Australian Dementia Network Registry

2022 Annual Report

Australian Dementia Network
REGISTRY. CLINICS. TRIALS.

MONASH University

This publication was produced by the Australian Dementia Network (ADNeT) Registry.

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Foreword

Dementia presents Australia with significant and growing challenges. In 2022, dementia became the leading cause of disability in Australians aged 65 years and older and remains the second leading cause of death overall. Over 400,000 Australians are estimated to be living with dementia, and nearly as many are engaged in caregiving activities. As the number of people living with dementia increases, the impacts on health and social care systems, including associated costs, grow.

Apart from system-wide effects, what cannot be overlooked is the impact of dementia on the person living with the disease, as well as their families. Dementia is a clinical syndrome that leads to changes in cognition, psychological well-being, daily functioning and quality of life, and can have a significant impact on the well-being of carers. Treatments for the many underlying pathological causes of dementia are yet to become available. Yet, high-quality clinical and social care can have a huge impact on the experience of, and outcomes for, people living with dementia and their families.

The ADNeT Registry is a clinical quality registry designed to measure the quality of clinical care that Australians receive at the time of diagnosis of dementia, or mild cognitive impairment. Data collected from clinical sites are benchmarked and integrated with experience and outcome data reported by participants and carers. At the individual practice level, these data help providers understand their practice profile in comparison to others and highlight discrepancies in the quality of clinical care.

At a system level, the ADNeT Registry provides high-quality clinical data on dementia that augments administrative data. Taken together, the ADNeT Registry helps unite clinical services involved in dementia diagnosis in Australia and provides the first concerted effort to monitor and improve the quality of care in this incredibly important area.

Whilst dementia presents us with significant challenges, recent developments present us with great hope. There are many exciting findings from clinical trials of addressing modifiable risk factors, of newer and cost-effective biomarkers, and of medications that may alter disease progression. The ADNeT Registry is well positioned to measure the uptake and real-world outcomes of such new developments as they are integrated into practice.

Establishing a clinical quality registry for a condition as complex as dementia has been a challenge, further amplified by the ADNeT Registry's first three years of operation occurring during a global pandemic. The ADNeT Registry team are to be applauded for their tireless commitment to overcoming so many challenges, with kindness and enthusiasm displayed at every step of the journey. We hope you will enjoy reading the ADNeT Registry 2022 Annual Report.

Dr Stephanie Ward

Steering Committee Co-Chair & Clinical Lead University of New South Wales, The Prince of Wales Hospital & Monash University

Professor Henry Brodaty

Steering Committee Co-Chair University of New South Wales

Professor Susannah Ahern

Academic Lead Monash University

As Director of the Australian Dementia Network (ADNeT), which brings together researchers and clinicians to advance dementia diagnosis, prevention, treatment and care, I am pleased to present the second annual report of the ADNeT Registry for dementia and mild cognitive impairment (MCI).

By systematically collecting, analysing and reporting on health data, the ADNeT Registry benchmarks the quality of care and management of persons newly diagnosed with dementia or MCI thereby driving continuous improvement. Looking forward, the ADNeT Registry will also be essential to monitor the uptake and impact of new innovations in dementia diagnosis and treatment. The ADNeT Registry will provide invaluable data to drive healthcare policy, inform healthcare providers, advance medical knowledge, and ensure that Australians get the best outcome from emerging treatments.

This is an exciting time for dementia diagnosis and treatment. Newly approved disease-modifying drugs in combination with new blood tests for Alzheimer's disease give great hope that with early and accurate diagnosis we will be able to slow cognitive decline and substantially delay or reduce the prevalence of dementia. As these new tests and drugs are introduced, the ADNeT Registry will grow in size and importance to Australian researchers, clinicians and consumers as it tracks real-world data on their effectiveness and safety.

The ADNeT Registry also has an important role in supporting other ADNeT initiatives. It connects interested participants to ADNeT Screening and Trials and researchers conducting trials, and this has given Australians unprecedented access to the latest disease-modifying therapies as they emerge. The ADNeT Registry will provide objective evidence of the impact and reach of new ADNeT Memory Clinic initiatives in diagnostics, treatments and post diagnostic care. It also provides data that underpins memory clinic accreditation. Participation in the ADNeT Registry is an important indicator of Memory Clinic quality.

We need to commend those who are maintaining and developing the ADNeT Registry and acknowledge its valuable synergy with other ADNeT initiatives to advance dementia diagnosis, prevention, treatment and care.

I am sure you will benefit from the information presented in this ADNeT Registry Annual Report.

Professor Christopher Rowe
Director, Australian Dementia Network

2020–2022 Key Findings

Registry Participation

2369 Participants

55 Total sites

27% Regional sites

44% Private sites

Key Clinical Quality Indicators

- **63%** First appointment within 90 days of referral
- **96%** Core blood tests undertaken
- **99%** Cognitive assessments completed
- **93%** Structural neuroimaging completed
- **98%** Capacity to undertake personal and instrumental activities of daily living assessed

Diagnosis

32% MCI

68% Dementia

Dementia subtypes:

- Alzheimer's disease only: **53%**
- Vascular dementia only: **10%**
- Mixed Alzheimer's & Vascular dementia: **23%**
- Others: **14%**

Demographics

MCI	Demographics	Dementia
77	Median age (years)	79
53%	Female	54%
32%	Born overseas	39%
83%	Completed secondary or higher education	78%
27%	Living alone	27%

This infographic pertains to data submitted to the ADNeT Registry from commencement of data collection on 10th March 2020, to 31st December 2022. For more details, please refer to relevant sections within the Annual Report where data are stratified by year to provide more in-depth information.

Cognitive Functioning[1]

MCI		Dementia
27	Mini-Mental State Exam (MMSE)	22
23	Montreal Cognitive Assessment (MoCA)	18
25	Rowland Universal Dementia Assessment Scale (RUDAS)	19

Daily Functioning[2]

MCI		Dementia
95%	Independent in personal activities of daily living	75%
74%	Independent in instrumental activities of daily living	25%
66%	Currently driving	32%

Self-reported Well-being

Participants

Good = 62%
Fair = 32%
Poor = 6%

Carers

Good = 88%
Fair = 9%
Poor = 3%

Experience with Diagnostic Services

Participants

Good = 88%
Fair = 9%
Poor = 3%

Carers

Good = 89%
Fair = 10%
Poor = 1%

[1]These are median scores of the MMSE, MoCA and RUDAS, which range from 0 to 30 with higher scores indicating high level of cognitive functioning.
[2]Level of daily functioning may be impacted by factors other than as direct results of dementia and MCI, such as physical and/or sensory impairments. Personal activities of daily living include activities such as dressing, showering and toileting. Instrumental activities of daily living include activities such as cooking, laundry and managing finances.

What is Dementia and MCI?

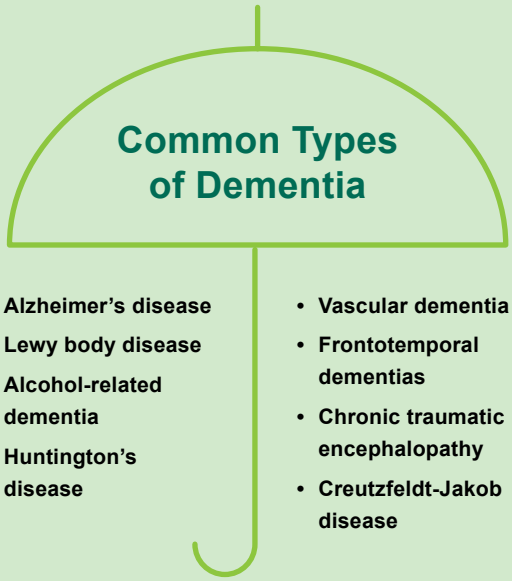
What is dementia?

Dementia is not a single disease; rather, it is a clinical syndrome that covers a wide range of conditions that are caused by abnormal changes to the brain[1-3]. These changes lead to impairment in cognition (e.g., memory, thinking, reasoning) and function sufficient to interfere with daily activities[1-3].

Early signs of dementia can be subtle and vary from person to person[2-4]. Common symptoms of dementia include memory loss, word finding difficulties, impaired reasoning or judgement, problems with language, difficulty performing everyday tasks, and changes in mood and personality[2-4]. There are over 100 types of dementia and it is common that more than one type is present[2-4]. Figure 1 lists the more common types of dementia[2-4].

Although age is the strongest known risk factor for dementia, dementia is not a normal part of ageing and can also affect people aged under 65 years (referred to as "young onset dementia")[2-4]. It is estimated that young onset dementia accounts for approximately 7% of dementia cases in Australia in 2022[3,4].

Figure 1 Common Types of Dementia



What is mild cognitive impairment (MCI)?

Some people may experience more memory or thinking problems than someone similar to their age, but are able to carry out normal daily activities[5, 6]. This condition is called mild cognitive impairment (MCI)[5, 6].

People with MCI are at a greater risk of developing dementia, especially Alzheimer's disease for those with amnestic MCI (in which memory is most affected)[5, 6]. However, not everyone with MCI develops dementia, and in many cases, the symptoms of MCI may stay the same or even improve over time[5, 6].

How are dementia and MCI diagnosed?

There is no single test to diagnose dementia or MCI[2-4]. Doctors diagnose dementia, dementia subtypes, and MCI based on:

- comprehensive history taking from the person, as well as from someone who knows them well
- a physical examination
- an assessment of cognitive function, mental state, and capacity to undertake activities of daily living
- review of medications
- laboratory tests (e.g., blood tests)
- neuroimaging (e.g., computed tomography [CT]) that assesses the structure, and sometimes function, of the brain[7]

Biomarkers (e.g., blood biomarkers) are used in research settings, but are not yet available for routine clinical practice.

How are dementia and MCI treated and managed?

Good clinical care starts with clear communication and explanation about the diagnosis[2,4,7,8]. It continues by linking people living with dementia, as well as their carers, with post-diagnostic programs[2,4,7,8]. A number of lifestyle modifications may attenuate risk of dementia for people with MCI, and rate of decline for those with dementia[2,4,8] Services, support and information can help people and family members adjust to the diagnosis and plan for the future[2,4,7,8]. Medications, such as acetylcholinesterase inhibitors, may help with symptoms of dementia[2,4,7,8,] whilst a number of disease-modifying drugs (e.g., the anti-amyloid monoclonal antibody lecanemab) have been developed or are at various stages of clinical trials[9].

Introduction

Background

Dementia is one of the greatest and growing challenges for health and social services in Australia and globally[2, 3]. In 2022, more than 400,000 Australians were estimated to be living with dementia[3]. This number is projected to more than double by 2060[3]. Dementia has become the second leading cause of death in Australia since 2013, up from fourth in 2006[3,10]. For women, it is the leading cause of death[3], and provisional data indicate that dementia is likely to become the leading cause of death for all Australians within the next few years[4]. Dementia became the second leading cause of disease burden in Australia in 2022, up from fourth in 2018[3,11]. For women and for Australians aged 65 years and over, it is now the leading cause of disease burden[3].

Dementia has a profound life-changing impact, not only on the person living with dementia, but also on their families, carers, friends, and society at large[3]. In 2022, it was estimated that between 137,600 and 354,200 people provide ongoing, unpaid care to someone living with dementia, with half providing on average more than 60 hours of care on a weekly basis[3]. At a societal level, an estimated $3.0 billion of health and aged care spending was directly attributed to dementia in 2018-2019, including $1.7 billion (56%) on residential aged care services, $596 million (20%) on community based aged care services, and $383 million (13%) on hospital services[3].

The quality of clinical care can influence the progression of dementia and the lived experience of people with dementia, their carers, and families[12], yet to date, there has been a lack of robust data to help understand variations in the quality of dementia care and inform quality improvement initiatives[13]. A clinical quality registry (CQR) can bridge this systemic gap by providing high-quality data on the processes and outcomes of clinical care provided to people living with dementia[14]. In 2016, the Australian Commission on Safety and Quality in Heath Care prioritised dementia as a clinical domain for CQR development[14]. Against this background, the Australian Dementia Network (ADNeT) Registry has been established to systematically collect data on the quality and outcomes of clinical care[15].

Vision and aims

The ADNeT Registry is a CQR for people with dementia and mild cognitive impairment (MCI)[15]. It captures data on people newly diagnosed with dementia or MCI, as diagnosis is the first step in managing these conditions. Such a focus enables the registry to follow up with participants after their diagnosis, to gain a better understanding of long-term outcomes and post-diagnostic care.

The ultimate vision of the registry is to register the entire population of Australians newly diagnosed with either dementia or MCI, and in doing so, systematically drive continuous improvement in the quality and outcomes of clinical care[15].

- ***Primary aim:*** to collect and analyse data to monitor and enhance the quality and outcomes of clinical care for people diagnosed with either dementia or MCI and their carers
- ***Secondary aim:*** to assist further study into the risk factors for, and the progression of, dementia and MCI in Australia and to facilitate the recruitment of interested participants, where appropriate, into research studies

Funding

The ADNeT is a multi-institutional, Australia-wide consortium of dementia researchers and clinicians. The Network receives an allocation of the Boosting Dementia Research Initiative grant from the National Health and Medical Research Council's National Institute for Dementia Research, as well as funding from philanthropic organisations.

The ADNeT Registry is funded through the broader ADNeT initiative. In 2022, the registry also secured additional funding from biotechnology companies Biogen and Roche to support specific project activities, such as the development of a customised clinical research platform.

Governance

The ADNeT Registry has been developed and implemented in accordance with the Framework for Australian Clinical Quality Registries (2014) and the Operating Principles and Technical Standards for Clinical Quality Registries (2008) that were developed by the Australian Commission on Safety and Quality in Heath Care[16,17]. The registry is governed by a Steering Committee which comprises representatives from key stakeholder groups, including clinicians, participating sites, people with lived experience of dementia and their carers, peak bodies, registry experts and researchers (refer to Appendix 1 for membership). The Steering Committee provides governance oversight and strategic direction and ensures that key deliverables are met on time and on budget. The Steering Committee meets formally on a quarterly basis and reports to the ADNeT Management Committee as part of the ADNeT governance structure.

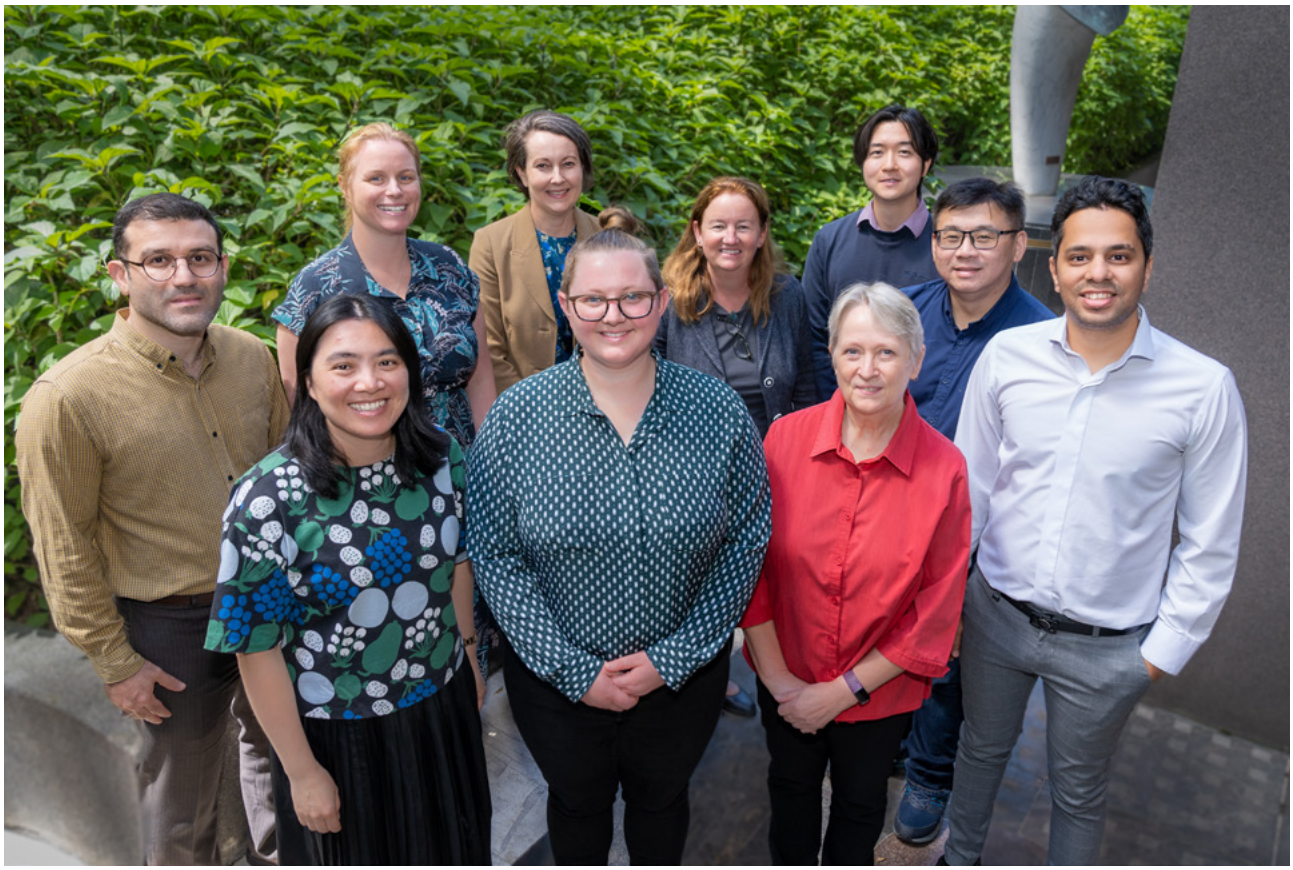
The ADNeT Registry is managed by the School of Public Health and Preventive Medicine, Monash University. A Management Committee comprising the Clinical Lead, the Academic Lead, and Monash University staff, has been established to oversee day-to-day operation of the registry. The Management Committee meets regularly and reports to the ADNeT Registry Steering Committee.

Additionally, a Clinician Management Committee was established in 2023 to provide clinical advice and guidance to the ADNeT Registry Steering Committee and to support engagement with participating sites.

Achievements

Figure 2 summarises the key milestones achieved by the ADNeT Registry from its establishment in 2019 to December 2022.

This is the second Annual Report released by the ADNeT Registry. It pertains primarily to 2022 data (i.e., data submitted to the registry between 1st January to 31st December 2022), but also includes previously collected data to allow comparison across years.



ADNeT Registry team at Monash University (from left to right)
First row: Xiaoping Lin, Jennifer Richardson, Cheryl Grant, Mohammad Amin Honardoost
Second row: Ahmad Reza Pourghaderi, Kasey Wallis, Susannah Ahern, Claudia Lassetter, Alan Tsui, John Liman

Figure 2 Key Milestones

2018

ADNeT funding awarded (Jul)

2019

First Steering Committee meeting (Apr)

Novel and inclusive recruitment model developed (Sep)

Minimum dataset and clinical quality indicators endorsed (Dec)

2020

First participating site enters data (Mar)

Co-designed participant and carer surveys (Dec)

2021

First participant and carer surveys received (Mar)

500 participants (Oct)

First benchmarked site reports (Dec)

40 sites across five states (Dec)

Industry funding secured (Dec)

2022

1000 participants (Apr)

First Annual Report (Jul)

Registry documents translated into other languages (Oct)

2000 participants (Nov)

55 sites across six states (Dec)

Methodology

Site recruitment

Site participation is voluntary. Potential sites are identified by the registry team through promotional activities, the ADNeT Memory Clinics network (another component of the broader ADNeT initiative), and word of mouth. Ethics and governance authorisation are obtained for each site prior to participation, assisted by the registry team.

Participating sites are specialised clinical services where dementia and MCI are diagnosed. These include multi-disciplinary memory and cognitive disorders clinics, other specialised dementia and MCI diagnostic services, aged care outreach services, as well as single-discipline medical practitioners (e.g., geriatricians, neurologists, and psychiatrists). Sites represent both public and private services and include clinics that deliver some or all of their services via telehealth.

Participant recruitment

Eligible participants are individuals aged 18 years and over who receive a new diagnosis of either dementia or MCI at a participating site. After a participant is deemed eligible by the participating site, they are recruited using an opt-out approach. A participant may be recruited using a waiver of consent in certain circumstances (e.g., the participant has impaired decision-making capacity and does not have a person who can make decisions on their behalf). The ADNeT Registry has ethical approval from the Alfred Hospital Human Research Ethics Committee under the National Mutual Acceptance Scheme (Project Number: 44037).

Data collection

The sites enter data for eligible participants at the time of diagnosis, based on the ADNeT Registry Minimum Data Set. These data include personal identifiers, demographics, and relevant clinical details pertaining to diagnostic work-up, diagnosis, cognition, function, comorbidities, and aspects of initial management (see Table 1 and Appendix 2). Please refer to Appendix 3 for information on the completeness of these data.

After a participant is recruited into the registry, where appropriate, data on health and well-being and the experience of clinical care at the participating site are collected via surveys completed by the participants and their carers (where identified). These surveys were developed by a working group comprising representatives of people with lived experience, carers, peak bodies, clinicians, and researchers (see Appendix 1 for membership). Feedback from people with lived experience of dementia and MCI and their carers (via consultation facilitated by Dementia Australia) was incorporated into these surveys.

When the number of participants is sufficient, the ADNeT Registry will conduct data linkage to access information that is routinely collected by government health and related services, such as Medicare and hospital and aged care information. These data will help us better understand long-term health outcomes and post-diagnostic care among people living with dementia and MCI.

Table 1 Data Collection Information

Source	Collection Time	Category	Examples of Data Elements
Participating sites	*At diagnosis*	*Personal identifiers*	*First name, Last name, Date of birth, Sex*
		Information to facilitate recruitment	*Capacity to opt out, Person responsible (if applicable), Identification of carer*
		Demographics	*Country of birth, Aboriginal and/or Torres Strait Islander, Preferred spoken language, Highest level of education, Living arrangement, Employment status*
		Diagnosis and clinical data	*Date of referral, Date of first appointment, Diagnosis date, Diagnosis and subtype, Diagnostic investigations, Comorbidities, Cognitive assessments and scores, Independence in activities of daily living, Number of medications, Falls*
Participants and carers (where identified)	*Post recruitment*	*Participant and carer-reported outcomes*	*Health, Well-being*
		Participant and carer-experiences	*Receiving adequate information about diagnosis, Involvement in decision making, Opportunity to ask questions, Overall experience of service*

Lived experience involvement

The ADNeT Registry is committed to the involvement of people with lived experience of dementia and MCI, their carers, and families in its strategic direction and operation. Lived experience involvement (also referred to as consumer involvement) is a key recommendation in the Australian Government's National Strategy for Clinical Quality Registries and Virtual Registries (the National Strategy)[18]. Specifically, the National Strategy highlights the importance of co-design with patients, their carers, and families through:

- Building capacity in engaging patients, their carers, families, and consumer organisations in the co-design of data requirements that measure outcomes that matter most to them and reflect their lived experience
- Strengthening patient participation and representation in governance activities

The ADNeT Registry promotes lived experience involvement through:

- Collaboration with Dementia Australia, the national peak body for Australians living with dementia, their carers, and families
- Representation of people living with dementia and of people who are carers on the Steering Committee
- Co-designing participant and carer surveys with people living with dementia, as well as with carers
- Consultation with people living with dementia and MCI and with carers on the language and terminology used by the ADNeT Registry in key documents (e.g., postcard, invitation documents, and surveys)

To date, more than 50 Dementia Advocates (i.e., people living with dementia or MCI and their carers) have made valuable contributions to the ADNeT Registry. In January 2022, the Registry team co-hosted a virtual event with Dementia Australia to acknowledge and celebrate these important contributions, and affirm the roles of Dementia Advocates in helping the ADNeT Registry incorporate the perspectives of people with lived experience. A highlight of the gathering was listening to four Dementia Advocates (Scott Cooper, Jenny Fitzpatrick, Ann Pietsch, Lyntara Quirke) who shared their experiences of working with the registry team.

To encourage participation among people from Culturally and Linguistically Diverse (CALD) backgrounds, in 2022, the ADNeT Registry embarked on a project to translate registry invitation letters and the Participant Information Sheet into Arabic, Chinese, Greek and Italian. According to the Australian Bureau of Statistics' most recent census data[19], these are the top languages spoken by older Australians, the age group most at risk of dementia and MCI[18]. With assistance from Dementia Australia and the National Ageing Research Institute, the ADNeT Registry engaged Dementia Advocates and community representatives from each of the four communities to review the translated documents to ensure their ease of understanding and cultural appropriateness.

Being a part of the Steering Committee allowed me to feel heard and valued. Following a dementia diagnosis, many become invisible and fear becoming just another statistic. The ADNeT Registry Steering Committee always showed genuine respect and interest and valued input from me as a person with lived experience in the community.

– Person living with dementia

What have we done since 2021? Well, ADNeT Lived Experience Representatives may truly have 'cut their teeth' this year. Objectives progressed and came to life, sometimes with ease, sometimes with difficulty. We probably thought we didn't want the difficulty, but no! It turns out, the difficulties are where new realisations and greater understandings lie. Our progress in 2022 gave me confidence that ADNeT Registry's skilled curation of the Lived Experience Representatives Group will authenticate and empower registry findings into the future.

– Carer of a person living with dementia

The ADNeT Registry Steering Committee continues to show a commitment to involving people living with dementia. It is empowering for me to be able to contribute and represent and advocate for people like me, and for people with mild cognitive impairment. I feel respected and I am supported to contribute at meetings by the committee, but most of all, I am encouraged that the registry continues to grow and collect and use the data for the overall better understanding and care of people living with dementia.

– Person living with dementia

Registry Participation

Site participation

The number of participating sites increased from 40 in 2021 to 55 in 2022 (see Figure 3). Of these sites, 15 (27%) are in regional areas and 24 (44%) are private clinics (see Table 2). A further four sites have received governance authorisation and are anticipated to commence data collection in 2023. Please refer to Appendix 4 for a list of ADNeT Registry sites.

Figure 3 Site Recruitment

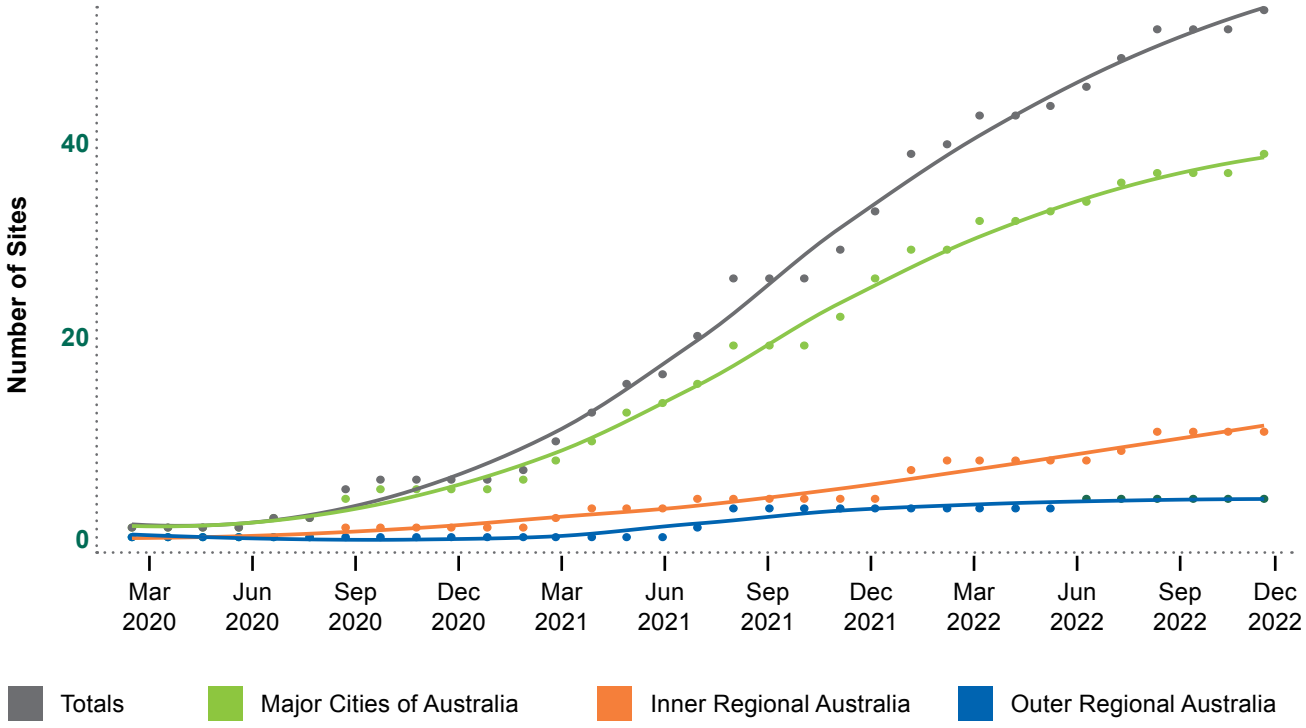


Table 2 Characteristics of Participating Sites

	Total	New South Wales	Queensland	South Australia	Tasmania	Victoria	Western Australia
Total	55	15	15	6	4	14	1
Location[1]							
Major city	40	11	11	6	0	11	1
Inner regional	11	4	0	0	4	3	0
Outer regional	4	0	4	0	0	0	0
Organisation type							
Public	31	10	8	5	0	8	0
Private[2]	24	5	7	1	4	6	1

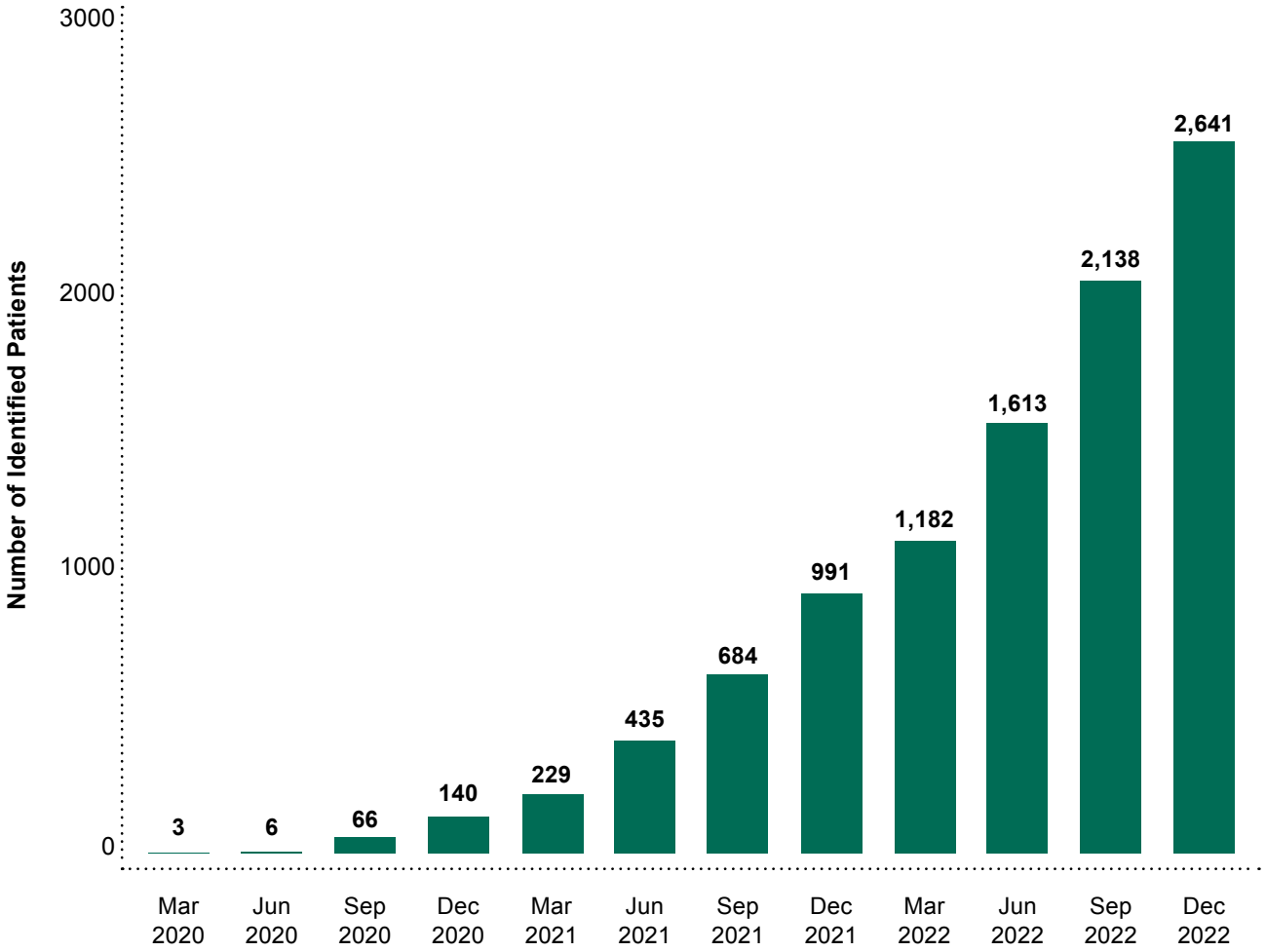
[1]Location categorised using Australian Statistical Geography Standard (ASGS) Edition 3 Remoteness Structure 2021

[2]Private sites include solo practitioners, group practices, university-based research clinics, and outpatient clinics within private hospitals

Participant recruitment outcome

The number of participants newly identified as eligible has almost doubled from 851 in 2021 to 1,650 in 2022. As a result, the total number of eligible participants reached 2,641 in 2022 (see Figure 4). As relatively few participants were identified in 2020, participants recruited in 2020 were combined with those recruited in 2021 to enable more meaningful comparison across years.

Figure 4 Participant Recruitment



Of the 1,650 newly identified participants in 2022, 146 (9%) elected to opt out, representing an improvement from the 13% opt-out rate in previous years (see Table 3). As a result, the total number of participants recruited into the registry has nearly tripled, increasing from 865 in 2021 to 2,369 in 2022.

Table 3 Recruitment Outcome

Recruitment Outcome (%)	2020-2021 (n = 991)	2022 (n = 1,650)
Recruited	87	91
Opted out	13	9

Opt-out information

Of the 146 newly-identified participants who elected to opt out, 57% did so during the four-week opt-out period, and 38% did so at the time of diagnosis. Compared to previous years, there was an increase in the percentage of participants who elected to opt out at the time of diagnosis in 2022 (22% vs 38%) (see Table 4). The ADNeT Registry has been working with sites that have a relatively high percentage of participants requesting to opt out at diagnosis to explore strategies to encourage registry participation.

Table 4 Opt-out Information

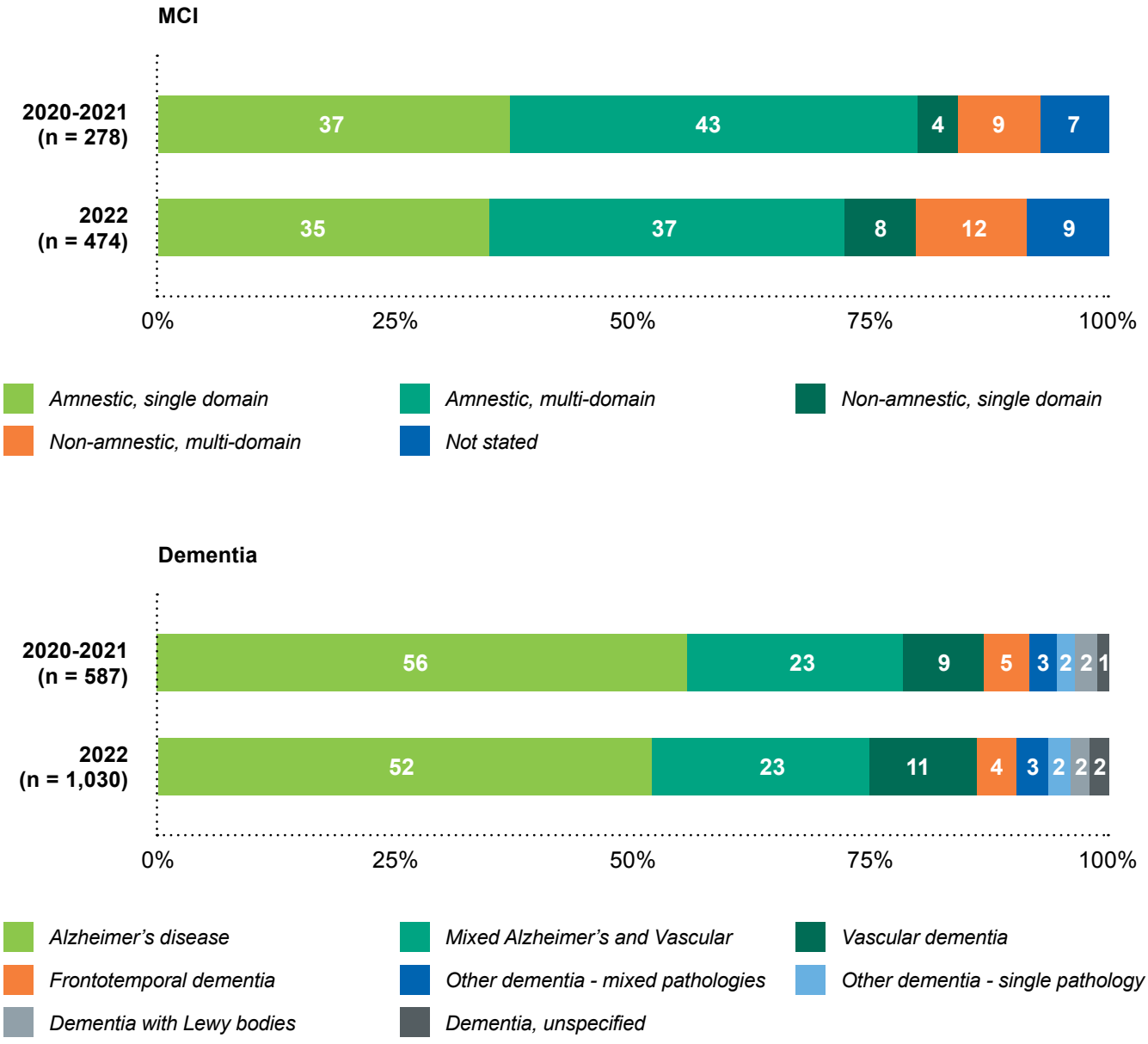
Opt-out information (%)	2020-2021 (n = 126)	2022 (n = 146)
Opt-out time point		
At the time of diagnosis	22	38
During opt-out period	63	57
Post opt-out period	15	5
Person making opt-out request[1]		
Participant themselves	49	38
Family or friend	51	62

[1]Information not available for participants who elected to opt out at diagnosis

Diagnostic Information

Of the 1,504 participants recruited in 2022, two thirds (n = 1,030, 68%) were diagnosed with dementia and one third (n = 474, 32%) with MCI. Alzheimer's disease remained the most common type of dementia, followed by mixed Alzheimer's and vascular dementia (see Figure 5).

Figure 5 Diagnostic Information



Demographic Information

Participants diagnosed with dementia were older than those diagnosed with MCI (see Table 5). Compared to participants with MCI, those with dementia were less likely to be born in Australia or have English as their preferred language. As national data regarding people living with dementia from CALD backgrounds in Australia are currently limited[3], the ADNeT Registry plans to conduct further analysis on this priority group to improve understanding of their unique care needs.

Participants diagnosed with dementia were less likely to have tertiary education and more likely to have retired from work compared to those diagnosed with MCI. There was no difference in residential settings and living arrangements between the two groups, with most participants living at home and one quarter living alone.

Table 5 Demographic Information

Variable	MCI		Dementia	
	2020-2021 (n = 278)	2022 (n = 474)	2020-2021 (n = 587)	2022 (n = 1,030)
Age in years (median)	**76**	**77**	**80**	**79**
Female (%)[1]	**52**	**54**	**56**	**52**
Aboriginal and/or Torres Strait Islander (%)[1]	**2**	**1**	**1**	**1**
Country of birth (%)[1,2]				
Australia	66	66	58	57
England	7	7	7	8
Italy	3	3	4	5
Greece	2	2	4	3
Other	20	20	24	23
Preferred spoken language (%)[1,2]				
English	91	92	86	87
Greek	1	1	4	3
Italian	1	2	1	3
Spanish	1	1	1	1
Chinese (Cantonese and Mandarin)	1	1	1	0
Arabic	0	0	1	0
Other	3	3	4	5
Highest education level (%)[1,2]				
Tertiary education or higher	25	27	23	21
Secondary education	62	55	59	54
Primary education or less	8	8	12	12
Labour force status (%)[1,2]				
Retired/not in labour force	89	85	96	93
Employed	10	9	3	3
Residential setting (%)[1,2]				
Own home	94	89	90	85
Retirement village	4	5	5	6
Residential aged care facility	1	1	2	3
Other	1	2	2	3
Living arrangement (%)[1,2,3]				
Living with family or others	71	70	73	73
Living alone	25	28	26	27

[1]Participants with missing responses are included in the denominator. Please refer to Appendix 3 for data completeness information

[2]Percentages might not add up to 100 due to rounding and missing responses

[3]Information is only collected for participants living in private residence or retirement village

Clinical Information

The ADNeT Registry seeks to measure aspects of clinical practice that define a high-quality approach to diagnosis and management of dementia and MCI. The Australian Clinical Practice Guidelines and Principles of Care for People with Dementia (the Guidelines) recommends making a diagnosis of dementia only after a comprehensive assessment[7], which includes:

- comprehensive history taking from the person, as well as from someone who knows them well
- a physical examination
- an assessment of cognitive function, mental state, and capacity to undertake daily activities of living
- review of medications
- laboratory tests (e.g., blood tests)
- brain imaging (e.g., computed tomography [CT]) as required

Cognitive and daily functioning

The ADNeT Registry records the scores of four cognitive assessments to help understand the levels of cognitive functioning at the time of diagnosis. These four assessments are:

- Mini-Mental State Exam (MMSE)
- Montreal Cognitive Assessment (MoCA)
- Kimberley Indigenous Cognitive Assessment tool (KICA)
- Rowland Universal Dementia Assessment Scale (RUDAS)

MMSE and MoCA are two commonly used cognitive assessments. KICA is recommended for use with Aboriginal and Torres Strait Islander peoples and RUDAS is recommended for use with people from CALD backgrounds[7]. Of these cognitive assessments, the MMSE was most commonly reported (see Table 6), and KICA was reported for only one participant. Compared to previous years, the use of MoCA and RUDAS increased in 2022, whereas the use of MMSE reduced.

Table 6 Completed Cognitive Assessments

Cognitive Assessment (%)	MCI		Dementia	
	2020-2021 (n = 278)	2022 (n = 474)	2020-2021 (n = 587)	2022 (n = 1,030)
MMSE[1]	70	62	72	68
MoCA[2]	24	26	16	20
RUDAS[3]	6	13	11	15

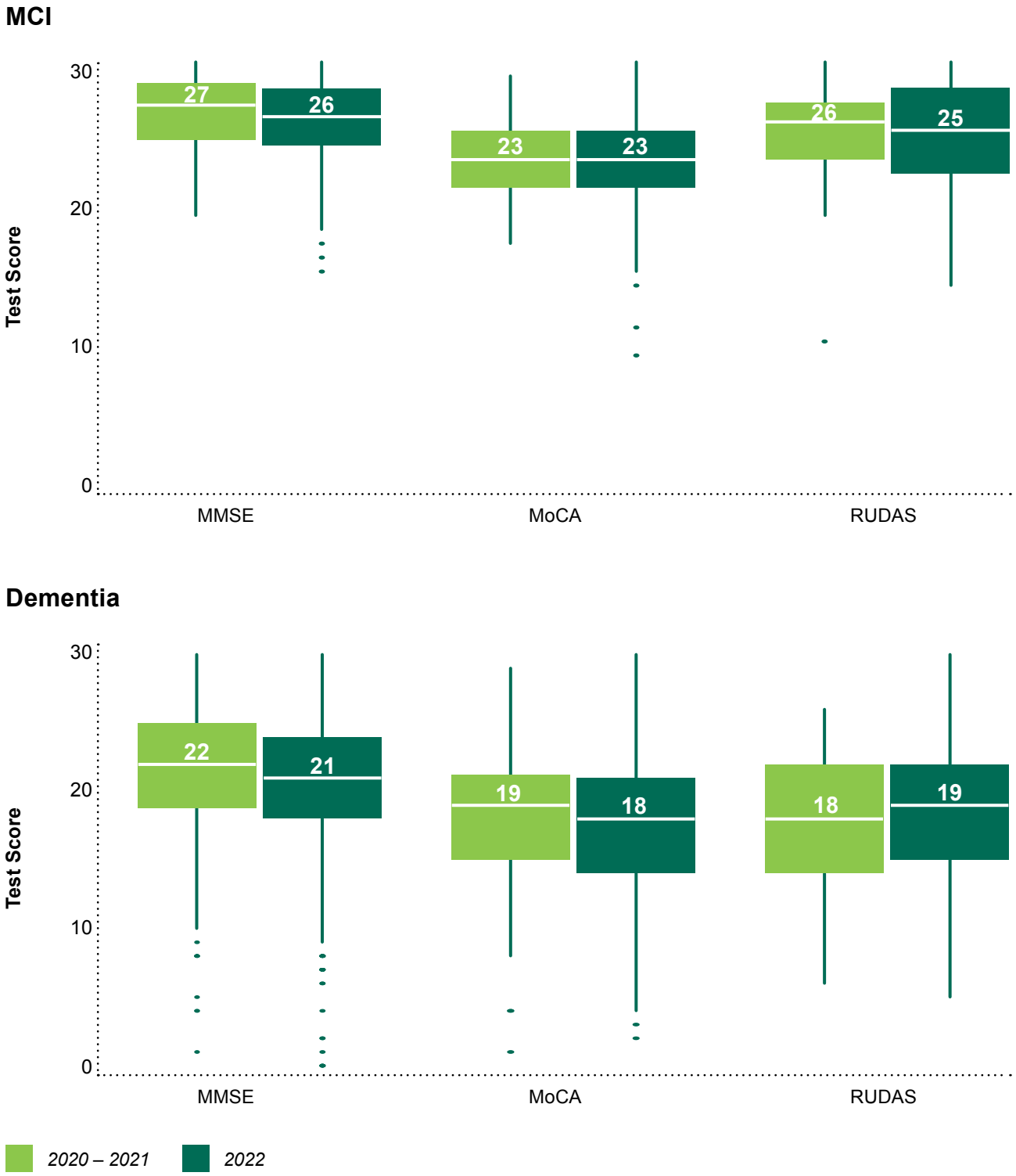
[1]MMSE: Mini-Mental State Exam

[2]MoCA: Montreal Cognitive Assessment

[3]RUDAS: Rowland Universal Dementia Assessment Scale

As expected, participants with dementia had lower scores in all three cognitive assessments than participants with MCI (see Figure 6).

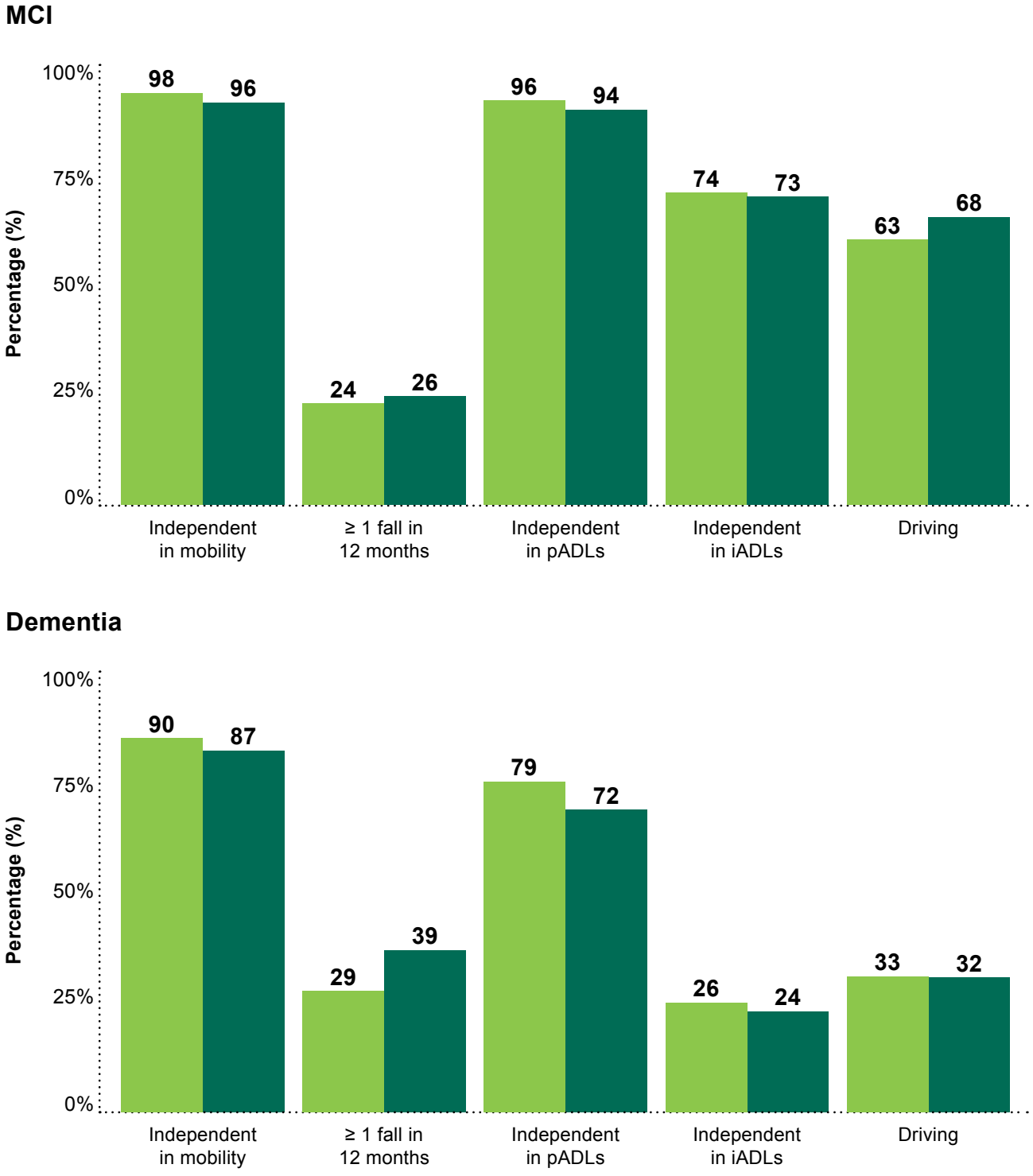
Figure 6 Boxplots of Cognitive Assessment Scores



The scores of MMSE, MoCA, and RUDAS range from 0 to 30, with higher scores indicating higher levels of cognitive functioning. Box plots are a visual representation of how the values in the data are spread out. It indicates five number summaries: 1) the minimum (shown at the end of the bottom whisker), 2) the first quartile (shown at the bottom edge of the box, 25% of the values in the data fall below the first quartile value), 3) the median (indicated by a line in the centre of the box and the numbers in the box), 4) the third quartile (shown at the top edge of the box, 75% of the values fall below the third quartile value) and 5) the maximum (shown at the end of the top whisker). Any data points that are located outside the whiskers of the box plot are considered outliers.

At the time of an MCI or dementia diagnosis, most participants were independent in their personal or basic activities of daily living. Participants with MCI had higher levels of independence overall than those with dementia (see Figure 7). Some participants with MCI were, however, not independent in activities of daily living, and this may reflect the impact of physical and/or sensory impairments. Approximately one third of participants with dementia were recorded as driving at the time of diagnosis, and 39% had experienced at least one fall in the 12 months preceding their diagnosis.

Figure 7 Daily Functioning



Comorbidities

Hypertension was the most common comorbidity, which was present in over half of all participants. This is followed by cardiovascular disease, which was present in over one third of all participants (see Table 7). Nearly 60% of the participants were prescribed five or more medications at the time of diagnosis.

Table 7 Comorbidity Information

Comorbidity (%)[1]	MCI		Dementia	
	2020-2021 (n = 278)	2022 (n = 474)	2020-2021 (n = 587)	2022 (n = 1,030)
Diabetes	21	21	22	22
Hypertension	60	55	62	57
Cardiovascular disease	37	36	39	35
Stroke	13	11	13	13
Polypharmacy[2]	57	57	58	54

[1]Participants with missing responses are included in the denominator. Please refer to Appendix 3 for data completeness information

[2]Defined as having five or more prescribed medications

Diagnostic Process and Initial Management

Diagnostic time intervals

Timely diagnosis is recognised as a key marker for good quality clinical care[7]. There can be many barriers to timely diagnosis, one of which is the wait time for an appointment with a memory and cognition clinic. In 2022, the median wait time from referral to first appointment was:

- 62 days (or 2.1 months) for participants with dementia
- 74 days (or 2.5 months) for participants with MCI

On average, participants waited 124 days (or more than four months) from referral for a diagnosis of dementia or MCI.

Table 8 Diagnostic Time Intervals

Median Wait Time (Days)[1]	MCI		Dementia	
	2020-2021 (n = 278)	2022 (n = 474)	2020-2021 (n = 587)	2022 (n = 1,030)
Referral to first appointment	81	74	70	62
First appointment to diagnosis	0[2]	29	42	35
Referral to diagnosis	122	139	133	117

[1]Excluded participants with a previous MCI diagnosis (n = 43 in 2021 and 140 in 2022) and missing values. Please refer to Appendix 3 for data completeness information

[2]A median of 0 day from first appointment to diagnosis indicated that in 2020-2021, of participants diagnosed with MCI, at least 50% received this diagnosis at their first appointment with the memory and cognition clinic

Diagnostic investigations

In 2022, most participants had cognitive assessments, functional assessments, core blood tests and structural neuroimaging (e.g., Magnetic Resonance Imaging [MRI]) completed as part of the diagnostic process (see Table 9). Compared to previous years, there was an increase in the use of brain Fluorodeoxyglucose Positron Emission Tomography (FDG PET) in 2022. This likely reflects the Medicare rebate that became available in 2022 for brain FDG PET to assist in elucidating a diagnosis of Alzheimer's dementia in the circumstance where all other clinical evaluation is equivocal.

Table 9 Completed Diagnostic Investigations

Diagnostic Investigation (%)[1,2]	MCI		Dementia	
	2020-2021 (n = 278)	2022 (n = 474)	2020-2021 (n = 587)	2022 (n = 1,030)
Cognitive assessment/s	**99**	**99**	**98**	**97**
Functional assessment/s[3]	**97**	**98**	**98**	**98**
Core blood tests	**91**	**94**	**90**	**93**
Structural neuroimaging	**89**	**91**	**90**	**92**
MRI[4]	56	62	54	53
CT[5]	44	40	43	49
Functional neuroimaging	**12**	**31**	**15**	**34**
FDG PET[6]	9	23	10	27
SPECT[7]	5	8	6	7
Amyloid/Tau PET	1	2	1	1
Lumbar puncture	**0**	**2**	**1**	**2**

[1]Some participants might have some investigations completed prior to attending the clinic and did not need to have them repeated

[2]Participants with missing responses are included in the denominator. Please refer to Appendix 3 for data completeness information

[3]Based on information on personal/basic and instrumental activities of daily living

[4]MRI: Magnetic Resonance Imaging

[5]CT: Computed Tomography

[6]FDG PET: Fluorodeoxyglucose Positron Emission Tomography

[7]SPECT: Single Photon Emission Computed Tomography

Acetylcholinesterase inhibitor (AChEI) prescription

The Guidelines recommend consideration of acetylcholinesterase inhibitor (AChEI) for managing symptoms of mild to moderately severe Alzheimer's dementia[7]. In Australia, a Pharmaceutical Benefits Scheme (PBS) subsidy exists for the use of AChEI as a sole PBS-subsidised therapy for people with a specialist confirmed diagnosis of a dementia that includes the Alzheimer's disease subtype, which is of mild to moderate severity. On therapy initiation, the PBS defines mild to moderate Alzheimer's dementia as:

- an MMSE score of 10 or higher
- an MMSE score lower than 10 in the setting of significant sensory impairments, or non-English speaking background, dysphasia or other significant communication impairments, low educational levels or cultural reasons which impacted performance on the MMSE

In 2022, of participants with Alzheimer's dementia and an MMSE score of 10 or higher, 64% were prescribed AChEI at diagnosis (see Table 10). The ADNeT Registry recognises that there may be many clinical scenarios where such medications are contraindicated, or patient preference was to refrain from trialling such medications.

Table 10 Prescription of Acetylcholinesterase Inhibitor in Participants Diagnosed with Dementia

Dementia Subtype (%)[1,2]	2020-2021	2022
Dementia with AD[3], MMSE ≥ 10[4]	**(n = 347)**	**(n = 527)**
AChEI[5] prescribed[6]	67	64
AChEI not prescribed	26	30
Dementia with AD, MMSE < 10	**(n = 8)**	**(n = 22)**
AChEI prescribed	12	32
AChEI not prescribed	75	64
Dementia with AD, no MMSE provided	**(n = 119)**	**(n = 243)**
AChEI prescribed	57	60
AChEI not prescribed	36	34
Dementia non-AD	**(n = 113)**	**(n = 238)**
AChEI prescribed	15	18
AChEI not prescribed	84	79

[1]Participants with missing responses are included in the denominator. Please refer to Appendix 3 for data completeness information

[2]Percentages might not add up to 100 due to rounding and missing responses

[3]AD: Alzheimer's disease

[4]MMSE: Mini-Mental State Exam

[5]AChEI: Acetylcholinesterase inhibitor

[6]Prescribed means either directly prescribed by the participating service, or participating service has recommended that the GP prescribe

Clinical Quality Indicators

Clinical quality indicators (CQIs) are specifically defined measures that are used to monitor, evaluate, and improve the quality of clinical care and important clinical outcomes[17, 20]. The ADNeT Registry has endorsed seven CQIs, based on a Modified Delphi Study[21] (see Table 11). Of these, the first six CQIs are used to help understand the quality of diagnostic care, as they capture aspects of clinical practice that are considered best standard. The seventh CQI, on AChEI prescribing, is used to examine variations in clinical practice and to facilitate benchmarking. Internationally, AChEI prescription is typically reported on dementia CQRs[22]. The ADNeT Registry recognises that in some clinical scenarios AChEI may be contraindicated, or that the participant may decline prescription of such medications.

Of the six CQIs on the quality of diagnostic care, in 2022, the performance was 90% or higher for five CQIs (see Table 11). The only exception is the first CQI, that is, "first appointment with dementia/MCI diagnostic service within 90 days of referral", which recorded a 64% performance. The ADNeT Registry will continue to monitor CQI performance to examine trends over time and evolve the set of CQIs in line with best practice.

Figure 8 is funnel plots of the seven CQIs. These plots are a visual representation of how individual sites perform compared to their peers and the overall average; they also identify those who are performing better or worse than the average. The funnel plot contours represent two standard deviations (95% control limits) and three standard deviations (99.8% control limits) from the mean; those above and below these lines are considered outliers, with a 5% and 0.2% chance of a false positive respectively (i.e., incorrectly identifying a site as an outlier).

As can be seen in the funnel plots, there were considerable variations across sites in the first CQI which measures wait time for first appointments. These funnel plots have been included in benchmarked site reports to help individual sites assess their performance compared to their peers and to identify areas for quality improvement.

Table 11 Performance on the Seven Endorsed Clinical Quality Indicators

Clinical Quality Indicator (%)[1]	2020-2021 (n = 865)	2022 (n = 1,504)
1: First appointment with dementia/MCI diagnostic service within 90 days of referral	**60**	**64**
2: Core blood tests undertaken as part of the diagnostic work-up	**95**	**96**
3: Multiple cognitive domains assessed as part of the diagnostic work-up	**99**	**98**
4: Structural neuroimaging completed as part of the diagnostic work-up	**93**	**93**
5: Ability to perform personal and instrumental activities of daily living assessed as part of the diagnostic work-up	**98**	**98**
6: Cognition re-assessed within 18 months of an MCI[2] diagnosis	**88**	**90**
7: AChEI[3] prescribed/recommended for persons diagnosed with mild to moderate Alzheimer's disease:		
• People < 85 years old	**76**	**75**
• People ≥ 85 years old	**59**	**48**

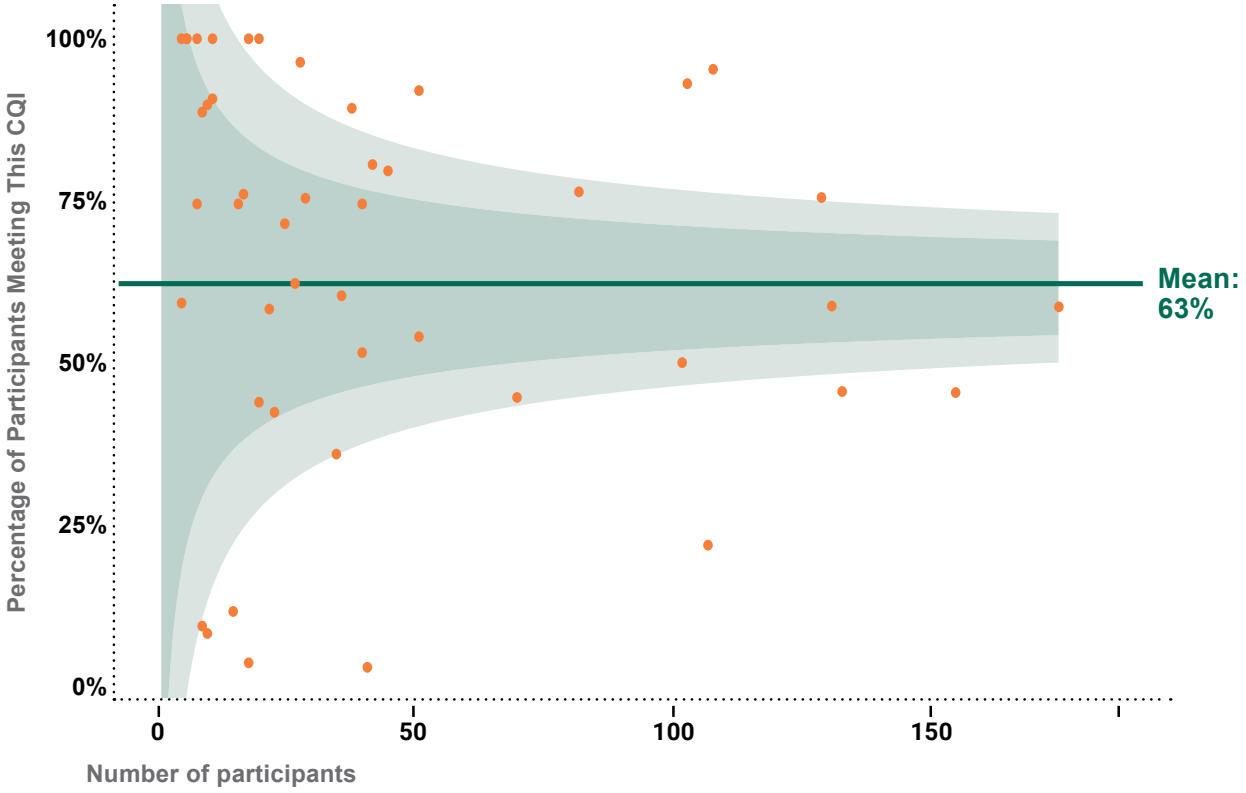
[1]Participants with "Not stated" responses are excluded in the denominators. Please refer to Appendix 3 for data completeness information

[2]MCI: mild cognitive impairment

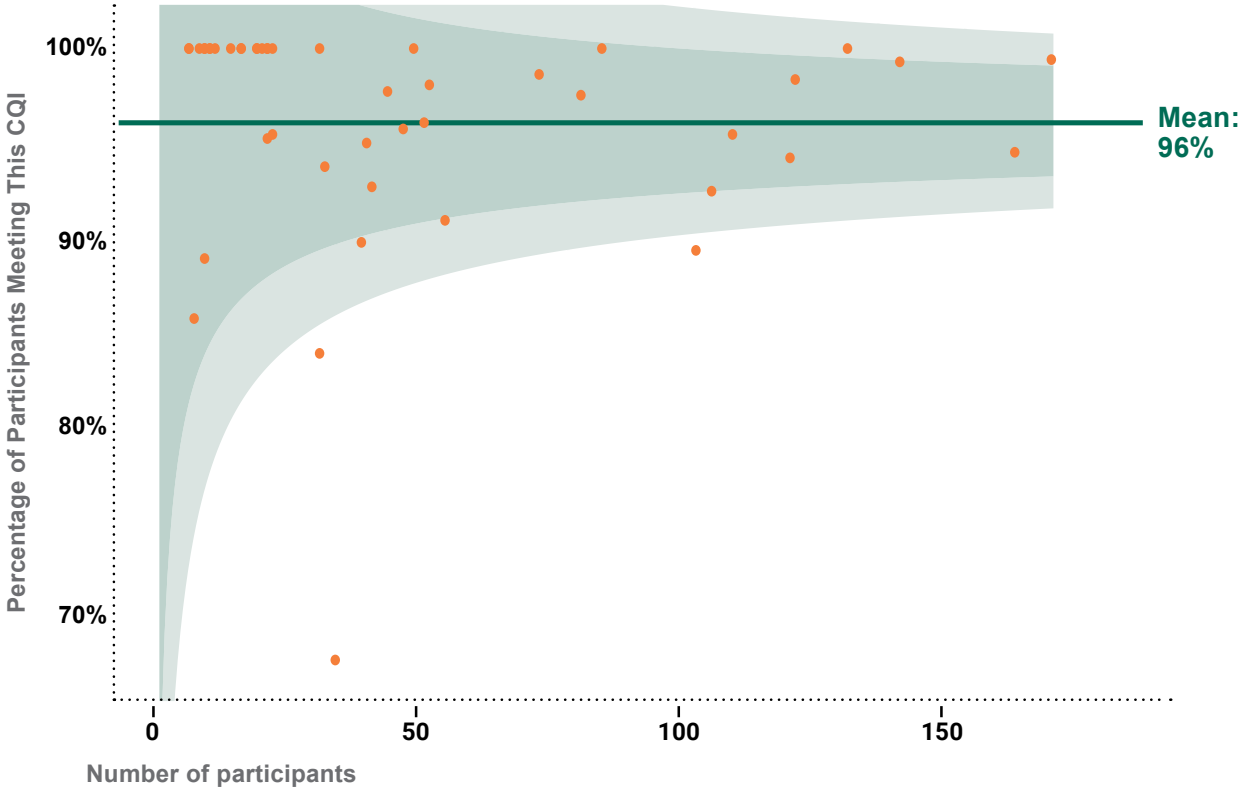
[3] AChEI: Acetylcholinesterase inhibitor

Figure 8 Funnel Plots of the Seven Endorsed Clinical Quality Indicators (2020-2022)

1. First appointment with dementia/MCI diagnostic service within 90 days of referral

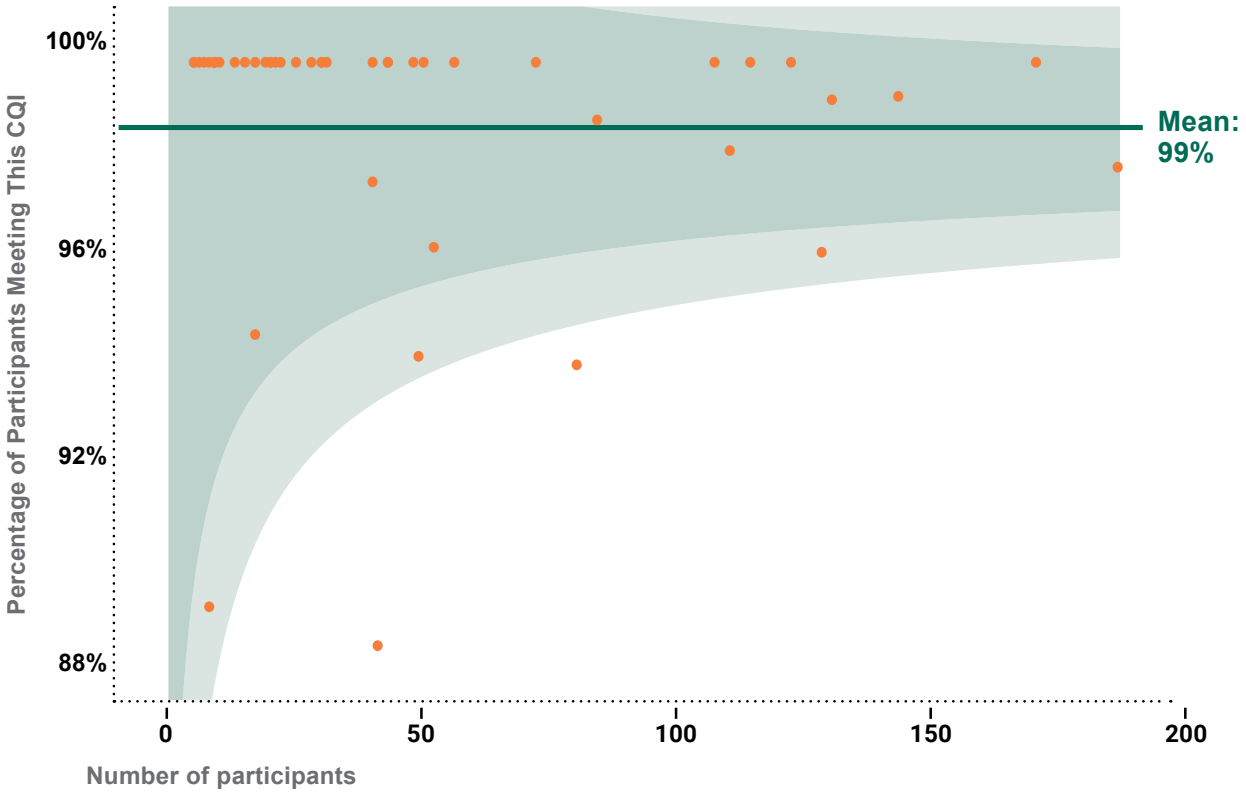


2. Core blood tests undertaken as part of diagnosis

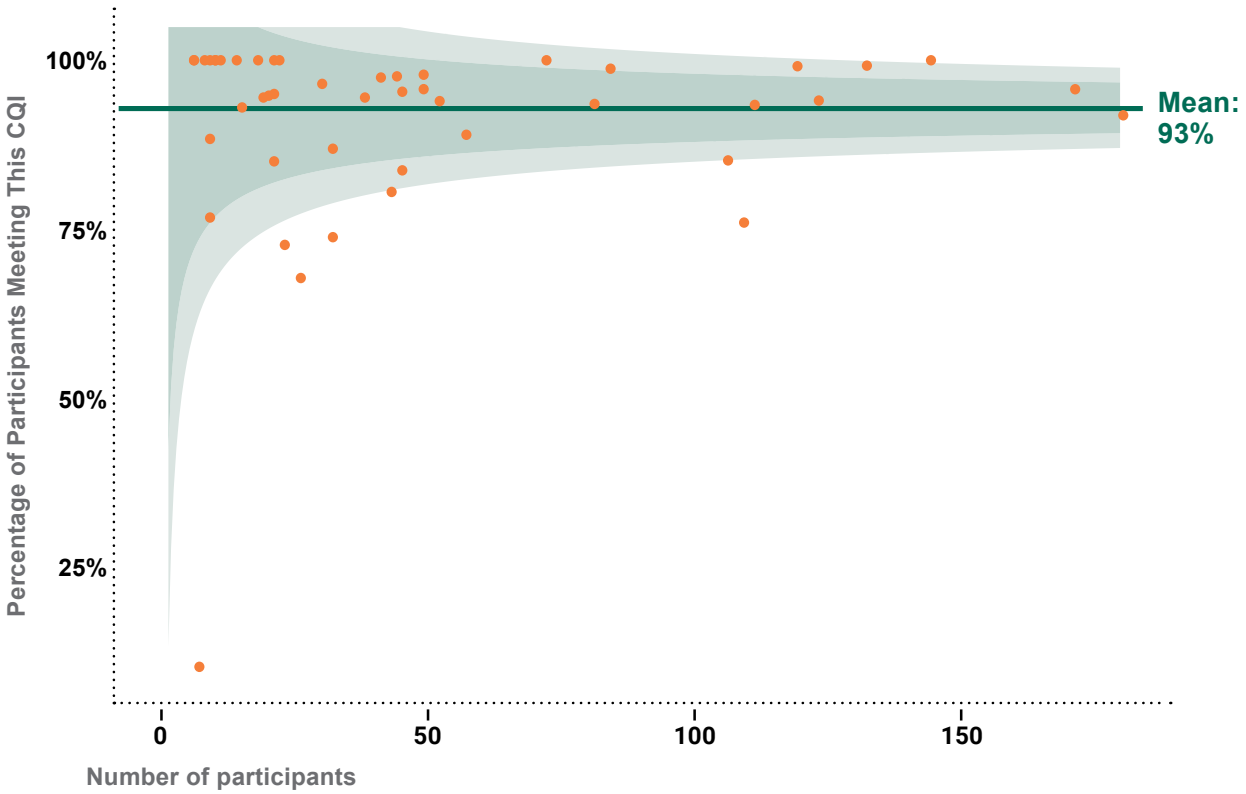


Sites with less than five participants were excluded from the analysis.

3. Multiple cognitive domains assessed as part of diagnosis

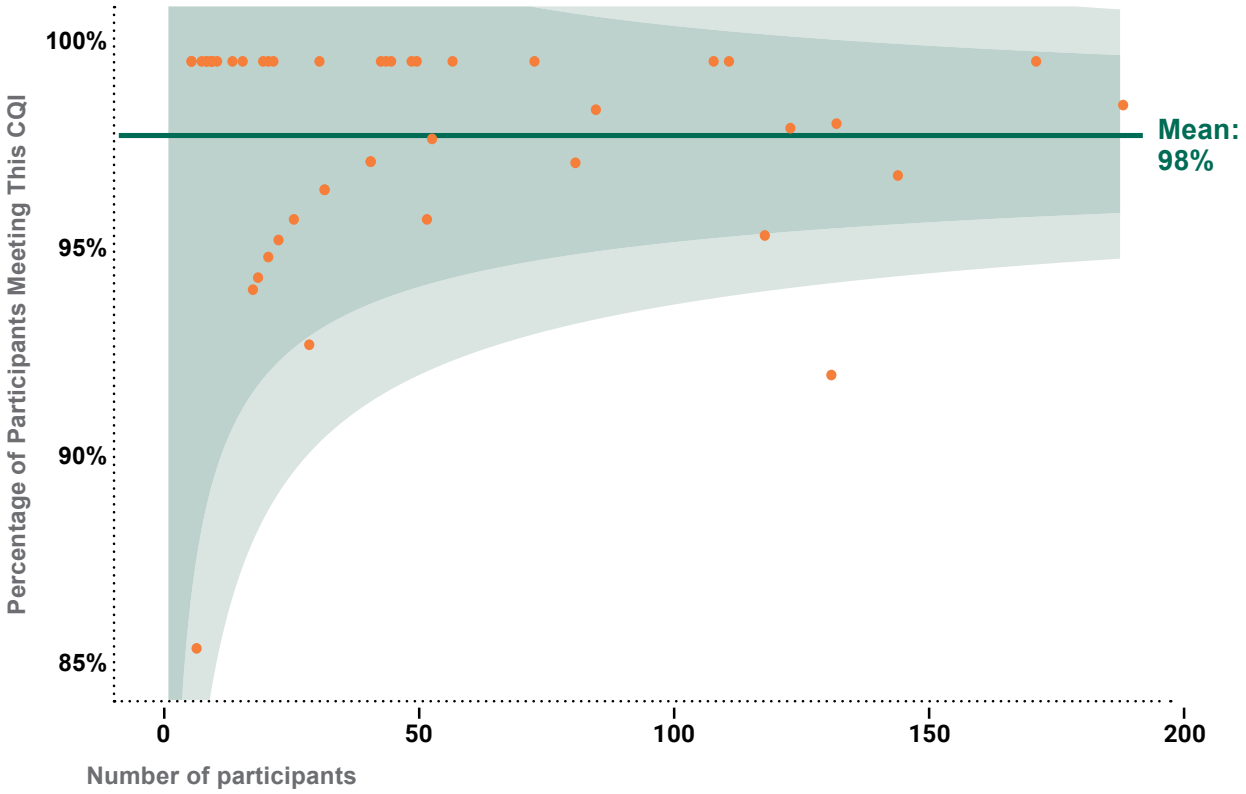


4. Structural neuroimaging completed as part of diagnosis

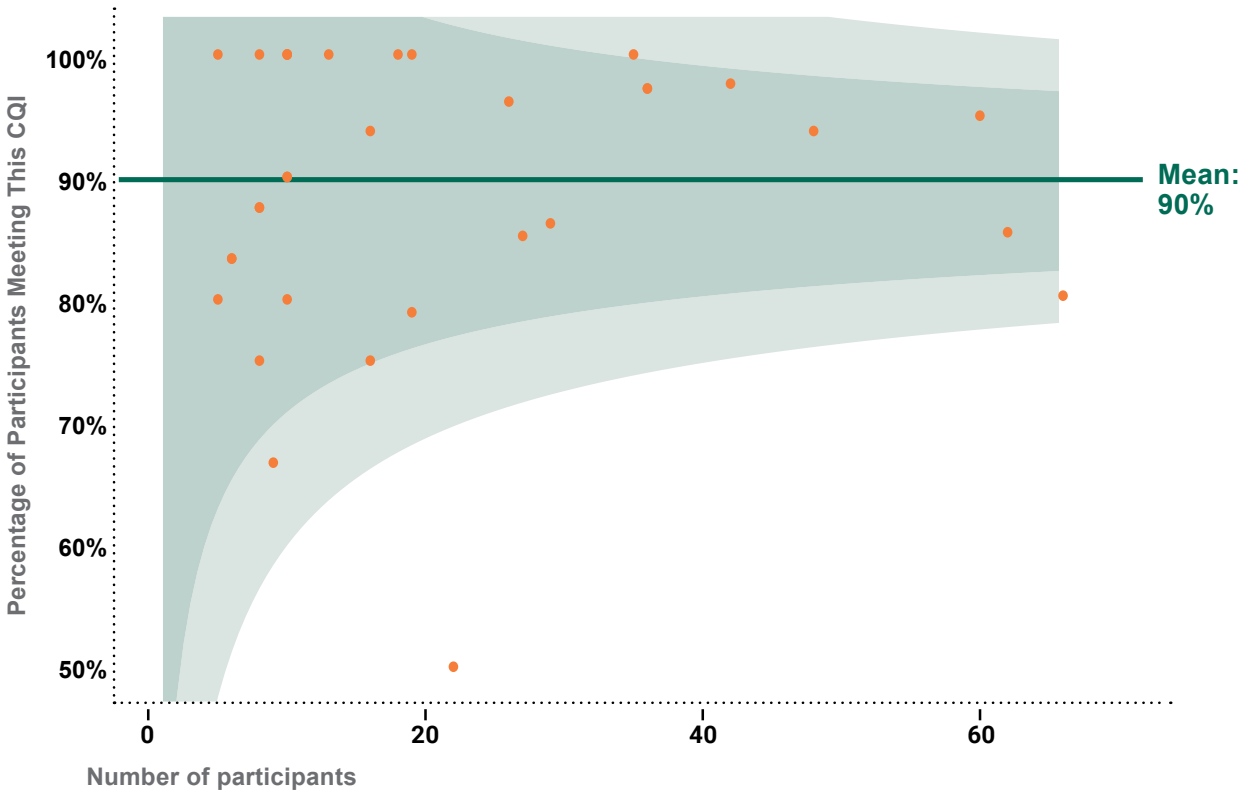


Sites with less than five participants were excluded from the analysis.

5. Ability to perform activities of daily living assessed as part of diagnosis



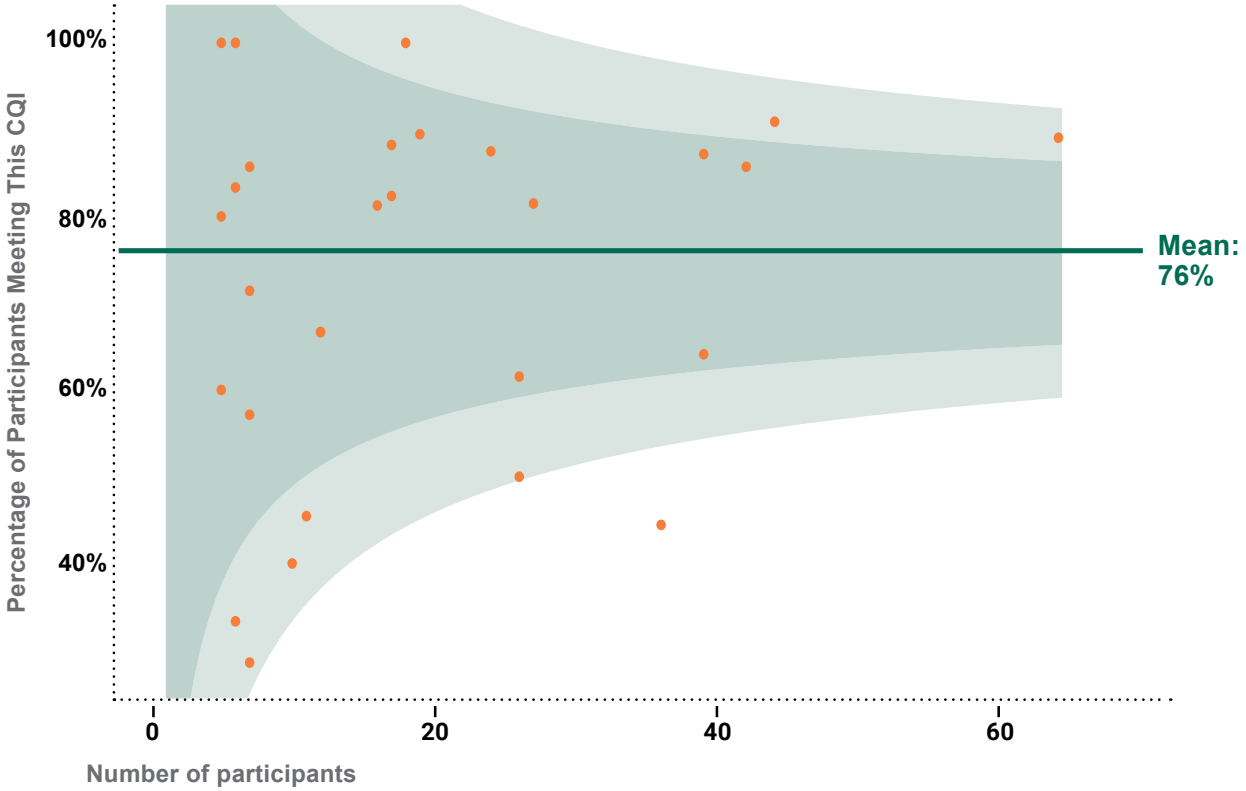
6. Cognition re-assessed for MCI



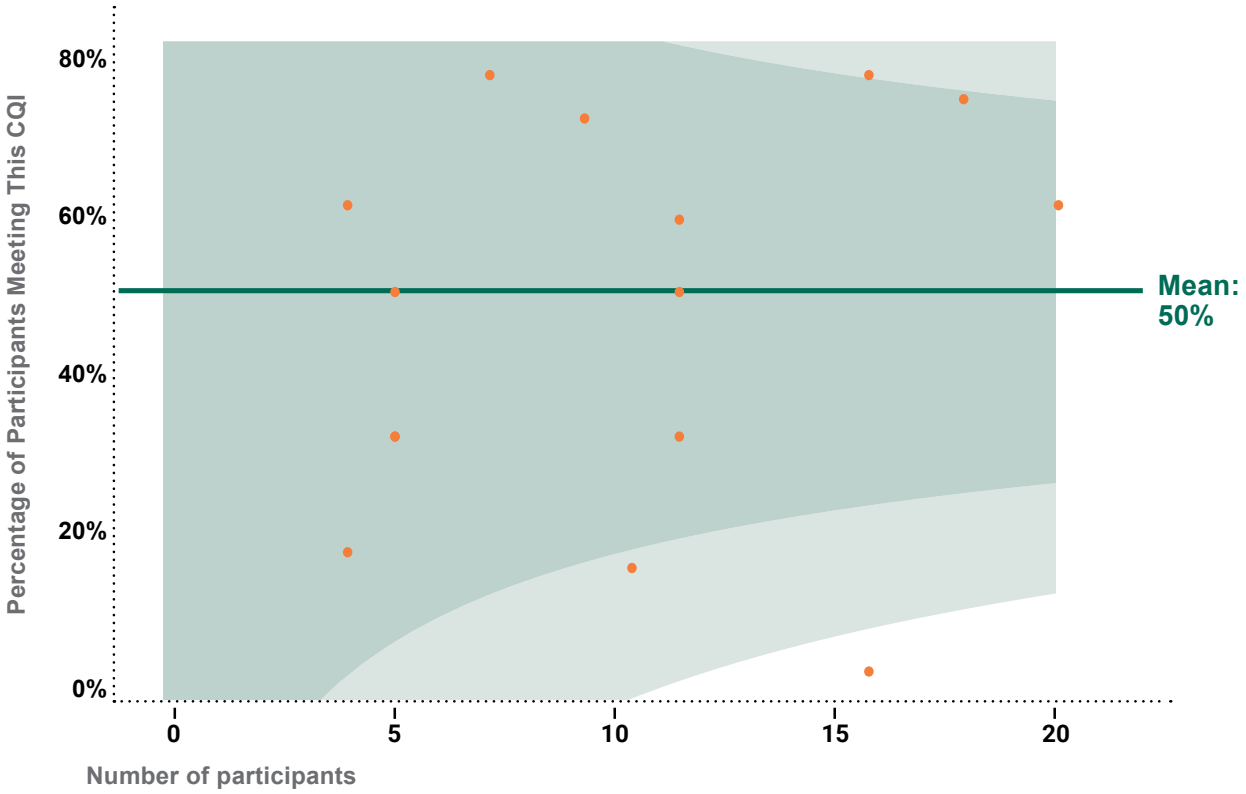
Sites with less than five participants were excluded from the analysis.

7. AChEI prescribed/recommended for mild to moderate Alzheimer's disease

a. People < 85 years old



b. People ≥ 85 years old



Sites with less than five participants were excluded from the analysis.

The information we have received from the ADNeT Registry has been extremely helpful to our hospital. It has been integral in improving the quality of our service and providing valuable benchmarking to enable us to raise the standards of care for our patients and their supports. This is challenging as a smaller stand-alone service and the collaboration with ADNeT Registry supports our continuous quality improvement cycle. We have been able to use the data from our site report to assisting in achieving a National Clinical Excellence Award at the Australian Private Hospital Association Awards for 2023. Thank you ADNeT Registry for your support.

– Dr Penny King, Robina Private Hospital Memory Clinic

We have already gained very valuable insights from being an early participant in the ADNeT Registry, particularly around the client satisfaction services and the ways they can inform our future practice. The benchmarking data provided, particularly around time to diagnosis and time to imaging, has been very useful in knowing how we perform against similarly resourced peers. We look forward to exploring research opportunities, both for the clinic and our patient cohort, with the ADNeT team in the future.

– Dr John Guinane, Western Health
Cognitive Dementia and Memory Service

We are a small rural CDAMS clinic and by joining the ADNeT Registry, we have been able to continuously improve our service by using benchmarked Site Reports. We recently showcased our experience with ADNeT Registry at a recent research symposium, and to Echuca Regional Health Management Group. We had great assistance in preparing the presentation from the registry team.

– Kerry Meiers, Echuca Regional Health
Cognitive Dementia and Memory Service

Outcomes and Experience of Clinical Care

The ADNeT Registry includes data on participant-reported outcomes and experience of clinical care at the point of diagnosis (see Appendix 5). Given the vital role that carers play in supporting people with dementia and the impact of caregiving on carers, the registry also includes data on carer-reported outcomes and experience. These data are collected via self-completed participant and carer surveys, which are sent to all eligible participants and their carers (if identified) post-recruitment.

In 2022, the survey response rate was 48% for the participant survey (786 sent, 381 returned) and 46% for the carer survey (646 sent, 299 returned) (see Table 12).

Table 12 Participant and Carer Survey Response Rates

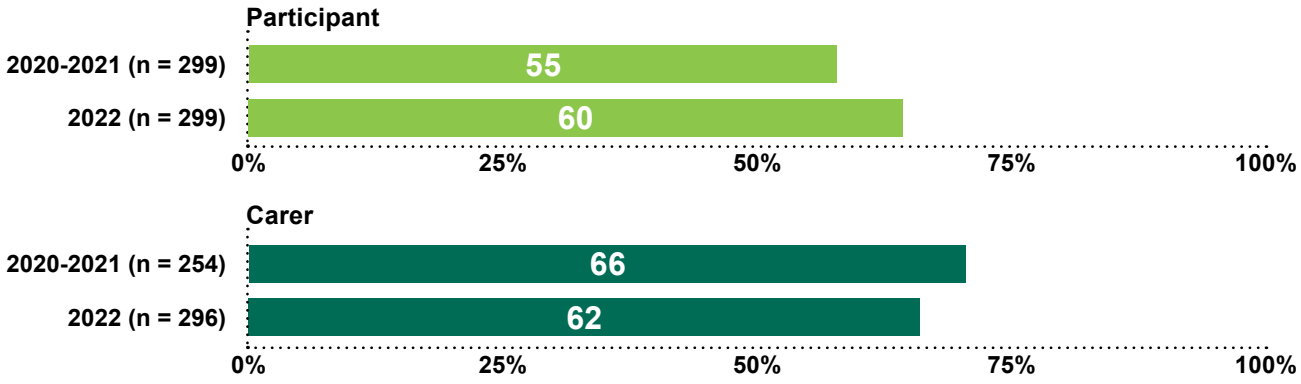
Response Rate (%)[1]	2020-2021	2022
Participant survey	56	48
Carer survey	56	46

[1]Survey response represents the proportion of surveys returned out of the total sent. For returned surveys, late responses (i.e., those returned four months after initial invitation) were excluded to allow timely analysis (n = 18 for the participant survey and 21 for the carer survey). For sent surveys, those that were sent within 4 months of data extraction (n = 329 for the participant survey and 220 for the carer survey) were excluded to allow sufficient time for survey completion. Finally, surveys that were returned to sender (n = 19 for the participant survey and 18 for the carer survey) were excluded from sent surveys to allow accurate calculation of response rates.

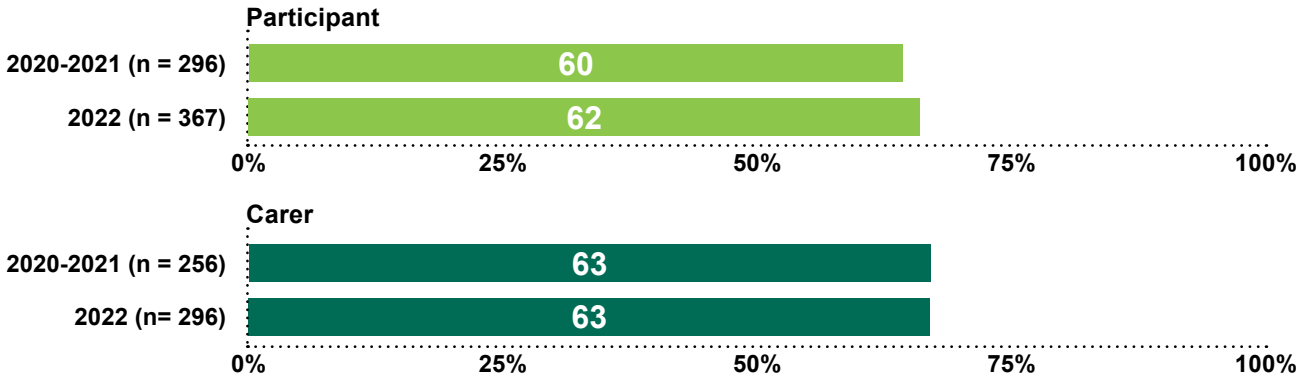
In 2022, approximately 60% of participants and carers rated their health and well-being as “Good” or “Very Good” at the time of an MCI or dementia diagnosis (see Figure 9).

Figure 9 Percentages of Participants/Carers Responding “Good” or “Very Good” for Outcome Questions

Self-reported health



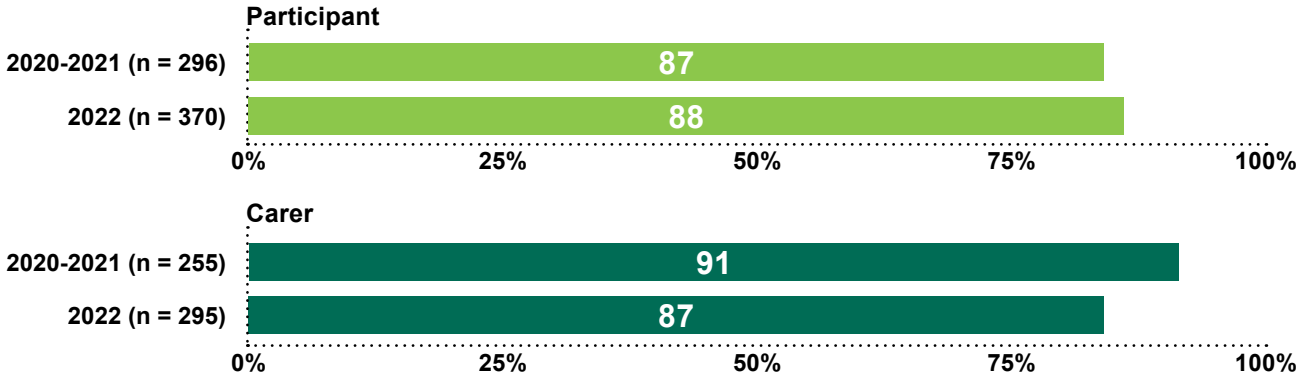
Self-reported well-being



Nearly 90% of participants and carers reported having overall “Good” or “Very Good” experience at participating sites (see Figure 10).

Figure 10 Percentages of Participants/Carers Reported Having Overall “Good” or “Very Good” Experience at Participating Sites

Overall experience with service

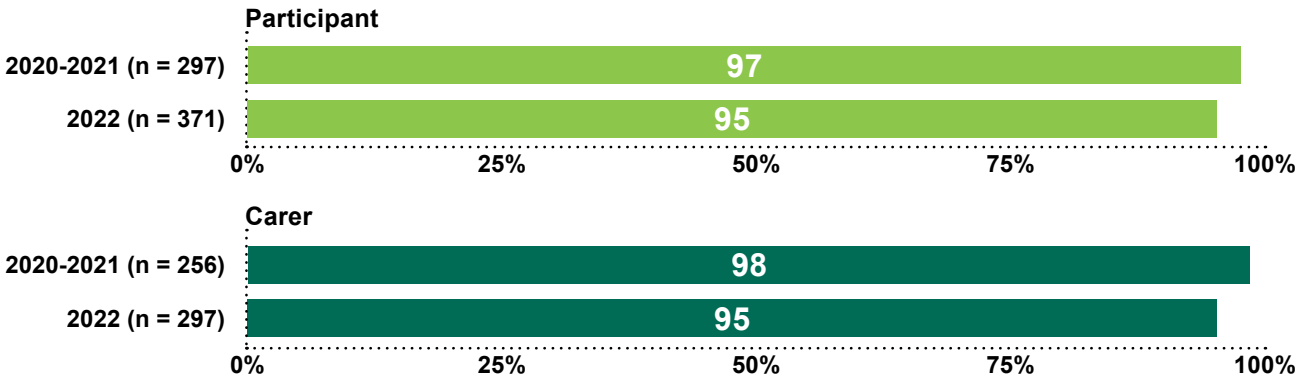


The aspects showing most positive experience were the same for both participants and carers:

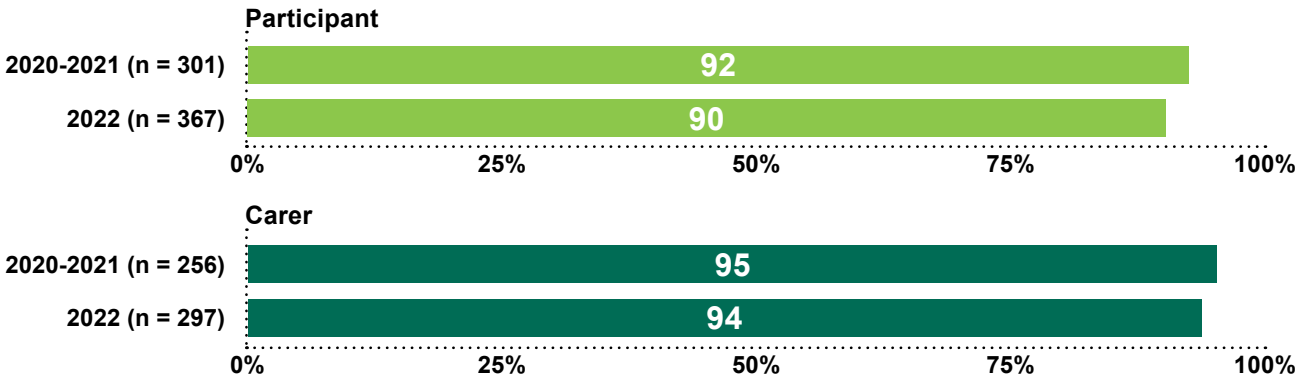
- "treated with dignity and respect" (agreed/totally agreed by 95% of participants and carers)
- "given the opportunity to ask questions" (agreed/totally agreed by 90% of participants and 94% of carers) (see Figure 11).

Figure 11 Experience Questions with Highest Percentages of Participants/Carers Responding "Agree" or "Totally Agree"

Treated with dignity and respect



Opportunity to ask questions

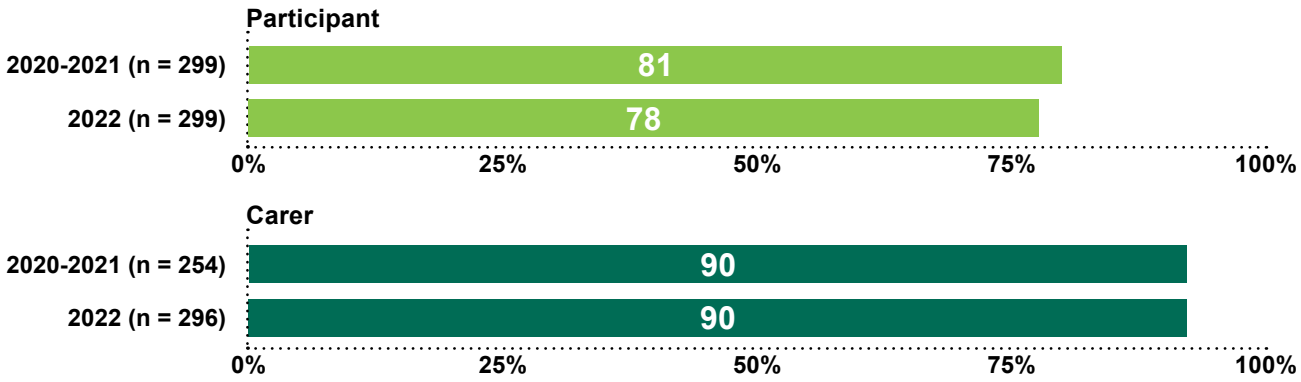


The aspects showing least positive experience were:

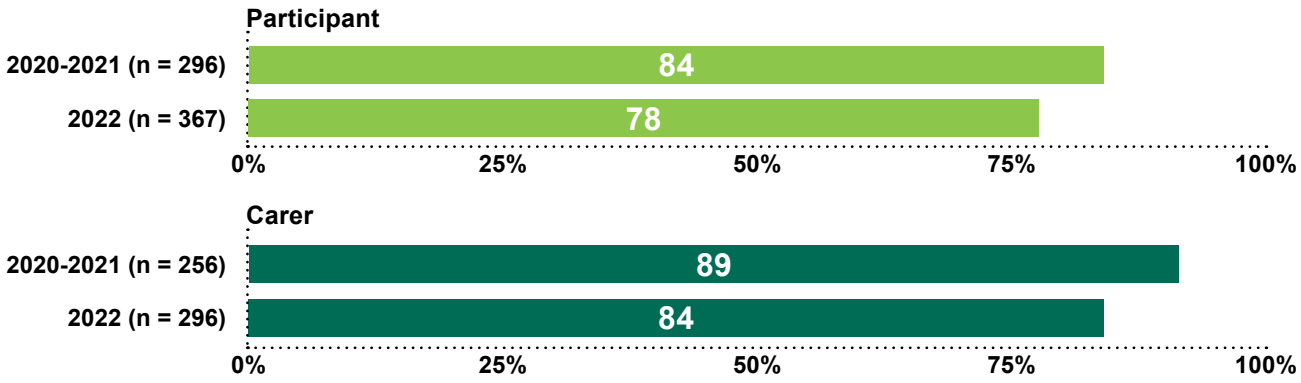
- "involved in decision making" and "meeting expectations" for participants (both agreed/totally agreed by 78% of participants)
- "given advice about how and where to get more information or help if needed" for carers (agreed/totally agreed by 83% of carers) (see Figure 12).

Figure 12 Experience Questions with Lowest Percentages of Participants/Carers Responding "Agree" or "Totally Agree"

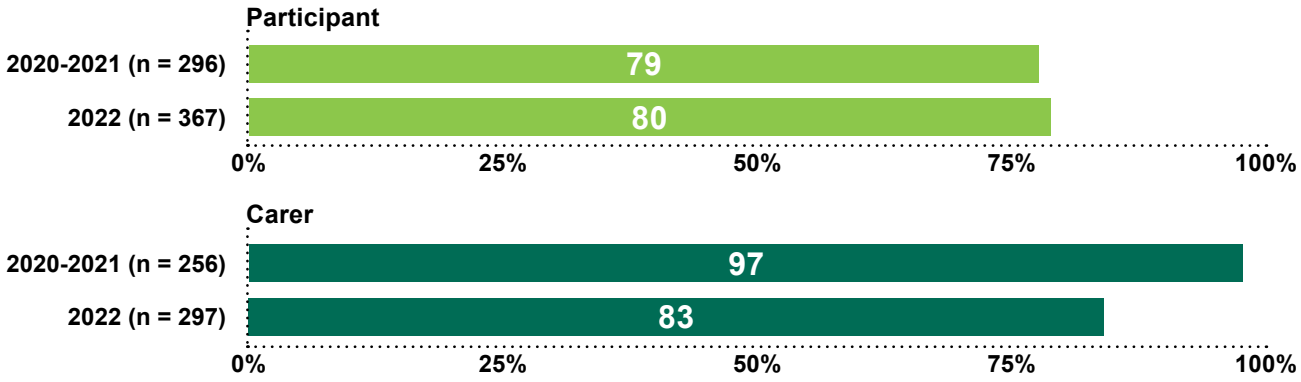
Involved in decision making



Meeting expectations



Given advice about information and help



Summary of 2022 Activities and Future Developments

The ADNeT Registry undertook a number of key activities in 2022, including:

- Continued expansion of the registry with an increase in participating sites from 40 in 2021 to 55 in 2022
- Revised Minimum Data Set to collect additional data to help better understand the quality and outcomes of clinical care (e.g., added data elements on dementia risk factors, neuropsychiatric symptoms, and appointments of future decision makers)
- Commenced development of a customised Clinical Research Platform (CRP), with funding support from Biogen and Roche
- Provided individualised benchmarked reports to participating sites
- Translated registry invitation documents into four other languages to encourage participation among people from CALD backgrounds
- Commenced development of a sub-study process to support secondary data analysis and recruitment of participants into research

The ADNeT Registry has been funded through the broader ADNeT initiative, which receives an allocation of the Boosting Dementia Research Initiative grant from the NHMRC. This funding will end in 2023 and the ADNeT Registry has secured a further 4-year funding from the Australian Department of Health and Aged Care as part of the National Clinical Quality Registries Program.

Looking beyond 2022, key areas of focus for the ADNeT Registry are:

- Continuing recruitment, expansion, and interaction with clinical services to increase registry coverage
- Implementing the revised Minimum Data Set
- Transitioning to the new CRP to improve user experience and registry efficiency
- Collaborating with the Australian Institute of Health and Welfare (AIHW) to use ADNeT Registry data to inform national dementia policy, reports, and planning initiatives
- Developing a sub-study data set, in collaboration with international partners (e.g., Alzheimer's Network for Treatment & Diagnostics [ALZ-NET] in the United States), to collect real-world safety and efficacy data when new dementia therapies (e.g., the anti-amyloid monoclonal antibody, lecanemab) become publicly available in Australia
- Developing a follow-up data set to capture key information on long-term outcomes and post-diagnostic care of people living with dementia and MCI, where possible from existing data sources, and bespoke data sets where not

The ADNeT Registry would not be possible without the funding and continued support from our partners, participating sites, clinicians, registry participants and their carers, lived experience representatives, peak bodies, industry, and government. We thank you all for your ongoing support.

Abbreviations

AChEI	Acetylcholinesterase inhibitor
AD	Alzheimer's disease
ADNeT	Australian Dementia Network
CALD	Culturally and Linguistically Diverse
CQI	Clinical Quality Indicator
CQR	Clinical Quality Registry
CRP	Clinical Research Platform
CT	Computed Tomography
FDG PET	Fluorodeoxyglucose Positron Emission Tomography
KICA	Kimberley Indigenous Cognitive Assessment tool
MCI	Mild Cognitive Impairment
MMSE	Mini-Mental State Exam
MoCA	Montreal Cognitive Assessment
MRI	Magnetic Resonance Imaging
PBS	Pharmaceutical Benefits Scheme
RUDAS	Rowland Universal Dementia Assessment Scale
SPECT	Single Photon Emission Computed Tomography

Publications (2022)

1. Lin, X., Ward, S. A., Pritchard, E., Ahern, S., Gardam, M., Brodaty, H., Ryan, J., McNeil, J., Tsindos, T., Wallis, K., Jeon, Y. H., Robinson, S., Krysinska, K., & Ayton, D. (2023). Carer-reported measures for a dementia registry: A systematic scoping review and a qualitative study. Australasian Journal on Ageing, 42(1), 34–52. https://doi.org/10.1111/ajag.13148

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Appendix 1

Committee Membership and Staff List (2022)

ADNeT Registry Steering Committee

- Professor Henry Brodaty*, ADNeT Registry Steering Committee Co-Chair, University of New South Wales
- Dr Stephanie Ward*, ADNeT Registry Steering Committee Co-Chair & Clinical Lead, University of New South Wales, The Prince of Wales Hospital & Monash University
- Professor Susannah Ahern*, ADNeT Registry Academic Lead, Monash University
- Professor Kaarin Anstey, Neuroscience Research Australia & University of New South Wales
- Professor Amy Brodtmann* (from May 2022), Inaugural President of the Australian Cognitive Neurology Society, Eastern Health, Royal Melbourne Hospital, Monash University
- Associate Professor Trevor Chong* (from May 2022), Monash University, St Vincent's Health Melbourne & Alfred Health
- Ms Gwenda Darling (from May 2022), Person living with dementia
- Professor Maria Inacio, South Australian Health and Medical Research Institute
- Professor Yun-Hee Jeon, University of Sydney
- Ms Barbara Kain, Carer of a person living with dementia
- Associate Professor Samantha Loi*, Royal Melbourne Hospital & University of Melbourne
- Ms Maree McCabe AM, Dementia Australia
- Professor Sharon Naismith*, Brain and Mind Centre, University of Sydney
- Dr Kannan Natarajan* (from May 2022), Logan Hospital, Queensland
- Professor Mark Nelson, University of Tasmania
- Dr Lyndal Newton*, Councillor, Australian and New Zealand Society for Geriatric Medicine & Department of Geriatric Medicine, Northern Beaches Hospital
- Ms Ann Pietsch, Person living with dementia
- Ms Lyntara Quirke, Carer of a person living with dementia
- Ms Elizabeth Rand, Alfred Health (retired in 2022)
- Professor Christopher Rowe*, Australian Dementia Network Director, University of Melbourne & Austin Health
- Associate Professor Mark Yates* (from May 2022), Grampians Health Ballarat (formerly Ballarat Health Service) & Deakin University

*also member of the ADNeT Registry Clinician Management Committee

ADNeT Registry Survey Working Group

- Dr Stephanie Ward, Chair, University of New South Wales, The Prince of Wales Hospital & Monash University
- Dr Jane Alty, University of Tasmania
- Professor Henry Brodaty, University of New South Wales
- Professor Yun-Hee Jeon, University of Sydney
- Ms Barbara Kain, Consumer Representative
- Mr Scott Cooper, Consumer Representative
- Ms Jenny Fitzpatrick, Consumer Representative
- Ms Sally Lambourne, Dementia Australia
- Dr Xiaoping Lin, Monash University
- Professor Lee-Fay Low, University of Sydney
- Ms Kerrie McAloney, QIMR Berghofer Medical Research Institute
- Professor Sharon Naismith, University of Sydney
- Professor Lyn Phillipson, University of Wollongong
- Ms Kasey Wallis, Monash University

ADNeT Registry Staff

- Dr Stephanie Ward, ADNeT Registry Steering Committee Co-Chair & Clinical Lead, University of New South Wales, The Prince of Wales Hospital & Monash University
- Professor Susannah Ahern, ADNeT Registry Academic Lead, Monash University
- Ms Kasey Wallis, ADNeT Registry Program Manager, Monash University
- Dr Xiaoping Lin, Research Fellow, Monash University
- Ms Valerie Arsenova, ADNeT Registry State Coordinator, University of New South Wales
- Ms Marisa Caruso (from August to October 2022)
- Ms Cheryl Grant, Administrative Officer, Monash University
- Dr Mohammad Amin Honardoost (from December 2022), Data Analyst, Monash University
- Dr Maria Kokkinos (from February 2022), Research Assistant, Monash University
- Ms Krupa Krishnaprasad (to April 2022), ADNeT Registry State Coordinator, Monash University
- Mrs Claudia Lassetter (from February 2023), Senior Project Officer, Monash University
- Mr John Liman, Senior Software Engineer, Monash University
- Ms Kerrie McAloney, ADNeT Registry State Coordinator, QIMR Berghofer Medical Research Institute
- Dr Ahmad Reza Pourghaderi (from August 2022), Senior Data Analyst, Monash University
- Dr Miia Rahja, ADNeT Registry State Coordinator, South Australian Health Medical Research Institute
- Ms Jennifer Richardson, ADNeT Registry Ethics Officer, Monash University
- Dr Farhad Salimi (from January to October 2022), Senior Data Analyst, Monash University
- Dr Sophia Tan (from May 2022), ADNeT Registry State Coordinator, South Australian Health Medical Research Institute
- Ms Anh Tran (from January to August 2022), Data Analyst, Monash University
- Mr Alan Tsui (from January 2022), ADNeT Registry Data Manager, Monash University

Appendix 2

ADNeT Registry Minimum Data Set

Personal identifiers and information to facilitate recruitment

- Name
- Date of birth
- Sex
- Capacity to be involved in the opt-out process
- Communication of diagnosis
- Contact details[1]
- Person Responsible name, preferred spoken language and contact details[1]
- Carer's name, preferred spoken language and contact details[1]

Demographics

- Aboriginal and/or Torres Strait Islander
- Country of birth
- Preferred spoken language
- Level of education
- Labour force status
- Residential setting
- Living arrangement[2]

Diagnosis and clinical data

- Past diagnosis of MCI[3]
- Date of referral
- Date of first appointment
- Date of diagnosis
- Diagnosis
- Mode of service delivery
- Dementia/MCI subtype
- Number of prescribed medications
- Number of strokes
- Hypertension
- Diabetes
- Cardiovascular disease
- Cancer
- Symptoms suggestive of REM-sleep behaviour disorder
- Falls history in past 12 months
- Functional measure/s completed
- Cognitive assessment/s completed
- MMSE/RUDAS/MoCA/KICA scores[1,3]
- Independence in activities of daily living[4]
- Continence
- Core blood tests undertaken within the 12 months prior to or at time of diagnosis
- Structural neuroimaging completed within the 12 months prior to or at time of diagnosis
- Functional neuroimaging completed within the 12 months prior to or at time of diagnosis
- Lumbar puncture completed within the 12 months prior to or at time of diagnosis
- Acetylcholinesterase inhibitor recommended or prescribed[5]
- Follow-up appointment offered at time of diagnosis[6]
- Interest in participation in research

[1]If applicable/relevant

[2]Restricted to participants living at home

[3]MCI: mild cognitive impairment, MMSE: Mini-Mental State Exam, RUDAS: Rowland Universal Dementia Assessment Scale, MoCA: Montreal Cognitive Assessment, KICA: Kimberley Indigenous Cognitive Assessment tool

[4]Include questions on mobility, personal activities of daily living, instrumental activities of daily living, and driving

[5]Restricted to participants with dementia

[6]Restricted to participants with MCI

Appendix 3

Data Completeness

Data completeness (%)	2020-2021 (n = 865)	2022 (n = 1,504)
Age at diagnosis	99	98
Sex	99	100
Aboriginal and/or Torres Strait Islander	92	90
Country of birth	97	96
Preferred spoken language	98	99
Highest education level	94	88
Labour force status	99	95
Residential setting	99	97
Living arrangement	94	91
Independent in mobility	99	98
≥ 1 fall in 12 months	95	95
Independent in pADLs[1]	99	99
Independent in iADLs[2]	98	99
Driving	97	98
Diabetes	99	99
Hypertension	98	99
Cardiovascular disease	98	99
Stroke	99	97
Number of medications	99	97
Time interval from referral to first appointment[3]	98	95
Time interval from first appointment to diagnosis[3]	99	96
Time interval from referral to diagnosis[3]	98	95
Diagnosis	100	100
Cognitive assessment	99	98
Core blood tests	94	97
Structural neuroimaging	97	98
Functional neuroimaging	90	95
Lumbar puncture	88	97
Acetylcholinesterase inhibitor prescription[4]	94	95

[1]pADL: personal (or basic) activities of daily living

[2]iADL: instrumental activities of daily living

[3]Excludes participants with a previous mild cognitive impairment (MCI) diagnosis (n = 43 in 2021 and 140 in 2022)

[4]Excluded participants with MCI (n = 278 in 2020-2021 and 474 in 2022)

Appendix 4

ADNeT Registry Participating Sites (2020-2022)

As of 31st December 2022, the ADNeT Registry had 59 sites with governance authorisation, of which, 55 have commenced data collection.

Site	Type[1]	Location[2]
New South Wales (n = 16)		
1. Brellah Medical	Private	Major City
2. Burwood Specialists	Private	Major City
3. Central Coast Neurosciences (CCN) – Procognition Clinic	Private	Major City
4. Geriatric Medicine Services, Western NSW Local Health District	Public	Inner Regional
5. Hornsby Ku-ring-gai Hospital Memory Clinic	Public	Major City
6. Memory Assessment Program, Pottsville	Public	Major City
7. Murrumbidgee Local Health District Aged Care Outpatient Clinic	Public	Inner Regional
8. Northern Beaches Geriatricians	Private	Major City
9. Prince of Wales Hospital Brodaty Clinic	Public	Major City
10. Prince of Wales Hospital Cognitive Disorders Clinic	Public	Major City
11. Prince of Wales Hospital Neuropsychiatry Clinic	Public	Major City
12. Rehabilitation and Aged Care Outpatient Clinics, Mona Vale Hospital	Public	Major City
13. Salus Clinic	Private	Major City
14. Shoalhaven Aged Care Service, Milton Hospital	Public	Inner Regional
15. Shoalhaven Aged Care Service, Shoalhaven District Memorial Hospital	Public	Inner Regional
16. Southcare Geriatricians, Sutherland Hospital[3]	Public	Major City
Queensland (n = 16)		
1. Agenda Health	Private	Major City
2. Beach Brain	Private	Major City
3. Cairns Memory Clinic, Cairns Hospital	Public	Outer Regional
4. Dementia Assessment Service, Kirwan Health Campus	Public	Outer Regional
5. Healthy Ageing Gold Coast	Private	Major City
6. Innisfail Memory Clinic, Innisfail Hospital	Public	Outer Regional
7. Ipswich Health Plaza Memory and Geriatric Clinics, Ipswich Hospital[3]	Public	Major City
8. Mareeba Memory Clinic, Mareeba Hospital	Public	Outer Regional
9. Memory Clinic Princess Alexandra Hospital	Public	Major City
10. Neurosciences Queensland	Private	Major City
11. The Prince Charles Hospital Memory Clinic	Public	Major City
12. Redcliffe Hospital Memory Clinic	Public	Major City
13. Robert Adam Neurology	Private	Major City
14. Robina Private Hospital - Memory Clinic	Private	Major City
15. STARS Memory Clinic	Public	Major City
16. Your Brain in Mind	Private	Major City

Site	Type[1]	Location[2]
South Australia (n = 8)		
1. Central Adelaide Local Health Network Department of Geriatrics and Rehabilitation Medicine, Royal Adelaide Hospital	Public	Major City
2. Flinders Medical Centre Memory and Aged Care Clinics	Public	Major City
3. Murray Bridge Soldiers' Memorial Hospital Geriatric Services[3]	Public	Inner Regional
4. The Queen Elizabeth Hospital Memory Service	Public	Major City
5. Riverland General Hospital Geriatric Services[3]	Public	Outer Regional
6. Royal Adelaide Hospital Memory Service	Public	Major City
7. Sensus Cognition	Private	Major City
8. Specialist Ambulatory Rehabilitation Centre Memory Clinic, Modbury Hospital	Public	Major City
Tasmania (n = 4)		
1. David Dunbabin Aged Care	Private	Inner Regional
2. Hazel Bucher Nurse Practitioner Consultancy	Private	Inner Regional
3. The ISLAND Clinic	Private	Inner Regional
4. Dr Krishna Kalpurath, Calvary Health Care Sessional Rooms, Launceston	Private	Inner Regional
Victoria (n = 14)		
1. Austin Cognitive Dementia and Memory Service (CDAMS), Austin Health	Public	Major City
2. Bass Coast Health Geriatric Medicine Outpatient Services	Public	Inner Regional
3. Caulfield Cognitive Decline and Memory Service (CDAMS), Alfred Health	Public	Major City
4. Central Geriatrician Associates	Private	Major City
5. Professor Dennis Velakoulis, Church Street Consulting Suites	Private	Major City
6. Eastern Cognitive Disorders Clinic, Eastern Health	Public	Major City
7. Echuca Regional Health Cognitive Dementia and Memory Service	Public	Inner Regional
8. Grampians Cognitive Dementia and Memory Service (CDAMS), Grampians Health	Public	Inner Regional
9. Irene Wagner's Clinic	Private	Major City
10. Dr Jagadeesh Herur, Glencairn Private Consulting Suites	Private	Major City
11. Dr Jagadeesh Herur, Harvester Private Consulting Suites	Private	Major City
12. Dr Rebecca Iseli, Geriatrician, practising at North Melbourne Ear, Nose & Throat	Private	Major City
13. Royal Melbourne Hospital Neuropsychiatry Clinic, Royal Melbourne Hospital	Public	Major City
14. Western Health Cognitive Dementia and Memory Service (CDAMS), Footscray Hospital	Public	Major City
Western Australia (n = 1)		
1. Murdoch Psychiatry	Private	Major City

[1]Private sites include solo practitioners, group practices, university-based research clinics, and outpatient clinics within private hospitals

[2]Location categorised using Australian Statistical Geography Standard (ASGS) Edition 3 Remoteness Structure 2021

[3]Data collection is yet to commence at these sites

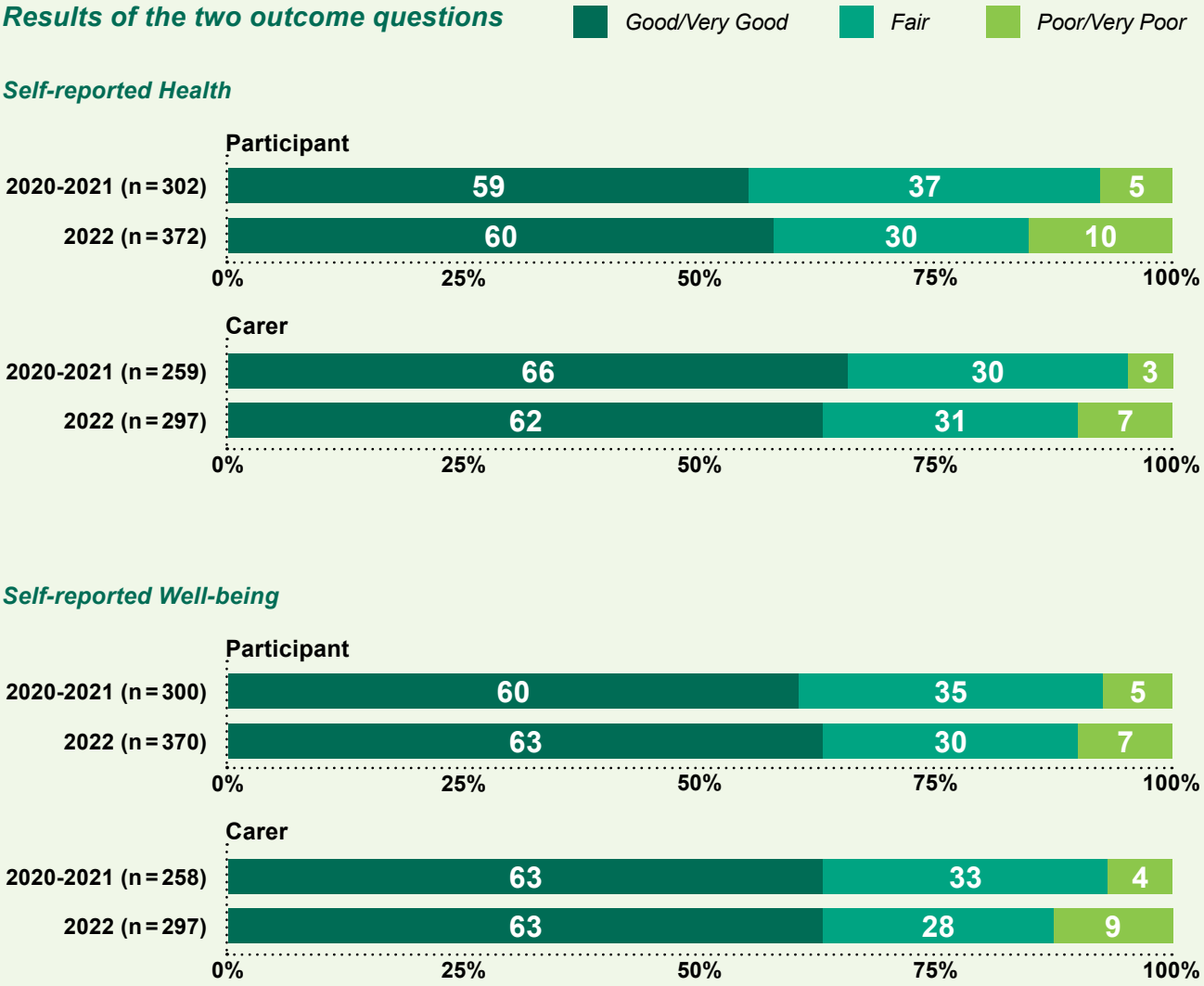
Appendix 5

Outcome and Experience Questions and Results

The ADNeT Registry Participant and Carer Surveys include two outcome and eight experience questions:

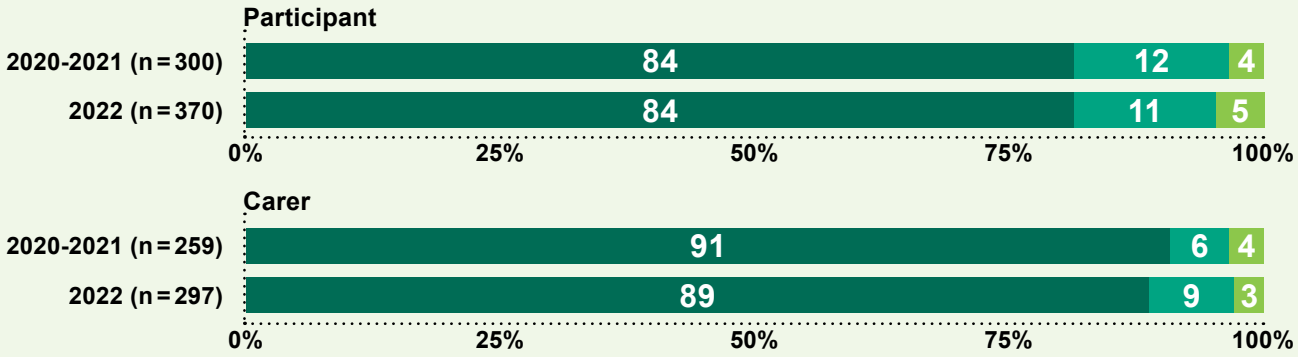
Participant Survey	Carer Survey
Outcome questions	
• Overall, how would you rate your health?	• Overall, how would you rate your health?
• Overall, how would you rate your well-being?	• Overall, how would you rate your well-being?
Experience questions	
• I received adequate information about my diagnosis.	• I received adequate information about my family member/friend's diagnosis.
• I was involved as much as I wanted in making decisions about my treatment and care.	• I was involved as much as I wanted in supporting my family member/friend in making decisions about their treatment and care.
• I was given the opportunity to ask questions.	• I was given the opportunity to ask questions as a family member/friend.
• My views and concerns were listened to.	• My views and concerns as a family member/friend were listened to.
• I was treated with dignity and respect.	• I was treated with dignity and respect.
• I was given advice about how and where I could get more information or help if needed.	• I was given advice about how and where I could get more information or help if needed.
• Overall my experience was (very poor, poor, fair, good, very good).	• As a family member/friend, my overall experience was (very poor, poor, fair, good, very good).
• Overall my experience met my expectations.	• Overall, my experience as a family member/friend met my expectations.

Results of the two outcome questions

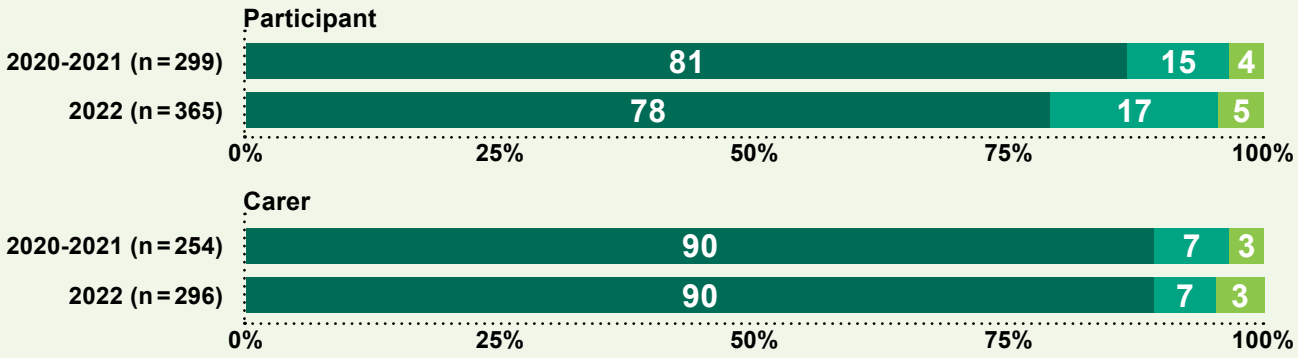


Results of the eight experience questions

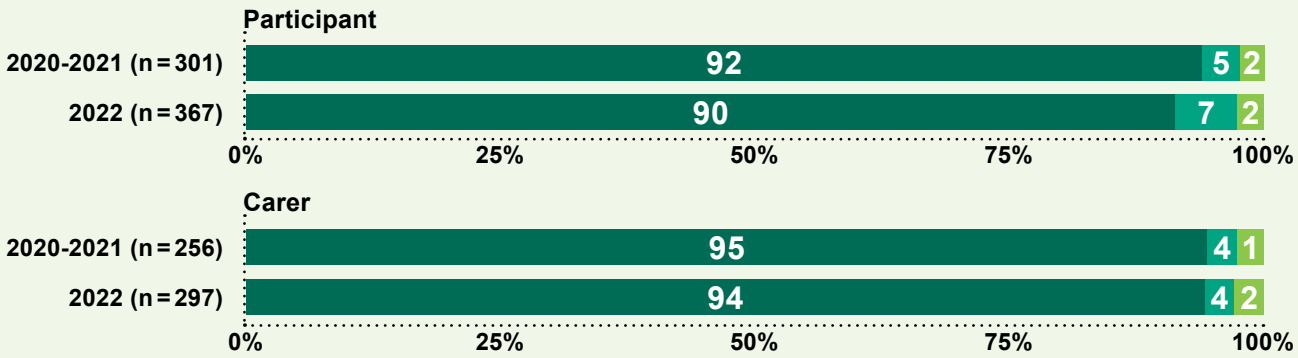
Received adequate information about diagnosis



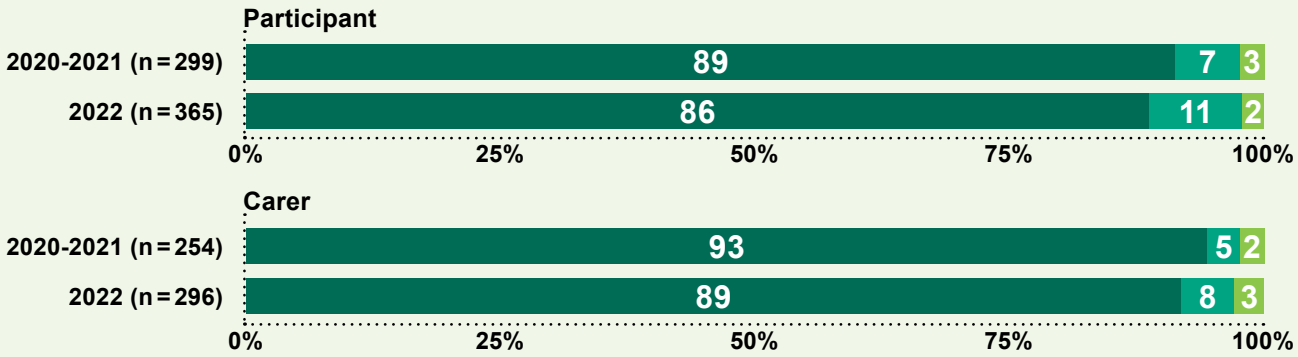
Involved in decision making

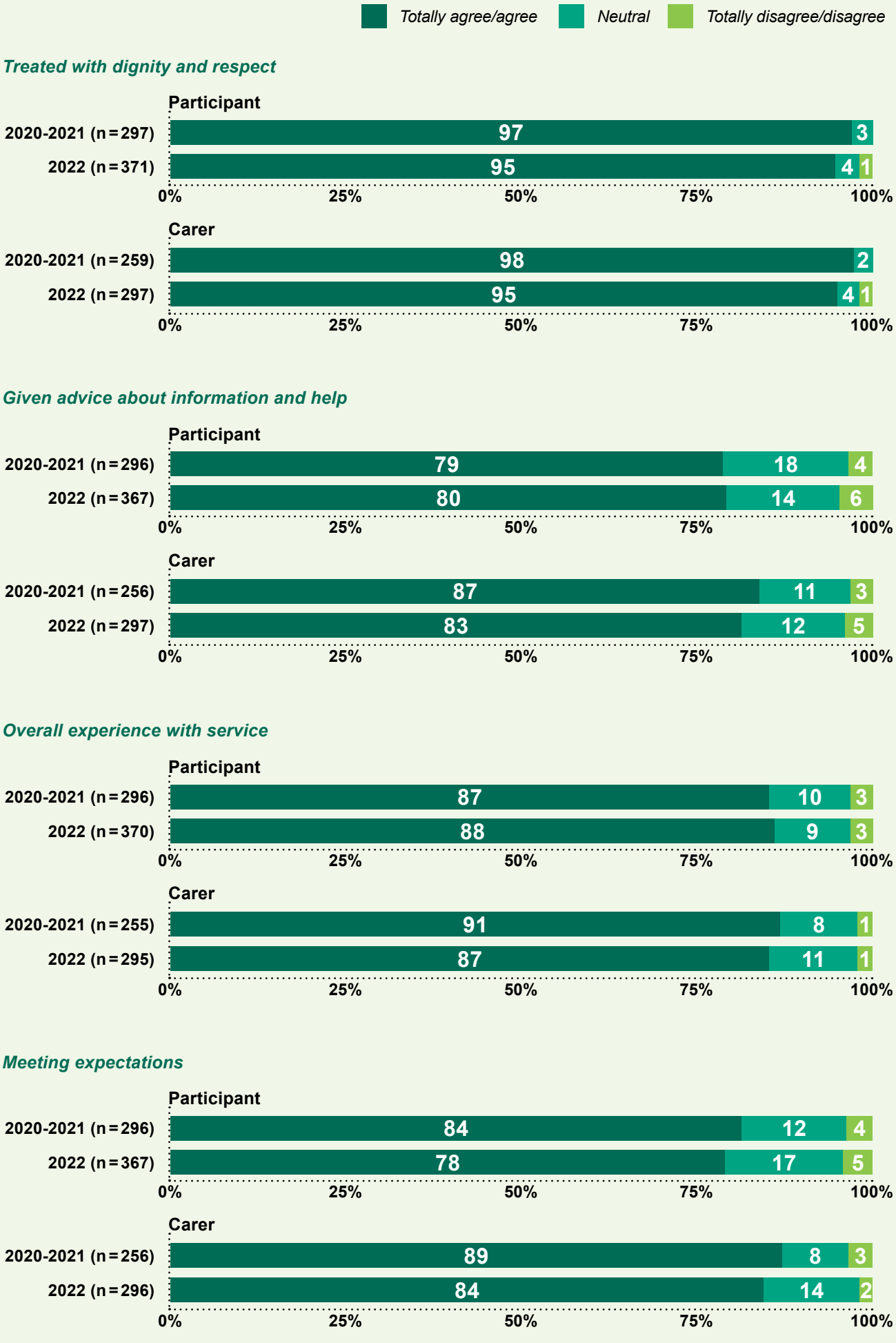


Opportunity to ask questions



Views and concerns were listened to




Totally agree/agree
Neutral
Totally disagree/disagree
Treated with dignity and respect
Participant
2020-2021 (n = 297)
97
3
2022 (n = 371)
95
4
1
0%
25%
50%
75%
100%
Carer
2020-2021 (n = 259)
98
2
2022 (n = 297)
95
4
1
0%
25%
50%
75%
100%
Given advice about information and help
Participant
2020-2021 (n = 296)
79
18
4
2022 (n = 367)
80
14
6
0%
25%
50%
75%
100%
Carer
2020-2021 (n = 256)
87
11
3
2022 (n = 297)
83
12
5
0%
25%
50%
75%
100%
Overall experience with service
Participant
2020-2021 (n = 296)
87
10
3
2022 (n = 370)
88
9
3
0%
25%
50%
75%
100%
Carer
2020-2021 (n = 255)
91
8
1
2022 (n = 295)
87
11
1
0%
25%
50%
75%
100%
Meeting expectations
Participant
2020-2021 (n = 296)
84
12
4
2022 (n = 367)
78
17
5
0%
25%
50%
75%
100%
Carer
2020-2021 (n = 256)
89
8
3
2022 (n = 296)
84
14
2
0%
25%
50%
75%
100%

2022 Annual Report

Australian
Dementia Network
REGISTRY. CLINICS. TRIALS.

MONASH
University

Ward SA, Brodaty H, Lin X, Wallis K, Honardoost MA, Tsui A, Lassetter C, Rowe C, Anstey K, Brodtmann A, Chong T, Darling G, Inacio M, Jeon Y-H, Kain B, Loi S, McCabe M, Naismith S, Natarajan K, Nelson M, Newton L, Pietsch A, Quirke L, Rand E, Yates M, Arsenova V, Earnest A, McAloney K, Pourghaderi AR, Rahja M, Richardson J, Tan S and Ahern S. The Australian Dementia Network (ADNeT) Registry 2022 Annual Report. Monash University, School of Public Health and Preventive Medicine, May 2023.