

ROYAL COMMISSION INTO AGED CARE QUALITY AND SAFETY

Submission in response to counsel assisting's final submissions

November 2020

ABOUT RESEARCH AUSTRALIA

We are the national peak body representing the whole of the health and medical research pipeline.

Our vision: Research Australia envisions a world where Australia unlocks the full potential of its world-leading health and medical research sector to deliver the best possible healthcare and global leadership in health innovation.

Our mission: To use our unique convening power to position health and medical research as a significant driver of a healthy population and contributor to a healthy economy.

Our goals:

Engage	Connect	Influence
Australia in a conversation about the health benefits and economic value of its investment in health and medical research.	researchers, funders and consumers to increase investment in health and medical research from all sources.	government policies that support effective health and medical research and its routine translation into evidence-based practices and better health outcomes.

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Summary of recommendations

Recommendation 55	Research Australia supports the recommendation for dedicated Australian Government funding of research and development into aged care and ageing related health conditions.
	The proposed Aged Care Research Council should commit to transparent application processes and require publication of all research that is funded.
	A special appropriation for the funding of research and development, linked to aged care expenditure, is supported.
	Research and development should be defined to include innovation, and should for example, support the development and evaluation of assistive technologies to be implemented under the new Assistive Technology and Home Modifications category proposed at Recommendation 16. It could also support the ongoing research into the use and evidence base for quality indicators proposed at Recommendation 30.
	<p>It is important to explicitly recognise that the implementation and scaling of research initiatives (the ‘development’ in research and development) is an equally critical endeavor to undertaking research. It is important to focus attention and funding on the activities that are required to enable research outputs to be translated into outcomes that can lead to impact, and appropriately resource these activities.</p> <p>Accountability for implementation of research outcomes also needs to be clearly assigned.</p>
Recommendation 56	Research Australia supports Recommendation 56, including the separate roles envisaged for the Aged Care Commission and the Australian Institute of Health and Welfare.
	<p>Research Australia supports the recommendation that an aged care national minimum dataset be developed, and further consultation with researchers in aged care and ageing on the contents of the dataset.</p> <p>It is important that this data is collected in ‘near real time’ and is curated and made available as rapidly as possible. This is essential to the capacity to evaluate the effectiveness of programs and policies, and to monitor performance outcomes.</p>

	<p>Research Australia urges the Commissioners to recommend that researchers be provided with appropriate access to data for research purposes, and not be limited to access to the published data set. This should include access to data at the level of an organisation and individual.</p>
	<p>In addition to being funded to curate and publish an aged care national minimum dataset, Research Australia submits the AIHW should be funded to support the timely sharing of data with researchers, the linkage of datasets, and meeting researchers' requests for access to data beyond what is routinely published.</p>
<p>Response to remarks made in relation to Research and Data Governance</p>	<p>Research Australia submits that it is appropriate for the Aged Care Research Council to fund research into aged care as defined in the proposal at Recommendation 1.3.</p>
	<p>Research Australia submits that the Council should fund research that covers a continuum from the onset of ageing related health conditions and aims to mitigate the impact of these conditions on quality of life, which is essentially the focus of aged care as per the proposed definition.</p>
	<p>Research Australia submits the precise boundaries of research funding to be provided by the Aged Care Research Council should be developed in consultation with the other funding bodies, with complementary changes made to the areas the other bodies fund so as to avoid gaps, confusion and unnecessary duplication.</p>
	<p>Research Australia submits the capacity of the Aged Care Research Council to function virtually may depend on the extent to which it outsources some of these administrative activities to other agencies, and the nature of its relationship with, and reliance on, the proposed Aged Care Commission.</p>
	<p>Research Australia supports the proposal at Recommendation 56 which would see the Aged Care Commission assume responsibility for governance of the minimum data set and engage the Australian Institute for Health and Welfare to provide a range of functions in relation to the establishment and operation of the minimum data set.</p>

ROYAL COMMISSION INTO AGED CARE QUALITY AND SAFETY

SUBMISSION IN RESPONSE TO COUNSEL ASSISTING'S FINAL SUBMISSIONS

Introduction

Research Australia welcomes the opportunity to make a submission in response to counsel assisting's final submissions.

As the peak body for health and medical research, many of our members are engaged in research relating to ageing and the provision of aged care services.

We have followed the progress of the Royal Commission closely. Research Australia urged the inclusion of research in the Commission's original terms of reference and we have liaised with the Commission's officers to connect them with researchers who were able to assist the Inquiry.

We have been pleased to see the reliance the Commission has placed on research to understand the current system and its failures as well as to explore alternatives. It is clear that research can play a critical part in improving the delivery of aged care services and in helping Australians to age well, and we welcome the prominence the final recommendation to the Commissioners gives to research.

Research Australia's response to the final submissions, via the spreadsheet and this document is limited to Recommendations 55 and 56, and to the request for public response to remarks made by Commissioner Briggs in respect of Research and Data Governance.

Recommendation 55

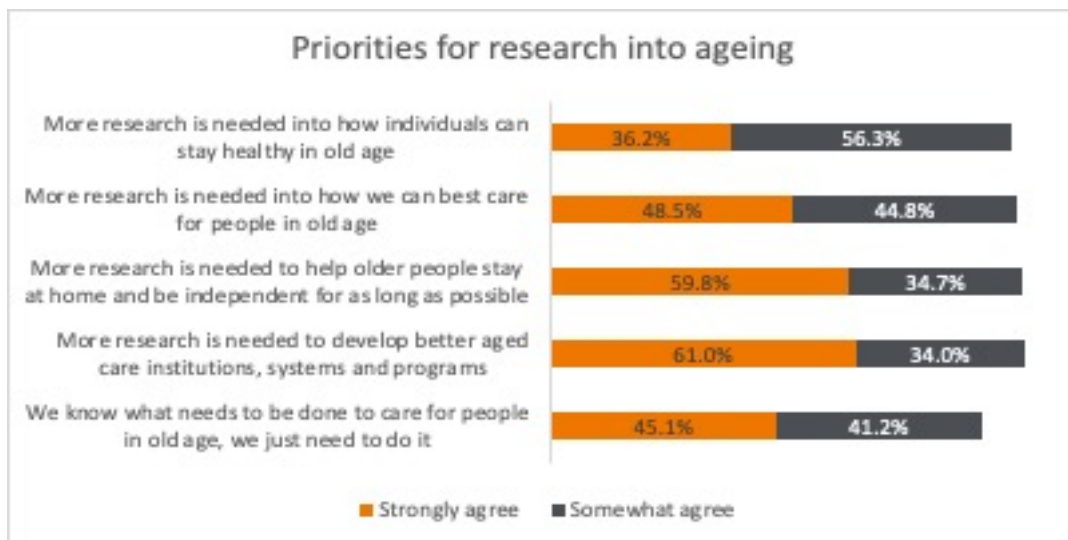
Research Australia supports the recommendation for dedicated Australian Government funding of research and development into aged care and ageing related health conditions.

Research Australia urged the inclusion of research in the Commission's original terms of reference and have liaised with the Commission's officers to connect them with researchers who were able to assist the Inquiry. We have been pleased to see the reliance the Commission has placed on research to understand the current system and its failures as well as to explore alternatives. It is clear that research can and must play a critical part in improving the design and delivery of aged care services and in helping Australians to age well.

Research Australia submits the proposed Aged Care Research Council should commit to transparent application processes and require publication of all research that is funded. The National Health and Medical Research Council has published an Open Data Access Policy for health and medical researchers which could guide the Aged Care Research Council's policies in this regard.¹

Research Australia undertakes annual public opinion polling. In our 2020 Opinion Poll we asked people about priorities in research relating to ageing and aged care. Most people believe more research is needed in a range of different areas related to ageing, including to develop better aged care systems and programs, and to help people stay healthy and independent for longer.

People are also of the view that 'we know what needs to be done to care for people in old age, we just need to do it.' Clearly we need to better at doing what we know works, as well as developing new and better ways to support and care for older Australians. The results are provided in the table below.²



¹ National Health and Medical Research Council, 2018 *Open Access Policy*, most recently amended April 2020

² Research Australia, Opinion Poll 2020, yet to be published.

Making a special appropriation for the funding of research and development, linked to aged care expenditure, is supported. Research Australia believes that this linkage helps emphasise that this research spending is related to the delivery of aged care services, and ageing related issues, and is to be focused on improving outcomes in these areas. **To this end, research and development for this purpose should be defined to include innovation, and should for example, support the development and evaluation of assistive technologies to be implemented under the new Assistive Technology and Home Modifications category proposed at Recommendation 16. It could also support the ongoing research into the use and evidence base for quality indicators proposed at Recommendation 30.**

The emphasis on co-design and creating networks is important. An active role for the Aged Care Research Council in supporting the translation of research into practice is also welcome; all too often, research fails to make this transition due to a lack of resources and leadership to support implementation.

Research Australia notes the recommendation calls for an agenda and strategy for ‘research and development’ but thereafter refers exclusively to ‘research’. **Research Australia submits it is important to explicitly recognise that the implementation and scaling of research initiatives (the ‘development’ in research and development) is an equally critical endeavor to undertaking research. It is important to focus attention and funding on the activities that are required to enable research outputs to be translated into outcomes that can lead to impact, and appropriately resource these activities. Accountability for implementation of research outcomes also needs to be clearly assigned.**

Research Australia is keen to understand more about the how the proposed Aged Care Research Council will be structured and how it will work with other funding bodies such as The National Health and Medical Research Council, the Australian Research Council and the Medical Research Future Fund.

Recommendation 56

Research Australia is pleased that the critical role of data to the future of aged care has been recognised and supports Recommendation 56, including the separate roles envisaged for the Aged Care Commission and the Australian Institute of Health and Welfare.

Research Australia notes the proposal the AIHW Act be amended. Consideration may need to be given to provisions in the legislation that currently prevent the AIHW publishing or providing data that identifies an organisation.

We support the recommendation that an aged care national minimum dataset be developed, and support further consultation with researchers in aged care and ageing on the contents of the dataset. It is important that this data is collected in ‘near real time’ and is curated and made available as rapidly as possible. This is essential to the capacity to evaluate the effectiveness of programs and policies, and to monitor performance outcomes.

Research Australia agrees with counsel’s submission that Data about aged care is vitally important to aged care research and innovation as it means that researchers have access to greater information than they otherwise would have were they to gather the data themselves.³

While publication of an annual dataset is essential, **we also urge the Commissioners to recommend that researchers be provided with appropriate access to data for research purposes, and not be limited to access to the published data set. This should include access to data at the level of an organisation and individual.** The recent exposure draft of the Data Availability and Transparency Bill provides an appropriate framework for the sharing of this data by Commonwealth agencies with researchers and a mechanism for participation by state and territory government agencies.

In addition to being funded to curate and publish an aged care national minimum dataset, **Research Australia submits the AIHW should be funded to support the timely sharing of data with researchers, the linkage of datasets, and meeting researchers’ requests for access to data beyond what is routinely published.**

³ Paragraph 889

Request for public response to remarks made by Commissioner Briggs in respect of Research and Data Governance.

We note the question posed by Commissioner Briggs on 22 October about ‘whether or not the dedicated research council should cover both aged care and ageing-related healthcare or be more tightly targeted on aged care only, avoiding health research yet again swamping aged care research.’⁴

Research Australia notes Recommendation 1.3 that ‘aged care’ be defined as

i. support and care for people to maintain their independence as they age, including support and care to ameliorate age-related deterioration in their social, mental and physical capacities to function independently.

ii. supports including respite for informal carers of people who need aged care

Research Australia submits that it is appropriate for the Aged Care Research Council to fund research into aged care as defined above.

Research Australia understands the Commissioner’s desire to ensure that priority is given to aged care research. We recognise that diseases related to ageing are currently part of the remit of the funding programs of The National Health and Medical Research Council and the Medical Research Future Fund. Nonetheless we do not think it would be wise to limit the proposed Ageing Research Council to funding only aged care research as defined in the proposal at Recommendation 1.3.

Research Australia submits that the Council should fund research that covers a continuum from the onset of ageing related health conditions and aims to mitigate the impact of these conditions on quality of life, which is essentially the focus of aged care as per the proposed definition. There is a role for the Aged Care Research Council to fund research relating to ageing in this broader context, but with a focus on how people can:

- prevent some of the consequences of ageing that lead to the need for increased levels of care (including promoting self care);
- how people adapt and respond to ageing; and
- how the community can better support older people to have a higher quality of life.

Research Australia submits the precise boundaries of research funding to be provided by the Aged Care Research Council should be developed in consultation with the other funding bodies, with complementary changes made to the areas the other bodies fund so as to avoid gaps, confusion and unnecessary duplication. In part, the extent of the research envelope

⁴ Transcript, 22 October 2020, T9756.419757.18

should be determined by the amount of funding ultimately available relative to the other funding programs. The Aged Care Commission is required to set an agenda and strategy for research, which gives it the ability to ensure appropriate priority is given to aged care research relative to research in ageing related health conditions.

The Commissioner has also asked for views on whether the Council could operate virtually. Research Australia has no fixed view on this matter but notes that Recommendation 55 establishes a broad range of functions for the Council including administration of a funding program and coordinating peer review. **Research Australia submits the capacity of the Aged Care Research Council to function virtually may depend on the extent to which it outsources some of these administrative activities to other agencies, and the nature of its relationship with, and reliance on, the proposed Aged Care Commission.**

Commissioner Briggs has sought comment on the proposed governance model for the minimum data set. **Research Australia supports the proposal at Recommendation 56 which would see the Aged Care Commission assume responsibility for governance of the minimum data set and engage the Australian Institute for Health and Welfare to provide a range of functions in relation to the establishment and operation of the minimum data set.** Research Australia believes the Commission's Inquiry has demonstrated the enormous value and importance of data to the provision of safe, high quality care. For this reason, overall responsibility for the data collected and how it is used should rest with the Aged Care Commission, which is proposed to be responsible for quality and safety regulation and system governance.

Conclusion

Research Australia is pleased to have had this opportunity to respond to counsel assisting's final submissions.

As noted in the introduction, it is clear that research can play a critical part in improving the delivery of aged care services and in helping Australians to age well, and we welcome the prominence the final recommendation to the Commissioners gives to research.

Research Australia would like to thank the Commissioners for their service to Australia in undertaking this Inquiry, and is pleased to provide further assistance or information the Commissioners might require.

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