

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

What is this?

The National Framework for Action on Dementia 2015 – 2019 (the Framework) guides the development and implementation of actions, plans and policies to reduce the risk of dementia and further improve outcomes for people with dementia and their carers.

This consultation is a nation-wide evaluation focussing on the Framework’s seven priority areas; from increasing awareness and risk reduction through to promoting and supporting research.

For more information on the Framework please view the link [here](#):

<https://agedcare.health.gov.au/ageing-and-aged-care-older-people-their-families-and-carers-dementia/national-framework-for-action-on-dementia-2015-2019>

Why is this evaluation important?

We require a broad range of responses and experiences from across Australia to gain an in depth understanding about the progress of the existing Framework. We are also seeking your recommendations to inform options for future dementia policy in Australia from 2019 onwards.

Therefore, we value your feedback and time to participate in the evaluation.

Who can participate in this evaluation?

- **A person with a lived experience of dementia:** Any person who has a diagnosis of dementia, a family member or a friend who knows of and or provides support to a person with a diagnosis of dementia.

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 the final forward arrow button at the bottom of the page in order to submit your responses.

Comments close 11.59pm Tuesday 31 December 2019.

Who is listening?

Western Australian Department of Health:

Email: CHPO@health.wa.gov.au

Phone: (08) 9222 2064

Section 1: Information about you:

1. What is your age in years? (required)

- 24 or younger
- 25 to 44 years
- 45 to 64 years
- 65 or older

2. What is your gender? (required)

- Female
- Male
- Prefer not to answer
- Self-described

3. What is the postcode of where you live? (required)

4. The Framework includes a number of identified priority groups. Please let us know which, if any of these groups you identify as being part of. (You can select more than one 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 and Queer people (LGBTIQ)
- Person who has personally experienced mental illness (lived experience)
- Person who has been diagnosed with younger onset dementia
- Person with a disability
- Person who provides 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)
- Veteran

5. Please indicate the relationship you have to someone living with dementia (You may choose all the options that best suit you)

- I have a diagnosis of dementia
- I am a family member (immediate or extended) of a person with a diagnosis of dementia
- I am a friend/neighbour of a person with a diagnosis of dementia
- I am a colleague of a person with a diagnosis of dementia
- I provide care to a person with a diagnosis of dementia (unpaid and/or reimbursed through centrelink)
- Other, please specify: _____

Section 2: Your experience with dementia

The broad aim of the National Framework for Action on Dementia (“The Framework”) is to further improve the quality of life for those living with dementia and their carers. There are seven (7) priority areas in the Framework that focus on significant aspects of care and support needed to achieve improvements in quality of life.

We want to know the level of importance that you put on each of these priority areas and if you have any ideas of areas that should be a priority that are not already listed.

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

- 1. Based on your own experience please rate the importance of each of the following seven (7) key priority areas:**

	Not at all important	Slightly important	Important	Fairly important	Very important	Don't know
1. Increasing awareness and reducing the risk of dementia.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. Getting a timely diagnosis of dementia.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. Being able to access care and support after a diagnosis of dementia.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. Being able to access ongoing care and support.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5. Being able to access care and support during and after hospital care.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6. Being able to access palliative care and other services to help at the end of life.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7. Promoting and supporting dementia research.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<i>Please tell us more about your experience in relation to your responses above (optional)</i>						

- 2. Please list anything that you think is missing as a key priority for dementia diagnosis, care, support and research in Australia:**

- _____
- _____
- _____
- _____
- _____

The questions below ask about the dementia support you have received. This information will allow us to see if there are gaps in the Framework or in the services available to people who have a lived experience of dementia.

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

3. Based on your lived experience of dementia, please rate your level of agreement with the following statements:

	Strongly Disagree	Disagree	Neither agree nor disagree	Agree	Strongly Agree	Unable to answer
1. I have received information that has increased my awareness of dementia.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. I am aware of community services and programs within my local area such as dementia friendly communities and cafes.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. I have received information about how to reduce my risk of developing dementia.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. My diagnosis with dementia happened in a timely manner.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5. I have had adequate access to care and support after a diagnosis of dementia.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6. I have received adequate access to care and support.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7. I have received adequate access to care and support during and after hospital care.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8. I have received adequate access to End of Life and Palliative Care services.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9. I have been asked to be a part of a research project focused on dementia.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Please tell us more about you experience in relation to your responses above (optional)						

4. Please tell us the things that have made your experience with dementia easier and the things that have helped you:

5. Please tell us the most helpful services or programs that you are aware or have accessed for people living with dementia and their support networks:

1. _____
2. _____
3. _____
4. _____
5. _____

6. Please tell us the things that have made your experience with dementia harder and the things that have not helped you:

7. Please tell us the things that you would like to see change or improve for dementia diagnosis, care, support and research in the future:

1. _____
2. _____
3. _____
4. _____
5. _____

The next section of this survey will ask you about the written content of the National Framework for Action on Dementia 2015-2019 (“The Framework”)

This section of the survey contains 6 questions including rating scales and will take approximately 10-15 minutes to complete.

8. Do you want to provide your feedback on this?

- Yes, (continue to section 3)
- No, (go to other comments section, p. 8)

Section 3: Feedback on the Framework

1. How familiar are you with the National Framework for Action on Dementia 2015 – 2019? (“The Framework”)

- Not familiar
- Slightly familiar
- Somewhat familiar
- Moderately familiar
- Extremely familiar
- Unsure

2. How did you become familiar with the Framework?

- Google
- Link from government website
- Heard from a friend/colleague/relative
- At an event
- Other _____

3. 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.

In your experience, how much would you agree or disagree that the principles were met when you were accessing services and support over the past five (5) years?

	Strongly Disagree	Disagree	Neither agree nor disagree	Agree	Strongly Agree	Unable to answer
1. People with dementia are valued and respected, including their rights to choice, dignity, safety (physical, emotional and psychological) and quality of life.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. Carers and families are valued and supported, and their choices are respected.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. Social participation is actively supported, and an approach that promotes enablement, wellness and inclusion is adopted.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. People with dementia, their carers and families have access to competent, affordable, timely care and support services.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
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.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6. People with dementia, their carers and families receive care and support services when needed without discrimination.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7. A knowledgeable and skilled workforce is essential in providing quality care.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8. A collaborative approach is adopted to inform change and improve services.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
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 type="radio"/>	<input type="radio"/>
<i>Please tell us more about your experience in relation to your responses above (optional)</i>						

4. 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’s 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 type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. Access and provision to appropriate assessment and timely diagnosis services by skilled and knowledgeable professionals.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
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 type="radio"/>	<input type="radio"/>	<input type="radio"/>
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 type="radio"/>	<input type="radio"/>	<input type="radio"/>
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 type="radio"/>	<input type="radio"/>	<input type="radio"/>
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 type="radio"/>	<input type="radio"/>	<input type="radio"/>
Please tell us more about your experience in relation to your responses above (optional)						

5. The Framework’s vision statement is: “Improve the quality of life for people living with dementia and their support networks”.

Do you think this vision has been achieved?

- Yes
- No
- Unsure
- Unable to comment

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

7. From your perspective, how has the Framework influenced your experience of dementia?

Section 4: Other Comments

1. Do you have any other comments?

2. Did you require assistance to complete this survey?

Yes, please state who:

No

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.

If you are interested in being involved further and or receiving information following the cessation of the survey, please leave your details below.

Please note – Your information will be managed responsibly to maintain your privacy and confidentiality and used to inform future dementia care in Australia.

Your Name (optional)

Your email (optional)

3. Would you be willing to be contacted in the future to provide feedback on Dementia in Australia?

- Yes
- No