ACCPA

Aged & Community Care Providers Association

National Dementia Action Plan

Consultation Paper

Submission

January 2023

About ACCPA

Aged and Community Care Providers Association (ACCPA) is the national Industry Association for aged care providers offering retirement living, seniors housing, residential care, home care, community care and related services.

ACCPA exists to unite aged care providers under a shared vision to enhance the wellbeing of older Australians through a high performing, trusted and sustainable aged care sector. We support our members to provide high quality care and services while amplifying their views and opinions through an authoritative and comprehensive voice to the government, community, and media.

Our sector serves to make better lives for older Australians, and so do we.

Background

Dementia is the second leading cause of death in Australia and the leading cause of death for women and is the third leading cause of disease burden in Australia and the prevalence of co-morbidities in people with dementia increases the complexity of their care needs. Whilst Australia is a global leader in many aspects of dementia care there are gaps that need to be addressed, this was recognised by the Royal Commission into Aged Care Quality and Safety (the Royal Commission).[1]

The National Dementia Action Plan Public Consultation Paper (the paper) states the purpose of seeking feedback is to inform the development of the National Dementia Action Plan 2023-2033 (the Action Plan) and ensure the voices of people with lived experience of dementia and their carers are reflected in Australia's priorities for action on dementia over the next 10 years.

The stated purpose of the Action Plan is to:

- provide a roadmap, setting out where we want to be in 10 years' time
- guide actions by governments (Commonwealth and state/territory)
- drive improvements to services and systems for people living with dementia and their carers
- enable measurement of progress against priority areas, and
- engage inform and involve the whole community.

The proposed Action Plan describes a vision, principles, and objectives.

ACCPA is pleased to provide a response to this important work that helps inform the National Dementia Action Plan.

[1] National Dementia Action Plan Public Consultation Paper, Australian Government Department of Health and Aged Care, November 2022, p5

Responses to the Action Plan

Vision

The proposed vision in the Plan is '*Australians understand dementia – people living with dementia and their carers have the best quality of life possible and no one walks the dementia journey alone.*'[2]

ACCPA supports the proposed vision.

Implicit in the statement is that as a society we develop a fuller understanding of dementia, its impact and that those living with dementia experience a good quality of life and are fully supported in their journey and remain integrated into, and connect with, their community.

Importantly the vision also recognises carers and their need for quality of life. Carers have historically been at risk of being under-recognised and under supported.

The Royal Commission recognised that the current aged care system fails to fully support carers and provides '*reactive, inadequate support*' that is often not provided '*until the strain on a caring relationship has already reached crisis point*.[3]

The principle that neither the person living with dementia nor their carers 'walk alone' on their dementia journey is important.

Principles

The paper proposes that the following principles '*underpin and are evident in the design and implementation of the Action Plan*'.[4] It states this will ensure all actions are:

- **directly informed, and evaluated** by the views of people living with dementia, their carers and families
- **person centred** and focused on **quality of life** for people living with dementia, their
- carers and families
- appropriate for, and **accessible to, all people**, including priority population groups and people from diverse backgrounds
- **culturally safe** for First Nations peoples
- evidence based and **outcomes focused**, and
- coordinated, **integrated** and planned.

The Action Plan must be developed fully utilising the concept of co-design. People living with dementia and their carers must be integrated into all stages of design, implementation and review of the Action Plan. They must be active participants in the design of the Action Plan, be on steering committees and on review panels utilising the principle of 'nothing for us without us.'

Their lived experience must inform development of the Action Plan.

Likewise, aged care providers must also be actively engaged in co-design of the Action Plan, as they are the bodies funded to deliver dementia services.

[2] National Dementia Action Plan Consultation Paper Summary, Australian Government Department of Health and Aged Care, November 2022, p3
[3] Final Report: Care, Dignity and Respect Vol 1 Summary and Recommendations, Royal Commission into Aged Care Quality and Safety, p103
[4] IBID, p4

This will help ensure a person centred approach where the focus is always on improving the quality of life of all people living with dementia and their carers. It is pleasing to see commentary in the paper that focuses on periodically measuring whether the Action Plan is actively making a difference to the lived experience of the person with dementia and their carer (a lack of a material difference to the actual experience of the individual or their carer being a criticism of earlier national dementia frameworks[5]).

The principle that actions that come out of the Action Plan are accessible to all people is vital.

People in Australia must have access to quality dementia services and supports no matter whether they live in major cities, in inner or outer regional areas or in more remote parts of our country. This means care and support services must be available across all regions.

Equity of access must be a given.

This will require strong coordination across all levels of government (Commonwealth, state/territory and local), across Commonwealth, state and territory health and social support services as they are all involved in funding, delivering and/or regulating services for people living with dementia and their carers.

Services work best when they are delivered and coordinated locally. For example, local hospital networks could create networks between primary health providers, community support services, specialised services, residential aged care and respite.

In terms of accessibility, face to face support for people living with dementia and their carers is always the ideal, but where this is not possible, supports must be available via other modes such as through mobile in-reach services or through the use of reliable technology such as internet-based service support.

Groups at higher risk of developing dementia or facing barriers to equitable access

The Action Plan recognises there are groups in society that have a higher risk of developing dementia or who face barriers to equitable access[6], including (but not limited to):

- **First Nations people living with dementia** – where dementia is estimated to be three to five times higher than in the general population and where stigma associated with dementia is 'amplified' in First Nations communities.[7]

  Access to services remains a challenge for many First Nations communities, particularly so for remote communities and where services are available, they may not historically always been culturally appropriate.

  In 2016/17 there were approximately 124,000 First Nations people aged fifty and over (representing sixteen per cent of the total First Nations population), with nearly 24,000 of them accessing aged care services.[8] Under the Aged Care Act 1997 Aboriginal and Torres Strait Islanders are designated a special needs group.

[5] National Dementia Action Plan Public Consultation Paper, Australian Government Department of Health and Aged Care, November 2022, p68
[6] IBID, pp9-12
[7] IBID, p9
[8] Insights into vulnerabilities of Aboriginal and Torres Strait Islander people aged 50 and over, Australian Institute of Health and Welfare, Australian Government, 2019, p6

Of the 1,679 First Nations people aged fifty and over who resided in residential aged care at 30 June 2017 nearly half had dementia, most commonly Alzheimer's type.[9]

The health of First Nations people living in rural and remote areas is said to be significantly worse than that of their non-indigenous counterparts.[10] It is well recognised that there are intergenerational traumas that contribute to their health outcomes.

Many indigenous services are geographically remote and small in size with low population densities, complicating service delivery and impacting directly on the cost of service delivery.[11] Funding to such services, including for the delivery of dementia supports, must address the cost burdens of delivering these services, with funding adequately addressing the needs of care recipients and their carers.

Equitable access to culturally appropriate dementia care and support services for First Nations people living with dementia and their carers must be addressed through coordinated actions embedded into the Action Plan and linked to the 'closing the gap' program.

Where possible, dementia support services should be available through community-controlled health services where care and support are provided in a culturally safe environment by a First Nations workforce that is trained to deliver dementia care.

Wherever possible, dementia support should be provided on-country by people able to speak in-language.

It is important to remember that First Nations people are not homogenous, but are individuals with individual experiences, traumas and needs and dementia support services must respond and cater to the individual.

The Royal Commission recognised that access to aged care services can be complex and confusing, this is especially so for First Nations people. It is recognised that First Nations people are not well served by the current aged care system and despite experiencing disproportionate levels of illness and disability they are under-represented in the aged care system. This must be rectified.

Additionally, mainstream aged care services are often not culturally appropriate or simply not available in remote regions. Greater engagement in aged care dementia supports is needed for First Nations peoples including aged care services being 'on country' where possible. Ongoing work is required to address these challenges so that First Nations people living with dementia have access to culturally appropriate aged care where and when they need it.

ACCPA advocates that governments at both Commonwealth, state and territory levels work to ensure that rural, regional and remote services, including dementia support services are designed, implemented and funded to be accessible equitably to all people who need them regardless of where they live, achieved through:

[9] IBID, p15
[10] The National Rural Health Alliance Fact Sheet, July 2019
[11] Royal Commission into Aged Care Quality and Safety, Interim Report Neglect Volume 1, p184

- Ensuring dementia support programs adequately address access for First Nations people regardless of where they live, with face to face services where ever possible or alternatively through access to reliable telehealth and on-line services
- Maintaining and expanding place-based, flexible funding approaches for all aged care programs (community and residential aged care) which recognise the additional costs associated with delivering dementia support services to remote indigenous communities
- Where there is market failure (i.e. a thin market outcome) resulting in no aged care services being available, the Australian Government should intervene as the system steward to incentivise the provision of services in country and remote areas, and
- Putting in place community-controlled health services staffed by a First Nations workforce with the requisite skills to deliver quality dementia support services.

- **People from culturally and linguistically diverse backgrounds living with dementia** – where people from culturally and linguistically diverse (CALD) backgrounds make up about one third of the population of people living with dementia. It is said these people can face some particular challenges when looking to navigate and access dementia supports[12] including:
  - Services not being culturally safe for them
  - Variability in access to culturally appropriate services
  - People being less likely to access formal care and support due to cultural expectations and preferences, and
  - Language barriers.

  The Action Plan must address provision of dementia services and supports for people from CALD communities who are living with dementia and their carers so that they are able to easily access culturally appropriate dementia care and support.

  Information must be made available to them in a form that is easily understood.

  Care finder supports must be available in their local community, by care finders who are culturally competent, skilled in dementia support and resourced to respond to diverse people living with dementia and their carers.

  Consideration should be given to the introduction of ‘CALD link workers’, people who are able to refer the person with dementia or their carer to the most appropriate services within their region to meet their needs.

  Australians from a CALD background who have a lived experience of dementia must be involved in the design of dementia care and support services and in developing the actions embedded in the Action Plan and participate in planned reviews of the plan.

[12] National Dementia Action Plan Public Consultation Paper, Australian Government Department of Health and Aged Care, November 2022, p10

The proposed In-Home Care aged care program that is currently under development by the Commonwealth Department of Health and Aged Care (the Department) must address the ease of access to, and navigation of, the aged care system for people from CALD communities so that they are able to access the dementia care and supports they need to enable them to live at home longer. This must include face to face navigation support from people (care finders) who are trained to provide culturally safe support.

The assessment process that will accompany the new program must recognise people from CALD communities and provide them with appropriate pathways to dementia care and supports.

Aged care providers continue to improve the provision of culturally appropriate care including providing cultural awareness training for their staff.

People from CALD communities who require dementia support in a residential aged care facility must be able to easily find a service that meets their cultural needs and be assured that the service can cater to them. This has recently been addressed with a new specialisation verification approach, a tiered approach to evidence requirements that need to be met for a service to claim that it caters to certain special needs groups. We need time to see whether the new approach has achieved its stated aims.

- **People living in rural and remote areas** – where people living in regional, rural and remote communities can face particular challenges in accessing specialist support services and health professionals with expertise in dementia.[13] Around seven million people, about twenty per cent of the population, are said to live outside Australia's major cities.

  This cohort has poorer health and welfare outcomes than those people who live in metropolitan cities. This inequity continues into old age. The Australian Association of Gerontology reports that on average older people in rural and remote areas have lower incomes, experience greater level of disability, reside in poorer quality housing and have lower levels of education.[14] To this list of health determinants the National Rural Health Alliance adds poorer health related infrastructure and a higher prevalence of common risk factors for health.[15] These factors have been associated with worse outcomes and a greater need for support.[16]

  Access to health services, including dementia supports is vital in regional, rural and remote locations to allow people to live and age close to family and in their local community with the same range of health service supports enjoyed by their metropolitan cousins. Equity of access must be 'a given'.

[13] National Dementia Action Plan Public Consultation Paper, Australian Government Department of Health and Aged Care, November 2022, p10
[14] Addressing Aged Care Workforce Issues in Rural and Remote Australia, Australian Association of Gerontology, July 2019, p9
[15] The Determinants of Health in Rural and Remote Australia, Fact Sheet 28, National Rural Health Alliance
[16] Under the Aged Care Act 1997 people who live in rural or remote areas are designated as a special needs group

There are a range of dementia support services that are available to aged care services to assist them to provide care and services to people living with dementia and their carers (Dementia Behaviour Management Advisory Service; and the Severe Behaviour Response Teams). These programs provide both in-person and virtual support to people living with dementia, carers and providers. As with all service types, further funding for additional localised supports for regional, rural and remote communities, and specialist supports for underserved groups, would be beneficial.

These support services should be available face to face as there are challenges posed to the person living with dementia when services change between in-person support and on-line support. People develop trust with face to face services, for example with community nursing services or nurse practitioners and should be supported to receive these services in person wherever they live and wherever practicable.

Martin Laverty, of the Royal Flying Doctor Service of Australia in his Witness Statement to the Royal Commission indicated he believes there are inadequate health and aged care services in rural and remote Australia. Mt Laverty indicated that a disparity in access to health services results in some people having to leave their homes and communities to access health and aged care services.[17]

ACCPA advocates that governments at both Commonwealth, state and territory levels work to ensure that dementia support services are designed, implemented and funded to be accessible equitably to all people who need them regardless of where they live. Equity of access should be achieved through:

- The provision of 'in person' support visits by health professionals whenever possible or alternatively through access to reliable telehealth and on-line services
- Barriers to securing 'right fit' workers (including First Nations workers) in remote communities are identified (housing, security, transport, remuneration, limited education opportunities, lack of infrastructure etcetera[18]), and strategies to address these barriers developed and implemented
- Identifying and addressing barriers to the recruitment of allied health professionals in regional, rural, and remote areas
- Adopting place-based approaches to delivering dementia support services to First Nations communities via a First Nations workforce, and
- National Cabinet taking the lead in coordinating the implementation of the National Dementia Action Plan.

- **Veterans** – where international studies suggest an increased prevalence of dementia among veterans compared to the general population, noting veterans have increased risk factors for dementia including traumatic brain injury sustained through active duty, post-traumatic stress disorder and major depressive disorder.[19]

[17] Statement of Martin John Laverty, CEO Royal Flying Doctor Service of Australia to the Royal Commission into Aged Care Quality and Safety, May 2019
[18] Addressing Aged Care Workforce Issues in Rural and Remote Australia Report, Australian Association of Gerontology, Regional, Rural and Remote Special Interest Group, July 2019, p11
[19] National Dementia Action Plan Public Consultation Paper, Australian Government Department of Health and Aged Care, November 2022, p12

Dementia support programs must identify the special needs of this cohort and cater to their needs (and the needs of their carers). Additionally, they must have access to specialist older persons mental health services, both community based and acute inpatient.

Coordination of the delivery of dementia support services between the Coordinated Veterans Care Program (Department of Veterans' Affairs) and aged care services will be important, as recipients of Veterans' Affairs supports are also often recipients of aged care services (whether in the community or in a residential aged care setting).

Their needs are often well met through aged care services that target this cohort and these services must be well supported by in-reach programs that provide dementia supports. There must not be artificial barriers between Veterans Affairs funded services and aged care.

It is well understood that once older people enter residential aged care, they can be at risk of losing the support of community based health supports, this cannot be allowed to happen. There must continue to be equity of access to community based programs, including dementia supports.

- **People living with dementia who are homeless or at risk of homelessness** – where it is recognised there are significant numbers of people in the homeless population with cognitive impairment including dementia.

  Due to their individual circumstances many have experienced trauma, abuse, neglect and discrimination and are at risk of experiencing a range of long term health problems.[20]

  Dementia support services must be designed to cater for the circumstances these people find themselves in. For example:
  - Traditional community-based programs may be based on the premise that people have a fixed address, this must not be a barrier to them being able to access services
  - Some members of this community may have mental health comorbidities that require specialist mental health supports in addition to dementia service supports, these separate supports must be designed to work in unison
  - Assessment services (for aged care supports) must have pathways that recognise the special needs of people who are homeless or at risk of homelessness and assessors must be trained to cater for this cohort, and
  - Targeted funding must be available to provide quality dementia support to this special needs group.

  ACCPA suggests that purpose-built cottage style residential care models is an option to be explored for older people who are experiencing or at risk of homelessness. Such models would provide permanent accommodation options for this vulnerable cohort with outcomes that include less social isolation, greater stability, improved access to mental health and spiritual support, improved quality of life and wellbeing and potentially less hospitalisations and earlier hospital discharges.

[20] National Dementia Action Plan Public Consultation Paper, Australian Government Department of Health and Aged Care, November 2022, p12

Objectives

It is proposed that the Action Plan includes seven objectives in support of the proposed vision, we offer comment on the following ones.

Objective 3: Improving dementia diagnosis and post-diagnostic care and support

ACCPA supports the *Outcome Statement* and the *Statement for people living with dementia* for this objective.

The Royal Commission recommended (Recommendation 15) establishment by the Australian Government of a '*comprehensive, clear, and accessible post diagnosis support pathway for people living with dementia, their carers and families*.'[21]

Their recommendation included:

- Providing information and advice on dementia and support services
- Facilitating access to peer support networks
- Providing education courses, counselling and support services, and
- Addressing respite for carers.

ACCPA supports these approaches.

Dementia support pathways

In its response to the above recommendation by the Royal Commission the government of the day indicated support for this recommendation stating that '*nationally consistent local dementia support pathways will be established to support general practitioners and other primary care clinicians with assessment and referral*.[22]

ACCPA recommends the current government continue to support this approach.

Identifying how the early diagnosis of dementia can be improved for Australians who live in their own homes and who live in residential aged care so that care and support can be put in place earlier should be an activity of the Action Plan. This will need to involve primary care health practitioners (including general practitioners, community nursing services and nurse practitioners, using appropriate diagnostic tools and pathways) as key stakeholders in the early and timely diagnosis of dementia.

Once diagnosed, there must be clear treatment and support pathways available to aged care providers to support people diagnosed with dementia and their carers aimed at improving their dementia journey.

These pathways once developed, must be communicated to primary health practitioners.

Referral pathways must include referral for reablement / rehabilitation services for those recently diagnosed with dementia, as there is evidence of the benefits of doing so.

They must address cultural needs and the services that people are referred to must be culturally appropriate.

Health practitioners must have access to agreed-to treatment and referral pathways that are consistent. We must avoid having multiple pathways within jurisdictions.

[21] Australian Government Response to the Final Report of the Royal Commission into Aged Care Quality and Safety, Department of Health, Australian Government, May 2021, p15
[22] IBID, p15

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

ACCPA supports the *Outcome Statement* and the *Statement for people living with dementia* for this objective.

There are currently a range of dementia support programs available to aged care providers (for example the Dementia Behaviour Management Advisory Service; Severe Behaviour Response Teams; and the Specialist Dementia Care Program). All government funded programs should be required, as part of their funding agreements, to submit outcome data reports to support Departmental analysis of provider performance and client needs and gaps and undertake appropriate responses. To ensure tailored reach to people living in regional, rural and remote locations, and peoples from First Nations and cultural and linguistically diverse communities, partnerships between these programs and a diverse range of organisations would support bespoke service delivery.

Care conferencing in-reach supports should be funded, this has occurred previously under some in-reach support services. These were very beneficial to providers in residential aged care.

The Short Term Restorative Care program has the opportunity to provide short term restorative care, including with allied health inputs to support those people with an early diagnosis of dementia and would provide great benefit to people still living in their own home.

Specialist Dementia Care Units (SCDUs)

Specialist Dementia Care Units are being rolled out across Australia. The efficacy and adequacy of these services should be reviewed and recommendations made as part of the actions of the Action Plan. There may be benefit in linking these units to local health networks to allow for coordination of services including for those older people who have multiple comorbidities that are influencing responsive behaviours.

Currently the program is aspirational, we must determine whether it is meeting its intended purpose and delivering on its stated aims.

Clarity is needed around the pathways for access to SCDUs, anecdotally access is prioritised for people who are in hospital, diminishing access to people who live in residential aged care services. Access must be based on need not on where people are located.

Consideration should also be given as to whether the SCDU model is sufficiently adaptable and does it have capacity for all those that need the service, including those with co-morbidities including mental health disorders?

The Royal Commission in its Final Report (Recommendation 16) recommended the Australian Government review and publicly report on the adequacy and capacity of these specialist units, noting that '*we have not had the opportunity to consider its effectiveness. It is not clear if the program will be sufficient to meet demand. We therefore recommend a review of the size and effectiveness of the program*…'

ACCPA supports this recommendation.

Referral pathways

Referral pathways for people living with dementia and their carers must be available to the single national aged care assessment service so that people entering or navigating the aged care system for the first time are given early and timely access to dementia support services and pathways, including referral to respite services should this be identified as a need.

In the primary health setting the HealthPathways program (for example HealthPathways SA) is an example of clinical referral pathways that are available to general practitioners and other health practitioners to support assessment, management and referral pathways for specific health conditions and which can be used at the point of care.

These pathways can be written by general practitioners in collaboration with specialist health practitioners at a primary health network level.

Such pathways must be adequately funded and available regionally across Australia to support those people living with dementia and their carers.

Care-finder workforce

Recommendation 29 of the Royal Commission[23] proposed that the Commonwealth government fund the development of a 'care-finder' workforce to assist older people and their carers with navigating the aged care system and to '*identify the best options for care to meet their individual needs.*' Such services will be well placed to provide advice that supports people on their dementia journey. The Government of the day accepted this recommendation, and ACCPA recommends the current government does so as well, implementing these face-to-face supports.

These supports must be available to people wherever they live.

Acute Care – Aged Care Interface

There are well recognised issues that occur at the interface of health care and aged care, these transition points of care often result in poor quality of information exchange, missed health information etcetera.

All these create risk of adverse or poor quality outcomes for the person living with dementia.

A lack of access to general practitioners is an issue for many residential aged care services and this can result in increased presentations to hospitals. This could be improved through increased resourcing and funding of specialist dementia/delirium services such as nurse practitioners etcetera to aid in coordination and delivery of dementia supports.

Funding should be available to aged care providers for short-term intensive one-to-one resident / client support during self-limited episodes where intensive supports are needed.

ACCPA recommends the Action Plan contain actions to improve communication and information exchange at the acute – aged care interface with a view to reducing hospital admissions and improving hospital discharge planning and information. This could include developing best practice guidelines and accompanying resources.

[23] Australian Government Response to the Final Report of the Royal Commission into Aged Care Quality and Safety, Department of Health, Australian Government, May 2021, p23

Objective 5: Supporting people caring for those living with dementia

ACCPA supports the *Outcome Statement* and the *Statement for people living with dementia* for this objective.

Supporting the carers of people living with dementia is vital. It is critical for the quality of life of the carer themselves (and their ability to sustain the caring role over time) and for the quality of life experienced by the person they care for.

Single comprehensive assessment service

Good quality support for carers must begin early, and as mentioned elsewhere, should commence at the time people enter the aged care system. Recommendation 28 of the Royal Commission[24] recommends development of a new single comprehensive assessment process which, among other things, includes an assessment of carer's needs.

ACCPA supports this recommendation. The earlier carer needs are identified the quicker supports can be put in place.

Care finder support

The Royal Commission noted '*Carers face many challenges with accessing services. The first is that there is no formal mechanism to link carers to services. Rather, the system relies on a carer self-identifying as a 'carer' and knowing where to go for support*.[25]

The Commissioners noted there are currently two distinct systems in place that provide information for informal carers of older people, the Carer Gateway and My Aged Care, which operate in different departments. There is no interoperability between the two systems, with the Commissioners stating '*They are accessed through separate online portals and helplines and do not share information or data*.'[26] This must be addressed to improve accessibility and ease of use for carers.

Recommendation 29 recommends the introduction of face to face care finder support for carers to help them identify and access services. As noted elsewhere in this submission, this is vital so that carers can be supported to understand their options, and to exercise informed choice.

Carers must have available to them good information that helps them to continue in their role as a carer.

These care finders will be vital in helping carers identify local supports and link them to these.

ACCPA supports their introduction.

[24] IBID, p22
[25] Final Report: Care, Dignity and Respect Vol 1 Summary and Recommendations, Royal Commission into Aged Care Quality and Safety, p103
[26] IBID, p104

Improved My Aged Care

Easy access to useable information on My Aged Care was also recognised by the Royal Commission[27] as being important. Currently My Aged Care is recognised as being complex and difficult to navigate.

Carers must have information that is easy to access, readily understandable and dependable.

Government must continue to enhance My Aged Care to ensure carer's needs are met.

Respite

Good access to quality respite support is required for carers of people living with dementia.

The Royal Commissioners noted that '*High quality respite is an important and highly valued support service for informal carers. It improves the emotional wellbeing and physical health of carers, as well as presenting an opportunity to benefit the person receiving care*.'[28]

Due to the progressive nature of dementia carers can suffer strain and fatigue, respite is crucial to these people to be able to maintain their support of their loved one and help keep that person in the location of their choosing for longer.

Carers must have available to them respite options that meet their needs (e.g. for day respite support, in-home respite, community respite, overnight respite, private respite (that may be funded through home care packages) and planned/emergency respite in residential aged care), is available when they need it and in the location they need.

Carers must also have available an adequate supply of emergency/crisis respite that they can access at very short notice. This is currently a significant area of unmet need. The Commonwealth government should incentivise the provision and availability of such respite.

Residential aged care providers must be funded appropriately to ensure they are not financially disadvantaged by providing this important community service. Changes have occurred to the way respite is funded under the new residential aged care funding tool introduced in October 2022. It is currently too early to tell whether the new arrangements will be successful in incentivising provision of adequate residential based respite.

Additionally, providers of home care services must also have funding available to provide respite services to their home care clients. Currently under development, the In-Home Care program must be designed with respite service provision comprehensively integrated into its design.

Anecdotally the provision of respite services in residential aged care and home care services is being negatively impacted by the acute workforce shortage. The workforce crisis is unlikely to be resolved in the short term and governments at all levels must continue to work with the sector to put in place strategies to address this matter.

ACCPA recommends the Action Plan include actions that address development of innovative models of respite care designed to address the range of respite needs and preferences of people living with dementia and their carers.

[27] Australian Government Response to the Final Report of the Royal Commission into Aged Care Quality and Safety, Department of Health, Australian Government, May 2021, p22
[28] Final Report: Care, Dignity and Respect Vol 1 Summary and Recommendations, Royal Commission into Aged Care Quality and Safety, p103

Financial supports

A diagnosis of dementia, particularly where it involves younger- onset dementia can result in a significant financial burden on families, especially so if the person diagnosed with dementia was a major money earner (as they may have mortgages in place and school aged children for example).

Financial supports must be available to ensure avoidance of financial hardships associated with their circumstances and that may come with their spouse or partner having to give up work to care for them.

Objective 6: Building dementia capability in the workforce

ACCPA supports the *Outcome Statement* and the *Statement for people living with dementia* for this objective.

The Royal Commission recognised that workforce skills and capability in relation to dementia needs addressing[29], noting that '*all mainstream aged care services should have the capacity to deliver high quality aged care for most people living with dementia—dementia care should be core business. This includes having the right number and mix of staff who are trained in dementia care*.'

Identification of dementia related training needs for aged care workers, including how this is to be funded and delivered across all regions is required.

Aged care training and education courses must contain mandatory dementia specific modules, a good example being the new CHC33021 Certificate III in Individual Support (Ageing) which includes a mandatory unit of competency in dementia care.

These mandatory modules must include recognising and responding to delirium.

All personal care workers who support people living with dementia must be required to have completed mandatory dementia training and cultural competency.

There has been significant criticism in recent years of the quality of some aged care training programs. To ensure a consistent quality of dementia training governments across states and territories must work together to set nationally consistent minimum dementia training and education standards.

ACCPA recommends the Aged Care Workforce Industry Council be charged with reviewing the qualifications and skills framework to ensure they reflect the skills, capabilities, knowledge and competencies required by the aged care workforce.[30] Their work should include development of national dementia education standards.

Separately, ACCPA suggests a review of the availability of health and allied professionals, and which identifies the barriers to their availability and develops strategies to address these to ensure adequate availability of health and allied health practitioners to deliver much needed dementia supports.

[29] A summary of the Final Report, Royal Commission into Aged Care Quality and Safety Final Report, 2021, p92
[30] Australian Government Response to the Final Report of the Royal Commission into Aged Care Quality and Safety, Department of Health, Australian Government, May 2021, p50

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

ACCPA supports the *Outcome Statement* and the *Statement for people living with dementia* for this objective.

ACCPA strongly supports improving data collection in aged care.

The Royal Commissioners noted their concern that the '*reliable, accessible and comprehensive data on safety and quality is not available in the aged care sector. At a system level, there is 'no comprehensive data on the outcomes of care'*.[31]

They went on to note '*Australia does not have a national aged care data asset to inform assessment of how the aged care sector performs for the benefit of older people, recommending that the Australian Institute of Health and Welfare should curate and make publicly available a National Aged Care Data Asset*.'[32]

ACCPA supports improved data acquisition in aged care, particularly as it pertains to dementia.

The collection of quality data can then be used to inform government on dementia related policy.

If data collection involves collecting data from providers in electronic form, consideration will need to the given to the variability of digital maturity across the sector.

The work of the Aged Care Industry Information and Technology Council will be useful in government understanding sector issues regarding electronic data management.

ACCPA supports the Action Plan's proposal to develop a national dementia data framework and data improvement plan.[33]

Implementing the Action Plan

The Action Plan mentions there have been two previous National Frameworks for action on dementia, the last of which expired in 2019. People living with dementia felt that these Frameworks had not made a practical difference to their experience.[34] It is said the lack of performance measures and monitoring further limited the value of the Framework.

To address these deficits it is proposed that implementation of the Action Plan will be supported by blueprints, monitoring activities, reporting requirements and governance measures.

We offer the following commentary on each of these.

[31] A summary of the Final Report, Royal Commission into Aged Care Quality and Safety Final Report, 2021, p144
[32] IBID, p145
[33] National Dementia Action Plan Public Consultation Paper, Australian Government Department of Health and Aged Care, November 2022, p66

Implementation Blueprints

ACCPA supports the proposed approach to utilise blueprints. We note that the first blueprint is to cover the period 2023 to 2026.

The paper states that the blueprint will be developed with input from dementia experts and people with lived experience of dementia (p71).

To this ACCPA recommends adding aged care providers and sector peak bodies as important partners with dementia expertise and direct experience in delivering dementia services to help develop the first blueprint.

Blueprints must be reviewed periodically during their life to ensure the listed activities are progressing effectively and evaluated for effectiveness at their completion.

Most importantly the people with a lived experience of dementia and their carers should be consulted and have input into the review of blueprints to determine whether the Action Plan is making a material difference to their lived experience.

Monitoring

The paper states that the National Centre for Monitoring Dementia at the AIHW will have a key role in monitoring progress of the Action Plan.[35] It describes the centre collecting a range of data and assessing performance against the Action Pan and reporting annually via an Action Plan Report Card.

ACCPA supports this approach.

Performance measures:

We agree that the performance measures should be specific, measurable and relevant to people living with dementia. The paper describes information to be collected as descriptive (listing types of activities being attended); categorical (giving yes / no responses to whether an action has been completed); and quantitative (containing numbers or rates to describe progress against an action).

To these we would add ‘qualitative data’ that describes outcomes achieved from the actions attended. We need to understand whether the actions undertaken are making a material difference to the lived experience of those living with dementia and their carers. This will help answer the ‘so what’ question. A lack of a material difference being experienced by people living with dementia being a criticism of the previous national dementia frameworks.

Reporting

The paper describes the production of Action Plan Report Cards being prepared by the AIHW[36] and being reported every year. It also describes the attending of a formal review in year five of the Action Plan (due in 2028) which will consider progress against the Action Plan and Implementation Blueprints.[37]

ACCPA supports this approach.

[35] National Dementia Action Plan Public Consultation Paper, Australian Government Department of Health and Aged Care, November 2022, p72
[36] National Dementia Action Plan Public Consultation Paper, Australian Government Department of Health and Aged Care, November 2022, p73
[37] IBID, p73

These reports must contain qualitative data that addresses and again comments on whether the actions contained within the Action Plan are making a material difference to the lived experience of people with dementia and their carers.

Governance

The paper indicates the Action Plan will be driven '*by a central body made up of Australian Government and state and territory officials*'[38] that will report through to Health Ministers.

ACCPA supports strong governance arrangements being in place. We recommend the National Dementia Action Plan be overseen by National Cabinet, thus giving it the full support and imprimatur of the Prime Minister, Premiers and Chief Ministers.

The Governance Structure[39] describes two important groups has having input, '*people living with dementia*' and '*carers and family for people living with dementia*'.

To these important groups ACCPA recommends 'providers' be added, as this equally important group are the ones funded to directly deliver care and support to older Australians living with dementia and their carers.

[38] IBID, p74
[39] IBID, p74