

## Conduct and context of the inquiry

- 1.1 Australia has an ageing population. Between 2010 and 2050 the number of older people (65 to 84 years) in Australia is expected to more than double, whilst the number of very old people (85 and over) is expected to more than quadruple.<sup>1</sup>
- 1.2 As Australia's aged population increases, so too will the number of individuals suffering from dementia. It is estimated there were 266,574 people with dementia in Australia in 2011.<sup>2</sup> Without new medications to treat dementia, this number is projected to increase to 553,285 people by 2030, and 942,624 people by 2050.<sup>3</sup>
- 1.3 Internationally, the number of people with dementia is also projected to increase at a similar rate to that of Australia. These projections have resulted in dementia now being recognised as a global public health priority. Concern over the impending escalation of numbers of people with the condition prompted the World Health Organization (WHO) to release a report in April 2012 urging nations to prepare for the increasing burden and cost of dementia. The report notes that:

There is little doubt that dementia poses one of the greatest societal challenges for the 21st century that must be addressed internationally, nationally and locally, as well as at family and personal levels. Dementia is exceptional in terms of size, cost and impact...worldwide, the large majority of people with dementia and their family caregivers do not benefit from the positive

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1 Australian Government, *Australia to 2050: future challenges, the 2010 intergenerational report overview*, 2010, p.4.

2 Deloitte Access Economics Pty Ltd, *Dementia across Australia: 2011-2050*, 9 September 2011, p.15.

3 Deloitte Access Economics Pty Ltd, *Dementia across Australia: 2011-2050*, 9 September 2011, p.15.

intervention and support that can promote independence and maintain quality of life.<sup>4</sup>

- 1.4 Despite this, dementia is underdiagnosed in most if not all health systems in the world, and when diagnosis does occur it is typically at a relatively late stage of the disease process.<sup>5</sup> In releasing the latest aged care reform package, the Commonwealth Government noted that:

Between 50 to 80 per cent of people with early stages of dementia are not being diagnosed in primary care. For those who are diagnosed, many do not receive a diagnosis until three years after they first notice symptoms.<sup>6</sup>

- 1.5 Although there is currently a lack of quantitative data, expert opinion is generally of the view that early diagnosis of dementia can be beneficial to patients, carers and society, and should therefore be promoted.<sup>7</sup> The most evident of these benefits is that early diagnosis provides people with the condition the opportunity to plan ahead while they still have the capacity to make important decisions about their future care. This can have important ramifications for continuing quality of life for not only the person with dementia, but also their carers and family.

## Referral and conduct of the inquiry

- 1.6 The inquiry into Dementia: early diagnosis and intervention (the inquiry) was referred to the House of Representatives Standing Committee on Health and Ageing (the Committee) on 20 March 2012. The inquiry was referred to the Committee by the Minister for Mental Health and Ageing, the Hon Mark Butler MP.
- 1.7 Immediately after referral, details of the inquiry were made available on the Parliament of Australia website and an advertisement was placed in *The Australian* calling for written submissions. The inquiry was also promoted through an extensive mail out to interested parties, including peak bodies and organisations, research institutions and the relevant government departments inviting submissions.
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4 World Health Organisation (WHO) and Alzheimer's Disease International (ADI), *Dementia: A Public Health Priority*, 2012, p.90.

5 Alzheimer's Disease International (ADI) 2011, *World Alzheimer's Report 2011: the benefits of early diagnosis and intervention*, September 2011, p.10.

6 Commonwealth of Australia, *Living Longer. Living Better.*, April 2012, p.22.

7 ADI 2011, *World Alzheimer's Report 2011: the benefits of early diagnosis and intervention*, September 2011, p. 30.

- 1.8 Over the course of the inquiry the Committee received 112 submissions from organisations, government authorities and individuals. A list of submissions is at Appendix A. A range of publications, documents and supplementary material tendered during the inquiry was received as exhibits. A list of exhibits is at Appendix B.
- 1.9 In addition, the Committee undertook an extensive program of public hearings. Between June 2012 and March 2013 the inquiry held 17 public hearings, including 12 interstate public hearings. Details of the public hearings, including a list of witnesses, are at Appendix C.

## Context of the inquiry

- 1.10 The implications for policy and services of Australia's ageing population are increasingly being recognised by all governments at all levels. This is evidenced by the highly dynamic policy environment which seeks to identify, quantify and address the needs of older Australians.
- 1.11 In this developing and changing policy environment, it is important to consider evidence submitted to the current inquiry in the context of other relevant but parallel processes.

## Relevant policy inquiries and reports

- 1.12 In 2005, the House of Representatives Standing Committee on Health and Ageing tabled a draft report developed by the previous 40<sup>th</sup> Parliament titled *Future Ageing*.<sup>8</sup> The inquiry focused on the long-term strategies to address the ageing of the Australian population over the next 40 years. The draft report noted the increasing prevalence of dementia and discussed the availability and quality of care for people with dementia. This inquiry did not consider early diagnosis and intervention into dementia, however members of that committee did note that:

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8 Parliament of Australia, House of Representatives Standing Committee on Health and Ageing, *Report on a draft report of the 40th Parliament: Inquiry into long-term strategies to address the ageing of the Australian population over the next 40 years*, March 2005.

The diagnosis of dementia is not straightforward and the Committee heard that many GPs are not well informed about its diagnosis and treatment.<sup>9</sup>

- 1.13 The Senate Community Affairs References Committee also released a report in 2005, titled *Quality and equity in aged care*.<sup>10</sup> The terms of reference for the inquiry directed the Committee to investigate the adequacy of aged care arrangements in Australia. This Senate Committee's final report contained extensive discussion regarding the provision of aged care to people with dementia, though did not delve into any matters relating to early diagnosis of the condition.
- 1.14 In July 2011 the Senate Community Affairs References Committee tabled a report titled *Disability and Ageing: lifelong planning for a better future*.<sup>11</sup> This inquiry examined the planning options and services available to assist people with a disability, and their carers, to plan for the future. Throughout the inquiry, Senate Committee members received evidence detailing the difficulties individuals and carers face in advance planning. Building on some of the evidence received by this Senate inquiry, the current inquiry examines the relationship between early diagnosis of dementia and improved planning for the future.
- 1.15 Within the 2011 Senate inquiry the Committee also considered the situation of the small minority of people who experience disability coupled with younger-onset dementia. Evidence received raised scenarios in which individuals with early-onset dementia were turned away from aged care services because they were too young. Processes to effectively diagnose, and intervene into, the condition of early-onset dementia is considered further within the current report.
- 1.16 The Productivity Commission has also published reports relating to aged care. In September 2008 it released *Trends in Aged Care Services: some implications*<sup>12</sup> which examined a range of issues including:

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9 Parliament of Australia, House of Representatives Standing Committee on Health and Ageing, *Report on a draft report of the 40th Parliament: Inquiry into long-term strategies to address the ageing of the Australian population over the next 40 years*, March 2005, p.136.

10 Parliament of Australia, Senate Community Affairs References Committee, *Quality and equity in aged care*, June 2005.

11 Parliament of Australia, Senate Community Affairs References Committee, *Disability and Ageing: lifelong planning for a better future*, July 2011.

12 Australian Government Productivity Commission, *Trends in Aged Care Services: some implications*, Research Paper, 25 September 2008.

- Trends in the demand for, and supply of, aged care services and implications in terms of emerging challenges for services to become more flexible, responsive and efficient;
  - Capacity of the aged care workforce to accommodate demands for services in the long term; and
  - The scope for productivity improvements in the aged care sector to contain future costs while improving service quality.<sup>13</sup>
- 1.17 In June 2011 the Productivity Commission released a further report titled *Caring for older Australians*.<sup>14</sup> The report arose from a broad ranging inquiry in which the Productivity Commission was asked to 'develop detailed options to redesign and reform Australia's aged care system and to recommend a transition path to a new system.'<sup>15</sup>
- 1.18 The report identified several key weaknesses with the current system of aged care noting:
- It is difficult to navigate. Services are limited, as is consumer choice. Quality is variable. Coverage of needs, pricing, subsidies and user co-contributions are inconsistent or inequitable. Workforce shortages are exacerbated by low wages and some workers have insufficient skills.<sup>16</sup>
- 1.19 The Commission made a number of proposals to address these weaknesses including:
- simplified 'gateway' for consumers to be assessed for services and to access services;
  - consumer directed care with more consumer choice and greater flexibility for service delivery;
  - simplify and regulate funding options; and
  - more support for informal (family) carers and improved career paths and more opportunities for formal carers to make the paid workforce more attractive.<sup>17</sup>

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13 Australian Government Productivity Commission (Productivity Commission), *Trends in Aged Care Services: some implications*, Research Paper, 25 September 2008, pp. xv.

14 Productivity Commission, *Caring for older Australians*, Inquiry Report no. 53, 2011.

15 Productivity Commission, *Caring for older Australians*, Inquiry Report no. 53, 2011, p. xxiii.

16 Productivity Commission, *Caring for older Australians*, Inquiry Report no. 53, 2011, p. xxii.

17 Productivity Commission, *Caring for older Australians*, Inquiry Report no. 53, 2011, p. lxxix.

1.20 The Australian Government's May 2012 response to the Productivity Commission report states:

The Productivity Commission found that Australia's aged care system has many weaknesses and is not well placed to meet the future challenges associated with an ageing population. In particular, the Commission argued the aged care system is difficult to navigate; provides limited services and consumer choice; supplies services of variable quality; suffers from workforce shortages that are exacerbated by low wages and some workers having insufficient skills; and is characterised by marked inequities and inconsistencies in the availability of services, pricing arrangements and user co-contributions.<sup>18</sup>

1.21 The Government response notes that the outcomes of the Productivity Commission's report have 'substantially informed development of the Government's *Living Longer, Living Better* aged care reform package.'<sup>19</sup> The Government response advises however:

The Department of Health and Ageing estimates that fully implementing the Commission's proposals would involve a significant cost to the Budget. In the current fiscal environment, these costs could not be absorbed in the Budget without significant reductions in other government policy areas and programs.

The Government's aged care reform package, *Living Longer Living Better*, seeks to address the problems identified by the Commission but gives greater weight to the potential difficulties the sector would face in absorbing and responding to significant structural change in the short to medium term.<sup>20</sup>

1.22 The *Living Longer, Living Better* - aged care reform package is discussed in more detail later in this chapter.

1.23 In February 2013 the Senate Community Affairs References Committee initiated an inquiry into *Care and management of younger and older Australians living with dementia and behavioural and psychiatric symptoms of dementia (BPSD)*. The inquiry is examining the scope, adequacy and

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18 Australian Government, , *Australian Government's Response to the Productivity Commission's Caring for older Australians Report*, May 2012, p. 1.

19 Australian Government, *Living Longer, Living Better*. April 2012.

20 Australian Government, *Australian Government's Response Productivity Commission's Caring for older Australians Report*, May 2012, p. 1.

resourcing of various models of care for people living with dementia and BPSD. The Senate Committee is due to report on 26 June 2013.<sup>21</sup>

## Australian Government policy frameworks

1.24 Over the years successive governments have implemented a range of policy initiatives to tackle dementia and meet increasing and changing demands for dementia support and services. The following section reviews significant policy initiatives introduced during the last decade.

### Dementia as a health priority

1.25 In the 2005-2006 Budget, the then Government acknowledged the significance of dementia by announcing \$320.6 million would be provided over five years to support people with dementia and their carers through the *Helping Australians with Dementia and their Carers – Making Dementia a National Health Priority* initiative (the Dementia Initiative).<sup>22</sup> According to a DoHA Budget 2005-2006 Factsheet:

Identifying dementia as an Australian Government National Health Priority provides focus for collaboration between the Australian Government, State and Territory Governments and other organisations to improve the quality of life and care for people living with dementia.<sup>23</sup>

1.26 The package provided funding for the following measures:

- Dementia – a national health priority supporting:
  - ⇒ additional research;
  - ⇒ improved care initiatives;
  - ⇒ early intervention programs to care for people with dementia;

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21 Parliament of Australia, *Senate Committees: Care and management of younger and older Australians living with dementia and behavioural and psychiatric symptoms of dementia (BPSD)*, <[http://www.aph.gov.au/Parliamentary\\_Business/Committees/Senate/Committees?url=clac\\_ctte/dementia/info.htm](http://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Committees?url=clac_ctte/dementia/info.htm)> viewed 14 March 2013.

22 Australian Government Department of Health and Ageing (DoHA), *Ageing Budget*, <<http://www.health.gov.au/internet/budget/publishing.nsf/Content/health-budget2005-abudget-afact1.htm>> viewed 3 June 2013.

23 DoHA, *Ageing Budget*, <<http://www.health.gov.au/internet/budget/publishing.nsf/Content/health-budget2005-abudget-afact1.htm>> viewed 3 June 2013.

- Extended Aged Care at Home Dementia (EACHD) packages designed to assist people with dementia to remain at home and in their community; and
  - Training to Care for People with Dementia initiative to provide dementia training for residential aged care workers and people in the community who come into contact with people with dementia, such as police, emergency services and transport staff.<sup>24</sup>
- 1.27 In 2009 DoHA commissioned an independent evaluation of the Dementia Initiative. The evaluation found that the Dementia Initiative had made ‘a substantial contribution to supporting people living with dementia and their carers’, but that ‘the lack of integration across Projects and Measures remained the most significant outstanding issue for the Initiative limiting the realisation of its full potential’.<sup>25</sup> The evaluation recommended continuation of the Dementia Initiative albeit with some restructuring to better align with the *National Framework for Action on Dementia 2006-2010* and to address concerns about coordination of projects.<sup>26</sup>
- 1.28 Another significant milestone was reached in April 2012 when the Standing Council on Health (which brings health ministers across all Australian jurisdictions and New Zealand together) received notice that the Commonwealth Government intended to propose dementia as a National Health Priority Area (NHPA) on the grounds that this would help focus attention and drive collaborative efforts aimed at tackling dementia at national, local and state and territory levels.<sup>27</sup>
- 1.29 On 10 August 2012 Health Ministers agreed to designate dementia as the ninth NHPA on the basis that this was warranted due to the increased burden of disease and opportunities to make significant gains in the health and well-being of people with dementia, their carers and families.<sup>28</sup> Health Ministers noted:

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24 DoHA, *Helping Australians with Dementia, and their Carers – Making Dementia a National Health Priority*, Budget 2005-2006, Ageing Factsheet 1, <<http://www.health.gov.au/internet/budget/publishing.nsf/Content/health-budget2005-abudget-afact1.htm>> viewed 20 April 2012.

25 LAMA Consortium, *Dementia Initiative National Evaluation Overview and Summary of Main Findings Final Report*, October 2009, p. 13 & p. 11.

26 LAMA Consortium, *Dementia Initiative National Evaluation Overview and Summary of Main Findings Final Report*, October 2009, p. 13.

27 Australian Government, *Living longer. Living Better*. April 2012, p.21. See also, Standing Committee on Health, *Communiqué*, 27 April 2012, p.1.

28 The other eight NHPA are: cancer control; cardiovascular health; injury prevention and control; mental health; diabetes mellitus; asthma; arthritis and musculoskeletal conditions; & obesity.



Recognising dementia as a National Health Priority Area will enhance the development of a new National Framework for Action on Dementia [2013-2017] which will contribute to the current and future work undertaken in response to dementia across Australia.<sup>29</sup>

## National Framework for Action on Dementia (NFAD)

1.30 In 2006, Australian health ministers agreed on an action plan to coordinate existing dementia care and support activities. The resulting *National Framework for Action on Dementia 2006-2010* (the framework) was developed following a nation-wide consultation that included the combined input of governments, service providers, peak bodies, and people with dementia, their families and carers.<sup>30</sup>

1.31 The five priority areas of the framework were:

- Care and Support services that are flexible and can respond to the changing needs of people with dementia, their carers and families.
- Access and Equity to dementia information, support and care for all people with dementia, their carers and families regardless of their location or cultural background.
- Information and Education that is evidence-based, accurate and provided in a timely and meaningful way.
- Research into prevention, risk reduction and delaying the onset of dementia as well as into the needs of people with dementia, their carers and families.
- Workforce and Training strategies that deliver skilled, high quality dementia care.<sup>31</sup>

1.32 In 2011 the framework was reviewed<sup>32</sup> and the following key findings summarised in the final report:

- The vision, objectives, principles and priorities for action identified within the NFAD were appropriately aligned to that of the various governments (where relevant).

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29 Standing Committee on Health, Communiqué, 10 August 2012, p.1.

30 NSW Department of Health on behalf of the Australian Health Ministers Conference, 2006, *National Framework for Action on Dementia 2006-2010*.

31 NSW Department of Health on behalf of the Australian Health Ministers Conference, 2006, *National Framework for Action on Dementia 2006-2010*, p. 7.

32 *The Review of the National Framework for Action on Dementia 2006 – 2010* was undertaken by Quantum Consulting Australia Pty Ltd in conjunction with Professor Barbara Horner (Curtin University) and Dr Colleen Doyle (National Ageing Research Institute).

- The NFAD assisted in prioritising the discussion of ‘dementia’ and formalised the priority for developing appropriate plans and strategies within their jurisdiction.
- There remains a need for a future NFAD, however there are divergent views as to how the NFAD should be designed in the future, for example:
  - ⇒ a series of principles to guide and support jurisdictions’ action plans (including articulation with other dementia initiatives that have associated funding); or
  - ⇒ a series of principles and an implementation plan (which demonstrates the relationship of jurisdictional priorities and associated planning with the principles of the NFAD).<sup>33</sup>

1.33 Following the review, the Australian Health Ministers Advisory Council agreed on the need for a new and updated national dementia policy framework. Development of the *National Framework for Action on Dementia 2013-2017* is currently in progress. The NFAD 2013-2017 is being informed by a series of consultations held between April and May 2013 in various locations across Australia. The consultation process also allows for written feedback in response to a consultation paper. According to the consultation paper:

The new Framework follows the stages of dementia care most people will experience in their journey of dementia as outlined in the Service Pathways Model. It is acknowledged that not all people living with dementia will experience each stage of care or will progress through the stages at the same pace. The new Framework is focused on the following stages of care:

- Risk Reduction, Awareness and Recognition
- Assessment, Diagnosis and Post Diagnostic support
- Management, Care, Support and Review
- End of Life<sup>34</sup>

1.34 Public consultations and submissions on the NFAD 2013-2017 were expected to be completed by 17 May 2013. At the time of writing, the

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33 Quantum Consulting Australia 2011, *Review of the National Framework for Action on Dementia 2006 – 2010*, Summary of Final Report, pp. 7-8, <<http://www.health.gov.au/internet/main/publishing.nsf/content/dementia-nfad-summary-2011>> 14 May 2013.

34 Australian Government, *Consultation Paper National Framework for Action on Dementia 2013-2017*, p. 2, <<http://www.health.gov.au/internet/main/publishing.nsf/content/dementia-nfad2013-2017>> viewed 14 May 2013.

outcomes of the public consultation processes have not been published, though it is expected that these will be available in the near future.<sup>35</sup>

## Living Longer. Living Better. – aged care reform package

- 1.35 The latest initiative of the Australian Government is the *Living Longer. Living Better.* package which came into effect in July 2012. Total funding of \$3.7 billion for the package includes designated funding of \$268.4 million over five years to tackle dementia.<sup>36</sup>
- 1.36 Noting that it can take over three years from noticing symptoms to receiving diagnosis, the package included a commitment to provide greater support for the timely diagnosis of dementia. Specifically the package has provision for:
- ... primary health care providers to undertake more timely dementia diagnosis. GPs and practice nurses will receive much needed training and education programs and improved support to help them better diagnose dementia. This will reduce the period from symptom onset to diagnosis.<sup>37</sup>
- 1.37 Other aspects of the dementia package include:
- expansion of the Dementia Behaviour Management Advisory Services (DBMAS)<sup>38</sup> into acute and primary settings;
  - a new Dementia Supplement to provide additional financial assistance to those receiving dementia care;
  - increased annual funding for service providers to endow staff with training, guidelines and procedures to ensure best practice dementia care;
  - additional assistance to people receiving home care packages;
  - training for staff in hospitals to identify early signs of dementia particularly at the point of admission and be able to implement appropriate protocols; and

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35 DoHA, *National Framework for Action on Dementia 2013-2017*, <<http://www.health.gov.au/internet/main/publishing.nsf/content/dementia-nfad2013-2017>> viewed 3 June 2013.

36 Australian Government, *Living Longer. Living Better.* April 2012, <<http://www.health.gov.au/internet/main/publishing.nsf/Content/ageing-aged-care-review-measures-living.htm>> viewed 20 April 2012.

37 Australian Government, *Living Longer. Living Better.* April 2012, p. 22.

38 The Dementia Behaviour Management Advisory Services (DBMAS). See Chapter 2 for more information on DBMAS.

- improved care and support for people with younger onset dementia, their families and carers.<sup>39</sup>

## Scope of the inquiry

- 1.38 The scope of the inquiry is largely defined by the terms of reference which direct the Committee to consider how early diagnosis and intervention can assist people living with dementia and their families to maximise quality of life and plan for the future.
- 1.39 The timing of the inquiry coincides with a period of significant policy activity resulting in reforms to initiatives to tackle dementia, structural and funding reforms which have implications for access to and delivery of a range of health and aged care services.
- 1.40 While acknowledging the dynamic policy environment and the broad implications of reforms to the health and aged care sectors, in accordance with the inquiry's terms of reference consideration will be confined to the implications of these reforms in the context of dementia early diagnosis and intervention.

## Structure of the report

- 1.41 Following the introductory material and context presented in Chapter 1, Chapter 2 presents an overview of the demographics of dementia in Australia and a brief outline of the main services available to people living with dementia, and their families and carers.
- 1.42 Chapter 3 examines the lack of awareness of dementia and stigmatisation of the condition. The chapter considers who needs to be better informed about dementia and their specific information needs.
- 1.43 Dementia diagnosis is considered in Chapter 4. The chapter outlines the benefits of a timely diagnosis, and examines processes for obtaining a diagnosis. Issues associated with future planning for people once they have received a dementia diagnosis are also considered.

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39 Australian Government, *Living Longer, Living Better*, April 2012, pp. 22-24.

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- 1.44 Chapter 5 examines barriers to obtaining a timely diagnosis of dementia in a range of medical settings, focusing on how to address barriers at the primary care provider level and at health system level more broadly.
- 1.45 The post-diagnosis pathway for people with dementia and their carers is discussed in Chapter 6. The focus of the chapter is on how early intervention of dementia may assist to improve quality of life, help individuals to remain independent for as long as possible, and increase opportunities for continued social engagement and community participation. It also examines the need for post-diagnostic services that are designed to meet the differing needs of people with dementia and their families.
- 1.46 The theme for Chapter 7 is a dementia friendly future. It examines current understanding of actions that can be taken by all Australians to reduce their risk of developing dementia or to slow progression of the condition. The chapter considers the dementia research in Australia, and concludes by investigating the concept of dementia friendly communities.

