

# RACP feedback to the draft National Dementia Action Plan 2023 – 2033

Department of Health and Aged Care February 2023

### About The Royal Australasian College of Physicians (RACP)

The RACP trains, educates and advocates on behalf of over 20,000 specialist physicians and 9,000 trainee physicians, across Australia and Aotearoa New Zealand. The RACP represents a broad range of medical specialties including general medicine, geriatric medicine, paediatrics and child health, cardiology, respiratory medicine, neurology, oncology, public health medicine, infectious diseases medicine, occupational and environmental medicine, palliative medicine, sexual health medicine, rehabilitation medicine, geriatric medicine, and addiction medicine. Beyond the drive for medical excellence, the RACP is committed to developing health and social policies which bring vital improvements to the wellbeing of patients and the community.



We acknowledge and pay respect to the Traditional Custodians and Elders – past, present and emerging – of the lands and waters on which RACP members and staff live, learn and work. The RACP acknowledges Māori as tangata whenua and Te Tiriti o Waitangi partners in Aotearoa New Zealand.

# **Executive summary**

The Royal Australasian College of Physicians (RACP) is pleased to provide expert specialist physician feedback on the draft National Dementia Action Plan 2023 – 2033. It is important to ensure that high quality, comprehensive and safe healthcare systems are available for people with dementia and their families and carers. Our feedback draws on the expertise and experience of our RACP member specialists.

Our RACP members are aware of how common dementia is in the population, with dementia being one of the major causes of disability and dependency among older people.<sup>1</sup> Most people with dementia are over the age of 65 years and have several comorbidities, which is of significance for the healthcare sector.<sup>2</sup> People with dementia also experience a trajectory of functional decline with dementia being one of the main drivers to residential aged care facility (RACF) placement in Australia. Australia also has a high rate of RACF placement compared to other similar Organisation for Economic Co-operation and Development (OECD) countries.<sup>3</sup>

Our RACP members are intrinsic to the health care of many people with dementia, including older patients. Although the Action Plan refers to geriatricians, psychogeriatricians, and neurologists as medical specialties involved in dementia diagnosis, there are other medical specialists (consultant physicians) involved in the treatment and management of people with dementia. These include, but are not limited to, palliative care physicians, rehabilitation physicians, general physicians, and those who specialise in pain medicine and acute medicine. Medical specialist involvement needs to be more explicit in the Action Plan.

The development and implementation of the National Dementia Action Plan that involves Federal and state/territory governments is a welcome strategic response to a multi-level set of needs. As a joint initiative between governments, it is essential to embed clear accountability and allocate dedicated funding to operationalise the Action Plan.

# **Recommendations**

- 1) **Direct engagement of clinical expertise through the RACP.** Including clinical leadership is fundamental to the successful systemic health care provisions for dementia and essential to inform the proposed "*central body comprising Australian Government and state and territory government officials*".
- 2) Further consideration of dementia related issues for Aboriginal and Torres Strait Islander people is needed, and it should include and objective, actions and performance measures to reduce the prevalence of dementia in priority populations. The Action Plan should be seen as an opportunity to better Close the Gap in related health care disparities for First Nations people.
- 3) Better recognition of the spectrum of dementia should be included. The Action Plan needs to encompass the spectrum of dementia, including mild, moderate, severe and profound features.
- 4) **Improved embedding and recognising medical practitioners.** Including both general practitioners (GPs), as the most constant point of care, and the role of specialist physicians (medical specialists), including those with interest in cognitive disorders, is suggested for the first 6 objectives.

<sup>&</sup>lt;sup>1</sup> WHO<u>|Global Action Plan on the Public Health Response to Dementia 2017–2025</u>. (accessed on 20 January 2023).

 <sup>&</sup>lt;sup>2</sup> Dyer SM, Laver K, Pond CD, Cumming RG, Whitehead C, Crotty M. Clinical practice guidelines and principles of care for people with dementia in Australia. Australian family physician. 2016 Dec;45(12):884-9.
 <sup>3</sup> Dyer SM, Valeri M, Arora N, Tilden D, Crotty M. Is Australia over-reliant on residential aged care to support our older

<sup>&</sup>lt;sup>3</sup> Dyer SM, Valeri M, Arora N, Tilden D, Crotty M. Is Australia over-reliant on residential aged care to support our older population?. The Medical Journal of Australia. 2020 Aug;213(4):156.

- 5) Greater attention on the need for effective functioning and support of referral processes and interface between general practice and specialist services (and other services). This is a vital component of any pathway through healthcare.
- 6) **Increased dementia training**. For all health practitioners, along with supporting cultural shifts regarding attitudes to people with dementia in healthcare settings.
- 7) The underlying approach to care needs to encompass both medical and psychosocial strategies.
- 8) **Develop a Clinical Care Standard for Dementia**. Similarly, as for delirium, which has driven significant improvements in care.
- 9) Further considerations for Behavioural and Psychological Symptoms of Dementia (BPSD) be included. The group, Tier 7 BPSD, be specifically included in the priorities and blueprints proposed to be developed for 2023 – 2026, and be given priority for collecting data, developing new models of care, building a research framework and enhancing service provision capacity.
- 10) **Memory Clinic models of care need to evolve.** It is important to provide multidisciplinary services with a holistic approach to patients' needs and include multiple nursing and allied health disciplines.
- 11) **Resourcing be considered.** ie. for those proposed performance measures that will lead to increased and desirable service activity; that is, where measures will drive activity, ensure they are correspondingly resourced.
- 12) **Develop data collection**. This will assist in directing resources to population groups and geographical areas most in need.

# Specific feedback

#### Aboriginal and Torres Strait Islander peoples

The RACP recommends the Action Plan be reviewed to include more direct address of dementia care-related needs for Aboriginal and Torres Strait Islander people and their families, carers and communities:

- The Action Plan notes that Aboriginal and Torres Strait Islander people are 3-5 times more likely to develop dementia; however the Action Plan includes no actions to reduce the prevalence of dementia in First Nations people. The Action Plan should include a specific objective on reducing the prevalence of dementia in priority populations, including First Nations peoples, people with disability, culturally and linguistically diverse people, LGBTQI people and veterans. Actions and performance measures should be developed in consultation with priority population groups and included within the plan.
- information on how Aboriginal and Torres Strait Islander people have been consulted in developing the Action Plan and further, how they will be specifically involved and/or consulted in the development of the final document.
- The Action Plan should include more evidence-based content, such as the current number or estimation of Aboriginal and Torres Strait Islander people living with dementia, along with additional information regarding the challenges faced. We note the Action Plan states there is a lack of research for this population group (page 64) and we support action on this.
- Cultural safety is included as principal in the Action Plan, but specific actions to implement cultural safety are not. Cultural safety will not be achieved unless there are specific actions, resources and performance measures developed to support the development of culturally safe services.

We suggest an amendment, page 9, first paragraph. As First Nations people collectively are referenced, we suggest this wording:

"There are often strong intersections between these groups. They may be an Aboriginal *[ADD]* and or Torres Strait Islander person living with dementia and

disability/chronic disease and live in a remote area. This intersectionality compounds issues of access."

#### **Objective 1: Tackling stigma and discrimination**

The RACP proposes an additional action linked to the focus area 1.2 Creating inclusive communities and environments for people living with dementia, their carers and families of creating dementia-friendly public spaces and services:

• [ADD] Providing more sites for appropriate dementia and cognitive impairment diagnosis and management, like the Cognitive Dementia and Memory service (CDAMS).

#### Objective 2: Minimising risk, delaying onset and progression

The RACP supports early intervention and prevention-based measures. Early intervention and timely supports can help to delay condition progression. It has been estimated that in Australia, even with a 10% reduction in dementia cases attributable to key modifiable lifestyle factors, savings of \$280 million might be achieved.<sup>4</sup> Delaying dementia onset therefore not only lessens the average number of years spent living with the disease but also has significant public health resource allocation implications.<sup>5</sup>

Prevention strategies that include a broader population-wide approach is a relevant part of this national plan, onethat encompasses promoting health and wellbeing (including relevant factors such as cardiovascular disease, cancer and dementia). This may encompass dementia prevention benefits of the promotion of increased physical activity, addressing hearing loss, healthy lifestyle factors (including alcohol and drugs) and addressing environmental factors, such as the known impact of air pollution.

We recommend Objective 2 be revised to consider the following:

- Prevention actions should target people aged under 65 years as well as those over 65 years. Noting that intervention needs to start well before the symptoms are apparent as pathology (eg. Alzheimer's pathology) can start ten years or more prior to that.
- Dementia training is essential for <u>all</u> health professionals, particularly where risk reduction is concerned, to ensure recognition of dementia, they are comfortable to have conversations about dementia, they know how to access dementia pathways, and that specialist physicians and other health professionals know when to refer to other specialists and other support services, such as Dementia Australia services.
- Reducing risk can be aided by reducing the high documentation burden in aged care services. This results in significant resource pressures, time delays and administration related fees (eg. regarding home care packages). Also, Aged Care Assessment Team (ACAT) document preparation is complex and requires time. This is also relevant to Objective 3.
- Including in the actions more of what we already know and promoting the scaling up of existing programs, eg. delirium is a known risk-factor for development of dementia. There are programs, such as <u>Eat Walk Engage</u> in Queensland, that can be implemented in hospital inpatient settings that have been shown to reduce the incidence of delirium. These programs should be implemented/funded in all hospitals across Australia.

We suggested amending the statement (page 26) *People living with mild cognitive impairment or in the early stages of dementia often aren't provided with information and support strategies to delay the onset [ADD] or progression of dementia, as it reads as nonsensical if people already have dementia.* 

<sup>&</sup>lt;sup>4</sup> Moore B, Miskovski K, Stupar M, Ng H. Reducing the Prevalence of Alzheimer's Disease: Modifiable Risk Factors or Social Determinants of Health. Sydney: Alzheimer's Australia. 2015.

<sup>&</sup>lt;sup>5</sup> Ashby-Mitchell K, Burns R, Shaw J, Anstey KJ. Proportion of dementia in Australia explained by common modifiable risk factors. Alzheimer's research & therapy. 2017 Dec;9(1):1-8.

We suggest adding these additional actions to the focus area 2.2 People are aware of what they can do to delay the onset and slow the progression:

- [ADD] Improving community awareness of what people can do to delay the onset and slow the progression of dementia.
- [ADD] Disseminating more evidence-based information through accessible channels regarding what works / does not work in dementia risk reduction.

#### Performance measures

- Regarding the measure 10% reduction in aged adjusted new dementia cases per annum by 2033, we suggest the timeframe is too short. The reasons are that:
  - Significant increases in annual new dementia diagnoses will be anticipated by 2033.
  - Access to diagnosis is a focus, which potentially will lead to increases in diagnosed cases.
  - The development of dementia in most cases is influenced by risk factors over a prolonged time and not confined to the preceding 10 years.

Regarding the two measures *Increase in awareness of the general population of at least one risk factor* and *Increase in understanding of dementia risk factors/preventive actions for primary (GPs, nurses and allied health) and aged care workforce,* the data source and reliability of that data is not stated in the Action Plan. We suggest this is included.

**Objective 3: Improving dementia diagnosis and post-diagnostic care and support** The RACP supports that timely specialist physician assessment be facilitated. The less-thanideal current situation is acknowledged on page 33 of the Action Plan:

Delays can be due to a lack of specialists (there is currently only capacity to diagnose 35% to 40% of new cases), challenges accessing specialists (due to cost or distance) or lack of awareness of assessment services. These issues are heightened for people in rural and remote communities.

Feedback from our Consumer Advisory Group also attested to the experience of delayed diagnoses for significant family members.

We recommend Objective 3 be revised to consider the following: <u>Assessment and diagnosis</u>

- The Consultation Paper highlights the lack of clear assessment processes and pathways for subsequent treatment. However, there is an inadequate analysis or discussion around the many and varied ways that a dementia diagnosis can be made in the healthcare system. This includes any clinical work/environment in which geriatricians, old age psychiatrists and neurologists practice. Many GPs can, and do, also diagnose dementia, particularly when symptoms are typical and/or progressed. If we are to improve timely diagnosis for dementia, the Action Plan and its strategies need to optimise all the diagnostic pathways to their fullest capacity and understand where these services are also lacking/not adequate.
- Memory Clinics need to evolve into multidisciplinary services with a holistic approach to
  patients' needs and include nursing and allied health disciplines like Nurse Navigators,
  Nurse Practitioners, Social Workers, Psychologists, Occupational Therapists, as these
  contribute to improving care for people with dementia. Specialist physicians who
  specialise in dementia diagnosis and management are increasingly recognising the
  deficiencies in traditional Memory Clinic staffing models, which are still heavily biased
  toward a single health professional providing a diagnosis and medical management. Our
  member feedback estimates that a minority of diagnoses are made in a Memory Clinic,
  although these are highlighted in the Action Plan.
- Data on dementia diagnosis in other settings (such as public hospital geriatric clinics, Old Age Psychiatry services, private specialist rooms etc) needs to be collected to understand the full range of diagnostic services/quality of care being provided.

- We suggest the Australian Dementia Network's (ADNet) clinical quality registry for people newly diagnosed dementia and mild cognitive impairment needs to be expanded to non-Memory Clinic settings.
- There is no Medicare Benefit Scheme (MBS) item number for formal cognitive assessment and therefore the Action Plan should address the need for further provisions needed for funded activity relating to conducting cognitive assessments, other than that in existing MBS items, such as for comprehensive geriatric assessment (Item 141). Other specialist physicians (non-geriatrician) can't access this item. This also applies to GPs.
- The actions should include address of the limited use of culturally appropriate validated dementia assessment tools which create difficulties/barriers for First Nations people and people from culturally and linguistically diverse (CALD) backgrounds.
- Oral health is important and is not mentioned in the Action Plan. On diagnosis, the medical practitioner should recommend that the person with dementia (or their carer[s] or family) make an appointment to see a dentist to conduct an assessment and formulate a long-term treatment plan.<sup>6</sup>

We suggest adding an action to increase the proportion of memory clinics with true multidisciplinary models of care – the lack of multidisciplinary provisions is also noted in Objective 4 concerning primary care.

We suggest adding the following actions to the focus area 3.2 *Quality and timely diagnostic services:* 

- Increase the number of staff specialists trained to operate the memory clinic or CDAMS.
- Support and fund the expansion of ADNet clinical quality registry to non-memory clinic settings.
- Analyse available data on all available specialist physician services and introduce specific targeted actions to expand dementia diagnostic services that lack these.

#### Post diagnostic care and support

The Action Plan must respond to the gap in ongoing post diagnosis treatment, management and/or support:

- Many CDAMS or Memory clinics are diagnostic clinics only and do not provide any
  ongoing post diagnosis treatment, management or support. This includes BPSD. For
  example, there is no public clinic in the Western suburbs of Melbourne that a person can
  go to for help with dementia. Often, the only way to access a specialist physician for
  BPSD is to pay privately or to present to hospital in crisis.
- Care and support must encompass psychosocial interventions. There is evidence supporting the use of psychosocial interventions in dementia care.<sup>7</sup> Findings highlight the importance of policies based on a comprehensive and well-integrated system of care, where the issue of psychosocial care and interventions is fully embedded.
- Lack of available services for management of BPSD in the community means that rates of hospitalisation presentations and admissions are high and people can be prematurely placed in RACFs.
- The compliance requirements must be streamlined so they do not deter from providing quality care.

<sup>&</sup>lt;sup>6</sup> Laver K, Cumming R, Dyer S, Agar M, Beattie E, Brodaty H, Broe T, Clemson L, Crotty M, Dietz M, Draper B. Clinical practice guidelines for dementia in Australia. <u>Clinical practice guidelines for dementia in Australia (anu.edu.au)</u>

<sup>&</sup>lt;sup>7</sup> Chirico I, Chattat R, Dostálová V, Povolná P, Holmerová I, de Vugt ME, Janssen N, Dassen F, Sánchez-Gómez MC, García-Peñalvo FJ, Franco-Martín MA. The Integration of psychosocial care into national dementia strategies across Europe: evidence from the skills in Dementia Care (SiDECar) Project. International journal of environmental research and public health. 2021 Mar 25;18(7):3422.

We suggest including these actions linked to the focus area 3.3: Postdiagnostic care and support.

- [ADD] Establish publicly available dementia care clinics in all areas to support people with dementia and their family/carers.
- [ADD] Develop and reinforce nationally supported pathways of care for BPSD that are standardised and monitored for quality outcomes.

#### Performance measures

- The measure At least 50% reduction in time from onset of symptoms to dementia diagnosis may be difficult to obtain meaningful data against. Furthermore, there is uncertainty inherent in the diagnostic process, and applying pressure to diagnose earlier may lead to an increase in incorrect diagnoses.
- Amend this measure to the following: *Increase in the number of primary care staff* [ie. not only GPs] *undertaking dementia training modules*.

We suggest the following additional measures be included:

- The number of referrals to dementia support agencies, such as Dementia Australia, Dementia Support Australia and others.
- New dementia diagnoses are reported to the ADNet clinical quality registry.
- Targets to drive improvements in regional, rural and remote areas, and services for First Nations people. This might include the proportion of regional, rural and remote centres with a fly-in-fly-out or telehealth memory clinic service.

# Objective 4: Improving treatment, coordination and support along the dementia journey

Here we raise a set of systemic, service and treatment related factors that this Action Plan needs to consider to improve care for people with dementia.

- **Dementia service navigation**. There are significant challenges navigating, accessing dementia care and understanding the system (acknowledged on pages 42 and p53).
- **Connectivity between GPs and specialist physicians**. A vital component of both Objectives 3 and 4 is the interface between general practice and specialist diagnosis and treatment. Significant attention needs to be given to how effectively this operates with dementia.
- **Dedicated resources.** Previously we noted the need for sufficient and dedicated resourcing to be allocated to this Action Plan. This is necessary to mitigate circumstances where medical / nursing / allied health are redirected and services for neurological conditions, such as outpatients/clinics, discontinued.
- Training health professionals:
  - Improving treatment and other supports involves training health professionals about dementia and how people with dementia should be treated. Individuals should be considered according to their abilities and not accorded one blanket "dementia" diagnosis.
  - The critical importance of skilled, sensitive approaches should be included in the health professional training action.
- Gaps in care under the Specialist Dementia Care Program (SDCP). Accessibility of this service can be very poor and in areas where the wait time for access is 12 months+, it not a feasible option.
  - The program does not take Tier 6 and 7 patients,<sup>8</sup> which are the patients most in need of this type of program.

<sup>&</sup>lt;sup>8</sup> Brodaty H, Draper BM, Low LF. Behavioural and psychological symptoms of dementia: a seven-tiered model of service delivery. Medical journal of Australia. 2003 Mar;178(5):231-4.

- The exclusion criterion of dual diagnosis, which is the coexistence of a mental health diagnosis along with dementia, should be eliminated from entry processes.
- Special Care Dementia Units (SDCUs) should have a minimum level of support in the form of a both specialist geriatrician and a psychogeriatrician.
- It is important that data is collected on the number of referrals to these programs, numbers of people who are declined, total wait times for access, and their total length of stay. The extent to which these programs are making a difference to patients with severe symptoms should be determined.
- Hospital services for people living with dementia. Hospital care for dementia patients must be improved through a hospital focused Action Plan to improve their hospital journey. Our member information described patients declining/deteriorating with a hospital experience, after delirium or becoming deconditioned. People with dementia are often considered a burden, a stigma is attached, and patients with dementia are often associated with a long length of stay and hard work. This reinforces the earlier statement that there needs to be dementia training and dementia-driven cultural shifts in healthcare settings. Improvements in a hospital journey must be explicitly driven, for example, through data collection.
  - The development of a Clinical Care Standard for Dementia is important to drive improvements in hospitals. This approach has seen vast improvements in the care of delirium.
  - There is no single cognitive screening tool to detect dementia that is standardised across hospitals.
  - The issue of severe BPSD in hospitals is often under recognised and under resourced, and this compromises both the health and safety of patients and staff.
  - There are no specific in-hospital supports for people with dementia admitted to hospital. Some hospitals have cognition or dementia nurses, but this is not the standard.
  - Data is not collected on dementia diagnosis, presence of BPSD and effects on length of stay, and barriers to discharge.
  - Data on both physical and chemical restraints is not made available locally or managed transparently to improve quality of care.
  - The actions in Objective 4 should include transparency regarding available measures of quality care already collected, eg. include electronic medical record (eMR) collected information on chemical restraints/antipsychotics/sedation and mechanical restraint episodes.
- Management of Tier 7 BPSD patients. This is an urgent clinical problem as there is no best model of care and we welcome the action to develop an optimal model of care and responsibility for people with extreme (Tier 7) BPSD (page 45). Tier 7 BPSD must be specifically included in the priorities and blueprints proposed to be developed for 2023-2026, including priority to data collection, development of new models of care, research framework and capacity building. Critical factors include:
  - There is no clear management pathway. In the past, people in this category would have been admitted to specialised psychogeriatric residential facilities, but nearly all of these have since been closed.
  - Care of Tier 7 BPSD patients is extremely high risk and is associated with high rates of adverse outcomes for patients, families and staff.<sup>9</sup> The burdens and costs associated with care is often not appreciated, eg. a patient with tier 7 symptoms may stay in hospital for 6 months or longer, having been "declined" by multiple RACF providers. Individuals often require one-to-one nursing for prolonged periods, there may be episodes of occupational violence with multiple staff

<sup>&</sup>lt;sup>9</sup> Cerejeira J, Lagarto L, Mukaetova-Ladinska EB. Behavioral and psychological symptoms of dementia. Frontiers in neurology. 2012 May 7;3:73.

injuries, and our members share that patients are highly likely to die in hospital before symptoms are controlled or a longer term care solution is found.

- **Palliative care**. The RACP underlines the value of specialist palliative care. There is a strong link between dementia care and palliative care, particularly for younger onset dementia but also for Alzheimer's Disease.
  - Care for people with advanced dementia should be based on a palliative approach and involve a palliative care service if indicated. Treatment and care should be provided as per the person's advance care plan.<sup>10</sup>
  - Palliative medicine should be considered a component of both multidisciplinary care approaches to dementia and as part of key transition stages in care for people with dementia.

We suggest an action added to focus area 4.3 End-of-life and palliative care:

- [ADD] Facilitate the early referral/involvement of palliative care services for people who have moderate dementia for support purposes and aid with symptoms management throughout the journey until end-of-life (recognising dementia is a progressive disease).
- **Home care packages.** These are not discussed in the Action Plan. An action or performance measure that addresses the need to reduce the wait time for approved home care packages for people with dementia is needed.
- **Planning and responding to imminent challenge for services**. The Action Plan needs to incorporate modelling for new therapies and diagnostics so that health services can be ready to respond.
  - This is urgent as many experts in the field expect these new technologies will be available in the next few years. Modelling needs to include capacity for positron emission tomography (PET) and magnetic resonance imaging (MRI) as new treatments incorporate these scans.
  - The impact of recent significant advances in both diagnostic tools (blood tests for Alzheimers disease such as serum P-tau) and therapeutics (eg. lecanamab) has not been considered in this Action Plan. The implication is that possibly within a couple of years, we might expect a large increase in demand in the community for dementia specialists and clinics.

Performance measures

- The measure Increase in the percentage of people using Transition Care Program (TCP) after a hospitalisation will lead to increased utilisation of an already saturated program in many health services and more TCP places will need to be resourced. More utilisation may not be the best outcome in comparison to focusing on appropriate utilisation of the service.
- The following three measures may discourage the use of hospital services, when hospital level care may be in the person's best interests:
  - Increase in the percentage of people living with dementia who have place of death recorded as home may lead to restricted access to seeking hospital care. We note there are no performance measures that address Advance Care Planning.
  - Reduced length of hospital stay for people living with dementia.
  - Increase in older Australians living with dementia being accepted into residential aged care following a hospital stay.
- Additional performance measures regarding Specialist Dementia Care Units (SDCUs) should be added, such as increased transparency of decision-making regarding acceptance to SDCUs and bed occupancy.
- Additional performance measures regarding Tier 7 BPSD patient related responsive behaviours should be added, such as all hospital districts have a specialist public

<sup>&</sup>lt;sup>10</sup> Laver K, Cumming R, Dyer S, Agar M, Beattie E, Brodaty H, Broe T, Clemson L, Crotty M, Dietz M, Draper B. Clinical practice guidelines for dementia in Australia. <u>Clinical practice guidelines for dementia in Australia (anu.edu.au)</u>

hospital unit available to manage patients with Tier 7 behaviours and these all have specialist geriatrician and psychogeriatrician input available, with all patients seen by a Severe Behaviour Response Team.

• A long-term performance measure appropriate for a 10 year visionary plan is that a greater proportion of people w dementia in RACFs reside in small group/dementia cottage arrangements.

#### **Objective 5: Supporting people caring for those living with dementia**

We recommend Objective 5 be revised to consider the following:

- Supports for carers are essential but must include actions that put in place staff and infrastructure so that these are delivered. Examples include initiatives towards improved respite care and better linkages between systems to improve the user experience accessing support.
- The RACP supports free carer training (refer performance measure that there be an increase in the number of carers accessing education and training, page 55).
- It needs to be acknowledged that respite care is not always an ideal support for carers.

#### Performance measures

- Add more specificity to the measure 25% increase in the number of people living with dementia accessing respite services by 2033. For example, stating which type of respite (residential respite, in-home respite, or centre-based respite, or all types).
- Recognising the substantial barriers for people with higher level responsive behaviours to
  accessing respite and adding a separate performance measure on access to respite for
  people with Tier 4 and higher level tier behaviours.

#### **Objective 6: Building dementia capability in the workforce**

The RACP supports the need to build dementia capacity in the workforce. We support the focus on training of health professionals and that dementia be viewed as a core part of curriculum for all health professionals including medical, nursing and allied health students. Further, we suggest that dementia training or practical coursework in units that deliver face-to-face/hands-on care of people with dementia be mandatory for all aged care workers.

We recommend Objective 6 be revised to consider the following:

- Specific actions need to be directed to addressing workforce needs in both rural and remote areas, and targeting the Aboriginal Community Controlled Health Sector.
- The RACP has recommended in a different <u>submission</u> that the Commonwealth Government establish and recurrently resource Primary Care Dementia Nurses positions in primary healthcare with the view towards also deploying these positions to purposebuilt dementia units for those with significant BPSD who cannot be managed by nonpharmacological means and/or are aggressive and physically able.
- Strategies for the recruitment of more:
  - General Medicine specialist physicians who have a special interest in dementia and cognitive impairment, and provide upskilling/training if necessary, to run a CDAMS clinic.
  - General Medicine specialist physicians who have a special interest in dementia and cognitive impairment in emergency departments (ED). This will assist in the management of people with dementia and BPSD who present to the ED, enable fasttracking management in ED and support improved care.
- As previously stated, broaden the Medicare MBS items coverage to allow nongeriatrician specialists to attract items 141 and 143 for dementia diagnosis and management.
- The value of including strong palliative medicine capability in the healthcare workforce where people with dementia receive care services is important for a strong link between dementia care and palliative care.

#### Performance measures

• Add the measure: Dementia practice leaders are represented in a XX (high) percentage of all residential aged care facilities and community care providers.

# Objective 7: Improving dementia data and maximising the impact of dementia research and innovation

We share the view that research needs to be supported and firmly embedded into the Action Plan. The RACP is pleased to see this made explicit.

We recommend Objective 7 be revised to consider the following:

- As the Action Plan states that there is a lack of research regarding dementia related to Aboriginal and Torres Strait Islander people, and other groups, it is recommended that data collection for Aboriginal and Torres Strait Islander people be included as an action.
- Recognise the importance of specialist physicians in contributing to datasets.
- Address the need to better estimate national prevalence of dementia. Lack of formal diagnosis of dementia is recognised in this Action Plan as a problem. This is evident in hospital settings where only a minority of those who present to hospital with persistent cognitive decline have a formal diagnosis of dementia or have been referred for investigation. The RACP supports investment towards this in community/primary care screening programs and note the action of continuing investment in dementia clinical quality registries. Further consideration could be given to large scale cognition screening tools in primary care.
- There is a lack of data about rates of dementia and undiagnosed dementia across different socioeconomic areas/areas of higher risk. The Action Plan points out there are groups at higher risk yet we do not have specific data regarding prevalence in these areas of higher risk. Specific data will support the development of actions to address inequitable outcomes in at risk areas.
- There is a need for more research on the impact of palliative approaches to dementia care. This has area has faced the difficulty of involving people in research at the end stage of their life, however research would help develop high quality and holistic care approaches, and also be of benefit for carers.
- An action should be included in the Action Plan that reports on access to memory clinics and other relevant services in at risk areas. An associated action could be to expand services where services are not available or are not adequate.

#### Performance measures

- Add the following performance measure: Specialist Memory Clinic Services are registered with ADNet and identify patients who would be eligible to participate in clinical trials.
- Data is not collected on dementia diagnosis, presence of BPSD and effects on length of stay, and barriers to discharge. This should be added as part of the proposed data collection framework.

# **Concluding remarks**

Thank you for preparing the National Dementia Action Plan 2023 – 2033 Consultation Paper. Our RACP comments are submitted to serve the needs of patients, carers, and health professionals.

When the Action Plan is final, we hope this will be made available across the community in accessible formats, such as large print, easy to read, multiple languages and audio, to be inclusive and to inform the community widely.

We note that to activate the final Action Plan, the Department of Health and Aged Care should also consider how well relevant MBS and PBS items support people with dementia and health service providers. These underpin appropriate health care delivery.

We would suggest inclusion of the RACP into the central body of Australian Government and State/Territory government officers, given the expert role our members have in the both clinical leadership and dementia care.

We look forward to contributing to ongoing improvements in health care for people with dementia.

For further information and continued engagement please contact policy@racp.edu.au.