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A compelling case for the development and adoption of data standards and interoperability in the Australian aged care sector – White Paper

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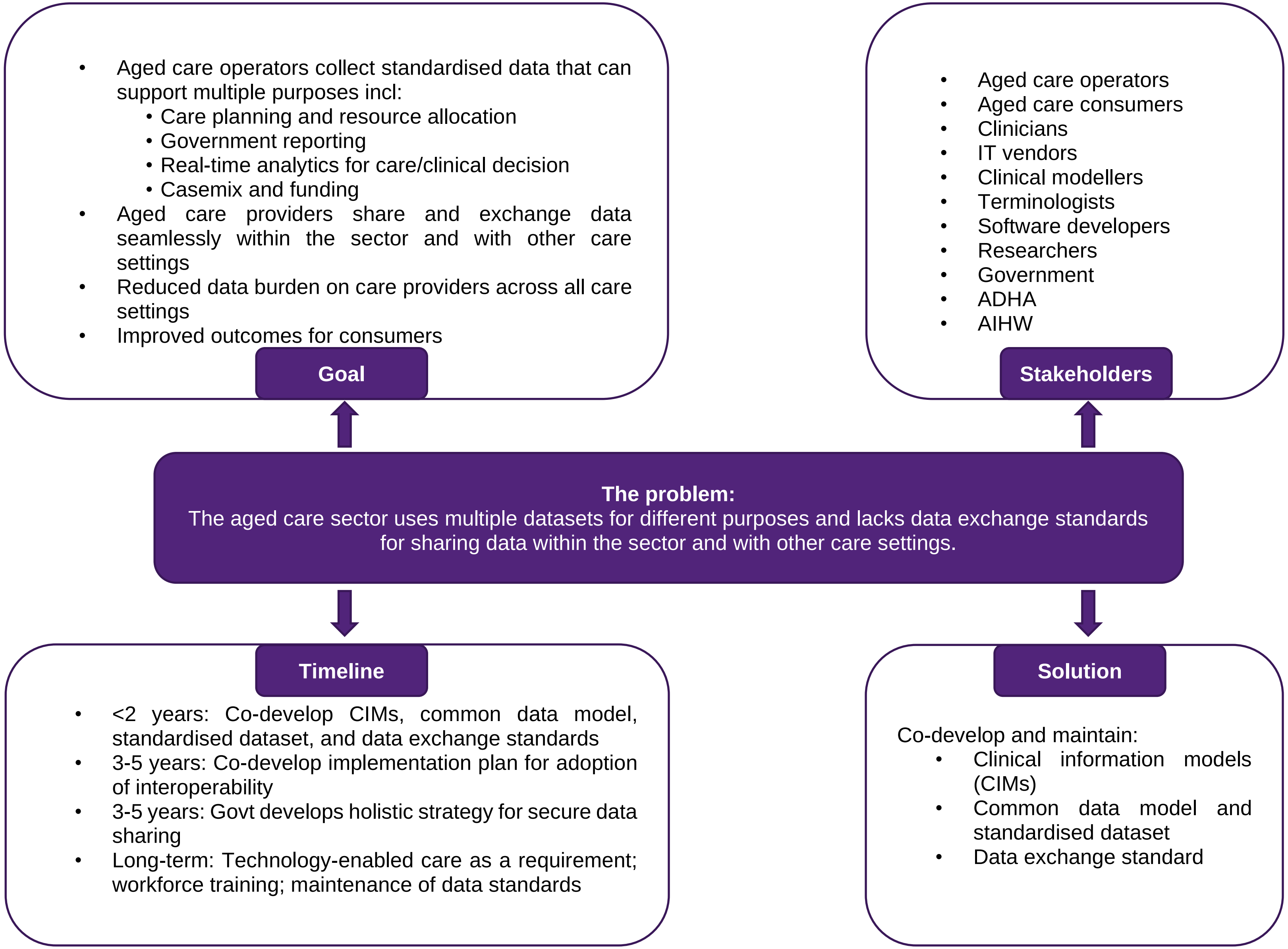
1. Executive Summary

The final report from the Royal Commission into Aged Care Quality and Safety (RC) identified deficiencies in data practices within the sector as a target for improvement. In this white paper we discuss the data-related problems in aged care, the goals that the sector should be striving for, the stakeholders, the proposed solution, and timeline to achieve those goals (see Figure 1).

The target audience for the paper includes stakeholders listed in Figure 1 but is also intended for anyone with an interest in the Australian aged care and/or data standards in general. We describe why a standardised aged care dataset is needed to promote consistency in data collection across the sector and support multi-purpose data use; improving care planning, decision support, quality, and government reporting. We advocate for this standardised dataset to be derived from a common data model that is built on a foundation of robust clinical information models (CIMs) for common data elements in routine aged care provision. The paper also discusses the need for data exchange standards to facilitate data sharing within the aged care sector, and across the other healthcare settings where older people regularly receive care.

In the paper, we call for a multi-stakeholder collaboration to co-develop the CIMs, common data model and data exchange standard for aged care. The paper proposes and details the steps and a timeline that highlights the feasibility for developing these outputs within five years. It also describes the role of the key stakeholders, emphasising the contribution of aged care operators and clinicians, and the important role that government must play in this endeavour by providing guidance and funding the development and maintenance of the data standards. Also, the government, through the Australian Digital Health Agency (ADHA) and Institute of Health and Welfare (AIHW), must provide policy and expert guidance to drive adoption of data standards. The paper identifies potential challenges but also highlights Australia's capacity to overcome them. We believe that the work described here will help to improve aged care services and ultimately deliver better outcomes for consumers.



Goal

- Aged care operators collect standardised data that can support multiple purposes incl:
  - Care planning and resource allocation
  - Government reporting
  - Real-time analytics for care/clinical decision
  - Casemix and funding
- Aged care providers share and exchange data seamlessly within the sector and with other care settings
- Reduced data burden on care providers across all care settings
- Improved outcomes for consumers

Stakeholders

- Aged care operators
- Aged care consumers
- Clinicians
- IT vendors
- Clinical modellers
- Terminologists
- Software developers
- Researchers
- Government
- ADHA
- AIHW

The problem:
The aged care sector uses multiple datasets for different purposes and lacks data exchange standards for sharing data within the sector and with other care settings.

Timeline

- <2 years: Co-develop CIMs, common data model, standardised dataset, and data exchange standards
- 3-5 years: Co-develop implementation plan for adoption of interoperability
- 3-5 years: Govt develops holistic strategy for secure data sharing
- Long-term: Technology-enabled care as a requirement; workforce training; maintenance of data standards

Solution

Co-develop and maintain:

- Clinical information models (CIMs)
- Common data model and standardised dataset
- Data exchange standard

Figure 1. Graphic summary of the white paper.

2. Background

Developments in digital technology and information standards are providing the aged care sector in Australia an opportunity to improve the use of information to raise the standard of care and improve the lives of older people. In its final report, the recently concluded Royal Commission into Aged Care Quality and Safety (RC) recommended an investment in information systems that could enable better services through interoperability, standardisation, improvements in data quality, and development of real-time and automated systems (Recommendation 109) (Royal Commission into Aged Care Quality and Safety 2021a).

The perceived quality of care in the Australian aged care sector has been the focus of increasing scrutiny and discussion in recent years. Currently, quality of care is not easily measured in the Australian aged care system due to lack of existing standardised data available to either government or to most providers. For example, the RC struggled to evaluate the extent of sub-standard care due to a lack of standardised high-quality data to measure the quality of care (Counsel Assisting the Royal Commission 2020). This lack of standardised and high-quality data makes it difficult to implement and evaluate the effectiveness of quality improvement strategies or programs.

In addition to the objective appraisal of quality, standardised data has broad desirability as it can serve a wide variety of functions, including:

In the immediate care setting:

- consistent recording of problems across provider organisations and settings
- real-time analytics to inform clinical / care decisions
- case profiling for planning and resource deployment
- information sharing with other involved providers, within and outside the immediate care setting.

At the system level:

- planning and development
- eligibility assessment and entitlements
- casemix analysis and funding
- inform consumer choice
- measuring system performance.

Older people often have complex needs, requiring support from multiple agencies and professionals. This support may occur simultaneously (e.g., GP, home care services) or sequentially (e.g., home care services and hospitals) with data needed to formulate care plans in each setting. Standardised data would present an opportunity to "collect once, use many times" and offer multiple advantages for key stakeholders as shown in Figure 2.

REGULATOR
- ✓ Support planning
- ✓ Casemix & payment
- ✓ Quality accountability through quality indicators & other measures

PROVIDER
- ✓ Decision support in assessment & care planning
- ✓ Caseload monitoring
- ✓ Quality improvement & planning

CONSUMER
- ✓ Better understanding of own care needs
- ✓ Monitor own progress
- ✓ Choice of program & provider

Figure 2. How a standardised aged care dataset would benefit key stakeholders

2.1 Lack of standardised dataset

Currently, there is a plethora of data embedded in the aged care system.

- Software suppliers enable the capture of free text and structured information, which is usually in supplier- or organisation-specific proprietary formats.
- Government and its related agencies hold data that identifies individuals who apply for and utilise aged care, underpins eligibility assessment, informs casemix classification and payment, and assists in quality appraisal.
- Somewhat separate from the immediate jurisdiction of the aged care program, data is recruited to support payment of health professionals (Medicare Benefits Schedule) and pharmaceuticals (Pharmaceutical Benefits Scheme).

A standardised dataset designed to enable data to be collected once and used for multiple purposes is needed but existing datasets for mandatory government reporting, and funding allocation are not comprehensive enough to inform routine care provision for individuals. The Aged Care Funding Instrument (ACFI) dataset captures basic information about individual consumers' care needs and diagnostic information (Australian Government Department of Health 2016). Similarly, the proposed AN-ACC (Australian National Aged Care Classification) (Commonwealth of Australia Department of Health 2021), the funding model proposed to replace the ACFI, is a casemix dataset designed to gather data for determining the level of funding required for the care of aged care consumers. The National Screening and Assessment Form dataset (NSAF) is more comprehensive than the ACFI and the AN-ACC, but unlike those two, its purpose is to determine the eligibility and the best care option for clients seeking aged care services. The outcomes of an NSAF assessment are not reflective of care being provided to the client and cannot support data re-use for on-going applications such as government reporting, funding or in quality monitoring and improvement programs. Also, the NSAF assessments have a range of supplementary but optional assessments, meaning that providers using the dataset do not necessarily collect the data consistently within or across organisations.

On the other hand, a dataset like the Electronic National Residential Medication Chart (eNRMC: see Textbox 1) could be a valuable source of data related to medications in residential aged care facilities (RACF). The Department of Health and the Australian Digital Health Agency (ADHA) are currently working with software suppliers to help them achieve conformance with the legislative and technical requirements for eNRMCs. Although the government notes the benefits of using an eNRMC, it is not mandatory for RACF operators to have an eNRMC system but funding for those that implement one was announced in the 2021-22 budget. The Australian Institute of Health and Welfare (AIHW) defines a national minimum data set (NMDS) for the health sector (available on the AIHW METeOR platform: see Textbox 2), specifying the data elements agreed for mandatory collection and reporting (Australian Institute of Health and Welfare 2021). However, like the other NMDSs from AIHW, the dataset is contingent upon a national agreement to collect uniform data and to supply it as part of the national collection but does not preclude agencies and service providers from collecting additional data to meet their own specific needs (Australian Institute of Health and Welfare 2021). This disjointed implementation of aged care datasets makes it virtually impossible to use data collected using such datasets for multiple purposes. Also, datasets for government reporting, consumer assessments and funding data are poorly integrated (e.g., the ACFI is partially informed by the NSAF data if a consumer is deemed

Textbox 1: Electronic National Residential Medication Chart (eNRMC)

The eNRMC is a medication chart designed to improve medication safety for residents in RACF. It is also designed to reduce the administrative burden for care staff, prescribers and pharmacists when administering, ordering and supplying medicines. The eNRMC enables prescribing and supply of most, but not all, medicines and PBS/RPBS claiming by pharmacists, where applicable, directly from the eNRMC without a need for a separate prescription. For a medication, the prescription and record of administration are both located in the eNRMC. The resident's details, including a photograph and known drug allergies, are visible on each page of the eNRMC to enable correct identification during prescription, supply and administration of medicines. A resident's relevant pathology, medical practitioners' instructions and other important information relating to the administration of the medicines are included in the eNRMC. The chart is designed so that faxed, photocopies and scanned copies contain all this information. The eNRMC offers many benefits for providers and residents including holistic and focused information in a single location; reduced incidents; standard fields for all staff, prescribers, and pharmacies; helping RACF to meet medication standards as part of the accreditation processes; and reduction of medication administration costs. The use of the eNRMC chart is not mandatory under the Aged Care Act (1997) or National Health Act (1953). It is the responsibility of RACF operators that deploy commercial versions of the eNRMC to ensure that such products comply with state and Commonwealth legislation.

eligible for RACF care (Davis, Morgans, and Burgess 2016)) and thus require some data elements to be collected more than once.

Most of these datasets, including both ACFI and proposed AN-ACC data, are collected at intervals (no more than annually) that are not well suited for other purposes, such as routine care provision or quality improvement activities, where measures are required at least every six months. In contrast, regular evaluations of individual health status and care needs for aged care consumers are usually conducted using comprehensive datasets to inform care plans. Comprehensive geriatric assessments are considered the best approach for identifying the complex care needs, and achieving better outcomes in the care of older people (Ellis et al. 2017) and they generate rich data, covering demographic, clinical, functional, and psychosocial domains. Such assessments are conducted, in a variety of formats, across the continuum of care: 75+ assessments performed by primary care practices, NSAF eligibility assessments performed by Aged Care Assessment Services; geriatric consultation and post-acute services in hospital; and assessment and care planning activities within community and residential aged care services. These comprehensive geriatric assessments would be a good foundation for a “collect once, use many times” standardised dataset that is primarily designed for the purpose of care provision but can allow re-use of data for government reporting, funding, quality improvement programs, data exchange and sharing among care providers. The interRAI Long-Term Care Facilities (LTCF) and Home Care (HC) datasets are part of a suite of assessment instruments designed on this philosophy (see Textbox 3) and the instruments enjoy the advantage of widespread, mandated uptake in many OECD nations, including our immediate neighbours in New Zealand and Singapore.

Textbox 2: Metadata Online Registry (METeOR)

https://meteor.aihw.gov.au/content/index.phtml/itemId/181162

METeOR is Australia's Metadata Online Repository for national metadata standards for the health, aged care, community services, early childhood and housing and homelessness sectors. It operates as a metadata registry designed to support a disciplined approach to the development, storage, and management of metadata, compliant with the international information modelling standard ISO/IEC 11179. METeOR provides users with a suite of features and tools to support metadata development:

- online access to nationally endorsed data definitions (metadata standards),
- tools for creating new definitions based on existing already-endorsed components,
- a search facility to help find metadata quickly,
- a collaborative forum to allow users to interact on metadata development,
- access to review and approval processes within the system. (Australian Institute of Health and Welfare 2021)

Textbox 3. The interRAI suite of assessment instruments (http://www.interrai.org)

The interRAI LTCF is one of over 20 systems developed by the interRAI research collaboration that comprise the interRAI Suite of Assessment Systems (Hirdes et al. 1999; Carpenter 2006). Its focus on functional and psychosocial issues complements healthcare data such as diagnoses, investigations, vital signs and medications. Applications developed within the interRAI suite share a common language which allows longitudinal progress tracking and facilitates continuity of care. Triggers are also built into the systems to alert clinicians, care staff, and facilities to opportunities for improved care and risks of adverse outcomes in real-time. interRAI systems adhere to the data principle of collect once, use many times.

The interRAI LTCF is by a considerable margin the most widely used assessment system in aged care, worldwide. It contains over 250 clinical observations which have excellent psychometric properties and from which a wide range of decision support tools can be calculated. It is mandated by governments in Europe and North America, and locally in New Zealand and Singapore. Uptake in Australia has been limited, but in the shadow of the Royal Commission there is growing awareness and interest at government and provider level. Jurisdictions that utilise interRAI systems are readily able to make international comparisons around caseload, quality of care and clinical outcomes (Noro et al. 2011; Feng et al. 2009; Onder et al. 2012; Morris et al. 2013; Gray et al. 2013).

In Australia, there are no mandatory datasets for comprehensive geriatric assessments for direct care provision: aged care operators use bespoke datasets and processes for data collection. Consequently, geriatric assessment data vary among operators. Furthermore, recent research shows that some aged care operators have separate datasets for financial, clinical, rostering and administration teams (Barnett et al. 2020). The resulting problem is data silos for each purpose and setting, leading to duplicate data collection (which creates data burden for care providers, increases costs for operators and makes the data prone to errors), and severely impairs the ability to re-use information.

2.2 Lack of interoperability and standards

In addition to bespoke datasets for comprehensive assessments, aged care operators use a variety of distinct, vendor-specific information technology (IT) solutions to collect, store and manage consumer data. Different IT products use varying clinical models (i.e., different data elements, data structures, data fields, data codings, terminology bindings, etc) and proprietary formats for data representation. These inherent, fundamental technical design differences render operator IT systems unable to ‘talk’ to each other i.e., they cannot achieve semantic interoperability. Semantic interoperability is “the ability of different information systems, devices and applications to access, exchange, integrate and cooperatively use data in a coordinated manner, within and across organisational, regional and national boundaries, to provide timely and seamless portability of information and optimize the health of individuals and populations globally” (HIMSS 2021). Even IT systems supplied by the same vendors are not necessarily interoperable as they are often highly customised according to an operator’s workflow needs and preferences. Frequently, Australian aged care operators are partnering one-on-one with vendors to install and configure IT solutions aimed at organisation-specific business, communication, and operational needs (Medical Device Research Institute 2017). The aged care sector lacks data exchange standards for achieving interoperability among Australian aged care operators (Medical Device Research Institute 2017). It is difficult to pinpoint the reason for slower adoption of data exchange standards in the sector compared to other care settings, but a likely contributing factor is that aged care lags other healthcare settings in adopting healthcare IT in general - only 59% of aged care operators in a recent survey were using electronic health records with the remainder still using paper-based systems (Barnett et al. 2020). However, this is a trend seen in other countries as well. For example, despite higher adoption of electronic health records in the American aged care sector, interoperable data exchange is still much lower than other settings (Kistler, Zimmerman, and Khairat 2021; Powell, Deroche, and Alexander 2020; Alvarado, Zook, and Henry 2017).

Without agreed data exchange standards and protocols, IT systems in the sector will continue to be siloed, perpetuating fragmented care, heightened risk of communication errors, or reduced organisational inefficiency. It also hinders effective and efficient exchange and re-use of data not only among aged care operators but also between aged care and other care settings when consumers transition between care settings (Davis, Morgans, and Burgess 2017; The Architecture Practice Team 2020; Barnett et al. 2020). Most aged care consumers have complex care needs due to frailty, chronic diseases, and conditions, and often require care or treatment in different healthcare settings simultaneously or sequentially (e.g., primary care, acute care, and mental health). Interoperable data exchange is therefore crucial for the health care of this population to ensure that care and treatment plans are based on the latest data to achieve optimal outcomes. Currently, the ‘Minimum information set for transfer form’ is completed and included in an envelope accompanying RACF residents during transfer to a hospital or emergency department (Belfrage et al. 2009; Australian Commission on Safety and Quality in Healthcare 2019). While this ‘Transfer Form’ has data fields for critical medical information at a minimum, it was designed in the era of paper forms, before aged care operators began using IT systems for managing resident data. There is currently no evidence that this ‘Transfer Form’ is being exchanged electronically but the Australian Digital Health Agency has recently committed to develop an Aged Care Transfer Summary as an enhancement to My Health Record (McDonald 2021).

The lack of efficient interoperable data exchange during transitions between RACFs and primary care or acute care can be stressful for older people, their caregivers, and their families and in some cases can cause serious issues (Counsel Assisting the Royal Commission 2020), especially if they must undergo duplicate assessments upon admission. The lack of electronic data exchange is particularly consequential for medication data as the rates of polypharmacy in aged care are high (Royal Commission into Aged Care Quality and Safety 2019; Page et al. 2019; Jokanovic et al. 2017) and careful medications management is necessary to minimise the risk of harm to consumers. A recent study comparing RACF and primary care medication records revealed discrepancies between the two data sources in more than 70% of all residents’ medications (Makeham et al. 2020). Interoperability in aged care is more necessary than ever as care models shift to a consumer-centred approach and as a growing number of aged care operators are now operating in technology-enabled and technology-enhanced environments. Wearable and implantable electronic medical devices, environmental sensors and other IoT (Internet of Things) devices that can gather clinical data are increasingly being used to facilitate care delivery (Medical Device Research Institute 2017). And with calls for the Commonwealth government to fund operators to ensure that these technologies become standard across the sector (The Architecture Practice Team 2020), such data is likely to become part of routine care soon. These technologies are capable of automatically collecting clinical data that can complement datasets gathered traditionally through assessments and measurements by caregivers and therefore data sharing standards for interoperability should cover data sourced from these devices.

There is an urgent need for the sector to agree on and adopt standardised aged care datasets and open standards to support interoperable data exchange and sharing (Medical Device Research Institute 2017). Some vendors have been building capability to integrate FHIR (Fast Healthcare Interoperability Resources) APIs (Application Programming Interfaces) into their products (more on FHIR later in the paper), perhaps due to expectations that the aged care sector will eventually catch up to other care sectors in implementing FHIR for data exchange and sharing. However, in the absence of guidance from standards development community or the Australian Digital Health Agency (ADHA), there is no coordinated industry-wide approach to adopting FHIR APIs or discussions towards co-developing interoperable data exchange standards in aged care. At this stage, it is not known whether aged care vendors participate in HL7 (Health Level Seven International – the organisation behind FHIR) open standards development working groups to support their own FHIR API integration efforts. Certainly, Australian aged care operators do not have a significant presence in the working groups, and this is not surprising given that most of them do not have dedicated IT divisions or in-house IT personnel. Australian aged care operators and vendors have a culture for one-on-one collaboration in developing IT solutions (Medical Device Research Institute 2017) and this appears to extend to interoperability. For example, Life Care, an aged care operator in South Australia, in 2017 partnered with Medi-Map to overcome the lack of interoperability and enable data sharing in an ecosystem consisting of the operator's residential facilities, consumers' GPs and a pharmacy chain (Medical Device Research Institute 2017). Whilst the operator showed great initiative in the absence of a coordinated sector-wide approach for data standards, this individually driven development is unlikely to advance interoperability within the sector or with other care settings and in-fact risks exacerbating data silos (and vendor lock-in!).

A coordinated and unified approach to standards development and adoption will pave the way for robust processes for standardised collection of reliable, consistent and high-quality data that can ensure efficient business to business (B2B) data sharing for seamless consumer transitions. Semantic interoperability standards for sharing healthcare data across organisation boundaries can improve patient safety by minimising the risk of mis-interpretations, foster coordination of care among care teams in different settings and ultimately lead to improved care outcomes for consumers. It will also reduce inefficiencies and costs in the healthcare ecosystem by reducing the time spent on communication and minimising duplicate tests or assessments. Reaching agreements on data sharing can also eliminate information blocking, which can prevent effective data sharing, and improve the trust among care providers that care data collected by others is of sufficient quality for deriving care decisions. Effective B2B data sharing can also underpin the calculation of quality indicators to measure and monitor the quality of care, facilitating programs for continuous quality improvement at a system level or for operators to benchmark care quality internally or across their branches and/or against their peers as a way to maintain high-quality care in the sector. Business to government (B2G) reporting would also become easier, enabling the aged care regulators to provide feedback to providers on their performance based on the quality indicators (Duckett 2021). Quality indicators could also underpin a publicly-accessible ratings systems, enabling prospective clients to make informed choices when selecting aged care providers (Duckett 2021; ANMF (VIC BRANCH) 2019; Royal Commission into Aged Care Quality and Safety 2021b).

3. Current activities and future needs

Although, the data problems in Australian aged care are longstanding and systemic throughout the sector, they are not insurmountable. Projections show that demand for services will grow significantly in the next few years as an increasing number of older Australians seek services (Australian Institute of Health and Welfare 2013), potentially worsening the current problems if they are not resolved with urgency. Therefore, it is imperative to act now. There needs to be a coordinated, multi-stakeholder effort to develop solutions for efficient, cost-effective data collection, sharing and exchange, and analytics for care quality measurement and benchmarking. The data solutions should be based on a 'collect once, use many times' principle which will limit data burden on consumers, providers and operators. It will take a collective effort of a wide range of stakeholders to solve these problems, with input from aged care operators, aged care consumer representatives, the government (through agencies such as ADHA and AIHW), IT vendors, software developers, researchers, clinicians, informaticians, clinical modellers, industry leaders, and bodies representing aged care operators and IT vendors (summarised in Figure 3).

In response to recommendations in the RC, the ADHA is proposing an Aged Care Program that aims to develop specifications and conformance profiles for digital enablement in aged care. The program appears to be focused on integrating IT systems with My Health Record (MHR) and improving MHR uptake and use within the sector. The program also proposes to enhance MHR with an 'Aged Care Transfer Summary' to facilitate sharing of care summaries as consumers transition between aged care and other healthcare settings.

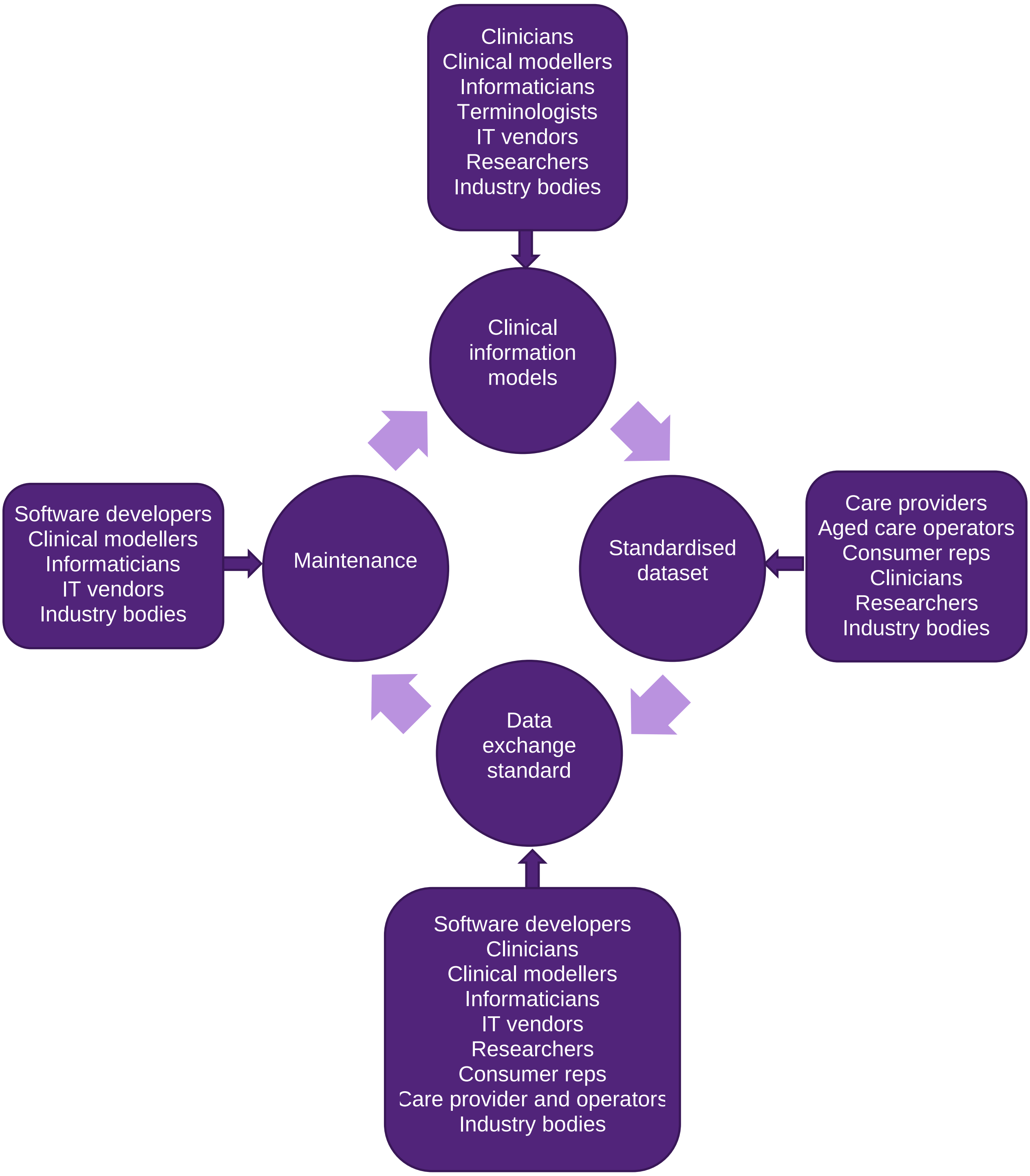


Figure 3. The stages of data exchange standard development and key stakeholders: the process is conducted with expert support and oversight of ADHA and AIHW; and policy and funding support from governments.

3.1 Clinical information models, common data model and standardised dataset

A standard dataset, an inventory of data elements agreed for collection, should be developed. In accordance with the ‘collect once, use many times’ principle, it is important that this dataset be based on common data elements routinely collected as part of the day-to-day care to minimise data burden – also, care providers are more likely to support collection of data that they deem useful for care provision or local administrative functions. For the data elements to support multiple use-cases across care settings, the data elements should have good psychometric properties. That is, individual data elements should be meaningful and relevant to users (face validity), appropriate for the intended use (content validity), be reliable when evaluated by separate assessors (inter-rater reliability) and when used to forecast future events (predictive validity).

Building this dataset should begin with developing robust clinical information models (CIMs) for common data elements (i.e., clinical and care concepts) relevant to aged care. Clinical information models define the structure and formal semantics for clinical concepts within electronic health records. For example, a CIM for ‘medication order’ might prescribe that this clinical concept must have attributes such as “dose”, “route of administration”, “frequency”, etc. CIMs can also specify if and how concepts under observation/evaluation can be coded, their data types and valuesets (i.e., set of acceptable values for recording the evaluation of a data item), and prescribe the use of standard terminologies like SNOMED CT, RxNorm, LOINC, etc. They are implemented to organise the structure of clinical information for a wide range of tasks that include data collection, storage, exchange, query, analysis, and decision support (Moreno-Conde et al. 2015; Moreno-Conde et al. 2016).

There are two primary methodologies for developing standards-based, atomic-level clinical information models: openEHR International Clinical Models program (openEHR 2021) and the HL7 Clinical Information Modelling Initiative (HL7 International 2021). Both schemes aim to create and maintain open and shared libraries of standards-based, vendor-neutral, and use-case agnostic information models of clinical concepts (Leslie 2020a): all important requirements for semantic interoperability. The openEHR approach has previously demonstrated efficient and quick collaborative development of clinical models designed for managing the COVID-19 pandemic (Leslie 2020a). The openEHR clinical model program employs archetypes – a computable specification for a single clinical concept and is based on the ISO 13606-2 Archetype interchange specification (Atlag et al. 2021). The openEHR archetypes represent clinical knowledge in a formal and computable format that is independent of software applications and when combined with standard terminologies provide a standardised and consistent way to collect, store, display, exchange and analyse health data (Leslie 2020a). The Clinical Knowledge Manager (CKM) (openEHR International 2021), the openEHR platform for drafting, publishing and governing archetypes is an excellent resource for collaborative development, re-use and maintenance of archetypes. Australia has clinical modellers with extensive experience in the openEHR modelling methodology as demonstrated in the Australian primary care interoperability project (Leslie 2020b). The development of the aged care clinical information models can leverage that work by identifying existing archetypes that can be re-used and developing new ones where archetypes relevant to aged care are not available. As the archetype development progresses, datasets for specific use-cases (e.g., aged care assessments, transfer summaries, casemix classification, payment, and quality appraisal, etc: see Section 1.1) can then be built using openEHR templates by drawing from the archetype library. openEHR templates put archetypes together to form whole compositions, i.e., complete lumps of information to be captured or exchanged for a specific use-case. With the openEHR CIMs, automated population of the several aged care datasets become feasible by querying multiple sources of already existing data as they are all based on a common data model, streamlining the generation of healthcare summaries such as the 'Aged Care Transfer Summary' being developed by ADHA (McDonald 2021).

It is critically important to get the modelling right because robust clinical information models are essentially the building blocks for good healthcare IT systems that can support interoperable data exchange for multiple use. A collaborative and broad multidisciplinary effort should be conducted to develop openEHR archetypes for common data elements related to aged care. The modelling team should include domain experts and clinicians with experience in medical informatics, particularly information modelling methodologies, and terminology specialists and more importantly, in the spirit of co-design and co-development, this work should have input from aged care IT vendors and IT professionals with healthcare experience from aged care operators. AIHW, with its experience in developing and maintaining national datasets and data set specifications, must help with the collaborative development as they are likely to build and maintain the metadata associated with the CIMs (possibly as part of METeOR or the system that will replace METeOR) as recommended by the RC (Royal Commission into Aged Care Quality and Safety 2021a). The ADHA should also provide expertise and guidance in the process to ensure alignment with the national strategy for interoperability. While the clinical modelling required for an aged care application would be much larger and more extensive in scope than previous work, it should take several months but not more than a year.

3.2 Data exchange standard

There are several standards development organisations (SDO) under which the healthcare data exchange standard can be developed but we expect HL7 would be the leading contender with the FHIR specification. In the United States of America, the Office of the National Coordinator for Health Information Technology (ONC) final rule that is part of the Cures Act requires providers receiving payments from the Centers for Medicare and Medicaid Services (CMS) to enable data exchange between EHRs and personal apps using FHIR APIs (Federal Register 2020). This essentially makes FHIR the de-facto standard for data exchange across systems in the US healthcare system. In England, the NHS digital, data and technology standards framework mandates that all services should support FHIR-based APIs for data exchange across organisational boundaries. To that end, the NHS has adopted nationally defined FHIR resources to implement its CareConnect Open APIs for data sharing across care settings in addition to mandating that discharge summaries during transfer of care should use FHIR messaging (NHS Digital 2020; NHS 2020). In Canada, a large-scale integrated reporting system for consumer assessments is using FHIR as the data exchange standard for multi-setting data sharing (Flores, McKenzie, and Shnaper 2019). Given these large initiatives in countries considered leaders in interoperability and data exchange standards, it is likely that other healthcare systems across the world will also adopt FHIR so that healthcare data can be exchanged worldwide. We also expect the adoption of FHIR to be boosted by the recent announcements by consumer-facing big tech companies (Amazon, Apple, Google, and Microsoft) to use FHIR as the standard for health data exchange in their products (Rae-Dupree 2020).

FHIR has several strengths that make it a suitable standard for interoperable data exchange for aged care. Firstly, it improves implementation capabilities by utilising modern web technologies such as JSON (JavaScript Object Notation), XML (extensive mark-up language) and REST (Representational State Transfer) (HL7 FHIR Release 4 2019). It has an open licence which minimises barriers to adoption and implementation. FHIR is supported by a large, global community and has many open-source tools. FHIR enables representation and transfer of granular data in a computable format (i.e., the information shared is usable in computer-mediated processes such as decision support, rules triggering and trend analysis, etc.) and is designed for fast development and deployment of health data exchange standards (HL7 FHIR Release 4 2019), making it an ideal specification for developing aged care data exchange standards that can support downstream analytics such as quality indicator computations.

The ‘Aged Care Data Compare’ (ACDC) project launched at the University of Queensland in June 2020 is developing a data hub underpinned by a FHIR standard to facilitate electronic exchange and sharing of assessment data for RACF residents with a purpose for measuring and benchmarking quality of care in RACFs (University of Queensland 2020; Digital Health CRC 2020). The project has taken a collaborative, co-design, and co-development approach through working groups where the community can contribute in an open and transparent, consensus-driven manner. The philosophy of the project is that provider and operator-driven quality improvement initiatives will better serve the needs of care providers, and therefore will be more likely to benefit consumers, than government-mandated initiatives. However, government regulators and others, including consumers, can still leverage the available infrastructure and data for external monitoring and public reporting, and research. Solutions that are co-designed and co-developed will better serve the needs of end-users and thus are more likely to have wider adoption in practice.

While the ACDC project is currently focused on producing a standardised dataset and interoperability standard for aged care to support RACF care quality analytics, submissions to RC and the final report have called for expansion of the project, with adequate government funding, to include community care data in the exchange standard (The Architecture Practice Team 2020) (Royal Commission into Aged Care Quality and Safety 2021a). Aged care operators, IT vendors, software developers, researchers, clinicians, informaticians, clinical modellers, industry leaders, bodies representing aged care operators and IT vendors, and relevant government agencies (ADHA, AIHW) should coalesce around this project to help develop these solutions. The input of clinicians and aged care operators is crucial to ensure that the resulting datasets and exchange standard meet their operational needs and because aged care operators also work closely with their IT vendors to achieve organisation-specific needs (Medical Device Research Institute 2017), IT vendors should also participate in the development of these standards. ADHA and industry bodies can play a facilitative role, providing a unified resource point for operators and vendors.

The ACDC project provides an opportunity for building impetus towards interoperability in aged care and ensure it is accounted for in the Australian national strategy for interoperability. The clinical models and FHIR profiles emerging from the project will feed back into the Australian FHIR Base profiles, helping to advance interoperability for the entire health sector. This would ensure that aged care sector operates as part of an Australian healthcare ecosystem seamlessly connected by agreed data standards enabling interoperable data exchange between aged care software solutions, electronic medical records in other care settings, My Health Record, My Aged Care and other stakeholders such as government and disability providers (Australian Medical Association 2019; Medical Device Research Institute 2017). The uptake of FHIR in Australia is not yet widespread but growing: several healthcare organisations are already using the standard to exchange data within their own branches and vendors are prepared to commit to support FHIR within their products or already building that capability (Intersystems 2020; Leftwich 2018), including aged care vendors. The Australian Digital Health Agency (ADHA) already supports FHIR APIs for mobile consumer applications to connect to the My Health Record System through the FHIR Gateway using the My Health Record FHIR Gateway API Specification (Australian Digital Health Agency 2021b, 2021a). The recently announced API gateway that will replace the My Health Record's Oracle API gateway will be built using modern web services and standards for healthcare data exchange including FHIR (Hendry 2021; Australian Government 2021). Also, there are already several streams of work developing FHIR data exchange standards in Australia for child health, medications, patient administration, and general practice (HL7 Australia 2016).

The Australian healthcare system has so far done well in laying the groundwork for interoperability and development of standards: healthcare systems and organisations (including aged care operators) are investing in healthcare IT; there is a large base of health informatics personnel; the Australian eHealth Research Centre develops internationally recognised interoperability products (e.g., Ontoserver, Pathling, etc); and the ADHA is a contributor to the development of international clinical terminologies and has driven the adoption of local coding systems such as AMT (Australian Medicines Terminology). Ultimately, stronger leadership and support from the government is needed to advance interoperability and the development of standards (Intersystems 2020). This responsibility falls to ADHA, which has a mandate to monitor and manage the development of standards. The ADHA, state and territory governments should publish guidance for where the industry should be headed in terms of interoperability (Intersystems 2020), which would give vendors, providers, and the standards development community a framework for investment towards those common goals – a good example is what the US has done with the ONC final rule of Cures Act (Federal Register 2020). It is encouraging to see that the ADHA has already committed to do some of this work, collaboratively with industry and other key stakeholders through the recently proposed Aged Care Program (Cheu 2021). As we have seen in New Zealand, the government has a crucial role in developing healthcare data standards and influencing the vendors (Australian Digital Health Agency 2017). Also, funding is needed for the development and on-going maintenance of these standards. Currently, there is little public investment in this area and a significant increase in public funding is needed to support development and maintenance of data exchange standards (Rowlands 2020).

Developing and adopting data exchange standards is a multi-year initiative that requires strategic planning for governments, providers, and vendors. In 2019, the Aged Care Industry IT Council (ACIITC) published a technology roadmap for the Australian aged care sector, including a road map for interoperability (Medical

Device Research Institute 2017). Adoption of the ACIITC roadmap would enable data standards to be developed and deployed in under 5 years and we describe how to use that roadmap as a blueprint to achieve the work advocated for in this paper. Firstly, in the short-term (< 2years), adapt existing standards for aged care by harmonising existing clinical information models and fill in any gaps through development of new models. In the medium term (3-5 years), an implementation plan should be co-developed to address issues associated with adoption of interoperability in the sector (these will include governance, legal considerations, privacy, security, and custodianship of data). Also in the medium term, the government develops a holistic strategy for the sector that provides B2B and B2G interfaces to create an open ecosystem for secure data exchange. In the long-term, government, through its agencies and in collaboration with all stakeholders, formulate and implement a strategy to embed technology capability as a requirement for aged care and reflected in standards for workforce training and accreditation.

3.3 Challenges

There are some technical challenges that need to be addressed to make interoperable data exchange work in this sector. Firstly, terminology standards are key to achieving semantic interoperability. Terminologies such as SNOMED CT (Systematised Nomenclature in Medicine Clinical Terms), AMT (Australian Medicines Terminology) and LOINC (Logical Observations Identifiers Naming and Codes) are used to encode healthcare data elements, allowing consistent, safe, and reliable data capture, storage, retrieval, aggregation, analysis and sharing across health care settings. SNOMED CT and LOINC codes are computer processable, making the terminologies ideal for data analytics. HL7 encourages, and in many cases mandates the use of terminologies when exchanging certain FHIR resources. Any aged care data exchange standards must therefore utilise standard terminologies bindings. The challenge, however, is that most aged care assessments use data elements that must be completed with free text or proprietary codes/valuesets. This means they are not currently fully represented in SNOMED CT or LOINC. If there are gaps in SNOMED CT or LOINC, the organisations behind these two terminologies have mechanisms and procedures to process requests from developers for codes to represent new health data concepts. LOINC already has a collaborative program for developing codes for patient assessment instruments (Vreeman, McDonald, and Huff 2010): data elements in the MDS[1] (versions 2.0 and 3.0) and other instruments used in the US aged care system already have LOINC codes. The Australian National Clinical Terminology Service supports SNOMED CT and LOINC, and the terminologies are already being used in electronic medical records and healthcare standards for other care settings. Therefore, it would be necessary for prospective aged care data exchange standards to use the same terminologies if data exchange with other care settings is to be achieved.

There are non-technical challenges too and as the work to develop data exchange standards matures, there will be a need to co-develop an implementation plan and governance framework to agree on the scope and timing of data sharing and to address barriers to data sharing. Data sharing agreements within the sector will need to be negotiated as their absence has been cited as one of the impediments to data sharing among aged care operators (The Architecture Practice Team 2020; Medical Device Research Institute 2017; Vest et al.

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[1] The USA MDS v2.0 is an early version of the aforementioned interRAI LTCF. V3.0 is v2.0 with additional items.

2019). Other examples of potential barriers include resistant clinical partners (Powell, Deroche, and Alexander 2020), concerns regarding privacy, security, and legal issues regarding sharing of consumers' health data (Medical Device Research Institute 2017). Submissions to the Royal Commission raised privacy and legal concerns regarding the collection, linking and sharing of aged care health data across the sector (The Architecture Practice Team 2020). Such concerns are not unique to aged care or Australian context and they arise out of fears of using individuals' health data for the purposes other than to provide care, including using the data for research or quality measurement without the explicit consent from consumers (Department of Health 2017). On-going research suggests that Blockchain technology could soon be utilised in healthcare data exchange (Rupasinghe et al. 2019; Barnett et al. 2019; Hylock and Zeng 2019; Zhang et al. 2018) and the ability to integrate Blockchain technology in FHIR is being explored (Rupasinghe et al. 2019). Although there is no indication yet of ADHA's position on integrating Blockchain technology in healthcare data exchange, if successful, this technology could provide the capability to document, exchange, and track data while the data owner maintains security and authorisation control for data access.

4. Conclusion

In the wake of the Royal Commission into Aged Care Quality and Safety, this paper discusses the Australian aged care sector's of lack of high-quality, care-derived consumer data, disjointed implementation of aged care datasets, and lack of clinical information models, common data model and interoperability standards for data sharing within the sector and across health care settings. The combined effect of these shortcomings is that it is virtualy impossible to collect aged care data once and use for multiple purposes. In this paper we have recommended:

- Development of a common data model based on use case-agnostic clinical information models
- Development of a standardised aged care dataset, derived from the common data model, that can support multiple use cases
- Development of a data exchange standard using the FHIR specification to facilitate data sharing within the aged care sector and with other care settings
- Multi-stakeholder collaboration in the development of these data standards through participation in an expanded ACDC project
- Addressing the development of these standards with urgency and we have proposed a timeline based on the ACIITC roadmap
- More government involvement in providing funding for standards development; guidance for interoperability direction and strategy

Australia has the expertise and experience in international standards development to conduct this work and should embrace this opportunity to lead this critically important work which will help deliver, among other benefits, long overdue care quality improvements in aged care and better outcomes for older Australians.

5. List of acronyms

ACDC – Aged Care Data Compare

ACFI – Aged Care Funding Instrument

ACIITC – Aged Care Industry Information Technology Council

ADHA - Australian Digital Health Agency

AIHW - Australian Institute of Health and Welfare

AMT – Australian Medicines Terminology

AN-ACC - Australian National Aged Care Classification

API – Application Programming Interface

B2B – Business to Business

B2G – Business to Government

CIM - Clinical Information Model

CKM - Clinical Knowledge Manager

CMS – Centers for Medicare and Medicaid

eNRMC - Electronic National Residential Medication Chart

FHIR – Fast Healthcare Interoperability Resources

HL7 – Health Level Seven

IT – Information Technology

JSON - JavaScript Object Notation

LOINC - Logical Observations Identifiers Naming and Codes

LTCF - Long-Term Care Facilities

MDS – Minimum Data Set

METeOR – Metadata Online Repository

MHR - My Health Record

NHS – National Health Service

NMDS - National Minimum Data Set

NSAF – National Screening Assessment Form

ONC - Office of the National Coordinator for Health Information Technology

RACF – Residential Aged Care Facilities

RC - Royal Commission into Aged Care Quality and Safety

REST - Representational State Transfer

SDO - Standards Development organisations

SNOMED-CT - Systematised Nomenclature in Medicine Clinical Terms

XML - extensive mark-up language

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