



Australian Government
Department of Health and Aged Care



Development of the National Dementia Action Plan

Summary report on consultation outcomes



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The Department of Health and Aged Care would like to acknowledge mpconsulting for their work in developing this report.

Context

The Plan

The Australian Government and state and territory governments are working together to develop a new National Dementia Action Plan (the Plan). The Plan will replace, and build on, the [National Framework for Action on Dementia 2015-19](#) (the Framework) and provide a roadmap for tackling dementia over the next 10 years. It is intended to:

- drive improvements to policies, services and systems for people living with dementia, their carers and families
- guide action by governments so that services are better integrated and meet the needs of people living with dementia, their carers and families
- enable measurement of progress against objectives and focus areas
- involve the whole community in building a society that understands dementia and is inclusive of people living with dementia.

Purpose of this report

Commonwealth, state and territory governments released a National Dementia Action Plan Consultation Paper from 18 November 2022 to 31 January 2023. It sought public feedback on the key elements of the proposed Plan, including a vision, objectives, focus areas, actions and performance measures.

Government received 906 responses to the online survey and an additional 146 submissions. Respondents included people living with dementia, friends, family or carers of someone living with dementia, health and aged care professionals, researchers, government officials and others.

This report summarises feedback from the public consultation, including in relation to:

- the structure and content of the Plan
- each of the seven objectives, including areas where focus could be strengthened
- implementation, monitoring and reporting
- aspirations for what the Plan could achieve for people living with dementia, their carers and families over the next ten years.

A more detailed report on the outcomes of consultation is also available [<here>](#).

Feedback will inform the further development of the Plan. It is anticipated the Plan will be endorsed by all Commonwealth and state and territory governments.

THANK YOU

Thank you to those who took the time to contribute to the public consultation on the national dementia action plan consultation paper. Your experiences, thoughts and expert advice are valued, and will help to improve the experiences of people living with dementia, their carers and families into the future.

Overarching Feedback

Australia needs strong action on dementia

Feedback from across the full spectrum of respondents highlighted the need for bold and rapid action on dementia. Many people welcomed the Plan and felt that it was a critical step in improving Australia's response to dementia.

Many people with lived experience of dementia described the challenges in seeking a diagnosis or accessing the services they need. Feedback indicated that urgent change is needed to improve the accessibility and quality of services and supports for people living with dementia, their carers and families.

'Change in the dementia space is long overdue'.

People broadly felt that the Plan addressed the right focus areas and that it was person-centred and reflective of the experiences of people living with dementia, their carers and families.

'It covers a lot of strategic points that are not currently covered. If this Action Plan goes ahead, it is exciting'.

Changes are needed to address broader systemic challenges

Many people highlighted existing systemic issues that extend beyond dementia, including:

- lack of integration between governments, programs and services
- challenges accessing a skilled and competent health and social care workforce
- limitations in the current aged care and disability systems
- broader challenges accessing services in regional, rural and remote areas.

It was acknowledged that broader improvements are needed in Australia's health and social services sectors.

The vision is strong but could be even more person-centred

The consultation paper set out a proposed vision to guide objectives within the Plan:

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.

Broadly, respondents supported the vision, commenting that it was comprehensive, ambitious and clearly sums up the focus for the future. People generally felt that it was person-centred, accessible and focused on quality of life for people living with dementia, their carers and families.

'It is person centered and accessible to all'.

Respondents provided suggestions to improve the vision, including by starting with the reference to people living with dementia and removing references to 'the dementia journey'. This would better reflect the focus of the Plan on achieving outcomes for people living with dementia, their carers and families.

The principles need to be reflected in the Plan's implementation

Respondents generally supported the principles, emphasising the importance of the Plan being codesigned with people living with dementia, their carers and families. Improvements were suggested, including to highlight the importance of:

- respecting and protecting the human rights of people living with dementia
- care that is driven by the preferences of people living with dementia
- equity of access to quality dementia services and supports (regardless of location)
- relationship-based and healing informed care
- culturally safe care and services for people from all backgrounds.

Respondents highlighted the importance of testing each action against these principles throughout the design, implementation and evaluation of the Plan to ensure the principles are being achieved in practice.

The actions included in the Plan should be specific and measurable

Feedback suggested that many of the actions were vague or unclear. Respondents sought more detail on the actions, including how they would be implemented and who would be responsible for ensuring all actions are implemented as planned. Respondents sought specific actions that would have a meaningful, systemic impact.

Some expressed concern that the outcomes would not be achieved in practice. It was noted that the Plan would require a big investment of funds and time, as well as commitment and coordinated efforts from governments.

Some actions should be addressed as immediate priorities

The paper set out a number of immediate priorities for action in the first three years of the Plan.

Feedback indicated broad support for the immediate priorities, noting these were 'strategically essential' to delivering on the objectives described in the consultation paper. Some respondents highlighted the importance of other priorities, including:

- reducing the dementia stigma
- building workforce capacity
- improving supports for people living with complex or advanced dementia
- supporting people living with dementia to navigate services
- improving carer support.

Respondents widely felt that actions aimed at addressing the dementia stigma and building workforce capacity must be prioritised, noting that these were 'foundational' to achieving the other objectives outlined in the consultation paper.

Strong governance and accountability will be critical

Respondents felt it was important that any actions included in the Plan are clear, specific and measurable and that there are mechanisms for holding people to account.

Respondents broadly supported the inclusion of performance measures but queried how governments would respond where actions are not having the desired impact. Many commented on the need for strong governance and clear accountabilities in implementing the Plan and delivering on the objectives.

Some themes could be strengthened throughout the Plan

Respondents identified a range of areas that were not adequately emphasised in the consultation paper and may benefit from greater focus:

- elimination and prevention of dementia
- respecting the human rights of people living with dementia
- quality of care, particularly in residential aged care
- dementia enabling physical environments, particularly accommodation
- actions to improve outcomes for people living with dementia, their carers and families from culturally and linguistically diverse backgrounds and First Nations people
- services and supports for people with more complex and advanced dementia

The objectives

Objective 1: Tackling stigma and discrimination

Respondents felt strongly that Objective 1 was central to improving outcomes for people living with dementia, building greater awareness and driving action on dementia.

Feedback showed the extent of the dementia stigma in Australia and the negative impact it can have in society. People living with dementia described their experiences, including disrespectful and dehumanising interactions, feelings of isolation and shame and instances of discrimination. Some respondents noted this objective should include a stronger human rights focus.

Respondents gave a range of examples of actions to tackle stigma and discrimination, including:

- raising awareness of dementia and the different ways it can impact people, including through:
 - improving visibility of a broad range of people living with dementia in the mainstream media
 - using social media channels
 - establishing a national campaign to raise awareness and funds for dementia
 - talking about dementia in schools

- providing free dementia awareness training for different groups of people in the community
- creating more dementia accessible public spaces and communities, through:
 - developing simple guidance on creating dementia inclusive public spaces
 - supporting people living with dementia to undertake dementia friendly audits of public spaces and businesses
 - celebrating or recognising ‘dementia-friendliness’ in the community or introducing a national dementia friendly tick that businesses and services can display
 - creating dedicated spaces for people with cognitive impairment to gather to address social isolation
 - better promoting and expanding the dementia friendly communities initiative.

Feedback highlighted the need to educate the public about dementia, normalise conversations about dementia and to treat people living with dementia as ‘valuable, functioning members of society’. Some also suggested employing or engaging people living with dementia to lead the development of dementia initiatives.

‘Addressing stigma and discrimination experienced by people living with dementia is important as it can be a factor in the loss of meaningful relationships and reduced community engagement’.

Objective 2: Minimising risk, delaying onset and progression

Respondents supported actions to promote understanding of the risk factors for dementia and ways people can delay its onset or progression.

Some additional actions were suggested, including:

- targeting certain cohorts, such as children, young people and people participating in sports or jobs where there is a risk of head injury
- raising awareness of dementia risk factors and their connection to brain health
- supporting GPs to educate patients about prevention and management of chronic diseases

- creating and maintaining social networks, community groups and other activities, including locally based inclusive groups to promote social connection.

Respondents noted the need to ensure resources, information and campaigns are accessible to First Nations communities and people from culturally and linguistically diverse backgrounds and are disseminated by organisations that can reach into target populations.

Feedback suggested the ‘Slip, Slop, Slap’ campaign provided an example of a simple but effective public health campaign with long-term impact.

‘Promoting messages of hope and living well with dementia will encourage people to seek a diagnosis and help others understand that a diagnosis is not a death sentence’.

It was noted that, even when people are knowledgeable and strongly motivated, adopting lifestyle change can be difficult and people may need support.

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

Recognising the signs and seeking diagnosis

Respondents acknowledged the many factors that can impact a person’s motivation and ability to recognise symptoms and seek diagnosis. This includes the stigma associated with dementia, and challenges recognising the signs, navigating pathways for assessment and diagnosis and accessing specialist services.

To encourage people to act early on the signs, respondents suggested promoting the benefits of early diagnosis, introducing regular cognitive screening and developing clear referral pathways.

Many respondents commented on the challenges getting a diagnosis. This can be due to a lack of qualified specialists, unsuitable assessment tools and the cost and availability of diagnostic tests.

Respondents supported actions to:

- increase the number of specialists skilled in assessing and diagnosing dementia
- improve access to diagnostic tests
- improve capacity of memory clinic services

- implement diagnostic tools and processes that are appropriate for identifying different types of dementia and for people from diverse backgrounds
- fund dementia diagnosis through Medicare.

It is taking increasingly longer for people to get a diagnosis due to a significant lack of access to specialist support especially for those who cannot afford private specialist support.

Supports immediately post-diagnosis

Feedback highlighted that people often feel ‘bereft’ following their diagnosis and need immediate support at this time. Respondents also felt that people living with dementia often don’t know what services exist or what supports they may benefit from at different times.

Respondents suggested actions to help people who have been diagnosed with dementia connect with the supports they need and develop a plan to help them manage their condition, such as:

- dementia care coordinators, who could:
 - educate people who have been diagnosed (and their carers and families) about dementia and what they can expect
 - help people understand the services available to them (including allied health services to help maintain and regain function) and connect them to these services
 - develop an individualised dementia management plan for the person

‘Would be ideal to have a care partner as such, somebody to support the person with dementia and their family to support them from diagnosis to palliative care’.

- individualised dementia management plans
 - A plan could set out the likely trajectory of a person’s dementia, the services and supports they could access and actions they could take to manage their condition and maximise their quality of life.

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

Many respondents commented on the importance of quality, coordinated and person-centred care for people living with dementia. This includes care that supports the holistic wellbeing of the 'whole person' and responds to their changing needs over time.

It was acknowledged that dementia care is often fragmented as it can be delivered through primary care, the NDIS, dementia specific accommodation, aged care, hospitals and palliative care services.

A number of respondents highlighted that, regardless of where care is delivered, it should uphold and protect the human rights of people living with dementia. Actions to improve awareness of elder abuse, improve use of supported decision-making tools and limit use of restraints and locked wards were supported.

Primary care

Some respondents suggested that GPs and allied health professionals need to be better supported to provide quality dementia care, including by:

- adjustments to Medicare to encourage longer, more complex consultations and case conferencing with others involved in a person's care
- supporting GPs to provide in-reach services in peoples' homes and in aged care services, including through telehealth and face-to-face visits
- improving dementia education and training (discussed under [Objective 6](#)), including to promote the benefits of multidisciplinary and allied health care for people living with dementia.

NDIS

Respondents highlighted the need to improve linkages between the NDIS and aged care, as people living with dementia can currently access different supports under each system. People living with younger onset dementia may experience additional challenges accessing the supports they need. It was suggested that a specific pathway should be established for people living with younger onset dementia to access the NDIS supports they need, including supports for families.

Dementia specific accommodation

A number of respondents felt a specific focus was needed on the creation of dementia inclusive accommodation, including residential aged care homes and accommodation for younger people.

Respondents commented that dementia inclusive accommodation should:

- minimise confusion and anxiety

- be accessible and easy to navigate
- adopt small ‘cottage style’ models
- use technology that helps maximise independence and autonomy
- provide food that ‘looks and tastes good’
- offer access to the outdoors
- not include locked wards or areas that unnecessarily restrict peoples’ movement.

Many cited the Korongee dementia village in Tasmania as an example of best practice dementia accommodation and felt that this model should be replicated across Australia.

Aged care

Many people living with dementia, their carers and families commented on broader challenges in accessing quality aged care services. This included challenges accessing skilled workers and limitations in the ability of providers to support people living with dementia.

Respondents felt that providers needed support to build their capacity to care for people with dementia, including to:

- provide strengths-based, holistic and person-centred support for people living with dementia
- deliver interventions that can help delay the onset and progress of dementia
- improve advocacy and use of supported decision making for people living with dementia
- care for people living with complex and advanced dementia
- embed dementia-friendly environmental design in residential aged care homes
- minimise use of restrictive practices.

Some respondents noted that the impact of existing services aimed at supporting aged care providers to deliver quality dementia support is not clear.

Hospitals

Feedback highlighted the need to improve the quality of dementia care within hospitals. For example, by introducing sensory rooms or quiet areas in hospital emergency departments and strengthening standards, guidance and training for hospital workers regarding quality dementia care.

Respondents commented on the interface between acute care and aged care. Some highlighted where poor transfer processes can cause harm to people with dementia (who may be less able to advocate for their care needs). Limitations in the aged care system can lead to people with complex or advanced dementia being hospitalised

unnecessarily or for longer than needed (where hospitals are unable to safely transition people back into the community).

Respondents suggested options to limit unnecessary hospitalisation from aged care, including:

- improving access to GPs, specialist dementia and delirium services and nurse practitioners in residential aged care homes
- providing short-term, intensive resident support
- improving access to specialist dementia care services to support people living with complex or advanced dementia.

Palliative care

Respondents broadly supported actions to improve advanced care planning and increase uptake of advance care directives for people living with dementia. Feedback emphasised the importance of early planning and education for people living with dementia, their carers and families around legal options for decision-making.

Respondents supported actions to ensure palliative care service providers and workers understand dementia, including how the symptoms of dementia can impact palliative care delivery, together with increased pain, reduced mobility / spatial awareness, challenges communicating, etc.

Objective 5: Supporting people caring for those living with dementia

Many respondents commented on the importance of recognising the value of carers and supporting carers to perform this role and prevent burnout.

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.

Respondents highlighted the importance of:

- promoting awareness of the carer role, the value of carers and the rights of carers
- supporting the physical and emotional wellbeing of carers, including through access to respite services and peer support
- adequate financial and income support for carers and flexible working arrangements

- educating carers about the different symptoms of dementia and how they can support their loved one
- supporting carers to navigate the services and supports available to them and their loved one
- improving information, services and support for carers from culturally and linguistically backgrounds and First Nations communities.

Feedback highlighted that quality and responsive respite support is critical for carers, including to prevent carer burnout and fatigue and limit the need for formal supports.

‘Access to regular, ongoing breaks from the caring role is key to sustaining carer health and wellbeing, and by default, maintaining caring arrangements’.

Some respondents described challenges accessing respite services, including due to:

- workforce shortages, impacting the ability to access respite in the home and challenges in securing ongoing, consistent workers
- residential care facilities unable to meet more complex care needs
- limited options to support people living with dementia from diverse backgrounds
- unwillingness of the person living with dementia to receive support from an unknown worker
- onerous processes for nominating representatives and applying for supports
- providers refusing services to people with more complex symptoms or behaviours.

Respondents noted that carers need access to a range of respite options that meet their needs, including day respite, in home respite, overnight respite, residential respite, planned respite and emergency respite. Feedback indicated a preference for cottage style respite models and support that enables people to live in their home for longer (e.g. through funding home modifications, funding family members to care for their loved ones, or improving access to consistent in home supports).

Objective 6: Building dementia capability in the workforce

The importance of a skilled, dementia aware and competent workforce was consistently highlighted by respondents. Many respondents noted shortcomings with

the current approach to education and training for care workers and health professionals, noting that:

- training on dementia is not mandatory and requirements regarding training are inconsistent (across jurisdictions and sectors) or unclear
- there is inconsistency in the level of dementia education provided as part of foundational medical courses
- there are examples of poor quality or 'superficial' modules on dementia
- education and training are often not informed by lived experience.

'There is a pressing need for better dementia education within health professional courses'.

Some also suggested that attitudes and stigma towards dementia play a role in diminishing workforce capability.

Respondents broadly supported improved dementia education, training and mentoring for all areas of the workforce that interact with people living with dementia across all care settings (including hospitals, aged care, disability support and primary care). Respondents also encouraged a focus on organisational culture.

Suggestions variously included:

- encouraging medical colleges, universities to improve the quality of dementia education provided as part of medical, nursing and allied health courses
- strengthening the allied health workforce to meet increasing demand
- supporting GPs to recognise signs of dementia and refer and support people living with dementia
- mandating dementia training for all aged care and disability support workers
- providing training regarding strategies to respond to behaviours and optimise wellbeing for people living with dementia
- providing career pathways that promote dementia specialisation
- proactively recruiting and training workers from culturally and linguistically diverse backgrounds and First Nations communities.

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

Respondents supported the objective of improved dementia research, collection and use of data. It was acknowledged that data is key to informing government action, measuring progress and improving outcomes for people living with dementia.

Some respondents highlighted existing challenges, including poor:

- integration of data across sectors, systems and jurisdictions
- collection of data that measures quality of care, experience and outcomes for people living with dementia, their carers and families
- promotion of research and recognition / celebration of examples of good practice.

Respondents variously suggested:

- continuing to include a question on dementia in future Australian censuses
- better utilising and integrating data already captured through the primary care, aged care and acute care systems
- developing shared data standards
- ensuring the public can easily access dementia related data
- undertaking more frequent National Aboriginal and Torres Strait Islander Health Surveys and including more dementia specific questions
- actively monitoring and reporting on differences in outcomes between the general population and people from diverse backgrounds
- involving people with lived experience in research projects.

Implementing the plan

Performance measures

While respondents generally supported the examples of measures included throughout the consultation paper, some highlighted that:

- there were inconsistencies between the proposed measurements against different actions
- the basis for some of the specific goals or targets was unclear
- measures should focus on assessing impact rather than volume, including to understand the impact of actions on peoples' experience

- there would be challenges in accessing, collating and integrating the data needed for some of the performance measures.

Respondents noted that performance measures needed to be specific, measurable and relevant to people living with dementia, their carers and families.

Implementation blueprints

Respondents were keen to understand how the Plan would be implemented and broadly supported the use of implementation blueprints to outline specific activities, timeframes, responsibilities and funding allocations.

Feedback highlighted the importance of:

- working closely with stakeholders in developing the blueprints
- assigning specific responsibilities so parties can be held accountable
- periodically reviewing the blueprints to ensure activities are progressing as planned
- evaluating the effectiveness of each activity described in the blueprints.

A number of respondents were keen to understand how the community could be involved in the delivery of the Plan. Some suggested developing blueprints to describe the actions that could be taken by different types of organisations, health professionals, workers, communities and individuals.

Monitoring and reporting

Feedback highlighted the importance of ongoing monitoring and public reporting of progress against the Plan.

Respondents supported the publication of annual report cards describing progress against the Plan and Implementation Blueprints. Respondents also felt it was important to ensure there are mechanisms for adjusting the activities / approach where they are not having the intended impact.

‘There needs to be constant review of what initiatives are working and what initiatives are not showing any results to ensure that all areas of assistance and support can move forward with new initiative’.

Governance

Many respondents commented on the need for strong leadership and effective communication between Commonwealth, state and territory governments to enable implementation of the Plan and achievement of the objectives.

Some respondents recommended that additional representatives be included on any governance group, including people with lived experience of dementia and service providers.

Ten year outlook

People responding to the online survey were asked what a best possible dementia experience would look like for them in 10 years' time. Their feedback is summarised below.

- People reduce their risk of dementia.
- People showing signs of dementia are diagnosed early.
- There is less fear around receiving a diagnosis of dementia.
- People have access to timely and appropriate assessment and diagnosis.
- Early action is taken to delay / minimise the onset of dementia symptoms.
- People get access to immediate support on diagnosis and a pathway for care.
- Supports are coordinated, timely and responsive.
- People have choice and access to a range of supports that are right for them.
- Care and supports are dementia appropriate and delivered by people who understand dementia.
- People with dementia are able to live a 'full life'.
- People living with dementia are treated with respect, included and feel supported.
- People living with dementia are involved in decision-making to the fullest extent possible.
- There are choices of suitable accommodation for people living with dementia.
- End of life conversations are held early and people can die with dignity.
- Carers are valued and supported and have access to respite care when they need it.
- Dementia is prevented or treated.

Next steps

The Commonwealth is working closely with state and territory governments to further refine the Plan to ensure it reflects feedback. Additional activities to inform the final Plan include:

- consideration of governance and reporting arrangements

- incorporating stronger emphasis on a human rights-based approach
- engaging with key organisations representing First Nations people and people from culturally and linguistically diverse backgrounds to incorporate specific actions for these groups
- meeting with a range of health and aged care peak bodies and professional associations.

Governments will commence negotiations to inform the development of the first implementation blueprint. The blueprint will be developed with input from dementia experts and people with lived experience of dementia.