

The Wicking Dementia Research Network
Wicking Dementia Research and Education Centre

Inquiry into Caring for Older Australians
Productivity Commission
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Dear Commissioners,

Response to Commission Draft Report - Caring for Older Australians

We welcome the opportunity to respond to the Productivity Commission's Draft Report - Caring for Older Australians. The Wicking Dementia Research Network is a collaboration of key Tasmanian stakeholders interested in research into dementia, in particular care and services for people with dementia. The network members are representatives of aged care sector organisations, including non-government, government and private industry groups.

This submission therefore represents the views of a diverse group of Tasmanian dementia researchers and health service providers. Our interest is in improving dementia outcomes and preparing health systems to cope with the rapid projected increase in numbers of people with dementia. Our members bring views from the whole health system, including acute care, community care and residential aged care. We take this opportunity to make recommendations focused on "whole of system" improvement.

Proposed Recommendation 13.2: Provide an intensive 10 year research funding quota focused on appropriate and sustainable aged care, which sits alongside health system change.

Rationale: In Section 13 the report clearly identifies three key issues for aged care policy research and evaluation: 1) the need to improve data collection and access, 2) the need to build a better evidence base for policies and reforms, and 3) the need to support research capacity in the aged care sector. We support

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the issues identified, but unfortunately, only the issue of data collection and access is addressed in the recommendations. We thereby propose that research funding needs to parallel reform.

In particular, we believe dementia care research needs particular focus in the next 10 years. There is a dearth of knowledge about the course of dementia and how best to care for people with dementia. Recent advances in knowledge, though, highlight the potential gains from early intervention and retraining for people with dementia and the terminal course of dementia (Mitchell et al., 2009). These advances provide a strong rationale for refocusing care in a manner that will provide strong quality of life benefits to people with dementia and their families, but that also promise health system cost savings. Some key examples include:

- The gains from improving community support for carers and people with dementia,
- The need to improve the appropriateness of many acute care interventions,
- The need for systems that promote a 'good death' for people with dementia.

Health system change needs good evidence of benefits from changing practice, and knowledge about how best to ensure sustainable changes, not just re-organisation. Good evidence and large scale trials help to prevent unexpected outcomes and perverse incentives. The current Australian model of small amounts of funding acquired through the research grant process, and small demonstration projects will result in only small and incremental change when projections suggest larger more systemic responses utilising collaborative, multidisciplinary and multi-organisational research are needed.

Following the recent recommendations from the November 10th 2010, NHMRC Scientific Symposium and workshop on "*Evidence into Primary Care – Research, research translation and improved outcomes for patients*", we suggest that dementia research should:

- Build research into the Medicare Locals model.
- Better access and utilisation of data available in the health system.

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- Highlight primary care as a consistent underlying focus.
- Highlight the importance of implementation research.
- Link to the infrastructure that will be generated by 'teaching in aged care facilities'.

However, further to these recommendations, we highly recommend elevating the importance of research into care and models of care, with the client journey as a central organising focus.

Proposed Recommendation 13.3: Develop a National Research Framework and Plan for Dementia

Rationale: This recommendation links to the issue of research capacity. The projected growth in the numbers of people affected with dementia, with a 50% increase in the next ten years (Access Economics 2010) and the anticipated increase in costs to the health system make it imperative that Australia urgently and seriously address health system adaptation for dementia. With a National Framework, Australia could focus research efforts into agreed priority areas and avoid piecemeal project solutions. A research framework would build on Priority 4 of the National Framework for Action on Dementia 2006-2010 (Australian Health Minister's Conference 2006). The expected outcomes from the framework were:

- Research is directed to the cause, cure and care of dementia.
- Research is translated into practice and is promoted and available to those who need it.
- Research findings are promoted more broadly in the community.

Key measures of success were linked to the percentage of national funds spent on dementia research, that research would underpin practice guidelines and service models, and that there would be evidence of research dissemination.

We suggest that while there has been some small incremental movement towards these outcomes, given the evident need, the funds and research for care models and translation into practice are clearly

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inadequate. A significant commitment is required for dementia research over the next decade to meet the approaching surge in demand.

References

- Access Economics. (2010). *Caring places: planning for aged care and dementia 2010-2050*. Canberra: Access Economics Pty Ltd.
- Australian Health Minister's Conference (2006). National Framework for Action on Dementia 2006-2010. Sydney : NSW Department of Health on behalf of AHMC.
- Mitchell, S. L., Teno, J. M., Kiely, D. K., Shaffer, M. L., Jones, R. N., Prigerson, H. G., et al. (2009). The clinical course of advanced dementia. *New England Journal of Medicine*, 361(16), 1529-1538.>>