Data and research for high quality aged care

Richard Cumpston

This is a submission to the ACT division of the Australian Association of Gerontology. The author is an actuary, and a director of Australian Projections Pty Ltd. Submissions he has helped make on aged care are available on www.australianprojections.com.au. He can be contacted on richard.cumpston@gmail.com, or 0433 170 276.

Summary

The work of the Royal Commission into Aged Care Quality and Safety was limited by the lack of quantitative data on the quality of aged care. Aged care regulators have relied on subjective assessments of care providers, rather than on measurements of care outcomes.

The Commission heard evidence about the compounding impacts of poor care. For example, poor nutrition can lead to reduced muscle mass, reduction in the body's ability to repair skin and a compromised immune system, which increases the risk of infection and pressure injuries. Data and research on such impacts are needed.

The Commissioners recommended ongoing research into the use and evidence basis for quality indicators. Quality data on individuals is currently held by providers, and is not available for research. The government's proposed reporting of service performance by the end of 2022 may face legal challenges as a result of inadequate research.

The Commissioners recommended that the Australian Institute of Health and Welfare collect and manage aged care information, with the first publication due by 1 July 2025. The Institute already has this role, but has been restricted by the Department of Health's failure to supply assessment data.

The government accepted the recommendation by Commissioner Briggs that case monitoring and reporting systems move progressively to real-time and automated reporting within five years. This would allow immediate help to individuals and providers where needed.

Some aspects of health, such as temperature and motion, can be measured by many different devices. Research is needed into the cost, reliability and acceptability of alternative devices in aged care. Which combination of devices will give useful information at reasonable cost? What information will have to come from other sources, such as pharmaceutical prescriptions and pathology tests?

Members of the Australian Association of Gerontology should be able to help bridge the large gap between the present manual quality indicators and a real-time automated quality measurement system.

1. Introduction

1.1 Royal Commission into Aged Care Quality and Safety

The Royal Commission received its initial terms of reference on 6 December 2018, and submitted its final report on 26 February 2021 [1, p iii]. It received 10,534 submissions and heard 641 witnesses. Total expenditure was about $91.7m. The final report had 2,779 pages, and made 148 recommendations.

1.2 Absence of quantitative data on the quality of aged care

A major limitation on the work of the Royal Commission was the lack of quantitative data on the quality of aged care. Until recently, the government has chosen to rely on subjective assessments of care providers, rather than on objective measurements of care outcomes.

1.3 New technologies and modern data analysis techniques

The Royal Commission largely heard evidence from care recipients, care providers and care regulators. These were people familiar with the present system, but perhaps not aware of the possibilities offered by new technologies and modern data analysis techniques. These may allow better care, and fairer regulatory control

2. Glimpses from the Royal Commission's data

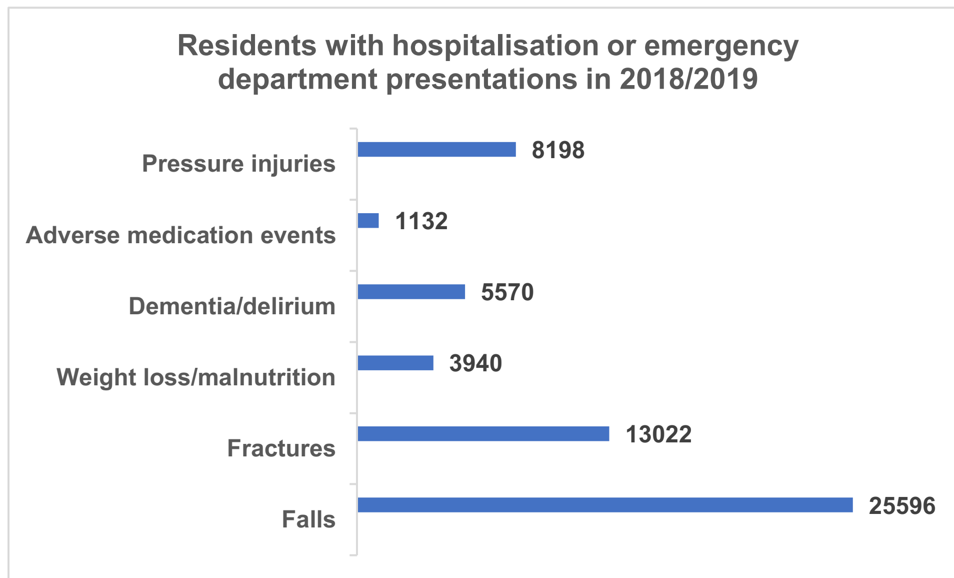
2.1 Compounding impacts of malnutrition

The Royal Commission noted that evidence at hearings and public submissions often highlighted the compounding impact of poor care [2, p94]. For example, poor nutrition can lead to reduced muscle mass, reduction in the body's ability to repair skin and a compromised immune system, which increases the risk of infection and pressure injuries. The Dietitians Association of Australia estimated that between 22% and 50% of older people in residential care are malnourished [2, p115].

2.2 Detrimental effects of poor continence care

"High quality continence care is critical because 71% of people in residential care have experienced urinary or faecal incontinence or both. Incontinence has negative effects on people's lives, including increasing the risk of depression and reduced quality of life. It can undermine a person's dignity and well-being as well as increase the likelihood of pressure injuries and infections. Poor continence care can lead to urinary tract infections, incontinence associated dermatitis, constipation and faecal impaction. Incontinence is also associated with an increased risk of falls…" [2, p124]

2.3 Selected causes of hospitalisation or emergency presentations



The above data are from Research Paper 18 of the Royal Commission, whose staff linked hospital records from 2014/15 to 2018/19 with data on aged care residents [3, p19-25]. I understand the above numbers are for persons reported as having that cause at least once in 2018/19, rather than the total numbers of admissions or presentations with that cause in the year.

2.4 Falls

It is disturbing that in 2018/19 25,596 permanent residents aged 65+ had a hospitalisation or emergency department presentation resulting from a fall. There were about 176,500 permanent residents aged 65+ on average in 2018/19, so this was a fall rate of about 15%. About 50 facilities had fall rates significantly higher than might have occurred by random chance.

2.5 Pressure injuries

There were 8,198 residents with hospital admissions or emergency presentations in 2018/19, as a result of pressure injuries. The number of residents reported with pressure injuries averaged 12,272 per quarter over the 6 quarters to 31 December 2020 [4].

2.6 Weight loss/malnutrition

There were 3,940 residents with hospital admissions or emergency presentations in 2018/19, as a result of weight loss or malnutrition. The number of residents reported with significant unplanned weight loss averaged 14,785 per quarter over the 6 quarters to 31 December 2020 [4].

2.7 Assaults

In 2019/20, 5,718 allegations of assault were made under the mandatory reporting requirements of the Aged Care Act, including 851 involving sexual assault [5, p63]. A study by KPMG estimated that a further 27,000 to 39,000 assaults occurred that were exempt from statutory reporting, as they involved assaults on residents by other residents [2, p94]. It is possible that some of the cases reported as falls to hospitals were in fact the result of assaults.

3. Quality indicators

3.1 National Mandatory Quality Indicator Program

The following indicators became mandatory from 1 July 2019

- Pressure injuries (stages 1 to 4, unstageable and suspected deep tissue injury)
- Physical restraint (all care recipients restrained, and those restrained only through the use of a secure area)
- Unplanned weight loss (significant loss in a quarter, and consecutive losses between months

The following indicators were added from 1 July 2021

- Falls (all, and with major injury)
- Polypharmacy (9 or more medications)
- Antipsychotics (all recipients, and those with a diagnosed condition of psychosis) [6].

3.2 Need for consent by care recipient

Care recipients are required to consent before they can be examined for pressure injuries, or have their weight measured. Providers have been required to report on the numbers of residents not consenting, and the percentages not consenting may be available from the Department of Health.

3.3 Suppression of individual information preventing research

Providers are required to keep records relating to information compiled for the purposes of section 26 of the Accountability Principles [6, p9], and provide quarterly summaries to the Secretary. Providers have to bear the expense of maintaining the data records and preparing summaries, but the Secretary only receives the summaries. It is not clear if the Secretary has access to the individual quality measurements, in order to audit the summary data. Importantly, the summary data will not allow crucial research about disease progressions and compounding impacts. The summary data will also not allow service quality indicators to be standardised for age and gender.

3.4 Potential legal challenges to public reporting on provider performance

In a presentation to an Australian Association of Gerontology forum on quality indicators in 2015, Richard Cumpston said

“Indicator data have to be reliable and appropriate, or the indicators will be rejected. A judicial order stopped publication of indicators for individual homes in Germany, as they were based on nursing documentation only, and the grading criteria were not transparent”.

In its response to the Commission’s recommendation 23, the government said that there would be public reporting through star ratings on services by the end of 2022 [7, p19]. Possible grounds for legal challenges to public reporting include

- Lack of an adequate audit system for quality indicator reports
- Failure to adjust indicators to allow for differences in care recipients
- Failure to allow for random variations, particularly for small services
- Inclusion of indicators such as falls which may reflect good care rather than bad.

3.5 Ability to release individual information under the Aged Care Act 1997

Under section 86.3, the Secretary may disclose protected information

“…if the Secretary certifies, in writing, that it is necessary in the public interest to do so in a particular case - to such people and for such purposes as the Secretary determines”

Under section 6(f) of the Information Principles 2014, the Secretary may disclose protected information to the Director of the Australian Institute of Health and Welfare, to perform its functions under the *Australian Institute of Health and Welfare Act 1987*.

Information on the health conditions of individual aged care residents, as assessed under the Aged Care Funding Instrument since March 2008, is being reported annually to the Institute. Subject to restrictions to protect the privacy of care recipients and providers, the Institute makes available these unit records for research purposes, and no problems with privacy breaches are known to have occurred.

The Department of Health’s aged care regulatory functions were transferred to the Aged Care Quality and Safety Commissioner from 1 January 2020. To carry out these functions effectively, the Commissioner will need health and quality indicator data on individuals.

4. Funds for aged care research

4.1 Aged Care Research and Innovation Fund

Recommendation 107 proposed the establishment of an Aged Care Research and Innovation Fund, with Australian government funding equal to 1.8% of Australian government expenditure on aged care [7, p68]. In 2019/20 this would have been about $360m. The 1.8% was chosen as reflecting the general level of research and development across the Australian economy, which varied between 2.25% in 08-09 and 1.79% in 17-18 [8, p573].

4.2 Present sources of funding for health and medical research

In its response, the government said that investment in aged care research should occur through existing well-established research bodies, in particular the National Health and Medical Research Council [7, p68].

Evidence to the Commission by Steven Wesselingh, chair of the Research Committee of the Council, was that

"In the last 10 years, in terms of aged care and quality of aged care, NHMRC has spent about $86 million. In contrast, in neurological disease we have spent about $1.8 billion." [8, p572]

4.3 Medical Research Future Fund: Dementia, Ageing and Aged Care Mission

The government's response referred to $200m of funding from this source, over the 10 years from 2018/19 to 2028/29. A recent presentation said the Fund's missions focus on an area of unmet need or a technology with transformational potential, and are planned and coordinated 10-year programs of work. In 2018/19 $10 million was awarded to the University of Queensland for development, research and clinical trials for a potential treatment of Alzheimer's disease using ultrasound [9]. The long timescale of the Fund makes it an unsuitable source of funding for research intended to urgently improve the quality of aged care.

4.4 Aged Care Centre for Growth and Translational Research

The government's response referred to its funding of the Aged Care Centre for Growth and Translational Research [7, p68]. On 1 May 2019 the Prime Minister announced an election commitment of $34 million to establish the Centre. It was scheduled to be established in early 2021, and to receive Australian government funding through to 30 June 2024 [10].

The Centre does not appear to be intended to help the government measure the quality of aged care. The chart on page 1 of the report by Flinders University and Wells Advisory shows the participants as consumers, providers, workforce, researchers and innovators, but not the government [11]. The 29-page report has 25 references to quality, but the report and its 311 pages of appendices have no references to quality indicators or quality measures.

It is unlikely that the present quality measurement problems will be resolved by June 2024, when government funding for the Centre is due to end. Nevertheless, the Centre should be a useful source of suggestions for the government about technologies and researchers.

4.5 Separate funding for research on quality measurements

It seems very desirable that research on quality measurements, and the capital costs of measurement devices, be funded separately from any existing or new grant process. The research is urgently needed, and going through a grants process would add delays and uncertainties. Some of the research will relate to measures to prevent provider fraud, and it may be undesirable for these to be publicly discussed while under development.

4.6 Research by the System Governor and the Quality Regulator

Part 4 of recommendation 108 notes that nothing is intended to prevent the System Governor or the Quality Regulator from collecting and analysing data in administering the aged care system, or commissioning research on the aged care system [7, p71].

Consumer experience reports were introduced in May 2017 by the Australian Aged Care Quality Agency, based on advice from the Australian Institute for Primary Care and Ageing. Initial responses were analysed by Wells and Solly [12]. This is an example of useful research by an aged care regulatory agency.

5. Data governance and a National Aged Care Data Asset

5.1 Statistical standards and data classifications relevant to aged care

Part 2 of recommendation 108 requires the Australian Institute of Health and Welfare, in consultation with the Australian Bureau of Statistics, to develop statistical standards and data classifications relevant to aged care services. To do this, they will need some idea of what aged care might look like in five or ten years. Real-time automated reporting could have profound implications for quality of care, quality measurements, provider payments and aged care research.

5.2 National Aged Care National Data Asset

Part 2 requires the Institute to curate and make publicly available a National Aged Care Data Asset. This sounds like the National Aged Care Data Clearing House, which the Institute has operated successfully since 1 July 2013, with the addition of workforce and financial performance data.

5.3 Development of software and communications technology systems

Part 7 requires the System Governor to facilitate development of software and communications technology systems to enable automatic reporting by providers on mandatory reporting obligations, quality indicators, prudential arrangement arrangements and data for the National Aged Care Data Asset [7, p70-72].

6. Real-time automated reporting within five years

6.1 Government investment in technology and communication systems

Recommendation 109 by Commissioner Briggs proposed that the Australian government invest in technology and information and communications systems to support the aged care system. These investments would include “case monitoring and reporting systems … that would move progressively to real-time and automated reporting within five years” [7, p73].

The government accepted this recommendation, and said

“The Government is examining Business-to-Government capability, which would allow seamless exchange of data and interoperability of information about aged care recipients between all stakeholders involved in aged care (aged care providers, aged care assessors and healthcare providers)…”

As Business-to-Government removes the need for manual entry of data and makes the data fully automated and available in real time, the data and information provided will therefore be complete, accurate and up to date…" [7, p73]

6.2 Prompt help to persons by providers

Cumpston, Sarjeant & Service, in a submission to the Royal Commission, proposed a data-based aged care system, similar in concept to the real-time automated system proposed by Commissioner Briggs. They suggested that such a system could rapidly detect individual health problems, and promptly advise providers:

"Help to persons could take many forms. A fall might require immediate attention. Changes to temperature and pulse rate might indicate an infection. Rises in odour levels would signal incontinence. An unexpectedly vacant room might prompt a search for a wandering resident. A lack of movement in bed might suggest over-medication or a cardiovascular event. Weight loss soon after admission might reflect an unsatisfactory mealtime environment, or unsuitable food." [13]

6.3 Prompt detection of system health threats

Cumpston, Sarjeant and Service commented

"Automated monitoring of all persons in residential care could provide strong early evidence of system health threats. For example, rising temperatures and mobility changes amongst residents in different locations could reflect a new antibiotic-resistant infection… Aged care residents may be like canaries in a coal mine, detecting threats."

6.4 Modern technology

In a submission to the Royal Commission, Cumpston and Bail said

"*Modern technology should make a wide range of quality measures feasible at low cost. For example, the HbA1c pathology test can be used to monitor diabetics. Regular weight measurements should be recorded to monitor undue weight changes. Specialists in different health fields should be invited to suggest quality measures which can be quickly implemented, at reasonable cost.*" [14]

6.5 Research on the least-cost set of technologies providing sufficient data

In a submission to the Department of Prime Minister and Cabinet, Richard Cumpston said

"Many aged care homes use call buttons to allow residents to request help, and record how long it takes to respond to calls. The movement detectors used in smart phones could detect falls and assaults, and perhaps also a lack of motion resulting from drugs or disease. Weight transponders in beds could report lack of motion as well as weight. Bedside monitors could report motion and pulse. Wall-mounted monitors could report individual temperatures and identities. Research is needed to find the least-cost set of technologies providing sufficient data, with the least possible discomfort for residents." [15]

6.6 Use of technology to help regulators

A recent information paper by the Productivity Commission said

“A basic principle of regulatory design is that regulations should achieve their goals at the lowest possible costs. They should … seek to target the problem they are trying to correct as closely as possible, be a proportionate response to the problem, and use processes that reduce compliance burdens. Advances in technology can help, and have long helped, to achieve these aims.” [16, p5]

Automated measurements of care quality could reduce the costs for providers of compiling manual quality indicators, and could also reduce the need for quality regulator staff to assess compliance with standards.

7. Help by members of the Australian Association of Gerontology

7.1 Many roles of Association members in aged care

The Association has members working in many different aspects of aged care, and in aged care research. For example, Kasia Bail led a project investigating real-time data entry at the Jindalee Aged Care Residence in the ACT [17]. Submissions to the Royal Commission were made by the Association, and by many of its members. In 2015 the ACT division ran a forum on quality indicators, attended by a number of Department of Health staff.

7.2 Helping introduce a real-time automated quality measurement system

Ways in which Association members could contribute to the overall effort to improve quality measurements include

- Requests for information from regulators and providers
- Literature searches on ways to measure aged care quality
- Estimates of the numbers of different types of health conditions caused by poor care
- Research into the capabilities and costs of sensors
- Estimates of the costs savings from the use of sensors
- Suggestions as to the most cost-effective combinations of sensors
- Proposals for randomised trials of equipment and data analysis methods
- Forums to exchange information and ideas.

In providing this help, Association members would not be speaking on behalf of the Association.

Acknowledgments

I am very grateful for the help given to me by members of the ACT committee of the Australian Association of Gerontology. The suggestions made here are my own.

References

[1] Royal Commission into Aged Care Quality and Safety. *Final report: Care, dignity and respect, volume 1, summary and recommendations*. Downloaded 2 March 2021 from https://agedcare.royalcommission.gov.au/publications/final-report.

[2] Royal Commission into Aged Care Quality and Safety. *Final report: Care, dignity and respect, volume 2, the current system*. Downloaded 16 March 2021 from https://agedcare.royalcommission.gov.au/publications/final-report.

[3] Royal Commission into Aged Care Quality and Safety. *Hospitalisations in Australian aged care: 2014/18-2018/19.* Research Paper 18, February 2021. Downloaded 4 May 2021 from https://agedcare.royalcommission.gov.au/publications/research-paper-18-hospitalisations-australian-aged-care-201415-201819

[4] Australian Institute of Health and Welfare. *Residential aged care quality indicators - October to December 2020.* Downloaded 12 May 2021 from https://www.gen-agedcaredata.gov.au/Topics/Quality-in-aged-care/Residential-Aged-Care-Quality-Indicators%E2%80%93October-t

[5] Department of Health. *2019-20 Report on the operation of the Aged Care Act 1997*. Downloaded 4 May 2021 from https://www.health.gov.au/news/announcements/2019-20-report-on-the-operation-of-the-aged-care-act-1997

[6] Department of Health. *National aged care mandatory quality indicator program (QI program) - Manual 2.0 - Part A - Final draft.* Downloaded 14 May 2021 from https://www.health.gov.au/resources/publications/national-aged-care-mandatory-quality-indicator-program-manual

[7] Department of Health. *Australian government response to the final report of the Royal Commission into Aged Care Quality and Safety May 2021.* Downloaded 12 May 2021 from https://www.health.gov.au/resources/publications/australian-government-response-to-the-final-report-of-the-royal-commission-into-aged-care-quality-and-safety

[8] Royal Commission into Aged Care Quality and Safety. *Final report: Care, dignity and respect, volume 3B, the current system*. Downloaded 16 March 2021 from https://agedcare.royalcommission.gov.au/publications/final-report.

[9] Department of Health. *Medical Research Future Fund: Dementia, Ageing and Aged Mission - national consultation on the roadmap and implementation plan.* Downloaded 25 May 2021 from https://www.aag.asn.au/documents/item/4147

[10] Austender. *Closed ATM View – Health/19-21/E20-10.* Downloaded 24 May 2021 from https://www.tenders.gov.au/Atm/ShowClosed/81e731d2-c6f9-44de-a436-a66a222dc05a?PreviewMode=False

[11] Flinders University & Wells Advisory. *Developing an operational model for the Aged Care Centre for Growth and Translational Research - final report, 16 March 2021.* Downloaded 25 May 2021 from https://www.tenders.gov.au/Atm/ViewDocuments/81e731d2-c6f9-44de-a436-a66a222dc05a

[12] Wells Y, Solly E. *Analysis of consumer experience report data: Final report to the Australian Aged Care Quality Agency, December 2018.* Australian Institute for Primary Care

and Ageing. Downloaded 14 June 2019 from
https://www.agedcarequality.gov.au/consumers/consumer-experience-reports-residential-aged-care-services#analysis%20of%20consumer%20experience%20report%20cer%20data

[13] Cumpston R, Sarjeant H & Service D, April 2020. *A data-based aged care system*. Available 21 May 2021 from
https://www.australianprojections.com.au/publications/a-data-based-aged-care-system.

[14] Cumpston R & Bail K, February 2019. *Data on residential aged care quality*. Available 21 May 2021 from https://www.australianprojections.com.au/publications/data-on-residential-aged-care-quality.

[15] Cumpston R, 21 May 2021. *Outcomes-focussed regulation of aged care.* Submission to the Department of Prime Minister and Cabinet consultation on the draft Regulator Performance Guide. Available 15 June 2021 from
https://www.australianprojections.com.au/publications

[16] Productivity Commission October 2020. *Regulatory technology.* Information paper downloaded 16 February 2021 from https://www.pc.gov.au/research/completed/regulatory-technology

[17] Bail K, Merrick E, Gibson D et al. *Evaluation of ACE in residential aged care = the impact of a digital point-of-care system on residents and staff*. Downloaded 1 June 2021 from https://www.canberra.edu.au/about-uc/faculties/health/research/ageing/Evaluation-of-ACE-in-Aged-Care_Cover_2F52.pdf