Australian Dementia Network Registry

2023 Annual Report

Australian Dementia Network
REGISTRY. CLINICS. TRIALS.

MONASH University

Data period:
The data contained in this report pertains to data submitted to the registry from commencement of data collection on 10 March 2020 to 31 December 2023, unless otherwise indicated. As the registry does not capture data in real time, there is a lag between occurrence of an event and data capture in the registry.

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Acknowledgement

The ADNeT Registry is supported by funding from the Australian Government, Department of Health and Aged Care, under the National Clinical Quality Registry Program.

The ADNeT Registry is part of the broader Australian Dementia Network (ADNeT) initiative. ADNeT Partners and ADNeT Supporters are listed below.

ADNeT Partners

ADNeT Supporters

ADNeT Registry Project Supporter

Foreword

Dementia continues to represent a significant public health challenge in Australia. In 2023, it was estimated that 411,100 Australians were living with dementia. It was the second leading cause of burden of disease, and the leading cause of burden of disease in those aged 65 years and over. Dementia was also the second leading cause of death. In the context of population ageing, the number of people with dementia is predicted to increase to 812,500 by 2054.

For people living with dementia, as well as their caregivers and families, dementia presents many challenges - from obtaining a diagnosis, to navigating support, to adjusting to changes in cognition and function. For clinicians too, meeting the demands of a growing number of people affected by dementia, within differing healthcare settings and with varying resources, presents almost an equal number of challenges.

The ADNeT Registry aims to improve the experiences of dementia diagnosis and treatment, from the perspectives of people living with dementia, their caregivers and their clinicians. It does this by the collection and reporting of data that can inform on the quality of clinical care, allowing sites to compare patient profiles, processes and to identify any areas for investigation and improvement. As this report presents, several sites have now been able to utilise ADNeT Registry data to formally evaluate their services, facilitate service planning, and even to support acquisition of a health service award for one service.

Nationally, such data can also identify disparities and trends at a broader level. In recognition of the value of the ADNeT Registry, and as detailed in this report, ADNeT Registry data will now be used by the Australian Institute for Health and Welfare to measure performance against the new National Dementia Action Plan. Registry data are also supporting aligned research studies, such as investigations into unique needs of diverse populations, and an investigation of factors associated with later dementia diagnosis.

Since 2020, the ADNeT Registry has been collecting clinical data from clinical sites where the diagnoses of dementia and mild cognitive impairment take place. We are indebted to the contributions from participating clinicians and clinical sites, from our diverse steering committee membership, including representatives from the Australian and New Zealand Society of Geriatric Medicine, the Australasian Cognitive Neurology Association, the Royal Australasian College of General Practitioners, Dementia Australia, and especially, to the many people with living experience who have made countless valuable contributions to the ADNeT Registry, through governance, working parties and co-design.

The Australian dementia clinical community stands on the cusp of anticipated great changes in diagnosis and treatment. Monoclonal antibodies targeting amyloid – the toxic protein plaques that accumulate in dementia due to Alzheimer's disease – have been approved for use in numerous countries worldwide. These represent the first of several novel dementia therapies that are anticipated to emerge in coming years. Meanwhile, blood-based biomarkers have the potential to revolutionise approaches to dementia diagnosis, providing a cheaper and more pragmatic solution to facilitate more accurate diagnoses. The ADNeT Registry is well poised to measure uptake, effectiveness and safety of any such new treatments and diagnostics, if, and when, they become available in Australia, by adaption of the minimum dataset.

For now, the 2023 Annual Report, containing data on 1,915 new participants from 60 clinical sites across all states in Australia, provides a much-needed snapshot into dementia and mild cognitive impairment diagnosis and initial management, and importantly, the experience of people living with these conditions as well as that of their caregivers.

We hope you will find this report of value.

Dr Stephanie Ward

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

Scientia Professor Henry Brodaty

Steering Committee Co-Chair University of New South Wales

Professor Susannah Ahern

Academic Lead Monash University

On behalf of the Australian Dementia Network (ADNeT), I am pleased to present the ADNeT Registry 2023 Annual Report. This report comes at a time when increasing dementia prevalence within our aging population highlights the urgent need for comprehensive, high-quality data to inform clinical practice, shape policy, drive critical research and improve health outcomes for Australians affected by dementia.

The ADNeT Registry has been driving continuous quality improvement in dementia diagnosis, treatment, service evaluation, and capacity building across participating sites. I am particularly proud of the Registry's growth to 60 contributing sites and 4,280 total participants in 2023. This increased engagement has enriched our data, allowing for more comprehensive analyses. With this broader involvement, more clinicians across the nation can leverage registry data to develop and refine their practice for dementia prevention, diagnosis, treatment, and care, while also gaining insights into long-term outcomes.

In 2023, the ADNeT Registry enhanced its scope by incorporating new data elements on dementia risk factors, underlying pathologies, neuropsychiatric symptoms, symptom duration, and initial post-diagnostic care. These additions have deepened our understanding of modifiable lifestyle factors, emphasised the critical value of neuropsychological and neuropsychiatric assessments, highlighted the urgent need for further research and the ongoing challenge of reducing wait times from referral to diagnosis and treatment. The insights gathered, as detailed in this report, will guide future efforts to better support healthcare providers, patients, and their carers and families.

The Registry's role in elevating clinical service standards is crucial in our ongoing efforts to combat dementia. However, our work is far from complete. We recognise the immense potential of the ADNeT Registry to further transform dementia and MCI treatment and care by monitoring efficacy and safety of new treatments and diagnostics.

My deepest gratitude to everyone who has contributed to this report and the dedicated work of the ADNeT Registry Team. Your commitment is vital to ADNeT's goal of service improvement and decreasing dementia prevalence in Australia.

Professor Christopher Rowe

Director, Australian Dementia Network

2023 Key Findings

Achievements

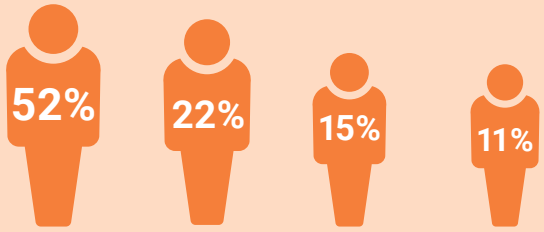
- 60 contributing sites
- 1915 new participants
- Expanded data collection
- Endorsement of a treatment module for post-market surveillance of new therapies

Diagnosis

37%
Mild cognitive impairment (MCI)

63%
Dementia

Dementia subtypes



Alzheimer's disease only | Mixed Alzheimer's & Vascular dementia | Others | Vascular dementia only

Demographics

MCI		Dementia
76 years	Median age	79 years
50%	Female	54%
2%	Aboriginal and/or Torres Strait Islander	2%
36%	Born overseas	34%
7%	Preferred spoken language as non-English	10%
7%	Primary or lower education	11%
90%	Retired	93%
88%	Living in private residence	83%
29%	Living alone	24%

Key clinical quality indicators

- **56%** Initial appointment within 90 days of referral
- **95%** Core blood tests undertaken
- **99%** Multiple cognitive domains assessed
- **90%** Structural neuroimaging completed
- **98%** Capacity to undertake activities of daily living assessed

This infographic pertains to data submitted to the ADNeT Registry between 1 January 2023 to 31 December 2023 (N=705 for MCI and 1210 for dementia) unless indicated otherwise. Refer to Appendix 1 for data from registry commencement in March 2020 to 31 December 2023.

Diagnostic wait times (median, days)

MCI		Dementia
83	Access time (referral to initial appointment)	76
26	Diagnosis wait time (initial appointment to diagnosis)	21
147	Overall wait time (referral to diagnosis)	126

Diagnostic investigations

MCI		Dementia
96%	Functional assessment/s	98%
93%	Core blood tests	92%
89%	Structural neuroimaging	89%

Initial management

MCI		Dementia
6%[1]	Acetylcholinesterase inhibitors	57%
50%	Future decision-maker appointed[1]	54%
Not collected	Referred to post-diagnostic program[1]	56%

Daily functioning

MCI		Dementia
93%	Independent in basic activities of daily living	73%
68%	Independent in instrumental activities of daily living	20%
66%	Currently driving	31%

Cognition (median test score)[2]

MCI		Dementia
26	Mini-Mental State Exam (MMSE)	21
22	Montreal Cognitive Assessment (MoCA)	17
24	Rowland Universal Dementia Assessment Scale (RUDAS)	18

Other management considerations

MCI		Dementia
40%	Neuropsychiatric symptoms[1]	52%
29%	Falls in past 12 months	32%
8%	Delirium history[1]	13%
56%	Five or more medications	53%

Living experience at time of diagnosis[3]

Participant	"Good" or "Very good" responses	Carer
64%	Self-reported health	67%
63%	Self-reported wellbeing	62%
91%	Overall experience with diagnostic services	92%
84%	Meeting expectations	87%

[1] Data were collected from April 2023 (N=542 for MCI and 904 for dementia)

[2] Test scores range from 0 to 30 with higher scores indicating higher levels of cognition

[3] Data were collected via self-completed surveys (N=661 for participant surveys and 533 for carer surveys in 2023)

Impact of the ADNeT Registry

Clinical quality registries (CQRs) take many years before they are mature enough to have population-level coverage and long-term outcome data. Despite this, CQRs can achieve impact within the first few years through supporting the community of clinicians and participating sites by providing valuable feedback regarding their clinical practice and patient-reported experience. Since its establishment in 2020, the Australian Dementia Network (ADNeT) Registry has supported participating sites in continuous quality improvement, service evaluation and planning, and capacity building. The registry has also supported research activities and is collaborating with the Australian Institute for Health and Welfare (AIHW) to provide much-needed data on dementia care.

Informing continuous quality improvement

The ADNeT Registry has been providing comprehensive individual benchmarked reports to participating sites every six months since December 2021. These reports include detailed information on participating sites' performance on key aspects of clinical practice benchmarked to other services and help participating sites to identify areas for quality improvement.

> *The ADNeT Registry site reports provide a useful summation of how our service is performing. We have utilised data on how our site is tracking in terms of clinical quality indicators and benchmarking these with comparable programs. This has assisted us to advocate for resource allocation to ensure our clients are receiving diagnostic assessments and investigations in a timely manner.*
>
> ***Beth Veevers, Austin Cognitive Dementia and Memory Service (CDAMS), Austin Health, Victoria***

> *The information we have received from the ADNeT Registry 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 assist in achieving a National Clinical Excellence Award at the Australian Private Hospital Association Awards for 2023.*
>
> ***Dr Penny King, Medical Director, Director of Older Persons Mental Health and Memory Clinic, Robina Private Hospital, Queensland***

Facilitating service evaluation

In addition to providing data on participating sites' performance on key aspects of clinical practice, the site reports also provide benchmarked information based on the demographic and clinical profile of their clients and patients' and carers' experience of the services. These reports help participating sites to better understand the characteristics of their patients and facilitate service evaluation and growth.

We have found the ADNeT Registry benchmarked data extremely useful in understanding our client profile and performance, as well as for the evaluation and future planning of our clinic. The value of this data was highlighted in our recent publication in 2023 which described the implementation and evaluation of our newly established clinic.

Associate Professor Jane Alty, The ISLAND Clinic, Tasmania

The ADNeT Registry has provided important feedback on patient and family experience of our service, which we have shared with our executive to support growth in the Cognitive Dementia and Memory Service.

Associate Professor Mark Yates, Grampians CDAMS, Grampians Health, Victoria

Supporting regular reporting and service planning

The ADNeT Registry also provides real-time site reports on the online data platform since 2023. Together with the comprehensive six-monthly site reports, these individualised reports support reporting activities at participating sites and provide valuable data to inform local service planning.

Our memory clinic has used data from the six-monthly and annual reports for educational sessions and benchmarking against other services. Participation in the ADNeT Registry also allows our clinic to use real-time data held within the registry's data platform to compile detailed reports for the Rehabilitation and Aged Care Clinical Network. These reports provide a snapshot into patient demographics, clinical outcomes, and service performance. Our post diagnostic follow-up service would not have been possible without the participant feedback data collected by ADNeT Registry, because comprehensive information on a patient's journey through our memory clinic is not readily available within the electronic patient record system.

Roseanne Hogarth, Clinical Nurse Consultant, Aged Care, Hornsby Ku-ring-gai Hospital, New South Wales

Participation in the ADNeT Registry has helped us understand our service better in terms of our patient profile, being able to benchmark against other services and assist us with resource allocation. The ADNeT Registry team provided us with an ad-hoc report to inform local service planning in anticipation of service expansion to support real-world roll-out of monoclonal antibody therapies for Alzheimer's disease. Access to this data has been invaluable and assisted us in developing a business case for disease modifying therapies in Alzheimer's disease within our region.

Dr Cathy Short, The Queen Elizabeth Hospital Neurology Memory Clinic, Central Adelaide Local Health Network, South Australia

Supporting research activities

The ADNeT Registry promotes secondary analyses of registry data to improve our understanding of dementia and MCI diagnostic care in Australia. The registry also supports research activities through connecting researchers with interested health services.

The ADNeT Registry is an inflexion point in improving care for people with dementia in Australia. As well as promoting practice improvement, we have found it an invaluable resource for our Geriatric Medicine Advanced Trainees to gain an understanding of the manifold benefits of registries and to utilise the rapidly growing dataset to generate their own research projects which they utilise for their Royal Australasian College of Physicians training.

Professor Gideon Caplan, Director of Geriatric Medicine, Prince of Wales Hospital, New South Wales

The ADNeT Registry team has been instrumental in facilitating engagement in our Enhanced Dementia Diagnosis research program with interested health services, supporting our understanding of data capture in ways specific to each of the health services and providing advice on databases and indicators. To date, through the ADNeT Registry team, we have been connected to five health services in Victoria who see diverse patient populations. Our team regularly reads the annual reports to understand the diagnosis landscape and this has informed our study processes and questions.

Associate Professor Darshini Ayton, School of Public Health and Preventive Medicine, Monash University, Victoria

Promoting capacity building

Participation in the ADNeT Registry has also helped capacity building among participating sites, particularly services with limited resources, such as services located in rural areas, as well as small and stand-alone services.

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 CDAMS, Victoria

Collaboration to support national dementia reporting

The ADNeT Registry has been recognised as an important initiative to improve dementia data in Australia [1,2] and is working with the AIHW to provide much-needed national data on dementia diagnostic care.

The ADNeT Registry collects high-quality clinical data that have the potential to work towards addressing key gaps in the national dementia data landscape. The AIHW have been collaborating with ADNeT Registry on providing data for outcome indicators that will be used to monitor the progress of the new National Dementia Action Plan, as well as exploring approaches to include registry data to administrative health and aged care datasets. The ADNeT Registry team has contributed greatly to this work, as both data providers and key advisors."

Melanie Dunford, Dementia Data Improvement Unit, AIHW

Dementia and Mild Cognitive Impairment (MCI) in Australia

What is dementia?

Dementia is a clinical syndrome that covers a wide range of conditions caused by abnormal changes to the brain[3-5]. These changes lead to impairment in cognition (e.g., memory, thinking, reasoning) and function sufficient to interfere with activities of daily living[3-5]. Common symptoms of dementia may include memory loss, word finding difficulties, impaired reasoning or judgement, problems with language, difficulty performing everyday tasks, and changes in mood and personality[3-5].

What is MCI?

Mild cognitive impairment (MCI) is a brain condition in which people experience subtle changes in their memory or other cognitive abilities (e.g., language, thinking) but remain independent in most activities of daily living[6-8]. People with MCI are at a greater risk of developing dementia[6-8]. However, not everyone with MCI develops dementia, and in many cases, the symptoms of MCI may stay the same or even improve over time[6-8].

Impact of dementia

Dementia is a major public health issue in Australia and globally[2, 9]. In 2023, more than 400,000 Australians were estimated to be living with dementia[2]. This is equivalent to approximately 15 people living with dementia per 1,000 Australians, and the number increases to 84 people with dementia per 1,000 Australians aged 65 and over[2]. With an ageing and growing population, the number of Australians living with dementia is projected to more than double and reach nearly 850,000 by 2060[2].

Dementia has become the second leading cause of death in Australia since 2013, accounting for 10% of all deaths in 2021[2]. For women and people aged 75 years and over, it was the leading cause of death[2]. Dementia was also the second leading cause of disease burden in Australia in 2023, and was the leading cause of burden for women and people aged 65 years and over[2].

Dementia has a profound impact, not only on the person living with dementia, but also on their families, carers, friends, and society at large. In 2023, it was estimated that at least 140,900 people provide ongoing, unpaid care to someone living with dementia, with half providing an average of 60 or more hours of care per week[2]. At a societal level, in 2020-2021, an estimated $3.7 billion of health and aged care expenditure was directly attributed to dementia, including $1.8 billion (49%) on residential aged care services, $740 million (20%) on community based aged care services, and $662 million (18%) on hospital services[2].

Diagnosis and management

Good clinical care for people living with dementia and MCI starts with a timely and supported diagnosis[10-13]. Medications, such as acetylcholinesterase inhibitors, may help with symptoms of dementia, and lifestyle modifications may attenuate risk of dementia for people with MCI, and rate of decline for those with dementia[10-13]. At the same time, connecting people living with dementia and MCI and their families and carers with post-diagnostic programs and support help them adjust to the diagnosis and plan for the future[10-13]. Additionally, there have been significant advances in the development of disease modifying therapies for dementia and MCI in recent years[14, 15,] and two monoclonal antibody therapies, that is, lecanemab and donanemab, have been approved for the treatment of MCI and Alzheimer's disease[16,17].

Current data gaps

There has been a persistent lack of high quality and comprehensive dementia data in Australia to inform evidence-based policy development, service provision and planning, and continuous quality improvement in dementia care[1,18]. The ADNeT Registry can help bridge this data gap by supporting national and international dementia benchmarking through purposefully collected data on the processes and outcomes of clinical care provided to people living with dementia[1,18,19]. In 2016, the Australian Commission on Safety and Quality in Heath Care prioritised dementia as a clinical domain for a clinical quality registry, based on the high burden of disease, significant consequences of poor-quality care, and support from relevant clinical groups[19]. Against this background, the ADNeT Registry has been established to track, benchmark, and report on the quality and outcomes of clinical care provided to people living with dementia and MCI[20].

Registry Overview

The ADNeT Registry is a clinical quality registry of people living with dementia or mild cognitive impairment (MCI)[20]. 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 post-diagnostic care and long-term outcomes.

Vision and aims

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[20].

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

Governance and funding

The ADNeT Registry is governed by a Steering Committee comprised of representatives from key stakeholder groups, including people with living experience of dementia, carers, peak bodies, clinical professional societies, clinicians, funders, as well as registry experts and researchers (refer to ***Appendix 2*** for membership). Additionally, a Clinician Management Committee provides clinical advice and guidance to the ADNeT Registry Steering Committee and supports engagement with participating sites.

The 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, oversees day-to-day operation of the registry.

The ADNeT Registry is part of Australian Dementia Network (ADNeT), a multi-institutional, Australia-wide consortium of dementia researchers and clinicians. The network was initially funded by the Boosting Dementia Research Initiative grant from the National Health and Medical Research Council's National Institute for Dementia Research and philanthropic organisations. ADNeT received additional funding from the Department of Health and Aged Care for fiscal years 2024 to 2025. From 1 July 2023, the ADNeT Registry is also supported by funding from the Australian Government, Department of Health and Aged Care, under the National Clinical Quality Registry Program.

Registry methodology

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

The ADNeT Registry collects data from participating sites, as well as participants and their carers (***Table 1***). After a participant is identified as eligible for the registry, the participating site enters personal, demographic, and clinical data based on the ADNeT Registry Minimum Data Set (see ***Appendix 3*** for detailed data elements and ***Appendix 4*** for information on data completeness). Following recruitment, where appropriate, the registry invites participants and identified carers to complete a survey which collects data on their health, well-being, and experience of clinical care of the participating site.

In the Registry's Third Annual Report, we present 2023 data (i.e., data submitted to the registry between 1 January to 31 December 2023), as well as comparison data collected from previous years.

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 (to participating site), Date of initial appointment (at participating site), 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 (if identified)	*Post recruitment*	*Participant and carer-reported outcomes*	*Health, Wellbeing*
		Participant and carer-experiences	*Receiving adequate information about diagnosis, Involvement in decision making, Opportunity to ask questions, Overall experience of clinical care*

Growth and Milestones

The ADNeT Registry achieved several key milestones in 2023, including:

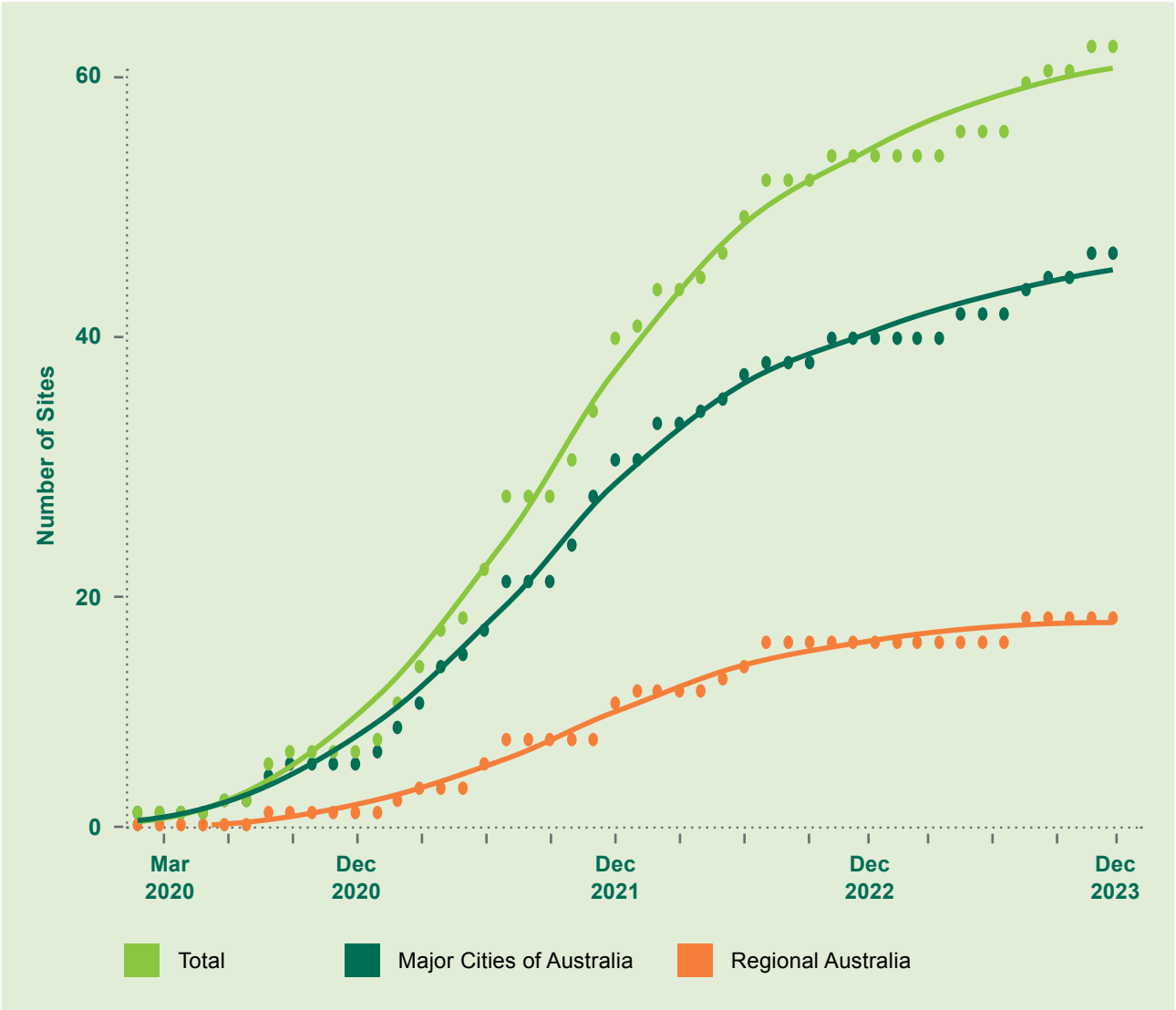
- **Increased site participation**
- **1915 new participants**
- **Expanded data collection**

Increased site participation

The ADNeT Registry continued to expand with an additional nine sites joining the registry in 2023, leading to a total of 64 participating sites (***Figure 1***). These sites 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).

Of the 64 participating sites, 60 (91%) contributed data in 2023 with 16 (27%) located in regional areas and 26 (43%) being private clinics (***Figures 2 - 3***). Refer to ***Appendix 5*** for a list of 2023 contributing sites.

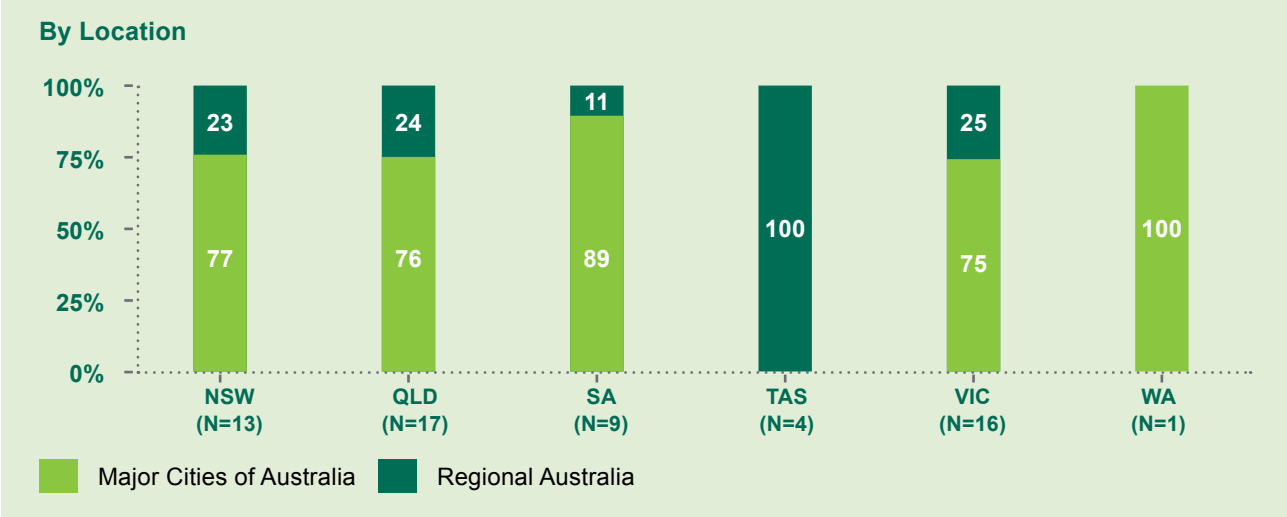
Figure 1 Participating sites over time

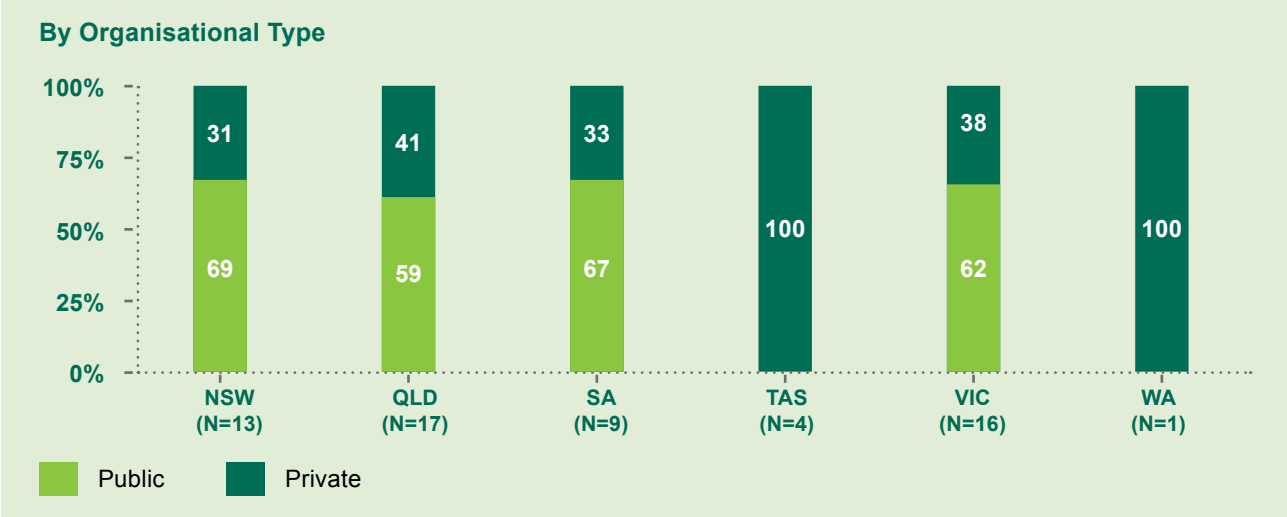


Note: Location categorised using Australian Statistical Geography Standard (ASGS) Edition 3 Remoteness Structure 2021

Figure 2 Geographic location of contributing sites

Figure 3 Characteristics of contributing sites





Notes:
Location categorised using Australian Statistical Geography Standard (ASGS) Edition 3 Remoteness Structure 2021
Private sites include solo practitioners, group practices, university-based research clinics, and outpatient clinics within private hospitals

Over 1900 new participants

In 2023, a total of 2092 participants were identified as eligible for inclusion in the registry. Of these, 1915 (92%) were recruited, leading to a total of 4280 participants at the end of 2023 (***Figure 4***).

Figure 4 Participant recruitment over time

The opt-out rate for the ADNeT Registry has maintained a downward trend and was 8% in 2023 (***Table 2***).

Table 2 Recruitment outcome information

Recruitment Outcome (%)	2020-2022 (N = 2640)	2023 (N = 2092)
Recruited	90%	92%
Opted out	10%	8%

Expanded data collection

In 2023, the ADNeT Registry transitioned to the revised Minimum Data Set, which included additional data elements on dementia risk factors, neuropsychiatric symptoms, and initial post-diagnostic care (e.g., appointments of future decision makers) to help better understand the quality and outcomes of clinical care. The results of these newly added data elements have been included in this Annual Report.

Other achievements

Other key achievements for the ADNeT Registry in 2023 included:

- Secured 4-year funding for the period between 2023 and 2027 from the Australian Department of Health and Aged Care under the National Clinical Quality Registry Program
- Implemented a more user-friendly online data platform where participating sites can see all their registry records in one place and generate real-time brief site reports
- Continued provision of bi-annual comprehensive individual benchmarked reports to participating sites
- Endorsed a treatment module to collect safety and efficacy data of new therapies following their approval by the Therapeutic Goods Administration
- Commenced collaboration with the National Centre for Monitoring Dementia to provide much-needed national data on dementia care
- Implemented translated registry invitation documents to encourage participation among people from non-English speaking backgrounds
- Commenced activities to support research projects and secondary analyses of registry data

ADNeT Registry Steering Committee and team members at the 2023 Australian Dementia Research Forum (from left to right): Xiaoping Lin, Stephanie Ward, Kasey Wallis, Alan Tsui, Susannah Ahern, Henry Brodaty, Lyntara Quirke

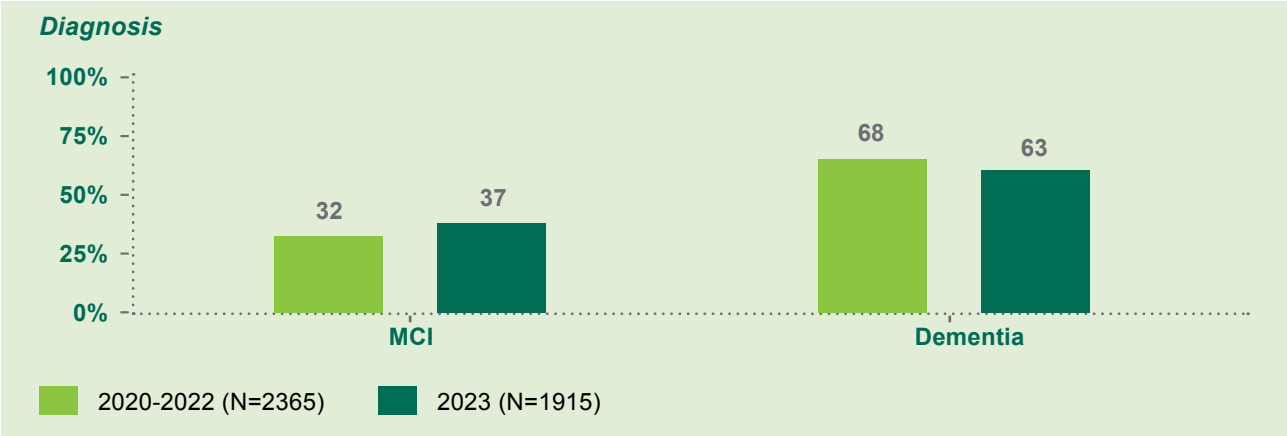
Who is in the Registry?

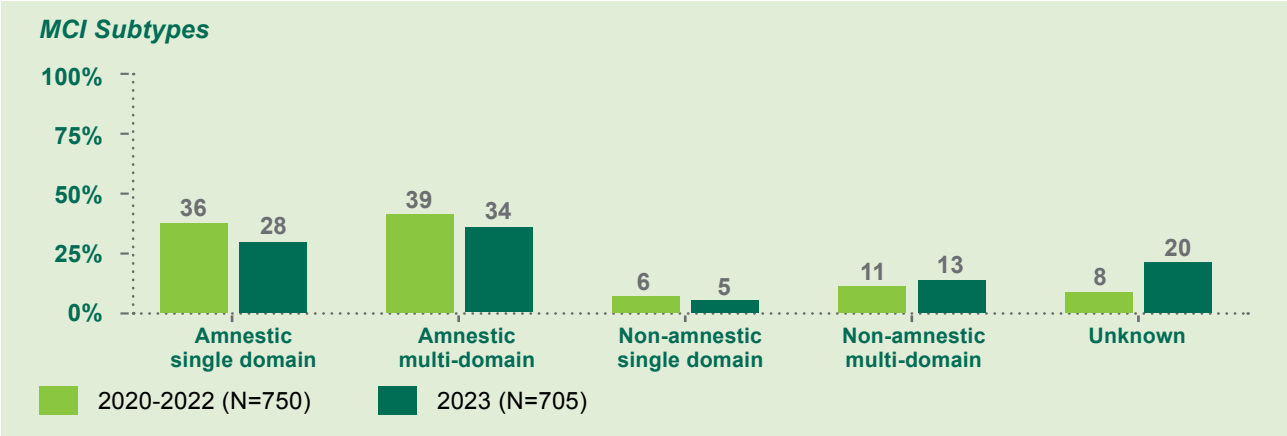
This section reports the diagnostic and demographic profile of people who have been recruited into the ADNeT Registry. This information helps us to understand the characteristics of Australians who were newly diagnosed with MCI or dementia.

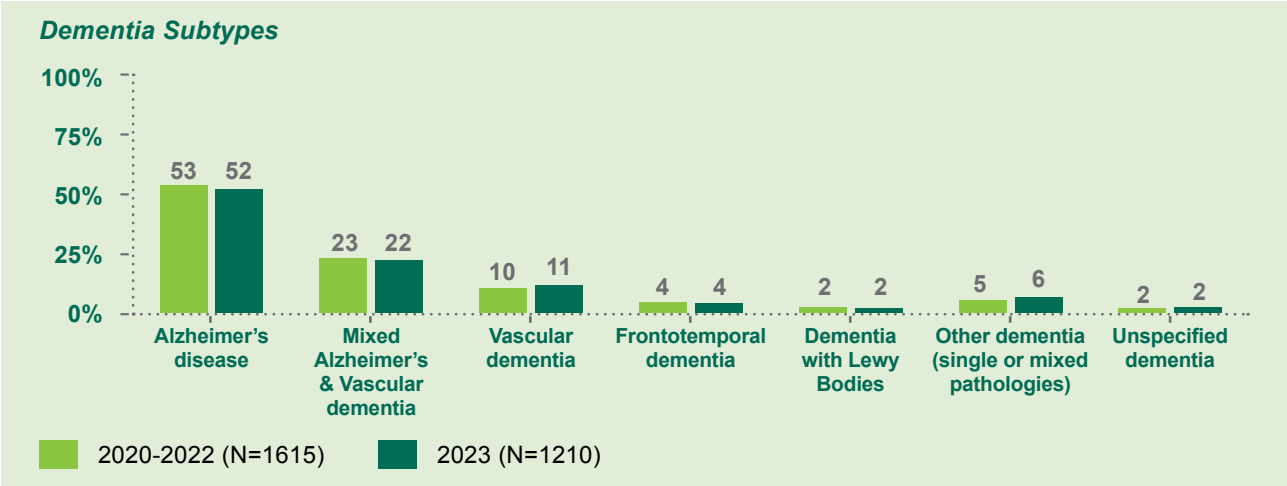
Diagnostic information

Of the 1915 participants who were recruited into the ADNeT Registry in 2023, 63% (n = 1210) were living with dementia and 37% with MCI (n = 705). Compared to previous years, there was a small increase in the percentage of people living with MCI in the registry. For the participants living with dementia, Alzheimer's disease remained the most common type, followed by mixed Alzheimer's and Vascular dementia (***Figure 5***).

Figure 5 Diagnostic information







In 2023, the ADNeT Registry has included an additional data element on probable underlying pathologies for MCI. Of the 542 participants who were eligible for this data element, 58% (n = 313) had known probable underlying pathologies, with Alzheimer's disease being the most common pathology, followed by Vascular cognitive impairment (n= 149, 27%). The remaining participants were not given a probable pathological diagnosis, probably because there is currently limited access to biomarkers to confirm the pathologies (see Section titled ***'Diagnostic investigations'*** for more information on the completion of biomarkers during the diagnostic process).

Demographic characteristics

In 2023, the median age at diagnosis remained as 76 years for people living with MCI and 79 years for those living with dementia. Over half of the registry participants were female and nearly 40% were born overseas (***Figure 6***).

Compared to the participants living with MCI, those living with dementia were more likely to have a language other than English as their preferred spoken language, have retired from work and live with family or others, but were less likely to have tertiary education or live in private residence.

Figure 6 Demographic information

2020-2022 (N = 750)	MCI	2023 (N = 705)
76 years	Median age	76 years
53%	Female	50%
2%	Aboriginal and/or Torres Strait Islander	2%
32%	Born overseas	36%
8%	Preferred spoken language as non-English	7%
8%	Primary education or lower education	7%
87%	Retired/not in labour force	90%
91%	Living in private residence	88%
27%	Living alone	29%
2020-2022 (N = 1615)	**Dementia**	**2023 (N = 1210)**
79 years	Median age	79 years
54%	Female	54%
1%	Aboriginal and/or Torres Strait Islander	2%
39%	Born overseas	34%
12%	Preferred spoken language as non-English	10%
12%	Primary education or lower education	11%
94%	Retired/not in labour force	93%
87%	Living in private residence	83%
27%	Living alone	24%

Notes:

Participants with unknown responses are included in the denominator

Data on living arrangement is not collected if residence is residential aged care facility, supported accommodation or unknown

Quality of Diagnostic Care

The primary aim of the ADNeT Registry is to collect and analyse data to monitor and enhance the quality and outcomes of diagnosis and care for people living with either dementia or MCI and their carers.
To achieve this aim, the registry collects and reports data on:

- Clinical quality indicators
- Diagnostic time intervals
- Diagnostic investigations
- Initial management post diagnosis

These data measure the 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 recommends making a diagnosis of dementia only after a comprehensive assessment, 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 activities of daily living
- Review of medications
- Laboratory tests (e.g., blood tests)
- Brain imaging (e.g., structural neuroimaging)[11]

Clinical quality indicators

Clinical quality indicators (CQIs) are specifically defined measures that can be used to monitor, evaluate, and improve key aspects of clinical care and important clinical outcomes[21, 22]. The ADNeT Registry Steering Committee has endorsed six CQIs (***Table 3***) based on a modified Delphi study[23].

Table 3 Performance on the six endorsed clinical quality indicators

Clinical Quality Indicator (%)	2020-2022 (N = 2365)	2023 (N = 1915)
1: Initial appointment within 90 days of referral	**62%**	**56%**
2: Core blood tests undertaken as part of diagnosis	**96%**	**95%**
3: Multiple cognitive domains assessed as part of diagnosis	**99%**	**99%**
4: Structural neuroimaging completed as part of diagnosis	**93%**	**90%**
5: Capacity to undertake activities of daily living assessed as part of diagnosis	**98%**	**98%**
6: Acetylcholinesterase inhibitor prescribed/recommended for mild to moderate Alzheimer's disease		
• People < 85 years old	**75%**	**78%**
• People ≥ 85 years old	**52%**	**51%**

Notes:

Participants with unknown responses are excluded in the denominators

Mild to moderate Alzheimer's disease is defined as having a score of 10 or higher on the Mini-Mental State Exam

Of these CQIs, the first five are used to help understand the quality of diagnostic care, as they capture the aspects of clinical practice considered the best standard. In 2023, most registry participants received good quality of diagnostic care, with four of the CQIs achieving 90% or higher. The only exception was the first CQI, that is, "initial appointment within 90 days of referral", where the performance was 56%.

The last CQI, that is, "acetylcholinesterase inhibitor (AChEI) prescribed/recommended for mild to moderate Alzheimer's disease", is used to examine variations in clinical practice. Internationally, AChEI prescription has been included as a CQI in dementia registries[24, 25]. The ADNeT Registry recognises that in some clinical scenarios AChEI may be contraindicated, or the participant may decline prescription of such medications. In 2023, of the participants living with mild to moderate Alzheimer's disease and aged under 85 years, three quarters (or 78%) were prescribed or recommended AChEI at the time of diagnosis, and the percentage decreased to 51% among the participants aged 85 years and over.

Compared to previous years, the performance on the six CQIs remained relatively stable in 2023. The only exception was the first CQI (i.e., initial appointment within 90 days of referral) where there was a reduction in the performance. Refer to the next section titled ***'Diagnostic time intervals'*** for more detailed data on access and wait times.

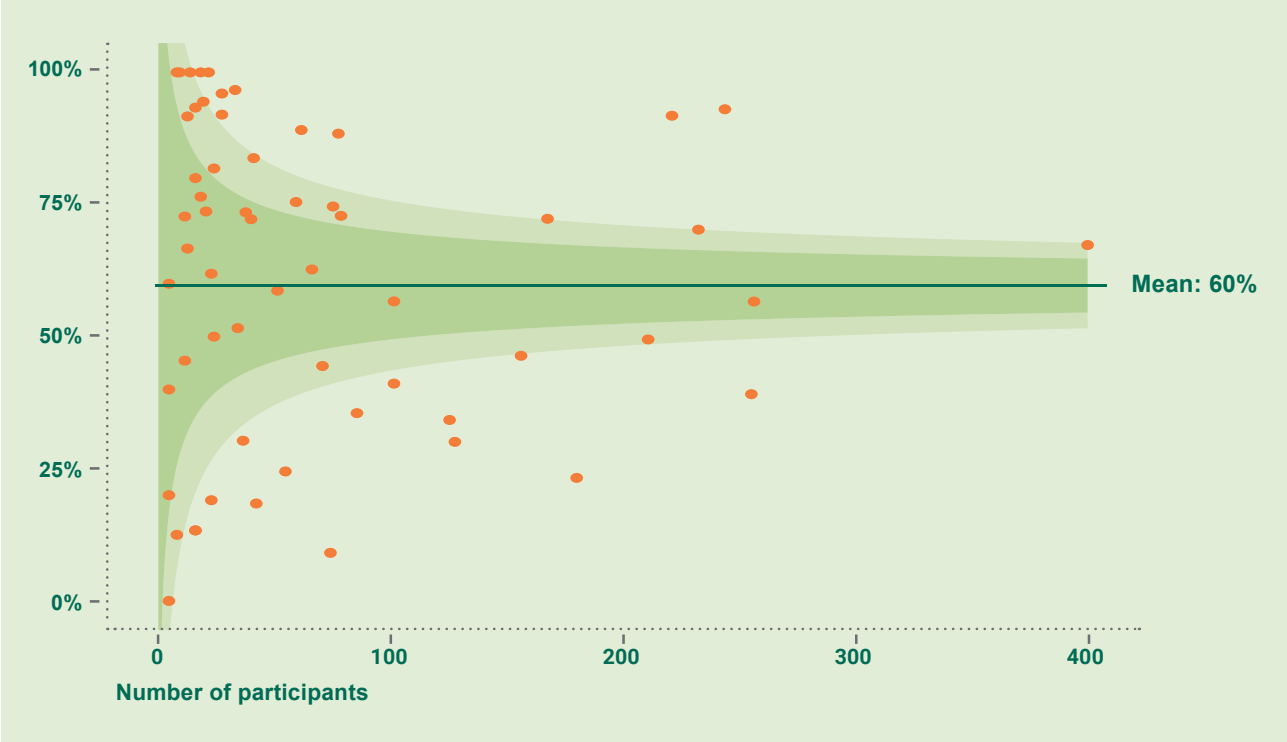
In addition to examining the performance on these CQIs over time, the ADNeT Registry explores the extent of variations in the performance across participating sites using funnel plots. Funnel plots are a visual representation of how an individual participating site performs compared to their peers and the overall average. To minimise misinterpretation of site performance, we used data from 2020 to 2023 and excluded sites having less than five participants.

In funnel plots (***Figures 7 to 12***):

- Each dot represents a site
- The horizontal axis (x-axis) indicates the number of the participants
- The vertical axis (y-axis) indicates the performance of the CQI
- The horizontal dashed line indicates the average performance across sites (noting the value might be different to those reported in ***Table 3*** as sites with less than five participants were excluded in funnel plots)
- The two shaded areas represent the 95% and 99.8% control limits, which are two standard deviations and three standard deviations from the average and reflect the expected variation due to chance

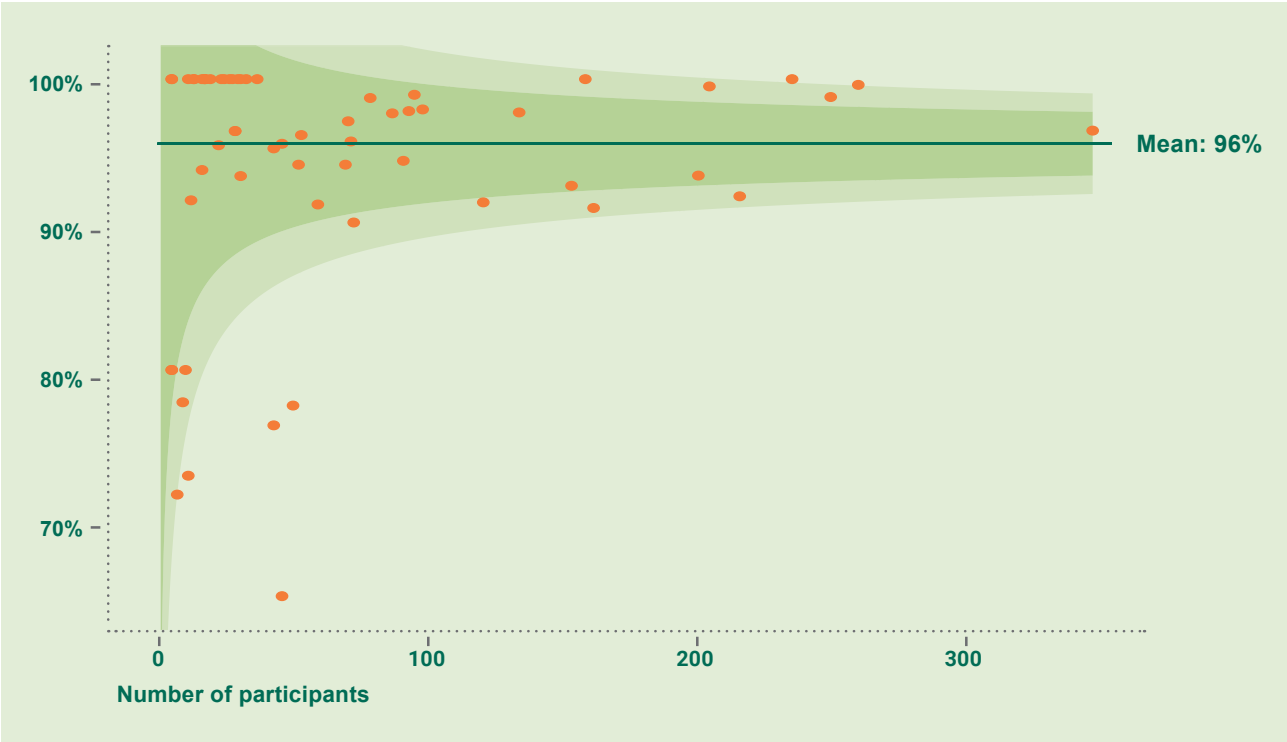
Fifty-nine (92%) of the 64 participating sites were included in the funnel plot for the first CQI (i.e., initial appointment within 90 days of referral) (***Figure 7***). Their performance on this CQI ranged from 0% to 100%, with 60% being the average. Thirty-three sites (56%) performed above average.

Figure 7 Funnel plot for "initial appointment within 90 days of referral"



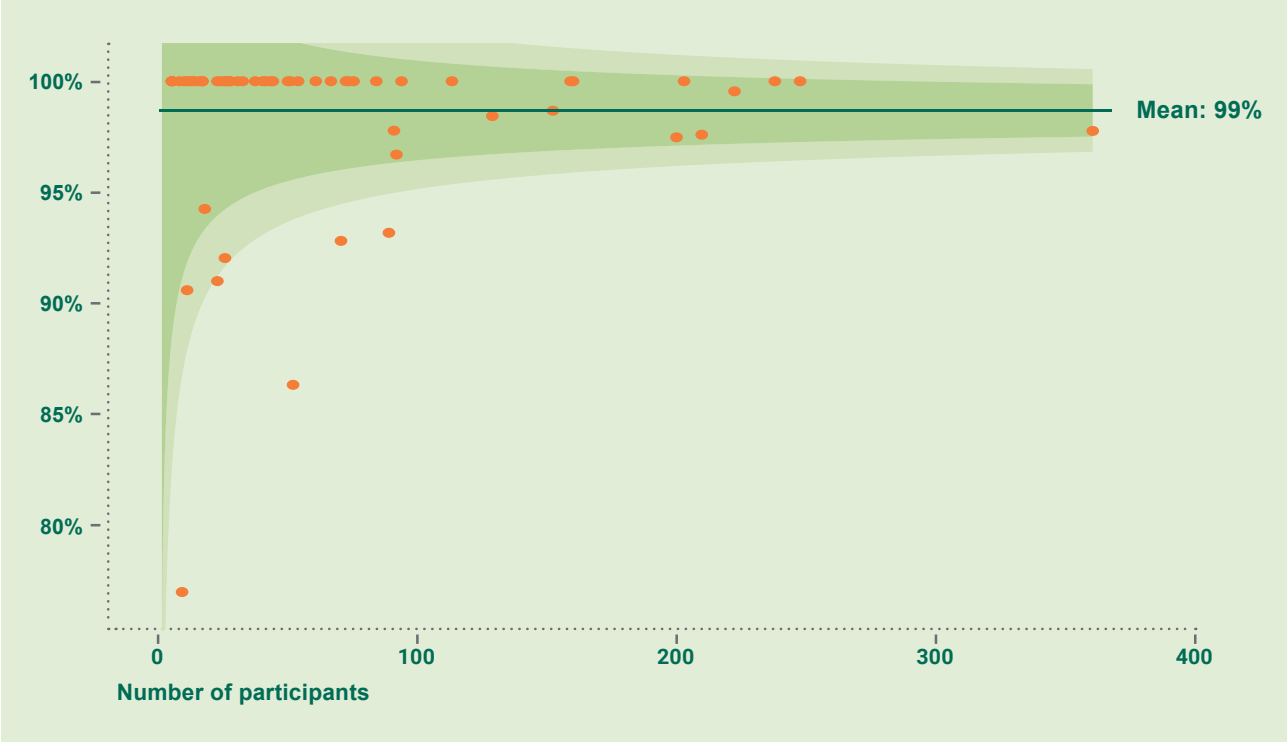
For the second CQI (i.e., core blood tests undertaken as part of diagnosis), the performance ranged from 64% to 100% across 60 (94%) included sites (***Figure 8***). The average performance was 96% and 35 (58%) sites performed above average.

Figure 8 Funnel plot for "core blood tests undertaken as part of diagnosis"



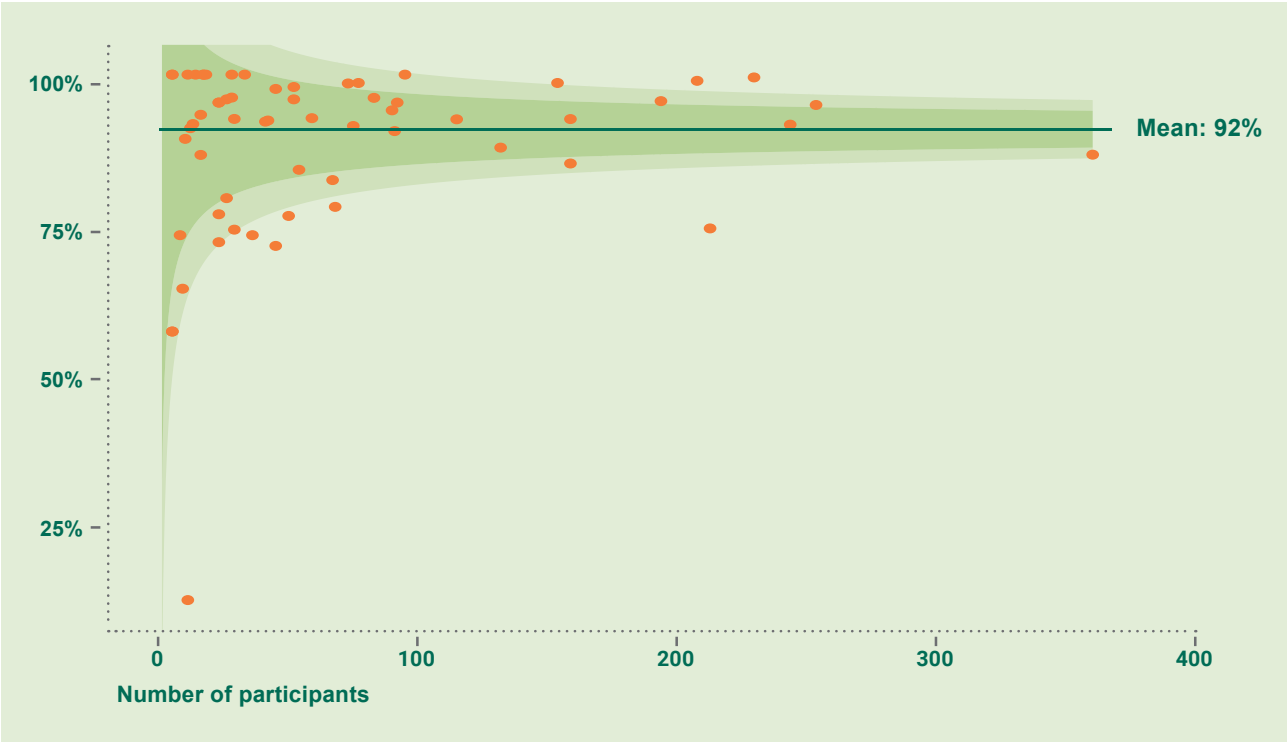
For the third CQI (i.e., multiple cognitive domains assessed as part of diagnosis), 60 sites (94%) were included in the funnel plot, with performance ranging from 78% to 100% (***Figure 9***). The average performance was 99% and 45 sites (75%) performed above average.

Figure 9 Funnel plot for "multiple cognitive domains assessed as part of diagnosis"



The funnel plot for the fourth CQI (i.e., structural neuroimaging completed as part of diagnosis) included 60 sites (94%) (***Figure 10***). The performance ranged from 18% to 100%, with an average of 92%. Thirty-eight sites (63%) performed above average on this CQI.

Figure 10 Funnel plot for "structural neuroimaging completed as part of diagnosis"

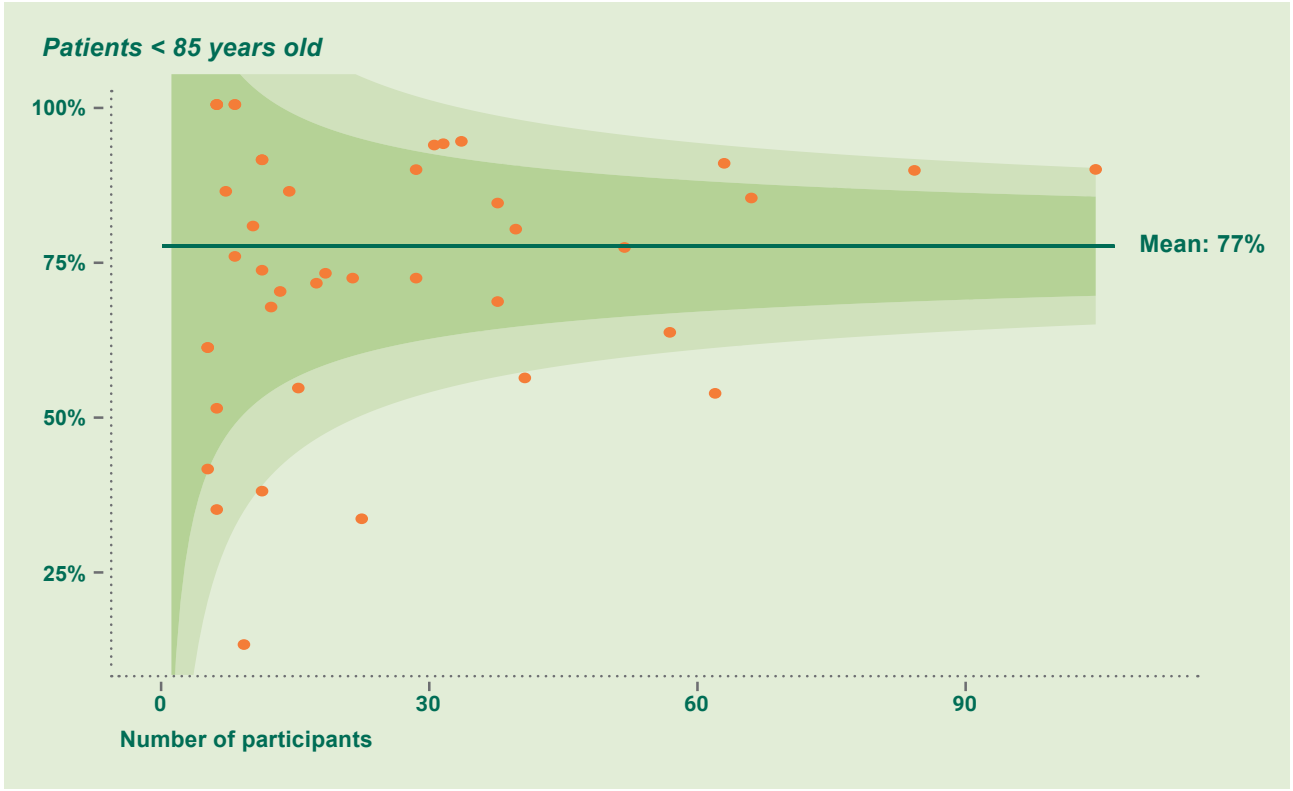


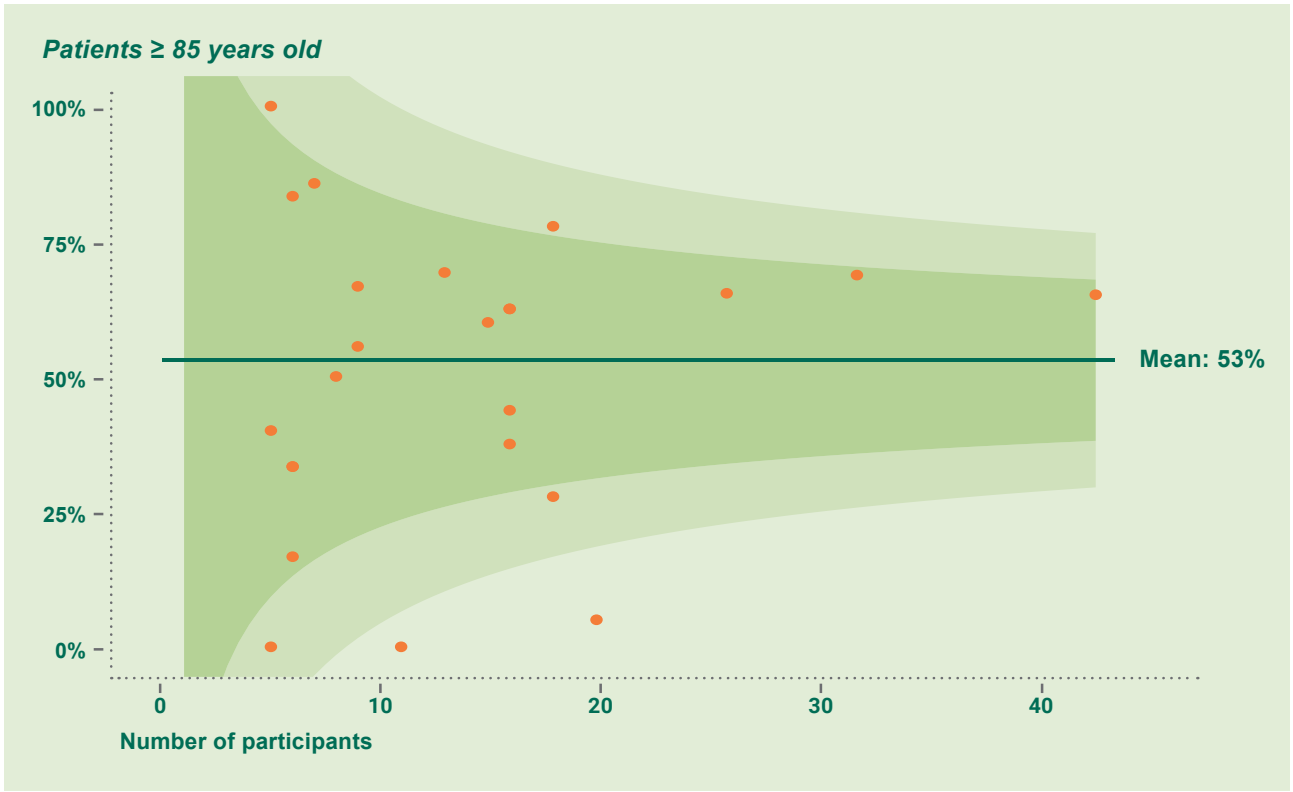
There were 59 (92%) sites included in the funnel plot for the fifth CQI (i.e., capacity to undertake activities of daily living assessed as part of diagnosis). The performance ranged from 91% to 100% and the average was 98% (***Figure 11***). Thirty-eight (64%) sites performed above average.

Figure 11 Funnel plot for "capacity to undertake activities of daily living assessed as part of diagnosis"

As in ***Table 3***, the funnel plots for the last CQI, AChEI prescribed/recommended for mild to moderate Alzheimer's disease, were stratified by two age groups (under 85 years vs 85 years and older). Compared to previous CQIs, fewer sites and participants were included in the funnel plots as this CQI is only applicable to participants living with mild to moderate Alzheimer's disease (defined as having a score of 10 of higher on the Mini-Mental State Exam). There were 43 (67%) sites included in the funnel plot for participants aged under 85 years, with the performance ranging from 11% to 100%, an average of 77%, and 20 (47%) sites performing above average (***Figure 12***). Only 25 (39%) sites were included in the funnel plot for participants aged 85 years. The performance ranging from 0% to 100% and the average was 53%, with 13 (52%) sites performing above average.

Figure 12 Funnel plots for "AChEI prescribed/recommended for mild to moderate Alzheimer's disease"





Diagnostic wait times

Timely diagnosis is a key marker for good quality clinical care[11]. There can be many barriers to timely diagnosis, one of which is access time, that is, wait time from referral to the initial appointment at a memory and cognition clinic[26]. In 2023, the median access time was:

- 83 days (or 2.8 months) for an MCI diagnosis
- 76 days (or 2.5 months) for a dementia diagnosis (***Figure 13***)

Following the initial appointment, many investigations need to be conducted before a diagnosis of dementia or MCI can be made. Diagnosis wait time refers to the time interval between the initial appointment and the diagnosis. In 2023, the median diagnosis wait time was:

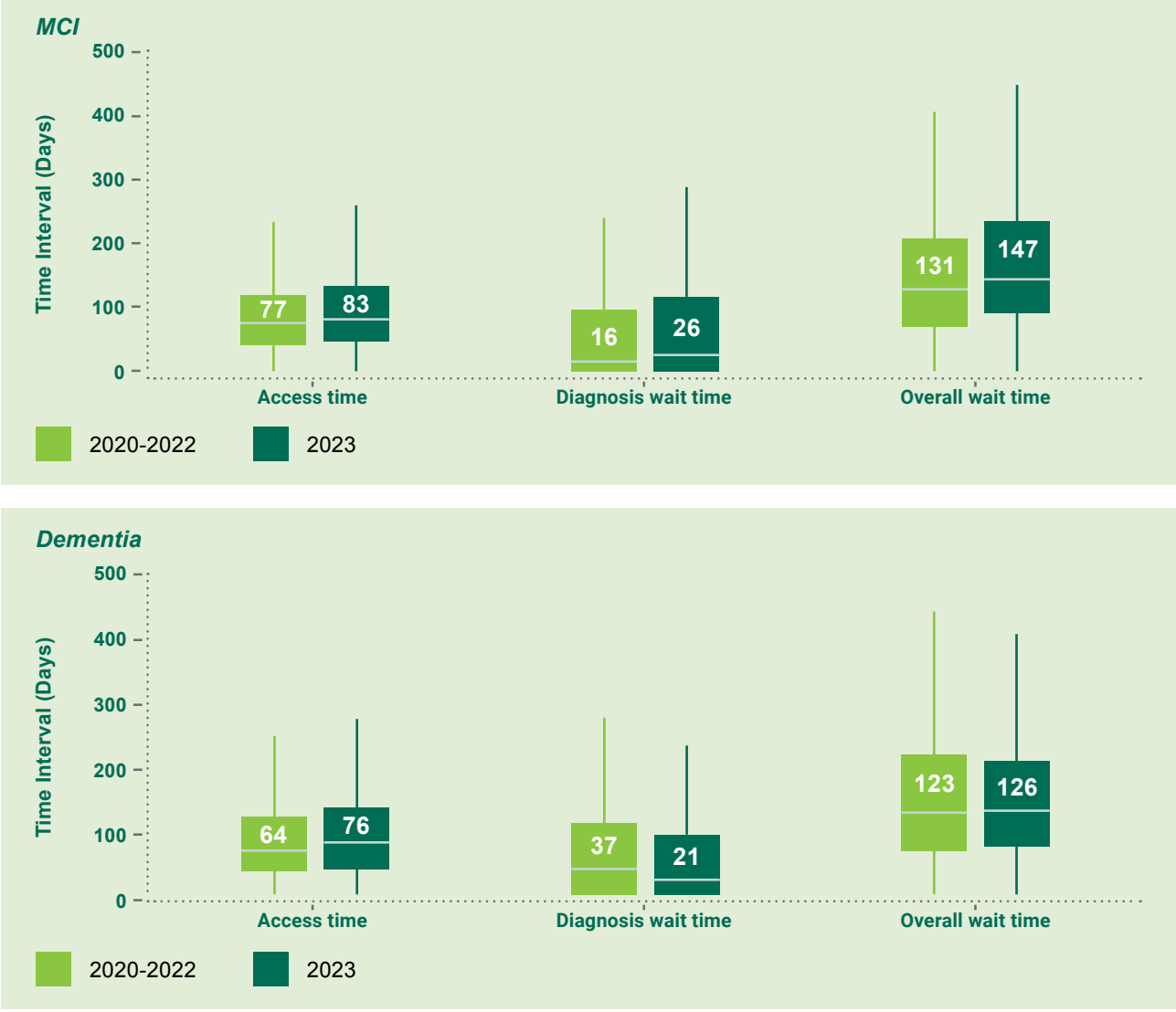
- 26 days (or 0.9 months) for an MCI diagnosis
- 21 days (or 0.7 months) for a dementia diagnosis

Taken together, in 2023, the overall wait time from referral to diagnosis was:

- 147 days (or 4.9 months) for an MCI diagnosis
- 126 days (or 4.2 months) for a dementia diagnosis

Compared to previous years, there was an increase in 2023 in all three wait times along the MCI diagnostic pathway. In contrast, although there was an increase in 2023 in the access time (76 vs 64 days), there was a reduction in the diagnosis wait time (21 vs 37 days). As a result, the overall wait time for a dementia diagnosis in 2023 was comparable to previous years (126 vs 123 days).

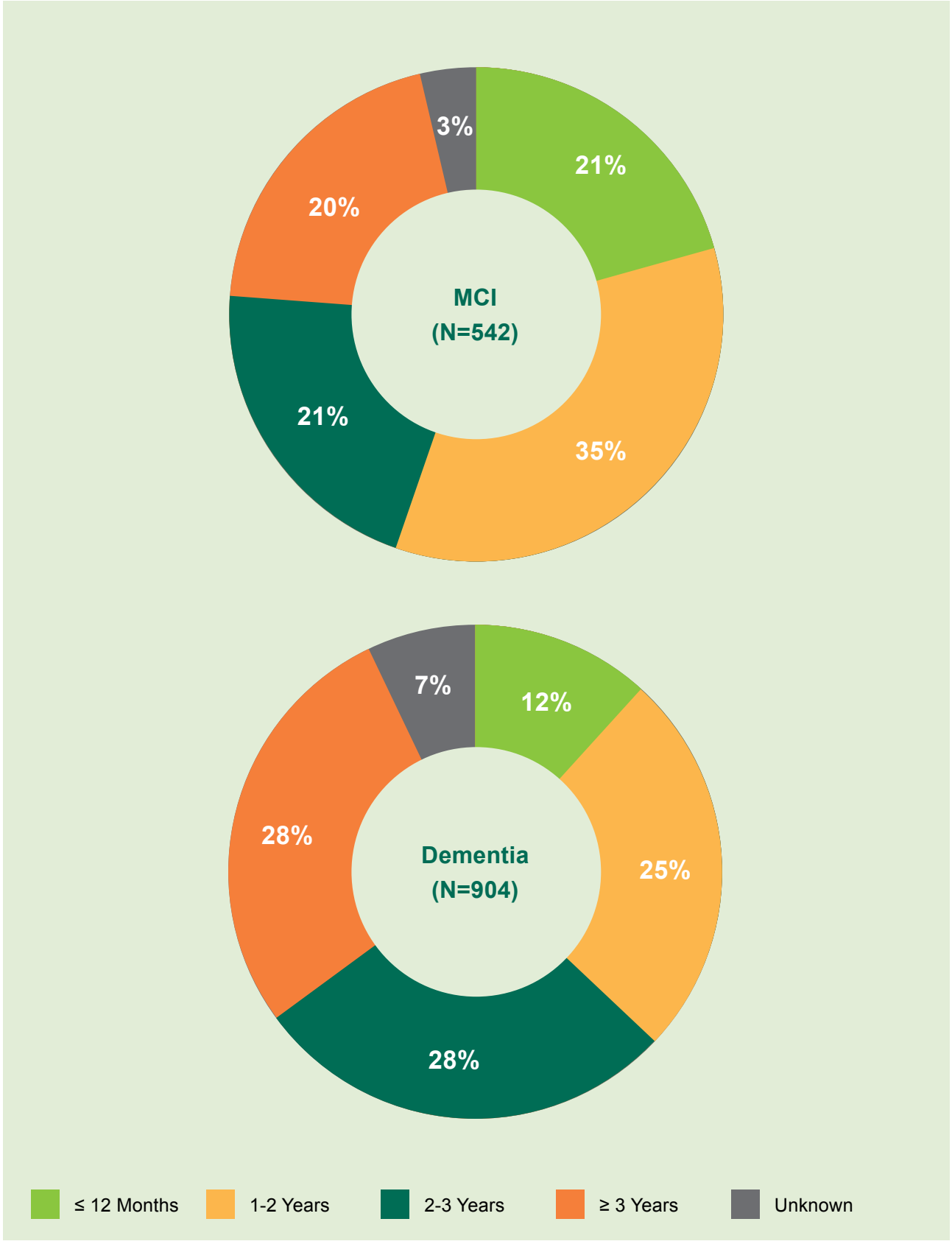
Figure 13 Box plots of diagnostic wait times



Note: Box plots are a visual representation of how the values in the data are spread out. The central box represents the interquartile range (IQR), which contains the middle 50% of the data. The line (and the number) inside the box indicates the median, which is the middle value of the data. The lower edge of the box represents the first quartile (the value at which the first 25% of the data falls up to) and the upper edge represents the third quartile (the value at which 75% of the data falls up to). The "whiskers" extend from the box to the smallest and the largest values (excluding outliers).

To better understand the dementia and MCI diagnostic pathway, the ADNeT Registry included a data element on symptom duration in the revised Minimum Data Set. As can be seen in ***Figure 14***, among the participants living with MCI, 41% had symptoms related to cognitive impairment for more than two years at the time of initial appointment, and the percentage increased to 56% among the participants living with dementia.

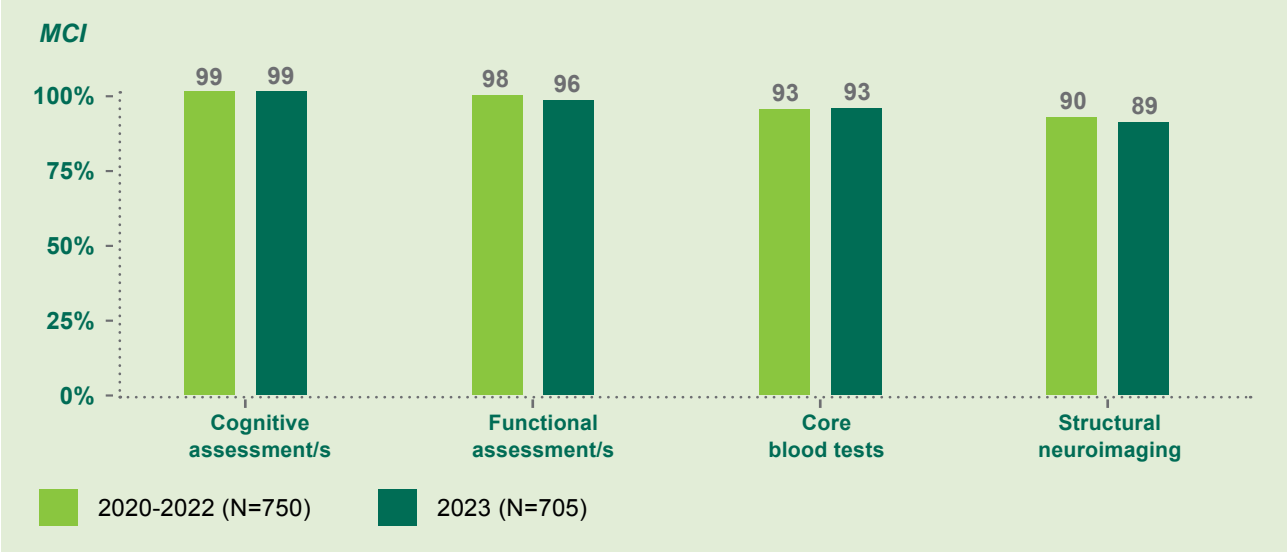
Figure 14 Symptom duration

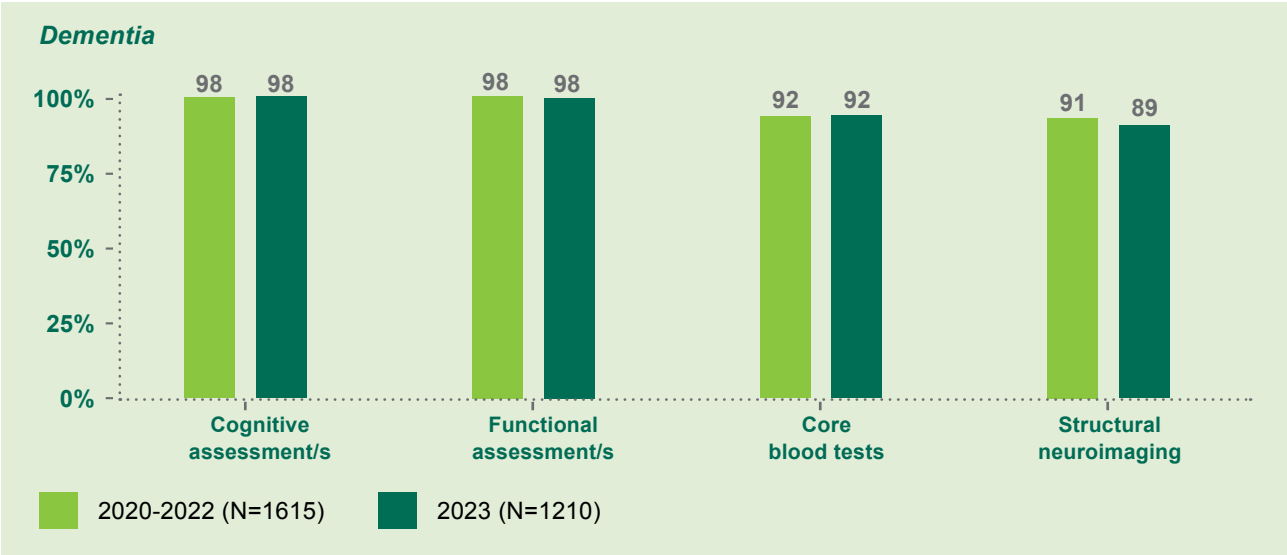


Diagnostic investigations

In 2023, most participants had comprehensive assessments completed as part of the diagnostic process, which comprised cognitive and functional assessments, blood tests, and structural brain neuroimaging (***Figure 15***).

Figure 15 Completed diagnostic investigations





Note: Participants with unknown responses are included in the denominator

For cognitive assessments, the ADNeT Registry records the use of the following four assessments, including:

- Mini-Mental State Exam (MMSE)
- Montreal Cognitive Assessment (MoCA)
- Kimberley Indigenous Cognitive Assessment (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 culturally and linguistically diverse backgrounds[11]. Of these assessments, MMSE remained most used and the use increased to over 70% in 2023 (***Figure 16***). The use of RUDAS was in line with the percentage of participants who had a language other than English as their preferred spoken language. Between 2020 and 2023, KICA was used only with two participants.

Figure 16 Completed cognitive assessments

Note: Participants with unknown responses are included in the denominator

Magnetic resonance imaging (MRI) remained more commonly used for structural neuroimaging than computed tomography (CT) (***Figure 17***). Functional neuroimaging, such as fluorodeoxyglucose positron emission tomography (FDG PET) or single-photon emission computed tomography (SPECT), may be required when other diagnostic methods are inconclusive[13]. There was a small increase in this use, with 30% participants having it completed in 2023 vs 25% in 2020-2022. Additionally, the use of FDG PET increased to 31% in 2023, whereas the use of SPECT decreased to 3%.

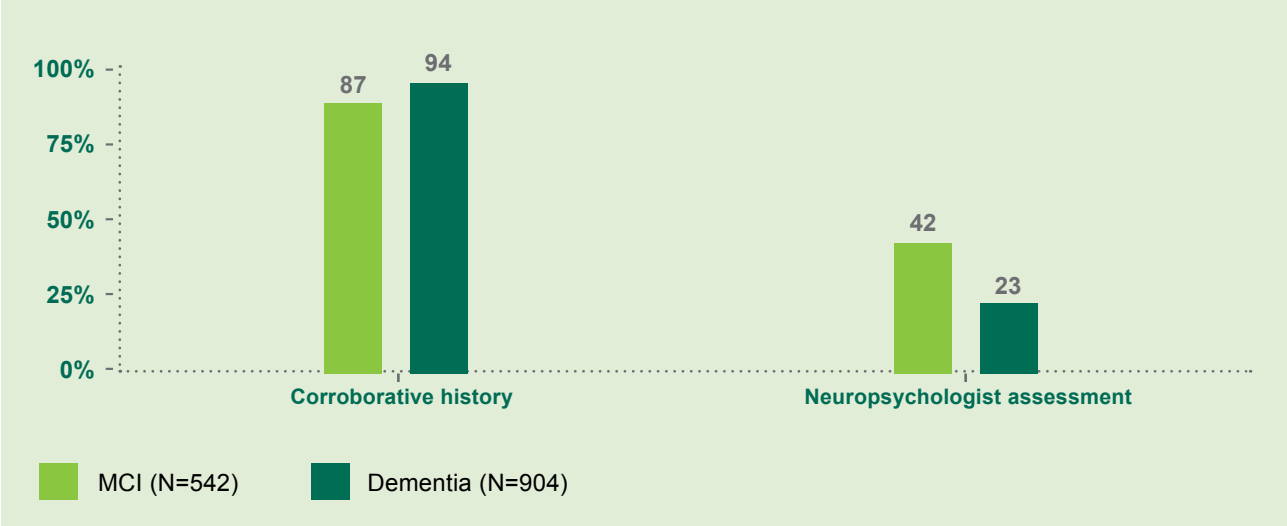
Figure 17 Completed neuroimaging

Note: Participants with unknown responses are included in the denominator

In line with recent developments in biomarkers[27], the ADNeT Registry expanded data collection to include additional types of biomarkers. However, biomarkers remained rarely used in 2023 (less than 5%), reflecting limited access to these investigations.

The registry has also included data elements on two other aspects of the diagnostic process (corroborative history provided by informant and neuropsychologist assessment) to better understand the quality of diagnostic care for people living with dementia and MCI. While most participants had history taken from an informant, less than half had a neuropsychologist assessment (***Figure 18***).

Figure 18 Corroborative history and neuropsychologist assessment



Note: Participants with unknown responses are included in the denominator

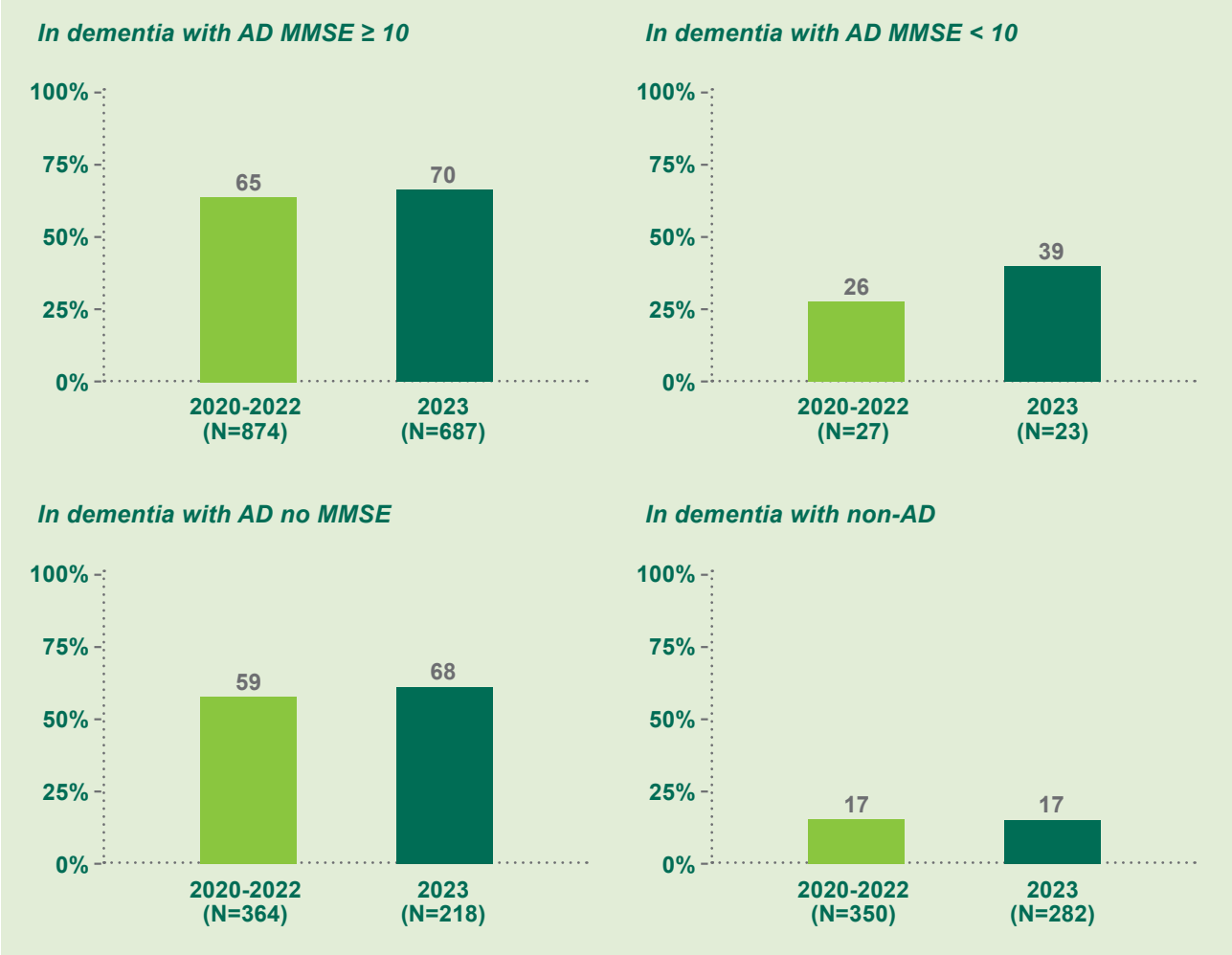
Initial management

The Australian Clinical Practice Guidelines and Principles of Care for People with Dementia recommends consideration of acetylcholinesterase inhibitor (AChEI) for managing symptoms of mild to moderately severe Alzheimer's dementia[11], and 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 and 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

There was a small increase in the percentage of AChEI prescription among the participants living with Alzheimer's dementia and an MMSE score of 10 or higher at diagnosis in 2023 (70% vs 65% in 2020-2022). This increase was also seen among the participants living with Alzheimer's dementia and an MMSE score lower than 10, as well as those living with Alzheimer's dementia and without an MMSE score (***Figure 19***).

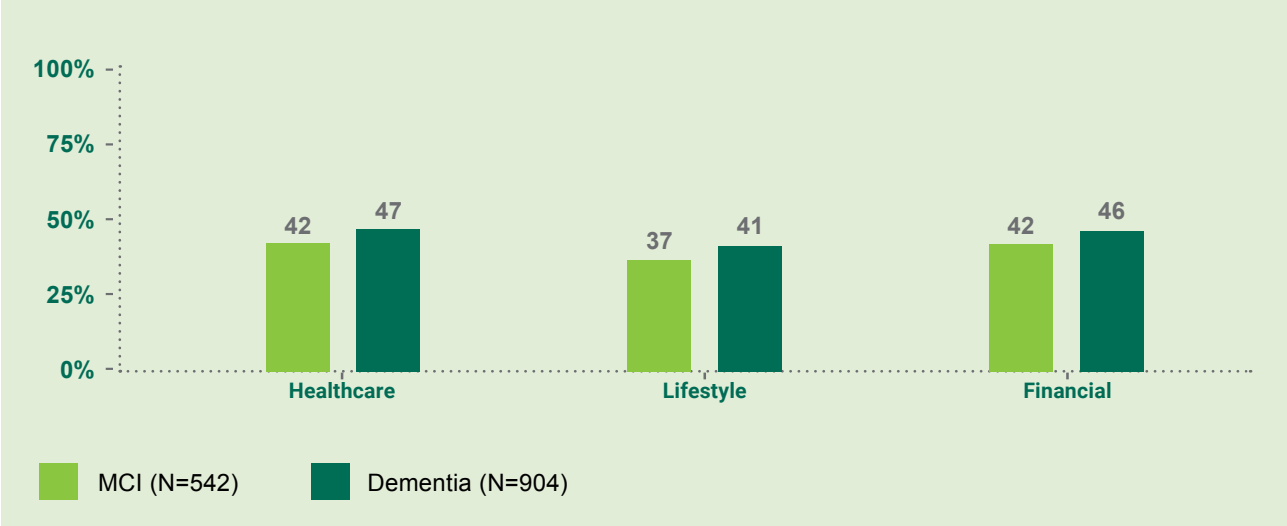
Figure 19 Prescription of acetylcholinesterase inhibitors among participants living with dementia



Notes:
Participants with unknown responses are included in the denominator
AD: Alzheimer's disease
MMSE: Mini-Mental State Exam

In 2023, the ADNeT Registry commenced data collection on appointment of future decision-maker and referral to a post-diagnostic program, because these management strategies can help people and their family members adjust to and live well with dementia or MCI, as well as plan for the future[11]. Approximately half of the participants had a future decision-maker appointed at the time of the diagnosis (50% for MCI and 54% for dementia), of which, most were for healthcare decisions and financial decisions (***Figure 20***). Of people living with dementia, over half (or 56%) were referred to a post-diagnostic program at the time of the diagnosis.

Figure 20 Type of future decision makers appointed



Note: Participants with unknown responses are included in the denominator

Clinical Data

It is important to collect clinical data of people living with dementia and MCI at the time of diagnosis to inform post-diagnostic care. To achieve this, the ADNeT Registry collects and reports data on:

- Cognition
- Daily functioning
- Neuropsychiatric symptoms
- Medication
- Dementia risk factors and comorbidities

Cognition

As mentioned earlier, the ADNeT Registry records the use of the four commonly used cognitive assessments, that is, MMSE, MoCA, KICA and RUDAS. The scores of these assessments can be used to help understand the levels of cognition, with higher scores indicating high levels of cognition. As expected, the participants living with dementia had lower scores in all three cognitive assessments than those living MCI (***Figure 21***, noting that KICA scores were not reported as the assessment was only used with two participants). Using common cut-off scores for these assessments[28,29], most participants living with dementia were considered as having mild to moderate cognitive impairment at the time of the diagnosis.

Figure 21 Box plots of cognitive assessment scores

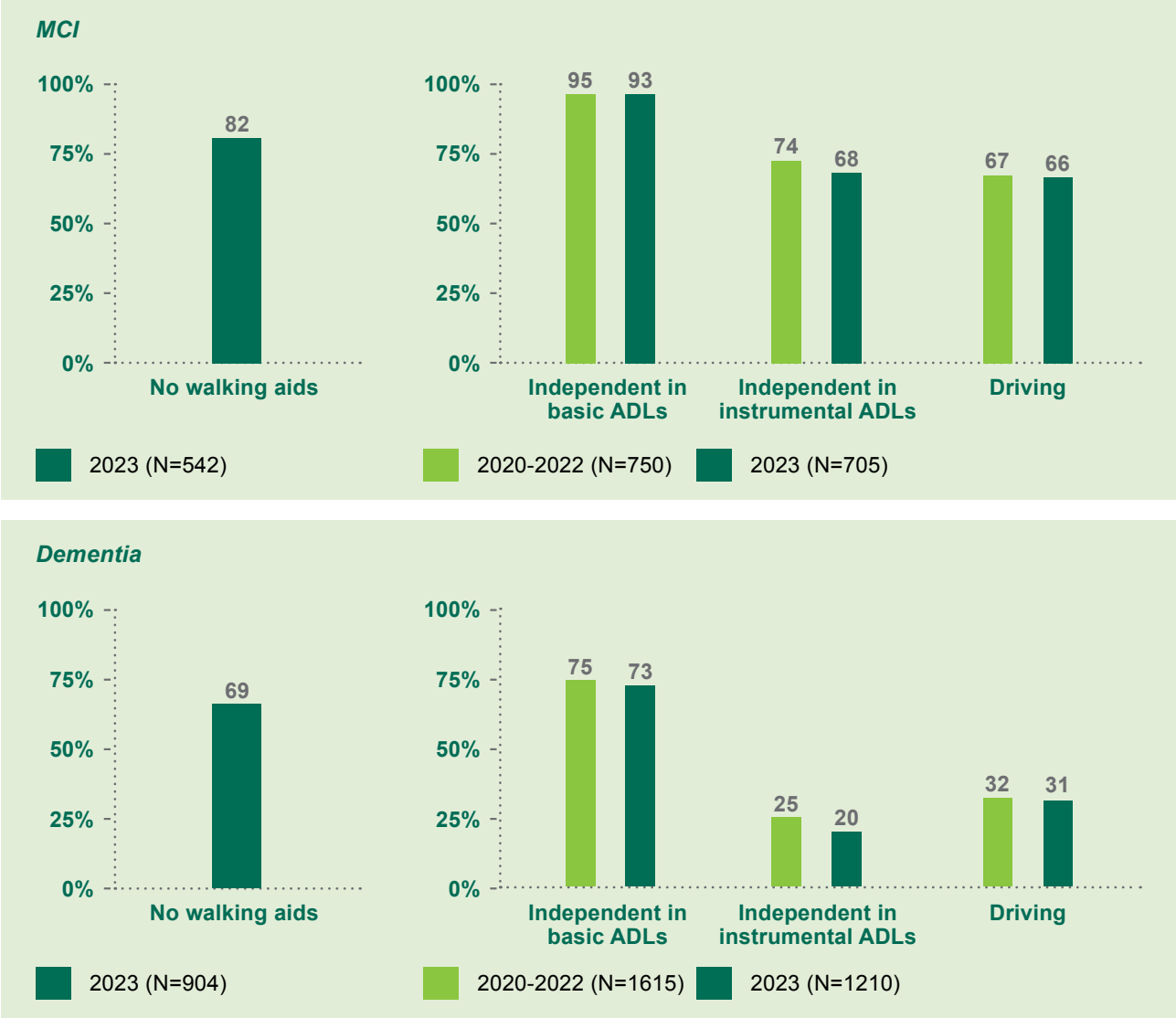
Note: The scores of MMSE, MoCA, and RUDAS range from 0 to 30, with higher scores indicating higher levels of cognitive functioning. Box plots are a visual representation of how the values in the data are spread out. The central box represents the interquartile range (IQR), which contains the middle 50% of the data. The line (and the number) inside the box indicates the median, which is the middle value of the data. The lower edge of the box represents the first quartile (the value at which the first 25% of the data falls up to) and the upper edge represents the third quartile (the value at which 75% of the data falls up to). The "whiskers" extend from the box to the smallest and the largest values (excluding outliers, which are shown as individual dots in the graph).

Daily functioning

Daily functioning refers to an individual's ability to perform daily activities, which include mobility (i.e., walking ability), personal or basic activities of daily living such as dressing, showering and toileting, and instrumental activities of daily living, such as cooking, laundry and managing finances. It is important to highlight that a person's level of daily functioning may be impacted by physical or sensory impairments (e.g., stroke and vision impairment), as well as cognitive impairment.

In 2023, of the participants living with MCI, most did not require a walking aid, were independent in both basic and instrumental activities of daily living and were recorded as driving at the time of diagnosis (***Figure 22***). As expected, the level of daily functioning was lower among participants living with dementia. While most of the participants living with dementia did not require a walking aid and were independent in personal or basic activities of daily living at the time of diagnosis, only 20% were independent in instrumental activities of daily living and 31% were recorded as driving.

Figure 22 Daily functioning

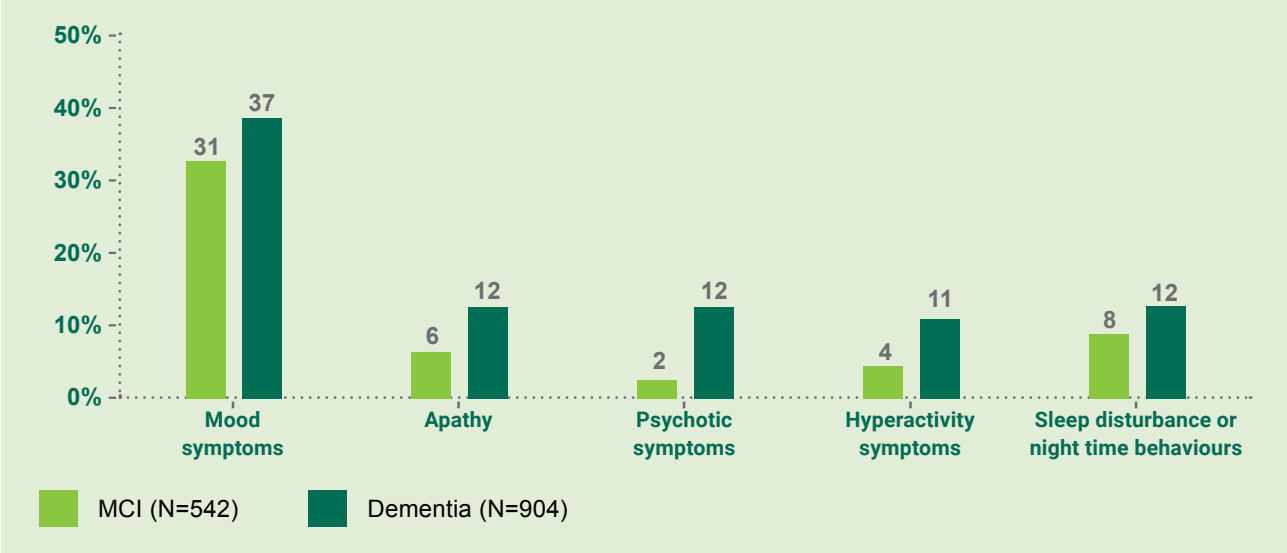


Notes:
Participants with unknown responses are included in the denominator
ADLs: activities of daily living

Neuropsychiatric symptoms

In 2023, the ADNeT Registry included additional data elements on neuropsychiatric symptoms in the Revised Minimum Dataset, because neuropsychiatric symptoms are common and have significant impact on the quality of life among people living with dementia and their family members[11]. More than half (or 52%) of the participants living with dementia and 40% of the participants living with MCI had at least one neuropsychiatric symptom at the time of the diagnosis, with mood symptoms being the most common symptom (***Figure 23***).

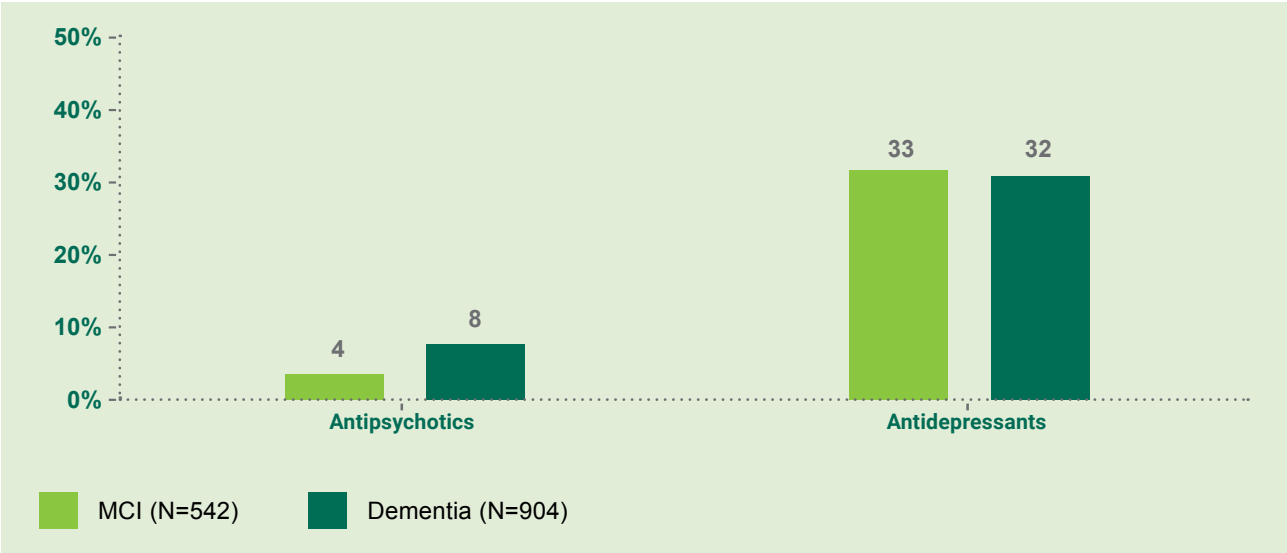
Figure 23 Neuropsychiatric symptoms



Note: Participants with unknown responses are included in the denominator

In line with the additional data collection for neuropsychiatric symptoms, the ADNeT Registry also commenced data collection on the prescription of antidepressants and antipsychotics in 2023. Additionally, approximately one third of the participants were already prescribed, or had newly prescribed antidepressants at the time of a dementia or MCI diagnosis, whereas 6% were already prescribed, or had newly prescribed antipsychotics (***Figure 24***).

Figure 24 Prescription of antidepressants and antipsychotics

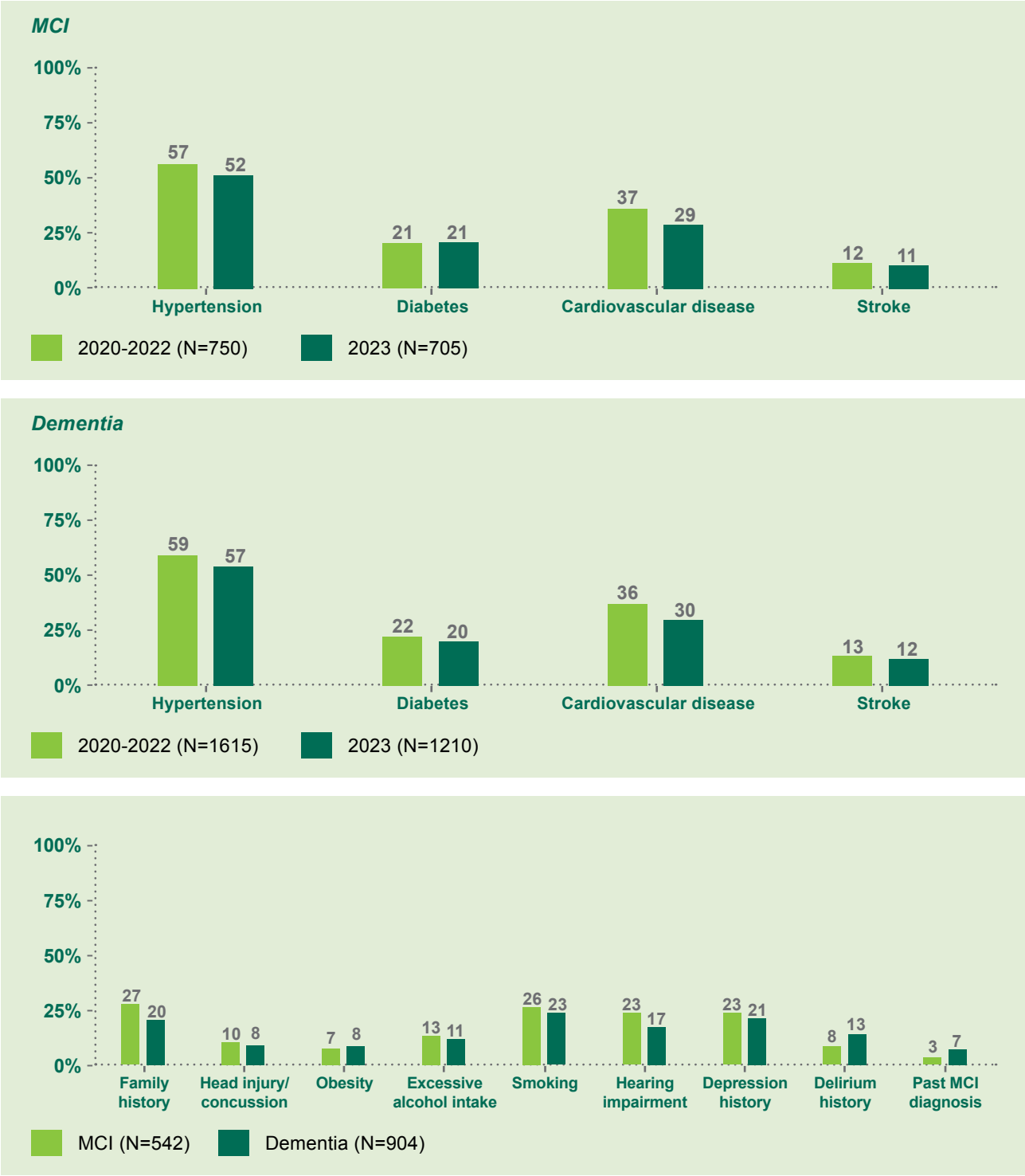


Note: Participants with unknown responses are included in the denominator

Risk factors and comorbidities

In 2023, the ADNeT Registry commenced data collection on key potentially modifiable risk factors, such as smoking, excessive alcohol intake and hearing impairment. This was in line with growing understanding of potentially modifiable risk factors to the overall burden of dementia cases[1,2]. Hypertension remained the most common dementia risk factor in 2023, present in over half of the participants (***Figure 25***). This was followed by cardiovascular disease, which was present in 30% of the participants. First degree family history, smoking, diabetes, hearing impairment and depression history were also common, present in approximately 20% of the participants.

Figure 25 Dementia risk factors



Note: Participants with unknown responses are included in the denominator

Falls are common among people living with dementia and are a major safety and quality risk for health services[30, 31]. In 2023, approximately 30% of the registry participants had one or more falls in the 12 months preceding their diagnosis (29% for MCI vs 32% for dementia) (***Figure 26***).

Monitoring polypharmacy (defined as the concurrent use of five or more medicines) is a key action area for improving medication safety in Australia and globally[32]. In 2023, more than half of the participants were prescribed five or more medications at the time of diagnosis.

Figure 26 Comorbidities

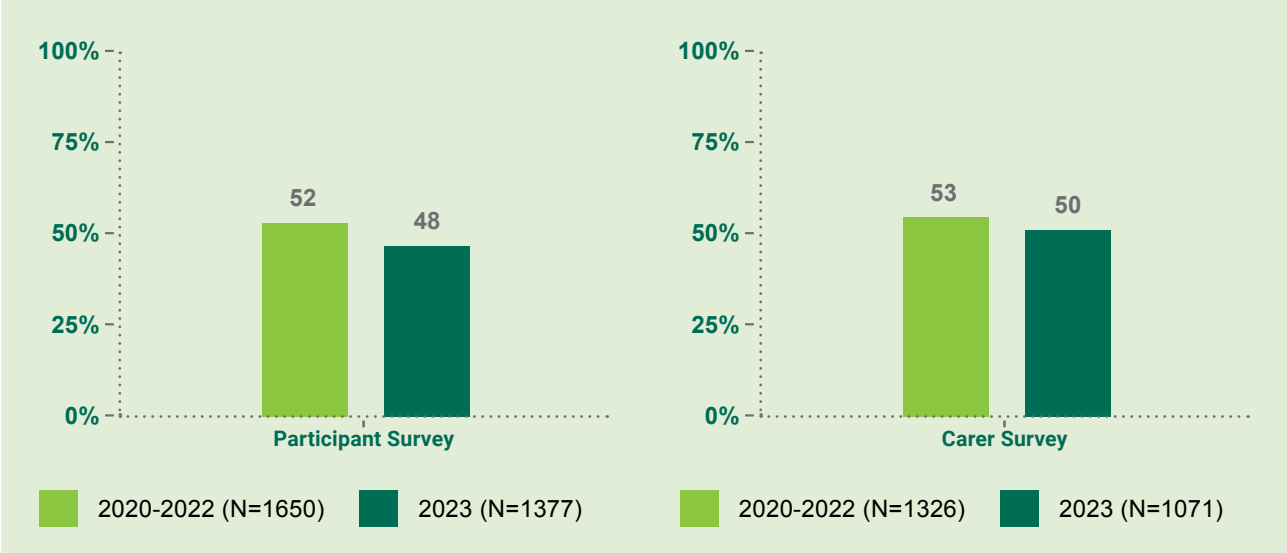
Note: Participants with unknown responses are included in the denominator

Living Experience

To help understand living experience, the ADNeT Registry has developed a participant and a carer survey to collect data on self-reported health and well-being, as well as the experience of clinical care of participating sites. These surveys were developed by a working group comprising representatives of people with living experience, carers, peak bodies, clinicians, and researchers (see ***Appendix 2*** for membership). Feedback from people with living experience of dementia and MCI and their carers were sought via consultation facilitated by Dementia Australia and incorporated into these surveys.

The surveys have been implemented since February 2021. In 2023, the survey response rate was 48% for the participant survey (1377 sent, 661 returned) and 50% for the carer survey (1071 sent, 533 returned) (***Figure 27***).

Figure 27 Survey response rates



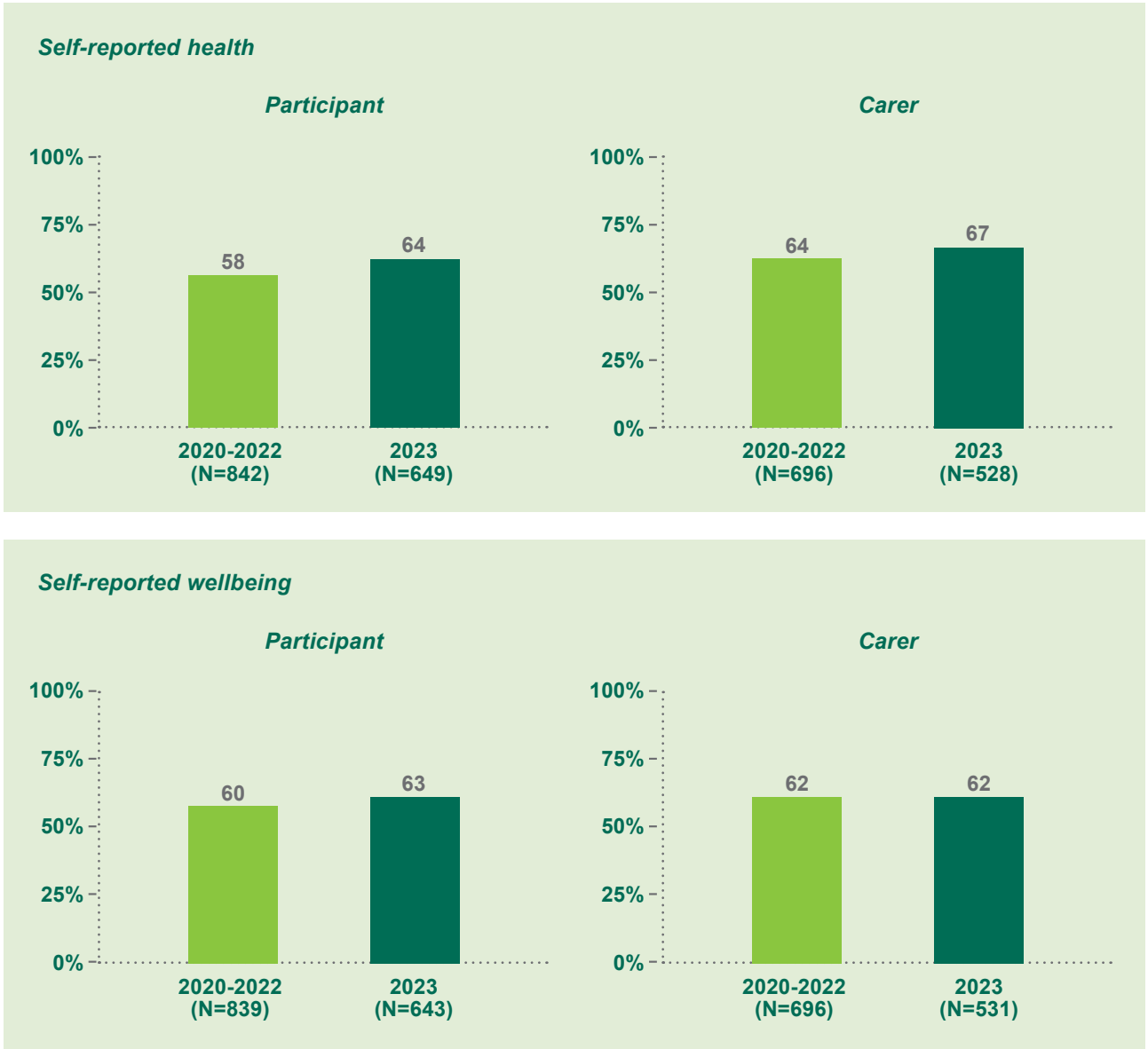
Note: For sent surveys, those sent within 4 months of data extraction were excluded to allow sufficient time for survey responses; Surveys that were returned to sender were also excluded to allow accurate calculation of response rates.

Photo by Fiona Wolf (WolfWorx Photography), courtesy of Gwenda Darling

Self-reported health and wellbeing

Compared to previous years, there was a small increase in the percentage of the participants and the carers who rated their health as “Good” or “Very good”, with over 60% of the participants and the carers reporting this in 2023 (***Figure 28***). This increase was also observed for self-reported wellbeing among the participants, but the percentage remained the same among the carers.

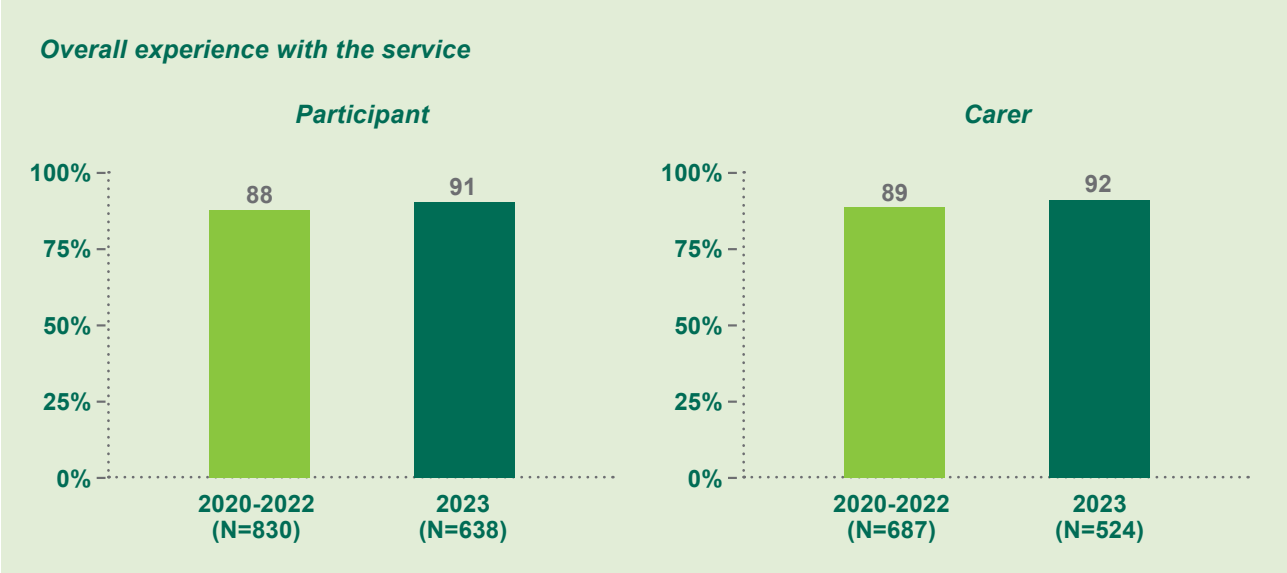
Figure 28 “Good” or “Very good” self-reported health and wellbeing

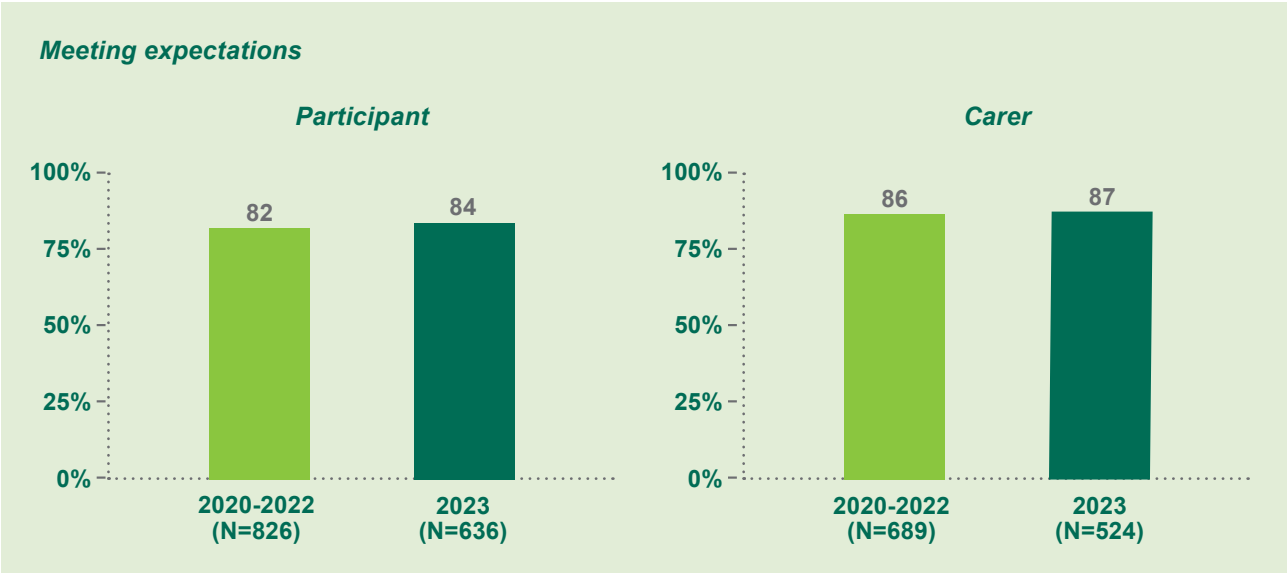


Experience of diagnostic care

The ADNeT Registry Participant and Carer Surveys have two questions on overall experience of clinical care of participating sites. Over 90% of the participants and the carers reported having overall “Good” or “Very good” experience of participating sites and approximately 85% of the participants and the carers agreed or totally agreed that the experience met their expectation (***Figure 29***). These results suggested a small increase in the percentages of the participants and the carers who reported overall positive experience between 2020-2022 and 2023.

Figure 29 “Good” or “Very good” experience of participating sites

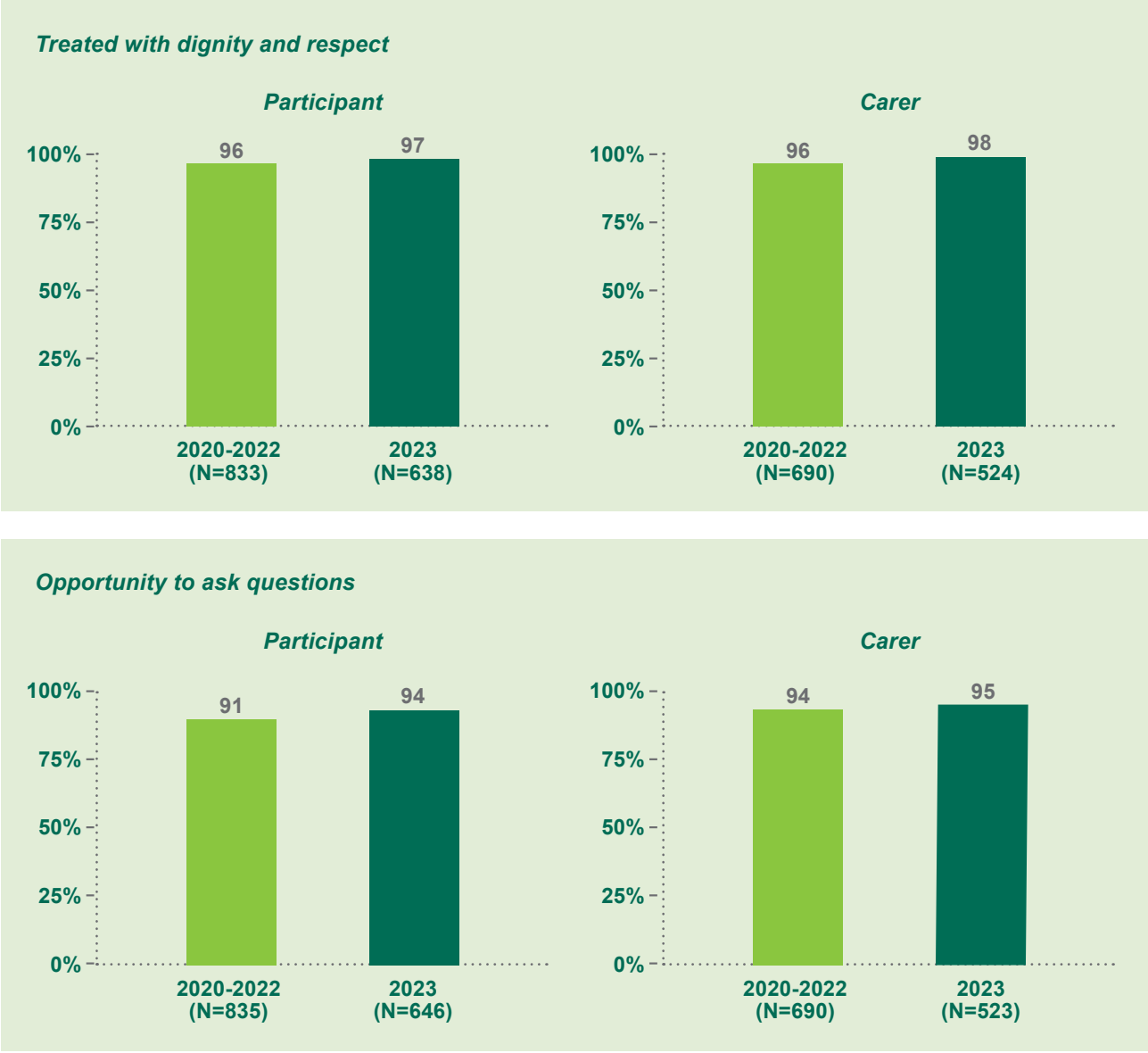




In addition, the ADNeT Registry Participant and Carer Surveys have six questions on experience of different aspects of clinical care. Consistent with the results from previous years, the aspects of care showing most positive experience in 2023 were:

- "treated with dignity and respect" (agreed/strongly agreed by 97% of the participants and 98% of the carers in 2023, respectively)
- "given the opportunity to ask questions" (agreed/strongly agreed by 94% of the participants and 95% of the carers in 2023, respectively) (***Figure 30***).

Figure 30 Aspects of care with most positive experience

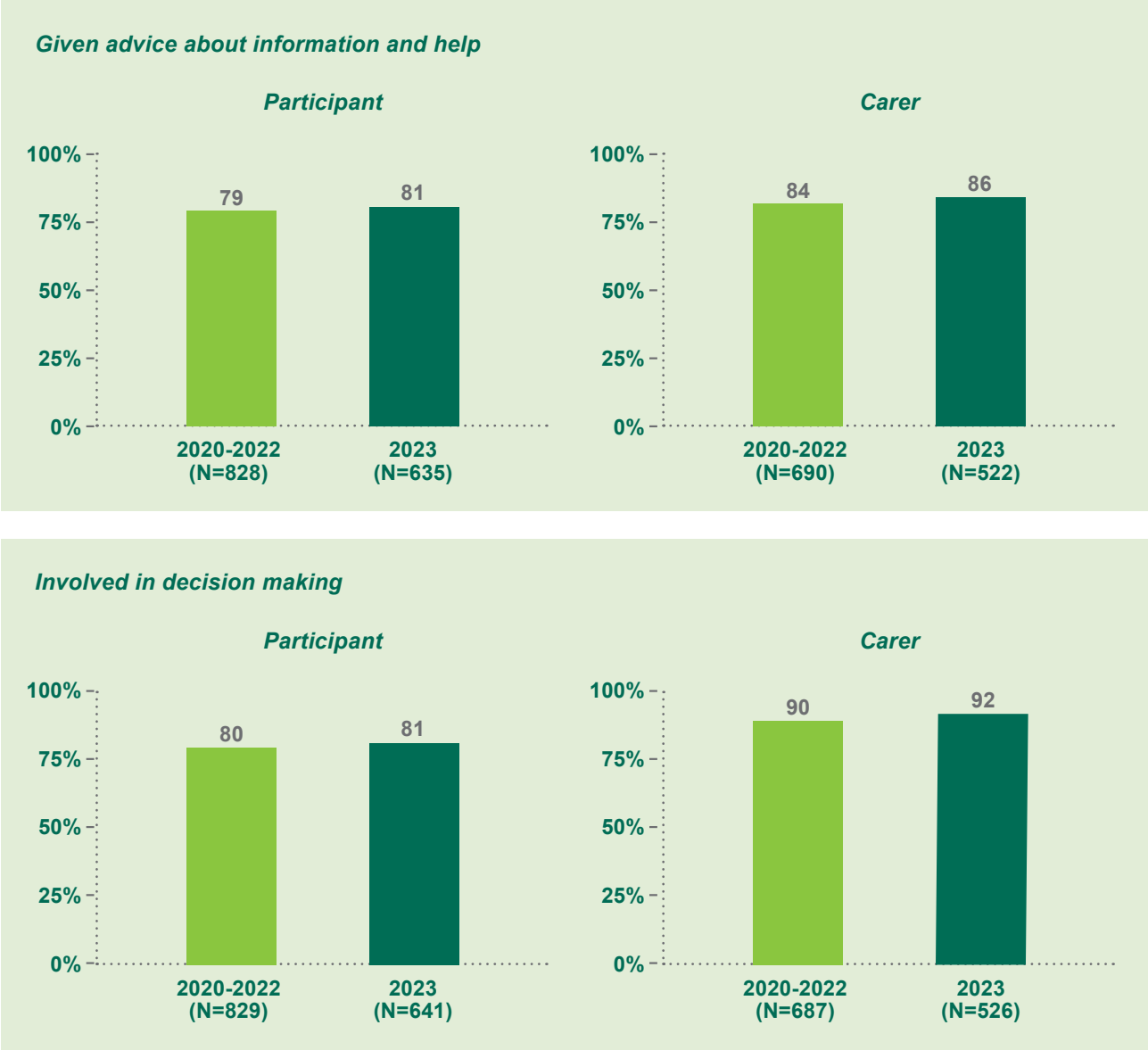


There was also no change in the aspect showing least positive experience in 2023, which were:

- "given advice about how and where to get more information or help if needed" and "involved in decision making" for participants (both agreed/strongly agreed by 81% of the participants)
- "given advice about how and where to get more information or help if needed" for carers (agreed/strongly agreed by 86% of carers) (***Figure 31***).

Compared to previous years, there was a small increase in the percentages of the participants and the carers who reported positive experience across all six aspects between 2020-2022 and 2023. The only exception was "receiving adequate information about diagnosis" where there was a small reduction among carers reporting positive experience (88% in 2023 vs 90% in 2020-2022) (see ***Appendix 6*** for detailed results).

Figure 31 Aspects of care with least positive experience



Future Developments

Looking into 2024 and beyond, key areas of focus for the ADNeT Registry are:

- Continuing recruitment, expansion, and interaction with clinical services to increase registry coverage
- Implementing the treatment module to collect real-world safety and efficacy data when these new therapies become approved by the Therapeutic Goods Administration
- Updating bi-annual site reports to indicate the changes in key aspects of clinical practice over time at a site level
- Transitioning to the new custom-built Clinical Research Platform to improve user experience and registry efficiency
- Continuing collaboration with international partners (e.g., Alzheimer's Network for Treatment & Diagnostics [ALZ-NET] in the United States) in collecting real-world safety and efficacy data for new dementia therapies
- Continuing collaboration with the National Centre for Monitoring Dementia at the AIHW to inform national dementia policy, reports, and planning initiatives
- Continuing to support researchers and secondary data analyses to enhance understanding of clinical care provided to people living with dementia and MCI

We sincerely thank our participating sites, clinicians, registry participants and their carers, living experience representatives, peak bodies, clinical professional societies, industry and government partners for their ongoing support. Without them, the ADNeT Registry would not be possible. We look forward to sharing with you further findings and achievements of the ADNeT Registry in our next Annual Report.

Publications and Presentations

Collaborative publications

1. Alty, J., Lawler, K., Salmon, K., McDonald, S., Stuart, K., Cleary, A., Ma, J., Rudd, K., Wang, X., Chiranakorn-Costa, S., Collins, J., Merl, H., Lin, X., & Vickers, J. C. (2023). A new one-stop interdisciplinary cognitive clinic model tackles rural health inequality and halves the time to diagnosis: Benchmarked against a national dementia registry. International Journal of Geriatric Psychiatry, 38(8), e5988. doi.org/10.1002/gps.5988

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4. Sluggett, J. K., Air, T., Cations, M., Caughey, G. E., Lang, C. E., Ward, S. A., Ahern, S., Lin, X., Wallis, K., Crotty, M., Inacio, M. C. (2023). Clinical Quality Indicators for Monitoring Hospitalizations Among Older People with Dementia Accessing Aged Care Services. Journal of Alzheimer's Disease, 96, 1747-1758. doi.org/10.3233/JAD-230730

Conference presentations

1. Ward, S. What can we learn from the ADNeT Registry. Invited lunchtime symposium at the 2023 ANZSGM Annual Scientific Meeting, 10-12 May 2023, Brisbane, Australia

2. Ward, S., Guinane, J. & Quirke, L. The ADNeT Registry: First 5 years, and into the Future, Symposium at the 2023 Australian Dementia Research Forum, 29-31 May 2023, Gold Coast, Australia

3. Ward, S., Brodaty, H., Rowe, C., Wallis, K., Lin, X., Ahern, S. on behalf of the ADNeT Registry Steering Committee, The Australian Dementia Network (ADNeT) Registry: A Nationwide Clinical Quality Registry to monitor and improve dementia diagnosis and care. Poster at the 2023 Alzheimer's Association International Conference, 16-20 July 2023, Amsterdam, Netherlands and Online

4. Tsui, A., Lin, X., Wallis, K., Ahern, S., Liman., J., Ward, S. Using REDCap to achieve real-time reporting and benchmarking for clinical quality registries (CQRs): an example from the Australian Dementia Network (ADNeT) Registry. Oral presentation at the 2023 Australian Clinical Registry Annual Scientific Meeting, 19-20 October 2023, Melbourne, Australia

5. Lin, X., Wallis, K., Ward, S., Ahern, S. Brodaty, H. on behalf of the ADNeT Registry Steering Committee, Dementia diagnostic care in multicultural Australia: early findings from the Australian Dementia Network (ADNeT) Registry. Oral presentation at the 56th Australian Association of Gerontology Conference, 14-17 November 2023, Gold Coast, Australia

6. Lin, X., Wallis, K., Brodaty, H., Kain, B., Cooper, S., Fitzpatrick, J., Jeon, Y., Naismith, S., Lambourne, S., Alty, J., Low, L., Phillipson, L., McAloney, K., Ward, S. Patient/carer-reported experiences of dementia diagnostic services: two-year findings from the Australian Dementia Network Registry. Oral presentation at the 56th Australian Association of Gerontology Conference, 14-17 November 2023, Gold Coast, Australia

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Appendices

Appendix 1

2020–2023 Status Report

Australian Dementia Network (ADNeT) Registry **2020-2023 Status Report**

A national clinical quality registry to drive continuous improvement in quality of care and patient outcomes from the time of diagnosis with dementia or mild cognitive impairment (MCI)

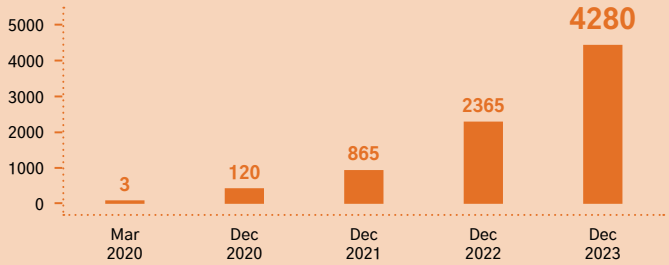
Contributing Sites

64 Total sites

27% Regional sites

44% Private sites

Cumulative Participant Recruitment



Key Clinical Quality Indicators

- **60%** First appointment within 90 days of referral
- **96%** Core blood tests undertaken
- **99%** Cognitive assessments completed
- **92%** Structural neuroimaging completed
- **98%** Ability to perform activities of daily living assessed

Impact

"We have found the ADNeT Registry benchmarked data extremely useful in understanding our client profile and performance, as well as for the evaluation and future planning of our clinic."

Associate Professor Jane Alty, The ISLAND Clinic, Tasmania

Median Diagnostic Wait Times

This infographic pertains to data submitted to the ADNeT Registry from commencement of data collection in March 2020 to December 2023 (n = 4280) unless indicated otherwise.

Australian Dementia Network
REGISTRY. CLINICS. TRIALS.

MONASH University

Australian Dementia Network (ADNeT) Registry
2020-2023 Status Report

adnet.registry@monash.edu
1800 314 421
www.australiandementianetwork.org.au

Demographics

Median age (years)	78 years
Female	53%
First Nations people	1%
Born overseas	36%
Primary or lower education	10%
Living alone	26%

Impact

"The ADNeT Registry has provided important feedback on patient and family experience of our service, which we have shared with our executive to support growth in the Cognitive Dementia and Memory Service (CDAMS) service."

Associate Professor Mark Yates, Grampians CDAMS, Grampians Health

Diagnosis

34% MCI

66% Dementia

Dementia subtypes

Alzheimer's disease only | **Mixed Alzheimer's & Vascular dementia** | **Others** | **Vascular dementia only**

Clinical Details

MCI		Dementia
40%	Neuropsychiatric symptoms[1]	52%
27%	Falls in past 12 months	34%
8%	Delirium history[1]	13%
56%	Polypharmacy[2]	54%

Management Considerations

MCI		Dementia
Not collected	Referred to post-diagnostic program[1]	56%
6%[1]	Acetylcholinesterase Inhibitors	54%
50%	Future decision-maker appointed[1]	54%
66%	Driving	32%

This infographic pertains to data submitted to the ADNeT Registry from commencement of data collection in March 2020 to December 2023 (n = 4280) unless indicated otherwise.

[1] Data were collected from April 2023 (n = 1446, including 542 participants with MCI and 904 with dementia).

[2] Defined as having five or more regularly prescribed medications.

Australian Dementia Network
REGISTRY. CLINICS. TRIALS.

MONASH University

Appendix 2

Committee Membership and Staff List

ADNeT Registry Steering Committee

- Scientia Professor Henry Brodaty*, ADNeT Registry Steering Committee Co-Chair, Centre for Healthy Brain Ageing, 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*, Inaugural President of the Australian Cognitive Neurology Society, Eastern Health, Royal Melbourne Hospital, Monash University
- Associate Professor Trevor Chong*, Monash University, St Vincent's Health Melbourne & Alfred Health
- Dr Stephanie Daly* (from June 2024), Royal Australian College of General Practitioners
- Gwenda Darling, Person living with dementia
- Professor Maria Inacio, South Australian Health and Medical Research Institute and Flinders University
- Professor Yun-Hee Jeon, University of Sydney
- Barbara Kain, Carer of a person living with dementia
- Associate Professor Samantha Loi*, Royal Melbourne Hospital & University of Melbourne
- Maree McCabe AM (to May 2024), Dementia Australia
- Professor Sharon Naismith*, Brain and Mind Centre, University of Sydney
- Dr Kannan Natarajan*, Logan Hospital, Queensland
- Professor Mark Nelson (to December 2023), University of Tasmania
- Dr Lyndal Newton*, Councillor, Australian and New Zealand Society for Geriatric Medicine & Department of Geriatric Medicine, Northern Beaches Hospital
- Megan Phelan (from February 2024), Australian Government Department of Health and Aged Care
- Ann Pietsch, Person living with dementia
- Lyntara Quirke, Carer of a person living with dementia
- Elizabeth Rand* (to February 2024), Alfred Health (retired in 2022)
- Professor Christopher Rowe*, Australian Dementia Network Director, University of Melbourne & Austin Health
- Kaele Stokes (from May 2024), Dementia Australia
- Beth Veevers* (from February 2024), Austin Health
- Associate Professor Mark Yates*, Grampians Health & 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
- Scientia Professor Henry Brodaty, Centre for Healthy Brain Ageing, University of New South Wales
- Professor Yun-Hee Jeon, University of Sydney
- Barbara Kain, Consumer Representative
- Scott Cooper, Consumer Representative
- Jenny Fitzpatrick, Consumer Representative
- Sally Lambourne, Dementia Australia
- Dr Xiaoping Lin, Monash University
- Professor Lee-Fay Low, University of Sydney
- Kerrie McAloney, QIMR Berghofer Medical Research Institute
- Professor Sharon Naismith, University of Sydney
- Professor Lyn Phillipson, University of Wollongong
- 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
- Kasey Wallis, ADNeT Registry Program Manager, Monash University
- Dr Xiaoping Lin, Research Fellow, Monash University
- Valerie Arsenova (to April 2023), ADNeT Registry State Coordinator, University of New South Wales
- Cheryl Grant, Clinical Registries Officer, Monash University
- Dr Mohammad Amin Honardoost, Data Analyst, Monash University
- Dr Maria Kokkinos (to July 2023), Research Assistant, Monash University
- John Liman, Senior Software Engineer, Monash University
- Kerrie McAloney, ADNeT Registry State Coordinator, QIMR Berghofer Medical Research Institute
- Dr Miia Rahja, ADNeT Registry State Coordinator, South Australian Health and Medical Research Institute
- Jennifer Richardson (to January 2024), ADNeT Registry Ethics Officer, Monash University
- Dr Sophia Tan, ADNeT Registry State Coordinator, South Australian Health and Medical Research Institute
- Kelly Tapley (from October 2023), Governance & Risk Manager, Monash University
- Alan Tsui, ADNeT Registry Data Manager, Monash University

Appendix 3

ADNeT Registry Revised 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 name, preferred spoken language and contact details[1]

Demographics

- Aboriginal and/or Torres Strait Islander
- Country of birth
- Preferred spoken language
- Highest education level
- Employment status
- Residence
- Living arrangement[2]

Diagnosis and clinical data

- New referral at this clinic[3]
- Date of referral[1]
- Date of initial appointment
- Informant provided corroborative history[3]
- Approximate duration of symptoms[3]
- Neuropsychologist completed an assessment as part of diagnostic process[3]
- Core blood tests completed as part of diagnostic process
- Structural neuroimaging completed as part of diagnostic process (and if yes, select types)
- Functional neuroimaging completed as part of diagnostic process (and if yes, select types)
- Lumbar puncture completed (non-biomarker)
- Biomarker studies[3] (and if yes, select types)
- Diagnosis
- Date of diagnosis
- Dementia/MCI[4] subtype
- MCI[4] subtype (suspected underlying pathology/ies) (and if yes, select pathology/ies)
- Dementia risk factors[3] (including first degree family history, past MCI diagnosis, delirium history head injury/concussion, hearing impairment, depression history, obesity, diabetes, hypertension, stroke, cardiovascular disease, smoking history, excessive alcohol intake)
- Neuropsychiatric symptoms[3] (and if yes, select symptoms)
- MMSE/RUDAS/MoCA/KICA scores[1,4]
- Other cognitive tests completed
- Independent in all personal activities of daily living
- Independent in all instrumental activities of daily living
- Mobility (usual walking ability)[3]
- Currently driving
- Falls in past 12 months
- Appointments for future decision making[3] (and if yes, select types)
- Referral to post-diagnostic program[3,5]
- Current number of regularly prescribed medications
- Acetylcholinesterase Inhibitors[3]
- Antipsychotics[3]
- Antidepressants[3]
- Memantine[3]
- Suitable for contact for current/future research studies at your site[3]
- Interested in contact by Registry for future research conducted by 3rd parties (if suitable)[3]
- Patient agrees to referral to ADNeT Screening and Trials via Registry and information about referring clinician[3]

[1]If applicable/relevant

[2]Not collected if residence is residential aged care facility, supported accommodation or unknown

[3]Data element added or revised in April 2023

[4]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

[5]Not collected for participants with MCI

Appendix 4

Data Completeness Information

Data element	Completeness (%)	
	2020-2022 (N = 2365)	2023 (N = 1915)
Age at diagnosis[1]	98	98
Sex	100	100
Aboriginal and/or Torres Strait Islander	91	90
Country of birth	97	95
Preferred spoken language	99	98
Highest education level	90	90
Employment status	97	96
Residence	98	96
Living arrangement[2]	98	99
Referral to initial appointment[1,3]	96	100
Initial appointment to diagnosis[1,3]	96	89
Referral to diagnosis[1,3]	97	88
Core blood tests	96	97
Structural neuroimaging	98	99
Functional neuroimaging	93	97
Lumbar puncture (non-biomarker)	94	96
Diagnosis	100	100
Independent in personal activities of daily living	99	98
Independent in instrumental activities of daily living	99	97
Currently driving	98	98
Falls in past 12 months	95	93
Number of medications	98	91

[1]Calculated variable

[2]Not collected if residence is residential aged care facility, supported accommodation or unknown (n = 142 in 2020-2022 and 153 in 2023)

[3]Not collected if participants having a previous referral or mild cognitive impairment diagnosis at the site (n = 183 in 2020-2022 and 185 in 2023)

Data element	Completeness (%) 2023 (N = 1446)
Informant provided corroborative history	98
Approximate duration of symptoms	94
Neuropsychologist completed an assessment as part of diagnostic process	97
Biomarker studies	95
Dementia risk factors	98
Neuropsychiatric symptoms	94
Mobility (usually walking ability)	96
Appointment for future decision making	83
Referral to post-diagnostic program[1]	90
Acetylcholinesterase inhibitors	98
Antipsychotics	96
Antidepressants	96
Memantine	96

[1]Not collected for participants with mild cognitive impairment (n=542)

Appendix 5

2023 Contributing Sites

In 2023, a total of 60 sites contributed data to the ADNeT Registry.

Site Name	Type	Location
New South Wales (n = 13)		
Brellah Medical Group, Dr Mark Hohenberg	Private	Major City
Burwood Specialists	Private	Major City
Central Coast Neurosciences (CCN) - Procognition Clinic	Private	Major City
Hornsby Ku-ring-gai Hospital Memory Clinic	Public	Major City
Memory Assessment Program, Pottsville	Public	Major City
Murrumbidgee Local Health District Aged Care Outpatient Clinic	Public	Regional Australia
Northern Beaches Geriatricians	Private	Major City
Prince of Wales Hospital Brodaty Clinic	Public	Major City
Prince of Wales Hospital Cognitive Disorders Clinic	Public	Major City
Prince of Wales Hospital Neuropsychiatry Clinic	Public	Major City
Rehabilitation and Aged Care Outpatient Clinics, Mona Vale Hospital	Public	Major City
Shoalhaven Aged Care Service, Shoalhaven District Memorial Hospital	Public	Regional Australia
Shoalhaven Aged Care Service, Milton Hospital	Public	Regional Australia
Queensland (n = 17)		
Agenda Health	Private	Major City
Cairns Memory Clinic, Cairns Hospital	Public	Regional Australia
Dementia Assessment Service, Kirwan Health Campus	Public	Regional Australia
Dr Logan, Geriatrician at Lakelands Medical Centre	Private	Major City
Healthy Ageing Gold Coast	Private	Major City
Innisfail Memory Clinic, Innisfail Hospital	Public	Regional Australia

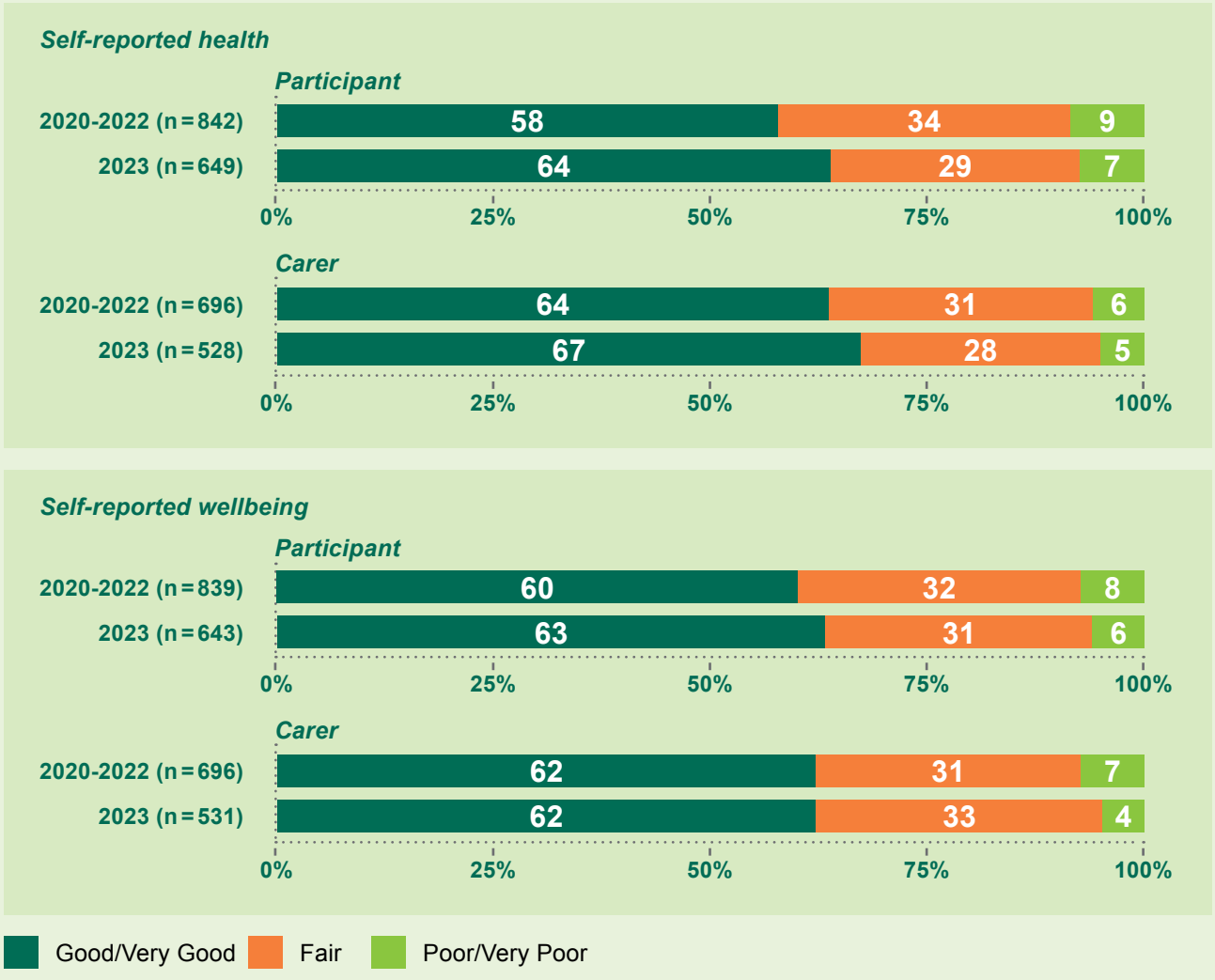
Ipswich Health Plaza Memory and Geriatric Clinics, Ipswich Hospital	Public	Major City
Mareeba Memory Clinic, Mareeba Hospital	Public	Regional Australia
Memory Clinic Surgical, Treatment and Rehabilitation Service (STARS)	Public	Major City
Neurosciences Queensland	Private	Major City
Princess Alexandra Hospital Geriatric Clinic	Public	Major City
Redcliffe Hospital Memory Clinic	Public	Major City
Robert Adam Neurology	Private	Major City
Robina Private Hospital – Memory Clinic	Private	Major City
The Memory Clinic Princess Alexandra Hospital	Public	Major City
The Prince Charles Hospital Memory Clinic	Public	Major City
Your Brain in Mind	Private	Major City
South Australia (n = 9)		
Acacia-Fiori Geriatrics	Private	Major City
Central Adelaide Local Health Network Department of Geriatrics and Rehabilitation Medicine, Royal Adelaide Hospital	Public	Major City
Flinders Medical Centre Memory and Aged Care Clinics	Public	Major City
QE Specialist Centre, Prof R Visvanathan	Private	Major City
Royal Adelaide Hospital Memory Service	Public	Major City
Riverland General Hospital Geriatric Services	Public	Regional Australia
Sensus Cognition	Private	Major City
Specialist Ambulatory Rehabilitation Centre (SpARC) Memory Clinic, Modbury Hospital	Public	Major City
The Queen Elizabeth Hospital Memory Service	Public	Major City
Tasmania (n = 4)		
David Dunbabin Aged Care	Private	Regional Australia
Dr Krishna Kalpurath, Calvary Health Care Sessional Rooms, Launceston	Private	Regional Australia
Hazel Bucher Nurse Practitioner Consultancy	Private	Regional Australia
The ISLAND Clinic	Private	Regional Australia

Victoria (n = 16)		
Austin Cognitive Dementia and Memory Service (CDAMS), Austin Health	Public	Major City
Bass Coast Health Geriatric Medicine Clinic	Public	Regional Australia
Caulfield Cognitive Decline and Memory Service (CDAMS), Alfred Health	Public	Major City
Central Geriatrician Associates	Private	Major City
Dr Jagadeesh Herur, Glencairn Private Consulting Suites	Private	Major City
Dr Jagadeesh Herur, Harvester Private Consulting Suites	Private	Major City
Dr Rebecca Iseli, Geriatrician, practising at North Melbourne Ear, Nose & Throat	Private	Major City
Eastern Cognitive Disorders Clinic, Eastern Health	Public	Major City
Eastern Health Cognitive Dementia and Memory Service (CDAMS)	Public	Major City
Echuca Regional Health Cognitive Dementia and Memory Service (CDAMS)	Public	Regional Australia
Goulburn Valley Health Cognitive Dementia and Memory Service (CDAMS)	Public	Regional Australia
Grampians Cognitive Dementia and Memory Service (CDAMS), Grampians Health	Public	Regional Australia
Irene Wagner's Clinic	Private	Major City
Royal Melbourne Hospital Neuropsychiatry Clinic	Public	Major City
Professor Dennis Velakoulis, Church Street Consulting Suites	Private	Major City
Western Health Cognitive Dementia and Memory Service (CDAMS), Footscray Hospital	Public	Major City
Western Australia (n = 1)		
Dr Roger Clarnette, Geriatrician, practising at Hollywood Specialist Centre	Private	Major City

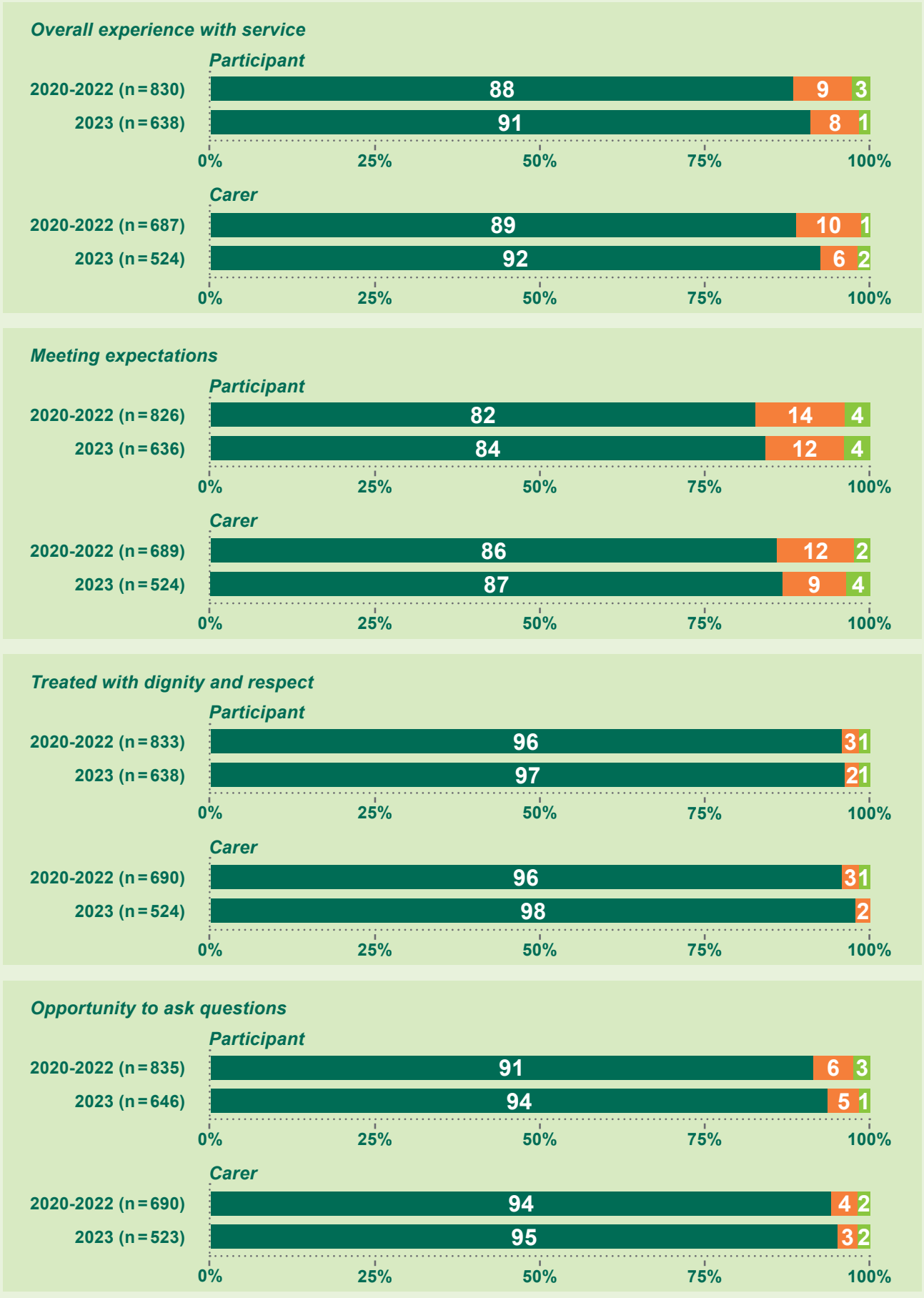
Appendix 6

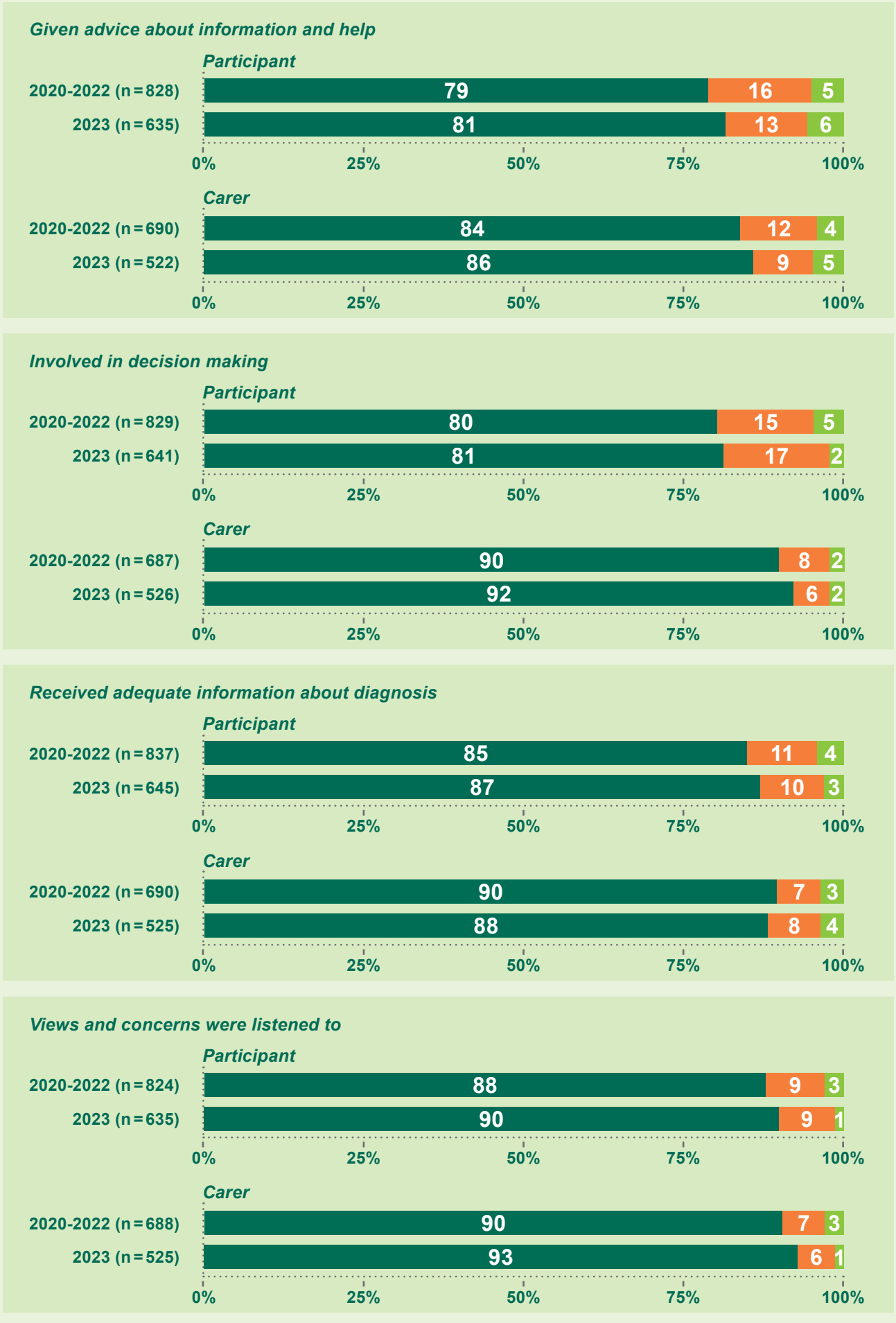
Detailed Baseline Participant and Carer Survey Results

Results of the two outcome questions



Results of the eight experience questions




Given advice about information and help
Participant
2020-2022 (n=828)
79
16
5
2023 (n=635)
81
13
6
0%
25%
50%
75%
100%
Carer
2020-2022 (n=690)
84
12
4
2023 (n=522)
86
9
5
0%
25%
50%
75%
100%
Involved in decision making
Participant
2020-2022 (n=829)
80
15
5
2023 (n=641)
81
17
2
0%
25%
50%
75%
100%
Carer
2020-2022 (n=687)
90
8
2
2023 (n=526)
92
6
2
0%
25%
50%
75%
100%
Received adequate information about diagnosis
Participant
2020-2022 (n=837)
85
11
4
2023 (n=645)
87
10
3
0%
25%
50%
75%
100%
Carer
2020-2022 (n=690)
90
7
3
2023 (n=525)
88
8
4
0%
25%
50%
75%
100%
Views and concerns were listened to
Participant
2020-2022 (n=824)
88
9
3
2023 (n=635)
90
9
1
0%
25%
50%
75%
100%
Carer
2020-2022 (n=688)
90
7
3
2023 (n=525)
93
6
1
0%
25%
50%
75%
100%
Totally agree/agree
Neutral
Totally disagree/disagree

ADNeT Registry 2023 Annual Report

Australian Dementia Network
REGISTRY. CLINICS. TRIALS.

MONASH University

Lin, X., Ward, S. A., Brodaty, H., Honardoost, M. A., Wallis, K., Tsui, A., Rowe, C., Anstey, K., Brodtmann, A., Chong, T., Daly, S., Darling, G., Inacio, M., Jeon, Y.-H., Kain, B., Loi, S., Naismith, S., Natarajan, K., Newton, L., Phelan, M., Pietsch, A., Quirke, L., Stokes, K., Veevers, B., Yates, M., McAloney, K., Rahja, M., Tan, S., & Ahern, S. (2024). The Australian Dementia Network (ADNeT) Registry 2023 Annual Report. Melbourne: Monash University, School of Public Health and Preventive Medicine. DOI: 10.26180/26984689