCDI will provide the driver for the Aged Care Minimum Dataset (NMDS) to be operationalised in the real world. Whilst the Sparked program is currently focused on primary care reform, it is fast tracking the standardisation of patient transfer data from clinical information systems into the My Health Record and across the broader healthcare ecosystem. The Sparked program thus provides a model for how the NMDS and artifacts like the Aged Care Transfer Summary might be progressed.

Of the initiatives listed in the major digital health reform documents, an AUCDI that supports an aged care transfer summary based on the data residing in aged care clinical information systems would represent a giant leap forward for recipients of aged care in Australia.

In summary

This explainer has sought to shine a light on the national digital health reform documents referencing aged care, that have been published since the release of the Royal Commission into Quality and Safety in Aged Care. It has attempted to highlight that data and digital reforms in aged care cannot take place in isolation of the broader digital health reforms in play today. Short-term 'reforms' to aged care in response to the Royal Commission are unlikely to represent cost-effective or sustainable investments for any stakeholder unless they are aligned to these broader sector-wide reforms. It is fundamental that clear policy decisions are made to define national best practice data sets for aged care or to mandate a national comprehensive assessment data set specification. Once these are defined in a national minimum data set and referenced in conformance and other standards documents, it will be possible for the aged care sector to transform digitally.

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