

Position Paper

Research and Aged Care

Introduction

The Royal Commission into Aged Care Quality and Safety has provided a landmark Report¹ that deserves detailed reading, reflection and response immediately and into the future. The National Ageing Research Institute (NARI) welcomes the recommendations of the Commission².

As Australia's longest standing and only independent medical research institute specifically focused on ageing, NARI has decades of experience in aged care research, advocacy and education. The goal of this paper is to share NARI's position the Royal Commission's recommendations relating to research and aged care, including recommendations 107 and 108.

We aim to stimulate further discussion and reflection, and to provide guidance on the way forward for Australian aged care research. The Commissioners based their recommendations on a comprehensive research base that included review of secondary data, submissions, interviews, and commissioned primary research, to which NARI actively contributed¹.

Summary of key points

Based on our research and experience in the aged care sector, NARI supports the following:

- Evidence-based aged care policy and practice.
- Funding for research about ageing and aged care that is cutting-edge, responsive to the needs of older people, their diversity, and the complexity of the aged care sector.
- A priority-setting body that gives equal voice to consumers and carers as well as researchers and providers.
- A national minimum dataset that facilitates the collection of data identified.
- A publicly available database for data collected for the Royal Commission to allow further analysis and investigation.
- Regular representative surveys of consumers of aged care conducted by an independent body.
- Timely data that enables real-time monitoring of policy and practice changes.
- Research, evaluation and education in the aged care sector should receive as much priority, funding, and prestige as in teaching hospitals in the acute sector.

¹ <https://agedcare.royalcommission.gov.au/publications/final-report>

² <https://www.nari.net.au/nari-responds-to-the-royal-commission-final-report>; <https://www.theage.com.au/national/victoria/to-rebuild-trust-aged-care-system-need-serious-overhaul-20210302-p5777a.html>

Royal Commission

Recommendation 107: Aged Care Research and Innovation Fund

Government Response

The Government **accepts-in-principle** this recommendation. Investment in aged care research should occur through existing well-established research bodies, in particular, the National Health and Medical Research Council, rather than establishing an Aged Care Research and Innovation Council.

The Medical Research Future Fund - Dementia, Ageing and Aged Care Mission will fund \$200 million over 10 years from 2018-19 to 2028-29.

The Government is also funding the Aged Care Centre for Growth and Translational Research to support investment in new approaches to training and teaching programs and support collaboration with educational institutions and research entities.

The Government considers the level of research funding recommended by the Royal Commission, equal to 1.8 per cent of total Australian Government expenditure on aged care each year, is not sustainable.

NARI Response

NARI believes funding for ageing and aged care is imperative. The findings of the Royal Commission into Aged Care Quality and Safety provide a critical opportunity to reimagine and reform aged care delivery in Australia. We emphasise that improvements to the Australian aged care system need to be evidence-based and supported by the kind of robust research NARI has been committed to for over forty years. There has never been greater need to underpin the care of older people, living at home or in residential aged care, with evidence, data and the needs and expectations of older people themselves and their families.

Although the Australian Government has invested in the Dementia and Aged Care Services Fund, the Boosting Dementia Research Initiative and the Medical Research Future Fund, the focus of this investment has been research on dementia, which is at risk of being confounded with research on ageing and aged care more broadly.

NARI welcomes funding for the Aged Care Centre for Growth and Translational Research Centre as a means of enabling access to expertise, translated research and support services, and to build workforce capability, and develop innovative solutions for delivery of aged care services. However, as the priorities of the Centre will be established by industry, there is also a need for research that privileges the voices and priorities of people using the system to ensure that it is fit for purpose, of high quality and meeting their care and wellbeing needs.

NARI calls for funding for research about ageing and aged care that is cutting-edge, responsive to the needs of older people, their diversity, and the complexity of the aged care sector. This means, there is a need for research designs that go beyond traditional paradigms such as randomized controlled trials.

It is also important research be guided by priorities identified through stakeholder engagement led by older people and their carers, and include industry, policy and researchers. We caution against the adoption of processes that privilege basic research on ageing over translational research and we call for greater investment in pragmatic real-world trials and studies that accommodate the complexity of older peoples' care needs and the environment.

Royal Commission

Government Response

NARI Response

Funding should not only focus on health-related, clinical or medical matters in aged care, but extend to research on issues such as:

- The use of technology in aged care
- The delivery of aged care, including system navigation
- Better governance of aged care providers
- The socioeconomics of ageing
- Workforce related research and technology, including translation from conception to market, to improve workforce productivity and quality of care.

NARI agrees with the Commissioners' recommendation that funding be strategically directed to identified problems and gaps to ensure that it delivers the greatest benefit for end-users. We call for independent priority setting by consumers, researchers and industry stakeholders.

NARI welcomes the Commissioners' recommendation for priority-driven co-design. Researchers at NARI have considerable expertise in co-design research that gives voice to older people, their families and the aged care workforce. Our research projects engage stakeholders not just in data collection but also design, execution, promotion, analysis, dissemination and driving future directions. We also co-produce knowledge translation resources to support the application of research to practice.

Stakeholder engagement should be a core part of the business of research. As a world-leader in the adoption of this human rights approach, NARI strongly supports the need for a priority setting body that includes an equal voice for consumers, carers, researchers and providers.

Royal Commission

Recommendation 108: Data governance and a National Aged Care Data Asset

Government Response

The Government **accepts** this recommendation and is responding through the measure **Residential Aged Care Quality and Safety - Empowering consumers of aged care with information to exercise choice**, noting implementation will require consultation with stakeholders.

The Government agrees with the intention of this recommendation as a positive and valuable extension of various public-facing data activities already underway.

The Government notes that the objectives of this recommendation may be best achieved through the new Aged Care Act, to commence from July 2023, rather than amending the existing *Australian Institute of Health and Welfare Act 1987*.

NARI Response

NARI supports recommendation 108: Data governance and a National Aged Care Data Asset and notes the Government's response.

NARI's work on quality indicators has shown minimum data sets can provide informative views of the progress of health care. The public are interested in mechanisms that enable them to judge the quality of care in aged care. NARI encourages the government to deposit data collected for the Royal Commission into a publicly available database to allow further analysis and investigation, so the rich information mined is not lost and is able to continue to draw attention to priorities identified by stakeholders.

NARI also sees a role for qualitative research in national data systems. It would allow older people and aged care staff to continue to tell their stories, open up the system to more transparency and reduce the stigma associated with aged care and ageing.

NARI supports the recommendation for a national minimum dataset that facilitates the collection of data identified. We particularly call for data collection on the prevalence, incidence, remission and management of potentially preventable conditions such as delirium, incontinence, malnutrition, pain, medication errors, dental decay, wounds and falls, as well as common mental health conditions such as depression, anxiety and loneliness. Data about deaths in residential aged care homes is also required, and there needs to be a transparent approach to determining the data needs of consumers and other stakeholders.

The Commissioners' recommendations for greater transparency of data concerning quality of care in residential and home care services are important. NARI views access to this information as a public right. We support regular representative surveys of consumers of aged care conducted by an independent body. Data should not only be available but timely, enabling real-time monitoring of policy and practice changes than is currently the case.

NARI also calls for data collection and methods informed by an understanding of the complexities associated with a 'good outcome' for people with a poor prognosis and chronic intractable conditions, such as dementia, and that accommodates the role of advocates.

Royal Commission

Government Response

NARI Response

NARI supports the development of software and Information and Communications Technology systems to enable automatic reporting by approved providers on mandatory reporting obligations, quality indicators, prudential arrangements, data for the Aged Care National Data Asset and other responsibilities. This is because current programs are developed to be commercial in-confidence products, with no requirement to be evidence-based or linked to other programs, or to enable data to be shared or standardised.

Gaps in research and development as highlighted by the Report

A chapter of the Report was devoted to research and development. The Commissioners noted the need for quality improvement research, and for aged care to be better informed by the best evidence from research. The quality improvement cycle of questions arising from practice, seeking evidence for ways to answer questions, and then applying the findings to practice, was noted as an ideal that is not often achieved in the current system. While many aged care providers have recognized the importance of research, few have dedicated the resources to supporting their staff in research and development. A small number of aged care providers have established research partnerships with local universities but in many cases the partnerships were underfunded and short lived. In a sector where funding for clinical services is considered in short supply, research and development is often deemed a low priority and not part of core business.

Role for research, evaluation and education in the aged care sector

The roles of research, evaluation and education in the aged care sector should receive as much priority, funding, and prestige as they do in acute sector teaching hospitals. The concept of the teaching nursing home model³ was first mooted in the USA in the 1980's, and has been discussed in Australia for many years without strong direction or implementation. Some aged care providers have adopted this model in association with universities, but its promotion to an established structure in the aged care system may not be practical without substantial and sustained government investment.

With most of the aged care workforce holding TAFE or VET qualifications, and the increasing separation of research and teaching roles in universities, Australia needs a bespoke model of engaging aged care providers in both responsive staff training and responsive research, and a way to link the two. NARI encourages the government and providers to consider research and teaching as core business for aged care. Without research-trained staff embedded in aged care settings, mentoring and modeling the translation of research into practice, the sector may continue to view research and teaching as separate from its core business.

NARI is well placed to advise on the best approach and models for embedding research and teaching into aged care, since it was set up in the 1970's to provide a practical link between research and practice in aged care. More recently, NARI has established research networks on ageing for the acute and aged care sectors (MARC)⁴. NARI looks forward to advising on development of the aged care workforce through increasing qualifications and training in aged care, but also by embedding research-trained staff in the aged care workforce to facilitate partnerships with universities and research institutes.

3 Barnett K (2014) Exploring the Teaching Nursing Home Model: Literature Review to Inform the National Evaluation of the TRACS Program, Adelaide: Australian Workplace Innovation and Social Research Centre, The University of Adelaide

4 <https://www.nari.net.au/marc>