NSW DEMENTIA SERVICES FRAMEWORK 2010–2015

Report on Implementation
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Executive Summary

The NSW Dementia Services Framework 2010-2015 (the Framework) was released jointly in September 2010 by the then NSW Minister for Health, the Hon. Carmel Tebbutt, and the then Minister for Ageing and Disability Services, the Hon. Peter Primrose. It set the direction for NSW to provide quality dementia care within the context of a rapidly ageing population and an increasing incidence of people living with dementia.

The Framework presents dementia care as a journey along a service pathway, beginning with dementia awareness and continuing along several stages requiring varying degrees of care. These stages include access to assessment, diagnosis and management, and information, counselling and carer education following a diagnosis. Stages on this pathway also include access to care and support across community, residential and hospital settings, allowing for specialist interventions for behavioural and psychological symptoms of dementia and palliative care.

The service pathway is underpinned by enablers that are not specific to any stage of care but are essential to the establishment of service infrastructure to enable the sustained delivery of quality care. These enablers provide the structures that support funding, planning and policy directions, improve workforce development and training for delivering quality dementia care, and improve the evidence base to inform the provision of dementia care.

The Framework has assisted health, community and residential services to plan and develop dementia services and programs. The practical recommendations for improving access, diagnosis and continuing care have been used as a checklist for reviewing the way services are currently provided and for reflecting on how services might be delivered differently to improve outcomes for people with dementia, carers and families.

The NSW Ministry of Health and the Department of Family and Community Services (FACS) have worked in partnership since 2010 to deliver on priority actions under the Framework.

This Report provides information on how well the Framework has achieved its objectives over the five years to the end of 2015 in the context of a rapidly ageing population and increasing numbers of people living with dementia. It illustrates that programs and services across NSW are improving outcomes for people living with dementia, their carers and families.

Two examples of this progress include the establishment of community-based dementia clinical nurse consultant (DCNC) positions in most Local Health Districts (LHDs) in 2011, to provide ongoing specialist clinical support and education to members of the community on issues related to dementia and ageing. DCNCs have an early intervention focus which encourages timely diagnosis and health monitoring and review, improving the support received by people with dementia. Many LHDs are also developing innovative models of care such as specialist palliative care and geriatric outreach to residential care. The Aged Care Emergency (ACE) program is one such model, providing outreach to residential care residents including those with dementia, working to prevent unnecessary admission to hospital or fast-tracking admissions when required.

The NSW Ministry of Health and FACS are now looking at future policy direction for dementia services in NSW and will take account of national priorities under the National Framework for Action on Dementia 2015-2019. Emphasis will also be placed on the need for quality data collection and outcome-based performance measurement in order to monitor and evaluate program performance over time and to optimise service access and availability to meet current and future demands.
SECTION ONE

Introduction

Background to NSW Dementia Services Framework 2010-2015

The NSW Dementia Services Framework 2010-2015 (the Framework) was released jointly in September 2010 by the then NSW Minister for Health, the Hon. Carmel Tebbutt, and the then Minister for Ageing and Disability Services, the Hon. Peter Primrose. It set the direction for NSW to provide quality dementia care within the context of a rapidly ageing population and an increasing incidence of people living with dementia.

In 2015 there were an estimated 112,000 people living with dementia in NSW. This is expected to increase to 128,500 people by 2020 and 272,000 by 2050. Dementia is the second leading cause of death in Australia and the single greatest cause of disability in older Australians (aged 65 years or older). It is predicted to become the third greatest source of health and residential aged care spending within two decades (Alzheimer’s Australia 2016).

The Framework reinforced the NSW Government’s commitment to working with the Commonwealth to improve outcomes for people living with dementia and their carers and families.

A draft Implementation Plan jointly released by the Minister for Health and the Minister for Ageing and Disability Services in September 2011 has guided key actions under the Framework since that time.

Ongoing implementation of the Framework was also a key commitment under the whole of government NSW Ageing Strategy 2012. While the NSW Department of Family and Community Services (FACS) has lead agency responsibility for coordinating statewide responses under the Ageing Strategy, NSW Health has had lead responsibility for continuing to develop strategies for implementing dementia-related initiatives in partnership with FACS.

Actions under the NSW Dementia Services Framework 2010-2015 are also consistent with the National Framework for Action on Dementia 2015-2019 released by the Commonwealth in July 2015.

Objectives

The objectives of the Framework are to:

1. Improve community awareness about dementia, available help and the link between healthy lifestyles and reduced dementia risk
2. Improve access to timely dementia assessment, diagnosis and management services
3. Improve access to information, counselling, carer education and support
4. Improve the availability and flexibility of community support programs and services
5. Improve the quality of and expertise for dementia care in hospitals
6. Improve the quality of and expertise for dementia care in residential aged care settings
7. Improve access to quality care and expertise for the assessment and management of behavioural and psychological symptoms of dementia
8. Improve access to quality care and expertise for palliative dementia care.
Implementation

NSW Health pursues the delivery of quality dementia care through provision of general health services as well as specialist health and mental health services for older people. Quality dementia care is dependent on all components of the health system working together and on effective integration of acute, primary and community services, including residential care. The NSW Ministry of Health is responsible for reporting on the progressive achievement of Framework outcomes.

FACS maintains primary responsibility under the Framework for younger onset dementia (people under the age of 65 years). People with younger onset dementia may be eligible for disability support through FACS unless they are eligible for and able to access the Commonwealth’s National Disability Insurance Scheme (NDIS) due to be fully implemented by July 2018.

More generally, actions under the Framework span both national and state areas of responsibility and involve multiple stakeholders working in partnership to improve the experience of people living with dementia and their carers and families in NSW.

Achievements

Considerable improvements have been made since 2010 to accessibility of dementia services, educational opportunities for staff and the development of more appropriate models of care in both the acute and the community settings.

Such achievements include the Dementia and Delirium Volunteer Program, supporting the care of hospitalised patients with dementia by providing a volunteer in a role that is similar to that of a family carer, giving emotional security as well as practice assistance to the patient. The program has been showcased on Innovations Exchange websites in Australia and the United States, and is being rolled out to a number of other Australian hospitals.

The Framework itself has been used as a template for the development of dementia plans in many Local Health Districts (LHDs). The establishment of dementia/delirium community clinical nurse consultant positions across NSW has also helped guide the development of local dementia pathways through partnership with Primary Health Networks (formerly Medicare Locals). These pathways facilitate more timely diagnosis and referral for support for people living with dementia.

LHDs are supported in the areas of health care service design, service delivery and education by the Agency for Clinical Innovation (ACI), the Clinical Excellence Commission (CEC) and the Health Education and Training Institute (HETI).

Future directions

The NSW Dementia Services Framework 2010-2015 acknowledges that specific population groups may have distinctly different dementia care needs and requirements for service. Increasingly all programs and services will need to be more responsive to the specific needs of individuals and groups, including:

- Culturally and Linguistically diverse communities (CALD)
- Aboriginal people with dementia
- Rural and remote communities
- People with younger onset dementia
- People with intellectual disability who develop dementia
- Gay men and lesbians, bisexuals, transgender and intersex (GLBTI)

The ongoing challenge is to increase equitable access to quality care (geographic as well as for specific population groups), while at the same time planning for the expected 30% increase in the numbers of people living with dementia by 2020 as the population ages.

As part of its governance role, the NSW Ministry of Health will continue to work with FACS during 2016 to review key outcomes and achievements under the Framework in order to set the future policy direction for dementia services in NSW and to guide ongoing improvement in the quality of life for people living with dementia and their carers and families.

NSW Ministry of Health and FACS will also continue working in partnership with key stakeholders at both state and local levels in order to build on achievements to date and identify new opportunities for improving care and service delivery.
Policy Landscape 2010-2015

There have been significant health, disability and aged care reforms since the *NSW Dementia Services Framework 2010-2015* was released in September 2010.

A brief chronological summary of key national and state developments impacting on and influencing the delivery of dementia services over the five years 2010-2015 is provided below.

<table>
<thead>
<tr>
<th>DATE</th>
<th>DEVELOPMENT</th>
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<tbody>
<tr>
<td>2010</td>
<td>Implementation of the <em>NSW Carers (Recognition) Act 2010</em> to support the social inclusion of all carers in NSW who provide support to another person because of disability, chronic illness, mental illness, dementia or ageing.</td>
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<tr>
<td>2011</td>
<td>Implementation of the National Health Reform Agreement, splitting ageing and disability services from 1 July 2012.</td>
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<tr>
<td>August 2012</td>
<td>Dementia designated as ninth National Health Priority Area by Australian Health Ministers.</td>
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<tr>
<td>2012</td>
<td>NSW Ageing Strategy identified NSW Government’s commitment to implement responsibilities under the <em>NSW Dementia Services Framework 2010-2015</em>.</td>
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<tr>
<td>2012</td>
<td>NSW is first Australian state to sign up to national rollout of National Disability Insurance Scheme (NDIS) – to be operating statewide by 30 June 2018.</td>
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<tr>
<td>July 2013</td>
<td>Phased implementation of the National Aged Care Gateway, with commencement of the national call centre and My Aged Care website.</td>
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<tr>
<td>2014</td>
<td>NSW Health <em>Integrated Care Strategy</em> implemented to promote innovative and locally led models of integrated care across the State. ‘Delivering truly integrated care’ recognised as one of the three strategic directions in the <em>NSW State Health Plan: Towards 2010</em>.</td>
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<tr>
<td>2014</td>
<td>Agency for Clinical Innovation (ACI) published <em>Building Partnerships: A Framework for integrating care for older people with complex health needs</em>. ACI has promoted 10 partnerships programs at LHD level including a dementia-specific project in Hunter New England LHD aimed at improving the early assessment, diagnosis and support of people living with dementia, their carers and families.</td>
</tr>
<tr>
<td>September 2014</td>
<td>Ministerial Dementia Forum on ‘Dementia Care - Core business for aged care’ identified key policy options affecting people living with dementia for the Australian Government.</td>
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<tr>
<td>September 2015</td>
<td>KPMG report on <em>Analysis of Dementia Programmes funded by the Department of Social Services</em> reinforced value of NFAD in providing an overarching framework for the development of dementia policy across Commonwealth and State/Territory health and aged care systems.</td>
</tr>
<tr>
<td>November 2015</td>
<td>New Commonwealth program of specialist Severe Behaviour Response Teams (SBRTS) implemented to complement the work of the existing Dementia Behaviour Management Advisory Services (DBMAS).</td>
</tr>
<tr>
<td>December 2015</td>
<td>New National Carer Gateway established to integrate support for carers.</td>
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</table>
This Report provides information on key strategic actions under the *NSW Dementia Services Framework 2010-2015*. In the context of a rapidly ageing population and increasing numbers of people living with dementia, it reflects the considerable progress made by the NSW Ministry of Health in partnership with FACS in implementing priority actions for supporting people living with dementia in NSW since 2010.

**Service Pathway**

Key achievements to December 2015 are outlined in relation to the dementia service pathway and enablers as described in the Framework, encompassing:

1. **Dementia awareness**
2. Assessment, diagnosis and ongoing management
3. Information, counselling and carer education
4. Community support
5. Hospital care
6. Residential care
7. Behavioural and psychological symptoms of dementia
8. Palliative care

Dementia care is presented in the Framework as a journey along a service pathway, beginning with dementia awareness and continuing along several stages requiring varying degrees of care, finally leading to end of life support. These stages include access to assessment, diagnosis and management, and information, counselling and carer education following a diagnosis. Stages on this pathway also include access to care and support across community, residential and hospital settings, allowing for specialist interventions for behavioural and psychological symptoms of dementia and palliative care.

1. **Dementia awareness**

**Successful initiatives:**

- The *‘Healthy Heart Healthy Mind’* community-based dementia risk reduction campaign was piloted in 2011 under a partnership arrangement between Illawarra-Shoalhaven Local Health District and the Centre for Health Initiatives, University of Wollongong. The campaign:
  - Used social marketing to create awareness and promote behaviour change in individuals to reduce their risk of developing a health condition.
  - Provided an important example of a population-based prevention strategy for dementia that suggests widespread adoption could have a longer-term impact on hypertension management and dementia prevention throughout NSW.
- FACS engaged *Alzheimer's NSW* to deliver a range of activities including a social marketing campaign to increase dementia awareness and to produce a ‘Guide to Becoming a Dementia Friendly Community’ in 2014.
- The Koori Dementia Care Project (KDCP) was delivered by Neuroscience Research Australia (NeuRA) with funding by FACS.
  - The KDCP has increased dementia awareness by working with Aboriginal community members and local services in the education of dementia assessment and care; risk factor detection and prevention through local dementia yarn-ups, workshops, and carer support groups; training and mentoring of local Aboriginal Dementia Educators and project support staff in each of the project’s communities; development and dissemination of information and communication strategies about dementia; and development and support of an Aboriginal-specific Visiting Geriatrician Program through Prince of Wales Hospital, South Eastern Sydney Local Health District.
- The DVD *‘It's not a disgrace, it's dementia’* was released by Alzheimer’s Australia NSW and funded by FACS. The DVD has been produced in a number of community languages including Mandarin, Arabic and Ukrainian.
2. Assessment, diagnosis and ongoing management

Successful initiatives:
- Community-based dementia clinical nurse consultant (DCNC) positions were established in most LHDs in 2011. DCNCs:
  - Provide specialist clinical support and education to members of the community on issues related to dementia and ageing, and complement the established roles of hospital-based acute DCNCs who were active prior to 2011.
  - Have assisted in the development of local dementia pathways with key stakeholders such as Medicare Locals (now Primary Health Networks) to improve timely diagnosis and referral for support.
  - Provide leadership, education and clinical advice to build the capacity of general staff to respond appropriately to the needs of people living with dementia and their carers. Their early intervention focus encourages timely diagnosis, health monitoring and medication review, as well as the provision of information to enable future financial and care planning and referral to support services.
- The Culturally and Linguistically Diverse (CALD) Dementia Awareness and Link Support Project in South West Sydney was delivered by Alzheimer’s Australia NSW and funded by FACS. This project:
  - Included the development of resources, the provision of dementia awareness education and establishment of support links into mainstream services for people living with dementia and their carers, through a service link function in three CALD communities.
- FACS has commenced individualised funding options for people with younger onset dementia, offering increased choice and control in the support planning services available to younger people. These consist of a range of non-government organisations, including an Aboriginal specific support planning provider. Assessment providers are committed to providing culturally appropriate services.
- Younger Onset Dementia e-learning training resources are being developed by Alzheimer’s Australia for frontline staff working with people with dementia. Alzheimer’s Australia will advise all disability-funded service providers of the e-learning resources and encourage all relevant staff to access and complete the training online.

3. Information, counselling and carer education and support

Successful initiatives:
- A range of valuable counselling, education, information and support programs are funded by the NSW Government, through FACS and the NSW Ministry of Health. These include the Carer Education; Support group leader training program; Aboriginal dementia awareness program; Disability & dementia training program; Dementia Awareness Week activities; and Dementia Advisory Services which are operated by NSW Health with funding provided by the NSW Department of Ageing, Disability and Home Care or through the Commonwealth Home Support Programme.
- The NSW Carers (Recognition) Act 2010 was introduced to provide legal recognition of carers and to create a NSW Carers Advisory Council to promote the interests of carers. Carer policy, planning and action across the NSW Government and NSW Health, including the Local Health Districts and Pillar organisations is guided by the NSW Carers (Recognition) Act 2010.
  - The NSW Health Carers (Recognition) Act Implementation Plan 2013–2016 builds on work done across the public health system to better acknowledge and support carers.
  - NSW Health reports annually on implementation and compliance with the legislation.
  - The NSW Carers Charter in Sch 1 of the Act contains 13 principles of significance for carers, such as respect and inclusion, and all NSW Government agencies in the NSW public sector are required to incorporate the support and recognition of carers who are clients into their core business. This encompasses the active support of carers of people living with dementia.
- The NSW Carers Strategy 2014–2019 was implemented with the aim of improving the position of carers in NSW.
  - The Strategy was developed by FACS with assistance from the Ministry of Health and Carers NSW and was launched by the Minister for Ageing and Disability Services, the Hon. John Ajaka, at Parliament House on 7 August 2014.
- It provides a broader context for ongoing implementation of the NSW Carers (Recognition) Act 2010 by government, non-government organisations, carers, and the private sector in new partnerships designed to deliver better services and supports for carers.
- The five focus areas for implementation are:
  • Employment and education
  • Carer health and wellbeing
  • Information and community awareness
  • Carer engagement
  • Improving the evidence base.

4. Community Support

Successful initiatives:
- The ‘Allied Health Professions: Supporting people with dementia and their carers' working group, an Allied Health subgroup of the ACI Aged Health Network, commenced work in 2015 on a Project ‘Allies in Dementia Health Care', funded by the Consumers Directed Research Network (CDRN) of Alzheimer’s Australia. The project is due for completion in 2016.
  - The project will develop a printed guide to provide people living with dementia with information, ideas and inspiration on partnering with allied health professionals to enhance quality of life.
  - A companion ‘Guide for Health Professionals’ will inform and guide health professionals about a range of evidence-based allied health interventions that respond to the needs and issues of people living with dementia.
- Alzheimer’s Australia NSW is developing a resource documenting pathways for community supports for people living with younger onset dementia. This resource will be finalised in 2016.
- Under the NSW Integrated Care Strategy, a 6 year investment to implement innovative, locally-led models of care, NSW Health is piloting a Geriatrician in the Practice project in the Illawarra Shoalhaven Local Health District that provides a joint, integrated GP and specialist appointment that is easily accessible for patients, in a familiar environment.
  - This initiative involves a geriatrician and an aged care nurse team joining the General Practitioner (GP) in their rooms to provide initial dementia assessment and follow-up of identified patients.
  - It is planned to expand this initiative over 2016-17.

5. Hospital Care

Successful initiatives:
- The Agency for Clinical Innovation’s (ACI) Care of the Confused Hospitalised Older Persons Program (CHOPs) aims to improve the experience and outcomes of confused older people and to help them, their carers and families find a more supportive environment in hospital. Confusion is most commonly due to dementia and/or delirium.
  - Funded through the NHMRC Cognitive Decline Partnership Centre until June 2015, CHOPS is being implemented and evaluated via a phased process in 13 hospitals in NSW.
  - The CHOPS study followed a Clinical Excellence Commission (CEC) report which found significant variation in the management of delirium in NSW public hospitals (2011).
  - The Key Principles for Care of Confused Hospitalised Older Persons was published by the ACI Aged Health Network in July 2014. Key principles included a focus on early identification and management, staff education, communication with carers and families, and improving the hospital environment for people with dementia. An implementation guide has also been developed.
  - The ACI Aged Health Network is guiding the continued implementation and sustainability of CHOPs across NSW.
- TOP 5 is a carer’s tool to support the continuity of care for people with thinking and communication difficulties, across all care settings.
  - The tool was developed in 2010 by the Central Coast LHD. The CEC, funded by the HCF Health and Medical Research Foundation, implemented and evaluated the TOP 5 strategy at 17 public sites to improve the hospital experience of people with dementia and their carers.
  - Further rollout and evaluation, funded by the HCF Research Foundation, is planned to examine the use of TOP 5 in referral linkages between hospitals, residential aged care facilities, NSW Ambulance Service and home care.
New models of care
- Many Local Health Districts are involved in innovative projects that have reduced medication use for behaviours of concern, falls and “specialling” in hospitals, or in trialling new models of care such as specialist palliative care and geriatric outreach to residential care.
- The ACI Individual Patient Specials (IPS) Working Group and the Nurses Subgroup have drafted **key principles for IPS** in hospitals. They aim to improve the experience and care for people who require one-to-one supervision during their admission in acute, sub-acute care and Multi-Purpose Services (MPS) settings. These patients may be disturbed, disoriented and confused and at risk of harm to themselves and others. The key outcome is for safe patient care to be delivered by appropriately skilled staff.

Aged Care Emergency (ACE) program provides outreach to residential care residents including those with dementia by preventing unnecessary admission to hospital or fast-tracking admissions.
- The ACE Model of Care (MOC) is a nurse-led integrated MOC that consolidates the successful outcomes from the ACE pilot project at John Hunter Hospital in 2010-11 and 2011-12.

The success of this pilot led to further funding for implementation of the ACE model in 10 Emergency Departments (EDs) in NSW over 2012-13 by the NSW Ministry of Health and NSW Emergency Care Institute. The ACI **Key Principles for Improving Healthcare Environments for People with Dementia** was published in 2014.
- The 10 key principles define an appropriate physical environment for people with dementia in hospital, as a poorly designed and inappropriately set up physical environment can negatively impact the care of patients with complex care needs.
- This document also contains an environmental audit tool to identify areas for improvement and to assist in planning new or refurbishing inpatient units.

The **Dementia and Delirium Volunteer Program** supports the care of hospitalised patients with dementia under the **NSW Dementia Services Framework 2010-2015**.
- The Program is based on a volunteer program implemented and evaluated at Bega Hospital in 2009 (Southern NSW LHD), in partnership with Alzheimer’s NSW.
- It has been showcased on the Innovations Exchange websites in Australia and the US and is being replicated in a number of other Australian hospitals.
- The volunteer role provides similar support to that of a family carer. Volunteers may provide emotional security as well as practical assistance to the person with dementia, including assisting with eating and drinking; ensuring patients are wearing vision and hearing aids and encouraging patients to walk when it is safe to do so.

- The project has links to the ACI, the CEC Falls Program, the Australian Commission on Safety and Quality in Health Care, and the Alzheimer’s Australia’s Consumer Dementia Research Network.
- In 2014, the NSW Agency for Clinical Innovation Care of Confused Hospitalised Older Persons Program (CHOPs) funded the development of a comprehensive training and implementation package to assist other NSW hospitals wishing to implement the program.

6. Residential Care
Successful initiatives:
- The **Mental Health/Aged Care Partnership Initiative (MHACPI)** has been shown to deliver quality care for older people with severe behavioural and psychological symptoms of dementia (BPSD) and/or mental illness within a mainstream residential setting, and to improve access to long-term community-based care, increasing quality of life for these patients.
- Services piloted in residential aged care settings for older people with severe BPSD and/or mental illness were evaluated in June 2011. NSW Health developed two pilot services within residential aged care facilities (RACF) operated by Catholic Health Care and Hammond Care.
- The NSW Health MHACPI Evaluation Summary Report demonstrated that the MHACPI model can successfully deliver quality care for older people with severe BPSD. The evaluation highlighted a high level of family, carer and staff satisfaction with MHACPI services.
- The MHACPI model promotes strong partnerships between specialist NSW Health (mental health and aged care) services and residential aged care providers, providing an important and unique service model in the spectrum of care for this target group.

7. Assessment and management of behavioural and psychological symptoms of dementia

Successful initiatives:
- The NSW Health Assessment and Management of People with Behavioural and Psychological Symptoms of Dementia (BPSD): A Handbook for NSW Clinicians was published by the NSW Ministry of Health and the Royal Australian and New Zealand College of Psychiatrists in May 2013.
  - The Handbook is a practical and ready reference for NSW Health staff working in settings where they will care for people with dementia and BPSD.
  - It articulates three essential principles and five priorities when providing care for the person with BPSD across different settings, with the objective of improving consistency of care, patient outcomes, and staff satisfaction in providing care.

8. Palliative dementia care

Successful initiatives:
- The NSW Health Advance Planning for Quality Care at End of Life – Action Plan 2013-2018 was published in 2013.
  - The Plan addresses the large proportion of people who currently die in acute care facilities, the projected ageing population, and the rise in dementia over the next 20 years. As the current approach to end of life decision-making and care will increasingly become inadequate in meeting the community’s needs over the next decades, it provides guidance on integrating Advance Care Planning with timely palliative care in the patient’s end of life management.
  - The goal is to normalise Advance Care Planning and improve end of life care by integrating patients’ wishes into the management of chronic life-limiting illness.

Enablers

Enablers provide the structures that support funding, planning and policy directions, improve workforce development and training for delivering quality dementia care, and improve the evidence base to inform the provision of dementia care. These enablers underpin the service pathway and are not specific to any stage of care, but are essential to the establishment of service infrastructure to enable the sustained delivery of quality care.

Education is a key means of improving service system capacity. Specialist education about managing people with dementia, whether in the hospital or the community setting, increases confidence and contributes to a positive attitude to providing dementia care.

Service Coordination

The majority of the NSW Local Health Districts are engaged in local dementia service networks and include integrated dementia service planning, in accordance with the Framework’s service requirements, in their local clinical service planning.

- For example, the Sydney Inner West Dementia Action Plan draws upon the NSW Dementia Services Framework 2010-2015 in setting priorities for dementia care and support across the region. The Plan has resulted from a consolidated planning process for dementia and dementia services for the Sydney Inner West region.
  - Wide consultation and broad stakeholder contribution focused attention on the need to continue to develop flexible services that take account of the individual needs, interests and abilities of the person living with dementia and their carer/s and to build capacity to respond to different groups with varying specific needs.

- Northern Sydney LHD (NSLHD) includes dementia in its overarching Clinical Services Plan 2015-2022.
  - NSLHD developed its Dementia Service Framework Implementation Plan in collaboration with key stakeholders, and aims to improve access to services and supports for patients with dementia and their carers. It includes implementing best practice principles and models of care to improve the experiences and outcomes of patients with dementia and confused hospitalised older persons (CHOPs) across NSLHD.
- The plan identifies 20 priorities for implementation. Raising awareness of dementia, risk factors and their management are key strategies requiring collaboration across the aged and primary care sectors. The development of integrated models between general practitioners, Aboriginal Medical Services and specialist memory assessment and review teams will be essential to promote earlier access to assessment and diagnosis.

- As a rural example, the Murrumbidgee Local Health District Aged Care Clinical Services Plan 2014–2018 refers to the NSW Dementia Services Framework 2010-2015 as setting the direction for improving quality of life for people with dementia, carers and families in NSW. It acknowledges that providing quality dementia care requires being responsive to the needs and experiences of people with dementia, carers and families.

- MLHD has established a consortium of representatives from a wide range of dementia service providers and consumers to guide planning and implementation of actions outlined in the NSW Dementia Framework.

Development of an Evidence Base

- The Hospital Dementia Services Project (HDS Project) provides a baseline against which to measure future improvement in hospital-based dementia services. This innovative study funded by the NHMRC explored how hospital-based aged care and dementia services influenced outcomes for people with dementia who used a public hospital in NSW in 2006-07.

- The HDS Project data provides a baseline to measure future improvement in hospital-based dementia services.

- The release of The interaction between hospital and community-based services for people with dementia and their carers, August 2013, was funded by FACS and developed by Alzheimer’s Australia NSW.

- This research sought to investigate and understand the perceptions of carers of people with dementia and community-based service providers who had experienced, in some capacity, the transition from hospital to home.

- The Service and Support Requirements of People with Younger Onset Dementia and their Families Report was also developed in 2012 by Alzheimer’s Australia with funding by Ageing, Disability and Home Care to determine the service and support requirements of this younger group of people with dementia.

Education, Training and Workforce Development

- Education is an important aspect of the role of NSW Health Dementia and Delirium Clinical Nurse Consultants (DCNCs).

- Evaluation of the role of community-based DCNCs in 2014 highlighted the important role they play in providing dementia specific education to aged care providers (in community and residential aged care settings), general practice (GPs and Practice Nurses) and inpatient nursing staff (where no other positions exist to undertake this role).

- FACS engaged Alzheimer’s Australia NSW to deliver 20 dementia training workshops for disability services in 2013-2014 with further workshops conducted in 2014–2015.

- The NSW Health Dementia Care Competency and Training Network (the Network) was established in 2007.

- The Network offers a highly successful, sustainable and economically viable web-based program that delivers high quality dementia education, provides resources and equips clinical staff to support people living with dementia.

- By the end of 2015, the Network:

  - Trained 174 facilitators across all NSW Local Health Districts;
  - Delivered 50 individual fully facilitated courses across NSW in 2015, including 12-week Positive Approach to Care of the Older Person with Dementia courses; 4-week Person Centred Care in the Community courses; 6-week Behavioural & Psychological Symptoms of Dementia courses; and 6-week Positive Approach to Care of the Aboriginal Person with Dementia courses;
  - Achieved an 80% completion rate across its courses, with all courses fully facilitated by clinical experts in dementia.
  - Had graduated over 3,000 clinicians.
The Network has developed a Dementia Competency Framework (DCF) in conjunction with the University of Wollongong for use by clinicians and managers working in Dementia Care. It has been developed into an online interactive program on the Network’s website and is being actively promoted to encourage take-up across all LHDs. It provides five learning modules addressing acute care, community care, behavioural and psychological symptoms of dementia, younger onset dementia, and Aboriginal and Torres Strait Islander-specific dementia care.

All courses are clinician facilitated and accredited and match the relevant level of clinical expertise required.
SECTION THREE

Future Directions and Next Steps

The NSW Dementia Services Framework 2010-2015 has assisted health, community and residential services to plan and develop dementia services and programs. In documenting the service pathway of dementia care, it has provided practical recommendations for improving access, diagnosis and continuing care and been used as a checklist for reviewing the way services are currently provided and for reflecting on how services might be delivered differently to improve outcomes for people with dementia, carers and families. It recognises that there are key enablers that span the services pathway.

The Ministry will continue working with FACS in 2016 on reviewing key outcomes and achievements under the Framework and setting policy direction for future dementia care and services in NSW.

This process will take into account the changes in service delivery that have occurred over the last five years as a result of significant aged care, disability and health care reform. It will also be important to consider the pending transformation of aged care programs over the next three years, and Commonwealth primary health care reforms that will transform the way primary care is delivered and funded. Partnerships will need to be strengthened with all key stakeholders – both government and non-government – in order to achieve effective integration and coordination of dementia services across NSW.

As the second leading cause of death in Australia and a national health priority, dementia should be recognised in the development and implementation of existing and future health and aged care policies.

What is needed now?

The recent KPMG report analysed existing Commonwealth-funded dementia programs, but some of the findings are worthy of consideration at the state level. The report suggests there should be a more structured approach to the design, development and funding of dementia programs and services in Australia. Clear objectives and outcome-based performance measures are needed to allow monitoring and evaluation of performance and to support a more effective interface between the multiplicity of dementia programs across the various sectors and jurisdictions.

The KPMG report identifies that greater effort is needed to raise awareness of the needs of people living with dementia, particularly those with younger onset dementia who may experience greater difficulty accessing a diagnosis and whose needs are not always met by existing dementia services targeted at older people.

KPMG consultations also highlight the need for an improved interface with other sectors, particularly mental health. The National Framework for Action on Dementia adds to this the need to promote better awareness, recognition and care of people with dementia in hospital and to ensure consistent care and support as a person moves between different settings. This extends to improving end of life and palliative care in the hospital setting, at home and in residential care.

A key message from the KPMG analysis for consideration at NSW level is the need to reduce the level of duplication and overlap of programs and services and to address existing gaps in support services available to people with dementia and their carers and families. This is particularly critical in regional, rural and remote areas.

Ideally multiple providers of similar services should be viewed positively as a means of ensuring coverage and offering choice, although the KPMG review found no clear rationale for funding similar dementia services through two different programs.

The 2014 Ministerial Dementia Forum also highlighted the importance of engaging people with dementia and their carers in policy and service development. This will help ensure policies and strategies are better aligned with consumer needs. Indicators should cover both quality of care and quality of life to assist consumers in making decisions about their choice of aged care service providers. NSW has developed many and diverse dementia programs and services in response to emerging need and changing demographics. Quality data collection and outcome-based performance measurement is needed to monitor and evaluate the performance of these programs over time and to optimise service access and availability to meet current and future demands.
## Acronyms

<table>
<thead>
<tr>
<th>Acronym</th>
<th>Description</th>
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<tbody>
<tr>
<td>AARCS</td>
<td>Acute to Age Related Care Services</td>
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<tr>
<td>ACAP</td>
<td>Aged Care Assessment Program</td>
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<td>ACI</td>
<td>Agency for Clinical Innovation</td>
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<td>AHMAC</td>
<td>Australian Health Ministers Advisory Council</td>
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<td>AIHW</td>
<td>Australian Institute of Health and Welfare</td>
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<tr>
<td>AMS</td>
<td>Aboriginal Medical Service</td>
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<tr>
<td>APDC</td>
<td>Admitted Patient Data Collection (APDC)</td>
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<td>ASET</td>
<td>AgedCare Services in Emergency Team</td>
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<tr>
<td>BASIS</td>
<td>Behavioural Assessment and Intervention Service</td>
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<tr>
<td>BHI</td>
<td>Bureau of Health Information</td>
</tr>
<tr>
<td>BPSD</td>
<td>Behavioural and Psychological Symptoms of Dementia</td>
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<tr>
<td>CALD</td>
<td>Culturally and Linguistically Diverse</td>
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<tr>
<td>CCSP</td>
<td>Community Care Support Program</td>
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<tr>
<td>CHOPS</td>
<td>Care of the (Confused) Hospitalised Older Person Study</td>
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<tr>
<td>CEC</td>
<td>Clinical Excellence Commission</td>
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<tr>
<td>CNC</td>
<td>Clinical Nurse Consultant</td>
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<tr>
<td>CW</td>
<td>Commonwealth</td>
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<td>DBMAS</td>
<td>Dementia Behaviour Management Advisory Services</td>
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<td>FACS</td>
<td>Department of Family and Community Services</td>
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<tr>
<td>GEM</td>
<td>Geriatric evaluation and management</td>
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<tr>
<td>GP</td>
<td>General Practitioner</td>
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<td>HDS</td>
<td>Hospital Dementia Services</td>
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<td>HITH</td>
<td>Hospital in the Home</td>
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<tr>
<td>HETI</td>
<td>Health Education and Training Institute</td>
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<td>IPS</td>
<td>Individual Patient Specials</td>
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<td>LHD</td>
<td>Local Health District</td>
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<td>LOS</td>
<td>Length of Stay</td>
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<td>MOC</td>
<td>Model of Care</td>
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<tr>
<td>NAMO</td>
<td>Nursing and Midwifery Office</td>
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<td>NDIS</td>
<td>National Disability Insurance Scheme</td>
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<td>NFAD</td>
<td>National Framework for Action on Dementia</td>
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<tr>
<td>NHMRC</td>
<td>National Health and Medical Research Council</td>
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<tr>
<td>NPC</td>
<td>National Partnership Centre for Dealing with Cognitive and Related Functional Decline in Older People</td>
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<td>NSW</td>
<td>New South Wales</td>
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<td>OPMH</td>
<td>Older People’s Mental Health</td>
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<td>RACF</td>
<td>Residential Aged Care Facility</td>
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<td>SBRT</td>
<td>Severe Behaviour Response Team</td>
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<tr>
<td>SMHSOP</td>
<td>Specialist Mental Health Services for Older People</td>
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<td>YOD</td>
<td>Younger Onset Dementia</td>
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APPENDIX TWO

Program Logic Underpinning Implementation of Framework

The following Program Logic diagram articulates the rationale underpinning implementation of the NSW Dementia Services Framework 2010-2015, what it has been expected to achieve, and how success may be measured.

It links inputs to activities and to expected outputs and outcomes. It graphically represents activities intended to be undertaken by key stakeholders and their expected short term, intermediate and long term impact.
Dementia has a significant and increasing impact on the individual, carers, families and on the community, health and aged care system.

### Rationale

Inputs
- Designated positions providing dementia leadership and expertise
- Existing and developing networks and governance structures
- Existing and developing networks and governance structures
- NSW Health state-wide projects
- Funding from FACS for disability support and research

MoH
- Continue and expand the Dementia Care Resource and Training Network Program
- Identifying and documenting sustainable models of care for NSW Health’s role in diagnosis and ongoing management

ACI
- Provide training to service providers that provide disability support for younger onset dementia
- ACI to deliver expert forums related to dementia and delirium
- ACI to further develop the Care of the Confused Hospitalised Older Persons Program Model of Care
- ACI to support improvement in hospital design
- CEC to support implementation of TOP5, a carer engagement strategy
- ACI to include dementia in palliative care framework and model of care
- Pilot and evaluate service models for specific population groups: 1. Young Onset Dementia (YOD) – person centred packages 2. Culturally and Linguistically Diverse (CALD) – link worker model
- Implement local service pathways and models of care for diagnosis and ongoing management, hospital care and palliative care
- Provide clinical support and advance care planning outreach to residential care

HETI
- Implement education strategies for health and disability workforce
- Undertake dementia awareness, risk reduction and advance care planning activities, including with specific population groups

LHDs/NGOs
- Establish or strengthen local dementia service networks and undertake dementia planning
- Implement education strategies for health and disability workforce
- Undertake research to further understand community needs
- Ensure access to Aboriginal assessors and support planners for those with younger onset dementia
- Provide people with increased choice and control of supports

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### Activities

**Health Pillars:** ACI, HETI, CEC
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### Outcomes

#### Short term
- Improved service coordination and progress in implementing local plans
- Increased uptake of planning ahead tools, earlier referrals for support
- Undertake research to further understand community needs
- Increased uptake of dementia training
- Greater access to carer education and support groups
- Provide people with increased choice and control of supports

#### Intermediate
- Improved health and wellbeing among people living with dementia, their carers and families
- A NSW workforce with the right skills, knowledge and attitude
- Increased willingness to seek help early, plan ahead and reduce risk
- Improved healthcare management in the community
- Improved palliative care approach

#### Long term impact
- Improved quality of life for all people living with dementia, their carers and families
- Improved quality end of life care and respect for end of life wishes
- Improved service delivery that is responsive to the needs of people with dementia, their carers and families
- Improved healthcare management in the community
- Improved palliative care approach

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