

Q1.1.

Evaluation of the National Framework for Action on Dementia 2015-2019 "The Framework"

Who can participate in this evaluation?

Policy development or service delivery professionals: Health professionals including community, disability or aged care workers who are involved in providing dementia care; and/or people who deliver services or develop policy that impacts on people with dementia and their support team

What will you be asked to do?

You are invited to participate in a two-part questionnaire on:

The Framework priority areas for people with dementia and the people involved in their care and support (informal and formal); and Innovations and options for future dementia policy in Australia

The questionnaire should take between 20 to 40 mins to complete. At the completion of the survey, please make sure that you click through to the 'Survey Completion' page at the end of the survey in order to submit your response. For more information, please refer to the Citizen Space page or contact

CHPO@health.wa.gov.au

Comment closing date extended to 4pm Monday 6th January 2020.

Q1.2. Do you consent to participate in this survey?

- Yes, and continue.
- No, and exit.

Q2.1. **SECTION 1: General information about yourself and your organisation/department**

Q2.2.

Are you providing a submission as a designated representative of an organisation/department OR as an interested individual?

- On behalf of an organisation/department
- As an interested individual

Q2.3. What is the name of the organisation/department that you are representing? **Optional**

Organisation

Dementia Australia

Department/ Site

Q2.4.

Organisation/Department information

Please answer the following questions about the organisation/department you work for or are answering on the behalf of.

Q2.5. Which category best describes your organisation/department? (please select one answer)

- Public health service
- Private health service
- Non-government agency
- Aged care provider
- Academic/ teaching/ research institution
- Primary health care service, including General Practice, community nursing and allied health
- Other public government agency (includes justice, housing, social services, child support and education services)
- Other, please specify:

Q2.6. Which category best describes the role of your organisation/department within the health sector? (please select one answer)

- Administration (e.g. planning, policy development, governance)
- Research/ evaluation/ teaching
- Hospital-based clinical services
- Residential aged care services
- Community-based clinical services (including general practice/general practitioner)
- Social/ community services (including home care services)
- Advocacy (e.g. carer, consumer)
- Peak body
- Other, please specify:

Q2.7. What is the postcode of the organisation you work for?

Q2.8.

Where does your organisation/department operate?

Please select all that apply

Australian Capital Territory

- New South Wales
- Northern Territory
- Queensland
- South Australia
- Tasmania
- Victoria
- Western Australia

Q2.9. What is the primary target location for your organisation/department? Please select one.

(please see this [map of remoteness](#) if you are unsure of your location definition)

- Major city
- Inner regional
- Outer regional
- Remote
- Very remote

Q2.10. Please provide an estimate of the size of your organisation/department (number of personnel):

Organisation:	<input type="text" value="600"/>
Department/ Site (if applicable)	<input type="text"/>

Q2.11. Is your organisation government or non-government?

- Government organisation
- Non-government organisation (NGO)
- Private organisation

Q2.12. What level is your organisation?

This question was not displayed to the respondent.

Q2.13. The Framework includes a number of identified priority groups. Please let us know which, if any that your organisation works with.

(You can select more than one group or leave unanswered if none apply)



Aboriginal and Torres Strait Islander

- Culturally and linguistically diverse (main language spoken at home is not English)
- Live in a rural or remote location in Australia
- Lesbian, gay, bisexual, transgender, intersex or queer people (LGBTIQ)
- People who have personally experienced mental illness (lived experience)
- People with a disability
- People who provide unpaid care and support to family members and/or friends who have a disability, mental illness, chronic condition, terminal illness, an alcohol or other drug issue or who are frail/aged (Carer)
- Veterans

Q2.14. What proportion of your organisation/department's role do you estimate is directly aimed at policy for people with dementia?

- 0 percent
- 1 - 25 percent
- 26 - 50 percent
- 51 - 75 percent
- 76 - 99 percent
- 100 percent
- Don't know

Q2.15. What proportion of your organisation/department's role do you estimate is directly aimed at service delivery for people with dementia?

- 0 percent
- 1 - 25 percent
- 26 - 50 percent
- 51 - 75 percent
- 76 - 99 percent
- 100 percent
- Don't know

Q2.16. What policies does your organisation have that impact people with dementia? Please list.

Policy 1

Dementia Australia Strategic Plan

Policy 2

Dementia language guidelines

Policy 3

How to engage with people living with dementia

Policy 4

Dementia Friendly Communities

Policy 5

Dementia Australia Advisory Committee and Advocacy Program

Q2.17. What services does your organisation provide for people with dementia? Please list.

1.
2.
3.
4.
5.

Q3.1.

SECTION 2: The Framework

Q3.2.

There is a National Framework for Action on Dementia 2015-2019 ("The Framework").

How familiar are you with the Framework?

- Not familiar
- Slightly familiar
- Somewhat familiar
- Moderately familiar
- Extremely familiar
- Unable to answer

Q3.3. What level/type of staff in your organisation/department are familiar with the Framework?

Please select all that apply.

- Senior executives and management staff
- Policy and project staff
- Service staff
- Other. Please specify:

Q3.4.

Within your organisation/department's policy and service delivery, in the past five (5) years how frequently has the Framework been used to:

	Never	Rarely	Sometimes	Often	Always/ almost always	Unable to answer	Not applicable
1. Inform strategic goals and objectives in dementia care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. Inform care planning for people with dementia	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. Inform health related service delivery for people with dementia	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. Promote a shared knowledge and understanding of quality health care	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5. Promote a shared understanding of evidence based health care	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6. Promote the delivery of evidence-based health care	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7. Encourage collaboration across the health sector	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8. Promote a shared vision of health reform in dementia	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q3.5.

Please provide us examples (positive and challenging experiences) from your organisation/department's policy and/or service delivery to support your responses:

The Framework was used to aid in the development of our Strategic Plan. One of the earliest activities was mapping the Framework against the areas outlined in the Global Plan of Action on Dementia and comparing these to the gaps in service/policy identified through our strategic consultations. Despite this process, our strategic direction was primarily shaped through the feedback we received rather than a conscious alignment with the Framework. Dementia Australia does, however, reports on the achievement of Framework priorities in our advocacy grant funding reports. Some challenges of the Framework include that it is pitched at a high level, without deliverables that can be directly mapped against our day to day work. As it is broad reaching in its scope, with no easily identified outputs or KPIs – it means everything Dementia Australia does can be aligned with something in the Framework at a thematic level. What is lacking, then, is the ability to measure impact or level of success (or scale). This also means it is not easy to apply to service delivery and doesn't translate into practice. Additionally, the Framework is not aligned with government policies and programs, so we are unable to use it to respond to government consultations or funding rounds.

Q3.6. The next section of the survey contains a series of rating scales and other questions organised under the seven priority areas outlined in the Framework. You may select the priority areas of relevance to you and/or your organisation by answering the question below. You will then be directed to questions that relate to those selected priorities.

Q3.7.

Which, if any, of the Framework priority areas would you like to provide comment on?

Please select all that apply.

- Priority 1: Increasing awareness and reducing risk
- Priority 2: The need for timely diagnosis
- Priority 3: Accessing care and support post-diagnosis
- Priority 4: Accessing ongoing care and support
- Priority 5: Accessing care and support during and after hospital care
- Priority 6: Accessing end of life and palliative care
- Priority 7: Promoting and supporting research
- None (you will be directed to the innovations in dementia care section)

Q3.8.

Priority Area 1. Increasing awareness and risk reduction

Australians have a greater awareness, acceptance and understanding of dementia and the actions they can take to reduce the risk of developing dementia.

Please rate your level of agreement with the following statements:

“In the last five (5) years, the organisation I represent/work for have developed or implemented actions, plans and policies that align with the following criteria:”

Q3.9. Dementia-friendly communities

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Unable to answer
1. Develop dementia friendly communities, where all aspects of the community's-built environment and approaches are dementia friendly, inclusive, promote respect, and acceptance and enable participation.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>
2. Support and resource community-based programs and initiatives to promote social engagement and develop dementia friendly environments.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>
3. Develop communities and workplaces that are dementia friendly	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>

Q3.10. Collaborative awareness and risk reduction approaches

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Unable to answer
1. Conduct awareness activities that highlight the need to understand and respect the rights of the person with dementia and treat people with dementia with dignity and respect.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>
2. Adopt a collaborative evidence-based approach for awareness and risk reduction activities having regard to other relevant National Health Priority Areas.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. Link and promote population health strategies to support a healthy and physically active lifestyle for all Australians including people with dementia and their carers.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. Provide accurate and evidence-based information on risk factors and risk reduction strategies for dementia are readily available to the community ensuring that it is easy for individuals to seek further information and adopt risk reduction behaviours.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>

5. Develop, deliver and promote programs to support health professionals and care workers increase their awareness and understanding of dementia.

Q3.11.

Please provide us examples (positive and challenging experiences) to support your responses:

Dementia Australia operates a Dementia-friendly Communities program that focuses on the built environment and approaches that are dementia-friendly (including Dementia Friends, DFCs and DF organisations). There are measurable KPIs against this program which align with the Framework, though it is difficult to measure outcomes over outputs as evaluation activities can be challenging. Until 2015, Dementia Australia was funded to provide the 'Your Brain Matters' program which focussed on prevention and risk reduction of dementia. Since funding ceased, we have found it difficult to meet the demand for risk minimisation which is coming from various sectors of the community. Through the Centre for Dementia Learning we deliver a comprehensive suite of evidence based education programs to health professionals. One of the largest is the Dementia Essentials program which we deliver nationally as part of Dementia Training Australia. We also offer a range of non-accredited programs both online and face to face. One of these programs is the award winning EDIE program which uses VR technology to provide participants with the experience of what it may be like to live with dementia. These programs are primarily delivered to the direct care workforce across aged care, health and disability settings. The challenge with this work is that not all providers see the value in investing in the ongoing professional development of its staff and without the right leadership promoting a culture of continuous improvement and learning the education provided is less likely to result in a positive change to practice. There is also a need to build the knowledge translation capability of the sector through skilling up staff to be effective mentors and coaches as well as other mechanisms such as communities of practice. The other challenge is the limited or poor levels of dementia education provided at both a vocational and tertiary level for workers entering the field. This combined with broader issues around poor remuneration, lack of clear career pathways and challenges associated with the culturally diverse nature of the workforce as well as lack of registration requirements for direct care workers makes building the capacity of the workforce particularly challenging. As Dementia Australia is no longer funded to provide risk reduction strategies, we have to be innovative in this area. We partner with other organisations such as the Neurological Alliance of Australia, the Australian Patient Advocacy Alliance and the Australian Health Policy Collaboration to promote risk reduction messaging where we focus of shared risk factors. Another challenge is community awareness that dementia is a terminal condition. It is difficult to translate the evidence into community health messaging. A particular challenge is the lack of awareness of changing behaviours in mid-life. Population health campaigns do not tend to recognise dementia in broader risk reduction messaging. Often people do not change behaviour until there is a problem and getting them to pay attention before then and make positive changes is problematic. This is evidenced by many participants in the Your Brain Matters program being aged 65+ when the target audience for this program was intended to be 40+. All in all the risk reduction work is difficult to identify KPIs and impact.

Q3.12.

Priority Area 2. The need for timely diagnosis

Australians will have access to skilled and knowledgeable health professionals who can support and provide an accurate and timely diagnosis of dementia.

Please rate your level of agreement with the following statements:

"In the last five (5) years, the organisation I represent/work for have developed or implemented actions, plans and policies that align with the following criteria:"

Q3.13. Access to high quality early detection services

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Unable to answer
1. Provide diagnostic processes that are delivered according to best available evidence/practice.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>
2. Encourage the appropriate and consistent use of validated clinical assessment and diagnostic tools.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>

3. Improve links to specialist diagnostic services through the development of referral pathways in all settings.

4. Provide education and ongoing training for GPs and nurse practitioners to ensure a knowledgeable and skilful workforce regarding the diagnosis of dementia.

5. Provide support and training in dementia for all levels of health professionals, including allied and community health professionals and paramedics

6. A diagnosis of dementia is made using a multi-disciplinary approach where available, involving a range of health professionals and value the participation and views of carers.

7. Support the use of telehealth and advances in information technology to improve access to timely diagnosis.

8. Expand the use of Aboriginal and Torres Strait Islander specific diagnostic instruments and assessment methods in rural and remote communities where applicable.

Q3.14. Access to information and support

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Unable to answer
1. Support people to have access to information regarding the early signs of dementia.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>
2. Support people with dementia, their carers and families, to access relevant information that enables them to make an informed decision about their care and treatment options.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>
3. Provide information, advice, counselling and support for people with dementia, their families, carers and community members.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>
4. Provide people with dementia, their carers and family members support as required to respond to grief, loss, conflict and relationship breakdown.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>

Q3.15.

Please provide us examples (positive and challenging experiences) to support your responses:

A significant portion of Dementia Australia’s funded and unfunded activities focus on this priority. It is also one of our three strategic priorities as an organisation. We have specific targets for each category and while these link to parts of the framework, it is nonetheless difficult to translate their efficacy to system-wide improvement because we don’t know how many people are diagnosed with dementia at any one time. We are funded under the National Dementia Support Program (NDSP) to provide service that specifically address timely diagnosis such as information, support, outreach targeted support, early intervention supports, innovation and technology. We also deliver the Dementia Essentials through our Centre for Dementia Learning. This is a three day nationally accredited unit of competency that provides participants with an understanding of: • Person-centred care and effective communication • The nature of dementia and its impacts • Identifying unmet needs • Understanding changed behaviours and developing effective responses • Activities to promote well-being; and • Community support and services available We have also delivered a specific program to Aboriginal Health Workers to improve their understanding of the various screening tools for cognitive impairment and we continue to deliver programs to aboriginal workers in rural and remote communities. The main challenges include working with the GP sector and getting traction in this space. There are specific programs to address timely diagnosis, however there is not a comprehensive approach across health and community engagement. As such, there is consistency in identifying the problem, but a lack of progress in changing behaviour at the service delivery level. Specifically: 1. There are no national diagnosis targets; 2. There is not an agreed diagnosis pathway so experiences differ significantly; 3. The buy-in of key stakeholders (e.g. GPs) is variable and adds to the complexity of measuring impact; 4. Some of the key drivers of impact/change are linked to regulation, funding or education – and there are limited dementia-specific mechanisms across these; and 5. There is no sense of target/scale/roll-out on how to achieve an impact.

Q3.16.

Priority Area 3. Accessing care and support post-diagnosis

Please rate your level of agreement with the following statements:

“In the last five (5) years, the organisation I represent/work for have developed or implemented actions, plans and policies that align with the following criteria:”

Q3.17. Accessible, flexible and quality dementia care is available to people living with dementia, and their carers are support in their care role.

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Unable to answer
1. Provide people with dementia, their carers and families with access to person-centred care and support post diagnosis, which is delivered by a skilled and knowledgeable workforce.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>
2. Improve support for people with younger onset dementia through the provision of a link or key worker.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>
3. Develop dementia specific interdisciplinary teams to coordinate the assessment and management of dementia service provision across all health care settings.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>
4. Develop clinical referral and care pathways that are flexible including for people with dementia from diverse needs groups and people with younger onset dementia.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>
5. Provide education, training and support for carers to enhance their skills to assist them in their caring role and connect carers and families to essential information about dementia and dementia services.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>

Q3.18. Planning for the future

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Unable to answer
1. Provide support for people with dementia, their carers and families to plan for the future including in relation to lifestyle and living arrangements (such as proximity to services and family, future loss of driver's licence) and advance care planning.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>
2. Maximise opportunities for people with dementia and their representatives to plan for the future by raising their awareness of options relating to enduring guardianship and enduring powers of attorney and wills.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>

Q3.19.

Please provide us examples (positive and challenging experiences) to support your responses:

Dementia Australia runs Younger Onset Dementia Support Coordination services which are funded under NDIS. This provides individualised support and services to improve the quality of life for people with younger onset dementia, their families and carers. Additionally, the Centre for Dementia Learning offers programs for care professionals to build capacity and access care and support. Some of these programs include dementia essentials, a day in the life, meaningful engagement mentors program, understanding dementia and many others. Dementia Australia plays a key role in helping people living with dementia, their families and carers navigate the aged care system and access the care and support services they need. Providing solid education base to workers which is then applied to practice can be limited due to a range of factors as outlined previously and relies on strong leadership and a positive learning culture with a strong emphasis on being person centred. The challenges are around the low dementia literacy and awareness that health professionals have about dementia, particularly in the palliative and end of life stages of care. There is also a lack of focus on or understanding of enablement or reablement for people living with dementia to maintain their independence and make decisions about their care while they still have the capacity to do so. We try to support people to plan for support, however the system is not geared towards facilitating independence. Another challenge is managing the intersection points between funding sources and being able to do this effectively to minimise the impact on people living with dementia. For example a person accessing the Dementia Advisory Service through CHSP funding, can no longer access this service once they transition to a home care package or into residential care, but they may still need the specialised dementia support provided by this service as their new providers are less likely to provide this specialist support. Similar challenges occur for clients at age 65 when they are transitioning between the disability and aged care service streams. Additionally, measuring scale and impact is still difficult because there is basic data missing on how many people accessing services even have dementia so it is impossible to measure the impact.

Q3.20.

Priority Area 4. Accessing ongoing care and support

Please rate your level of agreement with the following statements:

“In the last five (5) years, the organisation I represent/work for have developed or implemented actions, plans and policies that align with the following criteria:”

Q3.21.

People with dementia and their carers will have access to quality dementia care and support

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Unable to answer
1. Provide people with dementia, their carers and families access to home care services that are person-centred, and are delivered by a knowledgeable and skilful workforce.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>
2. Assist carers to access support services and education programs to support them in their care role.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>
3. Assist people with dementia, their carers and families to access the advice and support they need.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>
4. Provide people with dementia and their carers and families access to appropriate and responsive respite services.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>
5. Provide and promote dementia training and ongoing education for all staff that care for people living with dementia.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>
6. Support people with dementia in residential aged care facilities to continue to be socially engaged both within and outside the facility (in the broader community) to retain their choice and involvement in decision-making.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>
7. Support people with dementia in residential aged care facilities to have access to specialist medical and non-medical services, care and support.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>

Q3.22.
Behavioural and Psychological Symptoms of Dementia (BPSD)

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Unable to answer
1. Support system wide, organisational and workforce awareness of BPSD together with evidence-based prevention and management strategies, including the provision of dementia friendly environments.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>
2. Provide opportunities to staff, family and carers of people with dementia to learn skills to prevent and respond to BPSD using psychological, behavioural and environmental techniques.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>
3. Provide access to quality mental health services as required for people with BPSD.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>

Q3.23.
Diverse needs groups

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Unable to answer
1. Support culturally appropriate care for people with dementia from diverse needs groups including Aboriginal and Torres Strait Islander and CALD communities.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>
2. Provide support for people with younger onset dementia and their carers to remain in employment for as long as possible and to maintain family and community participation.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>
3. Provide age appropriate home, residential and acute care support services to meet the needs and preferences of people with younger onset dementia, their carers and families.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>

Q3.24.
Please provide us examples (positive and challenging experiences) to support your responses:

Accessing ongoing care and support is pivotal in the services and programs Dementia Australia offers, and it also falls under our second strategic priority – quality dementia care. All our funded services under the National Dementia Support Program (NDSP) are aimed at caring for and supporting people living with dementia, their families and carers to ensure the best care outcomes for them. Our Dementia Helpline is of particular support to carers, with approximately 66% of callers being carers, 11% being people with dementia or with memory concerns, and 23% being a mix of health professionals, service providers and the general public. Additionally, Dementia Australia has delivered respite services to carers and advocated for more flexible respite and dementia specific services and workforce training, with a specific focus on social support both within and outside of care. As a result, all of our activities align with the Framework but it is difficult to measure their broader impact, beyond the confines of our program deliverables. Our Centre for Dementia Learning programs are targeted at changing the culture in residential care to facilitate choice, involvement and decision making for people living with dementia. Starting from a base of first having strong skills around person centredness and engagement with the person living with dementia ensure that specific BPSD education programs then promote alternative behaviour management strategies that do not involve physical or chemical restraint. The person centred education programs also emphasise the importance of taking into account all aspects of the individual including cultural, LGBTIQ. We support diverse groups including CALD, ATSI, Rural and Remote and LGBTIQ through the National Dementia Support Program and National Ageing Institute. For example, the moving pictures project which includes five short films co-produced with people from Hindi-, Tamil-, Mandarin-, Cantonese- and Arabic-speaking communities. For each language, there are three films: Detection and Diagnosis, Navigating Care, and the Carer Journey. These films are based on the stories and lived experiences of carers of people living with dementia, and the expert views of key service providers. We also recently widely consulted with a diverse range of people with a lived experience of dementia to inform the communicate – Our Solution – quality care for people living with dementia - <https://www.dementia.org.au/files/documents/DA-Consumer-Summit-Communique.pdf> . This included speaking with 137 people across Australia, including those with diverse needs. Dementia Australia also facilitates support to younger people living with dementia through the Younger Onset Dementia Coordination of Supports Program through NDIS funding and supports people on their journey through dementia. An example of this work can be seen in the Lovell Foundation collaboration which raises awareness about Younger Onset Dementia, and to encourage better options for the care of younger people with dementia both at home and in respite and permanent care facilities. The key challenges include our capacity as an organisation to consistently support diversity and translate what we know into practice. Underpinning that is that we don't know the scope of the problem or the specific targets to break down the solutions into something achievable and measurable. There are many gaps in accessing care and support and the environment and behaviours are not changing at the pace which is needed. The same conversation is being had now as it was five years ago and this is a concern. People are aware of the problem, but not yet changing anything in the system or in themselves to better meet the needs.

Q3.25.

Priority Area 5. Accessing care and support during and after hospital care

Please rate your level of agreement with the following statements:

“In the last five (5) years, the organisation I represent/work for have developed or implemented actions, plans and policies that align with the following criteria:”

Q3.26.

Acute care health professionals are able to recognise and respond to people living with dementia

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Unable to answer
1. Improve assessment for cognitive impairment and identification of dementia on admission in the acute health care setting.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>
2. Develop and promote the use of an evidence based clinical care pathway when caring for people with dementia in an acute care setting.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>
3. Develop and implement training for relevant health care professionals in the acute care setting to recognise BPSD and respond effectively.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>
4. Support training and education programs to assist the acute health care workforce to provide evidence-based dementia care.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>

5. Support carers and families to be included as part of a team and ensure that their roles in assisting diagnosis and in the planning and provision of care are recognised and fully utilised.



Q3.27. Standards for quality care of people with dementia in an acute setting

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Unable to answer
1. Develop standards for quality dementia care to promote better awareness, recognition and response to people with dementia in the acute setting.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>
2. Develop processes to ensure standards are applied.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>
3. Support consistent use of admission and discharge planning initiatives for people with dementia entering and leaving an acute care setting.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>
4. Explore the expansion and utilisation of telemedicine to enable access to dementia specific follow-up post discharge from an acute setting, particularly for people with dementia living in regional or rural and remote communities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>
5. Examine options for hospital care in other settings, e.g. Hospital in the Home, Hospital in the Nursing Home.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>
6. Ensure that people with dementia have access to a safe and secure hospital environment which is suitable for their needs.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>

Q3.28.

Please provide us examples (positive and challenging experiences) to support your responses:

Dementia Australia was involved in the National rollout and evaluation of the dementia care in hospitals report available at: https://www.healthroundtable.org/Portals/0/PublicLibrary/2017/FinalReport_DCHP_Evaluation2015_2017.pdf, which highlighted key areas of concern for people living with dementia, their families and carers when experiencing care in hospitals. We advocated for holistic care approaches to staff awareness and education about dementia as well as how to support people with dementia within the service environment. Our Centre for Dementia Learning also offers a range of courses that educate providers and professionals about how to deliver quality care to people living with dementia regardless of the setting. This is covered in our foundational learning courses, immersive learning and accredited training. We have also delivered education specifically to hospital and healthcare staff through our community education programs. We have also worked closely with the Australian Commission for Quality and Safety to develop specific dementia quality indicators. Additionally, we have developed cognitive impairment and open disclosure in hospitals fact sheet, as well as a publication on dementia care in the acute hospital setting available here: <https://www.dementia.org.au/files/NATIONAL/documents/Alzheimers-Australia-Numbered-Publication-40.pdf> Our Dementia Friendly Communities program provides additional support for people living with dementia, their families and carers in the community. We work with individual services to improve their dementia friendliness and awareness about how they can best support people with dementia. The challenges, again, are consistency across the sector and not having a baseline against which to measure success and impact. Having Standards is one thing, but the understanding of how these work and the expectation of each are inconsistent. From what is reported to us through our Advocate program, practice on the ground is not changing, for example people with dementia in hospital care still experience more complications than people without dementia, and the strategies to address this are not consistent to achieve success and better outcomes. Another challenge is for health services to see the value and importance of identifying and responding to patients with dementia to ensure improved health outcomes. The changes to the health care standards in relation to cognitive impairment is a positive step but probably too early to see this having an impact yet. Also the limited time available to train staff means that to build capacity in this area can be challenging. We have developed specific programs for the health workforce which are of a shorter duration to accommodate these limitations but we know from the evidence that this also limits the effectiveness of such programs.

Q3.29.

Priority Area 6. Accessing end of life and palliative care

People with dementia have access to high quality care that supports a palliative approach during end of life.

Please rate your level of agreement with the following statements:

“In the last five (5) years, the organisation I represent/work for have developed or implemented actions, plans and policies that align with the following criteria:”

Q3.30. Advance care planning

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Unable to answer
1. Promote advance care planning in the early stages following a diagnosis of dementia.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>
2. Support advance care plans to be actively reviewed, refreshed and implemented in the care provided.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>
3. Provide training and education regarding advance care planning options.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>

Q3.31. Adoption of a palliative approach

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Unable to answer
1. Provide training and education regarding a palliative approach.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>
2. Develop effective care and referral pathways to enable seamless transition to palliative care services for people with dementia.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>
3. Support development of services and programs to meet the needs of people with dementia requiring end of life and palliative care living in rural and remote communities.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>

Q3.32. High quality end of life care

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Unable to answer
1. Develop and implement strategies to increase the awareness and understanding of end of life needs and preferences.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>

2. Provide education, training and information for carers to access and utilise culturally specific information to improve end of life care for people with dementia.

3. Develop links between research and practice to improve the quality of end of life care for people with dementia.

4. Provide options for end of life care outside the hospital setting, including at home and in residential care.

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>

Q3.33.

Please provide us examples (positive and challenging experiences) to support your responses:

Recently, Dementia Australia has had a strong focus on palliative and end of life care for people living with dementia and has developed a series of discussion papers across many State and Territories to improve the quality of care. It is our continued focus for the first half of 2020 through our Parliamentary Friends of Dementia events with MPs and key stakeholders and advocates. The paper is available here <https://www.dementia.org.au/files/documents/DA%20Dying%20Well%20Discussion%20Paper%20FINAL%20for%20online.pdf> We have also partnered with Palliative Care Australia and Advance Care Planning Australia to develop joint position statements on palliative care and dementia and advance care planning and dementia. Additionally, we sit on various networks and working groups where palliative and end of life care are a focus. Examples of these groups include palliated, End of Life Direction for Aged Care (ELDAC), and the Advance Care Planning Australia Working group. In partnership with Respecting Patient Choices at the Austin Hospital we piloted and evaluated a national advance care planning education program for community care workers to help them have the skills and confidence to start the conversation about advance care plans early. As part of other education programs for health professions we also include content on palliative care and advance care planning. We do not however currently offer any specific programs on palliative care and advance care planning as it is difficult to generate interest as the primary focus in relation to dementia tends to be on addressing behaviours. Specifically, we run the Nightingale Nurses Program in South Australia which is the only specialist palliative dementia program of its kind in Australia. Working in partnership with a geriatrician and other stakeholders, the program successfully provides person-centred care from the point of diagnosis to end of life. The key challenges include palliative care services for dementia are inconsistent in the way they are delivered, they lack equitable service provision, and services lack unified standards and accepted definitions. There are also no KPIs or processes to measure the impact in a co-ordinated and cohesive way. Improving palliative care for people with dementia therefore must be a policy priority, Australia-wide, across the different states and territories. There is also a low uptake of supported decision making and conversations about palliative and end of life care are not taking place at the point of diagnosis. This is limiting the choice and decision making capacity of people with dementia. People with dementia need access to supportive and knowledgeable staff that deliver holistic person centred care and involve them in decision making as much as possible. However, staff lack specific training about dementia and do not adequately meet their needs. A specific example of this is pain management.

Q3.34.

Priority Area 7. Promoting and supporting research

Health care providers and the community have access to evidence based research into dementia to inform prevention, care and treatment across all care settings.

Please rate your level of agreement with the following statements:

“In the last five (5) years, the organisation I represent/work for have developed or implemented actions, plans and policies that align with the following criteria:”

Q3.35.

Evidence based research

Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Unable to answer
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Causes	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>
Diagnosis	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>
Care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>
Treatment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>
Carers	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>
Identification of risk factors and risk reduction strategies	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>
End of life care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>
Cure	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>
Consumer driven initiatives	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>
2. Explore opportunities for collaborative research particularly in relation to other National Health Priority Areas.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>
3. Promote the translation of current and future evidence-based research into the practice of dementia care from diagnosis to end of life.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>
4. Improved hospital data collection of dementia, including clinical coding to better inform research activities.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q3.36.

Please provide us examples (positive and challenging experiences) to support your responses:

Dementia Australia has set up the Dementia Research Foundation, where we fund early and mid-career researchers. Our annual Dementia Grants Program provides funding to support innovative Australian research to: • Better understand the causes of dementia • Develop strategies to reduce dementia risk and slow the progression of the disease • Provide accurate and timely diagnoses • Improve treatment and care options for people living with dementia • Find a cure The courses we offer through the Centre of Dementia Learning are all backed by evidence based research and we participate in a range of projects across the dementia disease trajectory. We also add to the evidence base through the ongoing evaluation of our education programs. Additionally, we partner with AIHW on the dementia and hospitals project to improve data collection processes about dementia. The key challenges include the timing between research translating to practice – the process currently takes too long. Additionally, there is no link between research translation outcomes and their contribution to other parts of the Framework. There is also a lack of consistency in language about dementia and this makes data collection fragmented and problematic. Sometimes it is referred to as dementia, other times, cognitive impairment, Alzheimer’s Disease or cognitive decline. This also makes it difficult to code data about dementia. There are also issues with reporting and accuracy of data being collected. The other challenge is that the research is not necessarily addressing issues of concern to people living with dementia or the professionals providing support. They are also not necessarily focused on how the knowledge from the research can then be translated into practice, hence the 17 lag between what is established in research and any changes to practice.

Q3.37. General Framework vision, intent and priority feedback

Q3.38.

The Framework is underpinned by nine (9) key principles.

You will be provided with an opportunity to provide a written response to your reasoning for selections at the end of the table.

How much would you agree or disagree that the principles were met within your organisation/department over the past five (5) years?

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Unable to answer
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1. People with dementia are valued and respected, including their rights to choice, dignity, safety (physical, emotional and psychological) and quality of life.
2. Carers and families are valued and supported, and their choices are respected.
3. Social participation is actively supported, and an approach that promotes enablement, wellness and inclusion is adopted.
4. People with dementia, their carers and families have access to competent, affordable, timely care and support services.
5. Services are provided within a consumer-directed care philosophy, delivered in a person-centred way where individual needs and preferences are identified and met where possible.
6. People with dementia, their carers and families receive care and support services when needed without discrimination.
7. A knowledgeable and skilled workforce is essential in providing quality care.
8. A collaborative approach is adopted to inform change and improve services.
9. Evidence-based approaches, policies and practices are adopted for all dementia-related activities and services. Areas where the evidence base is inadequate should be prioritised for future research.

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>
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<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>

Q3.39. Please tell us more about your experiences in relation to your response above (optional)

Dementia Australia’s strategic vision, which was developed in 2018 is an inclusive future where all people impacted by dementia receive the care and support they choose. Our purpose is to transform the experience of people impacted by dementia by elevating their voices and inspiring excellence in support and care free from discrimination. Our values include Diversity and Equality; Respect and Inclusiveness; and Integrity and Accountability. This is underpinned with our strategic priorities that will help us to transform the experience of people living with dementia, their families and carers. This is a long-term strategy that will achieve real and sustainable benefits over five years. Our priorities include: timely diagnosis and support, quality dementia care, and reducing stigma and discrimination. Our strategic direction is in direct response to what people with a lived experience told us was important to them and it directly links to the principles outlined in the Framework. We are still in the progress of achieving the plan and it is important to note that previous plans aligned with elements of the Framework but were also based on state priorities before we became a unified organisation. Additionally, through the work of the Centre for Dementia Learning and as part of our collaboration as part of Dementia Training Australia we have a clear focus on building the capacity of the workforce as this is the foundation upon which quality dementia practice is built.

Q3.40.

The intent of the Framework is to inform strategies and initiatives in dementia diagnosis, care, support and research.

You will be provided with an opportunity to provide a written response to your reasoning for selections at the end of the table.

Please rate your level of agreement with the following statements:

"Over the past five (5) years, there have been improvements in the following areas..."

Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Unable to answer
-------------------	----------	----------------------------	-------	----------------	------------------

1. Community understanding of dementia, including the risk factors of dementia, so they may take advantage of opportunities to reduce the risk of developing dementia, or delay its onset

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>
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2. Access and provision to appropriate assessment and timely diagnosis services by skilled and knowledgeable professionals

<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
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3. Access and provision to post-diagnosis information and support services for people with dementia

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>
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4. Services are person centred and support engagement, good health, well-being and enjoyment of life

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>
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5. Understanding that dementia is a life-limiting condition that diminishes cognitive capacity over time.

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>
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6. People with dementia require appropriate end of life and palliative care services tailored to their needs and preferences.

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>
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Q3.41. Please tell us more about your experiences in relation to your response above (optional)

Diagnosis data is still lacking to appropriately measure change and there is no registry for dementia. There are still questions over the percentage of GPs with dementia specific knowledge and information as dementia training is only a small component of their training, and there is no follow up. There needs to be consistency of training health professionals and care staff to meet the needs and improve the quality of care of people living with dementia, their families and carers. Despite attempts at integrating dementia into core aged care business, this remains unseen. Additionally, a) we don't know the baseline state; b) people with dementia, families and carers report the same systemic challenges that they had 5 or 10 years ago; c) the ability of the sector to support dementia doesn't seem to have substantially changed; d) funding is largely aged care general rather than dementia specific; e) the mechanisms to achieve the Framework vision are still not in place; f) awareness of dementia at community, consumer, professional level is still low; and g) discrimination is still rife.

Q3.42.

The Framework's vision statement is: "Improve the quality of life for people living with dementia and their support networks".

Has the Framework achieved it's vision in what it set out to do?

- Yes
- No
- Unsure
- Unable to comment

Q3.43. To what level do you think the above statement is appropriate for the future of dementia care in Australia?

The statement "Improve the quality of life for people living with dementia and their support networks" is still entirely appropriate as it is not yet there. This needs to be at the front of mind and a collective vision that we continue to work towards to achieve better quality of care and supports for people living with dementia, their families and carers. It is essential that the future of dementia care takes into consideration the individual's perspective as no two people living with dementia are the same or have the same goals or expectations.

Q3.44. In your opinion, what are the five (5) main **strengths** of the Framework?

1.
2.
3.
4.
5.

Q3.45. In your opinion, what are the five (5) main **weaknesses** of the Framework?

1.
2.
3.
4.
5.

Q3.46. **SECTION 3: Looking to the future:
Innovations in dementia diagnosis, support
and care strategies for Australia**

Q3.47.
Please list current innovations implemented in your organisation/department.

Innovation 1:

Innovation 2:

Innovation 3:	The National Dementia Support Program, we have revitalised the program with a specific focus on innovation and technology and reach into specific special needs groups: Rural and Remote; CALD and Indigenous.
Innovation 4:	Dementia Friendly Communities program.
Innovation 5:	The Dementia Australia Advocates Program and the Dementia Australia Advisory Committee, which involves people with a lived experience in policy, strategy and advocacy activities and decisions within the organisation.

Q3.48. Please list any barriers to implementing innovations in your organisation/department:

1.
2.
3.
4.
5.

Q3.49. Please list five (5) key areas of innovation needed to advance dementia prevention, diagnosis, support, care and research in Australia:

1.
2.
3.
4.
5.

Q3.50. What do you suggest is required into the future to create a strategic and collaborative national response to further improve outcomes for people living with dementia and their carers?

A Framework that has specific funding attached to activities that incentivises the sector and workforce to change their culture and practices to better meet the needs of people living with dementia. The activities need to be measurable and there needs to be accountability i.e. people/sectors/organisations/services need to be given ownership and responsibility for implementation of principles and activities in the Framework. KPIs need to be developed and the Framework reviewed annually to track progress. The framework needs to be tied into global efforts and reflect global positioning and strategies. This should also include data collection in collaboration with the global observatory. There also needs to be a core focus on the involvement of people living with dementia, their families and carers in strategy review. They are the experts and should be included in the development and review of the Framework to ensure it still best covers their priorities and is designed to meet their needs.

Q3.51. Are you aware of any other countries or jurisdictions that have dementia care programs and/or resources of interest? If so, please list/describe.

If you have any electronic resources you believe would be of interest, please email CHPO@health.wa.gov.au with the heading "Dementia framework resources"

The Dementia Friendly Communities Team are currently working on a new website and resources including the option of online toolkits. In terms of looking at other jurisdictions the United Kingdom Dementia Friends and Alliance have an interesting and informative array of resources. <https://www.dementiafriends.org.uk/> https://www.dementiaaction.org.uk/who_we_are The Global Plan for Action on Dementia The tools that exist in the disability sector available at <https://www.ndis.gov.au/about-us/publications/booklets-and-factsheets> The Human Rights-Based Approach to dementia available at https://www.who.int/mental_health/neurology/dementia/dementia_thematicbrief_human_rights.pdf

Q3.52. Are there any additional comments that you would like to make?

People living with dementia, their families and carers need to be at the centre (heart) of the Framework. They need to be involved in consultation, decisions and identifying any additional perspectives and priorities. "Nothing about us, without us." Dementia Australia is pleased to participate in any further discussions and where we have capacity to assist, we are happy to do so.

Q3.53. Are you interested in participating in further research to improve prevention, diagnosis, care and support for people with dementia and their carers?

- Yes
 No

Q3.54. Following this survey we will be contacting a representative sub sample of respondents to take part in a focus group of approximately 1 hour. This may occur face to face or by video link.

Are you or other members of your organisation/department willing to participate in a focus group?

- Yes
 No

Q3.55. Please provide us with your name and contact details for further invitations to participate in research.

Your details will be removed from your survey response prior to analysis to protect your confidentiality.

Name

Kirsty Carr

Email address

Kirsty.Carr@dementia.org.au

Q3.56. Are you also a carer, friend or colleague for a person with dementia?

Yes

No

Q3.57. If you would like to complete the version of this survey for people with lived experience of dementia, [please follow this link](#)

Q3.58.

Thank you for providing us with your valuable input. Your feedback and information will be used to help shape the future of dementia diagnosis, care, support and research in Australia.

Please click the final arrow button to submit your response.

Location Data

Location: [\(-33.704895019531, 150.92001342773\)](#)

Source: GeoIP Estimation

