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*Authoritative information and statistics
to promote better health and wellbeing*

Dr Alison Clegg
Committee Secretary
Inquiry into Dementia: Early Diagnosis and Intervention
Standing Committee on Health and Ageing
PO Box 6021
Parliament House
Canberra ACT 2600

Dear Dr Clegg

Thank you for the invitation to make a submission to the *Inquiry into dementia: early diagnosis and intervention*.

The AIHW is a major national agency set up by the Australian Government under the Australian Institute of Health and Welfare Act to provide reliable, regular and relevant information and statistics on Australia's health and welfare. We are an independent statutory authority established in 1987, governed by a Management Board, and accountable to the Australian Parliament through the Health and Ageing portfolio.

Our aim is to improve the health and wellbeing of Australians through better health and welfare information and statistics. We collect and report information on a wide range of topics and issues, ranging from health and welfare expenditure, hospitals, disease and injury, and mental health, to ageing, homelessness, disability and child protection.

The AIHW has a strong track record in reporting on issues relating to ageing and aged care. Our *Aged Care Statistics* series includes annual reports on residential aged care, aged care packages in the community and the Transition Care Program. Other major contributions to the understanding of the characteristics and circumstances of Australia's older population include four editions of *Older Australia at a glance*, published between 1997 and 2007.

Expertise in dementia data collection, analysis, research and reporting

Many people currently live with dementia for some time before receiving a formal diagnosis, resulting in likely underestimates of the incidence and prevalence of this condition in the Australian population. This, in turn, hampers robust policy development and evidence-based service planning.

The AIHW is able to draw together a wide range of data sources to improve the evidence base about dementia. We are a leader in the development of data standards to improve consistency and comparability of data collections, and already apply these skills to the complex area of dementia data.

The AIHW has a long history of dementia-related analysis, reporting and research. Several recent and current projects focussing on dementia and its impact clearly demonstrate the insights we can provide.

These include:

- A major report, *Dementia in Australia*, to be released in late 2012. This report, commissioned by the Department of Health and Ageing (DoHA), updates the 2007 edition and brings together information from a wide and disparate range of data sources to present evidence and estimates of the nature and extent of dementia in the Australian population. Importantly, the report will provide estimates of the incidence, prevalence (with projections to 2030), burden of disease and cost to the health system of the condition. It will also include a summary of the major data gaps and inconsistencies which currently impede our understanding of dementia in this country.
- The Hospital Dementia Services Project, which is an NHMRC-funded collaborative research project with the University of Canberra and University of New South Wales. This innovative project aims to inform health practitioners, health and aged care policy makers and planners, and consumers about the influence of system-level factors on care outcomes for patients with dementia. The linked dataset developed for this project offers unique opportunities for further examination of other policy-relevant topics.
- Analysis of nationally-linked administrative hospital and aged care data to describe pathways of care followed by older people, including those with a diagnosis of dementia. Several reports have been published on this topic including *Pathways in aged care: program use after assessment* and *Pathways in aged care: do people follow recommendations?*
- A project for Alzheimer's Australia which uses the linked data from the Hospital Dementia Services project to estimate costs of dementia services in hospitals, and outline strategies that may reduce these costs and promote quality dementia care. The findings of this project will be published in 2013.
- *Dementia among aged care residents: first information from the Aged Care Funding Instrument* examined the characteristics and care needs of over 100,000 residents with a diagnosis of dementia in 2008-09. Data are now available to update this information and extend the analysis to June 2011.
- Development in 2010 of nationally consistent data and reporting tools for the Dementia Behaviour Management Advisory Services (DBMAS), which help aged care staff and carers improve their care of people with dementia.

Accurate information and statistics about the prevalence and diagnosis of dementia and the effectiveness of interventions for people with dementia are required to provide a firm evidence base for policy development and service delivery.

We would be pleased to discuss our understandings drawn largely from our published work, at your request, and we have enclosed several relevant publications for your information.

Yours sincerely

Mr David Kalisch
Director
Australian Institute of Health and Welfare

2 May 2012