






Australian Dementia Network Registry First Annual Report 2020-2021



Australian Dementia Network
REGISTRY. CLINICS. TRIALS.

MONASH University




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

Data period: The data contained in this report were extracted from the ADNeT Registry on 29th March 2022 and pertains to data submitted to the registry from commencement of data collection on 10th March 2020 to 31st December 2021. As the registry does not capture data in real time, there is a lag between occurrence of an event and capture in the ADNeT Registry.

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Abbreviations

ACSQHC	Australian Commission for Safety and Quality in Heath Care
AD	Alzheimer's disease
ADNeT	Australian Dementia Network
AChEI	Acetyl Cholinesterase Inhibitor
CQI	Clinical Quality Indicator
CQR	Clinical Quality Registry
CT	Computed Tomography
FDG PET	Fluorodeoxyglucose Positron Emission Tomography
KICA	Kimberley Indigenous Cognitive Assessment
MCI	Mild Cognitive Impairment
MMSE	Mini-Mental State Exam
MoCA	Montreal Cognitive Assessment
MRI	Magnetic Resonance Imaging
NHMRC	National Health and Medical Research Council
NNIDR	National Health and Medical Research Council National Institute for Dementia Research
RUDAS	Rowland Universal Dementia Assessment Scale
SPECT	Single Photon Emission Computed Tomography

Foreword

On behalf of the Australian Dementia Network (ADNeT) Registry Steering Committee, we are proud to present the First Annual Report for the registry. The ADNeT Registry is Australia's first clinical quality registry for people newly diagnosed with dementia and mild cognitive impairment (MCI). This report pertains to data submitted to the registry from commencement of data collection on 10th March 2020 to 31st December 2021.

In Australia, it is estimated that nearly half a million people are living with dementia, and many more individuals may live with prodromal dementia syndromes such as MCI. This number is continuing to increase. The past decade has seen important developments in dementia diagnosis and care, from the release of the very first Australian Clinical Practice Guidelines and Principles of Care for People with Dementia, to the growing national awareness of the importance of post-diagnostic services, to new diagnostic modalities and potential disease modifying medications on the horizon. Yet, all too frequently, people living with dementia and their carers report unsatisfactory experiences of diagnosis and care. Furthermore, population data suggests significant variations exist in clinical processes for people with dementia, leading to poor outcomes. This needs to change.

A missing piece of the puzzle has been data on the quality of care that is acquired at the point of care and clinical interface and is readily available as feedback directly to clinicians to inform on their own practice. These are the very data that the ADNeT Registry collects. This allows clinicians to participate in benchmarking, enabling ready identification of their patient cohort needs and highlighting variations in clinical care and outcomes compared to other clinical sites. Importantly, the ADNeT Registry also integrates the voice of the patient and/or caregiver and their perceptions of care and well-being, using co-designed surveys. These data are incredibly powerful in reducing variations in clinical care. Ultimately, it is this type of data that helps to improve outcomes for patients and their carers, while supporting clinicians to deliver best-standard care.

The ADNeT Registry was rolled out nationally in 2020. Despite the challenges of the COVID pandemic, the registry grew rapidly and had 40 participating sites across five states by the end of 2021. We continue to expand coverage of the ADNeT Registry, to include the multitude of clinical services involved in dementia and MCI diagnoses, and to support the valuable work of clinicians in delivering the best possible care to people living with dementia or with a prodromal dementia syndrome.

We sincerely thank participating sites, clinicians, registry participants and their carers, people with lived experience, peak bodies, industry and government, without whom the ADNeT Registry would not be possible.

We hope that you find the very first ADNeT Registry Annual Report interesting reading. We are pleased to commend it to you.

Dr Stephanie Ward
ADNeT Registry Steering Committee Co-Chair & Clinical Lead

Professor Henry Brodaty
ADNeT Registry Steering Committee Co-Chair

Professor Susannah Ahern
ADNeT Registry Academic Lead

I am pleased to present the First Annual Report of the Australian Dementia Network (ADNeT) Registry.

The ADNeT Registry is the first clinical quality registry established in Australia for dementia and mild cognitive impairment (MCI). It systematically measures the quality of diagnosis and care for people newly diagnosed with either dementia or MCI, including the important perspectives of people living with dementia or MCI and their carers through co-designed surveys. The aim, over time, is to register all persons diagnosed with dementia or MCI, independently of the diagnostic setting. The data, as with other clinical quality registries, is already used to drive improvements in diagnostics and care. Ultimately, these support clinicians to deliver best standard of dementia diagnosis and care, and enhanced patient outcomes which is the most important objective of all registries.

A unique strength of the ADNeT Registry is its integration with the other ADNeT initiatives. It is supported by the ADNeT Memory Clinics Initiative which launched the ADNeT Memory and Cognition Clinic Guidelines, and the ADNeT Screening and Trials Initiative which facilitates access to new diagnostic scans and blood tests and clinical dementia trials in Australia. These three ADNeT initiatives are distinct but synergistic, working collaboratively to improve dementia research and clinical practice in Australia.

I congratulate the ADNeT Registry team under the leadership of Dr Stephanie Ward and Professors Henry Brodaty and Susannah Ahern, for the successful national roll out in 2020. Despite the lock downs and challenges due to the COVID pandemic, the ADNeT Registry had 40 participating sites across five states by the end of 2021 and continues to grow. The Registry has attracted grants from industry who recognise the value of the registry for the post-market surveillance of the risks and benefits of new therapies.

I hope you enjoy the ADNeT Registry First Annual Report and thank you all for your ongoing support to ADNeT.

Professor Christopher Rowe
Director, Australian Dementia Network

Key Findings

40 participating sites

29 sites (72.5%) major cities

11 sites (27.5%) regional areas

866 patients

Dementia	67.9%
Mild Cognitive Impairment (MCI)	32.1%

Female:	Male:
55.2%*	44.8%*

Country of birth*

Born in Australia:	Born overseas:
62.3%	37.7%

Living arrangement*

Living with family or other	73.6%
Living alone	26.4%

*Unstated responses were excluded from denominators for percentages in the three infographics. This data can be found in Table 5 on page 22 and Table 12 on page 49.

Age groups

Dementia		MCI
Under 65: 7.4%		Under 65: 7.6%
65–74: 19.5%		65–74: 31.9%
75–84: 48.0%		75–84: 47.1%
85 and over: 25.1%		85 and over: 13.4%

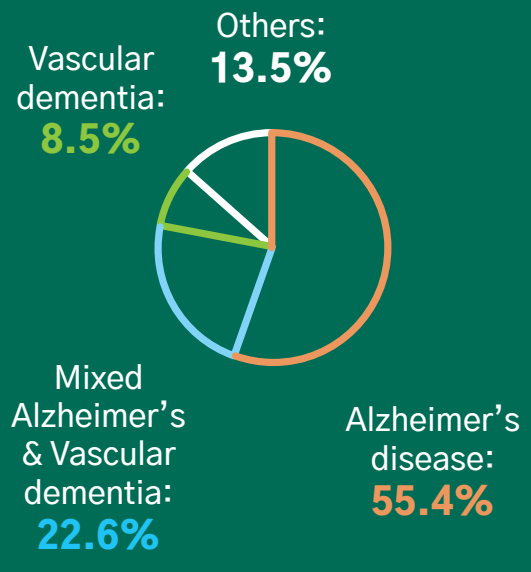
Median score of Mini-Mental State Exam

(Q1, Q3)

Dementia: 22.0 (19.0, 25.0)

MCI: 27.0 (24.5, 28.5)

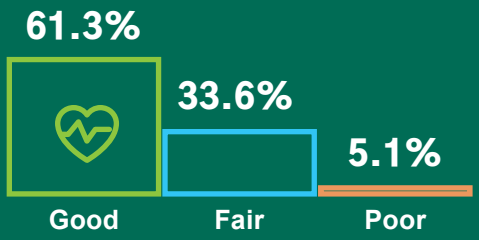
Dementia subtypes



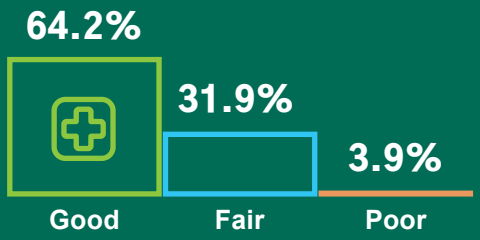
Months from referral to appointment

≤ 3 months:	> 3 months:
59.5%	40.5%

Patient reported well-being



Carer reported well-being



Registry Overview

Background

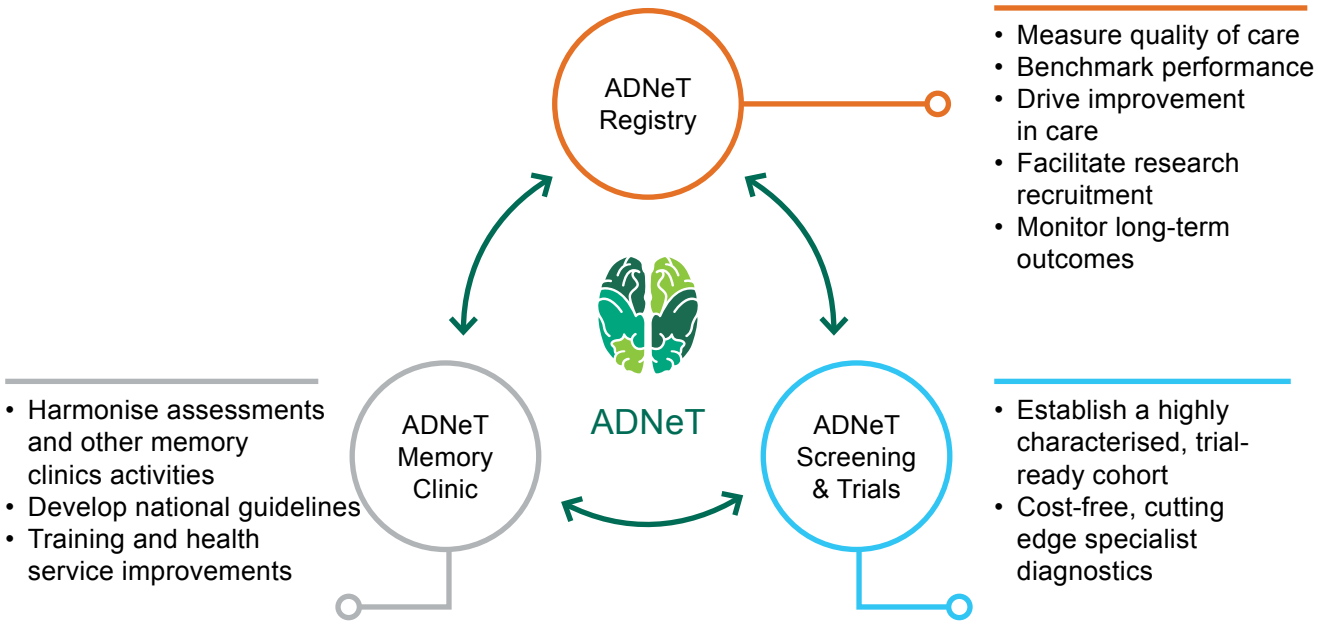
Dementia is the second leading cause of death and the third leading cause of burden of disease in Australia[1,2]. In 2022, nearly half a million Australians are estimated to be living with dementia, with this number projected to more than double by 2060[1]. Dementia leads to changes in cognition, in day to day function, in behaviour and psychological well-being, and has impacts on caregiver outcomes also[2]. People living with dementia face increased risks of hospitalisation, of falls and of entry into residential aged care[2]. The quality of clinical care can influence the trajectory of dementia and the lived experience of people with dementia and their carers[3], yet to date there has not been a systematic approach to measure variations in the quality of dementia care[4].

A Clinical Quality Registry (CQR) can facilitate a bridging of this systemic gap. The Australian Commission on Safety and Quality in Heath Care (ACSQHC) identified dementia as a priority area for development of CQRs in 2016, based on the high burden of disease, significant consequences of poor-quality care, and support from relevant clinical groups[5]. Against this background, the Australian Dementia Network (ADNeT) Registry has been established as part of the ADNeT initiative.

The ADNeT initiative is a multi-institutional consortium of dementia researchers and clinicians from across Australia funded by the National Health and Medical Research Council (NHMRC) National Institute for Dementia Research (NNIDR) program and philanthropic organisations. Whilst the NNIDR ceased operation on 30 June 2020, the ADNeT initiative was the beneficiary of the final grant made by the NNIDR. The ADNeT initiative has three key components: ADNeT Registry, ADNeT Screening and Trials, and ADNeT Memory Clinics (see Figure 1). These three components are synergistic and represent a comprehensive, integrated and coordinated approach to dementia research and clinical practice improvement in Australia.

This is the First Annual Report released by the ADNeT Registry. It pertains to data submitted to the registry from commencement of data collection on 10th March 2020 to 31st December 2021.

Figure 1 Key Components of the ADNeT Initiative



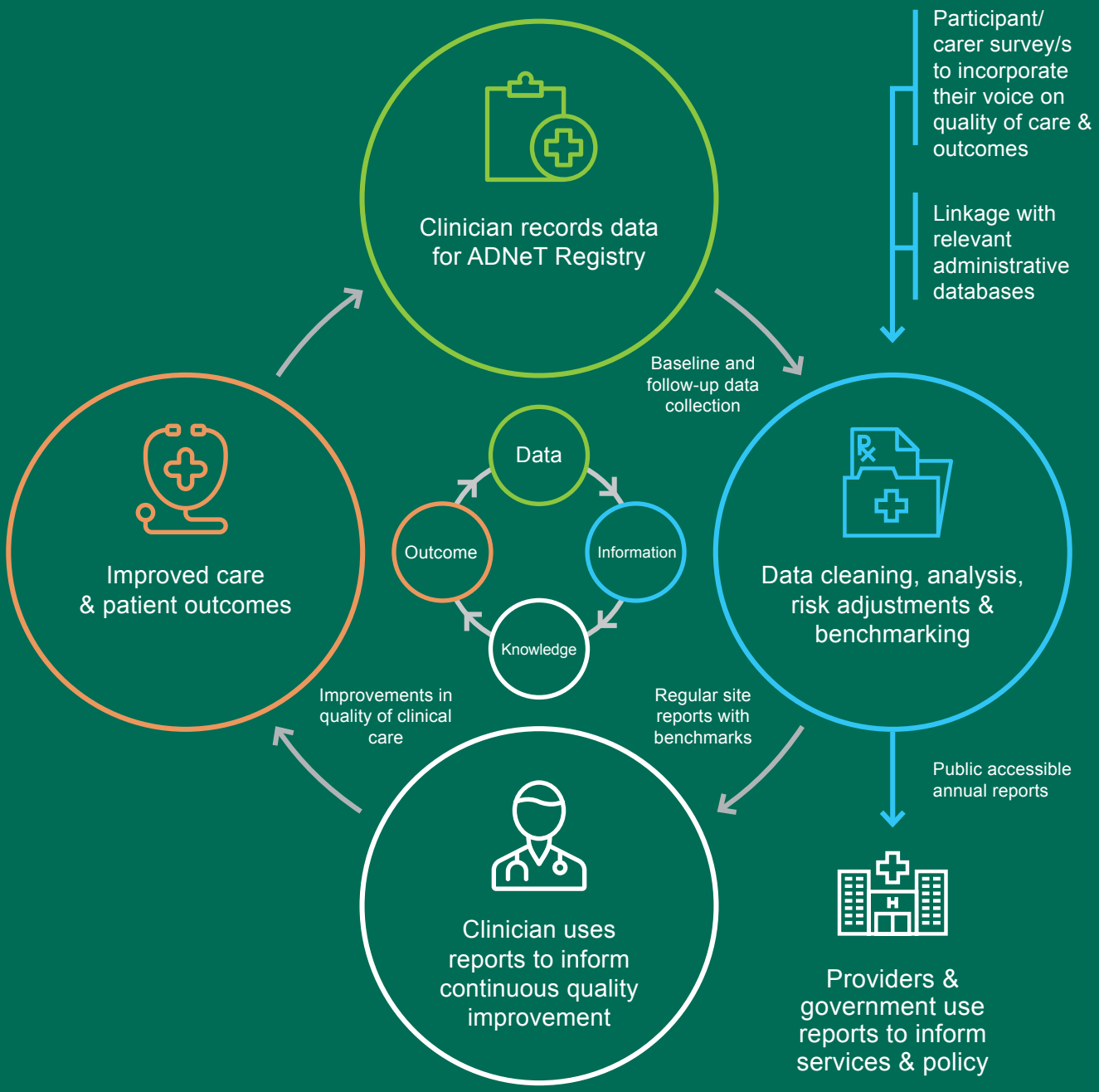
Vision and aims

The ADNeT Registry is a CQR for people newly diagnosed with dementia and mild cognitive impairment (MCI). 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 of care and patient outcomes (see Figure 2).

Primary aim: to collect and analyse data to monitor and enhance the quality of care and patient outcomes for people diagnosed with either dementia or MCI and their carers.

Secondary aim: to facilitate the recruitment of participants into research and establish a resource available to all to assist further study into the risk factors for, and trajectory of, dementia and MCI in Australia.

Figure 2 ADNeT Registry Quality Improvement Cycle



Governance

The ADNeT Registry has been developed and implemented in accordance with the ACSQHC Framework for Australian Clinical Quality Registries (2014)[6] and the Operating Principles and Technical Standards for Clinical Quality Registries (2008)[7].

The registry is governed by a Steering Committee which is comprised of representatives from key stakeholders including clinicians, people with lived experience, carers, peak bodies, and researchers. The Steering Committee provides governance oversight and strategic direction, and ensures that key deliverables are met on time and within budget. The Steering Committee meets formally on a quarterly basis and reports to the ADNeT Management Committee as part of the ADNeT governance structure.

Under the direction of the ADNeT Registry Steering Committee, a Management Committee comprising the Clinical Lead, the Academic Lead, and Monash University staff, meets regularly to oversee day-to-day operation of the ADNeT Registry. Refer to Appendix 1 for ADNeT Registry Steering Committee membership and staff list.

> The vision of ADNeT Registry is to drive improvement and quality of care and patient outcomes, and I think anything that can help to do that is working really well for dementia and people with dementia. The absolute commitment that has been shown to people like myself before the meeting and after, the way we are looked after is like royalty. Just knowing we have that respect, and it's a genuine respect, is terribly empowering. You make it so easy for us to have input. I value it very greatly.
>
> *– Person living with dementia*

> As a carer, I understand that a recurring part of the job is the management of successive difficulties and problems. Many arise directly out of aged care and health systems that have never been fit for purpose and are resistant to change. I see the ADNeT Registry as the first and only national initiative with the potential to effectively change this situation. I've been pleased to be among the consumer representatives who contribute meaningfully to ADNeT Registry's quality monitoring processes because I know our first-hand experience can help indicate where change is needed. I feel my hard-won experience is put to good use and that is rewarding.
>
> *– Carer of a person living with dementia*

> Out of all my involvement with many groups this has been one of the most inclusive, respectful groups that are interested in hearing our voice. Truly part and parcel of what we're doing, and I can only see it going from strength to strength.
>
> *– Carer of a person living with dementia*

Registry Methodology

The ADNeT Registry has received approval from the Alfred Hospital Human Research Ethics Committee under the National Mutual Acceptance Scheme (Project Number: 44037, Approval date: 27/08/2018).

Site recruitment

Site participation in the ADNeT Registry is voluntary, and ethics and governance authorisation is obtained by each site prior to commencing recruitment. Participating sites include memory and cognition clinics, other dementia and MCI diagnostic services, and individual medical practitioners involved in the diagnosis of dementia and MCI (e.g., geriatricians, neurologists and psychiatrists). Potential sites are identified by the registry team, registry promotional activities and word of mouth.

Participant recruitment

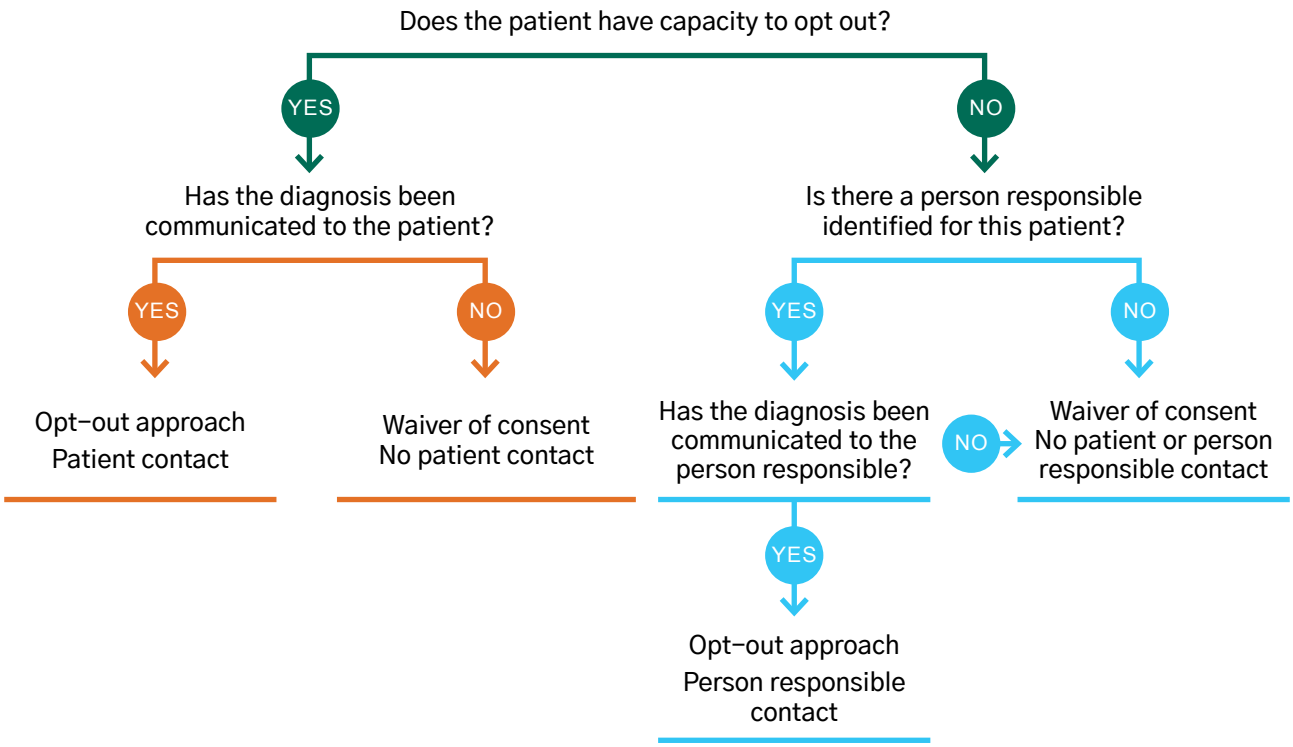
Inclusion criteria for the ADNeT Registry are patients aged 18 years and over who attend a participating site and receive a new diagnosis of either dementia or MCI.

Eligible patients are recruited using either an opt-out approach or waiver of consent based on three key determinants (see Figure 3):

- Capacity to be involved in the opt-out process
- Identification of a person responsible if applicable
- Communication of diagnosis to the patient or the person responsible

When patients are recruited using the opt-out approach, their data are entered into the registry once the four-week withdrawal period has lapsed. Patients and/or their families can also choose to withdraw from the registry at any time. When patients are recruited using waiver of consent, no patient contact is made and their data are automatically included in the registry.

Figure 3 Key Determinants of the ADNeT Registry Recruitment Methods



Data collection

The ADNeT Registry collects data from participating sites and, where appropriate, registry participants and their carers. Data collected from participating sites are based on the ADNeT Registry Minimum Data Set and includes patient identifiers and baseline demographic and clinical data (see Table 1 for key categories and Appendix 2 for the full dataset). A follow-up clinical dataset is currently in development and will be implemented in late 2022.

Following recruitment (i.e., following the four-week opt-out period), registry participants and, where appropriate, their carers are posted a self-completed survey which includes questions on patient/carer-reported outcomes and their experience of clinical care at the point of diagnosis. These surveys were developed through expert consensus by a working group which is comprised of people living with dementia, carers, peak bodies, clinicians and researchers. Feedback from consultation with people with lived experience and carers, facilitated by Dementia Australia, was incorporated into these surveys.

Refer to Appendix 3 for information on the quality of data included in this report.

Involvement of people with lived experience

The ADNeT Registry is committed to ongoing lived experience involvement and has been working in collaboration with Dementia Australia to incorporate the voice of people living with dementia, MCI and carers in the strategic direction and operation of the registry.

Key engagement activities undertaken between 2020-2021 included:

- Representation of people living with dementia and carers on the Steering Committee
- People living with dementia and carers co-designing the participant and carer surveys via the Survey Working Group
- Consultation of people living with dementia, MCI and carers on registry invitation documents and surveys

Table 1 Key Data Categories of the ADNeT Registry Baseline Minimum Data Set

Category	Examples of data elements
Patient identifiers	First name, Last name, Date of birth, Sex
Information to support recruitment	Capacity to opt out, Person responsible (if appropriate), Communication of diagnosis, Identification of carer
Patient demographic information	Country of birth, Aboriginal and/or Torres Strait Islander, Preferred spoken language, Highest level of education
Baseline clinical data	Referral date, Initial appointment date, Diagnosis date, Diagnosis and subtype, Diagnostic investigations, Co-morbidities, Cognitive assessments, Independence with activities of daily living

Participating Site Profile

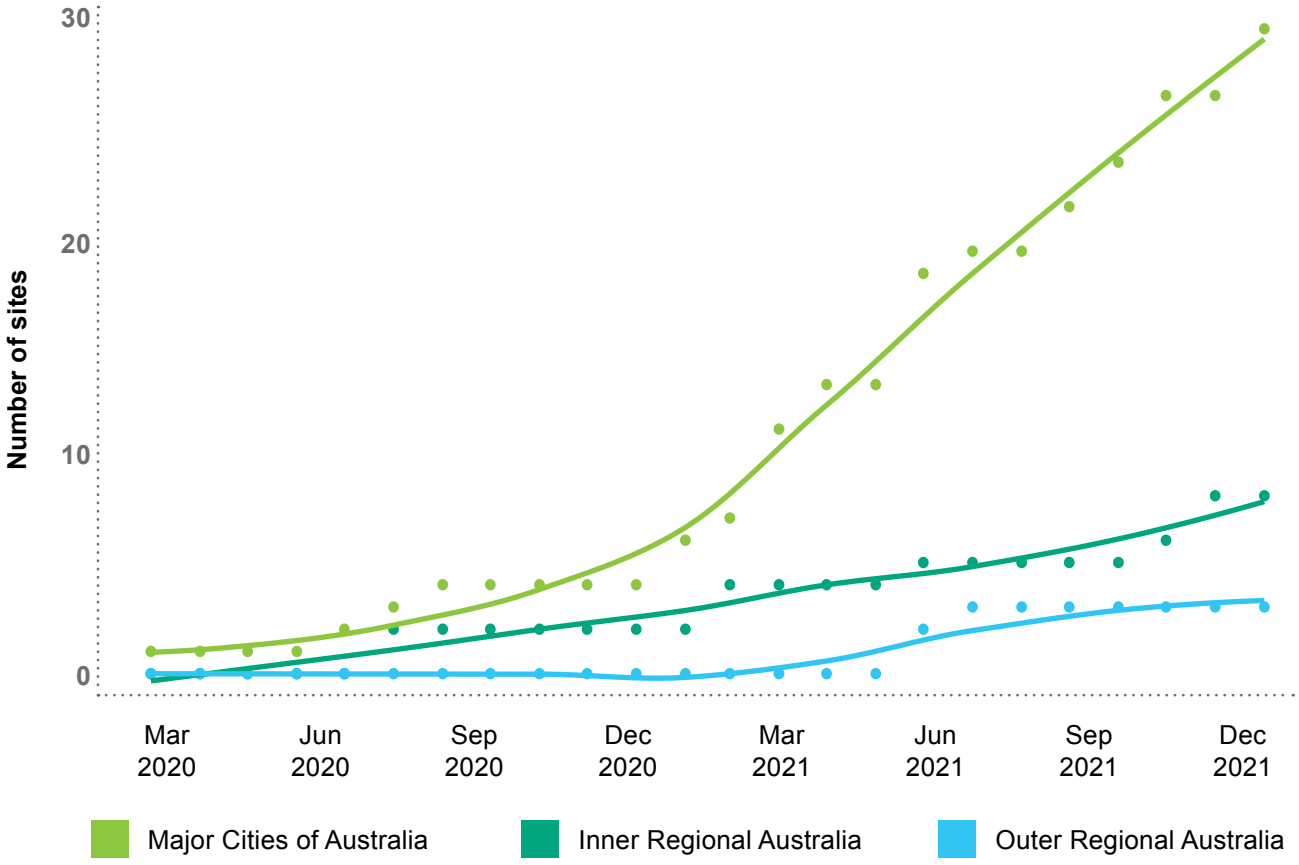
As of 31st December 2021, 40 sites across five states contributed to the ADNeT Registry, including 29 (72.5%) from major cities and 11 (27.5%) from regional areas (see Table 2 and Figure 4). Refer to Appendix 4 for a list of the 40 participating sites.

Table 2 Characteristics of Participating Sites

	Total	New South Wales	Queensland	South Australia	Tasmania	Victoria
Location[1]						
Major city	29 (72.5%)	9	6	5	0	9
Inner Regional	8 (20.0%)	3	0	0	4	1
Outer Regional	3 (7.5%)	0	3	0	0	0
Organisation type						
Public	22 (55.0%)	8	5	5	0	4
Private	18 (45.0%)	4	4	0	4	6
Total	40	12	9	5	4	10

[1] Location categorised using Australian Statistical Geography Standard Remoteness Structure 2016.

Figure 4 Site Recruitment (2020-2021)

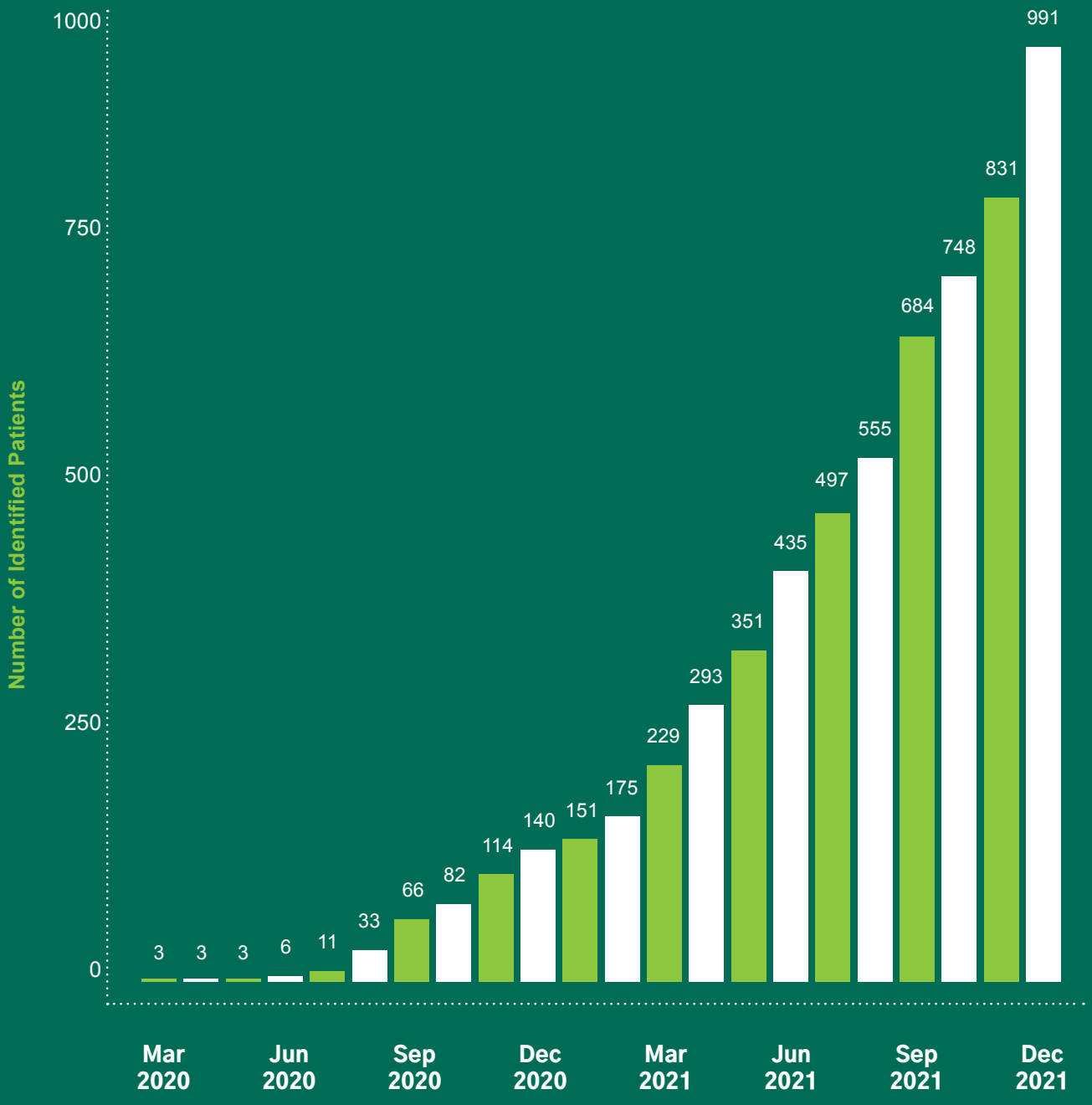


Participant Profile

Participant recruitment

As of 31st December 2021, a total of 991 patients were identified as eligible for inclusion in the registry (see Figure 5). Of these patients, 866 (87.4%) were recruited and 125 (12.6%) elected to opt out.

Figure 5 Participant Recruitment (2020-2021)



Opt-out information

Participants can elect to opt out at any time and make the request themselves or via a family member or a friend (see Table 3). Of the 125 patients who elected to opt out, 66 (52.8%) provided reasons for doing so. “Not interested” was the most common opt-out reason (n = 34, 51.5%), followed by “Privacy concerns” (n = 11, 16.7%).

To encourage participation, the ADNeT Registry sought feedback on registry invitation documents via consumer consultation facilitated by Dementia Australia in early 2021. Registry invitation documents were then revised to incorporate consumer feedback. The ADNeT Registry will continue to monitor the opt-out rate and explore additional strategies to encourage participation.

Table 3 Opt-out Information

Opt-out information	Number (%)
Opt-out time point (n = 125)	
At the time of diagnosis	28 (22.4%)
During recruitment	80 (64.0%)
Post recruitment	17 (13.6%)
Person making opt-out request (n = 97)[1]	
Participant themselves	47 (48.5%)
Family or friend	50 (51.5%)

[1] Information is only available among participants who elected to opt out during or post recruitment.

Participant diagnostic profile

Of the 866 registry participants, 588 (67.9%) were diagnosed with dementia, with Alzheimer's disease being the most common type of dementia, followed by Mixed Alzheimer's and Vascular dementia (see Table 4).

Table 4 Participant Diagnosis Subtype Information

Subtype	Number (%)
Dementia (n = 588, 67.9%)	
Alzheimer's disease	326 (55.4%)
Mixed dementia - Alzheimer's and Vascular[1]	133 (22.6%)
Vascular dementia	50 (8.5%)
Frontotemporal dementia	28 (4.8%)
Other dementia – other mixed pathologies[2]	19 (3.2%)
Dementia with Lewy bodies	14 (2.4%)
Other dementia – single pathology	11 (1.9%)
Dementia, unspecified	7 (1.2%)
MCI (n = 278, 32.1%)	
Amnestic, single domain	103 (37.1%)
Amnestic, multi-domain	119 (42.8%)
Non-amnestic, single domain	12 (4.3%)
Non-amnestic, multi-domain	24 (8.6%)
Not stated	20 (7.2%)

[1] Includes participants with or without another dementia subtype, [2]Includes participants with mixed dementia other than mixed Alzheimer's and Vascular (e.g., mixed Alzheimer's and Frontotemporal dementia)

Participant demographic profile

The median age of registry participants was 79 years and more than half were female (see Table 5). Thirty-seven percent of the participants were born overseas and less than 2% identified as Aboriginal and/or Torres Strait Islander.

Table 5 Participant Demographic Profile

Variable	Dementia (n = 588)	MCI (n = 278)	All (n = 866)
Age in years, median (Q1 to Q3)	**80.1 (74.5, 85.0)**	**76.7 (73.2, 82.2)**	**79.1 (73.8, 84.4)**
Female, n (%)	**329 (56.0%)**	**145 (52.2%)**	**474 (54.7%)**
Aboriginal and/or Torres Strait Islander, n (%)	**7 (1.2%)**	**6 (2.2%)**	**13 (1.5%)**
Country of birth, n (%)			
Australia	342 (58.2%)	184 (66.2%)	526 (60.7%)
England	45 (7.6%)	20 (7.2%)	65 (7.5%)
Greece	25 (4.2%)	6 (2.1%)	31 (3.6%)
Italy	21 (3.6%)	8 (2.9%)	29 (3.4%)
Other	138 (23.5%)	55 (19.8%)	193 (22.3%)
Not stated	17 (2.9%)	5 (1.8%)	22 (2.5%)
Preferred spoken language, n (%)			
English	506 (86.1%)	253 (91.0%)	759 (87.7%)
Greek	24 (4.1%)	3 (1.1%)	27 (3.1%)
Italian	8 (1.3%)	3 (1.1%)	11 (1.3%)
Spanish	6 (1.0%)	3 (1.1%)	9 (1.0%)
Other	34 (5.8%)	13 (4.6%)	47 (5.4%)
Not stated	10 (1.7%)	3 (1.1%)	13 (1.5%)
Highest education level, n (%)			
Tertiary education or higher	137 (23.3%)	69 (24.8%)	206 (23.8%)
Secondary education	346 (58.8%)	173 (62.2%)	519 (59.9%)
Primary education or less	70 (11.9%)	23 (8.3%)	93 (10.8%)
Not stated	35 (6.0%)	13 (4.7%)	48 (5.5%)
Labour force status, n (%)			
Retired/not in labour force	564 (95.9%)	248 (89.2%)	812 (93.8%)
Employed	17 (2.9%)	28 (10.1%)	45 (5.2%)
Not stated	7 (1.2%)	2 (0.7%)	9 (1.0%)
Residential setting, n (%)			
Private residence	530 (90.1%)	261 (93.9%)	791 (91.3%)
Retirement village	27 (4.6%)	10 (3.6%)	37 (4.3%)
Residential aged care facility	13 (2.2%)	4 (1.4%)	17 (2.0%)
Other	11 (1.9%)	3 (1.1%)	14 (1.6%)
Not stated	7 (1.2%)	0 (0.0%)	7 (0.8%)
Living arrangement, n (%)			
Living with family or others	405 (68.9%)	193 (69.4%)	598 (69.1%)
Living alone	146 (24.8%)	69 (24.8%)	215 (24.8%)
Not stated	37 (6.3%)	16 (5.8%)	53 (6.1%)

Participant clinical profile

Most participants were independent in activities of daily life. The most common co-morbidity was hypertension (see Table 6).

Table 6 Participant Clinical Profile

Variable	Dementia (n = 588)	MCI (n = 278)	All (n = 866)
Function, n (%)			
Mobility independent	527 (89.6%)	272 (97.8%)	799 (92.3%)
Continent	451 (76.7%)	242 (87.1%)	693 (80.0%)
pADLs[1] independent	466 (79.3%)	267 (96.0%)	733 (84.6%)
iADLs[2] independent	154 (26.2%)	206 (74.1%)	360 (41.6%)
Driving	191 (32.5%)	175 (62.9%)	366 (42.3%)
Number of medications			
Median (Q1, Q3)	5.0 (3.0, 8.0)	5.5 (3.0, 8.0)	5.0 (3.0, 8.0)
Co-morbidities, n (%)			
Hypertension	366 (62.2%)	167 (60.1%)	533 (61.5%)
Cardiovascular disease	226 (38.4%)	102 (36.7%)	328 (37.9%)
≥1 falls in past 12 months	171 (29.1%)	67 (24.1%)	238 (27.5%)
Diabetes	132 (22.4%)	58 (20.9%)	190 (21.9%)
Cancer	117 (19.9%)	67 (24.1%)	184 (21.2%)
Stroke	75 (12.8%)	37 (13.3%)	112 (12.9%)

[1] Personal (or basic) activities of daily living, [2] Instrumental activities of daily living

I think it's important for people living with dementia and their carers to provide input into the way the clinics are doing. The clinics have done a fantastic job of trying to diagnose and improve the outcomes of patients and their carers. Anything I can do to help that is pretty important. I am quite passionate about it. I don't spend time doing stuff I don't want to do, but this is certainly stuff I want to do... I am not good with words anymore because of my condition, but I can put a practical view on things. I think the team, the A-team as I call it, tries to come up with the best outcome for the patient and the carer.

– Person living with dementia

I feel so honoured to be invited to be a part of this and to find myself working with the survey consumer group. We just bounce off each other and support each other and it's amazing...There's a lot of humour, fun and energy in the group. The other part is that the raw data that I feel I still bring is taken very seriously, both in the survey consumer group and in the bigger survey working group.

– Carer of a person living with dementia

The information that we have received via the ADNeT Registry Site Report has been helpful not only in highlighting areas where our service needs to improve but has also identified areas that we are performing well in, compared to the rest of the country. The registry data has also helped provide validation for our model of care and it will help us improve the service we provide to patients and carers into the future.

– Participating clinician

Clinical Processes

The ADNeT Registry collects information on key clinical processes, including diagnostic time intervals, cognitive assessments and clinical investigations.

Diagnostic time intervals

The median diagnostic time intervals for registry participants were:

- 75 days from referral to first appointment,
- 32 days from first appointment to diagnosis, and
- 127 days from referral to diagnosis (see Table 7).

Table 7 Diagnostic Time Intervals (in days)

Diagnostic time intervals[1]	Dementia (n = 552)	MCI (n = 270)	All (n = 822)
Referral to first appointment			
Median (Q1, Q3)	70.0 (39.0, 119.0)	81.0 (42.0, 121.0)	75.0 (40.8, 120.0)
n	542	266	808
First appointment to diagnosis			
Median (Q1, Q3)	42.0 (0.0, 117.5)	0.0 (0.0, 77.0)	32.0 (0.0, 103.0)
n	548	267	815
Referral to diagnosis			
Median (Q1, Q3)	133.0 (70.0, 215.0)	121.5 (62.0, 199.8)	127.0 (69.2, 209.8)
n	540	266	806

[1] Excludes 44 (5.1%) participants with a previous MCI diagnosis

Cognitive assessments

The ADNeT Registry records scores of four cognitive 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 common cognitive assessments whereas the KICA is recommended for use with Aboriginal and Torres Strait Islander peoples living in remote and rural areas and the RUDAS is recommended for use with people from Culturally and Linguistically Diverse backgrounds[8]. Of the four cognitive assessments, MMSE was most used (n = 620, 71.6%); no participant undertook KICA. Figure 6 presents the scores on MMSE, MoCA and RUDAS. As expected, participants with MCI scored higher in these cognitive tests than participants with dementia.

Figure 6 Boxplots of MMSE, MoCA and RUDAS Scores

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), 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.

Clinical investigations

Of the various types of clinical investigations, participants were mostly likely to have core blood tests completed as part of diagnostic work-up, followed by magnetic resonance imaging (MRI) brain scan (see Table 8).

Table 8 Completed Clinical Investigations

Clinical investigations[1]	Dementia (n = 588)	MCI (n = 278)	All (n = 866)
Core blood tests, n (%)	**527 (89.6%)**	**253 (91.0%)**	**780 (90.0%)**
Structural neuroimaging, n (%)			
MRI[2] Brain	318 (54.1%)	156 (56.1%)	474 (54.7%)
CT[3] Brain	253 (43.0%)	121 (43.5%)	374 (43.2%)
None completed	40 (6.8%)	22 (7.9%)	62 (7.2%)
Not stated	21 (3.6%)	9 (3.2%)	30 (3.5%)
Functional neuroimaging, n (%)			
FDG PET[4]	58 (9.9%)	25 (9.0%)	83 (9.6%)
SPECT[5]	33 (5.6%)	13 (4.7%)	46 (5.3%)
Amyloid/Tau PET	7 (1.2%)	3 (1.1%)	10 (1.2%)
None completed	440 (74.8%)	215 (77.3%)	655 (75.6%)
Not stated	61 (10.4%)	29 (10.4%)	90 (10.4%)
Lumbar puncture, n (%)	**6 (1.0%)**	**0**	**6 (0.7%)**

[1] Some participants might have some investigations completed prior to attending the clinic and did not need to have these investigations repeated, [2] Magnetic Resonance Imaging, [3] Computed Tomography, [4] Fluorodeoxyglucose Positron Emission Tomography, [5] Single Photon Emission Computed Tomography

Prescription of acetyl cholinesterase inhibitors

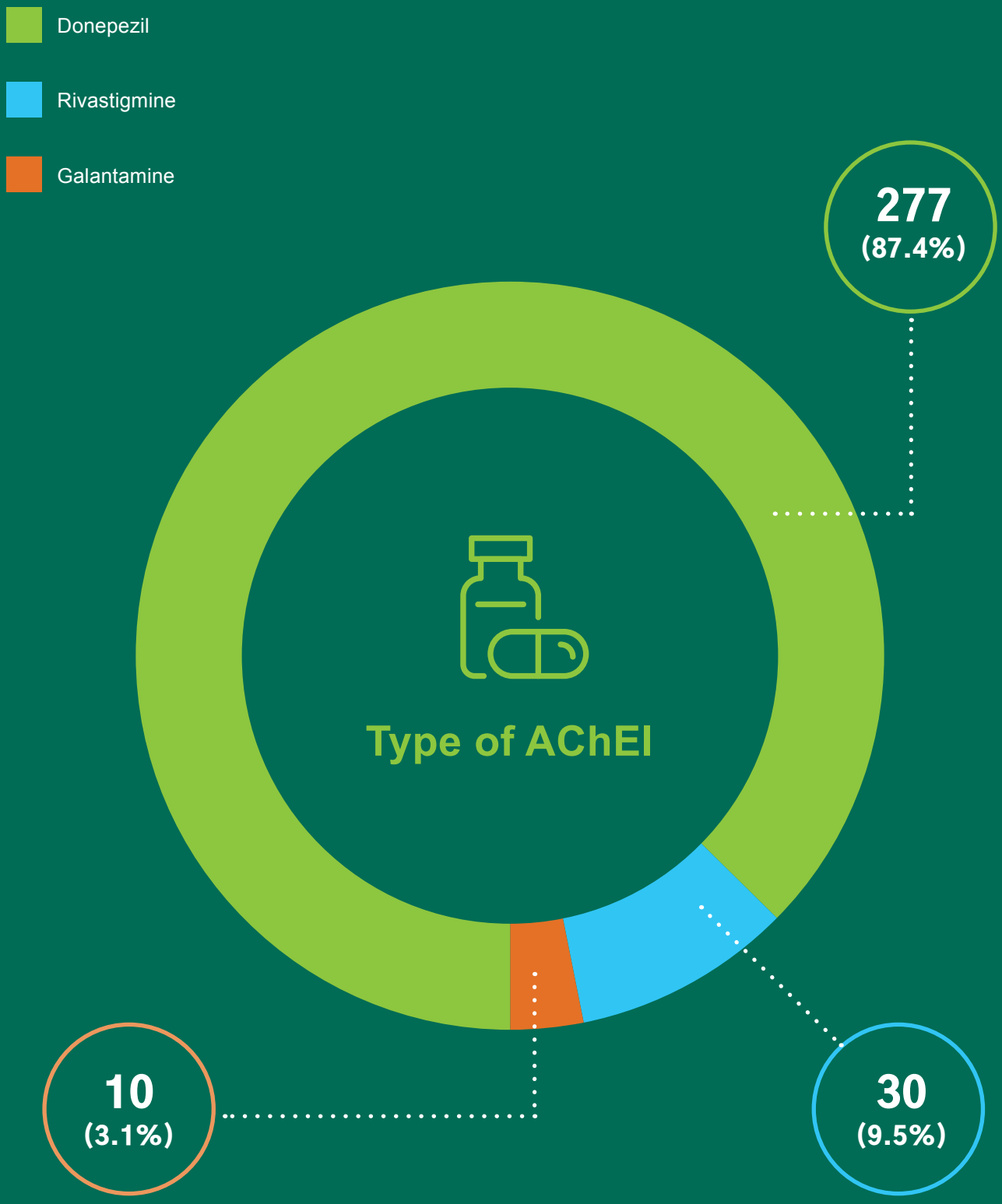
The Australian Clinical Practice Guidelines and Principles of Care for People with Dementia recommend acetyl cholinesterase inhibitor (AChEI) prescription as an option for managing the symptoms of mild to moderately severe Alzheimer's disease[8]. As such, the ADNeT Registry collects information on AChEI prescription for participants diagnosed with dementia. Of the 588 participants with dementia, 53.9% were prescribed or recommended AChEI (see Table 9), mostly Donepezil (see Figure 7).

Table 9 AChEI Prescription among Participants with Dementia

AChEI variables	Number (%)
AChEI prescription status	
AChEI prescribed[1]	317 (53.9%)
AChEI not prescribed	236 (40.1%)
Not Stated	35 (6.0%)
AChEI prescription by dementia subtype[2]	
AD[3]	300 (94.6%)
Dementia with Lewy bodies	10 (3.2%)
Neither AD nor Dementia with Lewy bodies	7 (2.2%)
AChEI prescription in dementia with AD by MMSE[4] **status**[5]	
In dementia with AD, MMSE ≥ 10[6]	231 (77.0%)
In dementia with AD, MMSE < 10	1 (0.3%)
In dementia with AD, No MMSE	68 (22.7%)

[1] Prescribed means either directly prescribed by the participating service, or participating service has recommended that the GP prescribe. This information is only collected for participants with dementia (n = 588), [2] Restricted to participants who were prescribed or recommended AChEI (n = 317), [3] Alzheimer's disease, [4] Mini-Mental State Exam, [5] Restricted to participants who were diagnosed with Alzheimer's disease with or without another dementia subtype and were prescribed or recommended AChEI (n = 300), [6] MMSE of 10 or above denotes mild to moderate dementia.

Figure 7 Type of AChEI



Clinical Quality Indicators

Clinical quality indicators (CQIs) are specifically defined measures, which describe the performance of clinical activities that are considered best practice in clinical care[9]. CQIs also measure the performance of important clinical outcomes of care[9]. To inform the development of the CQIs for the ADNeT Registry, a Modified Delphi Study was conducted prior to the establishment of the registry. The Modified Delphi study proposed a set of 18 CQIs which capture quality of care and patient outcomes across the trajectory of care for people with dementia and MCI[10]. These CQIs were presented to the ADNeT Registry Steering Committee in 2019 and of the 18 CQIs, seven have been endorsed. Of these, the first six CQIs capture elements of practice considered best standard. The seventh CQI, on acetyl cholinesterase inhibitor prescribing, was added to examine variations and to facilitate benchmarking. The ADNeT Registry recognises that there may be many clinical scenarios where such medications are contraindicated, or a trial of such medications is not consistent with patient preferences. However, internationally, AChEI prescription is typically reported in other dementia clinical quality registries[11].

Table 10 presents the performance on the seven endorsed CQIs among ADNeT Registry participants. The information is visualised as funnel plots in Figure 8. Funnel Plots are a visual representation of how individual units perform compared to their peers and the overall average; it also identifies 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).

It is important that CQIs are regularly reviewed to ensure that they are relevant and meaningful to clinicians and patients[6, 7]. Given the seven ADNeT Registry CQIs were endorsed three years ago, the ADNeT Registry will undertake a review of its CQIs in 2022.

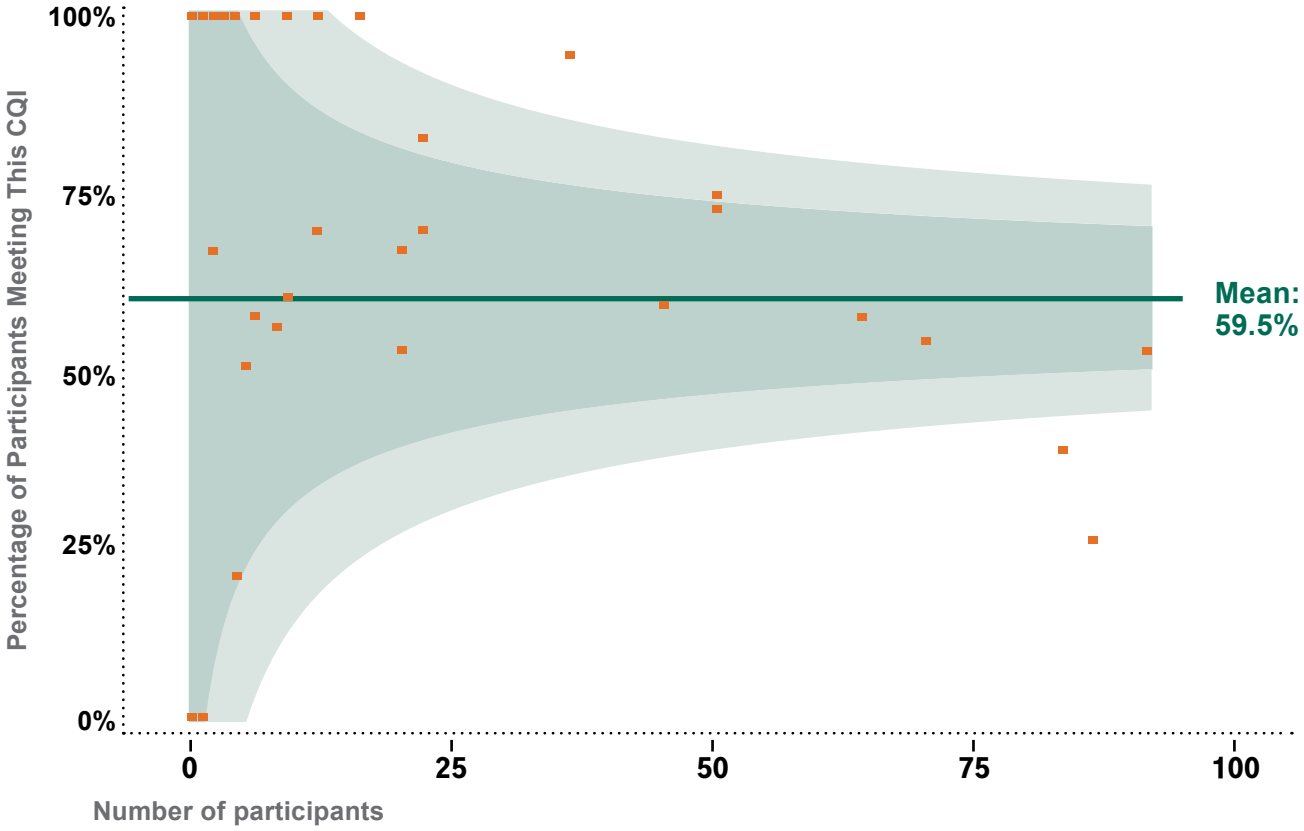
To drive quality improvement initiatives at participating sites, individualised bi-annual site reports including data on site CQIs benchmarked to other sites, as well as site participant demographic and clinical profile, have been circulated to participating sites since December 2021. These reports help participating sites to assess their performance compared to their peers and to identify areas for quality improvement at a site level.

Table 10 Performance on the Seven Endorsed Clinical Quality Indicators

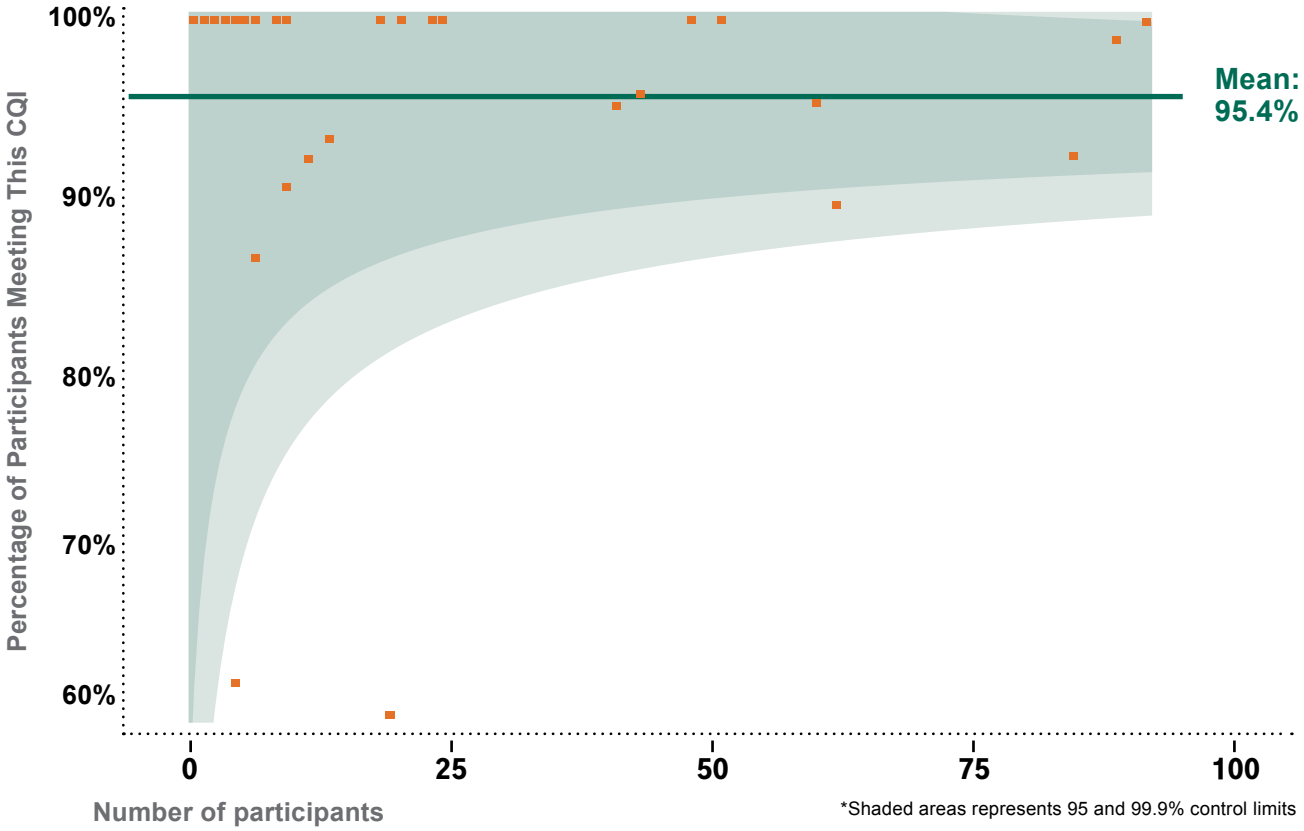
Clinical Quality Indicator	Value
1: First appointment within 90 days of referral	481/808 (59.5%)
2: Core blood tests undertaken as part of the diagnostic work-up	780/818 (95.4%)
3: Multiple cognitive domains assessed as part of the diagnostic work-up	853/861 (99.1%)
4: Structural neuroimaging completed as part of the diagnostic work-up	774/836 (92.6%)
5: Capacity to undertake personal and instrumental activities of daily living assessed as part of the diagnostic work-up	847/866 (97.8%)
6: Cognition re-assessed within 18 months of a MCI diagnosis	241/273 (88.3%)
7: Acetyl cholinesterase inhibitor prescribed/recommended for persons diagnosed with mild to moderate Alzheimer's disease:	
• ***Patients < 85 years old***	180/239 (75.3%)
• ***Patients ≥ 85 years old***	48/82 (58.5%)

Figure 8 Funnel Plots of the Seven Endorsed Clinical Quality Indicators

CQ1: Dementia diagnostic service appointment within 90 days

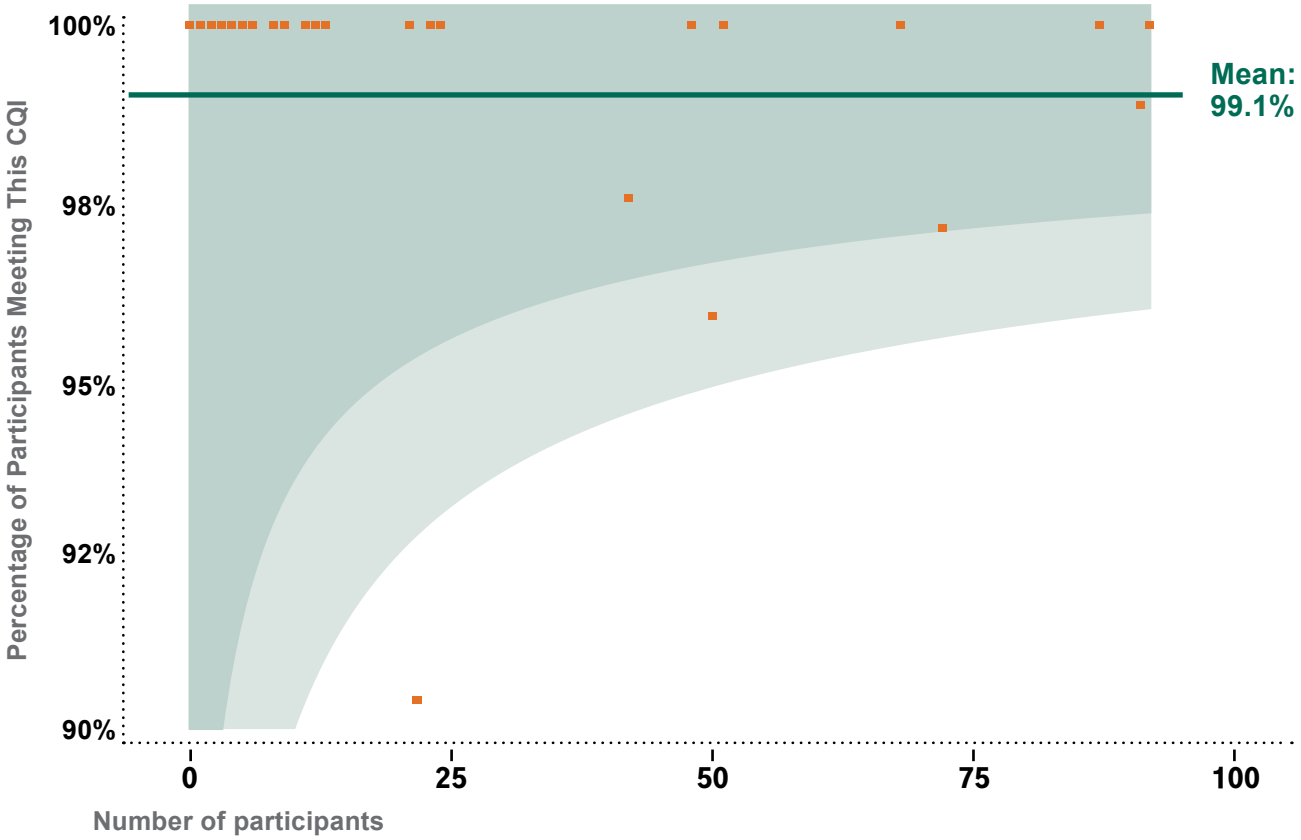


CQI 2: Core blood tests undertaken as part of diagnosis

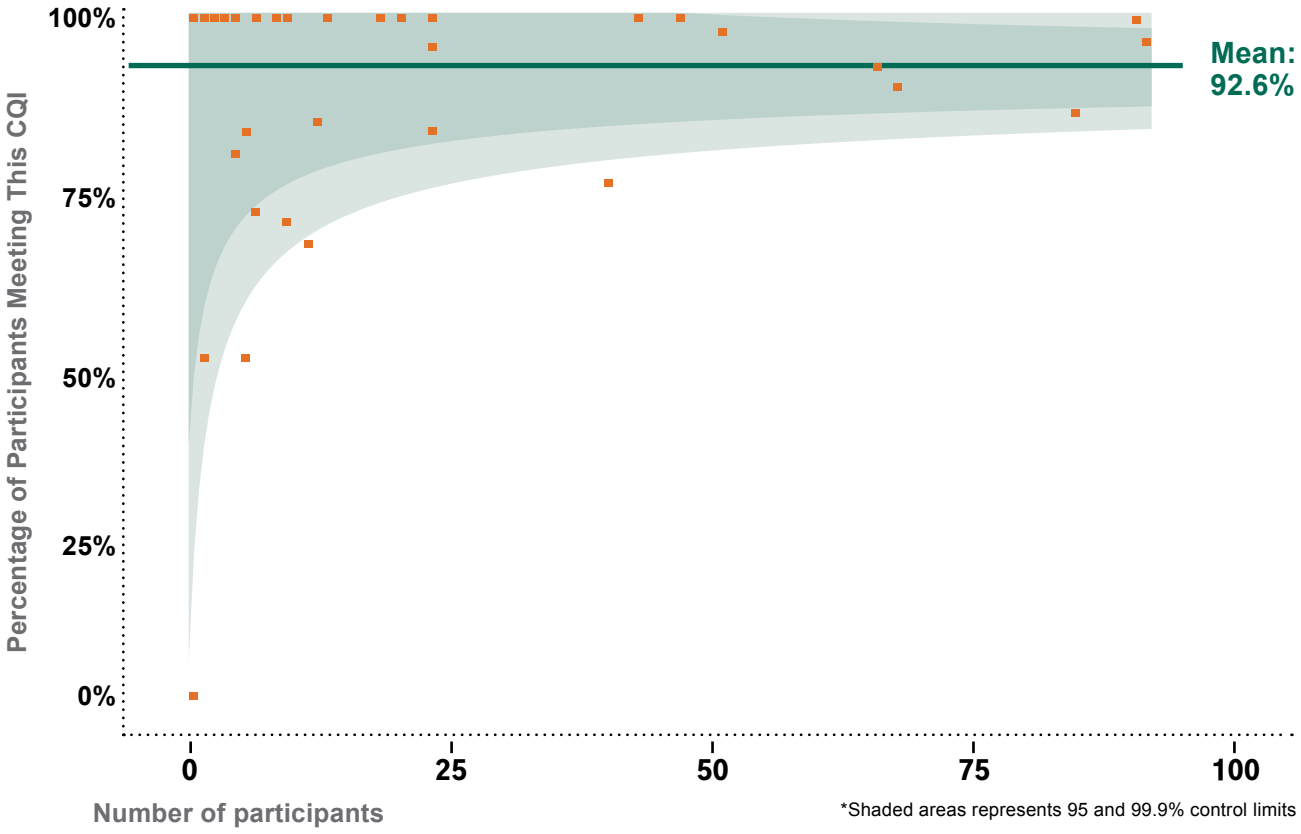


*Shaded areas represents 95 and 99.9% control limits

CQ3: Multiple cognitive domains assessed

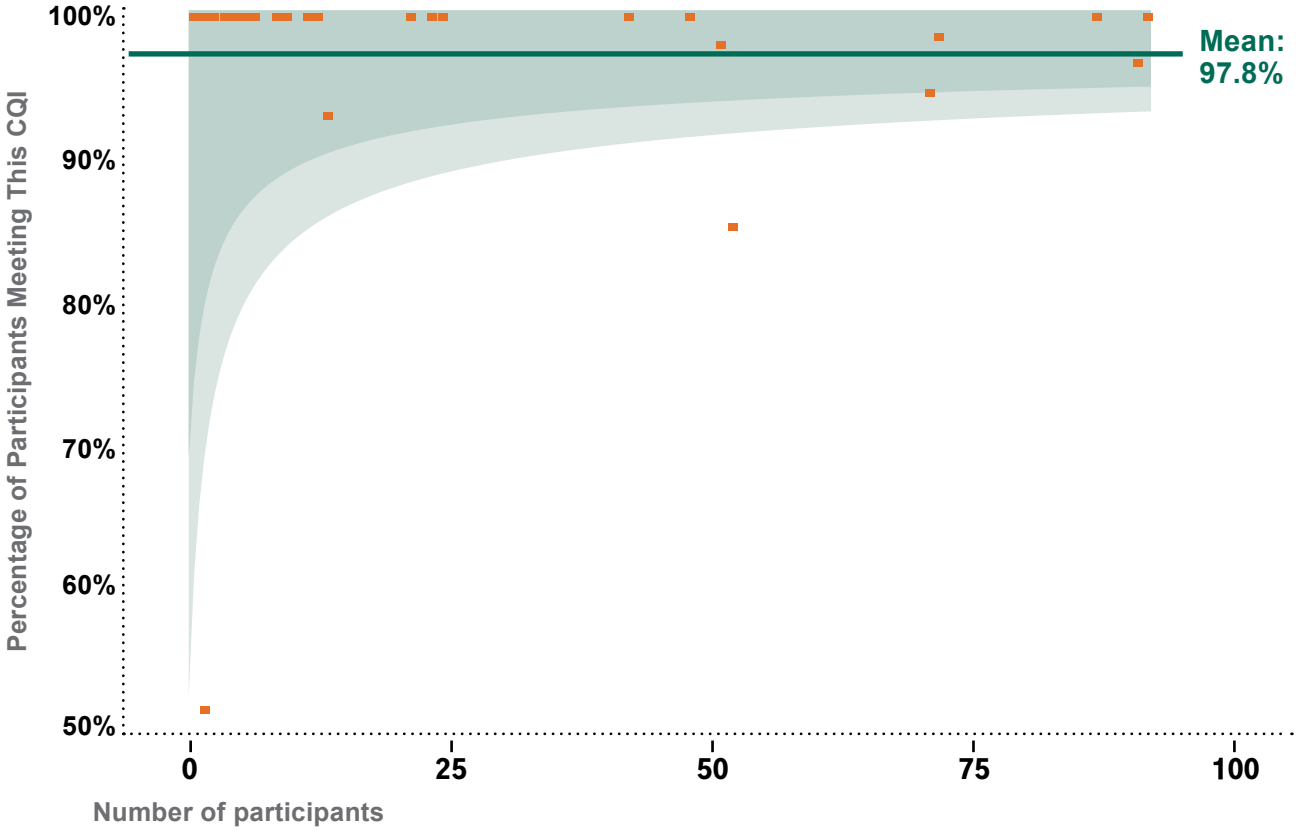


CQI 4: Structural neuroimaging completed as part of diagnosis

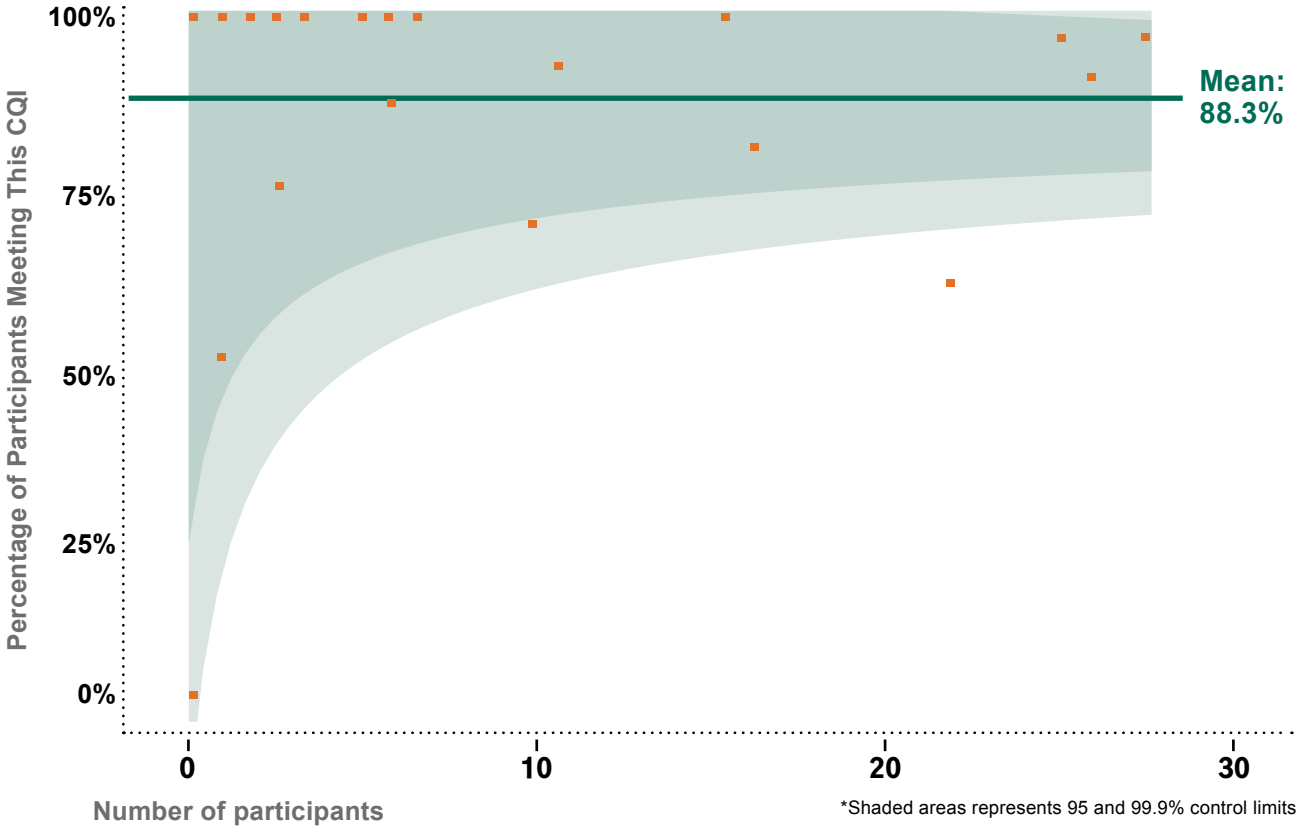


*Shaded areas represents 95 and 99.9% control limits

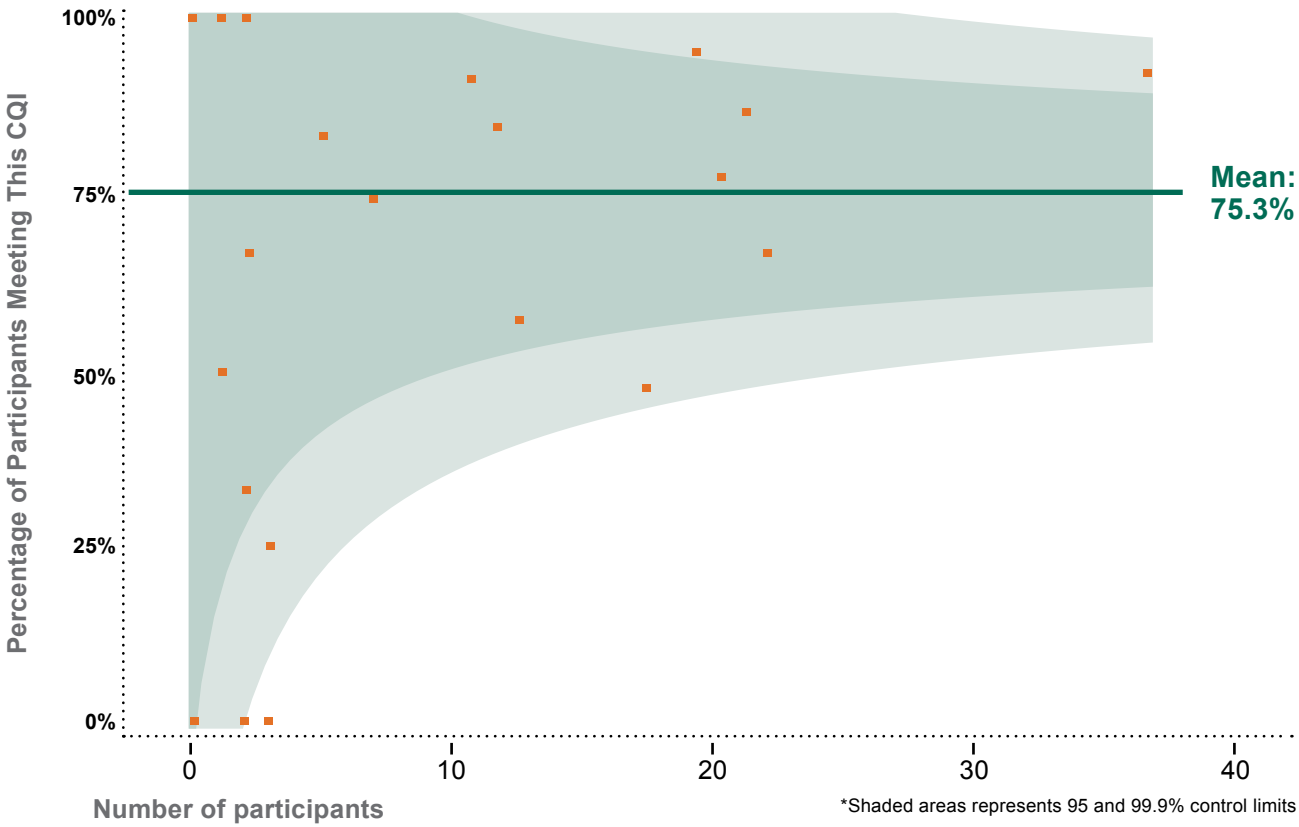
CQI 5: Capacity to undertake activities of daily living assessed as part of diagnosis



CQI 6: Cognition re-assessed within 18 months of MCI diagnosis



CQI 7: AChEI prescribed/recommended for mild to moderate Alzheimer's disease (patients < 85 years old)[1]



[1] Funnel plot for participants aged 85 years and over was not included due to a small sample size

> We have really appreciated the enthusiastic and comprehensive support that we have received from the ADNeT Registry. We have found the ongoing support, advice, and feedback from the ADNeT Registry to be extremely helpful with the setup of the clinic, current running and for our future planning.
>
> *– Participating clinician*

> ADNeT Registry is the 'best practice' in dementia care and ensures high quality. The registry has developed a framework with pertinent domains and enables capture of relevant information in busy out-patient clinics with ease. The routine collection, analysis and reporting of health information is an impetus to self-improve and benchmark the clinical quality indicators. The ADNeT Registry team works collaboratively to make this clinical journey effective and meaningful to all.
>
> *– Participating clinician*

> The introduction of the ADNeT Registry has been well received by our staff, clients and their families. The ADNET Registry team have been very supportive and responsive in developing and refining systems and processes to streamline the collection of data. The information generated is essential, both for service justification and for further development and improvement into the future.
>
> *– Participating clinician*

Patient- and Carer-Reported Measures

The ADNeT Registry collects data on patient- and carer-reported outcomes and experience of clinical care at the point of diagnosis via self-completed postal surveys. The surveys, implemented in February 2021, were sent to all eligible patients and, where available, their carers.

The survey response rate was 52% for the patient version and 54% for the carer version (see Table 11). Most patients and their carers rated their health and well-being as “Good” or “Very Good” at the time of the diagnosis (see Figure 9).

They reported overall positive experience of participating sites, with 88% of patients and 91% of carers rating their overall experience as “Good” or “Very good” (see Figure 10). The aspects showing most positive experience were the questions on “treated with dignity and respect” (agreed/strongly agreed by 96% of patients and 98% of carers) and “given the opportunity to ask questions” (agreed/strongly agreed by 93% of patients and 95% of carers). The aspect showing least positive experience was “given advice about how and where to get more information or help if needed” (agreed/strongly agreed by 80% of patients and 87% of carers). Refer to Appendix 5 for the results of other experience questions.

Table 11 ADNeT Registry Survey Response Rates

Survey type	Sent[1]	Returned	Response rate
Patient version	537	281	52.3%
Carer version	433	234	54.0%

[1] Excludes surveys that were sent within 14 days of data lock (n = 6 for the patient version and 32 for the carer version) and surveys that were returned to sender (n = 3 for both the patient version and the carer version).

Figure 9 Results of Patient- and Carer-Reported Outcomes

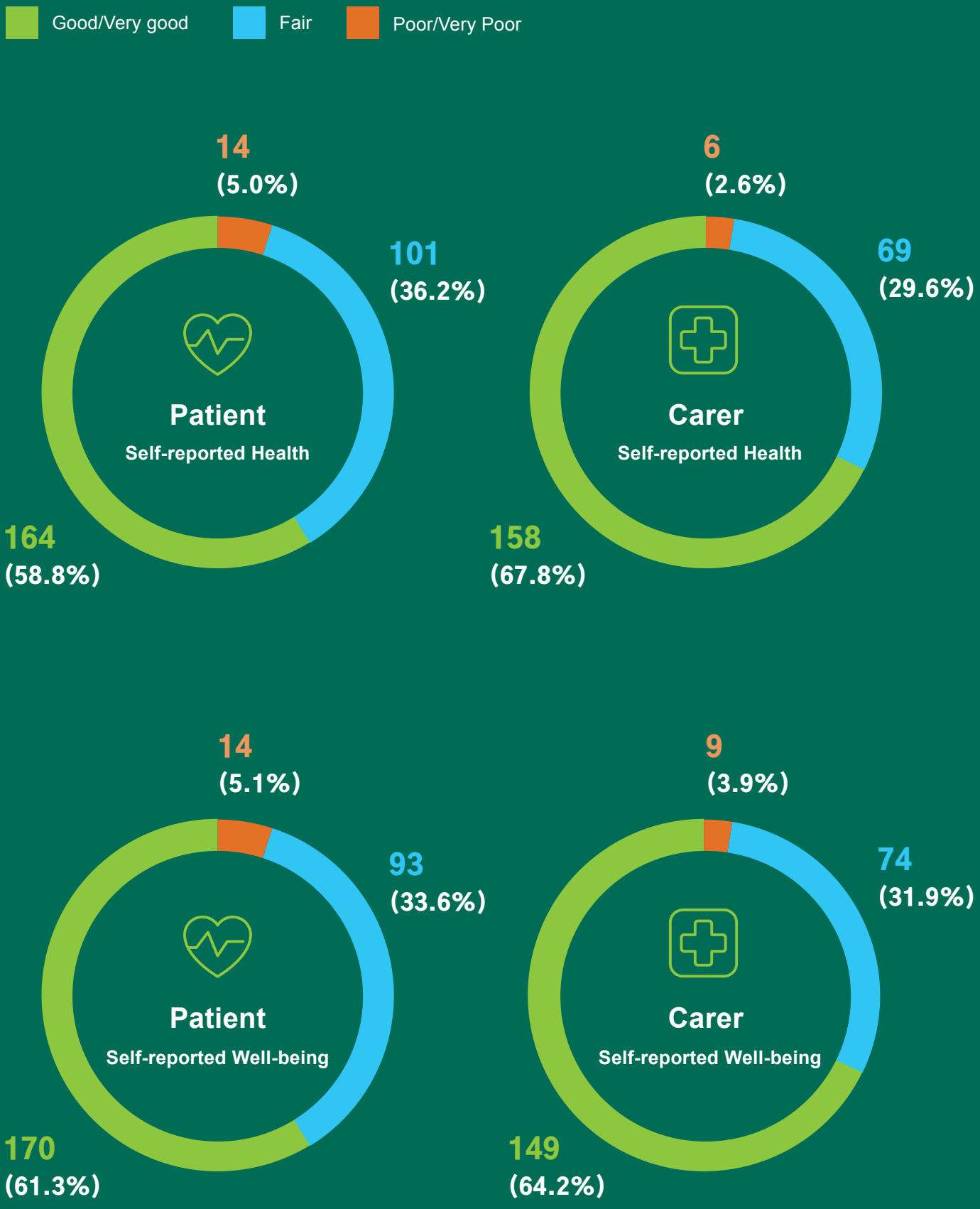
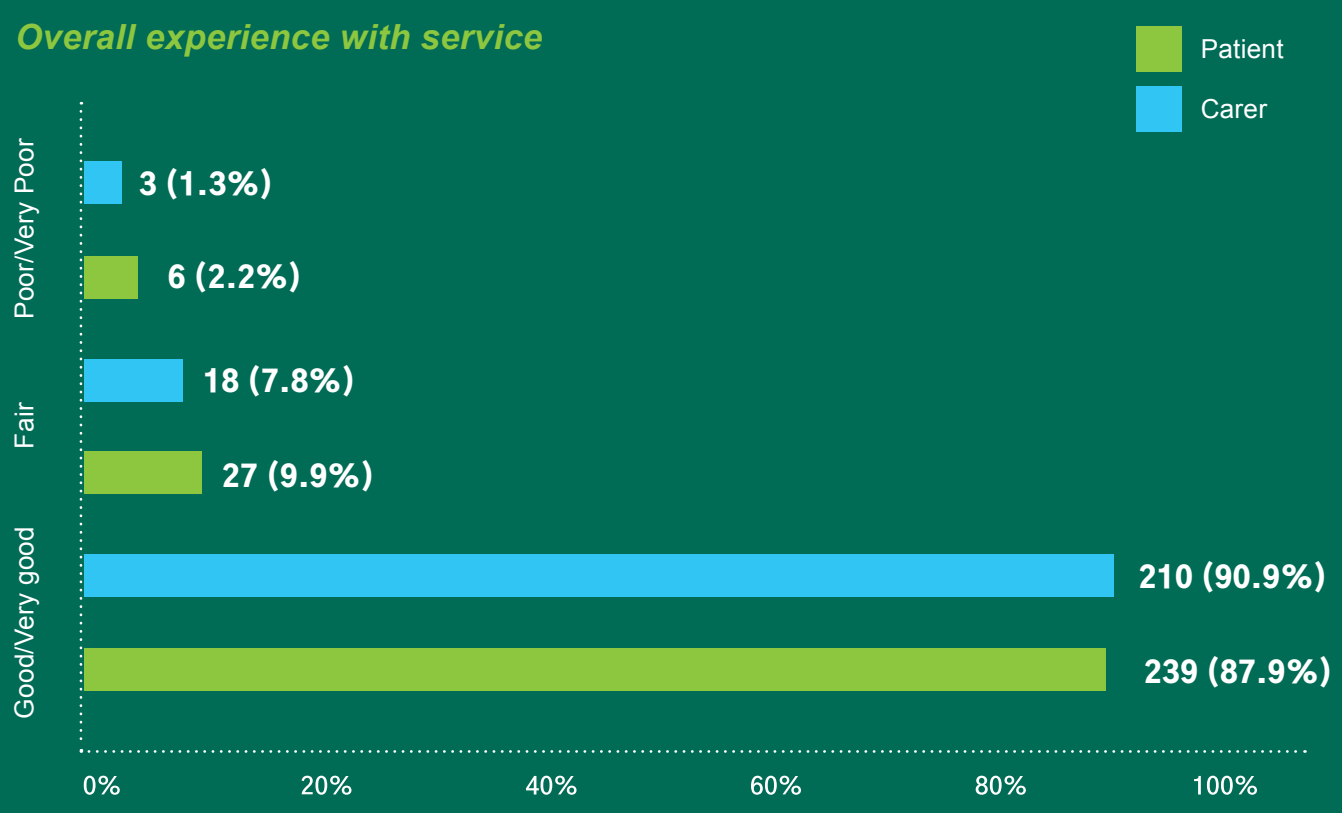
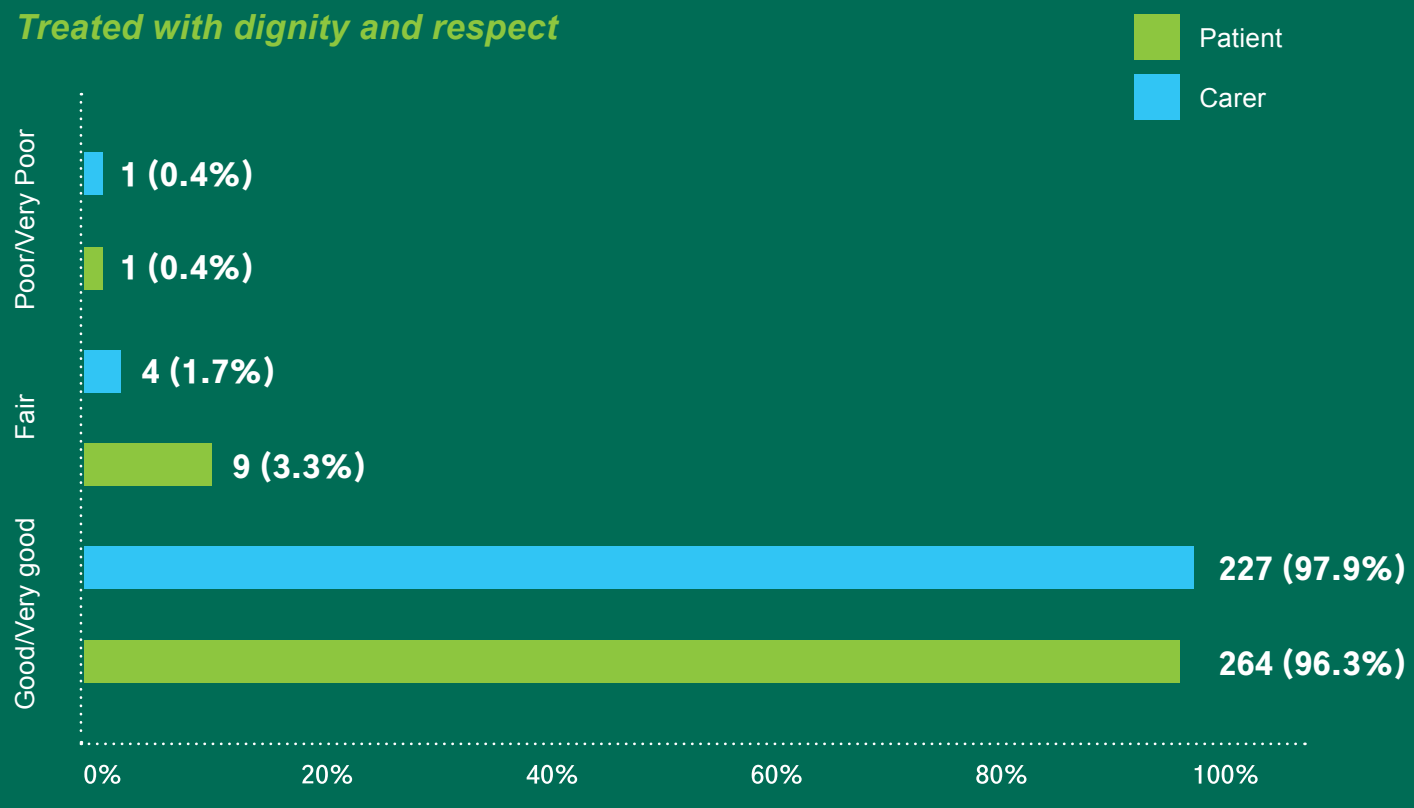
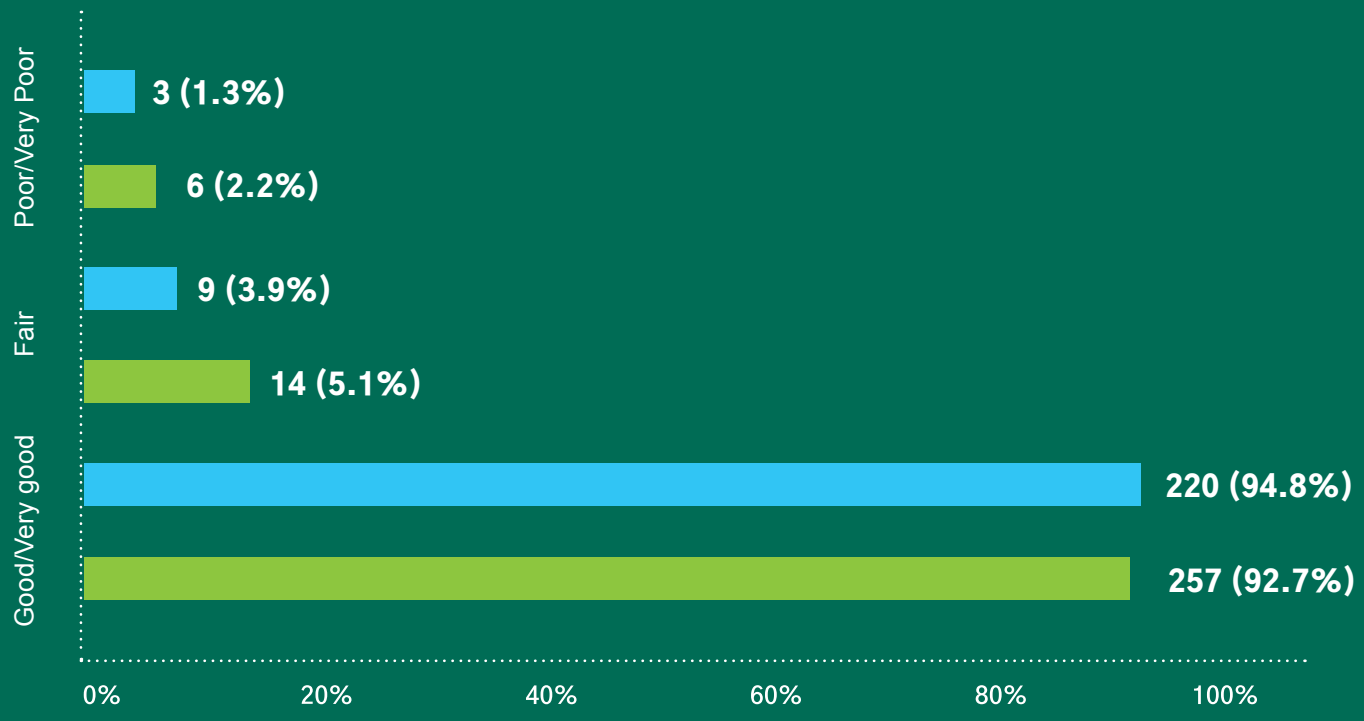


Figure 10 Results of Selected Patient- and Carer-Reported Experience Questions

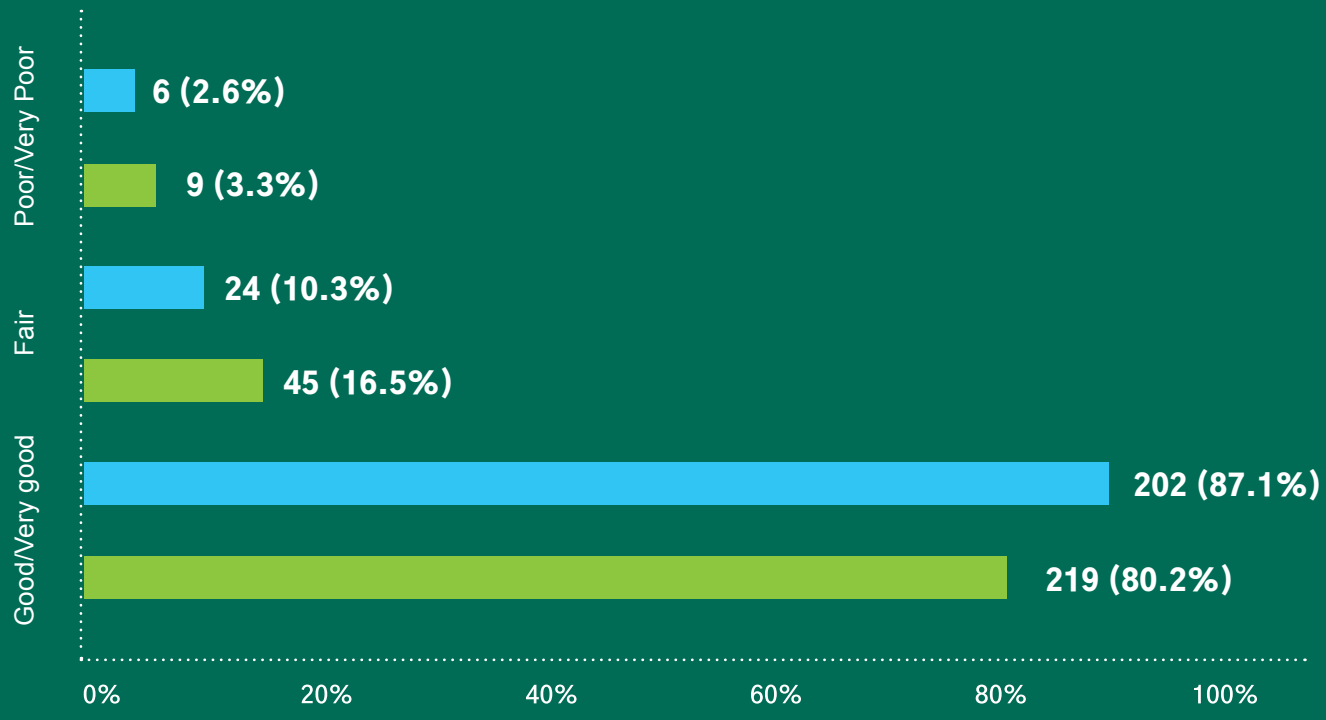




Opportunity to ask questions



Given advice about information and help



Future Development

Key areas of focus for the ADNeT Registry in 2022 are:

1. Continuing expansion of the number of participating sites to increase registry coverage, with a particular focus on regional and remote areas

2. Development and implementation of a follow-up clinical dataset. This will help to understand post-diagnostic clinical care for people with dementia and MCI

3. Reviewing ADNeT Registry CQIs

4. Transition to a customised Clinical Research Platform that will integrate current ADNeT Registry databases and have improved dashboard and reporting functions and automated processes, leading to a better user experience and increased registry efficiency

Other initiatives projected for the registry are:

- Updating bi-annual site reports to provide more feedback to participating sites

- Encouraging participation of Aboriginal and Torres Strait Islander peoples

- Translation of patient-facing documents into other languages

- Facilitating research by establishing a sub-study process to support secondary data analysis and recruitment of participants into research

- Development and implementation of follow-up participant and carer surveys

- Exploring feasibility of inclusion of people diagnosed with dementia from other clinical quality registries into the ADNeT Registry

We sincerely thank participating sites, clinicians, registry participants and their carers, people with lived experience, peak bodies, industry and government for their ongoing support of the ADNeT Registry. Without them, the ADNeT Registry would not be possible. We look forward to conferring further ADNeT Registry initiatives in our second Annual Report in 2023.

Publications

ADNeT Registry publications

Lin, X., Wallis, K., Ahern, S., Brodaty, H., Rowe, C., Kain, B., Lambourne, S., McNeil, J., & Ward, S. A. (2021). Optimising participation of persons with cognitive impairment in a national dementia registry: challenges and solutions. *Intern Med J,* 51(6), 988-992. https://doi.org/10.1111/imj.15357

Lin, X., Wallis, K., Ward, S. A., Brodaty, H., Sachdev, P. S., Naismith, S. L., Krysinska, K., McNeil, J., Rowe, C. C., & Ahern, S. (2020). The protocol of a clinical quality registry for dementia and mild cognitive impairment (MCI): the Australian dementia network (ADNeT) Registry. *BMC Geriatr,* 20(1), 330. https://doi.org/10.1186/s12877-020-01741-2

Collaborative publications

Ayton, D. R., Gardam, M. L., Pritchard, E. K., Ruseckaite, R., Ryan, J., Robinson, S. J., Brodaty, H., Ward, S. A., & Ahern, S. (2021). Patient-Reported Outcome Measures to Inform Care of People With Dementia-A Systematic Scoping Review. *Gerontologist*, 61(5), e185-e194. https://doi.org/10.1093/geront/gnz179

Cations, M., Lang, C., Ward, S. A., Caughey, G. E., Crotty, M., Whitehead, C., Ahern, S., Maddison, J., & Inacio, M. C. (2021). Using data linkage for national surveillance of clinical quality indicators for dementia care among Australian aged care users. *Sci Rep*, 11(1), 10674. https://doi.org/10.1038/s41598-021-89646-x

Cations, M., Lang, C. E., Ward, S. A., Crotty, M., Whitehead, C., Maddison, J., & Inacio, M. (2021). Cohort profile: Dementia in the Registry of Senior Australians. *BMJ Open*, 11(2), e039907. https://doi.org/10.1136/bmjopen-2020-039907

Ayton, D., Gardam, M., Ward, S., Brodaty, H., Pritchard, E., Earnest, A., Krysinska, K., Banaszak-Holl, J., McNeil, J., & Ahern, S. (2020). How Can Quality of Dementia Care Be Measured? The Development of Clinical Quality Indicators for an Australian Pilot Dementia Registry. *J Alzheimers Dis*, 75(3), 923-936. https://doi.org/10.3233/JAD-191044

Cations, M., Lang, C., Ward, S. A., Crotty, M., & Inacio, M. C. (2020). Dementia case ascertainment using aged care assessment data. *Aust N Z J Public Health*, 44(6), 517-518. https://doi.org/10.1111/1753-6405.13026

References

1. Dementia Australia. (2022). Dementia statistics. https://www.dementia.org.au/statistics

2. Australian Institute of Health and Welfare. (2021). Dementia in Australia. https://www.aihw.gov.au/reports/dementia/dementia-in-aus/contents/about

3. Fazio, S., Pace, D., Maslow, K., Zimmerman, S., & Kallmyer, B. (2018). Alzheimer's Association Dementia Care Practice Recommendations. *Gerontologist*, 58(suppl_1), S1-S9. https://doi.org/10.1093/geront/gnx182

4. Australian Institute of Health and Welfare. (2020). Dementia data gaps and opportunities. AIHW.

5. Australian Commission on Safety and Quality in Health Care. (2016). Prioritised list of clinical domains for clinical quality registry development: Final report. ACSQHC.

6. Australian Commission on Safety and Quality in Health Care. (2014). Framework for Australian clinical quality registries. ACSQHC.

7. Australian Commission on Safety and Quality in Health Care. (2008). Operating Principles and Technical Standards for Australian Clinical Quality Registries. ACSQHC.

8. Guideline Adaptation Committee. (2016). Clinical Practice Guidelines and Principles of Care for People with Dementia. Guideline Adaptation Committee.

9. Mainz, J. (2003). Defining and classifying clinical indicators for quality improvement. *Int J Qual Health Care*, 15(6), 523-530. https://doi.org/10.1093/intqhc/mzg081

10. Ayton, D., Gardam, M., Ward, S., Brodaty, H., Pritchard, E., Earnest, A., Krysinska, K., Banaszak-Holl, J., McNeil, J., & Ahern, S. (2020). How Can Quality of Dementia Care Be Measured? The Development of Clinical Quality Indicators for an Australian Pilot Dementia Registry. *J Alzheimers Dis*, 75(3), 923-936. https://doi.org/10.3233/JAD-191044

11. Religa, D., Fereshtehnejad, S. M., Cermakova, P., Edlund, A. K., Garcia-Ptacek, S., Granqvist, N., Hallback, A., Kawe, K., Farahmand, B., Kilander, L., Mattsson, U. B., Nagga, K., Nordstrom, P., Wijk, H., Wimo, A., Winblad, B., & Eriksdotter, M. (2015). SveDem, the Swedish Dementia Registry - a tool for improving the quality of diagnostics, treatment and care of dementia patients in clinical practice. *PLoS One*, 10(2), e0116538. https://doi.org/10.1371/journal.pone.0116538

Appendices

Appendix 1
Committee Membership & Staff List

ADNeT Registry Steering Committee

- Dr Stephanie Ward, ADNeT Registry Steering Committee Co-Chair & Clinical Lead, University of New South Wales, The Prince of Wales Hospital & Monash University
- Professor Henry Brodaty, ADNeT Registry Steering Committee Co-Chair, University of New South Wales
- Professor Susannah Ahern, ADNeT Registry Academic Lead, Monash University
- Professor Kaarin Anstey, Neuroscience Research Australia & University of New South Wales
- Ms Janice Besch (until June 2020), National Health and Medical Research Council National Institute for Dementia Research
- Professor Amy Brodtmann (from 2022), Inaugural and Immediate Past President of the Australian Cognitive Neurology Society, Cognitive Health Initiative, Monash University, Eastern Health & Melbourne Health
- Associate Professor Trevor Chong (from 2022), Monash University, St Vincent's Health Melbourne & Alfred Health
- Ms Gwenda Darling (from 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 (from March 2021), Royal Melbourne Hospital & University of Melbourne
- Dr John Maddison, Immediate Past President of the Australian and New Zealand Society for Geriatric Medicine & Modbury Hospital, Northern Adelaide Local Health Network
- Ms Maree McCabe AM (from September 2020), Dementia Australia
- Professor Sharon Naismith, University of Sydney
- Dr Kannan Natarajan (from 2022), The Prince Charles Hospital
- Professor Mark Nelson, University of Tasmania
- Ms Ann Pietsch (from June 2021), Person living with dementia
- Ms Tara Quirke (from June 2021), Carer of a person living with dementia
- Ms Elizabeth Rand, Alfred Health
- Professor Christopher Rowe, Australian Dementia Network Director, University of Melbourne & Austin Health

- Professor Perminder Sachdev (until March 2021), University of New South Wales
- Ms Kasey Wallis, Monash University
- Associate Professor Mark Yates (from 2022), Ballarat Health Service & Deakin University

ADNeT Registry Survey Working Group

- Dr Stephanie Ward, Chair, University of New South Wales, The Prince of Wales Hospital & Monash University
- Dr Jane Alty (from June 2020), University of Tasmania
- Professor Henry Brodaty, University of New South Wales
- Mr Scott Cooper (from August 2021), Person living with dementia
- Ms Jenny Fitzpatrick (from August 2021), Carer of a person living with dementia
- Professor Yun-Hee Jeon, University of Sydney
- Ms Barbara Kain, Carer of a person living with dementia
- Ms Sally Lambourne (from July 2020), Dementia Australia
- Dr Xiaoping Lin, Monash University
- Professor Lee-Fay Low (from November 2020), University of Sydney
- Ms Kerrie McAloney (from July 2021), QIMR Berghofer Medical Research Institute
- Ms Michelle Merenda (until June 2021), Monash University
- Professor Sharon Naismith, University of Sydney
- Professor Lyn Phillipson (from November 2020), 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 (from October 2020), ADNeT Registry State Coordinator, University of New South Wales
- Ms Cheryl Grant, Administrative Officer, Monash University
- Ms Elysia Greenhill (from September 2020 to April 2021), ADNeT Registry Data Manager, Monash University
- Dr Maria Kokkinos (from February 2022), Research Assistant, Monash University
- Ms Krupa Krishnaprasad (from January 2021 to April 2022), ADNeT Registry State Coordinator, Monash University
- Mr John Liman, Senior Software Engineer, Monash University
- Ms Kerrie McAloney (from July 2020), ADNeT Registry State Coordinator, QIMR Berghofer Medical Research Institute
- Ms Michelle Merenda (until June 2021), Research Assistant, Monash University
- Dr Miia Rahja (from February 2021), ADNeT Registry State Coordinator, South Australian Health and Medical Research Institute
- Ms Jennifer Richardson, ADNeT Registry Ethics Officer, Monash University
- Dr Farhad Salimi (from January 2022), Senior Data Analyst, Monash University
- Ms Kasia Stefaniuk (from February to December 2021), ADNeT Registry Data Manager, Monash University
- Ms Anh Tran (from January 2022), Data Analyst, Monash University
- Mr Alan Tsui (from January 2022), ADNeT Registry Data Manager, Monash University

Appendix 2
ADNeT Registry Baseline Minimum Data Set

Patient identifiers, recruitment and contact information

- Name
- Date of birth
- Sex
- Date of death[1]
- 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]

Patient demographics

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

Patient diagnosis and clinical data

- Past diagnosis of MCI[2]
- Date of referral
- Date of initial appointment
- Date of diagnosis
- Diagnosis
- Mode of service delivery
- Dementia/MCI subtype
- Number of prescribed medications
- Number of strokes
- Hypertension
- Diabetes
- Cardiovascular disease
- Cancer
- REM-sleep behaviour disorder
- Falls history in past 12 months
- Functional measure/s completed
- Cognitive assessment/s completed
- MMSE/RUDAS/MoCA/KICA scores[1,2]
- Independence in activities of daily living[3]
- Continence
- Core blood tests undertaken as part of diagnostic work-up
- Structural neuroimaging completed as part of diagnostic work-up
- Functional neuroimaging completed as part of diagnostic work-up
- Lumbar puncture completed as part of diagnostic work-up
- Acetyl cholinesterase inhibitor recommended or prescribed
- Follow-up appointment offered
- Interest in participation in research

[1] If applicable/relevant, [2] MCI = mild cognitive impairment, MMSE = Mini-Mental State Exam, RUDAS = Rowland Universal Dementia Assessment Scale, MoCA = Montreal Cognitive Assessment, KICA = Kimberley Indigenous Cognitive Assessment, [3] Includes questions on mobility, personal activities of daily living, instrumental activities of daily living, and driving

Appendix 3
Data Quality

The ADNeT Registry recognises that high-quality data is integral to effectively benchmark patient outcomes and evaluate variations in clinical processes and has implemented several strategies to ensure the quality, consistency and interpretability of data collected, including:

- A comprehensive data dictionary containing data elements, formats, ranges, validation rules and definitions to guide data entry
- Online databases with built-in logic checks and variable limits to reduce missing data and to ensure data meets formatting and value requirements
- Induction and ongoing training for participating sites to standardise data collection and interpretation, and
- Routine cleaning and quality checks of data before entry into the ADNeT Registry databases to ensure improved data consistency and quality.

Most data collected by the ADNeT Registry are compulsory variables in the ADNeT Registry database. For patients with missing information, clinicians are advised to select the “Not stated” response. Table 11 reports the number and frequency of “Not stated” responses of data elements included in this report.

Table 12 Quality of Key Data Elements

Variable	Not stated responses	Percent
Lumbar puncture	178	20%
Aboriginal and/or Torres Strait Islander	70	8%
Living arrangement	53	6%
Highest education level	48	6%
Initial appointment date	46	6%
Country of birth	22	2%
Preferred spoken language	13	2%
Labour force status	9	2%
Referral date[1]	11	1%
Sex	7	0%
Residential setting	7	0%
Diagnosis date	5	0%
Mobility independent	0	0%
Falls in past 12 months	0	0%
Continent	0	0%
pADLs[2] independent	0	0%
iADLs[3] independent	0	0%
Driving	0	0%
Number of medications	0	0%
Stroke	0	0%
Hypertension	0	0%
Diabetes	0	0%
Cardiovascular disease	0	0%
Cancer	0	0%
Core blood tests	0	0%

[1] Excludes 44 (5.1%) participants with a previous MCI diagnosis, [2] Personal (or basic) activities of daily living, [3] Instrumental activities of daily living

Appendix 4
ADNeT Registry Participating Sites (2020-2021)

As of 31st December 2021, the ADNeT Registry had 40 participating sites.

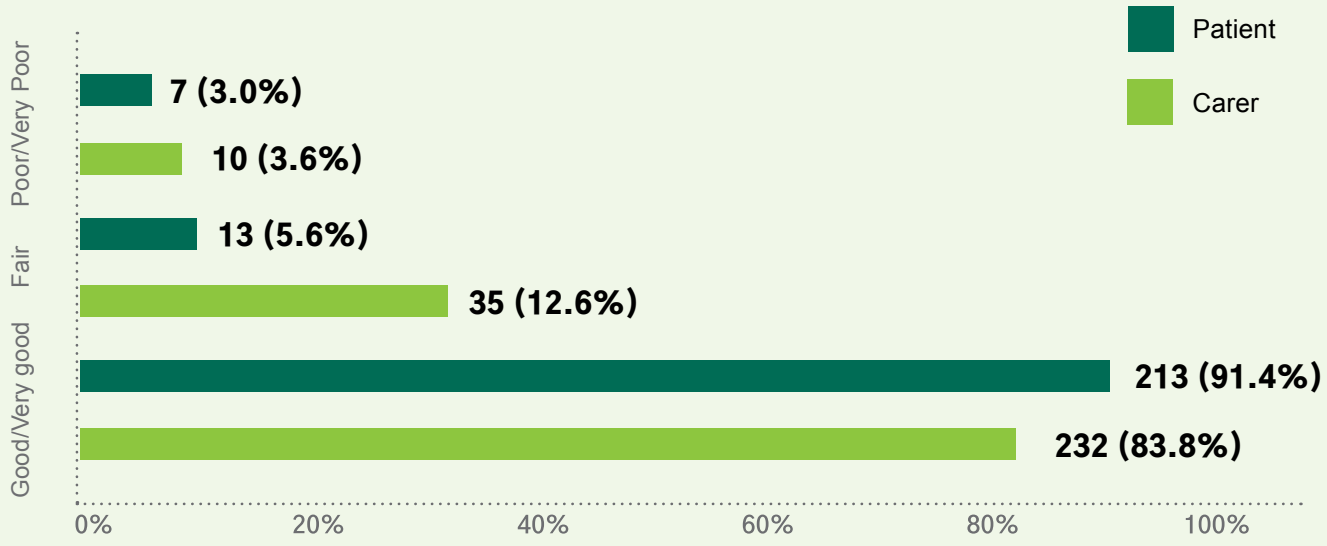
Participating Site[1]	Type	Location[2]
New South Wales (n=12)		
1. Brellah Medical	Private	Major City
2. Burwood Specialists	Private	Major City
3. Central Coast Neurosciences (CCN) – Procognition Clinic	Private	Inner Regional
4. Hornsby Ku-ring-gai Hospital Memory Clinic	Public	Major City
5. Memory Assessment Program, Pottsville	Public	Major City
6. Murrumbidgee Local Health District Aged Care Outpatient Clinic	Public	Inner Regional
7. Prince of Wales Hospital Brodaty Clinic	Public	Major City
8. Prince of Wales Hospital Cognitive Disorders Clinic	Public	Major City
9. Prince of Wales Hospital Neuropsychiatry Clinic	Public	Major City
10. Rehabilitation and Aged Care Outpatient Clinics, Mona Vale Hospital	Public	Major City
11. Salus Clinic	Private	Major City
12. Shoalhaven Aged Care Service, Shoalhaven Hospital	Public	Inner Regional
Queensland (n=9)		
1. Agenda Health	Private	Major City
2. Cairns Memory Clinic, Cairns Hospital	Public	Outer Regional
3. Innisfail Memory Clinic, Innisfail Hospital	Public	Outer Regional
4. Mareeba Memory Clinic, Mareeba Hospital	Public	Outer Regional
5. Memory Clinic Princess Alexandra Hospital	Public	Major City
6. Neurosciences Queensland	Private	Major City

7. Robert Adam Neurology	Private	Major City
8. Robina Private Hospital - Memory Clinic	Private	Major City
9. The Prince Charles Hospital Memory Clinic	Public	Major City
South Australia (n=5)		
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. Royal Adelaide Hospital Memory Service	Public	Major City
4. Specialist Ambulatory Rehabilitation Centre Memory Clinic, Modbury Hospital	Public	Major City
5. The Queen Elizabeth Hospital Memory Service	Public	Major City
Tasmania (n=4)		
1. David Dunbabin Aged Care	Private	Inner Regional
2. Dr Krishna Kalpurath, Calvary Health Care Sessional Rooms, Launceston	Private	Inner Regional
3. Hazel Bucher Nurse Practitioner Consultancy	Private	Inner Regional
4. The ISLAND Clinic	Private	Inner Regional
Victoria (n=10)		
1. Austin Cognitive Dementia and Memory Service (CDAMS), Austin Health	Public	Major City
2. Caulfield Cognitive Decline and Memory Service (CDAMS), Alfred Health	Public	Major City
3. Central Geriatrician Associates	Private	Major City
4. Cognitive Dementia and Memory Service Western Health, Footscray Hospital	Public	Major City
5. Dr Jagadeesh Herur, Glencairn Private Consulting Suites	Private	Major City
6. Dr Jagadeesh Herur, Harvester Private Consulting Suites	Private	Major City
7. Dr Rebecca Iseli, Geriatrician, practising at North Melbourne Ear, Nose & Throat	Private	Major City
8. Grampians Cognitive Dementia and Memory Service (CDAMS), Ballarat Health Services	Public	Inner Regional
9. Irene Wagner's Clinic	Private	Major City
10. Professor Dennis Velakoulis, Church Street Consulting Suites	Private	Major City

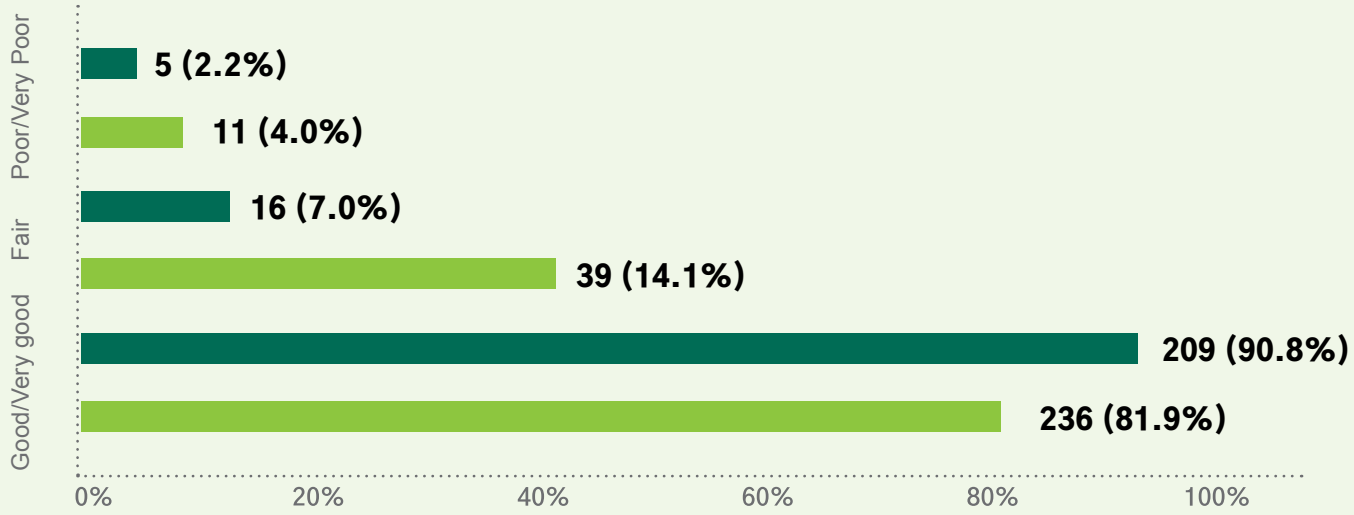
[1] Refers to sites that have been granted ethics and governance approval and data collection for the registry has commenced, [2] Location categorised using Australian Statistical Geography Standard Remoteness Structure 2016.

Appendix 5
Results of Patient- and Carer-Reported Experience Questions

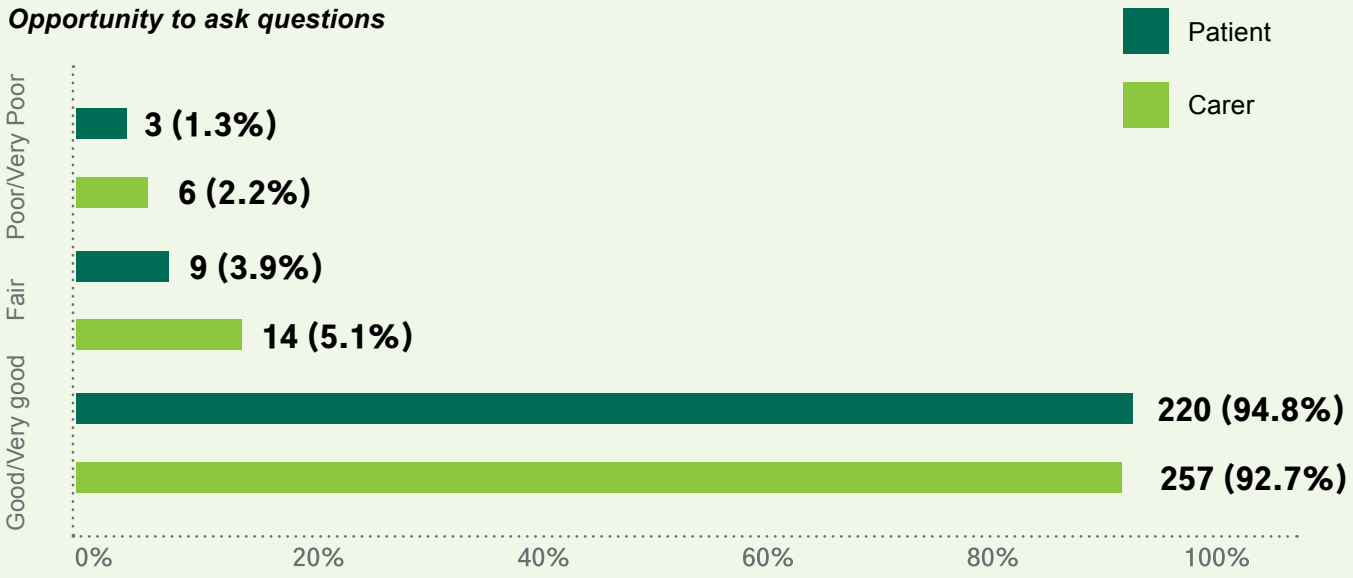
Received adequate information about diagnosis



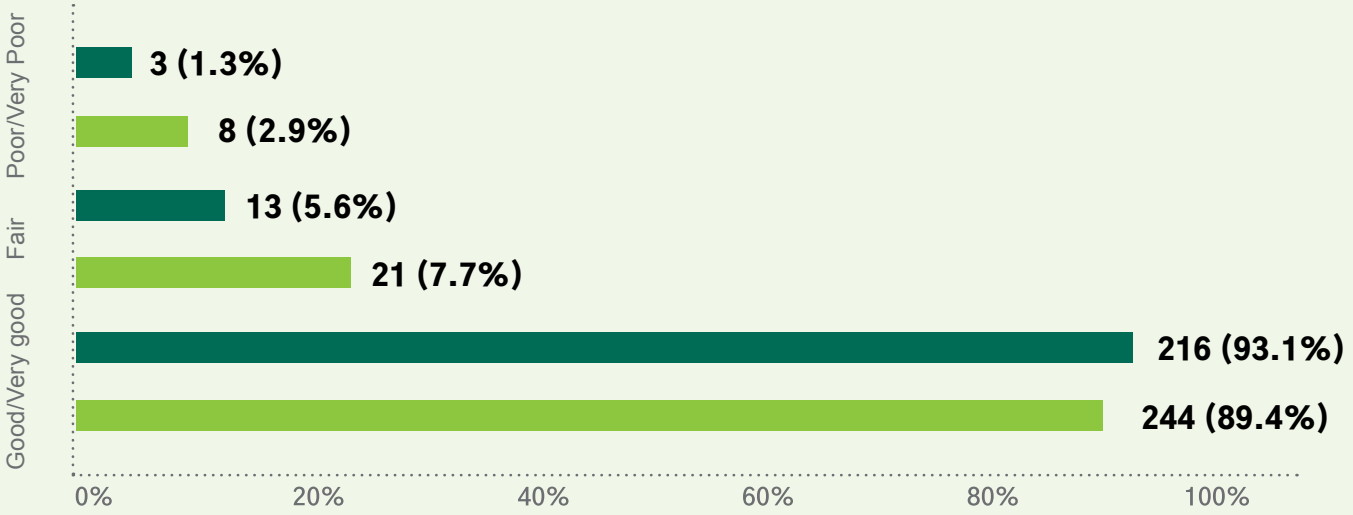
Involved in decision making



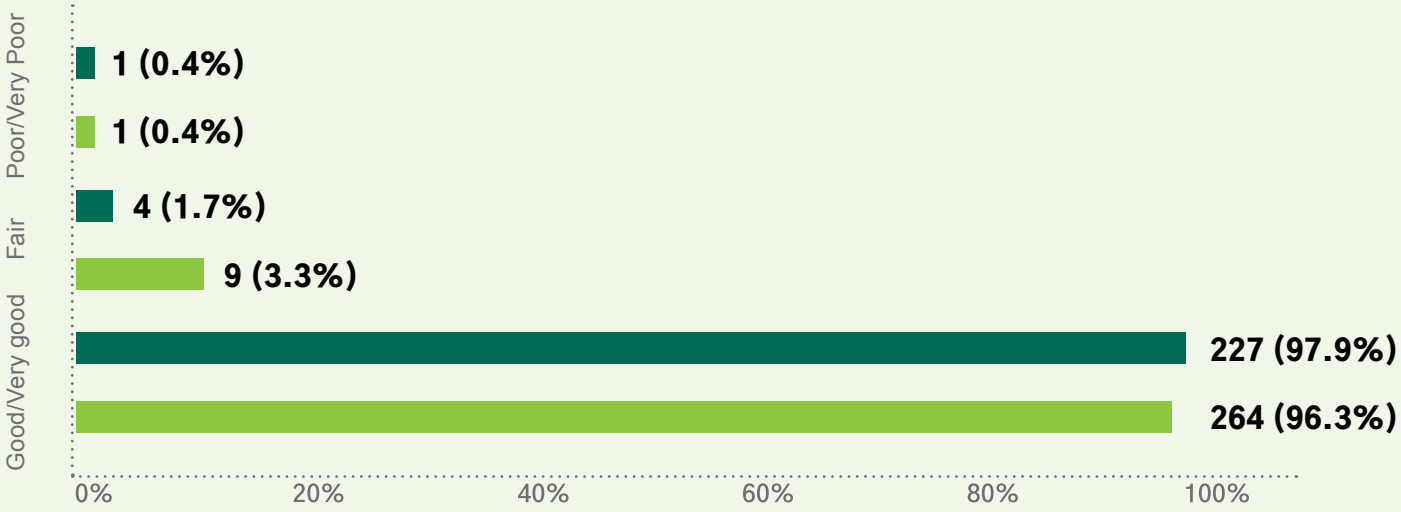
Opportunity to ask questions



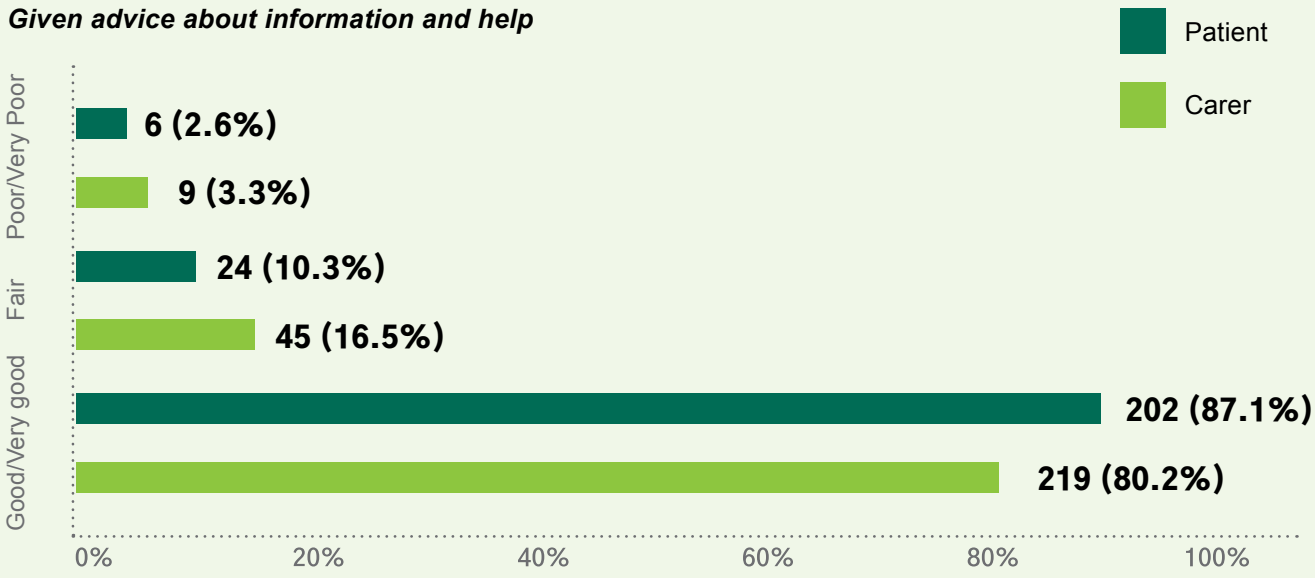
Views and concerns were listened to



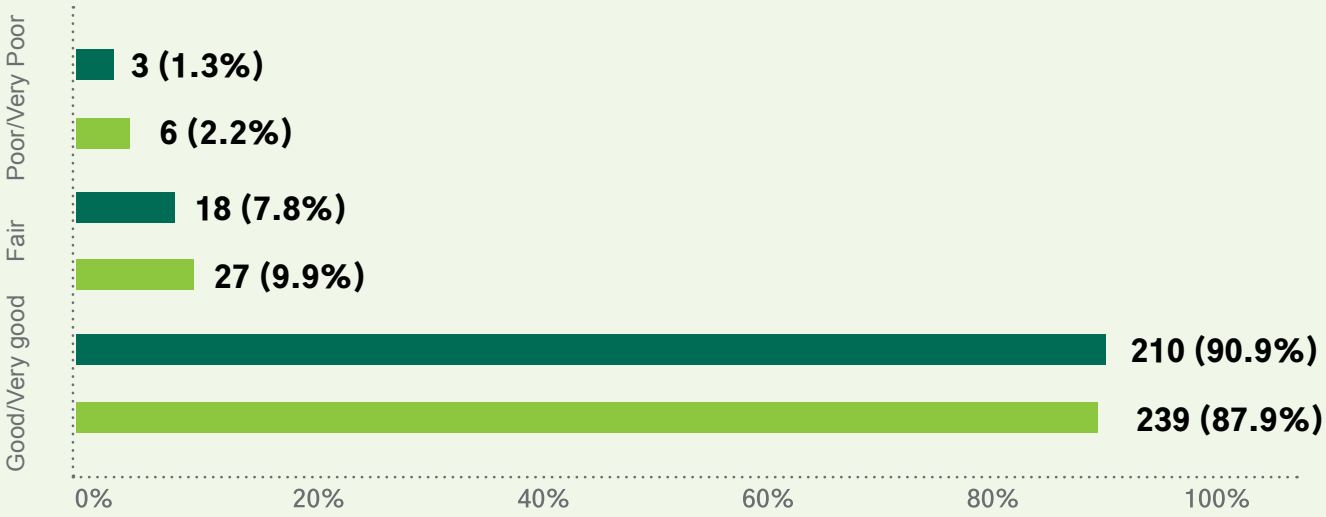
Treated with dignity and respect



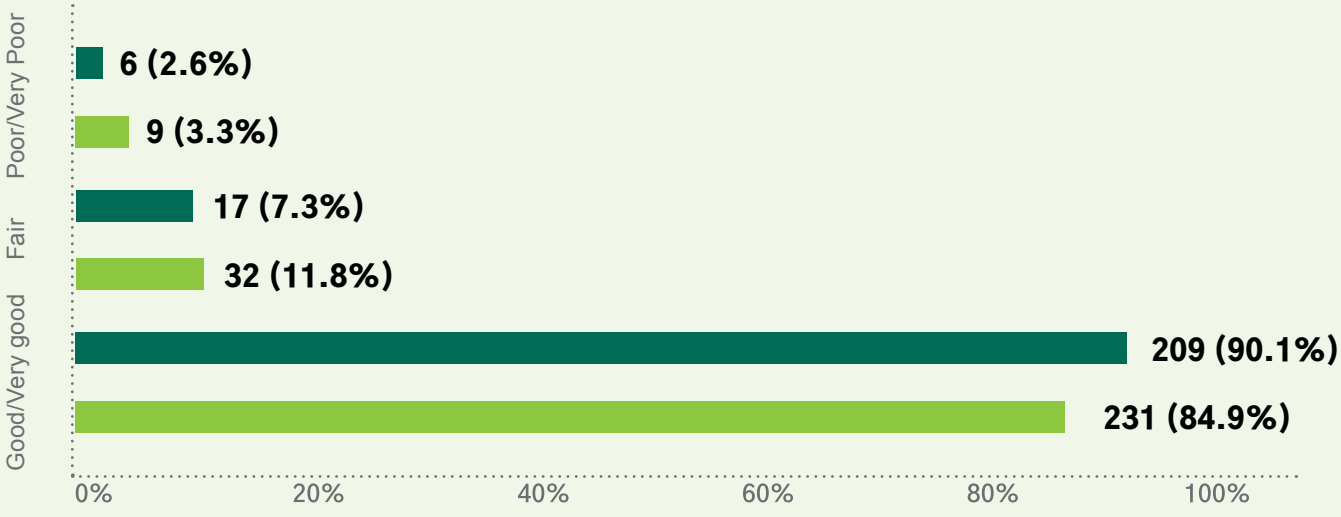
Given advice about information and help



Overall experience with service



Meeting expectations



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