Victorian Government Legislative Council Inquiry into Community Consultation Practices

A Dementia Australia submission

Introduction

Dementia Australia is grateful for the opportunity to make a submission to this important Victorian Government Legislative Council Inquiry into Community Consultation Practices. As the peak dementia advocacy organisation in Australia, we amplify the voices of people living with dementia by sharing their stories and helping inform others. As the trusted source of information, education, and support services, we advocate for positive change for people living with dementia, their families, and carers, and support vital research across a range of dementia-related fields.

As the peak dementia advocacy body, we regularly survey the community we represent on the issues that are important to them. Our submission to this Inquiry is informed by feedback from people living with dementia and former and current carers who participate in our **Dementia Advocates program**. For this submission, we have focused on the terms of reference most relevant to our stakeholders (c, d, and e). We surveyed Victorian Advocates in relation to issues related to standards required for community consultation, how to ensure underrepresented groups participate meaningfully in community consultations and the efficacy of the Engage Victoria community consultation platform. The survey results, in addition to other forms of Advocate feedback, form the basis of our submission. All quotes, unless otherwise indicated, are de-identified, verbatim responses from the Advocate survey.

People living with dementia, former and current carers were equally represented in the survey responses. All respondents were over 46 years of age, with the most respondents in 56- 65 years old category (31 per cent). 50 per cent of all respondents lived in a rural area, 46 per cent in a major city and 4 per cent identified as living remotely. 23 per cent identified as being from a culturally and linguistically diverse community, 8 per cent identified as Aboriginal or Torres Strait Islander and 12 per cent as LGBTIQ+.

Our key recommendations to this Inquiry, drawn from Victorian Advocate experiences and observations, are summarised here:

1. Design community consultative processes that actively support and encourage the participation of people living with dementia, their family members, and carers
2. This requires a range of inclusive, dementia-friendly, and supportive consultation options including dementia-friendly venues, and information provided in a variety of flexible and responsive formats that meet the communication needs of people living with dementia
3. Provide follow up support following the consultation process for people living with dementia, their family members, and carers
4. Community consultation opportunities should be promoted more expansively and extensively to ensure that underrepresented groups are aware of and enabled to participate in consultations and this promotional material should be provided in a range of flexible and responsive formats that meet the needs of people living with dementia
5. People living with dementia and their family members and carers in rural and regional areas should be targeted and supported to engage more actively in community consultation opportunities
6. To ensure that the diversity of Victorian voices is captured in community consultation processes, the Engage Victoria platform should be more actively promoted to underrepresented groups including people living with dementia, their family members, and carers

Understanding dementia in the context of community consultation

In 2025, there are estimated to be 433, 300 Australians currently living with dementia. In Victoria, it is estimated 110,600 people are currently living with all forms of dementia and this is projected to increase to an estimated 216,400 by 2054.[1] Recent surveys conducted by Australian Institute of Health and Welfare (AIHW) and Dementia Australia show that community awareness and understanding of dementia remains limited.

The inaugural 2023 AIHW Dementia Awareness Survey asked more than 5,400 Australians what they knew about dementia and their attitudes towards people living with the condition. The broad finding of the survey was: ‘Generally, Australians know little about dementia.’ [2]

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[1] Dementia Australia (2023) Dementia Prevalence Data 2024-2054, commissioned research undertaken by the Australian Institute of Health and Welfare.

[2] Australian Institute of Health and Welfare (2024) Dementia in Australia, Australian Government, ‘Dementia Awareness Survey’, https://www.aihw.gov.au/reports/dementia/dementia-awareness-survey/contents/about

The survey highlighted that misconceptions about dementia persist, including the erroneous belief that dementia is a normal part of ageing. The survey concluded that there was a clear need to improve the Australian community's knowledge of the condition.[3]

These findings are consistent with results from Dementia Australia surveys over the last decade, showing an ongoing lack of awareness and understanding about dementia in the Australian community. A 2019 report on Australian attitudes and beliefs found that while there was increased awareness and empathy over the past decade, two thirds of survey respondents were not confident about their knowledge of dementia. In the same survey, 63 per cent of people living with dementia believed that discrimination is common and 73 per cent of family, friends or carers of people living with dementia believe discrimination against people living with dementia is common or very common.[4]

This lack of awareness is at least in part because, unlike a physical disability, the cognitive and other changes that are associated with dementia are often under recognised or rendered 'hidden' or 'invisible.' People living with dementia relate the common experience of being told that they 'can't possibly have dementia' because they do not appear, speak or act in a way that corresponds with community expectations or understanding of the disabling nature of the condition.[5]

"If you just saw them and didn't know them, how would you even know if they had dementia?" (Australian resident with no lived experience of dementia).[6]

The invisible nature of a cognitive disability and the attitudinal and other societally imposed barriers mean people living with dementia can experience stigma, discrimination and other challenges when undertaking daily activities and engaging with people in the broader community. The Dementia Australia 2019 report found that people living with dementia experienced lower levels of social engagement, inclusion, and connectedness within their communities. [7]

These findings have clear implications in relation to how to support the active participation of people living with dementia in community consultations, including the consultation practices conducted by or on behalf of state and local government, statutory authorities and providers of essential services that are the focus of this inquiry.

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[3] Australian Institute of Health and Welfare (2024) Dementia in Australia, Australian Government, 'Dementia Awareness Survey', https://www.aihw.gov.au/reports/dementia/dementia-awareness-survey/contents/about

[4] Dementia Australia. Dementia Action Week Discrimination Survey (2019)5,767 valid responses collected from people living with dementia, families, carers, volunteers, health and aged care professionals, and people not directly impacted by dementia.

[5] Former CEO of Alzheimer's Switzerland Birgitta Martensen's account of her recent diagnosis includes the most recent and compelling example of this. https://www.alzint.org/news-events/news/my-life-with-alzheimers-disease-living-better-with-a-diagnosis/

[6] Dementia Friends & Dementia Friendly Communities Program. Exploratory report, Kantar Consultants, 2019

[7] Dementia Australia. Dementia Action Week Discrimination Survey (2019)5,767 valid responses collected from people living with dementia, families, carers, volunteers, health and aged care professionals, and people not directly impacted by dementia.

When we asked Victorian Dementia Advocates if they had ever taken part in a Victorian Government consultation or had given feedback in some form (for example, completing a survey, attending a community forum, or through the Engage Victoria website), 38 per cent answered in the affirmative.

43 per cent had not participated and 19 per cent were unsure. A subsequent question asked if respondents were aware of Engage Victoria; 62 per cent of respondents indicated that they had not heard of the platform.

These results are significant in indicating that more than 60 per cent of respondents have not been involved in Victorian Government community consultations, including accessing the Engage Victoria platform. These results, and our suggestions on how to improve engagement in community consultations for people living with dementia, their family members, and carers, will be explored in detail in addressing terms of reference (c), (d) and (e) that form the focus of our submission.

(c) standards of conduct, including preparedness, to be expected in community consultations;

‘Living with dementia, I often find it hard to take part in consultations because:

- The language is too complex or confusing.

- I need more time to understand the questions and give answers.

- I don’t always feel confident speaking in groups or with people I don’t know.

- Sometimes I don’t know when or where the consultation is happening.

- If I’m tired or unwell, I can’t take part.

- I don’t always feel like my voice will be heard or make a difference. Making consultations calmer, simpler, and more flexible would help a lot’

Given the survey results cited above, there is a clear need to improve awareness about and engagement with Victorian government community consultation processes for people living with dementia and their family members and carers. When respondents who *had* engaged with some form of Victorian government community consultation were asked to describe the experience, 56 per cent stated they felt respected and heard, but 44 per cent indicated that ‘my views were not listened to’.

People living with dementia have unique needs and challenges, particularly in relation to changes in cognition and associated changes in communication skills. When consultation practices are conducted by or on behalf of state and local government, statutory authorities, and providers of essential services, those conducting the c[illegible]es must be appropriately educated about how best to encourage and suppo[illegible]tia to participate in these processes.

This requires an informed, responsive, and flexible approach when devising consultation processes. This could include offering a range of options for consultation participation consisting of in-person consultations (small group or one-on-one), online or focus groups forums, surveys and correspondence via email or hard copy documents.

In preparing for in-person consultations, selecting a venue with dementia-friendly and supportive features will maximise the ability of people living with dementia to feel comfortable and fully participate in the consultation. The Dementia Australia resource **Making it Dementia-Friendly**, is written by a person living with dementia and offers a comprehensive guide to selecting an appropriate venue for meetings and other events that will support the participation of people living with dementia.

To optimise the inclusion and participation of people living with dementia in community consultations, information about the consultation process, what is involved, and any expected outcomes should be provided in appropriate and accessible formats that meet their diverse, and often changing, needs. This could include but is not limited to hard copy ’Easy’ or ‘Plain English’ resources, visual representations, audio, video, and other formats. Providing a range of information and resources in a range of languages will also support the inclusion and engagement of people living with dementia from culturally and linguistically diverse backgrounds.

There are a range of resources available, many developed collaboratively with people living with dementia, which can assist in preparing for respectful and inclusive community consultation practices that support the involvement of people living with dementia. We recommend several Dementia Australia resources, including **Half the Story**. This detailed guide to conducting meaningful consultation with people with dementia, their family members, and carers, was developed in close consultation with people living with dementia.

Dementia Australia’s Dementia-Friendly Communities program has recently developed two other resources that are relevant suggesting how state and local government, statutory authorities and providers of essential services can prepare for inclusive and supportive consultation practices involving people living with dementia. **The Toolkit for Councils** outlines the way in which local governments can make changes to transform their governance, consultation practices, and physical environments and ensure councils are more inclusive and dementia-friendly. **The First Steps to Building a Dementia-Friendly Future** is a community guide setting out practical tips for individuals and groups seeking to make their community more dementia-friendly. The information in these two documents offer insights into how to implement strategies to ensure people living with dementia, and their family members and carers, feel included, empowered and enabled to participate in their communities, including contributing to community consultations at local and state government level.

(d) groups or regions who are underrepresented by existing consultation practices, and options to improve their engagement;

> ‘The group we belong to are mostly not represented.’

Dementia Australia represents a broad and diverse community of stakeholders. People living with dementia have a cognitive disability and might identify as a part of an underrepresented group in this context. Many people living with dementia might also identify in additional, multiple ways as being part of a minority population or underrepresented group. As indicated in the introduction to this submission, the demographics of our survey respondents indicated that individuals identified as someone living with dementia, or caring for someone with dementia, and as an older person. Aboriginal and/or Torres Strait Islander, culturally and linguistically diverse groups, the LGBTIQ+ community and people living in regional or remote areas, were all well represented in the survey group.

To address the Inquiry’s focus on engaging more effectively with underrepresented groups and regions, we asked Advocates the following question: Do you feel that people with dementia and their carers are well represented in government and service provider consultation processes? More than three quarters of respondents answered no (76 per cent), 19 per cent were unsure and only 5 per cent answered yes. Follow up questions explored why people felt underrepresented and included the following observations:

‘Unaware of the opportunities.’

‘Work and family commitments. For my mum, distance to travel and English being her second language.’

‘I would have no trouble taking part or advocating for people with dementia's rights and needs if I knew where to go to do that.’

‘Too long, some time complicated.’

‘Not clearly understanding the reason and benefits.’

‘In person activities as my husband is end stage dementia and we are unable to attend many activities.’

‘If they actually came out and saw us heard us and didn’t make their assumptions and we said what we wanted to say.’

Respondents were then asked what would make it easier to participate in community consultation processes and the following responses were representative of the key issues identified:

‘What makes it easier for me to take part in consultations:

- Using simple words.
- Giving me the questions early.

• Letting me bring someone to help me.

• Talking to me one-on-one, not in a big group.

• Giving me time to think and speak.

• Making me feel my opinion is important.’

‘Face to face or come to us living with the disease and let us tell you what we need.’

‘For the consultation to be held in the regional areas.’

‘For me, consultations held at the beginning or later in the day work better due to existing work commitments. My mum, who lives 70km from Melbourne and with advanced dementia, relies on me to take part in any daily activities, which means that I need to be available. My suggestion would be to have multiple sessions offered for the same topic. Whilst this is time consuming and may not always be feasible, it does increase opportunities to participate. I also think simplifying topics to 2 or 3 agenda items may offer opportunities to discuss topics in greater detail.

‘Regular communication and invitation for opinion of people with lived experience.’

‘Need to be held face to face in the morning at a suitable venue for the person living with dementia E.g. not noisy and well lit. Easy, accessible venue with good parking or transport provided.‘

Consistent themes emerged on the issue of how to improve the active participation of underrepresented people living with dementia, family members and carers and can be summarised as follows:

- People living with dementia must be enabled to participate in all community consultations
- For those planning and conducting community consultations, it is vital that assumptions are not made about the capacities and abilities of a person living with dementia to participate in these consultations
- Offering a range of options to participate including in-person meetings in dementia-friendly venues, online focus groups (small group size), webinars, surveys (electronic and hard copy), emails and hard copy correspondence will assist in supporting people living with dementia to participate in community consultations
- Recognise that people living with dementia have diverse communication needs and challenges and provide information about consultation opportunities in a range of formats that accommodate and support these needs

- Acknowledge the challenges of people living in rural and regional areas and provide a range of flexible options for engagement to address these challenges
- Improve awareness of and actively promote opportunities for community consultation through a range of different channels including health care providers, residential aged care communities, direct mail, legacy media, and social media

(e) the Engage Victoria platform, its use and effectiveness, and areas for improvement; and

> ‘Accept the fact that many people with dementia still have the capacity to understand & contribute.’

As noted earlier in this submission, when asked if they had accessed Engage Victoria, 62 per cent of respondents indicated that they had not heard of the platform. A further 19 per cent had heard of it but not used it. 9.5 per cent of survey respondents who had interacted with Engage Victoria found it easy to navigate and 9.5 per cent found it difficult to use. To explore issues in relation to the access and efficacy of Engage Victoria in more detail, we asked respondents for suggestions on how the Victorian Government and service providers could improve the way they consult with people living with dementia and their carers.

There was an understandable duplication in some responses to this question and previous questions relating to improving support and participation in community consultations for underrepresented groups in the community.

In addressing this final aspect of the Inquiry, we have therefore chosen a representative selection of responses that specifically address how to improve engagement via the Engage Victoria platform and community consultations more broadly.

‘As someone living with dementia, I find it difficult when questions are wordy, rushed, or unclear. To improve how feedback is collected, the Victorian Government and service providers should:

- Use plain language – keep questions short and easy to understand.

- Allow more time – don’t expect instant answers. Give people time to think or have support if needed.

- Offer different ways to give feedback – like written surveys, phone calls, or speaking face-to-face with someone trusted.

- Include carers – carers often know what helps or makes things harder, so their voice is important too.

• Follow up with support – sometimes sharing feedback can bring up strong emotions. People should feel safe, heard, and supported afterward. This would help people with dementia feel respected and included in shaping better services.'

'Don't design questions on the platform or anywhere else with the intentional or even unintentional way to get a particular outcome.'

'Place clear pathways for feedback at nursing homes and on websites where people go to find at home carers.'

'Consider flexible modes of feedback, webinars, groups, online, directly over the phone or via email.'

'Send very simple and clear information emails to family members. Victorian Government attend community groups, such as Dementia Cafes. Victorian Government visit residential aged care homes as this is the only way to involve residents (and their family). Aged care providers asking people with dementia and their carers for feedback using a pre-developed form by Vic Gov. Simply promote information sessions via the Dementia Australia website, as well as other advocacy organisations like Carers Victoria. Overall, people living with dementia are hard to reach. Their cognitive and physical decline means they are reliant on others for care and support and to participate in activities. The 'others' do not always need to be family. They can be government, service and community providers that go to the person.'

'Reaching out through healthcare providers and professionals. If possible, dementia database should be invented to keep record of current cases across the states and the country.'

'Circulate flyers with questions and website links to reply. Advertise through Facebook or TV seeking input.'

'Regular smaller consultations. Create a 'consultations register' that involves members in a range of community engagement initiatives and updates members so they can see they are making a difference (which in-turn enhances further engagement). Also, engage local members from rural, regional, and even metropolitan areas to run consultations on behalf of Vic.Gov.'

Conclusion

Our submission to the Victorian Government Legislative Council Inquiry into Community Consultation Practices highlights the current challenges engaging in community consultations for people living with dementia, and their family members and carers. Equally, our submission illustrates that individuals in this underrepresented group have a commitment and desire to ensure their voices are heard and to make an ongoing contribution to Victorian Government planning, policy development and service provision, a contribution that will benefit all Victorians.

The following key **recommendations** are drawn from the compelling insights and suggested strategies for improved engagement provided by Victorian Dementia Australia Advocates.

1. Design community consultative processes that actively support and encourage the participation of people living with dementia, their family members, and carers

2. This requires a range of inclusive, dementia-friendly, and supportive consultation options including but not limited to in-person consultations (small groups or one-on-one), online webinars and focus groups, surveys (electronic and hard copy), and correspondence via email and hard copy

3. If in-person community consultations are planned, dementia-friendly venues should be considered to ensure that people living with dementia feel comfortable and supported to participate

4. Information about the community consultation opportunity or process should be provided in a variety of flexible and responsive formats that meet the needs of people living with dementia. These could include but are not limited to hard copy ’Easy’ or ‘Plain English’ resources, visual representations, audio, video and other formats, and resources in a range of language options

5. Provide follow up support following the consultation process for people living with dementia, their family members, and carers to ascertain if the process has been a positive experience, and if any further support or services are required

6. Community consultation opportunities should be promoted more expansively and extensively to ensure that underrepresented groups are aware of and enabled to participate in consultations. Promotional channels could include health care providers, residential aged care communities, peak bodies and not for profit organisations, direct mail, legacy media, and social media

7. Promotional information about consultation opportunities should be provided in a range of flexible and responsive formats that meet the needs of people living with dementia

8. People living with dementia and their family members and carers living in rural and regional areas should be targeted and supported to engage more actively in community consultation opportunities. This could include but is not limited to providing in-person consultation opportunities beyond metropolitan areas, online consultation opportunities that take account of work commitments and other flexible engagement options

9. To ensure that the diversity of Victorian voices is captured in community consultation processes, the Engage Victoria platform should be more actively promoted to underrepresented groups including people living with dementia, their family members, and carers. As with the broader promotion of community consultation opportunities, this could be undertaken through health care providers, residential aged care communities, peak bodies [illegible] for profit organisations, direct mail, legacy media, and social med

Dementia Australia believes that adopting these recommendations could make a significant contribution to encouraging people living with dementia, their family members, and carers to engage more fully in community consultations.

We conclude this submission with a clear and forceful call for inclusion from a Dementia Australia Victorian Advocate:

‘People with dementia still have something to say — we just need a fair chance to say it.’

Dementia Australia welcomes the opportunity to provide more information or to discuss any of the issues raised in this submission in more detail. The Dementia Australia policy team can be contacted at **PolicyTeam@dementia.or.au**