Dementia Australia's submission on the National Dementia Action Plan

31 January 2023

This page is left blank intentionally

Dementia Australia

Dementia Australia is the peak dementia advocacy organisation in Australia. There are over 400,000 people living with all forms of dementia and over 1.5 million people involved in their care.[i] Our organisation engages with people with dementia, their families and carers in our activities, planning, policy and decision-making, ensuring we capture the diversity of the lived experience of dementia across Australia. Our advocacy amplifies the voices of people living with dementia by sharing their stories and helping inform and inspire 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.

Introduction

Dementia Australia was grateful for the opportunity to play a facilitating role in consultations for the development of the draft National Dementia Action Plan (NDAP) and offers this further submission to inform ongoing consultation on the draft Plan.

Dementia Australia believes that the World Health Organisation's Global action plan on the public health response to dementia 2017-2025 is a critical initiative.[ii] The Australian government has recognised that it is equally critical that Australia has a national plan to inform and engage the community about dementia, and to provide a roadmap to guide planning, policy and service provision to support people living with dementia, their family members and carers over the next decade. To improve on the previous plan, it is imperative to refine the actions that underpin each of the objectives (including outlining responsibility and accountability for each action) as well as the proposed outcomes (including articulating how the outcomes will be measured).

As the peak advocacy organisation for dementia in this country, we regularly survey the community we represent on the issues that are important to them. Our resultant submission in this consultation is informed by feedback from people living with dementia and former and current carers who participate in our Dementia Advocates program, as well as Dementia Australia staff members, teams and subject matter experts, all of whom affirmed the critical importance of having a National Plan and being accountable to it over the next decade.

Dementia Australia broadly supports the draft National Dementia Action Plan's vision and objectives. We agree with the immediate priorities identified as the focus over the next three years but make a strong argument for the need to focus on risk reduction alongside these priority areas in the first phase. Mitigating the risks for dementia would both address the public health issues and reduce the pressure on the health care system which is already struggling to meet demand. Dementia Australia would also like to see clarity and additional detail around how all of the initiatives and proposed actions would be staged and funded.

Our submission provides general comments and recommendations in relation to some aspects of the language and terminology adopted in the Plan. Our central focus is on recommendations in relation to the proposed actions for each of the seven objectives as we believe that defining the actions and setting measurable outcomes will be the key to determining the success of the Plan over the coming decade.

Vision and language

> 'For me, it has always been about maintaining my 'independence' for as long as possible, and enjoying the 'best possible quality of life' and living 'a life that I value'.
> Person with dementia

The proposed vision is:

> 'Australians understand dementia - people living with dementia and their carers have the best quality of life possible and no one walks the dementia journey alone.'

Dementia Australia supports the key messages in the proposed vision but believes it is critical to make the sure the language in this foundational statement is clear and respectful. We therefore make the following recommendations for changes to the language and terminology used:

- Advocates advised us that some people with dementia do not like the use of 'dementia journey' to describe their experience with the condition. We recommend reviewing the use of this phrase in the vision statement and throughout the document.
- Advocates also advised that using the phrase 'walks with' may be 'disempowering to those with different abilities.' One of the alternative suggestions for this phrase was simply that: 'no-one faces dementia alone.'

- Dementia Australia supports the use of ‘the best quality of life possible’ in the vision statement and for consistency and clarity, recommends this be employed throughout the Plan (other phrases including ‘Live well’ [p. 31, 32] are used at different points in the Plan).
- Dementia Australia strongly supports the inclusion of families in the vision statement i.e., ‘‘Australians understand dementia - people living with dementia, their carers and families have the best quality of life possible and no-one faces dementia alone.’ This acknowledges the important role that family members play in supporting the person with dementia, and equally, that not all carers are family members. This is consistent with the language used throughout the Plan including the Purpose (p.4) and Principles (p.13).

In addition to the recommendations made above, it is recommended that consideration is given to a visual representation of the Plan which shows people living with dementia at the centre and how each Objective relates to their positive wellbeing.

On a minor note but important statistic, we note the typo on p 5 Typo ‘It is estimated that between 386,200 and 472,00 Australians which should be corrected to 472,000. [iii]

Dementia *is* a disability

Under the Purpose of the Plan, ‘Groups at higher risk of developing dementia or facing barriers to equitable access’, follows a sub-heading entitled ‘People with Disability.’ The text refers at times to people with an intellectual disability but also disability more generally. There are several references to people with ‘both a disability and dementia.’ The 2008 United Nations Convention on the Rights of People with a Disability (UN-CRPD) recognised dementia as a cognitive disability but unlike physical disability, community understanding of dementia as a disability remains limited. This is at least in part because, unlike a physical disability, the cognitive and other changes that are associated with the condition are often under recognised or rendered ‘invisible’. People living with dementia relate the common experience of being told that they ‘can’t possibly have dementia’ because they don’t appear, speak or act in a way that corresponds with community expectations or understanding of the disabling nature of dementia.[iv]

> “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) [v]

The ‘invisible’ nature of a cognitive disability means people living with dementia can experience additional stigma or challenges when undertaking daily activities, engaging with the health care sector or interacting with people in the broader community. Dementia Australia believes that the text in this section as it currently stands, with numerous references to ‘disability and dementia’ as if they are distinct conditions, might inadvertently perpetuate the lack of understanding about dementia as a disability. We recommend revising the wording and language to make clear that dementia is a cognitive disability.

Objective One: Tackling stigma and discrimination

> ‘When you say you have cancer, people say if you don’t mind me asking what type, have you had surgery but when you say you have dementia, they are off - they don’t know what to say’. Person living with dementia

Dementia Australia believes that tackling stigma and discrimination is the defining and most critical objective, and that addressing this underpins the vision, principles and everything else that follows in the Plan. There was a strong consensus from Advocates that in order to tackle stigma and discrimination it is important to educate the community and increase public awareness of dementia, ensuring that any awareness and information campaigns and public health initiatives reach all Australian communities, including ‘priority populations.’

1.1 Expanding dementia awareness and reducing stigma

Dementia Australia strongly supports all the proposed actions and makes the following recommendations to expand on or focus these more specifically on target groups, sectors or issues:

- We support the importance of information programs and media campaigns reaching diverse groups or ‘priority populations’ but emphasise that this needs to be delivered in ways that are accessible and meaningful to these groups to ensure the effectiveness of messaging. Partnering with Dementia-Friendly Alliances working closely with these communities to ascertain what supports and resources are needed offers one approach.

- Training bi-cultural workers, offering bi-cultural social support/visitors schemes is another strategy offered for consideration.
- Media campaigns must have a strong focus on social media channels, where many younger people get their information and where disinformation proliferates.
- It is important to get the message out about dementia/dementia awareness by enlisting prominent Australians in the arts/entertainment, sport and other areas who appeal to different cohorts/demographics and tailoring messages through different media channels and platforms.
- We support expanding the ‘free access to dementia training and awareness’ to focus on specific sectors and see this as critical. This could take the form of tailored scenario-based education to key sector groups including local government, transport, emergency services, sports and leisure.
- It is critical to provide information and raise awareness as early as possible. Dementia education programs and campaigns should start in primary schools so that an understanding about the condition is developed from an early age – this could tie in with initiatives to educate young people about brain health/risk reduction factors outlined in Objective Two.
- We suggest investing in and promoting intergenerational programs linking early childhood facilities with aged care homes.
- Ongoing funding for free education must be aimed not only at health care sectors but more broadly – the reference to first responders in the consultation paper is narrow, for example and needs to be expanded to public services, retail workers, local councils etc.
- Consideration could be given to a nation-wide Federal Government led awareness campaign promoting dementia-friendly communities and initiatives in addition to Dementia Action Week initiatives.
- Some advocates suggested a form of personal ID (bracelet) that provides information about the person’s condition/cognitive and other difficulties to help with

communication/understanding of needs in the community i.e. on public transport/in health care/retail and small business settings.

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

Comments from a wide range of stakeholders highlighted the following suggestions:

- Need to emphasise that dementia-friendly spaces include considerations such as access to public transport, spatial awareness and wayfinding, communication (sensory mapping/social scripts) and the importance of access to natural surroundings.
- For a national plan to be effective, it must be implemented at a local and community level. Tapping into local council, other community based-organisations and facilities will be crucial, including libraries, community centres etc to offer information/programs/activities and making these spaces dementia-friendly. Advocates strongly endorse the Dementia Australia Memory Lane Cafés initiative as an effective example of how information and support can be provided in a local, dementia-friendly environment.
- Support the need for dementia training for first responders including police, paramedics, fire fighters and emergency services workers but this must be expanded to all staff/volunteers and individuals associated with the dementia-friendly spaces outlined in this objective.
- As part of a nation-wide initiative to encourage inclusive, dementia-friendly communities and spaces, Federal, State and Territory customer service centres (for instance the Australian Taxation Office, Centrelink, Medicare) could be required to undertake dementia-friendly environmental audits and produce sensory maps and social scripts to support dementia-friendly service.
- Measuring progress in this context could include tracking the increase in the number of inclusive groups and dementia-friendly organisations who complete Dementia Australia’s Dementia-Friendly Communities Program recognition process.

Objective 2 – Minimising risk, delaying onset and progression

The language used in the Outcome statement and the Statement for people living with dementia is at times unclear in relation to what the person living with dementia and individuals in the community need to know and accomplish.

The Outcome Statement reads:

People understand the factors that increase their risk of dementias and are supported to take actions to reduce these risks, delay the onset and progression of dementia across all stages of life.

The Statement for people living with dementia reads:

‘I am aware of the risk factors for dementia and supported to take steps to reduce my risks or delay the progression.’

Feedback from a range of Advocates including people living with dementia noted that for a person already diagnosed with dementia, it seems erroneous to be aspiring to an awareness of risk factors, and risk reduction *post-diagnosis*. Dementia Australia suggests a rewording of the Statement, so it focuses on maintaining a healthy lifestyle, minimising ongoing risks and delaying progression of the condition.

On a minor point, the use of ‘dementias’ in the plural is puzzling as it does not occur anywhere else in the Plan.

Dementia Australia supports the proposed actions for Objective Two but makes the following recommendations:

2.1 Risk factors for dementia are well understood

- Positive messages about brain health in population health strategies and information campaigns need to be accessible to priority populations i.e. First nations communities, CALD and other groups via education campaigns that bring awareness to the public while also aligning messaging to those already diagnosed and/or with MCI to focus on delaying progression. Advocates living with dementia cited the ‘Slip, Slop, Slap’ campaign as a public health campaign with a simple but highly effective message that had a long-term impact.

- Support the push for positive messages about brain health, particularly for children and young people – this could take the form of incorporating ‘brain health’ information programs in school curriculums at all levels, State and Territory-wide.
- Messaging to young and old must include an emphasis on dementia as not just a ‘disease of old age’ – important to emphasise childhood and younger onset forms of dementia.

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

- As part of the ‘risk reduction information in broader dementia awareness campaigns’, focus could be given by Government to fund programs/projects where peak bodies work together to provide community programs around brain health e.g., Headspace, Heart Foundation, Diabetes Australia.
- The link between healthy choices and lifestyle factors needs to be a positive, enabling and empowering message so the community will connect with what they can do in terms of risk reduction on a personal level.
- Focus on the concept of social prescribing and the importance of maintaining and linking into social networks, community groups and other activities – linking GPs, allied health practitioners to alliances and other forms of locally-based inclusive groups/activities.

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

Consistent feedback from Advocates, the National Dementia Helpline and internal Dementia Australia sources affirms the importance of this objective and that significant systemic issues remain in relation to obtaining an early and accurate diagnosis and appropriate post diagnostic support and care. Long wait times for memory clinic and specialist appointments and for other diagnostic tests and services, and the absence of clear pathways for the planning and provision of post diagnostic supports and services are well known and longstanding issues. Dementia Australia strongly supports the idea of Dementia Care Coordinators, a role that would be integral to the coordination of services and supports, though we urge consideration of this role and how it relates to other care/service coordination roles across the health, disability and aged care sectors.

Advocate feedback consistently identifies the need for comprehensive dementia education for GPs and other health care professionals involved in the diagnosis and support of people living with dementia as an urgent imperative. Dementia Australia believes Nurse Practitioners could play an increasingly important role in cognitive assessment and referral processes and the planning of dementia treatment and care in a range of health care settings and should be encouraged to do so with appropriate education and other forms of support.

The Plan does not appear to formally identify challenges in relation to the provision of post-diagnostic care and support. Dementia Australia would suggest that the challenges are similar to those associated with obtaining an early diagnosis and require corresponding actions: namely, the need for timely access to appropriately skilled GPs, specialists and other services that can provide tailored treatment, care and support appropriate to each individual's needs (and know who their key points of referral are). Difficulties accessing appropriately skilled and educated health care professionals, including allied health practitioners, limitations around cultural competency in delivering dementia care for 'priority populations' and the specific issues around access to treatment, care and other support services in rural, regional and remote areas are clearly ongoing challenges in this context.

> '… if you go anywhere in Australia, you need to be able to find the same sorts of services and supports.' Person with dementia

Dementia Australia makes the following further recommendations in relation to proposed actions for Objective Three:

3.1: Recognising and acting on early signs and symptoms

- As a general observation in relation to all proposed actions for this objective, we would emphasise the unique diagnostic, support, treatment and care issues and challenges faced by people living with childhood forms of dementia and younger onset dementia, and the requirement to tailor services and supports accordingly.

- Promoting the benefits of early diagnosis to GPs, nurses and the general community' must be framed positively in terms of the range of treatments, supports and services available that will actively support a person post diagnosis (allied health, psychosocial supports and so on) and critically, that early diagnosis ensures the opportunity to clarify goals and aspirations, identify concerns and plan for the future. We would also recommend that awareness and education for health professionals around the unique diagnostic and support issues and challenges faced by people living with childhood and younger onset dementia are highlighted in this proposed action.
- Re: 'embedding clear pathways and processes for health practitioners to refer people to diagnostic services and/or Dementia Australia,' these pathways and processes must not just focus on medical/clinical issues but spell out the value of other forms of services and support i.e., social prescribing initiatives, psycho-social interventions (see Objective 4 also).
- Endorse the emphasis on need for health care professionals' training in assessment/diagnosis and referral pathways; and further, we would make a special recommendation in relation to the important role that appropriately dementia-educated Nurse Practitioners can play in a range of health care settings but specifically primary health/aged care.

3.2: Quality and timely diagnostic services

- We note the emphasis on 'Ensuring regional memory clinics are adequately staffed' and recommend the wording be widened to include rural, regional and remote areas given the increasing difficulty of access to these services in these regions.
- If the Medicare Benefits Schedule was reviewed 'to better support dementia diagnosis', we would support exploring a new or realigned item number for dementia diagnosis in this context.
- A review of the efficacy of the RUDAS and KICA diagnostic tools must be part of the proposed action to 'develop and implement culturally competent diagnostics tools and processes.'
- As noted above, promoting the role and responsibilities of Nurse Practitioners should be incorporated into the proposed action 'supporting nurses working in general

practice to recognise cognitive change, undertake cognitive screening and communicate with GPs and patients.'

3.3: Post-diagnostic care and support

- As noted above, we affirm our support for the proposed action 'considering the rollout of dementia care coordinators informed by international best practice.'

Objective Four: Improving treatment, coordination and support along the dementia journey

> 'When I had cancer, we had all sorts of support…everything to make living with cancer a positive thing not a negative thing…I'm not giving up that dream yet (for people with dementia to have something similar); I want that to happen not just for me but for everyone.' Person living with cancer and dementia.

As with Objective Three, the urgent imperative to improve the provision and coordination of treatment and support for people living with dementia is a key priority. Dementia Australia notes the many and complex challenges identified in the Plan and is broadly supportive of the proposed actions in relation to this objective. As noted in our introductory comments, on the basis of feedback from people living with dementia, we recommend considering alternative wording for 'dementia journey' in the objective's title. In relation to the Outcome statement, people with dementia experience a range of significant *physical* changes associated with the condition. We recommend acknowledging these changes in addition to the behavioural, psychological and end of life needs so the Statement reads:

> 'People living with dementia are connected to coordinated, dementia-inclusive services that meet a person's changing behavioural, physical, psychological and end of life needs.'

In relation to the Statement for people living with dementia, we recommend considering revising the wording from '… live my best life with dementia…' to 'living as well as possible with dementia' to be consistent with the language used throughout the Plan.

Our specific recommendations in relation to the proposed actions are as follows:

4.1: Quality care and ongoing support as a person’s needs change

- The first two proposed actions address significant changes in behaviour and important associated initiatives, but we feel beginning with these actions has the unhelpful effect of implying that all people with dementia are likely to experience these changes. We would recommend these actions be listed further down accordingly.
- Dementia Australia acknowledges that there is a diversity of opinion about language in relation to changed behaviour associated with dementia, but we note that some people with the condition dislike the use of Behavioural and Psychological Symptoms of Dementia (BPSD). The Plan uses a variety of terms including BPSD and behaviours of concern; for clarity and consistency, we would recommend the use of changed behaviour (noting this is an Advocate preference and that BPSD can be seen to describe a clinical indicator).
- Dementia Australia strongly endorses supported decision-making as an approach that recognises the importance of making decisions about health, legal and other matters *with* rather than for people living with dementia as outlined in our **Position Statement on Supported decision-making**. The proposed action to improve access to information is crucial in this context and could involve the provision and distribution of information through a range of avenues including acute/primary health/aged care settings, community centres, legal aid and private legal practices and other relevant outlets, organisations and institutions.
- We support ‘new family focused counselling support for people living with younger onset dementia, including services specifically for children’ but suggest this action also includes services for *children living with dementia,* and their family members and carers.
- We would like to see a proposed action that addresses the significant issue of appropriate accommodation for people with younger onset dementia as outlined in our recently revised Position Statement on **Residential Care Options for People with Younger Onset Dementia.**
- We emphasise the critical importance of early and tailored access to Allied and other health interventions for people with dementia of all ages as outlined in our recent Position Statement on **Access to Allied Health Services for People with Dementia**. While we support the concept of concentrating multidisciplinary teams in nationwide

‘Brain Hubs’, we would also advocate for the importance of referring to and ensuring timely access to these services in a range of health care settings including acute care, primary health care and aged care.

4.2: Care and support during and after hospital care

• In relation to the Australian Commission on Safety and Quality in Health Care Clinical Care Standards, we recommend a review of the strategies and standards for supporting people with dementia in a hospital setting for effectiveness and consistency of implementation.

4.3: End of life and palliative care

- Dementia is a progressive, life-limiting condition that will require a palliative approach to care at the end stages of the condition, including end of life care. Dementia Australia strongly supports the development and funding of specialist palliative care services, including services that would support community-based palliative care for people living at home and in residential aged care. The Nightingale program in South Australia involves specialist, dementia-educated palliative care nurses, and provides strategies and advice to support people living with dementia, their families and care providers with a focus on promoting choice and well-being. The program offers a potential template for how these types of specialist palliative care services and supports could be provided on a national scale.
- As noted in relation to the previous objective, Advocates strongly supported pathways that spelt out each step of the way from pre-diagnostic supports and referrals for someone concerned about cognitive changes onwards. Pathways must equally address the later stages of dementia, including the need for a palliative approach and end of life care referrals/services. To be effective and accessible for people with dementia, their carers and families, these pathways must be holistic and all-encompassing so that they can provide expert guidance and support at every point of the dementia trajectory.

Objective Five: Supporting people caring for those living with dementia

Dementia Australia supports this objective and the associated actions.

We note, however, that some Dementia Advocates expressed confusion about the ‘I’ statement being from the perspective of the carer rather than the person living with dementia.

At a general level, supporting carers to carry out their role and maintain their own mental and physical wellbeing is crucial for people living with dementia and crucial for the capacity of the healthcare system more broadly. Informal carers are an integral part of the lives of people living with dementia and are fundamental to their care and capacity to remain safe and supported in their own home or in residential aged care.

While the consultation draft addresses the lack of accessible and responsive respite care and includes actions to increase the availability, affordability, and flexibility of respite services, the paper does not specifically recognise the lack of appropriate respite for people living with younger onset dementia. Currently, neither the NDIS nor the aged care sector are able to cater to the needs of someone with younger onset dementia, leaving many individuals caught between both systems without suitable accommodation options. Without access to age-appropriate respite and residential care that allows carers to recuperate, carers can experience their own physical and mental health issues and impacts on financial security and quality of life.

Additionally, access to supports in regional, rural and remote locations is even more difficult. Without access to appropriate supports that meet their needs, individuals living with dementia, their family members and their carers are at greater risk of delayed diagnosis, diminished quality of life, declining function, unnecessary hospitalization, carer burnout and premature entry to residential aged care.

> “As aged care isn’t appropriate, there aren’t many residential care facilities that can be accessed for those with younger onset. They are often too far away and in a lot of country areas they are non-existent.” Person living with dementia
>
> “They [carers] are not appropriately (formally/officially) recognized for their caring role. They are expected to juggle their caring responsibilities alongside their job - and caring for someone with dementia isn't something you do as a side hustle, it's an immense responsibility that you need be available 24/7 to take on.” Carer

> “I would like to see carers better acknowledged and recognized in the action plan with more specifics around Carer Support Package, financial assistance, information where and how to get support, including emergency respite”. Carer

> “I believe improved carers support needs to go up the list further. The cost to the economy to support damaged carers when the patients journey is complete must be high.” Carer

Dementia Australia makes the following recommendations:

- Ensuring that supports and services are made more accessible for those living in regional, rural and remote locations.
- Ensuring the provision of age-appropriate respite for people living with younger onset dementia.

Objective 6: Building dementia capability in the workforce

Dementia Australia strongly supports this objective and much of our systemic advocacy over recent years has focused on the capacity of the workforce to deliver quality dementia care. Improving the dementia capability of the aged care, health and disability workforce is critical to ensuring people living with dementia, their families and carers receive the quality care and support they need.

> “When we employ someone to work as a cook in an establishment, we don’t just say oh, you have some experience cooking at home, you can work here….you make sure they are certified. The same should be in aged care.” Person living with dementia

Compulsory dementia education, ongoing professional development and mentoring for staff are essential to building the dementia capability of the workforce. Dementia education and capability needs to reach all areas of the workforce (including senior management, executives and Boards) that interact with people living with dementia and it is important to improve the level of knowledge, understanding and delivery of quality dementia care across all care settings including hospitals, aged care and home and community care. For further information about our view on the importance of dementia education, please see our position statement available at **https://www.dementia.org.au/sites/default/files/2022-06/Advocacy-Policy-Position-Statement-May-2022.pdf**

> “I would like to see the managers and those who are at the top of the hierarchy in aged care facilities strongly encouraged to attend training, to develop understanding of the importance and urgency of dementia care. The training of staff is important, but they are not the leaders in the field and often struggle against a conservative framework.” Dementia Australia staff member

Dementia Australia makes the following recommendations:

- Compulsory core competencies should form part of registration requirements for nursing, allied health and aged care staff.
- Regarding “Improving the capacity and capability of aged care providers to deliver quality dementia care including mandatory training on managing BPSD”, Dementia Australia recommends that a focus on person-centred care and effective engagement with people living with dementia will reduce the level of changed behaviour if done well.
- There is a need to have a requirement for providers to have dementia practice leaders – we recommend including in the longer-term priorities that every aged care provider has at least one dementia practice leader.
- Career pathways which promote dementia care as a specialisation are required.
- It is essential that organisational cultures support quality dementia care.
- More training in cultural diversity and use of existing tools and apps to assist with cultural competency.
- Support for specialist, dementia-trained palliative care nurses.

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

Improving dementia data and maximising the impact of dementia research and innovation will contribute to a more detailed understanding of the prevalence and consequences of dementia as well as counter misinformation.

Feedback received about the detail of this objective included comment that measurements against the proposed actions may be read as inconsistent and at times vague. For example, it is not clear as to why some actions have a percentage (measurable increase) and others simply state 'increase'. It is also unclear from the consultation paper how the increase percentage has been determined.

Dementia Australia makes the following recommendations:

- Administration of more frequent National Aboriginal and Torres Strait Islander Health Surveys (NATSIHSs), and the inclusion of dementia as a long-term condition in future NATSIHS.
- Collaboration with the AIHW to better understand the data gaps and opportunities and to ensure they are built into other aged care data systems.
- Accessibility to data should be considered to ensure data users can easily interpret the data as well as considering informed consent for people living with dementia.
- Monitoring benchmark data to assist in evaluating industry gaps and opportunities for improvement.
- Working to reduce barriers in obtaining data from CALD groups, Aboriginal and Torres Strait Islander people and LGBTIQA+ groups should also be a priority to ensure these groups are represented accurately in dementia data and research.
- Supporting programs and systems that facilitate the interface between consumers and researchers and make participating in clinical trials easier and more streamlined and review current mechanisms.
- Involve people with lived experience in more research projects (e.g. setting targets).
- Data collection for younger onset dementia and childhood dementia cohorts

Conclusion

Dementia Australia is grateful for the opportunity to make a submission to this important consultation in relation to the draft National Dementia Action Plan. We are happy to meet with the Department to discuss this feedback and collaborate on next steps which can be clearly communicated to the sector and to people with dementia, families and carers. It is important that a clear timeline of activities and next steps is mapped out to ensure an ongoing focus on inclusive consultation.

Executive Director of Policy and Advocacy, Dr Kaele Stokes or the Dementia Australia Policy team can be contacted on the details below.

Kaele Stokes

Executive Director, Advocacy & Research

Dementia Australia

| M: *0418 543 600*

Email *Kaele.Stokes@dementia.org.au*

Dementia Australia Policy team: policyteam@dementia.org.au

---

[i] Australian Institute of Health and Welfare (2022) Dementia in Australia, https://www.aihw.gov.au/reports/dementia/dementia-in-aus/contents/summary

[ii] [ii] World Health Organisation, (2017) Global action plan on the public health response to dementia 2017-2025, https://www.who.int/publications/i/item/global-action-plan-on-the-public-health-response-to-dementia-2017---2025

[iii] We now use the figure of over 400,000 people living with dementia living with all forms of dementia which reflects the most recent, 2022 AIHW statistics: Australian Institute of Health and Welfare (2022) Dementia in Australia, https://www.aihw.gov.au/reports/dementia/dementia-in-aus/contents/summary

[iv] 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/

[v] Dementia Friends & Dementia Friendly Communities Program (2019). Exploratory report, Kantar Consultants.