Exploring future data and information needs for aged care

Issues paper

Purpose

This paper is intended to progress engagement with stakeholders and to develop a shared understanding on what is needed to improve the aged care data system. We want to hear from a broad range of people who engage with the aged care system – from consumers entering information on My Aged Care, using the GEN aged care website or accessing aged care, to people working in aged care, as well as the services and providers who operate within aged care, through to researchers and policy makers who use aged care data.

We want to better understand how you currently use data and whether it meets your needs. We want to hear about the challenges and barriers you face in collecting, providing, accessing or analysing aged care data and what changes you would like to see. These insights will mean that the needs of different users can be taken into account in planning future data improvement activities.

This engagement is part of a broader process of engagement planned over coming years. We will collate the views we receive from stakeholders on this issues paper, and use this information as we move into the next stage: determining what an Aged Care National Minimum Data Set (NMDS) will look like, what information and data the first module will include as a priority, and how we go about implementing it. Key definitions are shown in Attachment 1.

Questions

❖ What is your role in the aged care system?

❖ What data do you currently provide or use? How do you provide or use these data?

❖ To what extent does current data meet your needs? What is missing?

❖ Does this paper appropriately represent the current picture? Are we missing something?

❖ Where would you most value improvements and why? What would you use that data for? What do you see as the barriers to getting that information?

❖ What opportunities/challenges do you see with the aged care reforms to collecting, using, reporting and accessing data?

We also welcome any other thoughts, ideas and feedback that this paper has raised for you.

Your responses

Responses to this issues paper can be provided during consultations with the AIHW team and/or electronically via email to agedcare.secretariat. Please get in touch if you would prefer to share your contribution another way.

Your input will be used to inform the future of aged care data in Australia. We encourage responses by **11 March 2022**.

AIHW Privacy Notice

Your personal information is protected by law, including the *Privacy Act 1988*. The AIHW may collect your personal information in support of these aged care data improvement activities.

The information you provide in response to this issues paper will be used by the AIHW and shared with other parties for these purposes, however your personal information will only be shared where you have agreed or it is required or authorised by law.

You can obtain more information about the way in which the AIHW will manage your personal information in our Privacy Policy at aihw.gov.au/about-us/privacy-policy.

Context

The Royal Commission into Aged Care Quality and Safety (Royal Commission) concluded in early 2021. A number of the final recommendations have implications for aged care data, and in particular the need to improve aged care data (e.g. Recommendation 108). Other changes are also taking place within the aged care data system, both in response to the Royal Commission's final recommendations and due to other reform activities that were already underway.

Existing data are neither comprehensive nor able to answer many important questions relating to the aged care system. Current data about the aged care system are fragmented and lack common data definitions. As a result, these data do not enable a person-centred view of pathways and outcomes within aged care (as well as across health and other support systems) and there are notable data gaps (such as detailed information on workforce, regular assessment of care needs, quality of life and quality of care).

The key recommendation arising from the Royal Commission was to put people at the centre of aged care. In the context of aged care data, this will require targeted actions for aged care data improvement to provide timely and comprehensive information that is responsive to the needs of the different participants and stakeholders in the aged care system. Providers (organisations) and services in the sector will play a critical role in both delivering person-centred aged care and supplying data and information needed for an effective data system.

There are multiple perspectives and users of aged care data, so it is critical that an aged care data system supports:

- people to make informed choices about their care
- services to provide safe, high-quality and dignified care
- government to administer and evaluate the aged care system
- secondary users of data (such as academic researchers) to study the aged care system.

Role of AIHW

The AIHW is an independent statutory authority operating under the AIHW Act, which offers strong protections to the management of data, including through our strong data governance arrangements. We have a long engagement with collecting, analysing and reporting aged care data and a legislated role to improve data collection of relevance to the health and welfare of Australians.

The AIHW has been funded by the Department of Health to work with a broad range of stakeholders on a number of aged care data improvement activities. These include developing a National Aged Care Data Strategy and addressing priority gaps and limitations in the data through the development of an Aged Care National Minimum Data Set and National Aged Care Data Asset. The AIHW will also work towards expanding reporting on aged care-related information and statistics (see GEN Aged Care Data) and, once built, enabling access to the data asset under appropriate data governance conditions. (Please refer to Attachment 1 for further details on these activities).

This work will be done in parallel with a range of other activities required to implement new programs and policies. The work being led by AIHW will not drive or delay those activities in the short term, but will provide a vehicle for tracking their implications for the future aged care data system.

Our aged care data improvement activities are supported by interlinked activities relating to data governance (for example, to establish the necessary arrangements for collecting, managing and sharing the data) and stakeholder engagement (for example, to understand other changes taking place within the aged care data system and to identify the stakeholders involved).
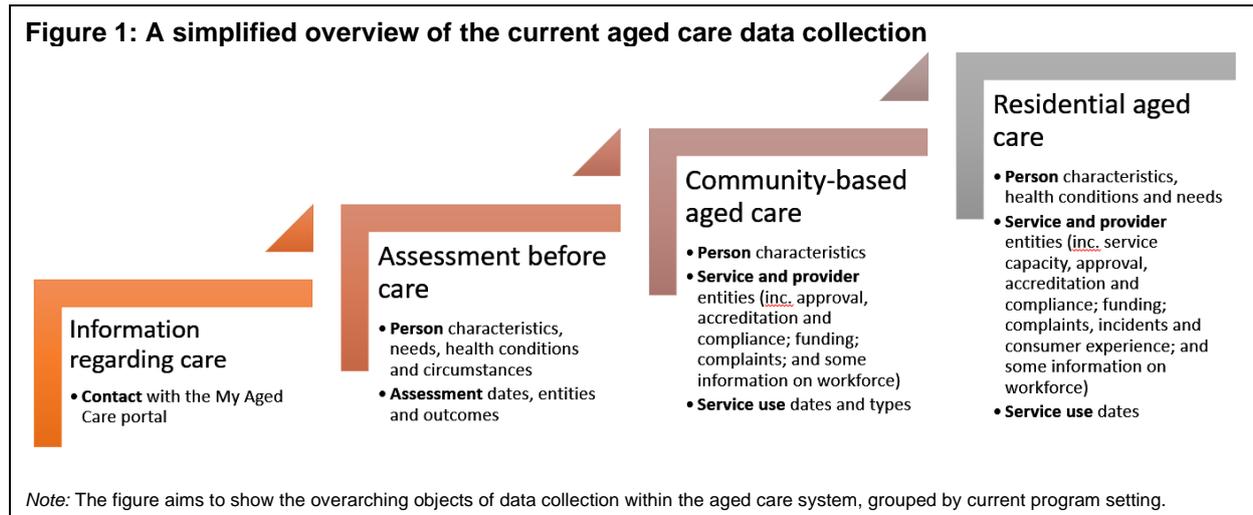
Understanding the current data landscape

Data domains

The current aged care data landscape is made up of a range of person-level data relating to the people assessed for aged care and people using aged care, as well as service- and provider-level data about the entities (services and providers) delivering aged care (Figure 1). The current state of aged care data will inform the future state that the data strategy and associated data improvement activities will work towards. A more detailed overview of the aged care data landscape is provided in Attachment 2.

This section on the current data landscape primarily focuses on administrative data, namely data that result from the information collected for the purposes of funding, delivering and regulating aged care services. In addition to these data, services and providers may collect other aged care information and data that do not feed into government data systems.

Figure 1: A simplified overview of the current aged care data collection

Residential aged care
- **Person** characteristics, health conditions and needs
- **Service and provider** entities (inc. service capacity, approval, accreditation and compliance; funding; complaints, incidents and consumer experience; and some information on workforce)
- **Service use** dates

Community-based aged care
- **Person** characteristics
- **Service and provider** entities (inc. approval, accreditation and compliance; funding; complaints; and some information on workforce)
- **Service use** dates and types

Assessment before care
- **Person** characteristics, needs, health conditions and circumstances
- **Assessment** dates, entities and outcomes

Information regarding care
- **Contact** with the My Aged Care portal

Note: The figure aims to show the overarching objects of data collection within the aged care system, grouped by current program setting.

Collecting, accessing and using data

Program manuals, guidelines and frameworks govern the various elements of the aged care system and strongly influence how associated data are collected. In addition, legislation, regulations and principles direct how aged care data are accessed and used (see Attachment 3 for a summary of key legislation).

In addition to the Report on the Aged Care Act and associated publications by the Department of Health, aged care data are published through other mechanisms, primarily the Report on Government Services and the AIHW's dedicated GEN aged care data website. Further aged care data are made available via the National Aged Care Data Clearinghouse (NACDC), through customised data requests and (where ethics approval has been granted) requests for linkage with other data sources.

Understanding future information needs

Data domains

While there is a large volume of data that is collected across different aged care programs and in support of other functions of the aged care system, coverage is currently inconsistent and incomplete, and data collections are fragmented. While administrative data for aged care has good coverage (meaning that all in-scope events are collected), it may have limitations for specific purposes, or for some population-level analyses, because the data are collected primarily for an administrative purpose.

From a person-centred view, some of the themes of information that are currently limited or missing from a data system perspective relate to:

- access to aged care – people may experience barriers, issues with availability or timeliness of services or changes to their circumstances before taking up care
- workforce – staff skills, characteristics and qualifications, and staffing levels, turnover and care hours can influence the quality of care people receive and inform service delivery planning by providers and government
- care needs – people require care tailored to their needs, where care is both planned and the planned care is delivered
- cost of care – cost can influence people's access to aged care, the quality of care received and people's out-of-pocket costs for aged care may vary

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- diversity – people's background, circumstances and prior experiences may affect what they need from aged care or how they experience aged care (potentially vulnerable population groups include: people who are experiencing or at risk of homelessness; care leavers; those who identify as lesbian, gay, bisexual, trans and gender diverse, intersex or queer; Aboriginal and Torres Strait Islander people; people living in rural or remote areas; younger people; and those with disability, dementia or other health condition of interest)

- quality of care, outcomes of care and quality of life – people using aged care should receive dignified, safe and high-quality care and a range of measures are needed to demonstrate this (particular issues for consideration may include: interactions with the health system; potentially avoidable hospital admissions or premature deaths; prescribing patterns; use of restraints; consumer experience; and reportable serious incidents and assaults)

- palliative care – aged care is often used towards the end of life and forms an important part of palliative care support.

When collected at the person-level, data can feed into reporting and analysis at the service, provider or system level. It can also be used to understand present and future demand for aged care services.

Collecting, accessing and using data

Understanding future needs for access and use of aged care data is key to understanding future information needs. From a data collection perspective, data improvement activities will focus on maximising the use of existing data collections and deploying established data standards wherever possible. This is with the aim to ensure the most efficient mechanisms for data capture are employed (for example, whether particular information needs are best met through data captured by services and providers of aged care, or through integration of existing data) and that data is collected with the multiple uses in mind.

Proposed data improvements will be guided by a set of agreed principles, for example:

- Putting people at the centre of aged care
- Providing for the needs of participants and stakeholders (e.g. people, providers (and aged care workers), governments and researchers)
- Safeguarding trust, privacy and security
- Collaborating and sharing information flexibly (e.g. data are fit for a purpose and timely)
- Making careful use of existing resources, assets and capabilities (e.g. collect once, use often)
- Evaluating the performance of the system and supporting future improvements.

As part of the government response to the Royal Commission's final recommendations, a new Aged Care Act will be drafted and implemented. New aged care governance arrangements are also expected to be established. Data improvements, including processes for continuous data improvement over time, will be considered in this context.

Attachment 1: Key definitions

Data improvement: Activities that improve the range, reliability, accuracy, validity, availability and/or timeliness of data. Improvements may relate to the scope, coverage, collection tools and methods, integration, accessibility and/or comparability of data.

National Aged Care Data Strategy (data strategy): The agreed vision for the future national aged care data system that describes why data improvements are needed and how they will be implemented. It will include a data improvement plan.

Data improvement plan (roadmap): A detailed plan of how we will go about implementing data improvements. The plan will also guide the development of the aged care NMDS and data asset.

National Aged Care Data System (data system): Data related to aged care in Australia, and the arrangements that support capture, use and sharing of these data (including data governance, ICT and infrastructure arrangements).

Aged Care National Minimum Data Set (aged care NMDS): A core set of standardised data elements agreed for mandatory collection and reporting at a national level about aged care.

National Aged Care Data Asset (data asset): A multi-source enduring linked data asset that integrates people-centred data related to aged care.

National Aged Care Data Clearinghouse (NACDC): An independent and centralised repository of aged care data in Australia. The NACDC holds data on residential aged care, community-based aged care and flexible aged care programs from 1997 to present.

Attachment 2: Current aged care data landscape

The following, more detailed, overview of the aged care data landscape focuses on aged care data that are available to the AIHW National Aged Care Data Clearinghouse. These data are collected across a number of platforms and mechanisms; however, this level of detail is not shown here.

Object of data collection	Data domain	Coverage
Person using aged care (person-level)	Demographic information	Name and date of birth are generally collected. Mix of sex and gender is collected; no specific and comprehensive data on other special populations.
	Cultural and linguistic background	Data on country of birth and Indigenous status are generally collected. Mix of data on main language and preferred language are collected; no data on English language proficiency or migratory background.
	Location	Specific and comprehensive data are collected or can be derived.
	Housing and living arrangements	Mix of data on living arrangements, accommodation setting, marital status and carer information are collected.
	Health and disability	In some instances, data on physical/mental health conditions are collected; no specific and comprehensive data on other aspects of health and disability.
	Finances	In some instances, data on income and asset details are collected.
	Education	No data are collected on education.
	Work	No data are collected on current employment or employment history.
	Social support and participation	No data are collected on social connections; minimal data are collected on social isolation.
	Justice and safety	Minimal data are collected on experiences of abuse, neglect or violence.
	Death	In some instances, data on date of death are collected.
Aged care service use (person-level)	Care needs prior to aged care use	Data on support needs in functional areas are collected.

Object of data collection	Data domain	Coverage
	Outcomes of assessments prior to aged care use	Data on dates, approvals and referrals to services are collected; some outcomes can be derived from other data (e.g. death and service use).
	Waiting times	Some information can be derived from assessment and episode dates; no data are collected on why people may wait.
	Barriers	No data collected on availability of services or reasons why people seek/do not seek care.
	Initiating care	Data on episode dates are collected.
	Type of care information	Data on episode dates and program type are collected.
	Care needs in aged care	Data on support needs prior to aged care use are collected. Mix of data on disability, functional status and funding-related needs assessments are collected; the Australian National Aged Care Classification (AN-ACC) will be implemented in residential aged care, replacing the Aged Care Funding Instrument, and the Modified Barthel Index (MBI) is used in transition care, but similar information is not currently collected in any other program type. No specific and comprehensive data on care needs.
	Care received in aged care	Data on program type are collected; in some instances, data on level of care and type of care delivered in a session are collected. No specific and comprehensive data on care received (and whether it meets care needs).
	Cost of care	Data on government expenditure (funding provided to services) are collected; in some instances, data on what person is assessed as paying are collected. No specific and comprehensive data on full cost (including total cost of care to person).
	Quality and safety of care	Data on quality and safety are collected at the service-level and do not relate to individual people using aged care.
	Interactions with other services	Data on transfers within aged care can be derived; no specific and comprehensive data on how people use other health/disability-related services concurrently.
	Outcomes of care	Data on functional status at episode end is collected for one program type; some information can be derived (e.g. death and service use). Next to no data on outcomes are collected.
	Leaving care	Data on episode dates and reason for leaving care are collected.
Workers, services and providers in aged care (service- or provider-level)	Workforce demographics	Some data are collected for one program type; some data are collected via the workforce census.
	Workforce skills, qualifications and education levels	Some data are collected for one program type; some data are collected via the workforce census.

Object of data collection	Data domain	Coverage
	Workforce wages and conditions	Some data are collected for one program type; some data are collected via the workforce census.
	Organisational information (service/provider)	Data on services and providers are collected.
	Type of care provided	Data on program type are collected.
	Size of services	In many instances, data on number of places offered are collected; data on number of people can be derived.
	Regulation	Data on service monitoring (against standards and for compliance) are collected.
	Resource allocation, cost effectiveness and financial performance	Data on funding provided are collected; in some instances, data on financial acquittals are collected. No specific and comprehensive data are collected on pricing, investment or competition.
	Quality and safety of services/providers	Data on complaints, serious incidents and quality indicators are collected.

Note: Green indicates data are available; orange indicates data are incomplete either in part (light orange) or in full (dark orange).

Attachment 3: Summary of key legislation

- *Aged Care Act 1987* which sets out many overarching functions of the aged care system and the mainstream aged care programs, and is supported by various principles (such as the *Information Principles, Accountability Principles,* the *User Rights Principles* and the *Quality of Care Principles)* – it also establishes reporting requirements to the government as well as on the government (the output of this is the annual Report on the Aged Care Act)

- *Aged Care Quality and Safety Commission Act 2018* which establishes the Aged Care Quality and Safety Commission and its regulatory functions relating to quality and safety of aged care and the quality standards

- *Australian Institute of Health and Welfare Act* which lays out the main functions of the AIHW and establishes strict confidentiality requirements that prohibit the release of certain information or documents. Furthermore, the AIHW Ethics Committee reviews and approves all data collections and projects involving identified data

- *Privacy Act 1988* and the 13 Australian Privacy Principles which govern standards, rights and obligations around the collection, use and disclosure of personal information.

Other legislation that may have an interaction with aged care include anti-discrimination laws on age, sex, disability and race, the *Australian Human Rights Commission Act 1986,* the *Carer Recognition Act 2010 and* state-based legislation on privacy, mental health, health care and advanced care planning.