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People's journey through aged care – the story in the data

8. People's journey through aged care – the story in the data

Australia's aged care system is intended to support people's health, wellbeing and quality of life into their older age. The sector offers various levels of care for people with a range of needs. It is commonly accessed by people with multiple medical conditions and complex support requirements, who are often seeking care at a time of crisis.

The demands on the system are growing. The number of people at older ages – those most likely to use aged care – is increasing. The number of Australians aged 85 and over is projected to increase from 529,000 at 30 June 2021 (2.0% of the population) to more than 1.5 million by 2066 (3.6%) (ABS 2018).

Older Australians are a diverse group, with varied backgrounds and life experiences. They come from different cultural, religious and socioeconomic backgrounds, live in different geographical settings and have their own identities and preferences (for more information on older Australians, see <https://www.aihw.gov.au/reports-data/population-groups/older-people/overview>). People also have varying needs regarding their physical or mental health and aged care – and the older population is not a static group.

The changing demography and diversity of Australia's older population has implications for policy, planning, service delivery and funding beyond the increasing demand for aged care. The aged care system needs to reflect the diversity to ensure safe, accessible, inclusive and quality care is provided to meet people's needs (both current and emerging). Looking even further ahead, it will also need to reflect the changing diversity of Australia's older population (AIHW forthcoming 2021b). Characteristics, experiences and needs evolve over time as cohorts of people age and move through the lifecycle.

The aged care system currently faces considerable change as the Australian Government (the Government) responds to the recommendations of the Royal Commission into Aged Care Quality and Safety (Royal Commission). This comprehensive inquiry, undertaken between 2018 and 2021, unpacked the inadequacies in the design, legislation, governance, funding and quality regulation that make up our aged care system. The inquiry showed that, over the last 3 decades, the system has seen numerous reviews and reforms, increased regulation, as well as program and funding changes; yet, despite this, the Royal Commission reported that the current system is not able to ensure that all people have access to (and receive) high-quality, safe and dignified care (RCACQS 2019c, 2021b).

The need for high-quality data on older people's use of aged care was highlighted in the Royal Commission's final report and recommendations (RCACQS 2021c) and recognised in the Government's response (Box 8.1). The coronavirus 2019 (COVID-19) pandemic also highlighted the lack of timely data on the experiences of people living in residential aged care. A considerable proportion (75%) of Australia's COVID-19 deaths occurred in these settings (Department of Health 2021c), and people were affected by the ensuing lockdowns and visitor restrictions. However, it has not been possible to examine these impacts systematically with existing data (boxes 8.1 and 8.2).

This article provides an overview of the current data available on older people during their journey through Government-funded aged care. It presents examples to illustrate people's experience in aged care, and identifies data gaps, limitations and opportunities to improve our understanding of these experiences.

For more information on the aged care system, see 'Health of older people' at <https://www.aihw.gov.au/reports/australias-health/health-of-older-people> and the AIHW's dedicated aged care data website at www.gen-agedcaredata.gov.au.

Box 8.1: Aged care data-related recommendations from the Royal Commission into Aged Care Quality and Safety and the Government's response

The final report and recommendations of the Royal Commission reflect the important role that data play in enabling better aged care services for older people. The Royal Commission noted its concerns that reliable, accessible and comprehensive data on safety and quality are not available. While governments, aged care providers and health professionals do routinely collect data about clients and services, these data are fragmented and incomplete. There is limited integration and analysis of data to inform a person-centred view of pathways and outcomes across aged care, health and other systems – or to articulate how to improve aged care.

The Royal Commission's recommendations outline how aged care data should be expanded to inform on many important themes:

- quality and safety of aged care services
- equity of access and ensuring the aged care system caters to diverse populations
- access to health services, allied health and dental care for people using aged care
- younger people in residential aged care
- aged care workforce planning
- experiences of both people receiving aged care and their families.

continued

Box 8.1 (continued): Aged care data-related recommendations from the Royal Commission into Aged Care Quality and Safety and the Government's response

Beyond collecting more data, the data collected must be of high quality, reliable and useable. Developing common data standards and data systems that work together and appropriately share information can aid this. The Royal Commission recommended that efforts also need to be focused on minimising delays and ensuring timely access to data.

In May 2021, the Government committed \$17.7 billion in aged care funding and accepted many of the recommendations of the Royal Commission, including those related to data. The reform agenda, which commits action over the next 5 years, is intended to empower people with the information they need to exercise choice. Key data related measures include:

- establishing a National Aged Care Data Strategy
- developing an Aged Care National Minimum Data Set
- curating a National Aged Care Data Asset
- improving information on quality and safety of aged care by implementing a star rating system for residential aged care services and expanding the quality indicator program and serious incident reporting scheme
- reporting on progress towards having no younger people entering or living in residential aged care
- collecting better data on people from diverse backgrounds and building information on quality of life and/or consumer experience in aged care.

For more information on the Royal Commission, including its final report and full list of recommendations, see <https://www.agedcare.royalcommission.gov.au>.

For information on the Government's response, see <https://www.health.gov.au/resources/publications/australian-government-response-to-the-final-report-of-the-royal-commission-into-aged-care-quality-and-safety>.

The aged care journey – what we do and don't know

A person's journey through aged care is rarely straightforward. While Australia's aged care system can be thought of as providing a continuum of care, individual people may not progress through it in a linear fashion. For some, a higher level of care is required after a sudden event, such as the loss of a carer or a health crisis – this then forms their point of entry into the system. Some might begin receiving aged care at a lower level and access increasing levels of services as their needs change. Others might only ever require lower levels of community based care (for example, home care and home support). The common elements of what people may encounter at different stages of the current aged care journey are shown in Figure 8.1.



Finding information on aged care services

My Aged Care is both a contact centre and a website that serves as the starting point to access aged care services subsidised by the Government. It provides information on care types, eligibility and services in the local area, as well as directing people to needs based assessments.

Some data are available on people's interaction with My Aged Care. For example, in 2019–20 almost 1.5 million calls were responded to, and there were over 4.0 million visits to the website (Department of Health 2020a). What is not known is how many individual people accessed the My Aged Care platform or how many times.

The Royal Commission noted that people have low levels of awareness of the platform and experience difficulty in finding information most relevant to them; furthermore, the platform lacks information on quality of care and how services perform against the Aged Care Quality Standards. The platform may also not meet people's needs particularly when there are literacy, language or technology issues, or where people are experiencing a sudden health crisis or have cognitive impairment (RCACQS 2019a, 2019b).

Throughout the aged care journey, older people and their families may need to gather and evaluate information about their care options and likely costs. They may have to reconcile information and advice from various sources, including their health care providers. These can be complicated and confusing situations. The proposed star ratings to be published on My Aged Care are intended to provide performance information for people seeking residential aged care and will allow services and providers to be compared. These ratings may be extended to cover home care services in the future.

Being assessed before aged care use

Following an initial screening through My Aged Care, people are directed to either a home support assessment (conducted by the Regional Assessment Service) or a comprehensive assessment (conducted by an Aged Care Assessment Team).

These processes assess people's circumstances and care needs and, where relevant, approve them for aged care services; they also refer people to service providers.

Administrative data collated by the Department of Health provide information on the number of people assessed and their characteristics at the point of entry. Generally, people who have a comprehensive assessment are somewhat older and have more complex health issues than those assessed for home support (Table 8.1). For example, people who had at least 1 comprehensive assessment in 2019–20 were almost twice as likely to have a carer as those assessed for home support, potentially indicating a greater need for assistance.

Table 8.1 People with completed assessments^(a) in 2019–20 by assessment type (home support or comprehensive) and selected characteristics

Selected characteristics	Home support ^(b)		Comprehensive ^(c)	
	Number ('000)	Per cent %	Number ('000)	Per cent %
Aged 85+	51,497	20.5	72,241	39.2
Female	147,616	58.7	107,003	58.0
Non-English speaking background	51,106	20.3	42,746	23.2
Aboriginal and/or Torres Strait Islander	5,400	2.1	3,583	1.9
Had a carer	103,887	41.3	139,349	75.6
Were a carer	33,228	13.2	20,686	11.2
Trigger for assessment was a hospitalisation	46,459	18.5	65,096	35.3
Had experienced slips, trips or falls	92,087	36.6	115,976	62.9
Had experienced memory issues or confusion	11,590	4.6	60,143	32.6
Had dementia diagnosis	11,360	4.5	30,537	16.6
Had multiple chronic health conditions ^(d)	105,905	42.0	120,212	65.2
Had cancer	45,590	18.1	46,807	25.4
Had a nervous system disorder	30,535	12.1	41,260	22.4
Had arthritis or other musculoskeletal disorder	141,122	56.1	107,139	58.1
Had heart disease ^(e)	58,738	23.3	62,343	33.8
Needed help to eat	8,350	3.3	50,112	27.2
Needed help to walk	93,089	37.0	123,646	67.1
Needed help to get places	138,850	55.2	166,606	90.3
Needed help to dress	34,311	13.7	105,595	57.2
Needed help to bathe	65,354	25.9	125,316	67.9
Total	251,615	100.0	184,423	100.0

(a) These assessments data have been subject to minimal data cleaning or quality assurance and should be considered in conjunction with information about completeness and comparability with previous Aged Care Assessment Program data.

(b) Home support assessments are delivered by the Regional Assessment Service for people seeking entry-level home support.

(c) Comprehensive assessments are administered by an Aged Care Assessment Team to determine eligibility for Australian Government subsidised aged care services such as residential aged care (permanent and respite), a home care package and flexible care services.

(d) Comprises arthritis, chronic lower respiratory illness (e.g. emphysema, chronic obstructive pulmonary disease, asthma), back problems (e.g. scoliosis, sciatica), cancer, heart disease (see footnote (e)), kidney or urinary conditions (e.g. renal failure, cystitis), mental or behavioural conditions (e.g. dementia, depression/mood affective disorders, schizophrenia), osteoporosis and diabetes (e.g. type 1, type 2 and other).

(e) Comprises rheumatic fever, rheumatic heart disease, angina, myocardial infarction (heart attack), acute and chronic ischaemic heart disease, congestive heart failure and other heart diseases.

Note: Percentage calculations include 'not stated' in the denominator.

Source: AIHW analysis of National Screening and Assessment Form data.

Assessments data can assist in understanding what people may need from care and provide a basis for assessing the extent to which needs are later met; however, the link between this information and subsequent supports offered is not currently strong. For the individual, the assessment process can also seem complex and time consuming, and elements of it may be duplicated (RCACQS 2021b).

No information is currently available on how long people wait between identifying a need and receiving an assessment for services. There is also a lack of reporting about the financial means and asset test carried out by Services Australia; this test occurs in parallel with aged care assessments to determine how much people need to pay towards their aged care. Determining people's contributions to the cost of aged care services is a Royal Commission recommendation accepted by the Government (Department of Health 2021b).

Waiting to access aged care services

People who have been approved for aged care after a comprehensive assessment – and are ready to take it up – may find themselves on a waiting list either to obtain a home care package (whether at all, or at the level of care required) or to enter an aged care service.

From the available data, only the time between assessment and take-up of care can be reported and this can vary greatly between types and levels of care. For example, in 2019–20, half of the people who took up the highest level of home care (Level 4) had the package in place within 5 months of approval if they were assessed as being 'high' priority and within 31 months of assessment if assessed as 'medium' priority. Around 4 in 10 (42%) older people who entered permanent residential aged care in that year did so within 3 months of their assessment (SCRGSP 2021). Little is reported on those still waiting to take up care.

These data do not take into account why people waited or what happened while they waited. The person themselves may not have perceived it as a 'wait', particularly if their needs were being met in other ways at the time. For example, while waiting for the approved level of home care to become available, people may access home support services (Department of Health 2021d). On the other hand, being unable to access required services may have an adverse impact on the health and wellbeing of both the person seeking care and their family and carers (Visvanathan et al. 2019). Waiting time for home support services may depend on the level of care required and the availability of services in the area; no data are available on these wait times.

Using aged care services

In 2019–20, more than 1 million people were using aged care in Australia. Over time, people can use both community-based aged care and residential aged care services. As shown by the data on assessments, people commonly use different aged care programs at different stages of their life. During 2019–20, 37% of people using permanent residential aged care were aged 90 and over, compared with 12% of people using home support services (SCRGSP 2021).

Information on people's use of aged care comes from a number of data sources. Individually, these sources generally provide counts of activities in the system but, together, they can show interactions.

To some extent, administrative data collected to inform planning and funding cover the characteristics of both people using care and the broad type of care they receive, as well as aspects of their care needs (for example, the Aged Care Funding Instrument – ACFI – collects information about care needs as they relate to funding levels for permanent residential aged care). While home support data capture information about services delivered, home care and residential aged care data do not.

Perceptions of care

Also missing from the picture are people's perspectives – whether the services they receive were tailored to meet their needs, and whether they were treated with dignity and respect. Consider, for example, the food people are provided in residential aged care: simply put, do people find it nutritional, is it appetising and does it meet their preferences? This was an aspect the Royal Commission noted in its final recommendations (RCACQS 2021a).

Factoring in other sources – such as surveys, tools and other instruments – can provide greater insight into people's experiences of aged care, such as their quality of life. However, information on how people experience care or what their quality of life may be like is not currently captured, representing a notable data gap (Box 8.2). Separately, population-based surveys such as the Australian Bureau of Statistics' (ABS) Survey of Disability, Ageing and Carers capture information about aspects related to people's use of aged care, including health status, functional abilities and met or unmet needs.

Quality and safety of care

Through public submissions and testimony, the Royal Commission revealed cases of abuse and neglect in the system that have not been captured in administrative data. The Royal Commission's final report documented the difficulties in identifying the extent of substandard care in Australia's aged care system (RCACQS 2021b). Information is needed about the quality and safety of aged care.

Some related information can be gleaned from routine data collection, such as those data relating to quality, accreditation, consumer experience, sanctions, quality indicators, serious incidents, complaints and feedback. However, each of these is a discrete type of information and the current focus of data is on service-level reporting. For example, since July 2019, residential aged care services in Australia have collected and reported on quality indicators as part of the National Aged Care Mandatory Quality Indicator Program. Initially, this included 3 indicators (pressure injuries, use of physical restraint and unplanned weight loss). From July 2021, there were 5 Quality Indicators (now also including falls and major injury, and medication management). For more information, see <https://www.gen-agedcaredata.gov.au/Topics/Quality-in-aged-care>.

In response to the Royal Commission, the Government has committed to developing additional indicators and implementing them across residential aged care and in home care by the end of 2022. Along with the new star ratings and the Serious Incident Response Scheme, this initiative is expected to lead to improvements in the quality and safety of aged care (Department of Health 2021e).

The aged care workforce

Quality of care and people's experiences of aged care are also influenced by the people who work in the sector. Aged care is one of Australia's largest service industries, with aged care workers making up 3.1% of our workforce. There is considerable overlap of workers within the sector and between sectors (for example, people may work concurrently in different aged care services or they may work in both disability and aged care sectors). This may add to the demands at the individual level and contribute to workforce shortages, but currently data are not available to understand the full impact (Box 8.2).

Some information about the aged care workforce has been captured in the past through the National Aged Care Workforce Census and Survey: over time, the number of qualified nursing and allied health staff has dropped with a concurrent rise in the number of personal care assistants (Eager et al. 2019; Mavromaras et al. 2017). The 2020 Aged Care Workforce Census may be useful in enabling a more recent understanding of people working in the sector, once data are available.

Limited data about the current workforce restricts our capacity to assess whether people with complex care needs receive suitable care. For example, increased workloads and reduced clinical capacity in residential aged care facilities may affect the care that people with dementia receive. Staff may have insufficient time to build relationships with the increasing numbers of residents with dementia (Duckett et al. 2020).

Currently, data on staffing levels, turnover and staff skills and qualifications are not routinely collected and no minimum requirements apply in aged care. Change is expected, with the Government's acceptance of the Royal Commission's recommendations on future staffing; for example, specifying the minimum staff time to be provided by registered nurses (RCACQS 2021a). As of July 2021, providers have been required to report on care staffing minutes for each facility and these types of information are expected to feed into the star rating system (Department of Health 2021b).

Further, the skill mix of aged care staff should be linked to people's need for care, ensuring that additional staff are engaged for residents with higher-than-average needs. The replacement for the ACFI – the Australian National Aged Care Classification or AN-ACC – is likely to capture precise information about residents' frailty and care needs. It may be used to assess staffing requirements in residential aged care, as well as to facilitate systematic measurement and quality benchmarking (Eager et al. 2020). The AN-ACC is currently being trialled in parallel with existing ACFI assessments and it is expected to be implemented from October 2022 (Department of Health 2021f).

Box 8.2: COVID-19 – a case study in aged care data gaps and their implications

The COVID-19 pandemic has disproportionately affected people using aged care. In Australia, 75% of COVID-19 deaths were among people living in residential aged care as at 30 April 2021. By way of comparison, at the same point in time, 65% of Canada's COVID-19 deaths were in care homes (Department of Health 2021c). Furthermore, the lockdowns and social restrictions applied to residential aged care were at times more restrictive than those applied to people living in the community. People living in the community may also have experienced ongoing disruptions to the formal and informal supports they were receiving (RCACQS 2020a). For more information, see Chapter 3 'The impact of COVID-19 on the wellbeing of Australians'.

The pandemic highlighted known issues in aged care, such as those related to workforce capacity and capability, infection prevention and control, and quality of life (RCACQS 2020a). As this article has shown, these issues are also known data gaps. In the absence of comprehensive and timely data, information has largely been limited to personal stories, media coverage and submissions to the Royal Commission.

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Box 8.2 (continued): COVID-19 – a case study in aged care data gaps and their implications

The COVID-19 pandemic may have affected people using aged care in many different ways, some of these indirectly, but there are little comprehensive data available. Linked administrative data can be years behind events, and there is no existing timely mechanism for capturing information on quality of life or changing care needs.

Information about the physical, mental and emotional impact of COVID-19 on people living in residential aged care may be limited given the nature of the administrative data available. From the data currently available, it is not possible to examine the full impact of COVID-19 on residents. In fact, the pandemic has highlighted that there is no common clinical data capture system across aged care facilities, and that there are substantial recognised workforce and Information and Communications Technology system gaps that need to be filled (RCACQS 2021c). Given the current state of these capabilities, creating standardised clinical information will be a considerable undertaking but one that will help with individualised care planning for each resident and potentially contribute to a much greater understanding of these needs at a service population level.

The Department of Health's disease surveillance data provide information on the number of deaths due to COVID-19 for people receiving Government-subsidised residential care at the time of their death. Whether the person died in residential care or a hospital is not reflected in the data. ABS analysis of place of death data show that, for people aged 85 and over in Australia, 44% of deaths due to COVID-19 that occurred by November 2020 were in residential aged care facilities, with 56% in a hospital/medical service area (ABS 2021).

Advice about COVID-19 vaccine eligibility and data on the vaccination rollout for people living and working in aged care have been developing over time. As at July 2021, there was no timely and comprehensive source of person-centred data about the vaccination rollout in the aged care system. Information about vaccinations among aged care workers, for example, are reported to government by aged care providers as this data are not available in the immunisation register or the records of vaccine doses administered. This has implications for understanding and responding to virus outbreaks. See the Department of Health's website (<https://www.health.gov.au>) for the latest information.

Aspects of health service use

There is currently little to no information about allied health use (for example, podiatry, occupational therapy, physiotherapy and dental) by people using aged care services – in part reflecting the lack of comprehensive information about these services for the general population. The Government has accepted the Royal Commission's recommendation to provide appropriate access as needed to these services. To ensure that progress towards this goal is transparent, data are required. Data linkage may also be part of this solution, where existing data can be linked (Box 8.3).

Box 8.3: Understanding the interactions between aged care and health service use

Data linkage is a process that brings together data on the same person or entity from different sources, providing more comprehensive information. Linking aged care data with other collections can enhance what is known about people's interactions across different settings, such as their use of general practitioners (GPs), medications, specialists and the hospital system while using aged care.

The AIHW Interfaces between the aged care and health system in Australia series of reports illustrated some insights that could be gained from linked data (for more information, see <https://gen-agedcaredata.gov.au/Resources/Reports-and-publications/Interfaces-between-the-aged-care-and-health-system>) – for example, that most people in permanent residential aged care see GPs, but that many other aspects of health care use are less frequent for those in aged care than for those not in aged care (AIHW 2020b). People's patterns of medication use also change before and after entry into permanent residential aged care, with a marked increase in the dispensing of some psychotropic medications after entry (AIHW 2020a).

As well, linked longitudinal data sets can identify patterns of aged care use and how these vary depending on people's characteristics. For example, research using the Australian Longitudinal Study on Women's Health has shown that characteristics such as being widowed, living in remote/regional areas or having a chronic condition were associated with increased odds of needing higher levels of aged care (Rahman et al. 2019).

One of the key gaps in aged care data is that they are often limited to information collected for administrative purposes, such as assessing claims and making payments. However, administrative data can be enhanced to address specific questions. For example, an indicator in Pharmaceutical Benefits Scheme (PBS) data was recently implemented to identify whether people are living in a residential aged care facility (Department of Health 2020b); however, this enhanced PBS information is still limited to medications where a PBS claim is made and excludes other types of medication (for example, those purchased over the counter).

In response to the recommendations of the Royal Commission, it is expected that, in the future, many health-related data sets will include an item identifying whether a person is receiving aged care services and the type of aged care. Greater connections between aged care and health systems are a welcome development to further enhance what is known about a person's interactions with different services.

Leaving aged care

Administrative data from the aged care system capture exits from residential aged care and from home care, including the reason for exit and time spent in aged care (for more information, see GEN <https://www.gen-agedcaredata.gov.au>). However, these data currently relate to claims submitted by the provider and, for example, time spent in aged care at the person level may be different (taking into account time spent in hospital or visiting the community).

Many Australians use aged care services towards, and at, the end of life. Often, aged care and end-of-life care overlap, and residential aged care is the most common form of aged care used in the final months or years of life.

Some people may leave residential aged care to return home or to the community but, for the majority, the aged care facility is their final home. For example, of older people in Victoria and Queensland who died aged 65 and over in 2016–17 and had been living in residential aged care shortly before their death:

- 78% died in residential aged care
- 19% died in hospital
- 1.7% died in emergency departments
- 0.2% died possibly in the community (such as at home with or without other supports in place).

These data compare with 71% dying in hospital, 26% in the community and 2.7% in emergency departments for those older people who had not been using residential aged care in the week before their death (AIHW 2021a).

Understanding the interactions between different settings and how and when people leave aged care is important not only for service planning and resourcing decisions, but also for understanding people's wellbeing. It can provide evidence for the quality and appropriateness of aged care and the person's needs and experiences. Analysing linked administrative data sets is currently the best way to take a person-centred view of the circumstances surrounding a person's exit from aged care.

Improving our understanding of the journey – a way forward

There is a wealth of system-based, administrative data on aged care, but there are notable data gaps in the individual data sources. The current disconnections between these disparate sources also represent a data gap, as does the lack of high-quality, comparable and critical information in a range of areas. A coordinated approach that takes a person centred view of aged care and enables an assessment of the health, wellbeing, safety and quality of care throughout the aged care journey is one way forward.

Overall, a greater focus on measuring the health, wellbeing and safety of people using aged care will be needed to drive better data systems and outputs and, importantly, better quality of life and better health outcomes for people.

Ensuring a coordinated approach to data capture

As Australia's aged care system has evolved, systems, programs and services have changed. Each information system that captures data has been developed separately, and their terminology and data definitions reflect this. Data are collected on particular components of aged care, health and other support services, as well as on population cohorts, yet there are few innate links between these data sources. Current data sources do not readily identify the way different services interact, and how people use them concurrently. This has implications for service planning and delivery. Without data systems that work together and share information, people's continuity of care within and across services is hampered.

The development of a National Aged Care Data Strategy will provide an overarching framework to identify, improve and better use aged care data to inform aged care policy development and service planning. The strategy will need to drive data improvements relating to current and future service demand, workforce, interactions with the health system, quality and safety, and outcomes of care, including for diverse populations. This will involve establishing broad agreement on the information needs across the system and coordinating future developments. The Aged Care Minimum Data Set will define the core data to be supplied from the various component data sources and inform future changes to the aged and health care data collection systems.

Taking a person-centred view

A person-centred view of aged care use will make it possible to assess what people need from aged care services, how those needs change over time and whether the care a person receives meets their needs. Some specific examples of what is missing in existing data from a person-centred view include:

- access to aged care: how long people wait at each step of the journey, why people wait for aged care places, what happens while they wait and whether people are able to access the care they need
- workforce: staffing levels, turnover and staff skills, characteristics and qualifications
- care needs: what people need from aged care, and whether those needs are met, including identifying and monitoring health conditions such as dementia
- cost of care: how cost influences access to aged care, the quality of care received and variation in people's out-of-pocket costs
- diversity: how people's background, experiences and needs may affect what they need from aged care or how they experience aged care – particularly 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 dementia or disability
- quality of care and quality of life: the quality of services received, as well as people's experiences of care more broadly and overall quality of life, to provide measurable outcomes of good person-centred care
- palliative care: whether people received appropriate palliative care and support towards the end of life.

In terms of the quality and safety of care, other measures of interest are potentially avoidable hospital admissions, use of chemical restraints, reportable serious incidents and assaults, as well as premature deaths. Providing greater transparency around these types of information, such as through the system of star ratings for services, can enable older people and their families to make comparisons (RCACQS 2021c).

Examining pathways and outcomes

When data from different sources are brought together, they can offer insights into the factors that prevent, delay or present a barrier to using aged care, as well as the causal pathways and outcomes for people using aged care. For this to happen, more comprehensive information is needed about people's health, wellbeing and quality of life at each stage of the journey through aged care. Information is also needed on the interactions across the aged care, health and other support systems, both in terms of meeting the needs of people and the quality and safety aspects of these services. Such information can improve our understanding, including our capacity to assess the impact of events such as COVID-19 and the bushfire season in 2019–20. It can also build our understanding of the experiences of vulnerable population groups. Filling data gaps relating to people who may have difficulty accessing or using aged care and other services are particularly important to ensure equity of access for all older Australians.

Having access to a broad set of information at the person level will provide opportunities to consider pathways and outcomes from different angles. For example, having comprehensive information about the costs of individual components of care and types of care could facilitate analysis of the costs and benefits to the public.

The current data gaps, and the lack of links between the data sources, limit both the measurement of outcomes and the extent to which data can inform policy development and service planning. While this has negative implications for the sector and providers, ultimately it is older Australians and their families who are most affected. In summary, relying on individual data sources limits the capacity to assess how the aged care system is faring.

Linking the data

Drawing disparate pieces of information together can provide a richer picture. In particular, integrating information from different sources through data linkage can support person-based analysis of people's wellbeing as they use aged care. It also becomes possible to examine the interactions between events and over time. The AIHW's National Integrated Health Services Information Analysis Asset (NIHSI AA), the Pathways in Aged Care (PIAC) link map and the ABS Multi Agency Data Integration Project (MADIP) are examples of the potential this process offers.

- PIAC brings together aged care data from the National Aged Care Data Clearinghouse and deaths data from the National Deaths Index to provide a person-level view of the journey from assessment to aged care use, and ultimately death.

- The NIHSI AA provides a similar view of health service use, such as Medical Benefits Schedule, PBS and hospital care, in combination with residential aged care.
- The MADIP connects information on a number of topics including health, employment and population demographics (including the Census) over time.

Each of these government-managed linked assets are valuable in their own right. However, this value can be enhanced if future governance and technological developments, consistent with community expectations, help them to work together as part of a broader data system.

Linked aged care data are being used by the research and clinical community to produce valuable person-centred information by, for example:

- the Registry of Senior Australians at the South Australian Health and Medical Research Institute
- the 45 and Up Study at the Sax Institute
- the Concord Health and Ageing in Men Project at the University of Sydney
- the Australian Longitudinal Study on Women's Health at The University of Newcastle and The University of Queensland.

Further insights into the health care needs of particular groups of people, such as those with dementia (representing around half of the people in permanent residential aged care, based on ACFI data), could be gleaned from linked aged care and health service use data in the future. However, there are opportunities to look beyond existing data and build on these to better meet the information needs and known data gaps.

Improving the data

There is an opportunity to improve what we know about people's journey through aged care. A National Aged Care Data Strategy will guide the development of an aged care data system that not only uses existing data sets effectively, but also addresses data gaps. The data strategy will also identify the governance and infrastructure arrangements that are necessary to support a cohesive aged care data system. As part of this broader system, the National Aged Care Data Asset – an enduring de-identified linked data set underpinned by an Aged Care National Minimum Data Set – will provide routinely collated, regularly updated and accessible data. One important input is routinely collected administrative data, which can be used in combination with population and service user surveys to build a stronger understanding of the experience of older people using aged care.

The aged care data system will support the integration of available data sets and enable a person-centred view of pathways and outcomes across aged care, health and other support systems. However, the current and projected need for high-quality aged care that is rights-based and person-centred will require more sophisticated data than currently exist. The development work will identify data gaps and develop common data definitions across the aged care sector, beginning with the Aged Care National Minimum Data Set.

Data improvements such as filling gaps, improving the quality and increasing availability and accessibility will be essential for policy development and service planning as well as for research and evaluation. Improving the data landscape also has the potential to encourage a culture of continual improvement, while providing the necessary information for policy, planning, system monitoring, service delivery improvements and research purposes. International comparisons across key measures may also be more readily undertaken. In addition, data improvements must support the evaluation of changes resulting from the implementation of the Royal Commission's recommendations, as well as the impact of events such as COVID-19 on people's wellbeing and use of aged care into the future.

Aged care should support people to live meaningful lives into their older age, protecting their quality of life, safety and wellbeing. Older people should have equitable access to information and services that are effective and appropriate to their needs, and that take into account individual circumstances. While current data shed some light on people's experiences and service use on their journey through aged care, the data are yet to tell the full story. Data improvement, including new and improved data capture and linkage of available data, is crucial in order to provide a reliable basis for further policy development and for service delivery models aimed at supporting older people. Most importantly, data improvements are needed to ensure that all older Australians using aged care are afforded dignity, respect and control.

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