Australian Government

Australian Government response to the
Senate Community Affairs References Committee report:

Care and management of younger and older Australians living with dementia and behavioural and psychiatric symptoms of dementia (BPSD)

December 2017

Government Response to the Senate Community Affairs References Committee on care and management of younger and older Australians living with dementia and behavioural and psychiatric symptoms of dementia (BPSD).

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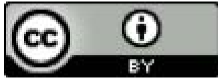

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Foreword

In 2017, there are an estimated 365,100 people in Australia living with dementia.[1] This is expected to increase to almost 900,000 by 2050.

The Senate Community Affairs References Committee report *Care and management of younger and older Australians living with dementia and behavioural and psychiatric symptoms of dementia (BPSD)* provides 18 recommendations on a range of issues affecting people living with dementia in Australia. Since the report was tabled, the Australian Government has taken action through a wide range of initiatives and reforms targeting dementia.

These actions are outlined in this response and underpinned by the *National Framework for Action on Dementia 2015-2019* (NFAD). The NFAD was endorsed by the Council of Australian Governments Health Council on 7 August 2015. It outlines Australian, state and territory government priorities across primary, acute and aged care to reduce the risk of dementia and improve the quality of life for people living with dementia and their support networks.

On 29 May 2017, Australia supported the adoption of the World Health Organisation Global Action Plan on the Public Health Response to Dementia 2017-2025 (GAP). The goal of the GAP is to improve the lives of people living with dementia, their carers and families, while decreasing the impact of dementia on them as well as on communities and countries. The GAP includes seven distinct action areas and outlines measurable targets for achievement.

The WHO Global Dementia Observatory provides the monitoring mechanism to track implementation and progress of the GAP and will be a valuable resource for knowledge translation and exchange. Australia is proud to be among the first countries supporting and sharing our data and resources on this platform.

The Australian Government is committed to the provision of quality services for people living with dementia, their families and carers, as well as research into the prevention, diagnosis, treatment and cure of dementia. In the 2014-15 Budget $200 million over five years was allocated to boost Australia's dementia research capacity and deliver best practice support for people with dementia across the health system. Key priorities of projects funded under this commitment are improving care and interventions for the behavioural and psychological symptoms of dementia and maximising the independence of people living with dementia. Research funding includes a strong knowledge translation component to translate research findings into practice within dementia policy and programs.

Phase one of the re-design of national dementia support programs and services was announced by the Government on 25 January 2016. The co-designed reforms are based on the advice of stakeholders and experts received through the Ministerial Dementia Forums of 2014 and 2015 and KPMG's nationwide consultation and analysis of dementia programs commissioned by the Government in 2015. Outcomes of the redesign address many of the report's recommendations.

Importantly, the redesign included the engagement of a single national provider to deliver nationally consistent accredited dementia training and education to the aged care workforce

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[1] Australian Institute of Health & Welfare (2012)

and health care professionals across Australia. Accredited training in best practice care of people with behavioural and psychiatric symptoms of dementia is available free to eligible health professionals and care workers.

Other key elements of service redesign include the establishment of the Severe Behaviour Response Teams (SBRT) and engagement of a single national provider to deliver the Dementia Behaviour Management Advisory Service (DBMAS) across all states and territories. The national DBMAS supports staff and carers in community, residential, acute and primary care settings with information, advice, assessment and short term case management interventions. Family carers, health professionals and aged care providers have access to 24 hour advice and support to improve the quality of life of the person living with dementia. The SBRT supports Commonwealth funded approved residential aged care providers requiring assistance with addressing the needs of people with severe and very severe BPSD.

A mobile workforce of multidisciplinary clinicians also provides locally delivered person-centred interventions, capacity building and resources for carers and organisations to improve skills in the care of people living with dementia in the longer term.

The Ministerial Dementia Forum held in December 2016 focused on redesigning dementia consumer supports to ensure national consistency and regional and remote coverage. The Government is now working with stakeholders on phase two of the redesign of national dementia support programs to develop an improved suite of dementia consumer supports for people living with dementia and their carers across the life-cycle of the disease.

The Government has also supported additional research and service improvement projects at a cost of more than $30 million through three rounds of the Aged Care Service Improvement and Healthy Ageing Grant Fund between 2012 and 2017. Projects address a range of priorities identified through the NFAD including improving dementia diagnosis and care in hospitals and primary care settings, delivering sensory experience interventions, reducing the use of antipsychotic medications in aged care facilities and development of tools and resources to manage and reduce behavioural and psychological symptoms of dementia (BPSD).

In June 2016, the Government committed to establishing Specialist Dementia Care Units (SDCUs) across Australia to support residents with very severe BPSD.

In addition, the Australian Government has provided funding over three years from June 2016 to Dementia Australia (formerly Alzheimer's Australia) to establish the Dementia Friendly Communities initiative, which is designed to help ordinary Australians better understand dementia. This educative, community awareness raising program aims to give people a greater understanding of dementia and the small things that can be done to make a real difference to people living with the condition. A national dementia-friendly community resource hub will also be developed, to enable communities to network, learn from other initiatives and provide the latest evidence and information on best practice approaches to increasing community awareness and support for people living with dementia.

Aged Care Reforms

The Australian Government is implementing significant reforms to the delivery of aged care services for older people and their carers to ensure that Australia has the best possible system, which is sustainable and affordable. The reforms are consistent with the long term

policy direction recommended by the Productivity Commission in its 2011 inquiry into *Care for Older Australians*.

A number of review processes have also recently been conducted that investigated how aged care services are delivered and the protections for vulnerable older Australians.

On 1 May 2017, the Government announced an independent Review of National Aged Care Quality Regulatory Processes (the Review). The Review was led by Ms Kate Carnell (AO), in conjunction with Professor Ron Paterson (ONZM), and examined Commonwealth aged care accreditation, monitoring, review, investigation, complaints and compliance processes. On 25 October 2017, the Minister for Ageing, the Hon Ken Wyatt AM, MP released the Review report. The Government is considering the Review recommendations.

On 15 June 2017, the Australian Law Reform Commission released its report into elder abuse, recommending tighter regulation and safeguards in relation to the use of restrictive practices in residential aged care. The Review panel considered these recommendations.

The Government recognises that care for older people living with dementia is an integral part of the aged care system.

The Australian Government is committed to the provision of quality services for all older Australians, including for people living with dementia, their families and carers, as well as research into dementia prevention and cure.

Responses to the recommendations have been developed collaboratively by the Department of Health, the Department of Social Services, the Australian Commission on Safety and Quality in Health Care and the National Health and Medical Research Council.

Acronyms

ACAP	Aged Care Assessment Program
ACAT	Aged Care Assessment Team
ACFI	Aged Care Funding Instrument
BPSD	Behavioural and Psychological Symptoms of Dementia
CDM	Chronic Disease Management
CHSP	Commonwealth Home Support Program
CRCC	Commonwealth Respite and Carelink Centres
DA	Dementia Australia (formerly Alzheimer's Australia)
DBMAS	Dementia Behaviour Management Advisory Services
DSA	Dementia Support Australia
DTA	Dementia Training Australia
DTP	Dementia Training Program
DTSC	Dementia Training Study Centres
DUE	Drug Use Evaluation
DUSC	Drug Utilisation Sub-Committee
GP	General Practitioner
MBS	Medicare Benefits Schedule
MPS	Multi-Purpose Service
NFAD	National Framework for Action on Dementia 2015-2019
NHMRC	National Health and Medical Research Council
NDIS	National Disability Insurance Scheme
NPS	National Prescribing Service
PBAC	Pharmaceutical Benefits Advisory Committee
PBS	Pharmaceutical Benefits Scheme
PHN	Primary Health Networks

QI	Quality Indicator
QUM	Quality Use of Medicines
RACF	Residential Aged Care Facility
RPBS	Repatriation Pharmaceutical Benefits Scheme
SBRT	Severe Behaviour Response Teams
SDCU	Specialist Dementia Care Units
TAFE	Technical and Further Education
TGA	Therapeutic Goods Administration
The Commission	Australian Commission on Safety and Quality in Health Care
TRACS	Teaching and Research Aged Care Services
TTP	Tailored Training Package
UoW	University of Wollongong
YOD	Younger Onset Dementia
YODKWP	Younger Onset Dementia Key Worker Program

Recommendation 1

The Committee recommends that the Commonwealth create a new Medicare item number that encourages General Practitioners, registered psychologists or other relevant accredited professionals, to undertake longer consultations with a patient and at least one family member or carer where the patient has presented with indications of dementia *(para 2.42).*

Noted

The Australian Government notes this recommendation.

The second priority area for action under the *National Framework for Action on Dementia 2015-2019* (NFAD) is “The need for timely diagnosis”. Under this priority, the Government has committed to the following outcome: Australians will have access to skilled and knowledgeable health professionals who can support and provide an accurate and timely diagnosis of dementia.

The Government recognises the important role that can be played by primary care providers in the identification, assessment and management of dementia.

The Government’s view is that rather than creating a new Medicare Benefits Schedule (MBS) item, it would be more appropriate to consider whether current items are effective through the Medicare Benefits Schedule Review and Primary Health Care Advisory Group, and also to improve doctors’ awareness of existing MBS items that allow for cognitive screening and care planning.

Whilst there are no specific items for dementia diagnosis and intervention under the Medicare Benefits Schedule (MBS) arrangements, a wide range of existing items may be used for these purposes. These include:

- health assessments provided for people aged 75 years and older that can be undertaken annually – MBS items 701-707
- comprehensive medical assessments in residential aged care facilities that can be provided annually - MBS items 701, 703, 705 and 707
- longer consultations using the standard general practitioner attendance items – Level C attendance item - lasting at least 20 minutes, and the Level D attendance item - lasting at least 40 minutes are available for people of any age with suspected or diagnosed dementia
- Chronic Disease Management (CDM) items such as MBS items 721-732. The package of CDM items includes Medicare rebateable items for GP-managed care planning and/or team assisted care planning, items to review care plans and contribute to care plans prepared by other providers including residential aged care services, and a mechanism for GPs to refer patients for Medicare rebateable allied health services
- MBS rebates available for professional attendance by specialists and consultant physicians in the practice of geriatric medicine – MBS items 141-149. Some of these services may be to diagnose, treat or monitor patients with dementia and some of these items are for consultations of over 60 minutes and can be undertaken at a hospital or in a patient’s home. One of these MBS items (145 for Consultant Physician or Specialist in

Geriatric Medicine, Referred Patient, Initial Comprehensive Assessment and Management - Home Visit) has a rebate of $469.35 as at January 2017.

On 22 April 2015, the Government, announced an MBS Review Taskforce. The Taskforce is undertaking a program of work to review all MBS items to ensure they are contemporary, reflect current clinical practice and allow for the provision of health services that improve health outcomes. Further, it will identify services that are considered unsafe or ineffective.

It is anticipated that the Mental Health Services Clinical Committee will be established to review psychiatry, GP mental health and psychology MBS items.

The Government also established the Primary Health Care Advisory Group, led by Dr Steve Hambleton, former Australian Medical Association President. The Advisory Group investigated options to provide: better care for people with complex and chronic illness; innovative care and funding models; better recognition and treatment of mental health conditions; and greater connection between primary health care and hospital care. Following an extensive national consultation process and review of the evidence, the Advisory Group provided a final report to Government in December 2015.

In response to that report, as announced on 31 March 2016, the Government is providing funding for stage one of the establishment of Health Care Homes in ten Primary Health Networks (PHNs) regions across Australia from 2016-17 through 2019-20. Under this model, eligible patients with chronic and complex health conditions will voluntarily enrol with a participating medical practice known as their Health Care Home. This practice will provide a patient with a ‘home base’ for the ongoing coordination, management and support of their conditions. The model moves away from current fee-for-service payments for these eligible patients except for routine health issues not related to their chronic illness.

Recommendation 2

The Committee recommends that the Commonwealth consider increasing funding for the Younger Onset Dementia Key Worker Program in order to provide support to all people living with dementia. The increased funding should also ensure that accurate data is collected for evaluation purposes *(para 3.39)*.

Not Supported

The Australian Government does not support this recommendation.

Priority four of the NFAD is "Accessing ongoing care and support".

The Younger Onset Dementia Key Worker Program (YODKWP) is transitioning to the National Disability Insurance Scheme (NDIS). Transitioning to the NDIS will provide the opportunity for Dementia Australia to receive significantly more funding whilst providing services to eligible people with younger onset dementia.

The Government's priority is to ensure that the NDIS is structured to provide support to those who need it. The NDIS is designed to provide people with disability, their families and carers greater choice and control over the course of their lives, including the flexibility to make decisions about which disability services and supports they use. Evidence suggests that when people with disability are given greater choice and control over their services they achieve better life outcomes.

Access rates for the YODKWP have not been high and performance statistics do not support expansion of the program. An evaluation of this program is currently underway and although initial reports suggest that the program has resulted in some good outcomes so far, it would be inappropriate to expand the program based on preliminary findings without the analysis of longer term, more meaningful data.

The Cognitive Decline Partnership Centre funded by the National Health and Medical Research Council (NHMRC) and industry groups recently conducted an evaluation of current models of key workers for people living with dementia in Australia, including a systematic review of the evidence in Australia and internationally. The key findings from the evaluation supported the role of dementia support workers and identified a need to further explore ways to increase access to the role within consumer directed care. Trialling and aligning the model with Primary Health Networks was also recommended. Key findings are relevant to future policy development.

Recommendation 3

The Committee recommends that each State and Territory develop dementia training facilities similar to the Perc Walkley Dementia Learning Centre in Victoria *(para 3.40)*.

Noted

The Australian Government notes this recommendation.

Priority four of the NFAD is "Accessing ongoing care and support". The related action to which the Government has committed is: Support system wide, organisational and workforce awareness of BPSD together with evidence-based prevention and management strategies, including the provision of dementia friendly environments.

The Government recognises the role that the physical environment and design of the care setting plays on providing high quality care to people living with dementia. Noting environmental design as an emerging priority, the Government is committed to providing flexible funding for a range of different approaches. The Government also notes that the aged care industry and the community share a role in ensuring environments are dementia friendly.

In 2013-14 the jointly funded Commonwealth-Victorian Home and Community Care program provided one-off funding to Dementia Australia Victoria towards establishment of the Perc Walkley Dementia Learning Centre in Victoria. The Perc Walkley Dementia Learning Centre is a dementia learning facility which showcases dementia friendly design. The goal of the Centre is to provide education on how workplaces, homes and public spaces can become dementia friendly. The Centre creates a multi-sensory simulation using light, sound, colour and visual content to create a virtual reality experience at the Centre, which enables aged care and health care workers to be taken into the world of people living with dementia.

The Australian Government funds the Dementia Training Program (DTP) to provide dementia-specific training to aged care, health care and other community providers and their staff in order to improve the care and wellbeing of people living with dementia. The DTP offers an environmental design workshop and consultancy for aged and healthcare services. A consultancy and resources specifically for the design, construction and maintenance of aged care facilities for Aboriginal and Torres Strait Islander peoples is also available. The program provides service managers and their design consultants with the knowledge, resources and tools required to understand the effects of the built environment on the person living with dementia and modify the environment to promote well-being while reducing confusion and depression. The information is provided through education and on-site consultation and is available in each state and territory.

The Government acknowledges the ongoing work of non-government organisations in improving environmental design. For example, Dementia Australia Victoria and HammondCare have both been involved in development of virtual reality dementia training technology which enables anyone to experience planned physical spaces from the perspective of someone living with dementia. The technology assists care staff, designers and builders to

understand sensory challenges for a person living with dementia and design environments that are much more welcoming and less confronting.

The Government-funded DBMAS provider notes that environmental factors contribute to over 70 per cent of referred cases. To inform practice, the DBMAS provider can use portable virtual reality technology to educate staff about how sensory challenges contribute to behavioural and psychological symptoms of dementia.

The Government currently funds Dementia Australia New South Wales for a trial of a dementia-specific experiential learning program in hospitals. The program uses a train-the-trainer model to engage hospital staff in simulation exercises to see how life might be experienced by their patients with dementia. The program is an opportunity for staff to reflect on the effect their work practices can have on the behaviour of those they are caring for.

Recommendation 4

The Committee recommends that the Commonwealth encourage relevant professional organisations, such as the Royal Australian College of General Practitioners, to ensure that patients diagnosed with dementia and their carers are informed by health professionals of the dementia supports available and how to access them *(para 3.53).*

Supported In-Principle

The Australian Government supports this recommendation in principle.

Two priority areas for action under the NFAD is "the need for timely diagnosis" and "accessing care and support post diagnosis".

The Australian Government has delivered multiple initiatives to increase awareness for patients, carers and General Practitioners about the pathways into support and care.

The NHMRC Cognitive Decline Partnership Centre (the Centre) has developed *Clinical Practice Guidelines and Principles of Care for People with Dementia* (the Guidelines) in consultation with an expert multi-disciplinary Guideline Adaptation Committee convened by the Centre. The Guidelines provide recommendations for the diagnosis and management of dementia and are intended for use by staff working with people living with dementia in the health and aged care sectors. The Guidelines also inform GPs about the key entry points for support services for the person with dementia, including Dementia Australia, My Aged Care, Carers Australia and the Aged Care Assessment Teams.

The Centre has also published *Diagnosis, treatment and care for people with dementia: A consumer companion guide to the Clinical Practice Guidelines and Principles of Care for People with Dementia*. This consumer version of the Clinical Practice Guidelines includes accessible information about the latest evidence on dementia as well as information about the full range of dementia services and support. It is available from: www.sydney.edu.au/medicine/cdpc/resources/dementia-guidelines.php. The guidelines and the consumer companion have both been promoted to GPs via the Primary Health Networks.

GPs also have access to the HealthPathways program which is a web-based information portal supporting primary care clinicians to plan patient care through the primary, community and acute health care systems. This is designed to be used at the point of care, primarily for General Practitioners but is also available to Hospital Specialists, Nurses, Allied Health and other Health Professionals.

Other activities undertaken by the Department of Health may also assist dementia patients and their carers to be aware of the supports available to them. This includes the establishment of Primary Health Networks (PHNs) which aim to improve the efficiency and effectiveness of medical services for patients, particularly those at risk of poor health outcomes, and improve coordination of care to ensure patients receive the right care in the right place at the right time.

PHNs have undertaken their baseline needs assessments and prepared their 2016-18 Activity Work Plans which have informed their commissioning decisions from 2016-17. While there are no activities specifically devoted to dementia in PHNs' first Activity Work Plans (submitted in May 2016), a number of them give consideration to dementia within broader activities that are focused on aged care including falls prevention, medication management, advanced care planning, palliative and end of life care, and promotion of healthy ageing.

Another important initiative was the launch of My Aged Care in 2013 and its expansion in 2015 to become a true gateway for consumers to have their needs assessed and where appropriate, be referred to government funded aged care services. My Aged Care now includes a central client record to facilitate the collection and sharing of information, holistic needs assessment through a national standardised assessment form, online referral management and web based portals for clients, assessors and service providers.

Prior to the establishment of My Aged Care, there was no central pathway for older people to access information and services. The transition to My Aged Care was a significant shift in how information, assessment and referral to access aged care services took place.

The My Aged Care Regional Assessment Service (RAS) conducts face-to-face home support assessments for clients seeking entry-level support at home, provided under the Commonwealth Home Support Program (CHSP). The Aged Care Assessment Teams (ACATs) conduct face-to-face comprehensive assessments to determine a client's eligibility for care types under *the Aged Care Act 1997*, including home care packages, residential care, residential respite care, Transition Care and Short Term Restorative Care.

In June 2017, the Government launched a national awareness campaign promoting the My Aged Care website and national 1800 phone line. The advertising campaign will run in newspapers, magazines, radio, digital and social media. Other public relations activities will also be undertaken, including materials being available in 4,820 GP surgeries across the country.

In addition, carers are able to access further support through the Carer Gateway at https://www.carergateway.gov.au.

Resources are also available to encourage clinicians in hospital settings to provide information on support and referrals for care. In 2014, the Australian Commission on Safety and Quality in Health Care (the Commission) released resources titled *A better way to care: safe and high quality care for patients with cognitive impairment (dementia and delirium) in hospitals*. This publication emphasises the importance of a comprehensive assessment that includes assessing and addressing the support needs for carers.

The booklet *Dementia and Your Legal Rights* created by Dementia Australia, contains practical information for people living with dementia, and their families and carers, for when the person with dementia no longer has the mental capacity to make decisions that affect them. This resource could assist GPs to support people living with dementia and their family and carers.

Recommendation 5

The Committee recommends that the Commonwealth facilitate and potentially fund the establishment of dementia-specific respite facilities, including in regional and remote areas *(para 3.95)*.

Noted

The Australian Government notes this recommendation.

Priority four of the NFAD is "Accessing ongoing care and support". The related action to which the Government has committed is:
Provide people with dementia and their carers and families access to appropriate and responsive respite services.

Given its prevalence amongst older people, the Government considers the provision of appropriate care and support of people with dementia, their families and carers to be core business for all providers of aged care (including respite care). To support this, the Government provides a broad range of training and resources in dementia care for the aged care sector, as outlined in other recommendations in this document.

The Government acknowledges the unique respite needs of people living with dementia and their carers, as well as the additional challenges faced by those living in regional and remote areas. Consequently, the Government currently funds a range of programs and initiatives that provide respite support for carers of people living with dementia.

The CHSP provides a range of planned respite services for older people including flexible respite such as in-home respite and host family respite; cottage respite; and centre-based respite. Respite services provided through the CHSP are complemented by other respite services including emergency respite, which can be accessed through the Commonwealth Respite and Carelink Centres (CRCCs), and residential respite (short term stays in aged care homes).

In response to the growing need for planned respite services for frail older clients, the 2016 CHSP Growth Funding Round targeted planned respite services as a priority area across a number of Aged Care Planning Regions for identified client groups. Through this funding round, an additional $115 million has been made available to deliver additional aged care services, including an increased number of planned respite services.

Residential respite is provided across Australia. In 2015-16, of the 2,669 aged care homes that claimed Australian Government residential care subsidies, 2,438 (91 per cent) claimed for delivering residential respite care. [2] This includes 944 (91 per cent) of the 1,042 aged care homes located in regional, remote or very remote areas of Australia.

The Australian Government funds 54 CRCCs nationally to assist carers, including those living in rural and remote locations. CRCCs provide a link to carer support services and assist carers with options to access short-term and emergency respite. Where appropriate, a Centre can help with putting in place regular respite for a carer to reduce the need for unplanned and

[2] 2015–16 Report on the Operation of the *Aged Care Act 1997*, pp 39 and 45.

emergency respite. CRCCs also provide information about carer support services in their local area.

As noted in response to Recommendation 4, My Aged Care is the primary entry point to Australia's aged care system. My Aged Care provides information about ageing and aged care, and also assesses people's needs, as well as locating and accessing suitable services, including respite care.

The Department of Social Services (DSS) administers a range of services and programs to specifically support carers. DSS is currently developing and implementing a new Integrated Plan for Carer Support Services which seeks to recognise, support and sustain the vital work of unpaid carers. The first stage of the plan is the implementation of the Carer Gateway, which supports carers to locate and access carer support services. The Carer Gateway can be accessed at https://www.carergateway.gov.au.

The Department of Health is working collaboratively with the DSS to ensure that the support needs of clients and their carers are can considered holistically and in recognition of the importance of supporting the ongoing care relationship.

Recommendation 6

The Committee recommends that the Commonwealth, in consultation with industry, develop guidelines regarding dementia-specific respite facilities that can effectively manage BPSD *(para 3.96)*.

Noted

The Australian Government notes this recommendation.

Priority four of the NFAD is "accessing ongoing care and support". The related action to which the Government has committed is:

- Provide people with dementia and their carers and families access to appropriate and responsive respite services.

The Government acknowledges that transitioning from home to respite and back again can be very difficult for a person living with dementia.

As noted in the Foreword, the national DBMAS supports staff and carers in community and residential care services (including respite care), as well as acute and primary care settings. DBMAS provides information, advice, assessment and short term case management interventions to improve the quality of life of the person living with dementia. SBRTs support Commonwealth funded approved residential aged care (including respite care) providers requiring assistance with addressing the needs of people with severe and very severe BPSD.

These services can be provided to support the transition of a person living with dementia to and from respite care. Through both programs, a mobile workforce of multidisciplinary clinicians provides locally delivered person-centred interventions, capacity building and resources for carers and organisations to improve skills in the care of people living with dementia in the longer term.

As previously noted, the Australian Government also funds 54 CRCCs nationally to assist carers, including those living in rural and remote locations. CRCCs provide a link to carer support services and assist carers with options to access short-term and emergency respite. Where appropriate, a Centre can help with putting in place regular respite for a carer to reduce the need for unplanned and emergency respite. CRCCs also provide information about carer support services in their local area.

In 2012, the Dementia Behaviour Management Advisory Service produced guidelines around the management of BPSD. Specifically, the *Behaviour Management: A Guide to Good Practice - Managing Behavioural and Psychological Symptoms of Dementia* (the Guide) is a comprehensive evidence and practice-based overview of BPSD management principles which enables practical strategies and interventions for assisting care staff and family members in any setting including facilities offering respite care.

Following the release of the Guide in 2012, the Government has also funded additional resources: the *Managing BPSD App for Clinicians* is a quick reference guide to assist clinicians when they are presented with BPSD and is based on the Guide. This clinicians' app has now also been modified into a *Managing BPSD App for Family and Carers* to assist

family carers in responding to and understanding the behaviours associated with the person's dementia.

Both apps cover topics such as:

- a description of the symptom and how it presents in dementia;
- potential causes and/or contributing factors
- precautions that can be taken to reduce the chance of some behaviours.

Research on BPSD will increase the evidence base to inform guidelines and implementation strategies for effective management of BPSD across a range of care settings including respite care facilities. One of the objectives of the NHMRC National Institute for Dementia Research (established under the Boosting Dementia Research 2014-15 Budget measure) is to strategically expand dementia research by identifying essential research priorities for Australia across the full spectrum from basic research to research translation. A comprehensive consultation with a diverse range of stakeholders, including researchers, clinicians, consumers and policy makers has been undertaken to identify priority areas for Australian dementia research and translation. An evidence based approach to manage BPSD to support dignity and quality of life of a person with dementia, as well as quality of care and the wellbeing of the carer, emerged as a key priority.

Recommendation 7

The committee recommends that the Commonwealth explore options for improving the provision of respite in rural and remote areas *(para 3.97)*.

Noted

The Australian Government notes this recommendation.

The Australian Government recognises that providers of aged care services located in rural and remote areas face particular challenges in service provision, including issues related to the operation of small services, higher infrastructure and supply costs, and difficulties in attracting and retaining staff.

The Australian Government supports a range of respite options, in both residential, flexible care and home care settings, which carers of people living with dementia in rural and remote areas can access.

Australian Government subsidised aged care facilities are able to provide short-term care in the form of residential respite. Providers of residential respite care do not have a separate allocation of residential respite places. Rather, a portion of each permanent allocation of residential care places is used for the provision of respite care. It is a matter for the provider as to the mix of respite and permanent residential care places delivered within the financial year. The provision of residential respite services depends on the willingness and ability of providers to provide respite care.

In 2015-16, of the 2,669 residential aged care services, 2,438 provided residential respite at some stage in the financial year.[3] Throughout 2015–16, there were 73,335 admissions to residential respite. Providing they are assessed as eligible for respite by an ACAT, people living with dementia are able to access these services.

Respite is also accessible through the Multi-Purpose Services (MPS) Program. The MPS Program is a joint initiative of the Australian and state and territory governments, and provides integrated health and aged care services for small rural and remote communities. MPS have an important role in small or isolated communities and allow services to exist in regions that could not viably support a stand-alone hospital or aged care home. At 30 June 2016, there were 177 MPS services providing 3,592 flexible aged care places. These places can be used to deliver residential care, respite care and home care services.

In addition to residential respite, the National Aboriginal and Torres Strait Islander Flexible Aged Care Program (the Flexible Aged Care Program) funds organisations to provide culturally appropriate aged care to older Aboriginal and Torres Strait Islander people close to home and community. Flexible aged care services funded under this program are located mainly in rural and remote areas, and can deliver a mix of residential and community services, including emergency or planned respite care, in accordance with the needs of the community.

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[3] 2015–16 Report on the Operation of the *Aged Care Act 1997*, pp 39 and 45.

As mentioned in response to Recommendation 5, the Government also funds more than 550 providers to deliver centre-based, cottage and flexible respite services through the CHSP, some of which are in rural and regional areas.

Also previously noted, the Australian Government funds 54 CRCCs nationally to assist carers, including those living in rural and remote locations. CRCCs provide a link to carer support services and assist carers with options to access short-term and emergency respite. Where appropriate, a Centre can help with putting in place regular respite for a carer to reduce the need for unplanned and emergency respite. CRCCs also provide information about carer support services in their local area.

Recommendation 8

The Committee recommends that the accreditation standards for Residential Aged Care Facilities include requirements for dementia-friendly design principles *(para 4.79).*

Supported In-Principle

The Australian Government supports this recommendation in-principle.

Priority four of the NFAD is "Accessing ongoing care and support". The Framework notes that a safe, secure and homely environment can reduce confusion and agitation, improve way finding and encourage social interaction.

The Government recognises the role that the physical environment and design of the care setting plays on providing high quality care to people living with dementia.

The Accreditation Standards for residential aged care services include requirements for dementia-friendly design principles. Standard 4: *Physical environment and safe systems* requires approved providers to ensure care recipients live in a safe and comfortable environment that meets regulatory requirements and ensures the quality of life and welfare of care recipients, staff and visitors.

Further, Expected Outcome 4.4: *Living environment*, states that approved providers of residential aged care services are expected to be actively working to provide a safe working environment. Assessment of a Residential Aged Care Facility's compliance against Standard 4 by the Australian Aged Care Quality Agency includes ensuring care recipients can access the environment easily and safely.

The Government has commenced the development of a single set of standards across all aged care services, including residential care. The new standards are being co-designed with industry and consumers, with advice from a Technical Advisory Group. Key objectives of the review are to increase the focus on outcomes for consumers in the standards and better support consumer choice and control.

As previously mentioned, the Government funds a number of initiatives to assist aged care providers to implement dementia-friendly design principles, including through the Dementia Training Program. This includes an environmental design education and consultancy for aged and healthcare services, which provides service managers and their design consultants with the information required to design high quality facilities for people living with dementia. The information is provided through education and on-site consultation.

Recommendation 9

The Committee recommends that the accreditation standards for Residential Aged Care Facilities reflect a better balance between clinical and quality-of-life outcomes *(para 4.80)*.

Noted

The Australian Government notes this recommendation.

One of the key principles underpinning the NFAD is “People with dementia are valued and respected, including their rights to choice, dignity, safety (physical, emotional and psychological) and quality of life.”

Consumer focus is one of the fundamental principles underlying the provision of quality care and services, whether the expected outcomes concern clinical care or lifestyle related outcomes. Residential aged care services are assessed against the Accreditation Standards by the Australian Aged Care Quality Agency. The Accreditation Standards contain four Standards and 44 Expected outcomes. The four standards are:

1. Management systems, staffing and organisational development
2. Health and personal care
3. Resident lifestyle
4. Physical environment and safe systems.

The Accreditation Standards were designed to protect and foster quality of care and quality of life of care recipients of aged care homes. They were also designed to support a structured approach to the delivery of quality care to care recipients.

The Accreditation Standards and expected outcomes cover a comprehensive range of care outcomes for consumers, from health and personal care through to considerations of independence, leisure interests, cultural and spiritual life, and the safety of consumers and staff. These care outcomes must be delivered in a way that enhance a consumer’s dignity and rights and promote well-being in a safe and comfortable living environment.

As previously noted, the Government has commenced the development of a Single Aged Care Quality Framework across the aged care sector. The new standards are being co-designed with industry and consumers, with advice from a Technical Advisory Group. In developing a single set of standards the intention is to:

- provide consumers with greater consistency in expectations and continuity throughout their aged care journey
- provide a greater focus on consumer engagement in line with a consumer directed care model
- reinforce the consumer’s right to take risks in the pursuit of quality of life.

Consultation has been conducted on the draft single set of standards. The standards are being refined based on feedback from consumers and the sector. Once revised, the standards will be tested with a small group of providers. This work will be led by the Australian Aged Care Quality Agency. Further work will also be undertaken to develop education and guidance material to support the implementation of the new standards. Any changes to the standards will also involve amendment to the aged care legislation.

In addition to changes to Accreditation Standards, the voluntary National Aged Care Quality Indicator (QI) Program commenced in January 2016 with three clinical indicators (pressure injuries, use of physical restraint and unplanned weight loss) for residential aged care services.

Throughout 2016, the Department of Health worked closely with the National Aged Care Alliance Quality Indicators Reference Group, providers and consumers about next steps for the QI Program. Three tools to measure consumer experience and quality of life were piloted in residential aged care and home care. At the same time, the department also undertook a pilot to measure consumer goal attainment in home care.

In the longer term, information on QIs will be published on the My Aged Care website to give consumers transparent, comparable information about the quality in aged care to assist decision making; and for providers to have robust, valid data to measure and monitor their performance and support continuous quality improvement.

Recommendation 10

The Committee recommends that a phased program of accredited training in dementia and the management of Behavioural and Psychological Symptoms of Dementia (BPSD) be required for all employees of Residential Age Care Facilities *(para 5.44)*.

Supported In-Principle

The Australian Government supports this recommendation in-principle and acknowledges workforce training and education is a shared responsibility between government and industry.

Priority four of the NFAD is "Accessing ongoing care and support". The related action to which the Government has committed is: Provide and promote dementia training and ongoing education for all staff that care for people living with dementia.

The *Aged Care Act 1997* requires approved providers of Commonwealth-subsidised residential aged care to meet the Accreditation Standards and ensure that all care recipients are provided with quality care and services. The Accreditation Standards require aged care providers to ensure that staff have the appropriate knowledge and skills to effectively perform their roles. Recognising that many of the levers to influence the workforce rest with employers and providers, the primary responsibility for workforce rests with providers. Aged care providers are best placed to determine and manage their workforce needs. The Government will assist the sector with the development of an aged care workforce strategy.

The Government funds a suite of programs to help embed best practice care of people living with BPSD in the aged care workforce.

On 25 January 2016, the Government announced a new national approach to dementia care and training, in response to the 2015 Analysis of Dementia Programs. The DTP is now funded to provide nationally consistent dementia-specific training to aged and health care providers and their staff in order to improve the care and wellbeing of people living with dementia. The DTP's training offerings for employees of residential aged care staff include the understanding of changed behaviours and the management of BPSD. Training is delivered across Australia, including in many rural locations.

DTP training for aged care providers and their employees includes:

- accredited dementia care vocational level training courses – free to eligible care workers in residential, respite, community care or the wider health services
- tailored onsite training to aged care providers who request assistance, including a dementia skills and environment audit, followed by a tailored training package.

As noted previously, the national DBMAS supports staff and carers in community and residential care services, including respite care. DBMAS provides information, advice, assessment and short term case management interventions to improve the quality of life of the person living with dementia. SBRTs support Commonwealth funded approved residential aged care (including respite care) providers requiring assistance with addressing the needs of people with severe and very severe BPSD. In addition to providing person-centred

interventions, both programs offer capacity building and resources for carers and organisations to improve skills in the care of people living with dementia in the longer term.

Recommendation 11

The Committee recommends that the Commonwealth take a proactive stance in highlighting the importance of staff training in dementia care, and develop linkages between care and education providers *(para 5.45).*

Supported In-Principle

The Australian Government supports this recommendation in-principle.

Priority four of the NFAD is “Accessing ongoing care and support”. The related action to which the Government has committed is: Provide and promote dementia training and ongoing education for all staff that care for people living with dementia.

As previously noted, the Australian Government now funds the DTP to provide nationally consistent dementia-specific training to aged and health care providers and their staff in order to improve the care and wellbeing of people living with dementia. In addition to the training for aged care providers and their employees previously noted, the DTA provides Continuing Professional Development training on dementia assessment, diagnosis and management to GPs, nurses, pharmacists, psychologists, specialists, allied health and other relevant professionals as appropriate.

Delivered by a consortium of five universities and Dementia Australia, the DTP has a strong Essential Collaborators Network with members from leading aged care, specialist dementia care, health education and research organisations and actively promotes training for staff in aged, primary and acute care settings.

The DTP engages strongly with aged care and health providers and provides a customised combination of recommended courses, services and resources in response to an audit of the environment and an assessment of staff dementia skills and knowledge.

The DTP learning pathway is designed to enable clients to participate in training options which progress their knowledge from a foundation level to advanced dementia knowledge. The DTP supports choice in learning preferences, depths of engagement, training modality, and accreditation needs. It enables flexible training entry and exit points according to topic, time, and organisational factors.

Recommendation 12

The Committee recommends that the use of antipsychotic medication should be reviewed by the prescribing doctor after the first three months to assess the ongoing need. *(para 6.19)*

Supported In-Principle

The Australian Government supports this recommendation in-principle.

Under priority four "accessing ongoing care and support", the NFAD notes:

> A decision about the use of medicine to treat BPSD is a clinical one made by the prescriber based on individual circumstances... Feedback should be obtained from people with dementia, their carers and families and regular pharmaceutical reviews by pharmacists and prescribers conducted.

As previously noted, the NHMRC Cognitive Decline Partnership Centre (the Centre) has developed *Clinical Practice Guidelines and Principles of Care for People with Dementia* (the Guidelines) in consultation with an expert multi-disciplinary Guideline Adaptation Committee convened by the Centre. Clinical Practice Guidelines have been shown to improve quality and consistency of care for people with a range of conditions.

The Guidelines advise that, if medication is used to manage BPSD, a range of consultations and medication management techniques should be implemented and:

- its use should be reviewed every four to 12 weeks, considering the need for antipsychotics and possible cessation of medication
- the review should include regular assessment and recording of changes in cognition and target symptoms.

The Guidelines also advise that, due to the increased risk of serious adverse events, people with mild-to-moderate behavioural and psychological symptoms of dementia should not usually be prescribed antipsychotic medications. In addition, the Guideline Adaptation Committee found that reducing over-prescription of antipsychotics should be prioritised for further research.

The decision to prescribe antipsychotic medicines for a resident of a residential aged care facility is a clinical decision made by the resident's treating medical practitioner in consultation with the resident and their family or representative and other clinicians. As with any prescribing decision, the treating medical practitioner must balance the potential benefits of treatment against the potential risks, while taking into account the particular clinical circumstances of each resident. This decision is part of the overall care plan that Commonwealth funded aged care providers are required to develop and implement for each resident, which includes a thorough assessment of the resident's physical and mental health to determine the most appropriate response to meet their care needs.

With respect to subsidy, in Australia there are already strict Pharmaceutical Benefits Scheme (PBS) restrictions, around the prescribing of antipsychotics to ensure they are used appropriately.

Most antipsychotic medicines available under the PBS require the prescriber to obtain and include an authority code on the prescription from the Department of Human Services. Prescribers are required to prescribe in accordance with the PBS restriction criteria and keep evidence of compliance and patient eligibility on patient records. The prescriber must also prescribe in accordance with his/her approved scope of practice under state or territory law, and comply with other State and Territory laws that regulate prescribing.

The independent, statutory Pharmaceutical Benefits Advisory Committee (PBAC) provides recommendations to the Government about PBS listings based on clinical evidence, and takes into account quality use of medicines issues in making its recommendations. As an example, at its November 2015 meeting, the PBAC recommended that an amendment be made to the PBS restriction for risperidone for the indication of behavioural disturbance in patients who have dementia and who have failed to respond to non-pharmacological methods of treatment, to align with the revised TGA indication. This amendment restricts use to moderate to severe dementia of the Alzheimer's type and limits duration of treatment to 12 weeks based on updated evidence about the efficacy and toxicity of this medicine. Further information is available at http://www.pbs.gov.au/industry/listing/elements/pbac-meetings/psd/2015-11/files/risperidone-psd-november-2015.pdf.

A Post-Market Review of PBS Anti-Dementia Medicines for Alzheimer's Disease was completed in 2012. The PBAC considered the Review report in December 2012 and accepted the Report's findings that these medicines are being used in a broader population and for longer periods of time than originally anticipated.

To account for the use of these medicines in a broader population, the PBAC made a number of recommendations including restriction changes to make access to these medicines clinically appropriate for prescribers and patients who respond to treatment. Further information is available on the PBS Post-Market review website at: http://www.pbs.gov.au/info/reviews/anti-dementia-drugs.

In addition, as part of the announcement of the outcomes of the Chemotherapy Review on 30 November 2013, the Prime Minister announced the Government's intention to review the Authority Required PBS Listings. The Department of Health conducted a Post-Market Review of Authority Required PBS Listings, under the Australian Government's National Medicines Policy framework. The objective of the Review was to improve patient safety and care by reducing administrative burden for health professionals.

The Review built on the PBAC's consideration of a submission from the Australian Medical Association that recommended the movement of a number of medicines from Authority Required to Authority Required (Streamlined). The PBAC recommended that all Authority Required listings be reviewed to ensure that restrictions appropriately reflect the level of monitoring required to manage the quality use of medicines and the identified risks.

The Review was undertaken in tranches. The PBAC considered the first tranche of PBS Authority Required listings in December 2014 (which included medicines of the highest regulatory burden), the second tranche in March 2015 (which included medicines for psychiatric conditions such as antipsychotics), the third in July 2015, antibiotics and opioids in August 2015 and dermatological listings in December 2015.

The Review of Authority Required PBS listings is now complete. Implementation of PBAC recommendations is being progressed. The final Review report is expected to be published on the pbs.gov.au website in September 2017.

Further information about the Review of PBS Authority Required medicines is available on the PBS Post-Market Review website at:
http://www.pbs.gov.au/info/reviews/authority-required-listings.

The Government has funded two separate projects through the University of Tasmania and the University of New South Wales at a total cost of $4.1 million (2013 to 2016) aimed at reducing the use of sedative and antipsychotic medications in residential aged care facilities (RACFs).

Both projects involved the:

- measurement of antipsychotic medication use in participating RACFs
- education and training of participating GPs, staff, pharmacists and families on risks related to inappropriate antipsychotic medication use
- regular review of individual residents taking antipsychotic medication by the prescribing doctor

Findings from these projects will inform future policy.

Recommendation 13

The Committee recommends that residential aged care facilities, as part of their existing Aged Care Standards and Accreditation Agency annual audit process, report:

- circumstances where an individual has been prescribed antipsychotic medication for more than six months, together with the reasons for and any steps taken to minimise that use; and
- general usage patterns of antipsychotic medications in each facility *(para 6.20)*.

Noted

The Australian Government notes this recommendation.

Under priority four "accessing ongoing care and support", the NFAD notes:

> It is vital to adopt a collaborative approach to the management of medications for people with dementia as many medicines may induce or worsen BPSD. Feedback should be obtained from people with dementia, their carers and families and regular pharmaceutical reviews by pharmacists and prescribers conducted.

Approved providers of residential aged care must meet the requirements of the Accreditation Standards under the *Aged Care Act 1997*. Further, each state and territory has legislation covering the use, administration and ordering of medicines. This may include the relevant minimum competency or qualification level required. Providers are required to ensure that all treatments and procedures, including medication, comply with the requirements of their specific state and territory laws (*Aged Care Principles 2014*; Schedule 1, part 2, item 2.4).

Each provider should consider the needs of their care recipients, the meeting of the Standards and the local legislation governing the use of medicines in determining the staffing skill mix they require and the processes they may use. While state and territory legislation provides the minimum requirement, a provider may need to implement additional steps or a higher skill mix depending on the specific needs of the care recipients in their care.

In considering the ability to meet the needs of care recipients, providers need to ensure that they are cognisant of the steps in medication management. Medication management involves more than the administration of a medicine. It also includes, for example, the monitoring of a care recipient after administration of a medication. It can also involve a decision about administering a medication versus withholding a medication while obtaining further medical advice. Providers need to ensure that they have a system that covers all aspects of medication management and regularly evaluate and review their medication management systems and processes. A resource in this area is the Australian Government's *Guiding principles for medication management in residential aged care facilities*, disseminated to all residential aged care homes.

The decision to prescribe antipsychotic medicines for a care recipient is a clinical decision made by the care recipient's treating medical practitioner in consultation with the resident and/or their representative. As with any prescribing decision, the treating medical practitioner must balance the potential benefits of treatment against the potential risks while taking into account the particular clinical circumstances of each care recipient.

Additionally, the Australian Government supported the development and testing of a standardised medication chart for residential aged care that has been trialled and was fully implemented during 2014-15. The new chart released in 2014 serves as both a prescription for most PBS and Repatriation Pharmaceutical Benefits Scheme (RPBS) medicines as well as a record of medication administration. Testing of the chart has demonstrated improved resident safety and will, over time, provide better aged care sector utilisation data on medicines, including rates of antipsychotic use.

Documents related to the medication chart are available on the Australian Commission on Safety and Quality in Health Care (the Commission) website: http://www.safetyandquality.gov.au/our-work/medication-safety/nrmc.

The Commission held a national roundtable on reducing inappropriate use of antipsychotics in older people in October 2016. The purpose of the roundtable was to seek expert advice on ways to reduce inappropriate use of antipsychotics in older people with BPSD, and to identify and prioritise strategies for action in the community, residential aged care and acute hospital settings.

The Government has funded two separate projects through the University of Tasmania and the University of New South Wales at a total cost of $4.1 million (2013 to 2016) aimed at reducing the use of sedative and antipsychotic medications in Residential Aged Care facilities (RACFs). Findings from these projects will be used to develop future policy.

Both projects involved the:

- measurement of antipsychotic medication use in RACFs
- education and training of GPs, staff, pharmacists and families on risks related to inappropriate antipsychotic medication use
- promotion of non-drug strategies to manage behavioural and psychological symptoms in people living with dementia.

Recommendation 14

The committee recommends that the Commonwealth develop, in consultation with dementia advocates and service providers, guidelines for the recording and reporting on the use of all forms of restraints in residential facilities *(para 6.31)*.

Noted

The Australian Government notes this recommendation.

The Australian Government has a regulatory framework in place to monitor the quality of care older Australians receive in aged care facilities through accreditation, complaints, quality reporting, compliance and compulsory reporting. As outlined in the response to recommendation 10, the *Aged Care Act 1997* requires approved providers of Commonwealth subsidised residential aged care to meet the Accreditation Standards and ensure that all care recipients are provided with quality care and services.

The decision to use restraints in residential aged care facilities is a clinical decision and must be made in consultation with the care recipient and/or their representative, staff and their medical practitioner. Any use of restraint should be included in the resident's care plan. In making decisions on the application of restrictive practices, care providers must balance a patient's basic legal and human rights (consistent with the aged care standards) with their duty of care to protect the patient, other residents and staff from harm.

In recognition of the issues facing aged care providers around restraint use the Australian Government has supplied providers with a decision making guide on this issue since 2004. This was updated in 2012 and expanded into the following separate guides for residential and community care:

- *The Decision-Making-Tool: Supporting a Restraint Free Environment in Residential aged care*
- *The Decision-Making-Tool: Supporting a Restraint Free Environment in Community aged care.*

The decision making tools provide staff, managers and carers with information and practical strategies on organisational, environmental, physical and psychosocial considerations that reduce the need to consider restraint as a care option. These toolkits include posters and information sheets which can be photocopied to provide in-house education and an information sheet that has been designed to be photocopied and handed to relatives.

An important avenue in which care recipients and their families can raise concerns about the quality of care provided is the Aged Care Complaints Commissioner, which includes responding to concerns about the use of any form of restraint. The Commissioner takes all complaints seriously and seeks to achieve quality and timely outcomes for care recipients and providers. Where the Department of Health identifies significant failures of an aged care provider to meet their legislative responsibilities compliance action can be taken.

The level of complaints to the Aged Care Complaints Commissioner from residents and/or their families or representatives in relation to the use of restraints is quite low. Analysis of complaints data in 2016 indicates that 1.3 per cent of all complaints are in relation to the use of chemical or physical restraint.

As outlined in the response to Recommendation 9, one of the three quality indicators in the National Aged Care Quality Indicator Program is use of physical restraint.

Recommendation 15

The committee recommends that the Commonwealth collect and report:
- the number of residents in aged care and acute care facilities with a diagnosis of dementia;
- the number of these residents who are taking, or have taken, antipsychotic medication;
- the number of instances where a patient has been prescribed multiple anti-psychotic medications;
- the reason the medication was prescribed; and
- the average duration of a course of prescribed antipsychotics. *(para 6.32)*

Noted

The Australian Government notes this recommendation.

Under priority four "accessing ongoing care and support", the NFAD notes:

> A decision about the use of medicine to treat BPSD is a clinical one made by the prescriber based on individual circumstances. It is vital to adopt a collaborative approach to the management of medications for people with dementia as many medicines may induce or worsen BPSD.

ACAT assessments and Aged Care Funding Instrument (ACFI) appraisals currently collect data about diagnoses of dementia among clients.

In the Aged Care Assessment Program (ACAP), dementia may be reported among the health conditions recorded in each ACAT assessment. Diagnoses of dementia that may be recorded include Alzheimer's disease, vascular dementia, and dementia as a symptom of other diseases. From 2016-17, ACATs' transition to use My Aged Care systems enables the availability of this data to the Department of Health at the individual client level.

ACFI appraisals also collect information about diagnosed health conditions, including dementia, for permanent residents in Australian Government-subsidised residential aged care facilities. The ACFI appraisal pack includes a mental and behavioural disorders checklist that allows for the reporting of up to three mental and behavioural diagnoses for each permanent resident. It has previously been reported that over half of all permanent residents with an ACFI appraisal had a diagnosis of dementia[4].

People admitted to hospital with dementia may have their diagnosis documented as part of the collection of data in Australian hospitals. Dementia may be recorded as a principal or additional diagnosis. However, research has confirmed that dementia is poorly recorded. [5] The Australian Commission on Safety and Quality in Health Care's resource titled *A better way to care: safe and high quality care for patients with cognitive impairment (dementia and delirium) in hospitals* emphasises the importance of recognising people with cognitive impairment to reduce increased risks of harm. Uptake of its key strategies may result in increased dementia and delirium coding and therefore a more accurate reflection of dementia rates in hospitals.

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[4] *Dementia* Australian Institute of Health and Welfare, See: www.aihw.gov.au/dementia. Accessed 10 March 2017.

[5] Australian Institute of Health and Welfare (2013). Dementia Care in hospitals: costs and strategies Canberra, AIHW.

Overall access to medicines in residential aged care is through the PBS and RPBS. The Drug Utilisation Sub-Committee (DUSC) considered an analysis of PBS antipsychotics prescription data in February 2013 and produced a report for the Pharmaceutical Benefits Advisory Committee (PBAC) in June 2013. The *Public Summary Document* detailing the PBAC's consideration, discussion and recommendation from the DUSC review is publicly available on the PBS website at www.pbs.gov.au/info/industry/listing/elements/pbac-meetings/psd/2013-08/antipsychotics.

The 2013 DUSC reports are available on the PBS website at www.pbs.gov.au/info/industry/listing/participants/public-release-docs/dusc-public-release-documents-by-medicine. In addition, PBAC recommended that DUSC review the whole class of antipsychotic drugs, 24 months after any changes in the pack size or number of repeats. This DUSC review was considered at the November 2016 PBAC meeting. The outcome statement of PBAC's consideration of the 2016 review can be viewed from the PBS website at www.pbs.gov.au/industry/listing/elements/pbac-meetings/pbac-outcomes/2016-11/dusc-report-2016-11.pdf. The PBAC noted that there was less use of low dose (25 mg) quetiapine indicating a reduction in the inappropriate prescribing of quetiapine for non-psychotic indications, such as sedation. The PBAC requested that DUSC continue to monitor the use of antipsychotics.

In addition, MedicineWise (NPS) is funded by the Government to assist prescribers and patients in the quality use of medicines and provide support for health professionals to assist their clinical management decisions. NPS has developed resources to help residential aged care staff understand and improve the management of medicines. These include Drug Use Evaluation (DUE) toolkits that help promote best practice medicines use in residential aged care homes. Two of these kits relate to sedation and use of antipsychotics.

As discussed in the response to Recommendation 13, a national standardised medication chart for residential aged care services was made available in 2014. Testing of the chart has demonstrated improved resident safety and will, over time, provide better aged care sector utilisation data on medicines, including rates of antipsychotic use.

The Commission held a national roundtable on reducing inappropriate use of antipsychotics in older people on 26 October 2016. The purpose of the roundtable was to seek expert advice on ways to reduce inappropriate use of antipsychotics in older people with BPSD, and to identify and prioritise strategies for action in the community, residential aged care and acute hospital settings.

The Government has funded two separate projects through the University of Tasmania and the University of New South Wales at a total cost of $4.1 million (2013 to 2016) aimed at reducing the use of sedative and antipsychotic medications in Residential Aged Care facilities (RACFs). Findings from these projects will be used to develop future policy.

Both projects involved the:

- measurement of antipsychotic medication use in RACFs
- education and training of GPs, staff, pharmacists and families on risks related to inappropriate antipsychotic medication use
- regular review of individual residents taking antipsychotic medication by the prescribing doctor.

Recommendation 16

The committee recommends that the Commonwealth undertake an information program for doctors and residential aged care facilities regarding the guidelines *Responding to Issues of Restraint in Aged Care in Residential Care. (para 6.48)*

Supported In-Principle

The Australian Government supports this recommendation in-principle.

One of the key principles underpinning the NFAD is "People with dementia are valued and respected, including their rights to choice, dignity, safety (physical, emotional and psychological) and quality of life."

As mentioned in the response to Recommendation 14, the Australian Government has supplied providers with a decision making guide on this issue since 2004. This was updated in 2012 and expanded into the following separate guides for residential and community care:

- *The Decision-Making-Tool: Supporting a Restraint Free Environment in Residential aged care*
- *The Decision-Making-Tool: Supporting a Restraint Free Environment in Community aged care.*

These toolkits include posters and information sheets which can be photocopied to provide in-house education and an information sheet that has been designed to be photocopied and handed to relatives.

An extensive information program has already been undertaken to support the uptake of the guidelines including:

- presentations based on the guidelines were made at the Better Practice Conferences sponsored by the Australian Aged Care Quality Agency held around Australia throughout 2013
- the toolkits were distributed to all Australian Government funded residential and home care providers nationally in late 2012. Additional printed copies of the resources are also available on request from National Mail and Marketing. In addition, the toolkits have been placed on the Department of Health's website and are currently available to download at https://agedcare.health.gov.au/publications-articles/resources-learning-training/decision-making-tool-supporting-a-restraint-free-environment
- since October 2012 over 7,560 copies of the toolkit have been distributed to residential aged care providers, and over 5,030 to home care providers from National Mail and Marketing.

As previously noted, the Australian Government funds the DTP to provide dementia-specific training to aged care, health care and other community providers and their staff. All of the training offerings promote the development of knowledge and skills and the creation of environments in which the use of physical and chemical restraints are not required. This includes the identification of strategies to prevent the emergence of BPSD and methods for identifying and minimising triggers of BPSD, which may include staff practices, pain, discomfort, environmental stressors or over stimulation.

DBMAS, SBRT and Dementia Training Australia all support minimal use of restraints including chemical restraints. DBMAS provides best practice guides for managing behavioural and psychological symptoms of dementia and conducts reviews to minimise the use of medication that has a negative impact on a person's emotional or cognitive state.

Recommendation 17

The Committee recommends that a review of the adequacy of respite facilities for Younger Onset Dementia patients be carried out urgently *(para 7.29).*

Noted

The Australian Government notes this recommendation.

Priority four of the NFAD is "Accessing ongoing care and support". The related action to which the Government has committed is:

- Provide people with dementia and their carers and families access to appropriate and responsive respite services.

People who are experiencing dementia and are under the age of 65 can face different challenges to those faced by older Australians with dementia and the Australian Government acknowledges the unique respite needs of people with younger onset dementia and their carers.

Under the Aged Care Services Improvement Healthy Ageing Grants process 2014 funding was available under priority 2 - responding to existing and emerging challenges including dementia care, for initiatives that supported good-practice models of respite care for younger people living with dementia and developed resources that assist organisations to tailor their services to younger people living with dementia.

Two projects were successful in this process:
1. Tailor Made, good practice model for respite services for people with Younger Onset Dementia and their families
2. Making Flexible Respite Care A Practical Reality.

There is no age restriction on residential respite care, so clients with Younger Onset Dementia (YOD) have the same access to respite as other people with an ACAT assessment. YOD clients can also access services from the National Disability Insurance Scheme (NDIS). The NDIS is rolling out nationally over three years (2016-2019) and currently operating in a number of locations across Australia. Findings from the NDIS trial sites coupled with the experience gained during roll-out provides an opportunity to learn, and ensure better outcomes for Australians with disability, their families and carers.

A number of reviews of the NDIS have been commissioned to take place between 2013 and 2017. The reviews will provide information on elements of launch, including performance against aims and objectives and the impact of some policy approaches. In particular, the Evaluation and Review of the NDIS Launch, conducted by the National Institute of Labour Studies, Flinders University and the review of the Lessons Learned from the Trial may provide insights relevant to this recommendation. The Government will reconsider this recommendation upon completion of these reviews.

Currently YOD clients are also able to access respite through other gateways, where there is another diagnosed disability or ailment. For example, the Government funds 109 Mental Health Respite Carer Support organisations across Australia, noting funding is transitioning to the NDIS for this program as care recipients are able to be supported by the NDIS. These services provide flexible respite and support to carers and families of people with mental

illness. Carers of people with YOD are able to access these services, provided the care recipient also has a mental illness which is impacting on their ability to function in the community.

In 2013, the Australian Government engaged the University of Wollongong (UoW) to undertake an *International Literature Review* and a *Needs and Feasibility Assessment of Services for People with Younger Onset Dementia*. The UoW review and assessment were completed in February 2014, and provided principles of appropriate care and can be used to inform future health care design regarding respite for people living with dementia, their families and their carers. Providers are aware of these principles, and have been encouraged to reference them. The principles are available to the sector online at: http://ahsri.uow.edu.au/chsd/projects/yod/index.html.

Recommendation 18

The Committee recommends that the Commonwealth fund the development of a pilot Younger Onset Dementia specific respite facility at either the Barwon or Hunter area National Disability Insurance Scheme trial sites.*(para 7.30)*

Noted

The Australian Government notes this recommendation.

Priority four of the NFAD is "Accessing ongoing care and support". The related action to which the Government has committed is:

- Provide people with dementia and their carers and families access to appropriate and responsive respite services.

The NDIS provides funding for long-term, individualised care and support that is reasonable and necessary to meet the needs of people with permanent disability, where a person's disability significantly affects their communication, mobility, self-care or self-management. This includes people with Younger Onset Dementia (YOD).

Under the NDIS people with permanent and significant disability, supported by their families and carers as appropriate, will work to develop their own personal plan for support, based on their goals and aspirations and their individual needs. The scheme will empower people with disability to engage as equal partners in decisions that will affect their lives. This includes having choice over the types of support they want and how these are delivered.

The National Disability Insurance Agency has a Catalogue of Supports that outlines the range of services that can be delivered to participants, provided they are related to the participant's disability, achievement of outcomes and ultimately their goals.

In addition to support through the NDIS, clients with YOD can also access respite care through the aged care system. As outlined in the response to Recommendation 17, there is no age restriction on residential respite care, so clients with YOD have the same access to respite as other people with an ACAT assessment.