



AUSTRALIAN MEDICAL
ASSOCIATION
ABN 37 008 426 793

T | 61 2 6270 5400
F | 61 2 6270 5499
E | ama@ama.com.au
W | www.ama.com.au

39 Brisbane Ave Barton ACT 2600
PO Box 6090 Kingston ACT 2604

Exploring future data and information needs for aged care

AMA submission to Australian Institute of Health and Welfare (AIHW) Enquiry

agedcare.secretariat@aihw.gov.au

The AMA welcomes this enquiry initiated by the AIHW. The AMA has previously recognised and raised concerns around the lack of data pertaining to specific areas of aged care, especially when it comes to areas where healthcare intersects with aged care.

The AMA regularly uses data available through AIHW for our policy and advocacy work. There is a noticeable lack of data availability for aged care when compared with healthcare data, such as public hospital data. The AMA believes that improving data collection and data linkages will lead to improvements in how healthcare and aged care are provided to older people, and to improvements in aged care and healthcare planning, especially planning of primary care and tertiary care provision.

The AMA acknowledges the Royal Commission into Aged Care Quality and Safety (Aged Care Royal Commission or Royal Commission) recommendation of facilitating the development of software for use by approved providers, to be accredited by the Australian Institute of Health and Welfare for the collection of aged care national minimum dataset elements and quality indicator data, incorporating compliance with the Aged Care Quality Standards. The AMA is in principle supportive of this recommendation, but also recognises the significant potential of My Health Record in residential aged care for improved data collection.

The AMA would like to see future regulation that will enable data collection and data matching while ensuring that privacy and security measures are put in place. This should be to the same standard that was applied to the implementation of My Health Record.

Data Domain: Person using aged care services (person level)

There is a clear need for improvement of data collection as well as data linkage at the person-level in aged care. By year 2035 Australia is expected to have over one million people over the age of 85. It is well known that the older cohort requires substantial medical care and tends to

rely more on hospital care and aged care services. The average age of admission to permanent residential aged care in Australia in 2020-21 is 82.9 years for men and 85.0 years for women.¹

Despite the evident need, it is extremely difficult to link Emergency Department (ED presentations) and hospital care data with the aged care recipient data. For example, at the time of the Aged Care Royal Commission's enquiry, the Australasian College of Emergency Medicine (ACEM) reported that the number of ED presentations that were the result of transfers from residential aged care facilities (RACFs) to public hospital emergency were not available to be extrapolated from the National Non-Admitted Patient Emergency Department Care Database (NNAPEDCD).² The AMA is aware that some states and territories have since started collecting these data.³ The AMA would like to see national consistency in this type of data collection.

Furthermore, within the current system, it is very difficult to follow a patient's/older person's journey throughout aged care and healthcare systems and where they intersect. For example, the current Aged Care Assessment Team (ACAT) services, that are linked to public hospitals, provide baseline clinical data for subsequent clinical monitoring and evaluation of patient outcomes. Yet, the AMA is not aware of any instances where these data are linked to any other data pertaining to recipients of aged care services, nor of their use for subsequent monitoring of health outcomes of aged care recipients.

A recent AMA research paper found that when people are transferred from aged care to hospital, they tend to stay longer than other patients in the same cohort who are hospitalised from the community.⁴ While deterioration in health as people age is expected, the AMA argues that appropriate data utilisation could limit ED transfers and prolonged hospital stays. This could be achieved by using the ACAT data for the purpose of baseline monitoring, accompanied by the development of adequate care plans by GPs (as recommended by the Aged Care Royal Commission)⁵ and aged care facilities. This would facilitate improved assessment of the quality of care provided to individual aged care recipients, as well as the devising of targeted medical care that could be provided on-site.

Furthermore, the AMA has consistently expressed concerns over the fact that the information that is available to an older person's usual GP, before they enter aged care, is not captured or used once that person is receiving aged care. For example, under the current system, GPs can refer patients to aged care, based on their assessment and the information they have available to them on the older person's deteriorating health condition, but they are at the same time completely cut off from contributing to their patients' assessments past the referral to My Aged Care. The health information GPs have available to them is not used for subsequent monitoring of health outcomes of older people in residential aged care.

¹ https://www.gen-agedcaredata.gov.au/www_ahwgen/media/ROACA/21520-Health_Report-on-the-Operation-of-the-Aged-Care-Act-2020%e2%80%932021.pdf

² https://agedcare.royalcommission.gov.au/system/files/2020-06/AWF_600.01256.0001.pdf

³ See for example <https://www.sahealth.sa.gov.au/wps/wcm/connect/f0b277b4-0940-4007-96e6-b4c7ad2e2b36/Non-Admitted+Emergency+Care+Data+Domain+-+Reference+Manual.pdf?MOD=AJPERES&CACHEID=ROOTWORKSPACE-f0b277b4-0940-4007-96e6-b4c7ad2e2b36-nIOVQoo>

⁴ <https://ama.com.au/sites/default/files/2021-04/130421%20-%20Report%20-%20Putting%20health%20care%20back%20into%20aged%20care.pdf>

⁵ Final Report Recommendation 31 iii and iv <https://agedcare.royalcommission.gov.au/sites/default/files/2021-03/final-report-recommendations.pdf>

Continuity of care is important in all settings and leads to improved health outcomes, especially for people with dementia. A recent UK study found that patients with dementia regularly seen by their own GP have lower rates of delirium, incontinence and emergency hospital admissions, leading to better overall health and quality of life.⁶ However, under the current system there is no way of monitoring, evaluating and therefore encouraging the continuity of care.

Hence, the AMA argues that the health and disability data domain needs substantial improvement.

The AMA would like to see improvements in data collection with regards to interactions with the health system for older people before they register for aged care, and once they start receiving aged care services. Data should be captured separately for home care services and residential aged care services so that the point of transition/deterioration can be captured, monitored and contribute to the implementation of targeted improvement actions and policies.

The Aged Care Royal Commission recommended that the “Australian Government should implement an aged care identifier by no later than 1 July 2022 in the Medicare Benefits Schedule and Pharmaceutical Benefits Scheme Schedule datasets to allow regular public reporting on the number and type of medical and pharmaceutical services provided to people receiving aged care.” The AMA supports in principle having identifiers to be able to collect, track and record data. However, it is the AMA view that the system should ensure minimisation of duplication and creation of multiple identifiers. Planned health system interoperability currently under consideration by the Australian Digital Health Agency and the Department of Health should be taken into consideration when planning this aspect of data collection and tracking.

The AMA supports the introduction of markers to link the type and level of approved aged care service with the MBS, PBS and hospitals services used by a person who receives an aged care service. Once all residential aged care providers register for the My Health Record, the only aged care services used by an older person that are not identifiable through the healthcare identifiers will be approved home packages. Instead of introducing a third identifier for each aged care recipient (Individual Healthcare Identifier - IHI, My Aged Care plus a new ID to track the health services used by a person who is supported by a home care package), the AMA suggests consideration of:

- a) Linking the person’s My Aged Care services ID to their IHI for the purpose of data matching and reporting; or
- b) Adding a marker to the age care service recipient’s IHI.

Option (b) has the disadvantage of requiring My Aged Care to track and update each older persons IHI marker when they transition from one level or type of age care service to another.

Data domain: Aged care service use (person level)

As outlined above, the AMA sees the need for improvement in data collection in the **Care needs prior to aged care use domain**. The AMA believes that this domain needs to capture the data available to an older person’s usual GP. As outlined above, often it will be the GP referring an older person to aged care services. The referral is commonly based on the GP’s knowledge of the

⁶ <https://bjgp.org/content/bjgp/72/715/e91.full.pdf>

patient and the assessment of their health deterioration. Even though GPs hold an abundance of data that could be helpful for aged care planning, analysis and monitoring of patients' health outcomes and their movement through aged care, these data are not used for any of those purposes.

Waiting times data domain should capture reasons for waiting. The AMA argues that capturing the reasons for an extended wait for receiving aged care services, whether home care or residential aged care, will be helpful in better targeting policies and opening more aged care spaces in RACFS or releasing more home care packages.

Furthermore, long waiting times for home care packages or places in RACFS often result in use of other services such as emergency department and public hospitals. These need to be appropriately linked and properly quantified.

In the past we have seen instances where the Commonwealth would limit the supply (release of home care packages), as evidenced by the Royal Commission.⁷ The Royal Commission's interim report found that "during the 12 month period ending in June 2018, more than 16,000 people died waiting for a Package on the national prioritisation queue".⁸ The Royal Commission also evidenced instances of people who preferred a home care package moving into residential aged care – a much more expensive form of care– because they were unable to access one.

Many of the older people who died waiting to access the appropriate level of home care and would not enter residential aged care, would spend increased time in hospital before they died, and many would have died in hospital. Yet there are no data available to quantify the cost to the health system of their extended wait or the increase in cost to the aged care system.

The AMA argues that if the reason for the wait for an appropriate level of home care package is a delay in availability of packages, then that needs to be measured/costed against the deterioration in the older person's condition and the cost of any resulting hospital stay. Better capturing the data about the reasons for wait and how they impact other areas of the health/aged care systems would improve Government aged care and healthcare policy.

The result is cost shifting. Right now the Commonwealth is only concerned with the overall cost to the aged care system, while the additional costs to public hospitals are considered to be the sole concern of the States and Territories. The reality is that these costs are shared by all Australian taxpayers. Improving data collection and data availability should lead to improvements in policy and service provision.

Improving data collection within the **Barriers for not seeking care domain** should look at issues such as:

- Social disadvantage,
- English as a second language,
- lack of access or awareness of availability of Aboriginal and Torres Strait Islander specialised aged care and aged care navigation,
- low computer literacy,

⁷ <https://www.royalcommission.gov.au/system/files/2021-03/interim-report-volume-1.pdf>

⁸ <https://www.royalcommission.gov.au/system/files/2021-03/interim-report-volume-1.pdf>

- social isolation (it can be linked to data on social support and participation under the Person Level data domain), and
- access to care finders/navigators that will be rolled out under the Aged Care Royal Commission's recommendations that were accepted by the Federal Government.⁹

It is the AMA view that the **Care needs in aged care** domain will be significantly improved with the implementation of the new assessment model in residential aged care – the Australian National Aged Care Classification (AN-ACC) model. By capturing the factors impacting the cost of care, such as mobility, cognitive ability for people with assisted mobility needs, the risk of falling, medical needs, and wound care and function and pressure sore risk for people who are non-mobile,¹⁰ this model will provide an abundance of data on individual care users that, once de-identified, can be further used and studied to inform aged care and health care policy. As explained above, these data should not be looked at in isolation, but in combination with other health data available through aged care assessments done by ACATs and health information available to older people's GPs.

Furthermore, the Modified Barthel Index assessments that are used on entry to, and exit from, the Short Term Restorative Care (STRC) Programme capture important data that can be linked to other patient's/aged care user's data, to monitor their health outcomes beyond the access to restorative care, and throughout their entire aged care journey.

Finally, the AMA argues that little or no data are captured on uptake of Advance Care Directives (ACDs) in aged care. ACDs could and should play an important role in aged care and as such should be encouraged. While it is accepted and understood that individuals' ACDs will be different in terms of level of detail included, at a minimum they should capture an older person's preference for hospital transfer, healthcare preference and any palliative care plans. Yet use and application of ACDs in aged care is minimal. An Aged Care Royal Commission's study found that around 48 per cent of people over the age of 65 in residential aged care had an ACD, but that less than three per cent of them had a statutory advanced directive outlining preferences for care.¹¹

Revision of the aged care quality standards has been announced as part of the ongoing aged care reform that the Commonwealth committed to following the Royal Commission. The revision will encompass amending the standards to require providers to assist people receiving care to make and update advanced care plans if they wish to, and ensuring that those plans are followed.¹² It would be beneficial to be able to monitor the resulting increased uptake of ACDs in aged care, as well as their application in terms of honouring the wishes and preferences expressed in ACDs.

In the AMA view the **cost of care domain** needs to be person centred and capture the entire aged care and medical care cost. IHI could be used for this purpose. As explained previously, because the costs of healthcare and aged care are considered separately, we often see cost (and responsibility) shifting. For example, a recent enquiry conducted by the Queensland Parliament found there were around 550 and 600 people in hospitals in the Gold Coast alone that could not

⁹ <https://www.health.gov.au/sites/default/files/documents/2021/05/australian-government-response-to-the-final-report-of-the-royal-commission-into-aged-care-quality-and-safety.pdf>

¹⁰ <https://www.health.gov.au/health-topics/aged-care/aged-care-reforms-and-reviews/residential-aged-care-funding-reform/assessment-process-and-classification>

¹¹ <https://agedcare.royalcommission.gov.au/sites/default/files/2019-12/background-paper-5.pdf>

¹² <https://www.health.gov.au/sites/default/files/documents/2021/05/australian-government-response-to-the-final-report-of-the-royal-commission-into-aged-care-quality-and-safety.pdf>

be discharged because they were not able to obtain the appropriate level of aged care services or NDIS services in the community.¹³

Currently it is very hard to identify and quantify the number of aged care type patients in hospitals at any given time. The AMA suggests that significant data collection improvements are needed in this domain. The AMA supports the proposal put forward by the researchers engaged by the Aged Care Royal Commission who conducted the research into hospitalisations from aged care in 2021 for the Royal Commission enquiry purposes. They recommended that “Hospitalisation indicators could be facilitated more effectively in the future if enduring agreements were established by the Australian, State and Territory Health departments to allow data to be shared, linked and analysed”.¹⁴

The AMA argues that the **Interactions with other services domain** represents the key data point for collection and analysis. This domain must capture all healthcare, including GP care, ED transfers, hospital stays, use of PBS and MBS, number of hospital episodes, and re-admissions and potentially preventable admissions. The rollout of My Health Record in RACFs should help facilitate data collection, along with interoperability with GP and other clinical software.

One area where this will be crucial is palliative care. At the moment, aged care data do not adequately capture palliative care data. This is a key area where aged care and healthcare intersect, yet the data are insufficient, as the Aged Care Funding Instrument (ACFI) is the only source of data used for this purpose. There is minimal incentive for aged care providers to record palliative care needs against ACFI, as the residents receiving palliative care are commonly already on the highest level of ACFI funding. The AMA hopes that the new AN-ACC funding model will bring improvements in this regard, along with the roll-out of My Health Record in residential aged care.

Data domain: Workers, services and providers in aged care (service or provider level)

Capturing the data on **workforce demographics** in a meaningful way is of crucial importance to the AMA. This will enable proper analysis and assessment of quality of aged care services based on the availability and training/education of its staff. It will also contribute to better implementation and monitoring of targeted policies, such as staff to resident ratios in aged care.

Currently the main way of obtaining information on the aged care workforce is through the workforce census. However, aged care providers are not obligated to participate and previously their response rates have been below 50 per cent. In addition, the census only captures the total number of staff employed by providers, without providing further detail on any staff that may work across multiple RACFs for a single aged care provider or across multiple providers.

Aged care staff working across multiple providers was a major issue during COVID-19 outbreaks in aged care facilities in 2020 and 2021-22, causing the Commonwealth to issue strict orders and

¹³ <https://documents.parliament.qld.gov.au/com/HEC-B5E1/INDISQ-3CD2/Transcript%20-%2010%20February%202022%20-%20HEC%20-%20Hearing-%20Inquiry%20into%20the%20provision%20of%20primary,%20allied%20and%20private%20health%20care,%20aged%20care%20and%20NDIS%20care%20services%20-%20Southport.pdf>

¹⁴ <https://agedcare.royalcommission.gov.au/sites/default/files/2021-02/research-paper-18-hospitalisations-australian-aged-care.pdf>

provide funding to prevent the staff being sent to multiple facilities. Yet to this day we do not know how many of the roughly 280,000 aged care workers work across multiple sites.¹⁵

The AMA also argues that **resource allocation, cost effectiveness and financial performance** must be reported by aged care providers, and that these data must be collected. In our submission to the Royal Commission, the AMA warned that there was no visibility of quality performance on an individual provider level, nor how the data collected are used by individual providers to improve or maintain their levels of performance.

It could be argued that the lack of data and data collection combined with minimal expenditure reporting requirements for funding they receive from the Government allows aged care providers are able to get away with allotting \$6 per day for meals per resident. The AMA is aware that requiring the providers to report on the expenditures, including on meals, will require legislative amendments and that previous attempts to legislate this have failed several times. However, we are hopeful that the recommendations of the Royal Commission and their implementation will lead to improvements in this regard. Once the data are reported and made available, it will be easier for consumers of aged care services to assess the quality of aged care providers and their service provision and make better choices about their care.

Conclusion

There is serious need for improvement in data collection and analysis in most of the data domains outlined in the Consultation Paper.

Primarily, the AMA sees a pressing need to improve data collection on the intersections between aged care and the broader healthcare system, as explained above. Improvements in data collection will require legislative changes to harmonise the legislation between the Federal and State/Territory levels, as well as potentially significant investment. However, the AMA argues that this type of investment will be justified on the long run, as the benefits from improved data collection will lead to improvements in government policies and health outcomes.

21 MARCH 2022

Contact

Aleksandra Zivkovic
Senior Policy Advisor
Policy Department
Ph: (02) 6270 5456
azivkovic@ama.com.au

¹⁵ <https://www.health.gov.au/sites/default/files/documents/2021/10/2020-aged-care-workforce-census.pdf>