



Development of the National Dementia Action Plan

Summary of 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 services and systems for people living with dementia, their families and carers
- guide action by governments so that policies, services and systems are better integrated for people living with dementia and their carers
- enable measurement of progress against priority areas
- engage and involve the whole community in working towards a society that is more understanding of dementia and inclusive of people living with dementia.

Purpose of this report

The Commonwealth Department of Health and Aged Care (the department) published a joint Commonwealth and state and territory Government consultation paper on 18 November 2022. The paper set out the key elements of the proposed Plan, including a vision, objectives, focus areas, actions and performance measures.

The paper was published for public consultation over 10 weeks, concluding on 31 January 2023. Stakeholders were able to provide feedback through an online survey. People could also provide written submissions via email, give feedback by phone or via post to the department. Targeted consultation was also undertaken through workshops with people with lived experience of dementia and their carers, and some peak bodies (representing health professionals, research institutions and Aboriginal Community Controlled Health Organisations). Further detail on the consultation process and the profile of people who responded to the survey is at Attachment A.

This report summarises feedback from the public consultation on the key elements of the consultation paper. Feedback will inform the further development of the Plan by 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.

Executive summary

The department received substantial feedback on the consultation paper; with 906 survey responses, 144 email submissions and more than 50 phone calls. Of people responding to the survey, 24% identified as being a friend or family member of someone living with dementia, 24% a carer, and 2% people living with dementia themselves.

The department also undertook a second round of workshops with people with lived experience of dementia, including people living with dementia, people caring for those living with dementia, with specific sessions for First Nations people and people with younger onset dementia.

People described their experiences, both positive and negative. Many stories highlighted the resilience of people living with dementia, the immense value of carers and support provided by families and friends, the skilled and compassionate workforce and the tailored services that exist to support people living with dementia, their carers and families.

However, many also described poor experiences, including instances of ignorance or discrimination, feelings of loneliness and despair on being diagnosed, challenges getting the supports they need to live well and the burnout experienced by carers unable to access information, support or respite. People's stories of lived experience highlighted the extent of the issues in the current system and the need for significant improvement in this space.

Comments highlighted the sense of isolation people living with dementia, their carers and families can feel – particularly on diagnosis – and the need to normalise dementia (particularly given it is the second leading cause of death in Australia and the leading cause of death for women), remove the stigma and provide people with hope and a plan for the future (as is the norm for any other serious health condition).

In relation to the consultation paper itself, stakeholders broadly commended the structure and content, noting it was clear, comprehensive and obviously informed by engagement with people with lived experience of dementia. Stakeholders commented positively on the vision for the Plan, with some providing suggestions on ways this could be made more meaningful for people living with dementia, their carers and families. Likewise, stakeholders gave ideas for how the principles might be strengthened, noting it is important that these principles actually guide the design and implementation of actions set out in the Plan (rather than just offering 'lip service' to these matters).

Feedback on the objectives highlighted that they are, for the most part, addressing the right things and 'cover all areas that require significant effort to improve dementia support in our community'. Stakeholders sought priority action to address key issues, including to:

- address the stigma and improve community understanding of dementia
- improve access to, and coordination of, services
- ensure people are well supported and have a plan for action following their diagnosis
- build workforce capacity in understanding dementia and delivering quality dementia care
- support those caring for people living with dementia, including by improving access to respite care that meets their needs.

Stakeholders mostly supported the actions set out in the consultation paper, providing a range of suggestions for improvements, specific examples of models that have worked well and additional actions to consider.

Many stakeholders, while commending the consultation paper, expressed concerns regarding the feasibility of achieving the objectives set out, noting the need for:

- more detail about the specific actions to be undertaken to achieve the objectives, including proposed roles and responsibilities, timeframes and funding needed
- effective communication and coordination between all parties involved, including all levels of government, health professionals, service providers and the broader community
- strong performance measures that accurately reflect the impact of the actions on people living with dementia, their carers and families, and mechanisms to adjust the actions if they are not achieving outcomes
- ongoing monitoring and transparent reporting, including to review the effectiveness of actions.

Stakeholders were keen to be involved in developing the implementation blueprints, which will set out the detail around how actions would be implemented.

The vast feedback received on the consultation paper demonstrates the enthusiasm and excitement that people with lived experience of dementia feel at the prospect of achieving the objectives and implementing the actions outlined.

Many stakeholders offered their support in delivering on the actions outlined in the consultation paper, noting it would be a whole of community effort to achieve the improved outcomes sought for people living with dementia, their carers and families.

Broad feedback on the Consultation Paper

Australia needs strong action on dementia

Feedback from across the full spectrum of stakeholders highlighted the need for 'bold' and 'rapid' action to improve the quality of services and supports for people living with dementia, their carers and families.

A number of comments underlined the importance of achieving the goals set out within the consultation paper. Many shared their experiences of isolation, despair and frustration in trying to seek a diagnosis (for themselves or a loved one) or seeking access to the services and supports they needed. Feedback demonstrated that urgent change is imperative, and according to many, 'long overdue'.

'As someone who was left dealing with a loved one with dementia, I felt I was majorly alone. No explanations no insights, I have no family and I was alone with my grief. I am a graduate and trying to find my way around services was baffling and frustrating.'

'Not sure that Australia understands dementia. Discrimination for example...this starts at home with the family, they avoid crowds and unfamiliar places to minimise agitation. They avoid friends and even family to avoid embarrassment and fake empathy, not necessarily for the sufferer but themselves.'

'Change in the dementia space is long overdue.'

'I feel I walk alone, friends don't understand and we have lost many.'

'Provides an opportunity to boldly improve outcomes and quality of life for people with dementia and their carers.'

However, some felt that the vision and objectives outlined in the consultation paper would not be achieved in the current environment unless action was taken to address broader systemic issues, such as:

- lack of integration / cooperation between governments, programs and services
- poor dementia literacy of the community
- limited workforce skilled in dementia care
- limitations in the current aged care system
- broader challenges accessing services in regional, rural and remote areas.

The consultation paper is clear and addresses the right things

Stakeholders generally felt that the consultation paper was clear, ‘accessible, well-structured and well-informed’. Feedback indicated that the consultation paper was:

- clear and easy to read
- ‘comprehensive’ and broadly addresses the right matters, with varying views on different elements to be elevated or emphasised
- person-centred, meaningful to, and reflective of the experiences of, people living with dementia, their carers and families.

Stakeholders who were familiar with the World Health Organisation’s [global action plan on the public health response to dementia 2017-2025](#) (the WHO Action Plan) noted that the consultation paper aligned well with the intent in this document.

‘The paper provides governments with a solid foundation on which to build and sustain a new, integrated 10-year national dementia action plan. From our conversations with older Australians, we are confident the actions highlighted in the paper complement their expectations.’

‘It is thorough and I support the objectives.’

‘The development of a National Action Plan is a step forward in working towards best practice health outcomes for people with dementia and all stakeholders.’

‘We feel this plan aligns with the WHO Global Action Plan 2017-2025, all the important aspects of supporting people living with dementia and their carers is well covered including the challenges and potential responses.’

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

'Well rounded plan - covers all areas that require significant effort to improve dementia support in our community.'

'I think it correctly focuses on the individualised needs of people living with dementia, that extends equal focus to not only the individual living with the diagnosis but their support network including family, friends and professional carers / clinical / medical teams involved in offering assistance and support.'

'By shining a light on the fact that people of all ages (carers, family members, health care workers) are impacted by this disease, hopefully dementia can be raised in the public's consciousness.'

'We find the approach to the Plan accessible, well-structured and well-informed, as a high-level roadmap.'

'I want to shake your hands! This is a huge task but it only takes one small step to begin.'

The consultation paper reflects the voices of people with lived experience of dementia

A number of stakeholders felt that the consultation paper clearly reflected the voice and experiences of people living with dementia, their carers and families.

Stakeholders felt that:

- the challenges drawn out under each objective spoke to the experiences of 'real people'
- the statement for people living with dementia put people with lived experience 'at the centre'

- it was important to draw out the role and experiences of carers and families throughout the Plan.

'The proposed focus areas and actions are informed by the experience of living with dementia (people with dementia carers and dementia experts).'

'Its focus on mapping a clear-sighted way forward rather than deliberating on what is dementia and/or attributions of praise or blame for the current service system.'

'The consultation from the beginning including with people with the lived experience of dementia and people caring for dementia is obvious in the way the topics are listed and points of reference given.'

'We also welcome that the proposed Plan is carer-inclusive throughout, that it identifies key supports that carers need for themselves, and reflects that carers are partners in care.'

In response to survey questions about the key changes sought and what a 'best possible dementia journey' would look like for them in 10 years' time, many people with lived experience of dementia described what they would like the future of dementia in Australia to look like. While this feedback is incorporated through this report, it is summarised at [Attachment B](#) to give a holistic picture of stakeholder aspirations for the future.

The Plan should include actions that are specific and measurable

While commending the items included in the consultation paper, some stakeholders expressed cynicism about the feasibility of achieving the objectives described. Many stakeholders 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.

Some expressed cynicism as to whether the outcomes would be achieved in practice, noting that the Plan would require significant investment of funds and time, and considerable commitment and coordinated efforts from governments.

'The ideas are good but always loose in implementation.'

'The vision is admirable although unlikely to be achieved for both practicable and financial reasons.'

Strong governance and accountability will be critical

Stakeholders felt it was important that any actions included in the Plan are clear, specific and measurable and that there are mechanisms for holding people (governments, organisations, etc.) to account for delivering on the objectives. Some felt it would be important to get key stakeholders responsible for delivering on elements of the Plan (such as local governments, health professionals, service providers, etc.) on board early and to have mechanisms for ensuring clarity of roles and responsibilities.

Stakeholders 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

Stakeholders 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
- valuing people living with dementia and respecting their human rights, including legal protections and clarity regarding decision-making requirements
- quality of care – noting the importance of person-centred, strengths-based and enabling care that gives people living with dementia purpose
- dementia enabling physical environments
- specific interventions to improve outcomes for people living with dementia, their carers and families from culturally and linguistically diverse backgrounds and First Nations people
- actions to improve the delivery of quality and person-centred dementia care in residential aged care
- services and supports (including residential services / accommodation) for people with extreme behaviours.

While these matters are currently touched on in different areas of the consultation paper, stakeholders sought elevation and strengthening of these concepts, including specific actions to address existing gaps in the service systems.

Key elements of the Plan

Vision

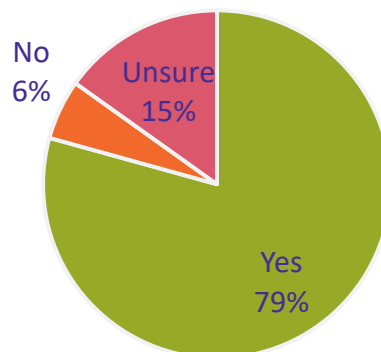
The consultation paper set out a proposed vision to guide objectives within the Plan:

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

In response to the online survey, 79% of people thought the vision was right (see Figure 1).

Figure 1. Do you think the proposed vision is right?



'The vision is based on sound research and the importance of credible quantitative and qualitative analysis of dementia with a national and international spectrum.'

'It's person centred and accessible to all.'

'To see the current stigma of dementia dropped will be a very big step in the right direction.'

'Sums up clearly key focus for the future.'

'It's great there is a 'vision' and that we've a plan to deal with the increasing number of people who will be living with dementia - and their carers. The 'stigma' has to go, and this is a great beginning. talking about dementia in this way will help reduce the stigma and encourage all to work together to manage what is to come!'

'The Vision is thorough, clear and comprehensive.'

'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.'

Stakeholders provided some suggestions to improve the vision, including:

- starting with the reference to people living with dementia, such that the focus on achieving outcomes for these people is emphasised.

'I would just reword it to have the primary focus on people living with dementia and their carers who are supported by the rest of the community, so perhaps: People living with dementia and their carers have the best quality of life possible and are supported by Australians who understand dementia, so that no one walks the dementia journey alone.'

'Maybe "All Australians living with dementia and their carers have access to the best quality of life possible throughout the dementia journey"?'

- removing the sentence 'no one walks the dementia journey alone', noting that:
 - this was unnecessary as it is implied by the other components of the vision
 - references to the 'dementia journey' was not preferred by people living with dementia
 - references to 'walking' may be 'disempowering to those with different abilities' (suggesting replacing this with 'no one faces dementia alone').

'Could you please not use 'journey'. Everybody uses it for every illness it seems these days and it implies a pleasant trip or holiday.'

'I think the vision has more impact without the last component "no-one walks the dementia journey alone", which is implicit in the other two components of the vision. I would prefer "Australians understand and accommodate dementia so that people living with dementia and their carers have the best quality of life possible".'

Some stakeholders commented that the vision was aspirational, 'utopic' or not realistic. While a number of people felt that the Plan 'set a high bar', they also acknowledged that 'we have to start somewhere'. Some suggested the vision should mention prevention, however others felt that aiming for prevention within the next ten years was 'a bit pie in the sky'.

'Previous action plan outcomes indicate this vision is over ambitious and language should be "working towards".'

'The plan is ignorant. It offers false hope and sadly lacking insight and experience in the actual care of dementia sufferers.'

'I am not sure it is ambitious enough, the direction is good, but it is small gains on what we already have (which is perhaps portrayed as better than the reality I see).'

Principles

The consultation paper described a set of principles to underpin the design and implementation of the Action Plan to ensure that 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**
- coordinated, **integrated** and planned.

Stakeholders generally supported the principles, emphasising the importance of the Plan being codesigned with people living with dementia, their carers and families – noting that people living with dementia must be ‘integrated into all stages of the design, implementation and review of the Plan’.

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

'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.'

Some stakeholders suggested additional principles be included, for example:

- respecting and protecting the human rights of people living with dementia
- equity of access to quality dementia services and supports (regardless of location)
- codesign with impacted stakeholders including health professionals, health and aged care services providers, etc.
- relationship-based care

- localised service delivery and coordination
- culturally safe care and services for all people from all backgrounds, including people from culturally and linguistically diverse backgrounds.

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

Immediate priorities

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

- timeliness of diagnosis / detection of dementia
- better coordinated post-diagnostic care (immediately following a diagnosis) but noting this need is ongoing
- increased dementia capability of the health and aged care workforce
- improved carer supports
- improved data collection, intelligence and monitoring systems.

Stakeholder feedback indicated broad support for the immediate priorities, noting these were ‘strategically essential’ to delivering on the objectives described in the Plan.

‘I agree with all the objectives but feel that upskilling the workforce should be a priority.’

‘As time and funding are always critical for success, consider giving priority to objectives 4 and 6 to improve the lives of those currently living with end stage dementia, and to objective 7, so that research can provide evidence to inform the realisation of objectives 1-6.’

‘Prioritise implementation of Objectives 3 to 6, with the others to follow once initial outcomes had been achieved.’

Groups at higher risk or facing barriers

The consultation paper set out a number of groups that are at higher risk of developing dementia or that face barriers to equitable access to dementia supports. These included:

- First Nations people
- People with culturally and linguistically diverse backgrounds
- People living in regional, rural and remote areas
- People with disability
- People who identify as lesbian, gay, bisexual, transgender, intersex, queer, asexual or sexually or gender diverse (LGBTIQ+ people)
- Veterans
- People who are homeless or at risk of homelessness.

Stakeholder feedback highlighted the importance of ensuring that dementia supports are equally accessible to all people – particularly those facing barriers to access.

Some felt that the Plan needed to include discrete actions to improve outcomes for people from these groups, particularly for:

First Nations people living with dementia

- Stakeholders highlighted the prevalence of dementia in First Nations people, the ‘amplified’ stigma associated with dementia in First Nations communities and the challenges First Nations people experience accessing quality and culturally safe services (particularly in remote communities). Stakeholders highlighted the impact of intergenerational traumas that contribute to poor health outcomes.
- Stakeholders suggested specific actions were needed to support this cohort, including to:
 - address the complexities of service delivery in remote locations and ensure access to face to face services wherever possible and alternatively through reliable telehealth or online services
 - delivering services through community controlled health services
 - recruiting and training a First Nations workforce to deliver dementia care and support
 - ensuring access to culturally appropriate aged 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.’

People from culturally and linguistically diverse backgrounds

- Stakeholders suggested specific actions were needed to support this cohort, including to:
 - ensure culturally safe and appropriate diagnostic tools and assessments
 - ensure equitable access to services that meet diverse cultural needs and support workers who speak the language of the person living with dementia.

People with other disabilities

- Stakeholders noted that community understanding of dementia as a disability is poor, in part because ‘unlike a physical disability, the cognitive and other changes that are associated with the condition are often under recognised or rendered ‘invisible’.
- The invisible nature of a cognitive disability means people living with dementia can experience additional stigma or challenges when undertaking daily activities, engaging with the health care sector or interacting with people in the broader community.
- Some stakeholders noted that wording in this section needed to be clear that disability and dementia are not distinct conditions as this might ‘inadvertently perpetuate the lack of understanding about dementia as a disability’.

‘People living with dementia relate the common experience of being told that they ‘can’t possibly have dementia’ because they don’t appear, speak or act in a way that corresponds with community expectations or understanding of the disabling nature of dementia.’

People living in regional, rural and remote communities

- Stakeholders noted that people living in rural and remote communities can often have poorer health outcomes than those living in metropolitan cities, in part due to limited access to health professionals and specialist services. Stakeholders noted that travelling long distances to access diagnostic services (such as scans) and post-diagnostic supports can be particularly challenging and / or disorienting for people living with dementia.
- Stakeholders highlighted the importance of equitable access to services, including both in-person and remote services (supported by skilled on site care workers, allied health professionals or nurse practitioners).

Veterans

- Some stakeholders suggested that veterans can be at increased risk of developing dementia (due to a higher rate of traumatic brain injury, post-traumatic stress, and depression).
- Stakeholders highlighted the importance of appropriate services for this cohort, including mental health supports and coordination of dementia supports and aged care services with the Coordinated Veterans Care Program.

People living with dementia who are homeless or at risk of homelessness

- Stakeholders noted that people who are homeless or at risk of homelessness may be more likely to have experienced trauma, neglect or discrimination and may be at higher risk of experiencing other long-term health problems.
- Stakeholders noted that traditional services may not cater to this cohort, including where these assume a fixed address. This cohort may have additional needs, to enable them to access assessment and diagnostic services and mental health supports. Some stakeholders suggested that purpose-built cottage style residential care models could support people who are homeless or at risk of homelessness and may assist in addressing social isolation, provide stability and improve quality of life.

Some stakeholders highlighted some additional groups that can face barriers to access and emphasised the need to ensure actions work to achieve outcomes for these people:

- **People with younger onset dementia**
 - Stakeholders highlighted the importance of supports for the families of people with younger onset dementia, particularly children with parents who have been diagnosed with younger onset dementia.
- **Children living with dementia**
 - There are unique challenges faced by people living with childhood forms of dementia, their carers and families
- **People living in residential aged care**
 - Some stakeholders felt that people living in residential aged care were at risk of 'falling through the gaps', particularly where they have limited engagement with friends, family or health professionals outside the service.
- **Women**

- Noting the disproportionate impact of dementia on women, stakeholders suggested specific interventions were required to address the leading cause of death in women.
- **People with comorbidities**
 - Stakeholders felt that additional actions were required to support people with multiple illnesses or conditions that could potentially worsen the symptoms of dementia.

Objectives and focus areas

The consultation paper set out seven proposed objectives to support achievement of this vision:

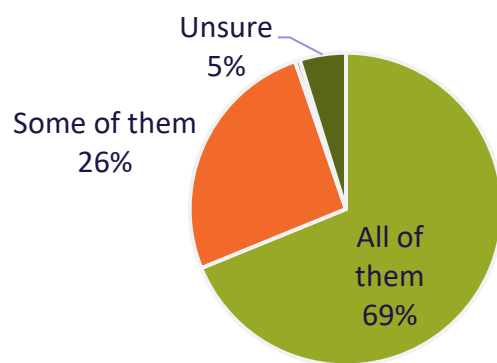
- 1. Tackling stigma and discrimination*
- 2. Minimising risk, delaying onset and progression*
- 3. Improving dementia diagnosis and post-diagnostic care and support*
- 4. Improving treatment, coordination and support along the dementia journey*
- 5. Supporting people caring for those living with dementia*
- 6. Building dementia capability in the workforce*
- 7. Improving dementia data and maximising the impact of dementia research and innovation*

Overarching comments

In response to the online survey:

- 69% of people thought all the objectives were right, 26% thought some of them were right and 5% were unsure (see Figure 2)
- 65% of people thought all the focus areas were right, 28% thought some of them were right and 7% were unsure
- 59% of people thought all the actions were right, 33% thought some of them were right, 7% were unsure and 1% thought none were right.

Figure 2. Do you think the proposed objectives are right?



Stakeholders generally felt that the objectives covered the spectrum of outcomes sought, with focus areas ‘well divided’ across the objectives.

While stakeholders supported the intent of all objectives, stakeholders noted:

- the ordering of the objectives may be seen to indicate priority, with stakeholders suggesting various orderings (with a number of stakeholders suggesting that objective 6 – building dementia capacity in the workforce should be prioritised)
- the overlap between actions in objectives 1, 2 and 3, with suggestions that objective 2 could be rolled into objectives 1 and 3.

Objective 1: Tackling stigma and discrimination

Outcome statement	Australia is a dementia-inclusive society where people living with dementia and their carers can fully participate, feel safe and empowered to live independently with respect and dignity, free from stigma and discrimination.
Statement for people living with dementia	I feel engaged in my community and empowered to thrive. I live a life free from stigma and discrimination.

Focus area 1.1 Expanding dementia awareness and reducing stigma

Stigma and discrimination

Feedback illustrated the extent of dementia stigma in Australia. People living with dementia, their carers and families consistently commented on 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’.

'Dementia Australia believes that tackling stigma and discrimination is the defining and most critical objective, and that addressing this underpins the vision, principles and everything else that follows in the Plan.'

- People living with dementia are currently treated differently to those without dementia
 - A number of people living with dementia described the 'poor' or 'dehumanising' treatment they have been subject to since their diagnosis. People living with dementia described examples of disrespectful interactions with strangers, where they have been 'talked down to' or communicated 'around' (i.e. talking to a person's family or carer rather than the person themselves).
- People diagnosed with dementia and their carers can feel 'ashamed'
 - The stigma associated with dementia means that people and/or their carers are less inclined to discuss a dementia diagnosis with friends, family, colleagues, etc., which can cause people to become isolated and feel unsupported.
 - Many stakeholders (particularly people living with dementia, their carers and families) highlighted the importance of dignity.

'We need to normalise the disease so that people have understanding and compassion.'

'Removing the stigma, addressing the fear or reluctance of diagnosis will significantly improve the situation. It does not offer a cure but will improve the quality of life of the person with dementia and the carer.'

'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.'

Improving community awareness

- **Greater visibility / representation of people living with dementia in the mainstream media, including:**

- examples of different types of people living with dementia, including people both in the early stages and the more advanced stages, people at different ages or with different symptoms and who have experienced different journeys or trajectories
- examples of people living well with dementia, including people who are continuing to participate in activities they enjoy, socially connected, engaged in their community, etc.
- role models of people living with dementia who are doing important work, achieving goals, etc.

'Highlight people with dementia on media channels like TV or movies in a positive and realistic manner. There are positive ways to live with dementia instead of the negative narrative dominating our mainstream media. Also train reporters on how to report on dementia.'

'It is important to get the message out about dementia/dementia awareness by enlisting prominent Australians in the arts / entertainment, sport and other areas who appeal to different cohorts / demographics and tailoring messages through different media channels and platforms.'

- **Use of social media channels**
 - Stakeholders noted this is where many younger people get their information and also is where 'disinformation can proliferate'.
- **Establishing a national campaign to raise awareness and funds for dementia**
 - Stakeholders cited examples of days / events that seek to promote awareness of and raise funds for other conditions in the mainstream community, such as Movember, Steptember, Pink Ribbon Test Match, etc.
- **Talking about dementia in schools**
 - A number of stakeholders highlighted the impact that could be had by educating children on dementia in schools, including promoting awareness of risk reduction strategies, signs and symptoms and exposing them to 'what someone with dementia looks like' by having people living with dementia deliver talks.
 - Some stakeholders also suggested investing in and promoting intergenerational programs linking early childhood facilities with aged care homes.

- **Providing free dementia awareness training, including:**
 - tailored modules for specific sectors including common scenarios and mistakes for key groups including local government, transport, emergency services, sports and leisure
 - education for first responders, public services, retail workers, local councils, etc.
- **Creating ways that a person with dementia could be easily identified**
 - Some stakeholders suggested a form of personal ID or bracelet that provides information about the person's cognitive condition and associated symptoms to help with communication / understanding of needs in the community, i.e. on public transport / in health care / retail and small business settings.

Stakeholders commented on the key areas where improved dementia awareness was needed, including an understanding of:

- the different types of dementia, including the signs, symptoms and ways it can impact people
- the trajectory for people diagnosed with dementia, including different scenarios and rates of onset / progression
- the services and supports that can support quality of life over time
- how people can 'live well' and continue to participate with dementia.

'When increasing awareness of dementia, reinforce the different kinds of dementia, including the rarer types, and different disease trajectories and treatments.'

'It is important for Australians to understand that all people with dementia are not the same and they have different needs.'

Many stakeholders also commented on the need for improved dementia awareness within the health and aged care workforce (discussed under [Objective 6: Building dementia capability in the workforce](#)).

Focus area 1.2 Creating inclusive communities and environments for people living with dementia, their carers and families

A range of stakeholders provided suggestions for improving the dementia inclusiveness of communities and environments, including:

- **Creating dementia inclusive public spaces**
 - Stakeholders highlighted the importance of dementia inclusive public spaces, including government shopfronts, shopping centres, transport services and other community services.
 - Stakeholders noted that simple guidance could be created to help governments and businesses to ensure spaces are as dementia friendly as possible, including guidance for new builds and refurbishments as well as simple changes that could be made to existing spaces.

‘Need to emphasise that dementia-friendly spaces include considerations such as access to public transport, spatial awareness and wayfinding, communication (sensory mapping¹/social scripts²) and the importance of access to natural surroundings.’

‘As part of a nation-wide initiative to encourage inclusive, dementia-friendly communities and spaces, Federal, State and Territory customer service centres (for instance the Australian Taxation Office, Centrelink, Medicare) could be required to undertake dementia-friendly environmental audits and produce sensory maps and social scripts to support dementia-friendly service.’

- **Undertaking audits of public spaces by people living with dementia**
 - Some stakeholders suggested supporting businesses to engage people living with dementia to undertake environmental audits of their businesses, including to give them tips and suggestions on how to make their business more dementia inclusive.
- **Training on interacting with people with cognitive impairment**
 - Stakeholders suggested training for first responders, government, business and retail workers.

¹ Sensory mapping is a technique that identifies sensory highlights with a view to creating inclusive visitor experiences. Maps show where people may encounter particularly strong sensory stimuli, including, sights, sounds, smells, textures and tastes

² A social script is a document that uses storytelling techniques to explain new experiences and environments to people with cognitive impairment through simple language and images

'Generalised community understanding, creation of dementia friendly communities in every postcode. Industry and retail support to enable people with early-stage dementia or contributing diseases to access services more easily.'

- **Dedicated spaces for people with cognitive impairment to gather**
 - Some stakeholders commented on the prevalence of social isolation for people living with dementia and suggested that dedicated spaces for people living with dementia (and broader cognitive impairment) to gather and engage with others in similar situations could be helpful.
 - Some stakeholders suggested that dedicated spaces could also be used to educate people about dementia, provide information about available services and connect people seeking to support people with dementia.

'Information/programs/activities and making these spaces dementia-friendly. Advocates strongly endorse the Dementia Australia Memory Lane Cafés initiative as an effective example of how information and support can be provided in a local, dementia-friendly environment.'

DEMENTIA FRIENDLY COMMUNITIES

A number of stakeholders highlighted the positive impact of the dementia friendly communities initiative. Stakeholders suggested ways this initiative could be better leveraged or expanded, including:

- better promotion of dementia friendly communities, including through signage, posters for business (declaring they are 'dementia friendly'), local radio advertisements, etc
- engagement with the broader community to raise awareness and priorities spending (e.g. to create the biggest impact / value for money)
- getting Local Councils on board, including by developing their own action plans for creating dementia / disability inclusive communities.

'Funding for Dementia Friendly Community activities needs to be promoted at the ground level to engage with the general community to ensure changes to how people living with dementia are perceived and supported'

'For a national plan to be effective, it must be implemented at a local and community level. Tapping into local council, other community based-

organisations and facilities will be crucial, including libraries, community centres etc’.

‘Maroondah City Council in Victoria has actions on addressing dementia contained within their Positive Ageing Framework and Action Plan 2021-2025’.

Objective 2: Minimising risk, delaying onset and progression

Outcome statement	People understand the factors that increase their risk of dementias and are supported to take actions to reduce these risks, delay the onset and progression of dementia across all stages of life.
Statement for people living with dementia	I am aware of the risk factors for dementia and supported to take steps to reduce my risks or delay the progression.

Some people with lived experience of dementia noted that for a person already diagnosed with dementia, it seems ‘erroneous to be aspiring to an awareness of risk factors, and risk reduction *post-diagnosis*’. Stakeholders suggested rewording the outcome statement, to focus on maintaining a healthy lifestyle, minimising ongoing risks and delaying progression of the condition.

Focus area 2.1 Risk factors for dementia are well understood

Stakeholders supported proposed actions to promote understanding of the risk factors for dementia.

Stakeholders noted the need to ensure:

- resources, information and campaigns are accessible to vulnerable groups, including First Nations communities and culturally and linguistically diverse people
- messaging supports people with mild cognitive impairment to take steps to delay progression
- targeted messaging about brain health to children and younger people, including by incorporating brain health programs in school curriculums.

People with lived experience of dementia cited the ‘Slip, Slop, Slap’ campaign as a public health campaign with a simple but effective message that had a long-term impact.

'There has been a large reduction in investment in health promotion across the health care sector in recent years. It is pleasing to see a commitment to and an increased focus on prevention / education.'

Focus area 2.2 People are aware of what they can do to delay the onset and slow the progression

Stakeholders suggested that actions could include:

- communications regarding the benefits of preventative health measures in reducing risk of dementia
- reviewing the MBS to eligible GPs to spend more time with their patients and educate them about prevention and management of chronic diseases
- funding projects where peak bodies work together to provide community programs around brain health e.g., Headspace, Heart Foundation, Diabetes Australia
- including positive and empowering messages about the link between lifestyle factors and dementia so the community 'will connect with what they can do in terms of risk reduction on a personal level'
- creating and maintaining social networks, community groups and other activities, including locally based inclusive groups to promote social connection.

'By using the term of minimising risk, it can suggest that patients are to blame for their own demise.'

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

Outcome statement	Ensure that dementia signs are recognised and people are diagnosed as early as possible, helping them to slow progression, maximise their abilities and plan for the future. People are provided with information and connected to coordinated, inclusive supports immediately following their dementia diagnosis.
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Statement for people living with dementia

I can recognise the signs of dementia and understand where to go if I have concerns. I can access health professionals who are willing and able to assess my symptoms and provide a timely diagnosis. I am linked with information and supports to assist me and my family immediately following a dementia diagnosis.

Focus area 3.1 Recognising and acting early on signs and symptoms

Some stakeholders commented on the challenges in recognising and acting on dementia signs early, variously commenting that:

- the signs of dementia can present in various ways and are not always readily recognisable as dementia
- people with co-existing health conditions can struggle to recognise the signs of dementia
- dementia can cause some people to become paranoid or distrustful of medical professionals such that getting a diagnosis is particularly challenging
- where people don't have close loved ones / peers who can recognise changed behaviours, they will experience delays accessing diagnosis
- GPs don't always recognise the signs of dementia
- GPs refer people to specialists for diagnosis and this 'takes too long'
- there is no clear pathway for screening, assessment and diagnosis.

While many stakeholders felt that improved community awareness and stigma reduction would contribute significantly to recognising and acting on the signs of dementia, some stakeholders also suggested:

- **Promoting the benefits of early diagnosis**
 - A number of stakeholders felt the benefits of early diagnosis (and timely access to services and supports) needed to be better promoted to GPs, nurses and the broader public.
- **Regular screening**
 - A number of stakeholders supported the introduction of regular cognitive screening, suggesting that Medicare funding be provided for GPs to undertake regular cognitive screening from the age of 50 (including baseline assessments from a certain age, such that any future decline can be easily recognised).
- **Clear referral pathways**

- Stakeholders sought the introduction of a clear, nationally consistent pathway for assessment and diagnosis (including referrals to specialist diagnostic services such as geriatricians and Memory Clinics). It was proposed this should include clarifying the roles and expectations of different health professionals / services, identify best practice / validated assessment tools, set out triggers for escalation / referrals and describe the information and support to be provided to people seeking assessment.
- Stakeholders noted that these pathways must not just focus on clinical issues but spell out the value of other forms of services and support i.e., social prescribing initiatives, psycho-social interventions.

Some stakeholders also highlighted the unique diagnostic, support, treatment and care issues and challenges faced by people living with childhood forms of dementia and younger onset dementia, and the need to tailor services and supports accordingly.

Focus area 3.2 Quality and timely diagnostic services

Many stakeholders commented on the challenges getting a diagnosis, including due to a lack of skilled / qualified specialists, use of assessment tools that were not right for the person and the cost and availability of diagnostic tests (such as CTs, MRIs or PET scans).

Stakeholders supported actions to:

- increase the number of specialists skilled in assessing and diagnosing dementia
- improve access to diagnostic tests, including to address the cost (particularly where people need to travel long distances) and reduce wait times
- implement diagnostic tools and processes that are appropriate for:
 - identifying different types of dementia
 - people from diverse backgrounds, including people from culturally and linguistically diverse backgrounds and First Nations people (including reviewing the efficacy of the Rowland Universal Dementia Assessment Scale (RUDAS) and the Kimberley Indigenous Cognitive Assessment Tool (KICA))
- review the MBS to better support dementia diagnosis, including the addition of a new item for dementia diagnosis
- improve access to biomarker testing for dementia.

'Better diagnosis is needed - my family member passes the quick questions test but have some conversations with them and clear that they have vascular dementia.'

'There needs to be better access to biomarker testing for dementia.'

'Better diagnosis - family member is in denial that they have dementia, which means that we can't give them the support that someone with dementia needs because it insults them. So they're now so scared to drive anywhere because they can't remember where they are but won't get help because they don't think they have dementia, so don't need support. Frustrating.'

'Access to timely dementia diagnosis, it is taking increasingly longer for people to get a diagnosis due to a significant lack of access to specialist support esp. for those who cannot afford private specialist support.'

'More access particularly to regional areas to geriatrician support (use of Nurse Practitioners & Telehealth options are required to address this gap).'

MEMORY CLINICS

While stakeholders commented positively on the role of Memory Clinics, they highlighted some challenges, including:

- the name 'Memory Clinic' reinforces the misconception that dementia always or only impacts a person's memory
- Memory Clinics do not have a consistent structure and function across Australia
- there are not necessarily 'working clinical pathways' for GPs and other specialists to refer to Memory Clinics for specialist advice

- Memory Clinics do not have a strong presence in rural and remote areas and other actions may be needed to address the 'increasing difficulty of access to diagnostic services in these regions'.

Focus area 3.3 Post-diagnostic care and support

Stakeholders acknowledged that while there are a range of dementia supports available (as noted in the consultation paper), people often don't know what services exist or what supports they may benefit from at different times. People who have just been diagnosed expressed a feeling of hopelessness, particularly because the benefits of, and options for, reablement and services to support long-term maintenance of function are not well known.

Immediate support

A number of stakeholders highlighted the need for immediate support for people living with dementia, their carers and families at the time of diagnosis, noting that people often feel 'bereft' following their diagnosis. Stakeholders noted that people may need support to help them come to terms with the diagnosis (and what it means for their life) and to maintain their sense of self-worth and purpose.

Care coordinator

Many stakeholders supported the idea of a care coordinator, suggesting a range of different ideas for this role.

- While many responses focused on the support this role could provide to people once they have been diagnosed with dementia, a number of people suggested that this role should be available before a person is diagnosed, i.e. when signs of potential cognitive impairment are first recognised. It was suggested the coordinator could help people to navigate the diagnostic pathway and to access screening and assessment services and should continue right through to palliative care.
- Stakeholders suggested that this role could:
 - help people come to terms with their diagnosis, including providing referrals to psychological and peer supports
 - educate people living with dementia, their carers and families about dementia, including the likely trajectory, signs and symptoms and services that can help them
 - refer people, or facilitate access, to services and supports
 - initiate conversations about advanced care planning
 - develop an individualised dementia management plan for the person living with dementia (as described below)

- be available to answer questions or discuss concerns at any point in a person's journey
 - provide people with information and options about how they might manage their dementia.
- Some stakeholders suggested that nurse practitioners may be well positioned to undertake this role, including to support cognitive assessment, referrals and the planning of dementia treatment and care in a range of health care settings.
 - A number of stakeholders felt it was important this role also provide advice regarding financial support, access to government funded programs and services and practical support to navigate access and complete forms and paperwork.
 - Some stakeholders suggested this role should facilitate linkages between the health, aged care and disability systems, including to support information sharing, coordination and continuity of care. Stakeholders also highlighted the need to consider how this role relates to other care / service coordination roles across the health, disability and aged care sectors.

'Carers need access to financial & practical help & advice - the burden is high even when not living nearby.'

'Objective 3 needs better Medicare remuneration for GP's so they claim a double consult for inclusion of the carer in the consult. Nurse Practitioners specialising in dementia could be employed and be able to claim Medicare rebate for memory clinic and supporting GPs to deliver more dementia comprehensive services and follow ups.'

'GP screens, referral to memory clinic, dementia work up completed, 1st assessment booked within 90 days. Specialist review followed by care navigator support. Continued support for access to community services or residential care, ongoing education. Also, a one stop portal to find all the necessary services.'

'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.'

Dementia management plan

Many stakeholders highlighted the need for an individualised plan setting out the likely trajectory of a person's dementia and the services and supports they could access to manage their condition and maximise their quality of life.

Some stakeholders highlighted that this was the norm for other serious health conditions (such as cancer) but did not typically occur for people diagnosed with dementia. A number of stakeholders referenced recommendation 15 from the Royal Commission, which recommended establishment of a 'comprehensive, clear, and accessible post diagnosis support pathway for people living with dementia, their carers and families'.

'A focus area should be on developing a pathway for wellbeing, physical and emotional wellbeing. I would like to see a long-term action for community centres to be safe for people living with dementia and used for educating the community about dementia based on best practice research.'

'What was missing is overall health and wellbeing plan to see a psychologist, dietician, nutritionist etc. There is no set plan for Dementia as a terminal illness.'

Stakeholders sought a tailored plan that set out:

- the future trajectory of the disease, including possible timeframes for progression and signs of deterioration
- potential symptoms and behaviours
- actions for people living with dementia to delay the progression or onset of symptoms
- services and supports to help people living with dementia to reable, maintain function and optimise their wellbeing, including allied health services, social supports and technological supports (including culturally appropriate services for people from diverse backgrounds)
- supports for carers.

Stakeholders felt it was important for people living with dementia, their carers and families to have access to such a roadmap promptly following diagnosis so they could 'retain hope' and 'start acting'.

‘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.’

‘People wouldn’t be so scared of getting or admitting they have dementia because they know that the supports are there to help them.’

‘An early diagnosis often does not add to management or prevention of progression unless adequate needed supports are put in place in an equally early manner.’

Some stakeholders suggested these plans could be developed by GPs (for example, through changes to MBS arrangements for Chronic Disease Management), while others felt these should be developed by someone with specialised knowledge of dementia and the supports available.

Stakeholders also remarked that post-diagnostic supports / dementia management pathways must be clear, consistent across jurisdictions (noting that the services available locally may differ) and well communicated to GPs, specialists and other health professionals who may be involved in supporting people during their diagnosis.

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

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

Outcome statement	People living with dementia are connected to coordinated, dementia-inclusive services that meet a person’s changing behavioural, psychological and end of life needs
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Statement for people living with dementia	I have hope and a pathway to live my best life with dementia as my needs change, and I am supported as I approach the end of my life.
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Some stakeholders highlighted that the outcome statement for Objective 4 should reference a person's changing physical needs.

Stakeholders suggested that 'live my best life with dementia' be adjusted to 'living as well as possible with dementia'.

Focus area 4.1 Quality care and ongoing support as a person's needs change

Quality of care

Many stakeholders commented on the importance of quality, person-centred care for people living with dementia, including the need for improved access to quality, responsive and appropriate services and supports for those living with dementia.

Stakeholders sought:

- a simple service system that is easy to navigate, with improved coordination between services and systems (such as primary care, acute care, aged care and disability support)
- person-centred care that is tailored to the individual, noting that each person living with dementia is different and is impacted in different ways by dementia
 - This includes mechanisms for ensuring responsive care and services that adapt as the person's symptoms change.
- supporting people living with dementia to maintain their identity, dignity, purpose and quality of life
- care and services that are holistic, evidence-based and best practice
 - Stakeholders observed that interventions should focus on optimising the person's skills and strengths and enhancing wellbeing.
 - Stakeholders specifically noted that behaviours should be recognised as expressions of unmet need and use of restraints (particularly psychotropic medications and polypharmacy) must be minimised in care delivery.
- prioritising supported decision-making where a person's capacity to make decisions is impacted by their dementia (and only using substitute decision-making as a last resort)
 - Stakeholders supported actions to improve guidance regarding the use of supported decision-making

- Stakeholders noted guidance could be made available in (and distributed through) a range of settings, including acute/primary health/aged care settings, community centres, legal aid and private legal practices and other relevant outlets, organisations and institutions
- ensuring sufficient workers are available to support people with severe symptoms and behaviours (this was particularly in relation to residential aged care and respite services)
- ongoing communication with the person living with dementia and the people important to them.

'Navigating support services and help is missing as an objective. This is a very challenging area for unpaid carers and family members to understand.'

'Applied Education of all persons involved and including the person with dementia. As symptoms occur then lifestyle changes need to be implemented and a focus on ensuring the safety and happiness of both sufferer and carer. Making the most of what the sufferer can do and not trying to make them fit the carers lifestyle or expectations.'

'Actions need to address both care and social support both of which must be directed in assisting and maintaining independence, and feeling of self-worth. These are reasons that address more than just the anatomical and neurochemical deficits that the person is currently branded with.'

'Anglicare Sydney's program funded under CHSP Specialised Support Dementia Advisory Services focus on reablement for the person living with dementia in providing 1:1 to practice activities of daily living and leisure to improve quality of life and independence - we strongly suggest this type of funding continues due to the difference it makes to people's lives - the person and their family.'

Primary care

Some stakeholders suggested that GPs need to be better supported to provide good dementia care including by:

- adjusting the MBS structure to 'value longer more complex consultations'

- remunerating GPs to case conference with others involved in the person's care (including carers and families, specialists and allied health professionals)
- supporting GPs to provide in reach services in peoples' homes and in aged care services, including through telehealth and face-to-face visits
- 'elevating' the role of GPs in aged care services
- improving dementia education and training (discussed under [Objective 6](#)).

A number of stakeholders commented on the need for actions to improve access to coordinated and holistic multidisciplinary care.

NDIS

A number of stakeholders highlighted the need for improved linkages / interfaces between the NDIS and aged care, noting that people living with dementia can access different supports based on the system they enter (i.e. the age at which they are diagnosed). Stakeholders also reflected experiences of younger people living with dementia falling between the gaps of NDIS and aged care.

Aged care

Many people living with dementia, their carers and families commented on the challenges they had experienced (or were currently experiencing) in accessing aged care services, citing long waits to get an ACAT assessment, extensive waitlists to access a Home Care Package or a place in a residential care service and challenges accessing workers to provide care in the home.

Families and carers expressed feelings of hopelessness and despair that they were unable to provide their loved ones with the care, comfort and dignity they deserved in their final days of life. Many stakeholders noted that, while they would have preferred to support their loved one at home, insufficient access to skilled home care workers made this impossible.

'Focus on reassurance and acknowledgement for the challenging and confronting experiences that family may encounter living this journey is also a very important aspect - when families come into aged care we find they have already started the grieving process for their loved one, if there could be more focus on the 'normality' of this feeling and the support on offer this would assist the resident's transition, families expectations and staff experience.'

'Need to move away from large excessively funded dementia specialist services that are metro centric...and disperse the funds to many more rural / regional

centres that can support dementia care at the local site, thus not moving people away from their local support network and treating team.'

Stakeholders noted that, while there are a range of dementia support programs available to aged care providers, the impact of these services in lifting the quality of dementia care delivered by aged care providers is not clear.

Stakeholders variously suggested:

- improving outcomes reporting to help assess provider performance and identify systemic needs and gaps
- improving dementia education and training for the workforce (discussed under [Objective 6](#))
- fostering engagement and linkages between providers and in-reach services, including through funding case conferencing
- providing short-term reablement / restorative care for people living with dementia to help them to maintain function and independence
- improving advocacy arrangements for people living with dementia in residential aged care with no representative or family to prevent these people from 'falling between the cracks'
- ensuring dementia referral pathways are available through 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'
- introducing a 'care-finder' workforce (as per recommendation 29 of the Royal Commission) to assist older people, their carers and families to navigate the aged care system and identify the best option for care to meet their individual needs
- reviewing the effectiveness of the Specialist Dementia Care Program (SDCP) to ensure it is meeting its intended aims and provides the best model of care for people with very severe behavioural and psychological symptoms of dementia
 - Some stakeholders suggested that clarity is needed regarding pathways for accessing the SDCP as anecdotally access has been 'prioritised for people who are in hospital, diminishing access to people who live in residential aged care services'.
 - It was also suggested to rename some of the existing programs to make them sound less negatively geared e.g. the Severe Behaviour Response Team.

Dementia specific accommodation

A number of stakeholders felt a specific focus was needed on the creation of dementia enabling environments and residential services for people living with dementia. Stakeholders commented on both the need to ensure existing residential aged care services are dementia inclusive and also on the need to build dementia specific accommodation or villages (particularly for people with more severe or extreme behaviours).

Stakeholders commented that dementia inclusive environments should:

- minimise confusion and anxiety, including through consideration of matters such as colour, noise, etc.
- be accessible and easy to navigate, including simple layouts, use of clear signage, etc.
- adopt small 'cottage style' models
- use technology that helps maximise independence and autonomy
- food that 'tastes and looks beautiful'
- access to the outdoors, including gardens and areas for engaging with loved ones
- 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.

'Where people live. Locked units are not a way to help people live out their lives with dignity or inclusion. Villages with freedom to be keep some normality, would bring more encouraging and joyful for those living with dementia and their families'.

'Normalisation for those living with dementia. Places to live where you are safe, secure, respected and encouraged to live with dignity, value and worth. Where food tastes and looks beautiful and positive interactions and normal life activity is the way of living'.

'Environmental design standards, 40% of distress, anxiety, confusion, delirium and changed behaviours in dementia are caused by the environment. In Australia we do not have a clear design framework to improve dementia

environments for the future. A National framework is required to at least guide main issues like design principles, lux levels, colour contrast, noise etc like other parts of the world leading in dementia care.'

ACCOMMODATION FOR YOUNGER PEOPLE LIVING WITH DEMENTIA

A number of stakeholders highlighted the need to improve accommodation options for younger people living with dementia. Some stakeholders referenced government commitments and targets regarding reducing the number of younger people in residential aged care, noting that an appropriate alternative model needed to be identified.

Focus area 4.2: Care and support during and after hospital care

A number of stakeholders commented specifically on the interface between acute care and aged care, pointing out issues with transition that can result in negative outcomes, including poor information exchange, poor communication, etc.

CARE FOR PEOPLE WITH EXTREME BEHAVIOURS

A number of stakeholders commented on the lack of appropriate care options for people with extreme behaviours, noting services are very limited and fragmented (both across jurisdictions and care systems). Many carers and family members expressed concerns about the lack of options for their loved ones and gave examples where residential and respite services had turned their loved ones away as they were 'unable to care for them' due to their behaviours.

Stakeholders noted that this can result in unnecessary extended hospitalisation where hospitals are unable to safely transition people back into the community.

'Inability to discharge patients with extreme BPSD, and patients with dementia in general, contributes to public hospital bed access block.'

'Patients with BPSD require intensive care from providers with high levels of expertise to provide effective interventions.'

Stakeholders commented on use of the terminology 'behavioural and psychological symptoms of dementia (BPSD)', noting that (while this may be appropriate as a clinical indicator) this is not the preferred terminology. People

with lived experience of dementia preferred the terminology ‘changed behaviours’.

Stakeholders variously suggested:

- improving access to GPs in residential aged care services to limit unnecessary presentation and admission to hospital
- increased resourcing for specialist dementia and delirium services and nurse practitioners in aged care services to reduce unnecessary transfers and pressure on hospitals
- funding aged care providers for short-term, intensive, one-to-one resident support to prevent moving them to hospital
- standardised systems and protocols for communication and information exchange between acute care and aged care settings, including to improve admissions to hospital and discharge planning
- improved access to specialist dementia care residential services with capacity to support people with extreme behaviours
- reviewing the National Safety and Quality Health Service (NSQHS) Standards to ensure they support effective dementia care.

Focus area 4.3: End of life and palliative care

Stakeholders broadly supported actions to improve advanced care planning and increase uptake of advance care directives for people living with dementia. Stakeholders also supported actions to increase community based palliative care for people living with dementia, enabling them to die in their homes, where they wish to do so.

A number of stakeholders commended actions to develop specialist dementia specific palliative care services – citing the South Australian Nightingale program as a best practice model that could be expanded. However, not all stakeholders supported this, with some noting that the focus should instead be improving the capacity of residential aged care services to provide quality palliative care.

Stakeholders suggested the development of a dementia-specific palliative care tool to support providers in identifying people who may need palliative care (in the coming 6-12 months) and recognise and respond to symptoms. One stakeholder suggested the Palliative Care Outcomes Collaborative (PCOC) (which helps palliative care providers to identify and measure the impact of their service delivery on people with a life-limiting illness, their families and carers) could be adapted into a dementia-specific tool.

'From a Palliative Care perspective, there would be a systematic approach whereby we identify all people with dementia who would benefit from Palliative Care. Shared care and cross referrals where appropriate between treating teams - GP, geriatricians, Palliative Care teams, Psychogeriatricians or other specialist services to achieve good clinical outcomes. Community engagement, bringing nursing homes back into the spotlight in a positive way, increased workforce and workforce efficiency, adequate psychological and bereavement support for carers.'

'Need increased education for aged & carers about legal options around decision making capacity, supported decision making, making legally binding documents about wishes for enduring guardian to make decisions when unable. Normalise this - could be any one of us if have a stroke or hit by bus tomorrow. Increase access to low-cost legal services for this and run legal talks in aged care groups.'

Objective 5: Supporting people caring for those living with dementia

Outcome statement	Carers have the information, training and support they need to undertake their caring role and maintain their own health and wellbeing.
Statement for people living with dementia	As a carer, I am supported in my caring role and able to have a genuine break when I need it.

Some stakeholders suggested this statement should be from the perspective of the person living with dementia rather than the carer.

Some stakeholders also noted the importance of clarity of language (throughout the Plan), noting that carers should be defined as per the Carer Recognition Act 2010 and that paid workers should not be referred to as 'carers'.

Focus area 5.1: Recognising carers and assisting carers in their role

Many stakeholders commented on the importance of recognising the value of carers and supporting and assisting 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.'

Stakeholders highlighted the importance of:

- awareness of the carer role (and the value of this role) and rights of carers

'We agree with the ongoing support of family carers in this plan - dementia is an evolving condition and the support network for a person needs to adapt and change along with the person living with dementia. Funding for support for carers also needs to be offered more broadly to ensure no carers are missed.'

- physical and emotional wellbeing of carers
 - Stakeholders highlighted the significant physical and emotional toll that caring for a loved one can take, including factors such as stress, concern, lack of sleep and limited opportunity to properly care for themselves. Carers looking after someone in the more advanced stages of dementia (where the disease has dramatically altered who they are) are often grieving for their loved one while caring for them.
 - People caring for someone living with dementia expressed their concerns that if they experience burnout or something happens to them, there will be no one to care for their loved one.
 - Stakeholders also noted that some carers may be subject to emotional, verbal or physical abuse due to behavioural changes as a result of their loved one's dementia. Stakeholders suggested there needed to be specific supports available to address these issues.
- financial impact of dementia
 - A number of stakeholders commented on the significant financial burden dementia can have on individuals and families, particularly where the person diagnosed with dementia was a major money earner (and may have mortgages in place or school aged children for people with younger onset dementia) or the person's family members need to stop working (or reduce their working hours) to care for their loved one.
 - Stakeholders described how challenging it can be to access financial support, including completing forms, providing evidence of a diagnosis (noting this can take years and the tests themselves can be expensive), etc.

- Many stakeholders also expressed concerns that family members cannot be paid for their work as carers (citing that this could help to alleviate existing workforce shortages in the health and aged care sectors).

'Dementia steals so much from us mentally, physically and emotionally, but the daily struggle is made a million times worse by the rapid slide into poverty when you suddenly have to give up work (as the person with dementia and their carer) and the income that allows you to have a car, occasional holidays, gifts at Christmas, interesting outings that don't involve a bus full of oldies, even just getting to a medical appointment without having to allow 3 hours of bus travel for what would otherwise be a 30 minute drive. Without all these stresses we could concentrate on dealing with the disease and managing the grief and anger of the person with dementia without it escalating into abuse of the Carer.'

- education for carers
 - A number of carers expressed the need for improved education of carers, particularly in relation to the symptoms of different types of dementia, what they can expect and how these can change over time, how they can support their loved one, activities and services that can help to minimise and delay onset of symptoms, the importance of advance care planning, supports available to them and their loved ones.
 - Some stakeholders also highlighted the need to build carers' capacity to advocate for the person living with dementia and for themselves.

Some stakeholders highlighted opportunity for the carers and families with loved ones receiving aged care services to be better recognised and valued, including for example:

- assessing carer needs (and supports to address these) as part of assessment for aged care services
- improving mechanisms for linking carers to services (including through improving interoperability between My Aged Care and the Carer Gateway)
- introducing a face to face mechanism to help carers identify and access services
- improving services and support for carers from culturally and linguistically backgrounds and First Nations carers
- providing information for carers that is easy to 'access, readily understandable and dependable' (including by improving My Aged Care).

Focus area 5.2: Increasing access to carer respite services

A range of stakeholders highlighted the importance of access to quality respite support for carers, noting that ‘due to the progressive nature of dementia, carers can suffer strain and fatigue’. Stakeholders noted that respite is critical to enable carers to maintain their support of their loved one and help keep them in the location of their choosing for longer.

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

- limited options to meet the diverse needs of people living with dementia, including:
 - people with younger onset dementia (noting that neither the NDIS or the aged care system currently offer appropriate respite services or this cohort)
 - First Nations people
 - people from culturally and linguistically diverse backgrounds
 - people in rural and remote locations
- workforce shortages, limiting access to respite in the home
- providers refusing services to people with more severe symptoms or behaviours

Stakeholders 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. Stakeholders highlighted that different models may suit different people but respite options must be able to cater to the needs of all individuals, including those with more severe or extreme behaviours.

‘Equitable access and early referral to respite care, both planned and emergency, is critical to ensure sustainability of care relationships, and the health and wellbeing of carers. In many cases, lack of access to respite care can be the difference between maintaining the caring role or having no alternative but to seek other more costly government-subsidised care and accommodation options, cease or reduce employment, or risk further strain on carer and wider family relationships.’

Stakeholders suggested that governments prioritise:

- the design and implementation of innovative models of respite care
- establishing respite care services that can support people with extreme behaviours

- availability of affordable respite care, including care in the home, day therapy, overnight and residential care
- development of appropriate models of respite care for people with younger onset dementia
- opportunities for people living with dementia and their carers to participate in some normal activities together.

‘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.’

‘Carer support, practical, affordable, timely, appropriate. I don’t want a talk fest, i.e. support groups etc, just cold hard reliable practical support.’

‘Respite that isn’t institutional care, such as opportunities for the person with dementia and their carer to participate in some normal life activities together that are otherwise unaffordable or impossible to access – a day at the zoo, an overnight trip to see relatives in another town. Assistance to continue to have pets at home. Supports that recognise that Carers often have their own chronic health conditions to manage (even if they are not eligible for formal assistance such as NDIS or DSP themselves) and the stress of being a Carer can have a huge impact on their ability to cope. Better support for Carers to stay in the workforce for longer – for example practical support for Carers to work from home while receiving Carer Payment, and income alignment with the recently increased Work Bonus for pensioners.’

Objective 6: Building dementia capability in the workforce

Outcome statement	The primary care, acute, community, health and aged care workforces receive the training and support they need to provide high quality care to people living with dementia, their families and carers. High quality care focuses on optimising quality of life, is person-centred, culturally safe, trauma- informed and healing-aware.
Statement for people living with dementia	The people supporting my care understand dementia and take time to learn about me and listen to my concerns. I am provided with care, support and information that meets my needs and is sensitive to my individual circumstances.

Focus area 6.1 A skilled, dementia aware health and aged care workforce

The importance of a skilled, dementia aware and competent workforce was consistently highlighted by stakeholders. Many stakeholders suggested this objective should be a priority as other objectives / actions relied on a sufficient and skilled workforce.

Stakeholders broadly supported actions regarding compulsory dementia education, ongoing professional development and mentoring for all areas of the workforce (including senior management, executives and boards) that interact with people living with dementia across all care settings including hospitals, aged care and home and community care.

Many stakeholders highlighted shortcomings with the current approach to education and training for aged 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 are many examples of poor quality or ‘superficial’ modules on dementia
- education and training are often not informed by lived experience.

Systemic issues

While many stakeholders supported actions to improve education and training for health and aged care workers, some (particularly health professionals and peak bodies) highlighted structural / systemic issues impacting on the ability of health professionals to diagnose dementia and provide quality dementia care, including:

- the lack of appropriate MBS items for dementia care (noting that ‘adequate dementia care cannot be provided within short 15-minute consults’ and that MBS items ‘fail to cover the cost’ of GP visits to aged care services to provide dementia care)
- fragmentation of care for older people and lack of coordination between the multiple health professionals / services involved in providing care to people living with dementia.

These stakeholders suggested that actions needed to focus on:

- remunerating GPs to provide preventative care and advice to patients
- adequately remunerating GPs to spend more time with patients during consultations
- sharing of information between different care providers (including disability and aged care)
- care coordination for people living with dementia
- continuity of care as older people enter aged care, including continued access to their own GP.

GPs

Many health professionals were opposed to actions exploring opportunities for semi-specialist GPs or nurse practitioners to focus on dementia care, noting that this has potential to fragment patient care and that dementia care should be core business for all GPs.

Aged care

Many stakeholders commented on the lack of aged care workers skilled in dementia care and strongly supported actions to improve dementia education and training for aged care workers.

Stakeholders suggested:

- all aged care training courses should include mandatory modules / units of competency on dementia
- requiring providers to offer regular training in dementia and cultural competency
- developing nationally consistent minimum dementia training and education standards
- the Aged Care Workforce Industry Council review the qualifications and skills framework to ensure they reflect the skills, capabilities, knowledge and competencies required by the aged care workforce (including education on dementia)

- ensuring training covers how socialising, physical activity, good nutrition and activities such as music and arts / crafts contribute to improved wellbeing of people living with dementia
- improved access to allied health services for people living with dementia in aged care homes, including to address poor food intake/swallowing/dentition issues, poor mobility/falls, challenges with speech, etc.
- introducing requirements for each provider to have a dementia practice leader
- providing career pathways that promote dementia specialisation.

Some stakeholders noted the current workforce shortages, particularly in aged care, and the impact this has on people living with dementia. Stakeholders felt that services are often short-staffed and don't recognise that people living with dementia may require additional worker support / time.

'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.'

'Rather than targeting the highest trained practitioners in the system (the GPs), the strategy should focus on improving the basics of poorly trained, poorly paid staff, with rapid turnover, variable English language skills and cultural awareness.'

Worker attributes

Stakeholders variously highlighted the need for workers to be:

- well educated about dementia
- compassionate, kind and caring
- engaged and skilled communicators
- appropriately resourced, with a sufficient number of workers to provide the individualised support needed
- able to recognise signs of deterioration or out of character behaviours / signs of unmet need
- skilled in strategies to respond to behaviours and optimising the wellbeing of people living with dementia
- informed about the likely trajectory of a person's dementia journey, including potential changes, symptoms and the services and supports available to help address symptoms.

Diverse workforce

A number of stakeholders emphasised the need for a strong and diverse workforce to provide appropriate care for the diverse range of people living with dementia. In particular, people commented on the need to proactively recruit and train workers from culturally and linguistically diverse backgrounds and from First Nations communities.

Stakeholders commented on the value of multilingual workers who can speak the language of the person with dementia, noting that dementia can result in people reverting to their first language.

Multidisciplinary care

Stakeholders commented on the importance of multidisciplinary care for people living with dementia, including support from allied health workers, specialists and community services. They suggested:

- reviewing the health and allied health workforce to identify (and address) barriers to access and ensure there is sufficient availability to meet demand

‘Compulsory dementia education, ongoing professional development and mentoring for staff are essential to building the dementia capability of the workforce. Dementia education and capability needs to reach all areas of the workforce (including senior management, executives and Boards) that interact with people living with dementia and it is important to improve the level of knowledge, understanding and delivery of quality dementia care across all care settings including hospitals, aged care and home and community care.’

‘The creation of another layer of workforce by recruiting and educating (an education programme) volunteers/hired carers/government funded carers/family on the simple non pharmacological approaches to managing agitation, delirium and other symptoms, recommended by specialist nurses and which residential nursing staff may not have time to do. Harnessing movements such as the Compassionate communities movement or Arts on Healthcare movement to counter social isolation, public programmes. Identifying particular grief issues for carers of people with dementia, regular psychological support e.g. START program in UK.’

‘Sufferers of dementia (and their family members) need to be able to talk to health professionals that they are confident have their interests at the core of

their advice... All too often the methodology and strategies developed to provide health services forget the people they are supposed to be looking after.'

Focus area 6.2 Organisational culture supports quality dementia care

Stakeholders supported a focus on organisational culture as well as capacity building for individual workers. Stakeholders highlighted the importance of:

- empathy, relationship-building, partnership-based business models
- the work of 'contemporary thought and practice leaders across the world', specifically mentioning Dr Allen Power and the Canadian [Research Institute for Aging](#), Michael Verde and [Memory Bridge](#), the UK University of Bradford [Centre for Applied Dementia Studies](#), [The Eden Alternative](#)

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

Outcome statement	Improve availability of dementia data at a national level to inform policies and programs and enable the monitoring of improvements over time. Ensure that research supports innovations in dementia including early detection and diagnosis, treatment and care.
Statement for people living with dementia	Research is focussed on improving my life and those that might be diagnosed in the future. Innovative practices are in place to make it easier for me to thrive with dementia. Dementia data is regularly reported so I can see if improvements are being made.

Stakeholders supported the objective of improved dementia research, collection and use of data, noting data is imperative to informing government action and improving quality of care and outcomes for people living with dementia.

Some stakeholders 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.

Stakeholders were highly supportive of actions seeking to improve collection of data for monitoring improvements to outcomes for people living with dementia, their carers and families. Some stakeholders highlighted issues regarding inconsistency between the proposed measurements against different actions.

'For example, it is not clear as to why some actions have a percentage (measurable increase) and others simply state 'increase'. It is also unclear from the consultation paper how the increase percentage has been determined.'

Stakeholders variously suggested:

- ensuring the public can easily access dementia related data to provide transparency and inform broad research / policy development
- ensuring data collection does not result in additional burden or duplicative reporting on service providers and people living with dementia
- monitoring complaints in relation to dementia care (across the primary care, acute care, disability care and aged care systems)
- including population metrics such as age, gender, LGBTIQ+ status, cultural background, etc to ensure different cohorts are considered in program design
- undertaking more frequent National Aboriginal and Torres Strait Islander Health Surveys (NATSIHSs) and including more dementia specific questions
- actively monitoring and reporting on differences in outcomes between the general population and people from diverse backgrounds (including Aboriginal and Torres Strait Islander people, people from culturally and linguistically diverse backgrounds, LGBTIQ+ people, younger people living with dementia, etc.)
- involving people with lived experience in research projects.

Implementing the Plan

Implementation blueprints

Stakeholders were keen to understand the detail behind how the Action Plan would be implemented and sought detail on the specific actions that would be undertaken, the respective roles and responsibilities and timeframes for implementation. Some stakeholders also sought clarity on the funding / resourcing required to achieve the objectives.

'It should be done in stages. It should be planned. There should be a plan for health care, financial management, long-term care, and end-of-life care. Every structure of the state should have its plan and program to implement the actions.'

'It will be important to ensure the funding and systems are set up to make the objectives tangible and ensure a better quality of life for people living with dementia and their families.'

'Being a cynic, whilst the objectives and proposals seem good, the reality is that State Governments and Territories need to budget for ALL PORTFOLIOS, money will not be available for all proposals. Governments will need to prioritise their spending.'

Stakeholders broadly supported the use of more detailed implementation blueprints to outline responsibilities, specific actions / steps and funding allocations. Many stakeholders expressed that they would like to be involved / consulted in the development of the implementation blueprints.

Stakeholders highlighted the importance of:

- working closely with key stakeholders in developing the blueprints, including people with lived experience of dementia, health professionals, service providers, local governments and others
- assigning specific responsibilities so parties can be held accountable for delivering on these activities
- periodically reviewing the blueprints to ensure the identified activities are progressing as planned

- evaluating the effectiveness of each activity described in the blueprints.

A number of stakeholders were keen to understand how a diverse range of organisations can be involved in the delivery of the Plan. Some stakeholders suggested the development of clear action plans / implementation blueprints describing actions that could be taken by different types of organisations, health professionals, workers, communities and individuals.

Some stakeholders were keen to fast-track implementation of the Plan such that objectives could be achieved within their lifetime.

Monitoring and reporting

Stakeholders supported the proposed approach to monitoring and public reporting of progress towards achieving the Plan. In particular, stakeholders gave positive feedback on the key role to be played by the National Centre for Monitoring Dementia at the AIHW.

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

While stakeholders agreed on the need for quantitative data to demonstrate progress, stakeholders also highlighted the importance of qualitative data to measure the outcomes achieved through actions undertaken (to demonstrate that the actions are making a materials difference to the lived experience of people with dementia). For example, measuring things such as:

- satisfaction with different services
- wellbeing and quality of life
- experience / ease of navigating systems.

Stakeholders supported the proposed approach of Action Plan Report Cards being annually reported by the AIHW and the formal review in year five of the Action Plan which will consider progress against the Action Plan and Implementation Blueprints.

'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).'

'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 initiatives.'

'Since research into Dementia will continue, and as the numbers of people with the condition continues to grow, we will need to review the current focus areas.'

'These reports must contain qualitative data that addresses and 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 carer's.'

Governance

Many stakeholders 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 actions described.

Some stakeholders recommended that additional representatives be included on this governance group, including people with lived experience of dementia and dementia support providers.

'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 projected numbers of those with dementia is overwhelming so the Vision will need leadership and commitment to ensure outcomes are achieved sooner rather than later.'

Next steps

The Commonwealth will work closely with state and territory governments over the coming months to further refine the Plan to ensure it reflects consultation feedback. Additional activities to inform the final Plan include:

1. consideration of governance and reporting arrangements
2. incorporating stronger emphasis on a human rights-based approach
3. commissioning the National Aboriginal Community Controlled Health Organisation (NACCHO) to assist with consultations to identify specific actions for First Nations people
4. engaging with key organisations representing people from culturally and linguistically diverse backgrounds to incorporate specific actions for these diverse groups
5. meeting with a range of health and aged care colleagues, including the Australian Medical Association (AMA), Older Persons Advocacy Network (OPAN), NACCHO, Royal Australian College of General Practitioners (RACGP), Australian Association of Rural and Remote Medicine, the Aged Care Quality and Safety Commission and the Australian Commission on Safety and Quality in Health Care.

Governments will also 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.

Attachment A: Profile of stakeholders responding to the online survey

Context

In total, 906 responses to the online survey were received and an additional 146 submissions were uploaded or sent to the department by email. This attachment only includes data from stakeholders who responded to the online survey.

Please note that the number of responses in some tables does not correlate with the number of surveys completed because stakeholders were able to select multiple responses to some questions.

Table 1. Role of stakeholders

Please select the option that best relates to you:	
Response	Number (percentage)
A friend or family member of someone living with dementia	198 (23.9%)
Carer of a person living with dementia	196 (23.6%)
Health care professional	145 (17.5%)
Aged care professional	123 (14.8%)
General public	57 (6.9%)
Researcher/academic	24 (2.9%)
Person living with dementia	15 (1.8%)
Government official	7 (0.8%)
Other	65 (7.8%)
Total	830

Table 2. Diversity of stakeholders

Do you identify as any of the below population groups?	
Response	Number (percentage)
Born overseas	201 (23.5%)
Person living in a rural or remote area	148 (17.3%)
From a non-English speaking background	56 (6.5%)
LGBTQIA+ person	33 (3.9%)
Aboriginal or Torres Strait Islander	10 (1.2%)
Prefer not to say	8 (0.9%)
None of the above	399 (46.7%)
Total	855

Attachment B: Ten-year outlook

People responding to the online survey were asked what a best possible dementia journey would look like for them in 10 years' time. While this feedback is incorporated through this report, feedback is summarised below to give a holistic picture (supported by feedback and quotes from people with lived experience of dementia).

- **Dementia is prevented or treated**
- **People reduce their risk of dementia**
 - That workplaces are supportive of actions workers need to take to reduce their lifestyle risks to developing dementia.
 - More focus on risk reduction by primary health care providers.
 - The community understands dementia, the risk factors and lifestyle changes they can make to minimise their risk of developing dementia.
 - All Australians are aware of the signs / symptoms; to be aware of factors that may reduce dementia risk; know how and where to access assessment / diagnosis when concerned.
- **People showing signs of dementia are diagnosed early**
 - GPs / pharmacies undertake dementia screening.
 - People are diagnosed in a timely way to allow early decision making and actions to prepare themselves and their families for later progression.
 - Diagnostic services are at a reasonable price and without prolonged waiting periods.
- **There is less fear around receiving a diagnosis of dementia**
 - Diagnosis of dementia would be seen as a condition that people can progress safely with and it would not be seen as so terrifying as supports and education will be there.
 - People affected by dementia and their families and carers do not take the diagnosis as an end to their life. They are still supported to live and participate to a social, engaging life.
 - People live without fear and feel equipped to navigate their journey
 - A friendly diagnosis.
- **Early action is taken to delay / minimise the onset of dementia symptoms**
 - Short, medium and long term plans are put in place for the person at the outset and the person's needs are regularly reviewed to ensure they're getting the support they need when they need it.

- **People get access to immediate support on diagnosis and a pathway for care**
 - People are connected to a memory clinic on diagnosis for early support and intervention.
 - Home based services contacted and coordinated with dementia care. Short medium long-term planning commenced or the process outlined for the person and family to access as they come to terms and need to.
 - Responsive services to increase care at home as needed without long waits – retrospective approval after ACAT assessment to avoid wait and crisis or need for acute admission.
 - A tailored management plan is put in place, with a person to guide you from beginning to end.
 - A clear pathway with milestones and triggers.
 - Linking with a ‘navigator’.
- **Supports are coordinated, timely and responsive**
 - People don’t have to wait a long time or go through a lengthy approval process to access services.
 - A consultant or central ‘go to’ person to talk to and help refer to / manage services.
 - People can access as much support as wanted and as soon as possible.
 - Seamless care and transitions between services.
 - Ability to continue to live an independent life with appropriate support in place.
 - GP's are able to make a diagnosis and refer to a dementia specialist who works as part of a multidisciplinary team in the person’s local area. This team have clinical nurse educators and specialists, as well as a full range of allied health professionals. The team is able to liaise with the person to educate them early regarding strategies and treatments to assist with memory / recall, maintaining skills of living, driving, sleep and health. They can continue to act as a resource throughout the progress of the person's condition, assisting with home modifications, transitions to supported living if needed, or palliative care.
- **People have choice and access to a range of supports that are right for them (including in thin markets)**
 - People living with dementia and their carers are confident that they will be able to easily access education, equipment and support.
 - Services are flexible and easy to access.
 - Lots of different care models are available.
 - People can live at home for as long as they want to.

- Technological supports enable people to live safely / independently.
 - People are offered a range of rehabilitation and reablement supports.
 - Equality of access regardless of socioeconomic status, language.
 - The available services are age appropriate – including for younger people living with dementia.
- **Care and supports are dementia appropriate and delivered by people who understand dementia**
- The workforce is well-resourced.
 - Care focuses on minimising triggers.
 - Dementia management in aged care is understood.
 - All staff who care for people living with dementia have received education about dementia and its impact on the person and their families.
 - People are confident that health professionals have their best interests at heart.
 - Comfortable worker / resident / patient ratios
 - GPs and nurses are engaged and understand dementia.
 - Workers collaborate with and listen to the person living with dementia.
 - Healthcare students work in dementia care as part of their training.
 - All health care professionals, including paid carers will have completed training on dementia - at least the 9-week FREE Wicking Institute MOOC, Understanding Dementia.
 - Care is individualised and takes a ‘whole of family’ approach.
 - A full suite of rehabilitation and other allied health services are available.
- **People with dementia are able to live a ‘full life’**
- Active engagement in meaningful activities.
 - Rights, interests and needs are understood and responded to by staff
 - People living with dementia are supported and enabled to live a meaningful, purposeful and enjoyable life based on their strengths at different times. This gives them hope and a reason to keep going, keeps them independent and in the community for longer, and reduces the care burden on carers and the public health system.
 - Carers and facilities enable people living with dementia to experience joy at least a part of every day. Help them to retain their unique characters.
 - When needing to access residential care, people have a place to live where they feel safe, secure, respected and encouraged to live with dignity, value and worth. Where food tastes and looks beautiful and positive interactions and normal life activity is the way of living.
 - People with younger onset dementia are supported to stay at work.

- **People living with dementia are treated with respect, included and feel supported**
 - Acceptance of dementia in everyday conversations.
 - Greater community understanding of dementia.
 - Dementia is not a taboo word.
 - People of all ages are aware of (and not frightened by) dementia.
 - Communities as a whole recognise dementia and respond appropriately, instinctively and compassionately.
 - General community awareness means that people know what dementia is, that it is different for everyone but that it progresses over time.
 - Support is not judgmental, and is flexible and available when needed.
 - Dementia and the behaviours which accompany it do not elicit reactions of embarrassment, lack of respect and avoidance from family members, friends or the general community.
- **People living with dementia are involved in decision-making to the fullest extent possible**
 - People are provided with information and options, without having to ask many questions or feeling like a nuisance.
 - People are able to have open conversations about end of life, palliative care and dying.
 - People and carers / families are involved in all aspects of their care.
- **There are choices of suitable accommodation, including integrated and innovative models of living**
 - Villages are set up for people living with dementia to live as normally as possible for as long as possible with staff who are trained in dementia to assist without making them feel they are a drain on the society.
 - Respite facilities, which mimicking home as much as possible (small house model care) are available. These have a less clinical feel, more access to outdoor areas and 'no wrong door'.
 - Accommodation that facilitates normal life activities for people living with dementia. These have a shop, hairdresser, doctors' office a pharmacy as well as a cafe. Their environment do not look like a hospital or a childcare centre.
 - The environment supports people to live as freely and independently as they can, and where independence is not possible, participation is.
 - Improved accommodation options for people with extreme behaviours.
 - Respite services with more focus on quality of life
 - Assisted living options that are not all institutional in nature, that do not segregate people with dementia, and if locked, are monitored under the

Operational Protocol to the Convention on Torture and Inhuman or Degrading Treatment or Punishment (OPCAT).

- **End of life conversations are held early and people can die with dignity**
 - Advance care plans are put in place and reviewed often.
 - Dying with dignity and adequate pain relief.
 - The right to choose to die.
- **Carers are valued and supported and have access to respite care**
 - Carers are regarded as partners in care by the medical profession and other health providers and by aged care providers and their staff.
 - People caring for those living with dementia are able to support their loved ones at home (if that is their preference) without feeling 'burnt out, burdened, guilty or trapped'.
 - Carers (particularly younger carers) do not have to give up their own livelihood (e.g. work, which impacts on their income stream) to support a family member with dementia.
 - Loss and grief counselling for person with dementia and their families.
 - More support for carers – financially, emotionally and physically.
 - Carers feel confident that their loved one is receiving consistent, positive, celebratory healthy care from providers, and can spend time enjoying being with their loved one.
 - Short-term case management to help carers organise respite care, particularly in an emergency.
 - Multiple respite options in dementia appropriate facilities across Australia that allow carers to maintain their pre-caring life as much as possible, including work life, social and family life.