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Organisational aspects and assessment practices of Australian Memory Clinics: An Australian Dementia Network (ADNet) survey

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Organisational aspects and assessment practices of Australian Memory Clinics: An Australian Dementia Network (ADNeT) survey

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Abstract

Objectives: Conducting a national survey of clinicians and administrators from specialised dementia assessment services (hereafter: Memory Clinics) in Australia to examine their current organisational aspects and assessment procedures and inform clinical tool harmonisation as part of the Australian Dementia Network (ADNeT) – Memory Clinics project.

Design: A cross-sectional survey.

Setting: Public and private Memory Clinics across Australia

Participants: 150 individual clinicians completed the survey between May and August 2019. Responses could be given anonymously. Most clinics were publicly funded services (83.2%) and in metropolitan regions (70.9%).

Outcome measures: Descriptive data on organisational aspects of Memory Clinics (e.g., waiting times, staffing); the three most commonly used assessment tools per assessment type (e.g., self-report) and cognitive domain (e.g., attention).

Results: Since the last national survey in 2009¹, the number of Memory Clinics across Australia has increased substantially but considerable variability has remained with respect to funding structure, staffing and assessment procedures. The average clinic employed 2.4 effective full-time staff (EFT; range 0.14 to 14.0). The reported waiting time for an initial assessment ranged from 1 week to 12 months with a median of 7 weeks. While most clinics (97%) offered follow-up assessments for their clients, only a few (31%) offered any form of cognitive intervention. We identified over 100 different cognitive assessment tools that were utilised at least ‘sometimes’, with widespread use of well-established core screening tools and a subset of common neuropsychological tests.

Conclusion: This paper presents a current snapshot of Australian Memory Clinics, showing considerable heterogeneity with some common core elements. These results will inform the development of national Memory Clinic guidelines. Furthermore, our data make a valuable contribution to the international comparison of clinical practice standards, and advocates for greater harmonisation to ensure high-quality dementia care.

Strengths and limitations of this study

- Our study is the first national Memory Clinics survey that presents responses from all Australian states.
- A broad definition of 'Memory Clinic' was used to include all clinicians specialising in dementia diagnosis to gain a broad overview of current clinical practice
- The survey presents a comprehensive list of the most commonly used cognitive assessment tools that can inform the development of a national Memory Clinics guidelines for harmonisation of assessment tools.
- While several strategies were used to identify Memory Clinics across the country, the survey cannot be considered to be exhaustive.

INTRODUCTION

About 459,000 Australians are currently living with dementia and numbers are expected to increase dramatically over the next 30 years². Interestingly, little is known about where and how Australians with dementia get diagnosed and no clear pathways for a dementia diagnosis are recommended to clients, family/ carers and general practitioners, thereby inhibiting early diagnosis of dementia and cognitive decline^{3,4}.

Since the late 1980s, Memory Clinics have been an integral part of Australia’s dementia care service^{5,6} and have repeatedly been recommended as the best services to obtain an early diagnosis of dementia^{3,4}. Despite such recommendations, to date, there is no consensus definition of a Memory Clinic and no published national or international agreement on the composition, services and standards of Memory Clinics⁷. Memory Clinics are most commonly described as multidisciplinary medical assessment centres that are highly specialised for the diagnostic work-up of cognitive decline and dementia⁸. Memory Clinic surveys from six different countries (Australia¹, Ireland⁷, Netherlands^{9,10}, British Isles¹¹, Israel^{12,13} and New Zealand¹⁴) also showed considerable heterogeneity in the diagnostic protocols that were used. Such variability was attributed to many factors including differences in the Memory Clinics’ organisational structure, the area they service (regional vs. metropolitan), the funding received by clinics, the composition and level of staffing and the frequency of clinical services and may also be caused by the lack of evidence-based guidelines at the time.

The first Australian survey of Memory Clinics in 2009¹ provided the first benchmark data for international comparison. The 2009 survey reported results from 16 Memory Clinics located in 5 Australian states (Victoria [8], New South Wales [4], South Australia [2], Queensland [1] and Western Australia [1]). The results showed a comparatively long average waiting time of 10 weeks prior to the initial assessment and a relatively low average effective full time (EFT) staff allocation of 1.7 EFT. They also reported differences in the assessment protocols used across Memory Clinics though with relative agreement in the use of blood tests, imaging and the Mini Mental State Examination (MMSE) as a cognitive screen¹.

Importantly, it has been argued that such variability in structures and assessment procedures may contribute to delays in diagnosis, reduce accuracy and impede the provision of early interventions^{3,15}. The benefits of harmonised diagnostic procedures for clinical practice and dementia research are undeniable¹⁶. A harmonised assessment protocol has the potential to boost collaboration between different Memory Clinics and between clinicians, community dementia care services and research. Moreover, greater harmonisation is required to implement best practice standards across services, enable the establishment of a framework for models of care and to improve comparability of and data from different services, making it easier for patients to acquire a second opinion and for researchers to ensure a greater generalisability of research findings (e.g., harmonised assessments could be used as outcome measures for studies)³.

The call for greater harmonisation of diagnostic methods and processes has sparked a number of international initiatives, for example in the United Kingdom (Memory Services National Accreditation Program [MSNAP])¹⁷, the United States (National Alzheimer's Coordinating Centres [NACC])¹⁸ and the Netherlands⁹. In 2018, Australia followed this international movement and supported the establishment of the Australian Dementia Network (ADNeT), funded through the Australian NNIDR Boosting Dementia Research Fund¹. ADNeT incorporates three main components - Clinical Quality Registry, Memory Clinics and Clinical Trials - to improve the quality and accessibility of dementia care services across Australia.

ADNeT-Memory Clinics (ADNeT-MC) set out to establish a national network of clinicians and dementia care services to boost multidisciplinary collaboration, to harmonise diagnostic standards and develop clear pathways for post-diagnostic care and support. Given this new national initiative the current survey is important to assess baseline Memory Clinic practices and evaluated the resources available to deliver their services. Since the publication of the last national Memory Clinics survey in 2009¹, best practice guidelines for the state-funded Cognitive, Dementia and Memory Services (CDAMS) in Victoria⁵ as well as clinical

¹ provided by the National Health and Medical Research Council (NHMRC) – National Institute for Dementia Research (NNIDR)

practice guidelines and principles of care for people with dementia¹⁹ have been published and potentially changed clinical practice compared to 10 years ago. Hence, an updated national Memory Clinics survey is warranted.

The aims of this survey were to present a comparative update on some of the organisational data reported in the previous survey¹ (e.g., staffing, funding) in a larger sample of Memory Clinics and to obtain current information about the variety of assessment procedures used in Australian Memory Clinics and to determine the most commonly used cognitive/neuropsychological test instruments.

METHODS

Sample and Setting

Due to the lack of a consensus definition of Memory Clinics, potential participants for this survey included any clinician or coordinator who self-identified as working for a diagnostic assessment service for dementia. This was done to avoid missing out on responses of dedicated cognitive assessment services that do not identify as a Memory Clinic and other specialised clinicians. Using this broad definition of a Memory Clinic we will, in the following, refer to the services that responded to our survey as “Memory Clinic” or just “clinic”. We employed a number of recruitment strategies including using already established contacts (e.g., official contact list of state-funded Cognitive Dementia and Memory Services [CDAMS] in Victoria), advertisements in professional associations (esp., Australian and New Zealand Society for Geriatric Medicine [ANZSGM] and the Royal Australian and New Zealand College of Psychiatrists [RANZCP]), and recommendations from professional networks. Due to our broad distribution strategies it is difficult to estimate how many potential participants received the survey link.

Survey and Procedure

A Clinical Assessment Harmonisation survey was developed in Qualtrics²⁰. All potential respondents were required to read the Participant Information Sheet and Consent form and

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provide consent to their participation before they were able to start the survey (HREC No: HC190221). Respondents were not obliged to provide any personal information (e.g., name, contact address) but had the opportunity to do so, if they wished to be added to our ADNeT contact list. Participants who did not wish to be contacted again, were also able to express that at the end of the survey.

The survey comprised three main parts. The first part was directed at clinical coordinators and clinicians involved in the operational management of a clinic. Here, the respondents were asked to give details about the specific organisational structure of their clinic: staffing, clinical activity (e.g., frequency of clinical assessments, waiting times, regulations for follow-ups), characteristics of the clinical population (e.g., proportion of indigenous and non-English speaking population) and funding support. Any respondent who was not involved in administrative tasks was able to skip this section of the survey.

The second part of the survey contained questions about the clinical and cognitive assessment tools used by the individual clinicians. Here, we investigated seven sub-categories: 1) cognitive screening tools, 2) self-reported scales, 3) informant-rated scales, 4) clinician-rated scales, 5) measures of subjective cognitive concern, 6) computerised cognitive tests, 7) standardised pen-and-paper neuropsychological measures. Within the 'neuropsychological measures' category, we further distinguished between standardised neuropsychological batteries and individual tests in nine cognitive domains (premorbid ability, processing speed, attention/working memory, memory, language, visuo-spatial abilities, executive functions, social cognition and effort). For each category, the survey listed commonly used test instruments determined by experienced neuropsychologists (NK, SN). Respondents rated on a 5-point Likert scale how often they used each test instrument in their everyday clinical practice. Under 'other' the respondents were able to add up to five test additional instruments they currently use to ensure that we captured all instruments that were not originally considered. Options to skip this component of the survey were available to those respondents who did not conduct clinical assessments (e.g., dedicated coordinators of Memory Clinics).

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The third part of the survey asked if respondents offered any form of cognitive intervention to their clients. If the response was no, respondents were asked to provide reasons; if yes, they were asked to provide further details about the methods and the frequency of this intervention. A copy of the full survey can be acquired from the corresponding author upon request.

Patient and Public Involvement

The design of this survey was based on previous national and international memory clinic surveys^{1,7,9} to ensure a comparability of results. People living with dementia and/or cognitive decline or other members of the public were not involved in the design of this specific survey. The dissemination of the survey was supported by the national professional associations “The Australia and New Zealand Society for Geriatric Medicine (ANZSGM)” and “The Royal Australian and New Zealand College of Psychiatrists (RANZCP)” as well as Dementia Australia to increase our outreach and involve as many members of the target population as possible. Some of the participants of this survey were informed about the results of this survey during ADNeT-Memory Clinic meetings and/or national conferences. A link to the published results paper will be provided to all respondents that provided contact details in their survey response.

Data analysis

All survey responses were recorded and saved in Qualtrics and the data later exported into Excel. One member of the ADNeT-MC team (IM) de-identified the data and assigned a unique study ID to each response. Identifiable information (e.g., profession, clinic location) was coded and comments that contained identifiable information were separated from the response sheet and securely saved. Only anonymised data were used for the analyses presented in this paper. All statistical analyses were carried out with IBM SPSS Statistics, version 25. We conducted descriptive analyses to provide an overview of the variety of clinical settings and assessment tools that were reported by clinicians and clinical coordinators across Australia.

To compare categorical variables of different groups we performed a Chi-Square test. When the skewness of continuous data was within the recommended range of -1 and 1 , we performed parametric tests (e.g., t-test), when the data was skewed, we performed non-parametric tests (e.g., Mann-Whitney U). Spearman correlations were used to investigate associations between skewed continuous data.

RESULTS

Respondents

Between May and August 2019, we obtained 318 responses. We excluded responses from 163 who did not complete the survey (e.g., some data provided but did not press the “complete button” at the end) as well as data from 5 respondents who accidentally completed the survey multiple times. Consequently, 150 individual responses, with representation from each of the Australian states and territories, were included. By matching addresses, postcodes and other identifiable information the respondents voluntarily provided (e.g., name of clinic), we were able to identify responses from 90 different Memory Clinic services.

[FIGURE 1 – near here]

The majority of responses were from Victoria and New South Wales, reflecting a large number of Memory Clinics located in the two most populated states (see Figure 1). Unsurprisingly, the highest density of Memory Clinics was found in metropolitan areas (68.4% of respondents). Most of the respondents were employed in public clinics (82.8%), compared to 17.2% employed in private clinics.

While most respondents identified as geriatricians (42.7%) and neuropsychologists (23.3%), we also received responses from occupational therapists (7.4%), neurologists (6.7%), psychiatrists (5.3%), registered nurses (3.3%), speech pathologists (2.0%), clinical psychologists (1.3%), social workers (1.3%), pharmacists (0.6%), trainee doctors (3.3%) and clinical coordinators who are not involved in any clinical work (2.7%).

Organisational Aspects

Overall, 38 respondents from 38 different Memory Clinics reported that they fulfil the duties of a clinical coordinator/ manager at their clinic site. Eighteen of these services voluntarily identified as a Memory Clinic or CDAMS while the remaining services identified as geriatric services (mostly private), cognitive/ memory assessment services or did not provide clear information. Responses from all Australian states and territories were represented in this sample.

Table 1 summarises the main results from the survey regarding the clinics’ general organisational aspects. The table shows the overall responses as well as the results split for metropolitan versus regional, and public versus private clinics.

Table 1: Result summary – general organisational structures

	all	metropolitan	regional	public	private
Respondents (n)	38	24	14	26	12
Clinic Type					
public	26	17	9	/	/
private	12	7	5	/	/
Service area					
1 community	14 (37%)	11 (46%)	3 (21%)	10 (38%)	4 (33%)
> 1 community	24 (63%)	13 (54%)	11 (79%)	16 (62%)	8 (67%)
Frequency (n=38)					
< 1x week	4 (10%)	1 (4%)	3 (21%)	3 (12%)	1 (8%)
1x week	6 (16%)	5 (21%)	1 (7%)	6 (23%)	0
>1x week	28 (74%)	18 (75%)	10 (71%)	17 (45%)	11 (92%)
Waiting Times (n=37)	9.9 weeks (± 9.7)	10.4 weeks (± 10.3)	9 weeks (± 8.6)	11.9 weeks* (± 10.8)	5.3 weeks* (± 3.1)
Waiting Times Range	3 days – 12 months	3 days – 12 months	1 week – 9 months	2 weeks – 12 months	1 week – 10 weeks
Average EFT per Clinic (n=34)	2.4 (± 3.2)	3.1 (± 4.0)	1.4 (± 1.2)	2.7 (± 3.5)	1.6 (± 2.4)
EFT Range	0.1 EFT – 14.0 EFT	0.1 EFT – 14.0 EFT	0.2 EFT – 3.6 EFT	0.1 EFT – 14.0 EFT	0.2 EFT – 8.0 EFT
Average number new patients per each clinic day (n=38)	3.3 (± 2.4)	3.2 (± 2.6)	3.5 (± 2.1)	3.1 (± 2.1)	3.7 (± 3.0)
Number of new patients per each clinic day - Range	1 - 11	1 - 11	1 - 8	1 - 10	1 - 11
Follow-ups conducted – yes/no (n=38)	37 (97%)	24 (100%)	13 (93%)	25 (96%)	12 (100%)
Average number of follow-up patients per each clinic day (n=37)	4.2 (± 3.3)	4.4 (± 2.9)	3.7 (± 4.1)	4.5 (± 3.8)	3.5 (± 2.0)

Number of follow-up patients per each clinic day - Range	1 - 16	1 - 12	1 - 16	1 - 16	1 - 8
Proportion of patients from an indigenous background (n=25, who assess people with an indigenous background)					
≤5%	22 (88%)	12 (92%)	10 (83%)	16 (84%)	6 (100%)
> 5% - 10%	2 (8%)	1 (8%)	1 (8%)	2 (11%)	0
>10%	1 (4%)	0 (0%)	1 (8%)	1 (5%)	0
Proportions of patients from a CALD background (n=38)					
≤10%	24 (63%)	11 (46%)	13 (93%)	14 (54%)	10 (84%)
> 10% - 20%	3 (8%)	3 (13%)	1 (7%)	3 (12%)	1 (8%)
>20% - 30%	2 (5%)	2 (8%)	0 (0%)	2 (8%)	0
>30% - 40%	1 (3%)	1 (4%)	0 (0%)	1 (4%)	0
>40% - 50%	5 (13%)	5 (21%)	0 (0%)	4 (15%)	1 (8%)
>50%	2 (5%)	2 (8%)	0 (0%)	2 (8%)	0
Main source of referrals					
GP	35 (92%)	22 (92%)	13 (92%)	24 (92%)	11 (92%)
Other (Neurologist, Geriatrician)	3 (8%)	2 (8%)	1 (8%)	2 (8%)	1 (8%)
Main source of funding					
State-health funds	19 (50%)	12 (50%)	7 (50%)	19 (73%)^	0
Patient charges/ Medicare	9 (23%)	7 (29%)	2 (14%)	1 (4%)	8 (67%)
State funds +patient charges	3 (8%)	3 (13%)	0	3 (12%)	0
commonwealth	1 (3%)	0	1 (7%)	1 (4%)	0
State-health funding + other	1 (3%)	1 (4%)	0	1 (4%)	0
Patient charges + other	5 (13%)	1 (4%)	4 (29%)	1 (4%)	4 (33%)

T-test and Chi-Square were used to compare metropolitan vs regional and public vs private services for each variable. Only significant differences are highlighted in the table.

* significant public vs private Memory Clinics (Mann-Whitney-U, $p=.031$)

^ significant difference according to Chi-squared test comparison (Chi-square; $p<.001$)

Community = defined catchment area; Frequency = indicates how often a clinic is operating; CALD = culturally and linguistically diverse; GP = general practitioner; Medicare = Australian public health fund

We observed no statistically significant differences between metropolitan and regional clinics for any of the reported organisational aspects we surveyed (see Table 1). A comparison of public and private Memory Clinics, unsurprisingly, revealed a significant difference in the clinics' funding sources (Chi-square= 30.18, $p<.001$). Seventy-three percent of public clinics report some support from state health funds while the private services mainly rely on patient charges and rebates from the Australian public health insurance Medicare. Funding support is also commonly supplemented by research funds, commonwealth funding, support from the department of veteran affairs, donated time of their staff members or rural workforce support.

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In terms of waiting times, overall, the average reported waiting time for an initial assessment was 9.9 weeks (SD= 9.7; median = 7 weeks). However, substantial variability was observed, ranging from less than one week to about 12 months waiting time. Some clinics also reported that they follow a triaging procedure to reduce the waiting times for urgent cases. We observed a difference in the waiting times reported by private (mean: 5.3, SD:3.1) and public clinics (mean: 11.9, SD: 10.8; $p_{\text{Mann-Whitney-U}}=.031$).

Most clinics reported that they run services at least once per week or more often (see Table 1). Very few clinics, mostly in regional areas, ran less frequently. Thirty-four respondents (89%) reported on their clinic's staffing. The mean allocation per clinic was 2.4 (SD= 3.2) effective-full time (EFT) positions (range: 0.1 EFT to 14.0 EFT). No significant correlation was found between the clinics' EFT and waiting time (Spearman's $r=.288$, $p=.104$).

Few differences were observed in terms of the representation of the various professions in public versus private, and metropolitan versus regional Memory Clinics (Appendix A). Specifically, private clinics reported lower EFTs for a dedicated clinical coordinator (mean EFT: 0.01; $p_{\text{Mann-Whitney-U}}=.020$) than public clinics (mean EFT: 0.32) and metropolitan Memory Clinics reported a higher average EFT for trainee doctors (mean EFT: 0.35) compared to regional clinics (mean EFT: 0.01; $p_{\text{Mann-Whitney-U}}=.038$).

Almost all clinics (97%) reported that follow-up assessments/ reviews form part of their standard services. These follow-ups are mostly conducted on an ad hoc basis, and the frequency may differ from case to case (e.g., after 6 months, after 12 months). In a number of clinics, follow-ups were predominantly scheduled for people initially diagnosed with mild cognitive impairment (MCI). On a regular clinic day an average of 3.3 (SD= 2.4) new patients and 4.2 (SD= 3.3) follow-up patients are assessed (see Table 1). All clinics reported seeing patients from cultural and linguistically diverse (CALD) backgrounds. In some cases, CALD patients were reported to represent up to 50% of the clinic's case load. While a wide variety of languages were reported (e.g., Cantonese, Arabic, Spanish, Maltese) for CALD clients, the most commonly represented languages were Italian, Greek and Mandarin. Twenty-five clinics

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(66%) reported that they regularly assessed patients with an indigenous background but only three clinics reported this proportion to be larger than 5%.

General Practitioners were the most common referral source for 35 (92%) Memory Clinics. The remaining three clinics reported that most of their referrals come from a Neurologist or a Geriatrician.

Clinical Assessments

The 141 clinicians who responded to this part of the survey, represented 14 different professions, with the majority being geriatricians (42%) or neuropsychologists (24%). The types of assessments carried out by different professionals are presented in Figure 2. As expected, neuropsychological tests are most commonly conducted by trained Neuropsychologists. However, clinicians from other professions (e.g., Neurologists, Psychiatrists, Speech Pathologist) also reported the use of neuropsychological tests (see Figure 2).

[FIGURE 2 – near here]

Overall, the respondents reported the use of more than 100 different test instruments across all assessment types and cognitive domains. Table 2 summarises the most commonly used test instruments across different assessment types in a routine dementia assessment, while Table 3 summarises the top three neuropsychological test instruments reported for each cognitive domain included in our survey. Both tables display the percentage of respondents at each frequency of test use on a 5-point Likert Scale (1=always; 5=rarely/never) and the mean Likert Scale ratings (smaller mean represents more frequent test use). The tables also display the total number of respondents who reported using of any of the listed tools within a specific assessment type or within a cognitive domain.

While 126 (90%) of the respondents reported the use of self-reports, substantially fewer respondents reported the use of clinician rated measures (30%) or formal assessments

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of subjective cognitive concerns (14%; see Table 2). Respondents reported that they assess domains like *language*, *executive function* or *processing speed* ‘most of the time’ during their routine assessment. In contrast, even the most popular test instruments assessing domains like *social cognition* and *effort* were on average only used ‘sometimes’ (see Table 3).

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Table 2: 3 most commonly used general mood, sleep, self and informant rated and clinical/ cognitive assessment tool

		Percentage of respondents					
		always (1)	most of the time (2)	about half the time (3)	sometime (4)	rarely/ never (5)	mean rating (SD)
Self-report (n=126)							
1	GDS -15	15.9	32.5	15.1	17.5	19.0	2.9 (1.4)
2	DASS-21	6.3	11.1	7.9	16.7	57.9	4.1 (1.3)
3	Epworth Sleepiness Scale	0.8	3.2	1.6	32.0	62.4	4.5 (0.8)
Informant-rated measures (=77)							
1	IQCODE	20.8	13.0	5.2	24.7	36.4	3.4 (1.6)
2	CBI-R	5.2	5.2	2.6	16.9	70.1	4.4 (1.1)
3	Zarit Burden	9.1	5.2	0	9.1	76.6	4.4 (1.3)
Clinician-rated measures (n=42)							
1	Clinical Dementia Rating	7.3	22.0	2.4	29.3	39.0	3.7 (1.4)
2	Neuropsychiatric Inventory	11.9	14.3	11.9	19.0	42.9	3.7 (1.5)
3	Hamilton Depression Rating	2.4	2.4	0	9.8	85.4	4.7 (0.8)
Subjective cognitive concerns (n=19)							
1	IQCODE	31.6	5.3	5.3	42.1	15.38	3.0 (1.6)
2	ECog (Self)	0	5.3	0	5.3	89.5	4.8 (0.7)
3	ECog (informant)	0	5.3	0	0	94.7	4.8 (0.7)
Cognitive Screening (n=141)							
1	Clock drawing	39.7	31.2	8.5	9.9	10.6	2.2 (1.3)
2	MMSE	34.0	36.9	6.4	8.5	14.2	2.3 (1.4)
3	MoCA	7.8	18.4	13.5	34.0	26.2	3.5 (1.3)

GDS= Geriatric Depression Scale; DASS= Depression Anxiety Stress Scale; IQCODE= Informant Questionnaire on Cognitive Decline in the Elderly; CBI-R= Cambridge behavioural Inventory-revised; ECog= Measurement of Everyday Cognition; MMSE= Mini-mental State Examination; MoCA= Montreal Cognitive Assessment

Table 3: 3 most commonly used neuropsychological test instruments for each cognitive domain

		Percentage of respondents				rarely/ never (5)	mean rating (SD)
		always (1)	most of the time (2)	about half the time (3)	sometime (4)		
Premorbid Function (n=44)							
1	TOPF	15.9	34.1	6.8	9.1	34.1	3.1 (1.6)
2	WAIS-IV Vocabulary	4.5	15.9	6.8	18.2	54.2	4.0 (1.4)
3	NART	6.8	2.3	6.8	11.4	72.7	4.4 (1.2)
Processing Speed (n=51)							
1	Trail Making A	35.3	39.2	7.8	15.7	2.0	2.1 (1.1)
2	WAIS-IV Coding	17.6	29.4	5.9	19.6	27.5	3.1 (1.5)
3	WAIS-IV Symbol Search	13.7	19.6	9.8	21.6	35.3	3.1 (1.5)
Attention/ Working Memory (n=48)							
1	Digit Span (2 subtests)	33.3	16.7	2.1	12.5	35.4	3.0 (1.8)
2	Digit Span (3 subtests)	14.6	25.0	4.2	20.8	35.4	3.4 (1.5)
3	TEA	0	2.1	6.3	14.6	77.1	4.5 (1.1)
Memory (n=47)							
1	WMS-IV Logical Memory	29.8	23.4	12.8	6.4	27.7	2.8 (1.6)
2	Rey Complex Figure (30min delay)	21.3	21.3	8.5	17.0	31.9	3.2 (1.6)
3	WMS-IV Visual Reproduction	17.0	21.3	12.8	17.01	31.9	3.3 (1.5)
Language (n=54)							
1	Category Fluency (Animals)	46.3	33.3	7.4	7.4	5.6	1.9 (1.2)
2	COWAT (FAS)	42.6	20.4	7.4	7.4	22.2	2.5 (1.6)
3	Boston Naming (60 items)	16.7	27.8	13.0	20.4	22.2	3.0 (1.4)
Visuo-spatial abilities (n=57)							
1	Clock drawing	40.4	33.3	5.3	12.3	8.8	2.2 (1.3)

2	Rey Complex Figure (copy)	33.3	33.3	3.5	8.8	21.1	2.5 (1.5)
3	Cube copying/drawing	26.3	31.6	5.3	21.1	15.8	2.7 (1.5)
Executive function (n=54)							
1	Trail Making B	29.6	44.4	7.4	13.0	5.6	2.2 (1.2)
2	WAIS-IV Similarities	29.6	24.1	7.4	9.3	29.6	2.9 (1.7)
3	Stroop (D-KEFS)	7.4	11.1	3.7	16.7	61.1	4.1 (1.3)
Social Cognition (n=8)							
1	Reading the Mind in the Eyes	0	0	12.5	62.5	25.0	4.1 (0.6)
2	The Awareness of Social Interference Test	0	0	12.5	37.5	50.0	4.4 (0.7)
3	Facial Expression of Emotion/ Ekman Faces	0	0	0	12.5	87.5	4.9 (0.4)
Effort (n=30)							
1	WAIS-IV embedded measure - reliable digit span	0	16.7	6.7	36.7	40.0	4.0 (1.1)
2	WAIS-IV embedded measure logical Memory - delayed recognition	0	10.0	13.3	33.3	43.3	4.1 (1.0)
3	Advanced Clinical Solutions – word choice	0	10.0	13.3	30.0	46.7	4.1 (1.0)

TOPF= Test of Premorbid Function; WAIS= Wechsler Adult Intelligence Scale; NART= national Adult Reading Test; TEA= Test of Everyday Attention; WMS= Wechsler Memory Scale; COWAT= Controlled Oral Word Association Test; D-KEFS= Delis-Kaplan Executive Function System

A comparison of the test use of clinicians from metropolitan and regional Memory Clinics showed that self-reported measures were more commonly used in metropolitan clinics (see full table in Appendix B: chi-square= 4.59, $p=.032$). Moreover, we observed that the “NART” (National Adult Reading Test), was more frequently used by clinicians from metropolitan than regional areas ($t= -2.21$, $p=.032$) and the test “WAIS-IV embedded measure: reliable digit span” was more frequently reported by clinicians from public than private clinics ($t= -2.80$, $p=.010$, see full table in Appendix B).

Only 10 respondents (7%) reported the use of computerised assessment tools, and these were used infrequently. The “Q-Interactive” test was the most commonly used (mean rating= 3.9, SD=1.7) followed by the computerised “Wisconsin Card Sorting Test” (mean rating= 4.3, SD=1.1).

Cognitive Interventions

Only 46 (31%) of the 150 respondents reported that they offer any form of cognitive intervention. No differences were found between respondents working for public or private (chi-square= 0.003, $p =.956$) and metropolitan or regional Memory Clinics (chi-square= 0.07, $p =.791$). Most respondents who offer cognitive intervention reported the use of a combination of different cognitive interventions, with a mix of *psychoeducation*, *involvement of family members* and *input to rehabilitation* being the most commonly reported combination (33%). Moreover, 89% of clinicians (41 out 46) reported that they conduct an individualised rather than a standardised approach. Interestingly, more than half (52%) of the respondents who offer interventions are only able to provide one session. Only 7 out of the 46 respondents (15.2%) reported that they can provide more than 5 sessions of cognitive intervention to their patients. Respondents who do not provide cognitive intervention reported a lack of resources, often accompanied by a lack of appropriate training as the most common reason for not offering cognitive interventions.

DISCUSSION

This survey provides an updated overview of the current clinical situation of Memory Clinics across Australia. It further identified the most commonly used assessment tools, which marks an important first step in ADNeT's effort to harmonise and improve standards of diagnostic procedures across Australian Memory Clinics.

Our survey included a substantially larger number of respondents than previous Memory Clinic surveys in Australia¹ or internationally^{7,11}. We broadened our target group to all clinicians involved in the specialised assessment of dementia and cognitive decline and identified responses from 90 different Memory Clinic services. This broad recruitment approach provided a more comprehensive overview of current clinical practices in the specialised assessment of people with dementia and cognitive decline across Australia.

The survey confirmed the large heterogeneity in the organisational aspects (e.g., staffing, number of patients, waiting times) of Memory Clinic services across Australia, previously reported in the national survey from 2009¹. Similar variability in Memory Clinic services has been observed in the Netherlands, Ireland, the UK, Israel and New Zealand and greater harmonisation has been internationally endorsed^{7,9,11,12,14}.

Previous surveys^{1,7} identified relatively long waiting times for an initial assessment and understaffing as the main issues that may compromise a timely and accurate dementia diagnosis in a Memory Clinic setting. Woodward and Woodward¹ reported an average of 10 weeks waiting time in their first Australian survey. Our results suggest that the waiting time remained largely unchanged over the past 10 years (average waiting time = 9.9 weeks). However, waiting times also greatly varied between services. The services with the shortest and the longest waiting time were both operating in metropolitan areas at relatively high frequency (4-5x a week). The clinic with the shortest waiting time was a private service and with one of the largest staff numbers in our survey. However, over all respondents, no meaningful relationship between staffing and waiting times was observed. The UK National Health Service's *Implementation guide and resource pack for dementia care*²¹ recommends a maximum waiting time of six weeks to diagnosis as the minimum standard for Memory Clinics. Our survey showed that only 43% of cognitive assessment services would be able to offer an

initial assessment within 6 weeks, with the majority falling short of this, most likely due to understaffing. Time to initial diagnosis was not assessed in our survey and should be added to future Memory Clinic surveys.

Indeed, staffing varied largely across Memory Clinics. Our survey results suggest that the average EFT increased from 1.7 EFT reported in 2009¹ to 2.4 EFT. In an international comparison, however, this staffing allocation is still comparatively low (e.g., Ireland⁷: 3.4 EFT). A clinical coordinator position to handle general administration issues was included in only 44% of services. It can be assumed that clinicians in the remaining services must fulfil administrative duties in parallel to their clinical work. This is likely to affect the clinicians' capacity to see more clients for assessment and could potentially add to the delay in establishing a dementia diagnosis. The composition of Memory Clinics teams varied widely between clinics, a finding also observed internationally^{7,9,11}. The majority of clinics reported the employment of geriatricians (76%). This result might have been influenced by our participation call in the regular newsletter of Australia's largest geriatric society (ANZSGM). Importantly, our survey showed that only a small number of clinics include allied health professionals like occupational therapists (24%) or speech pathologists (12%). A similar observation was made in the Irish Memory Clinics survey⁷. We expect this would inevitably restrict post-diagnostic care options provided by these services and should be further assessed.

All respondents were asked if their Memory Clinic offered any form of cognitive intervention. Our survey showed that less than a third of respondents (30%) reported that they offer cognitive interventions with the majority only offering a single session. In comparison, a recent survey conducted across Memory Services in the Netherlands showed that 72% offer psychosocial interventions. We would like to argue that due to its high specialisation, Memory Clinics would be well equipped for the provision of high-quality and evidence-based cognitive interventions, but most of the Australian clinics reported a lack of funding or adequate training to do so. This is one possible reason why post-diagnostic care provided by Memory Clinics has not been shown to be more effective than general practitioner services²². If and how

Memory Clinics could be involved more actively in post-diagnostic care is part of a larger discussion about the goals and purpose of Memory Clinics^{7,23}. In Australia, ADNeT as well as other projects²⁴ have been commissioned to address this issue in due course.

There appears to be international agreement on the main components of a comprehensive assessment of dementia and cognitive decline including family and medical history, blood tests and structural neuroimaging, yet notably cognitive assessment protocols remain variable^{7,9,11}. Our survey results made a similar observation. We identified more than 100 cognitive test instruments that clinicians use at least 'sometimes' in their assessments. Some agreement was observed in the use of cognitive screens, with the MMSE and clock drawing test being the most commonly used test tools^{9,12,14}.

Based on our survey results, we identified the three most commonly used tests across the major cognitive domains (e.g., attention, language, memory) and types (e.g., self-report, informant-rated, see Table 2 and 3). This forms the basis for the development of a harmonised neuropsychological test protocol. Such a protocol would provide a minimum data set that would be uniform across Memory Clinics, thereby enabling comparison of practices and outcomes across clinics, the pooling of patient data for joint examination, and the ready recruitment nationally for clinical trials. A core minimum dataset does not constrain any clinic if there is a wish or need to expand the assessment to meet client and/or service needs.

CONCLUSION

This national survey of Memory Clinics in Australia presents a picture of considerable heterogeneity in assessment procedures, while identifying some common elements that can be the basis of future harmonisation of practices. While the Memory Clinics have expanded since the previous survey a decade earlier, the service largely remains a diagnostic one with relatively little post-diagnostic care in most clinics. With the rapid ageing of the population, the demand for Memory Clinics is growing. This survey is the first step toward an effort to develop standards for Memory Clinic assessments and post-diagnostic care such that each individual with cognitive deficits can receive prompt state-of-the-art assessment and care.

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All ADNeT initiatives work closely together to achieve these improvements. The ADNeT clinical quality registry will monitor the ongoing improvements of Memory Clinics procedures through regular feedback and benchmarked outcome measures. Harmonised diagnostic procedures that map onto common research outcomes across Memory Clinics also facilitates translation of research findings into practice and the clients’ participation in research. Memory Clinics will be an important entry point into clinical trials as new drugs and therapies are developed with national support through ADNeT-Trials.

To further the harmonisation of Memory Clinics procedures, we will employ Delphi-methods, including expert opinions from of clinicians, researchers, people living with dementia and carers from all Australian states and territories to develop national best-practice standards. Furthermore, the survey results confirm the need for better resourcing of Memory Clinics and cognitive assessment services to further support early diagnosis of dementia and cognitive decline by increasing staff levels to match international standards. With projections of exponentially increasing numbers of people who will develop dementia in the next decades, it is essential that Memory Services are well-equipped in terms of funding and best practices to provide early diagnosis and evidence-based post-diagnostic care.

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Contributors: I.M. designed study method and data collection tools, organised and facilitated data collection, cleaned, analysed and interpreted the data and drafted and revised the paper. N.A.K. designed the study method and data collection tool, interpreted the data and revised the manuscript for intellectual content. MY.O. made major contribution to the design of the

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data collection and reviewed the manuscript. J.D.C. made major contributions to the analyses and interpretation of the data and revised the manuscript for intellectual content. S.L.N. and P.S.S. designed and conceptualised the study and its methods, interpreted the data, and revised the manuscript for intellectual content. All authors read and approved the final manuscript.

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Patient consent for publication: Not required

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Data sharing statement: A copy of the survey and the de-identified dataset analysed for the current study are available from the corresponding author on reasonable request.

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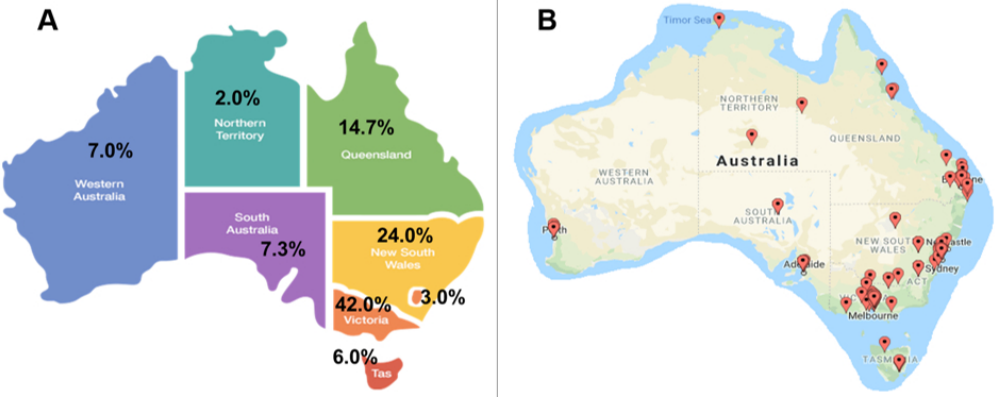


Figure 1: Panel A - National distribution of respondents in percent; Panel B -National distribution of individual respondents

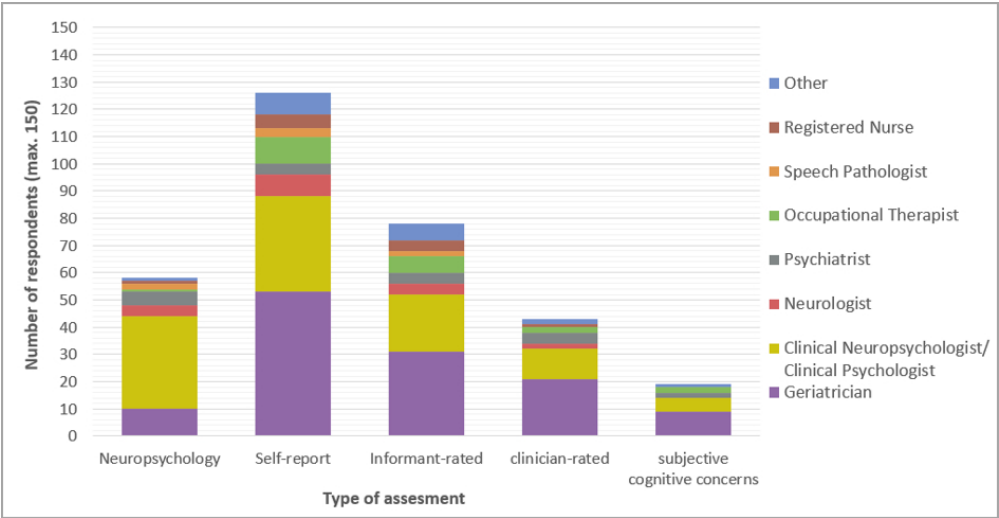


Figure 2: Types of assessments conducted by clinicians of different professions
Note: Other = GP; administration staff, social worker, geriatric advanced Trainee, Geriatric Registrar

Appendix A

Profession	# of clinics (%) (max.: 34)	Mean EFT (SD)	Public Mean EFT (SD)	Private Mean EFT (SD)	metropolitan Mean EFT (SD)	regional Mean EFT (SD)	public vs private – p^{\wedge}	metropolitan vs regional p^{\wedge}
Geriatrician	26 (76%)	1.23 (2.14)	0.77 (1.71)	1.41 (2.51)	1.33 (2.45)	0.39 (0.03)	.163	.274
Clinical coordinator*	15 (44%)	0.52 (0.34)	0.32 (0.37)	0.01 (0.03)	0.24 (0.35)	0.24 (0.35)	.020*	.986
Clinical Neuropsychologist	13 (38%)	0.69 (0.59)	0.32 (0.54)	0.11 (0.33)	0.34 (0.55)	0.16 (0.41)	.140	.180
Trainee doctor	10 (29%)	0.68 (1.52)	0.28 (0.49)	0	0.35 (1.13)	0.01 (0.03)	.072	.038*
Registered nurse	9 (26%)	0.78 (0.54)	0.28 (0.49)	0	0.17 (0.33)	0.26 (0.57)	.120	.849
Occupational Therapists	8 (24%)	0.81 (0.59)	0.26 (0.50)	0	0.28 (0.55)	0.06 (0.17)	.163	.377
Social worker	8 (24%)	0.23 (0.16)	0.08 (0.14)	0	0.07 (0.12)	0.04 (0.13)	.154	.199
Psychiatrist	6 (18%)	0.28 (0.36)	0.07 (0.20)	0	0.07 (0.22)	0.01 (0.05)	.298	.416
Clinical Psychologist	4 (12%)	0.63 (0.40)	0.10 (0.27)	0	0.03 (0.08)	0.14 (0.34)	.489	.416
Speech Pathologist	4 (12%)	0.16 (0.16)	0.03 (0.08)	0	0.01 (0.03)	0.03 (0.11)	.489	.743
Neurologist	3 (9%)	0.20 (0.10)	0.02 (0.07)	0	0.03 (0.08)	0	.618	.478
Rehabilitation Physician	1 (3%)	0.30	n/a	n/a	n/a	n/a	n/a	n/a
Aged Care Physician	1 (3%)	0.30	n/a	n/a	n/a	n/a	n/a	n/a
Consultant Physician	1 (3%)	0.20	n/a	n/a	n/a	n/a	n/a	n/a
General Practitioner	1 (3%)	0.20	n/a	n/a	n/a	n/a	n/a	n/a

EFT = effective full time (1.0 = 35 hours/ week).

* paid time uniquely dedicated to clinic administration tasks

\wedge Mann-Whitney-U test used due to skewed data

* significant p value, $p < .05$

Appendix B

	All	metro-politan	regional	Chi-square (p)/ t (p)^^	public	private	Chi-square (p)/ t (p)^^
All respondents involved in clinical assessments (n)	140	99	41		116	24	
Self-reported measures	90%	92%	80%	4.59 (.03)*	90%	83%	1.07 (.30)
1) GDS (15 items)	2.9 (1.4)^	3.0 (1.4)	2.9 (1.4)	0.13 (.90)	2.9 (1.4)	3.2 (1.4)	0.95 (.35)
2) DASS (21 items)	4.1 (1.3)	4.2 (1.2)	3.7 (1.6)	1.70 (.10)	4.1 (1.3)	4.1 (1.4)	0.07 (.94)
3) Epworth Sleepiness Scale	4.5 (0.8)	4.5 (0.8)	4.5 (0.7)	0.12 (.90)	4.5 (0.7)	4.5 (0.9)	-0.40 (.70)
Informant-rated measures	55%	51%	66%	1.51 (.22)	56%	50%	0.38 (.54)
1) IQCODE	3.4 (1.6)	3.6 (1.6)	3.1 (1.6)	1.34 (.19)	3.4 (1.6)	3.6 (1.3)	0.45 (.66)
2) CBI-R	4.4 (1.1)	4.4 (1.1)	4.4 (1.1)	-0.08 (.93)	4.4 (1.2)	4.8 (0.6)	1.71 (.10)
3) Zarit Burden	4.4 (1.3)	4.2 (1.4)	4.7 (1.0)	-1.49 (.14)	4.3 (1.3)	4.8 (0.9)	1.42 (.17)
Clinician-rated measures	30%	29%	32%	0.02 (.90)	29%	33%	0.09 (.76)
1) Clinical Dementia Rating	3.7 (1.4)	3.8 (1.3)	3.6 (1.6)	0.33 (.74)	3.7 (1.4)	3.6 (1.5)	-0.27 (.80)
2) Neuropsychiatric Inventory	3.7 (1.5)	3.5 (1.5)	4.2 (1.3)	-1.56 (.13)	3.6 (1.6)	4.1 (0.6)	1.60 (.12)
3) Hamilton Depression Rating	4.7 (0.8)	4.7 (0.9)	4.8 (0.4)	-0.70 (.50)	4.7 (0.9)	4.7 (0.5)	-0.9 (.93)
Subjective Cognitive Concerns	14%	13%	15%	0.04 (.85)	14%	13%	0.03 (.85)
1) IQCODE	3.0 (1.6)	3.2 (1.7)	2.8 (1.5)	0.42 (.68)	2.9 (1.7)	3.7 (0.58)	1.35 (.21)
2) ECog (Self)	4.8 (0.7)	4.7 (0.9)	5.0 (0.0)	-1.30 (.22)	4.8 (0.8)	5.0 (0)	1.29 (.22)
3) ECog (Informant)	4.8 (0.7)	4.8 (0.8)	5.0 (0.0)	-0.67 (.51)	4.8 (0.8)	5.0 (0)	1.00 (.33)
Cognitive Screening	99%	99%	100%	0.04 (.84)	100%	100%	0.99 (.32)
1) Clock drawing	2.2 (1.3)	2.1 (1.3)	2.4 (1.5)	-1.22 (.22)	2.2 (1.3)	2.4 (1.6)	0.70 (.49)
2) MMSE	2.3 (1.4)	2.2 (1.3)	2.7 (1.6)	-1.87 (.07)	2.3 (1.4)	2.6 (1.5)	1.11 (.28)
3) MoCA	3.5 (1.3)	3.6 (1.3)	3.4 (1.4)	0.50 (.62)	3.5 (1.2)	3.5 (1.5)	-0.26 (.80)
Neuropsychological Measures							
	All	metro-politan	regional	Chi-square (p)/ t (p)^^	public	private	Chi-square (p)/ t (p)^^
n	59	42	17		51	8	
Premorbid function	76%	79%	71%	0.20 (.65)	76%	75%	0.35 (.55)
1) TOPF	3.1 (1.6)	3.2 (1.5)	2.6 (1.7)	1.19 (.25)	3.1 (1.6)	2.8 (1.5)	-0.41 (.69)
2) WAIS-IV Vocabulary	4.0 (1.4)	4.2 (1.2)	3.3 (1.6)	1.90 (.08)	4.0 (1.4)	3.7 (1.5)	-0.51 (.63)
3) NART	4.4 (1.2)	4.3 (1.3)	4.8 (0.4)	-2.21 (.03)*	4.5 (1.1)	3.8 (1.6)	-1.01 (.36)
Processing Speed	86%	90%	76%	2.03 (.16)	86%	88%	0.01 (.93)
1) Trail Making A	2.1 (1.1)	2.2 (1.2)	1.9 (0.9)	0.76 (.45)	2.0 (1.1)	2.6 (1.4)	1.0 (.35)
2) WAIS-IV Coding	3.1 (1.5)	3.1 (1.6)	3.1 (1.5)	0.06 (.95)	3.1 (1.5)	3.0 (1.6)	-0.17 (.86)
3) WAIS-IV Symbol Search	3.1 (1.5)	3.6 (1.5)	3.1 (1.5)	1.05 (.31)	3.5 (1.5)	3.1 (1.8)	-0.51 (.63)
Attention/ Working Memory	81%	83%	76%	0.78 (.54)	80%	87%	0.23 (.63)
1) Digit span (2 subtests)	3.0 (1.8)	3.1 (1.8)	2.9 (1.8)	0.36 (.72)	3.0 (1.8)	3.3 (1.9)	0.44 (.67)
2) Digit span (3 subtests)	3.4 (1.5)	3.3 (1.6)	3.5 (1.5)	-0.45 (.66)	3.5 (1.5)	2.6 (1.7)	-1.36 (.21)

3) TEA	4.5 (1.1)	4.8 (0.6)	4.2 (1.0)	2.05 (.06)	4.6 (0.7)	4.9 (0.4)	1.22 (.24)
Memory	80%	83%	71%	1.21 (.27)	80%	75%	0.12 (.73)
1) WMS-IV Logical Memory	2.8 (1.6)	2.9 (1.6)	2.5 (1.6)	0.71 (.49)	2.9 (1.7)	2.3 (1.2)	-0.93 (.38)
2) Rey Complex figure (30min)	3.2 (1.6)	3.0 (1.6)	3.8 (1.4)	-1.62 (.12)	3.2 (1.6)	3.3 (1.9)	0.23 (.82)
3) WMS-IV Visual Reproduction	3.3 (1.5)	3.4 (1.6)	2.8 (1.4)	1.17 (.25)	3.3 (1.6)	3.0 (1.4)	-0.47 (.66)
Language	92%	93%	88%	0.33 (.56)	90%	100%	0.86 (.36)
1) Category Fluency (Animals)	1.9 (1.2)	1.8 (1.1)	2.3 (1.3)	-1.46 (.16)	1.9 (1.1)	2.1 (1.4)	0.46 (.66)
2) COWAT (FAS)	2.5 (1.6)	2.3 (1.6)	2.8 (1.7)	-0.92 (.37)	2.4 (1.6)	2.6 (1.7)	0.30 (.77)
3) Boston Naming (60items)	3.0 (1.4)	2.8 (1.4)	3.7 (1.3)	-2.34 (.03)*	3.0 (1.4)	3.4 (1.8)	0.60 (.56)
Visuo-spatial	97%	98%	94%	0.45 (.50)	96%	100%	0.33 (.57)
1) Clock drawing	2.2 (1.3)	2.1 (1.3)	2.4 (1.4)	-0.74 (.46)	2.0 (1.2)	2.9 (1.8)	1.26 (.24)
2) Rey Complex figure (copy)	2.5 (1.5)	2.3 (1.5)	3.0 (1.6)	-1.45 (.16)	2.5 (1.6)	2.6 (1.6)	0.22 (.83)
3) Cube copying/ drawing)	2.7 (1.5)	2.7 (1.5)	2.6 (1.4)	0.20 (.84)	2.7 (1.5)	2.8 (1.5)	0.14 (.90)
Executive Function	92%	90%	94%	0.21 (.65)	90%	100%	0.86 (.36)
1) Trail Making B	2.2 (1.2)	2.2 (1.1)	2.3 (1.3)	-0.41 (.68)	2.2 (1.2)	2.1 (1.3)	-0.20 (.85)
2) WAIS-IV Similarities	2.9 (1.7)	2.8 (1.6)	3.1 (1.7)	-0.59 (.56)	2.8 (1.7)	3.0 (1.8)	0.26 (.80)
3) Stroop (DKEFS)	4.1 (1.3)	4.2 (1.4)	4.0 (1.2)	0.49 (.63)	4.2 (1.3)	3.6 (1.7)	-0.95 (.37)
Social Cognition	14%	12%	18%	0.34 (.56)	16%	0	1.45 (.23)
1) Reading the Mind in the Eyes	4.1 (0.6)	4.0 (0.7)	4.3 (0.6)	-0.73 (.50)	4.1 (0.6)	n/a	n/a
2) The Awareness of Social Interference Test	4.4 (0.7)	4.6 (0.5)	4.0 (1.0)	0.96 (.42)	4.4 (0.7)	n/a	n/a
3) Facial Expressions of Emotion / Ekman Faces	4.9 (0.4)	4.8 (0.4)	5.0 (0)	-1.00 (.37)	4.9 (0.4)	n/a	n/a
Effort	51%	48%	59%	0.61 (.44)	51%	50%	0.00 (.96)
1) WAIS-IV embedded measure reliable digit span	4.0 (1.1)	4.3 (0.9)	3.4 (1.3)	2.03 (.06)	4.2 (1.0)	2.8 (1.0)	-2.8 (.05)*
2) WAIS-IV embedded measure logical Memory, delayed recognition	4.1 (1.0)	4.3 (0.9)	3.8 (1.1)	1.09 (.29)	4.2 (0.9)	3.8 (1.5)	-0.52 (.63)
3) Advanced Clinical Solutions – word choice	4.1 (1.0)	4.3 (0.9)	3.8 (1.1)	1.21 (.25)	4.3 (0.8)	3.0 (1.4)	-1.80 (.16)

^ the values refer to the mean rating on the Likert Scale (1=always; 2=most of the time; 3=about half the time; 4=sometimes; 5=never/rarely)

^^ chi-square applies for nominal data describing if assessments of a particular type were conducted (highlighted in green) / t-tests were performed for to determine differences in test use across different clinical settings

* highlights a significant difference $p < .05$

Appendix C

ADNeT Chief Investigators	
ADNeT Chief Investigators	Principal Institution
Christopher Rowe	The University of Melbourne
Perminder Sachdev	University of New South Wales
Sharon Naismith	University of Sydney
Michael Breakspear	The Council of the Queensland Institute of Medical Research
Henry Brodaty	University of New South Wales
Kaarin Anstey	Neuroscience Research Australia
Ralph Martins	Macquarie University
Stephanie Ward	University of New South Wales
James Vickers	University of Tasmania
Colin Masters	The University of Melbourne

ADNeT Associate Investigators	
ADNeT Associate Investigators	Principal Institution
Peter Schofield	Neuroscience Research Australia
Rob Grenfell	The Council of the Queensland Institute of Medical Research
Susan Kurrle	University of Sydney
Elizabeth Beattie	Queensland University of Technology
Ashley Bush	Florey Institute of Neuroscience and Mental Health
Maria Crotty	Flinders University
Annette Dobson	University of Queensland
Leon Flicker	University of Western Australia
Paul Maruff	The University of Melbourne
John McNeil	Monash University
Peter Nestor	University of Queensland
Olivier Salvado	University of Queensland
Susannah Ahern	Monash University

Revised Standards for Quality Improvement Reporting Excellence (SQUIRE 2.0)
September 15, 2015

Text Section and Item Name	Section or Item Description
Notes to authors	<ul style="list-style-type: none"> • The SQUIRE guidelines provide a framework for reporting new knowledge about how to improve healthcare • The SQUIRE guidelines are intended for reports that describe system level work to improve the quality, safety, and value of healthcare, and used methods to establish that observed outcomes were due to the intervention(s). • A range of approaches exists for improving healthcare. SQUIRE may be adapted for reporting any of these. • Authors should consider every SQUIRE item, but it may be inappropriate or unnecessary to include every SQUIRE element in a particular manuscript. • The SQUIRE Glossary contains definitions of many of the key words in SQUIRE. • The Explanation and Elaboration document provides specific examples of well-written SQUIRE items, and an in-depth explanation of each item. • Please cite SQUIRE when it is used to write a manuscript.
Title and Abstract	
1. Title	Indicate that the manuscript concerns an initiative to improve healthcare (broadly defined to include the quality, safety, effectiveness, patient-centeredness, timeliness, cost, efficiency, and equity of healthcare)
2. Abstract	<ol style="list-style-type: none"> Provide adequate information to aid in searching and indexing Summarize all key information from various sections of the text using the abstract format of the intended publication or a structured summary such as: background, local problem, methods, interventions, results, conclusions
Introduction	<i>Why did you start?</i>
3. Problem Description	Nature and significance of the local problem
4. Available knowledge	Summary of what is currently known about the problem , including relevant previous studies

5. Rationale	Informal or formal frameworks, models, concepts, and/or theories used to explain the problem , any reasons or assumptions that were used to develop the intervention(s) , and reasons why the intervention(s) was expected to work
6. Specific aims	Purpose of the project and of this report
Methods	<i>What did you do?</i>
7. Context	Contextual elements considered important at the outset of introducing the intervention(s)
8. Intervention(s)	a. Description of the intervention(s) in sufficient detail that others could reproduce it b. Specifics of the team involved in the work
9. Study of the Intervention(s)	a. Approach chosen for assessing the impact of the intervention(s) b. Approach used to establish whether the observed outcomes were due to the intervention(s)
10. Measures	a. Measures chosen for studying processes and outcomes of the intervention(s) , including rationale for choosing them, their operational definitions, and their validity and reliability b. Description of the approach to the ongoing assessment of contextual elements that contributed to the success, failure, efficiency, and cost c. Methods employed for assessing completeness and accuracy of data
11. Analysis	a. Qualitative and quantitative methods used to draw inferences from the data b. Methods for understanding variation within the data, including the effects of time as a variable
12. Ethical Considerations	Ethical aspects of implementing and studying the intervention(s) and how they were addressed, including, but not limited to, formal ethics review and potential conflict(s) of interest
Results	<i>What did you find?</i>
13. Results	a. Initial steps of the intervention(s) and their evolution over time (e.g., time-line diagram, flow chart, or table), including modifications made to the intervention during the project b. Details of the process measures and outcome c. Contextual elements that interacted with the intervention(s) d. Observed associations between outcomes, interventions, and relevant contextual elements e. Unintended consequences such as unexpected benefits, problems, failures, or costs associated with the intervention(s) . f. Details about missing data
Discussion	<i>What does it mean?</i>
14. Summary	a. Key findings, including relevance to the rationale and specific aims b. Particular strengths of the project

15. Interpretation	<ul style="list-style-type: none"> a. Nature of the association between the intervention(s) and the outcomes b. Comparison of results with findings from other publications c. Impact of the project on people and systems d. Reasons for any differences between observed and anticipated outcomes, including the influence of context e. Costs and strategic trade-offs, including opportunity costs
16. Limitations	<ul style="list-style-type: none"> a. Limits to the generalizability of the work b. Factors that might have limited internal validity such as confounding, bias, or imprecision in the design, methods, measurement, or analysis c. Efforts made to minimize and adjust for limitations
17. Conclusions	<ul style="list-style-type: none"> a. Usefulness of the work b. Sustainability c. Potential for spread to other contexts d. Implications for practice and for further study in the field e. Suggested next steps
Other information	
18. Funding	Sources of funding that supported this work. Role, if any, of the funding organization in the design, implementation, interpretation, and reporting

Table 2. Glossary of key terms used in SQUIRE 2.0. This Glossary provides the intended meaning of selected words and phrases as they are used in the SQUIRE 2.0 Guidelines. They may, and often do, have different meanings in other disciplines, situations, and settings.

Assumptions

Reasons for choosing the activities and tools used to bring about changes in healthcare services at the [system](#) level.

Context

Physical and sociocultural makeup of the local environment (for example, external environmental factors, organizational dynamics, collaboration, resources, leadership, and the like), and the interpretation of these factors (‘sense-making ’) by the healthcare delivery professionals, patients, and caregivers that can affect the effectiveness and [generalizability](#) of [intervention\(s\)](#).

Ethical aspects

The value of [system](#)-level [initiatives](#) relative to their potential for harm, burden, and cost to the stakeholders. Potential harms particularly associated with efforts to improve the quality, safety, and value of healthcare services include [opportunity costs](#), invasion of privacy, and staff distress resulting from disclosure of poor performance.

Generalizability

The likelihood that the [intervention\(s\)](#) in a particular report would produce similar results in other settings, situations, or environments (also referred to as external validity).

Healthcare improvement

Any systematic effort intended to raise the quality, safety, and value of healthcare services, usually done at the [system](#) level. We encourage the use of this phrase rather than “quality” which often refers to more narrowly defined approaches.

Inferences

The meaning of findings or data, as interpreted by the stakeholders in healthcare services – improvers, healthcare delivery professionals, and/or patients and families

Initiative

A broad term that can refer to organization-wide programs, narrowly focused projects, or the details of specific interventions (for example, planning, execution, and assessment)

Internal validity

Demonstrable, credible evidence for efficacy (meaningful impact or change) resulting from introduction of a specific intervention into a particular healthcare [system](#).

Intervention(s)

The specific activities and tools introduced into a healthcare [system](#) with the aim of changing its performance for the better. Complete description of an intervention includes its inputs, internal activities, and outputs (in the form of a logic model, for example), and the mechanism(s) by which these components are expected to produce changes in a [system](#) performance.

Opportunity costs

Loss of the ability to perform other tasks or meet other responsibilities resulting from the diversion of resources needed to introduce, test, or sustain a particular [improvement](#) initiative

Problem

Meaningful disruption, failure, inadequacy, distress, confusion or other dysfunction in a healthcare service delivery [system](#) that adversely affects patients, staff, or the [system](#) as a whole, or that prevents care from reaching its full potential

Process

The routines and other activities through which healthcare services are delivered

Rationale

Explanation of why particular [intervention\(s\)](#) were chosen and why it was expected to work, be sustainable, and be replicable elsewhere.

Systems

The interrelated structures, people, [processes](#), and activities that together create healthcare services for and with individual patients and populations. For example, systems exist from the personal self-care system of a patient, to the individual provider-patient dyad system, to the microsystem, to the macrosystem, and all the way to the market/social/insurance system. These levels are nested within each other.

Theory or theories

Any “-ing” account that asserts causal relationships that makes sense of an otherwise obscure [process](#) or situation (explanatory theory). Theories come in many forms, and serve different purposes in the phases of [improvement](#) work. It is important to be explicit and well-founded about any informal and formal theory (or theories) that are used.

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Organisational aspects and assessment practices of Australian Memory Clinics: An Australian Dementia Network (ADNet) survey

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Organisational aspects and assessment practices of Australian Memory Clinics: An Australian Dementia Network (ADNeT) survey

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Abstract

Objectives: Conducting a national survey of clinicians and administrators from specialised dementia assessment services (Memory Clinics) in Australia to examine their current organisational aspects and assessment procedures and inform clinical tool harmonisation as part of the Australian Dementia Network (ADNeT) – Memory Clinics project.

Design: A cross-sectional survey.

Setting: Public and private Memory Clinics across Australia

Participants: 150 individual clinicians completed the survey between May and August 2019. Responses could be given anonymously. Most clinics were publicly funded services (83.2%) and in metropolitan regions (70.9%).

Outcome measures: Descriptive data on organisational aspects of Memory Clinics (e.g., waiting times, staffing); the three most commonly used assessment tools per assessment type (e.g., self-report) and cognitive domain (e.g., attention).

Results: Since the last national survey in 2009, the number of Memory Clinics across Australia has increased substantially but considerable variability has remained with respect to funding structure, staffing and assessment procedures. The average clinic employed 2.4 effective full-time staff (EFT; range 0.14 to 14.0). The reported waiting time for an initial assessment ranged from 1 week to 12 months with a median of 7 weeks. While most clinics (97%) offered follow-up assessments for their clients, only a few (31%) offered any form of cognitive intervention. We identified over 100 different cognitive assessment tools that were utilised at least ‘sometimes’, with widespread use of well-established core screening tools and a subset of common neuropsychological tests.

Conclusion: This paper presents a current snapshot of Australian Memory Clinics, showing considerable heterogeneity with some common core elements. These results will inform the development of national Memory Clinic guidelines. Furthermore, our data make a valuable contribution to the international comparison of clinical practice standards, and advocates for greater harmonisation to ensure high-quality dementia care.

Strengths and limitations of this study

- Our study is the first national Memory Clinics survey that presents responses from all Australian states.
- A broad definition of 'Memory Clinic' was used to include all clinicians specialising in dementia diagnosis to gain a broad overview of current clinical practice
- The survey presents a comprehensive list of the most commonly used cognitive assessment tools that can inform the development of a national Memory Clinics guidelines for harmonisation of assessment tools.
- While several strategies were used to identify Memory Clinics across the country, the survey cannot be considered to be exhaustive.

INTRODUCTION

About 459,000 Australians are currently living with dementia and the numbers are expected to increase dramatically over the next 30 years¹. Nevertheless, Australia is currently lacking clear diagnostic pathways for people with dementia and cognitive decline, which may delay an early diagnosis^{2,3}. A diagnosis can be made in a number of ways, for example through a GP, incidentally in a hospital or in a specialised assessment service or Memory Clinic².

Since the late 1980s, Memory Clinics have been an integral part of Australia’s dementia care services^{4,5} and have repeatedly been recommended as the best services to obtain an early diagnosis of dementia^{2,3}. Despite such recommendations, there is no consensus definition of a Memory Clinic and no published national or international agreement on the composition, services and standards of Memory Clinics⁶. Memory Clinics are most commonly described as multidisciplinary medical assessment centres that are highly specialised for the diagnostic work-up of cognitive decline and dementia⁷. Memory Clinic surveys from six different countries (Australia⁸, Ireland⁶, Netherlands^{9,10}, British Isles¹¹ and England in particular¹², Israel^{13,14} and New Zealand¹⁵) also showed considerable heterogeneity in the diagnostic protocols that were used. Such variability was attributed to many factors including differences in the Memory Clinics’ organisational structure, the area they service (regional vs. metropolitan), the funding received by clinics, the composition and level of staffing and the frequency of clinical services. The lack of evidence-based guidelines at the time may have also contributed to the variability. Interestingly, studies from England^{16,17} and the Netherlands^{18,19} that evaluated the economic aspects of a Memory Clinic reported mixed results with regard to the cost-effectiveness of multi-disciplinary Memory Clinic services. Despite all studies showed an advantage in the clinical outcomes of a multi-disciplinary Memory Clinic (e.g., measured by various quality of life indices), the extent of this advantage did not always justify the higher cost associated with such a service.

The first Australian survey of Memory Clinics in 2009⁸ provided the first benchmark data for international comparison. The 2009 survey reported results from 16 Memory Clinics located in 5 Australian states (Victoria: 8 clinics, New South Wales: 4 clinics, South

1 Australia: 2 clinics, Queensland: 1 clinic and Western Australia: 1 clinic). The results showed
2 a comparatively long average waiting time of 10 weeks prior to the initial assessment. For
3 example, a survey of English memory assessment services reported that 73% of the 80
4 surveyed services are able to provide an initial appointment in 6 weeks or less¹². Moreover,
5 Australian Memory Clinics reported a relatively low average effective full time (EFT) staff
6 allocation of 1.7 EFT, compared to the average Memory Clinic staffing in other countries
7 (e.g., Ireland: 3.4 EFT⁶; England: 9.9 EFT¹²). They also reported differences in the
8 assessment protocols used across Memory Clinics though with relative agreement in the use
9 of blood tests, imaging and the Mini Mental State Examination (MMSE) as a cognitive
10 screen⁸. Cost-effectiveness measures have not been assessed.

11 Importantly, it has been argued that a large variability in organisational structures and
12 assessment procedures may contribute to delays in diagnosis, reduce accuracy and impede
13 the provision of early interventions^{2,20}. The benefits of harmonised diagnostic procedures for
14 clinical practice and dementia research are undeniable²¹. A harmonised assessment
15 protocol has the potential to boost collaboration between different Memory Clinics and
16 between clinicians, community dementia care services and researchers. Greater
17 harmonisation would also be required to implement national best practice standards and
18 thereby improve the quality of diagnosis and care throughout the country².

19 The call for greater harmonisation of diagnostic methods and processes has sparked
20 a number of international initiatives, for example in the United Kingdom (Memory Services
21 National Accreditation Program [MSNAP])²², the United States (National Alzheimer's
22 Coordinating Centres [NACC])²³ and the Netherlands⁹. In 2018, Australia followed this
23 international movement and supported the establishment of the Australian Dementia
24 Network (ADNeT), funded through the Australian NNIDR Boosting Dementia Research
25 Fund¹. ADNeT incorporates three main components - Clinical Quality Registry, Screening

¹ provided by the National Health and Medical Research Council (NHMRC) – National Institute for Dementia Research (NNIDR)

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3 1 and Trials and Memory Clinics - to improve the quality and accessibility of dementia care
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5 2 services across Australia.
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7 3 ADNeT-Memory Clinics (ADNeT-MC) set out to establish a national network of
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9 4 clinicians and dementia care services to boost multidisciplinary collaboration, to harmonise
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11 5 diagnostic standards and develop clear pathways for post-diagnostic care and support.
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13 6 Given this new national initiative the current survey is important to assess baseline Memory
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15 7 Clinic practices and evaluated the resources available to deliver their services. Since the
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17 8 publication of the last national Memory Clinics survey in 2009⁸, best practice guidelines for
18
19 9 the state-funded Cognitive, Dementia and Memory Services (CDAMS) in Victoria⁴ as well as
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21 10 clinical practice guidelines and principles of care for people with dementia²⁴ have been
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23 11 published and potentially changed clinical practice compared to 10 years ago. Hence, an
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25 12 updated national Memory Clinics survey is warranted.
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28 13 The main aim of this survey was to obtain current information about the variety of
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30 14 assessment procedures used in Australian Memory Clinics and to determine the most
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32 15 commonly used cognitive and neuropsychological test instruments. These results will be
33
34 16 important to establish harmonised assessment protocols that are feasible for clinicians from
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36 17 different states and Memory Clinic settings. Moreover, the survey obtained some basic
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38 18 benchmark information to present a comparative update on some of the organisational data
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40 19 reported in the previous survey⁸ (e.g., staffing, funding) in a larger sample of Memory Clinics
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42 20 and to evaluate differences between public and private as well as metropolitan and regional
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44 21 clinics where it is appropriate.
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49 23 **METHODS**

50 24 **Sample and Setting**

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52 25 Due to the lack of a consensus definition of Memory Clinics, potential participants for this
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54 26 survey included any clinician or coordinator who self-identified as working for a specialised
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56 27 diagnostic assessment service for dementia. This was done to avoid missing out on
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58 28 responses of dedicated cognitive assessment services that do not identify as a Memory
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Clinic and other specialised clinicians. Using this broad definition of a Memory Clinic we will, in the following, refer to the services that responded to our survey as “Memory Clinic” or just “clinic”. We used various recruitment strategies including the use of already established contacts (e.g., official contact list of state-funded Cognitive Dementia and Memory Services [CDAMS] in Victoria) and recommendations from professional networks. Hence, this group of potential participants was previously known to the ADNeT research team. We sent a single invitation to participate in the survey but no reminder email. We also advertised our study in professional associations (esp., Australian and New Zealand Society for Geriatric Medicine [ANZSGM] and the Royal Australian and New Zealand College of Psychiatrists [RANZCP]) to increase our outreach and disseminate the survey to colleagues that were unknown to the immediate ADNeT-Memory Clinics research Team. Due to our broad distribution strategies it is difficult to estimate how many potential participants received the survey link. All respondents were able to remain anonymous or to provide voluntary identifiable information if they wished to be contacted again for future projects and information about ADNeT.

Survey and Procedure

A Clinical Assessment Harmonisation survey was developed in Qualtrics²⁵. All potential respondents were required to read the Participant Information Sheet and Consent form and provide consent to their participation before they were able to start the survey (HREC No: HC190221). Respondents were not obliged to provide any personal information (e.g., name, contact address) but had the opportunity to do so, if they wished to be added to our ADNeT contact list. Participants who did not wish to be contacted again, were also able to express that at the end of the survey.

The survey comprised three main parts. The first part was directed at clinical coordinators and clinicians involved in the operational management of a clinic. Here, the respondents were asked to give details about the specific organisational structure of their clinic: staffing (e.g., average EFT per profession and clinic), clinical activity (e.g., frequency

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2
3 1 of clinical assessments, waiting times, regulations for follow-ups), characteristics of the
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5 2 clinical population (e.g., proportion of indigenous and non-English speaking population) and
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7 3 funding support. Any respondent who was not involved in administrative tasks was able to
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9 4 skip this section of the survey.

11 5 The second part of the survey contained questions about the clinical and cognitive
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13 6 assessment tools used by the individual clinicians. Here, we investigated seven sub-
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15 7 categories: 1) cognitive screening tools, 2) self-reported scales, 3) informant-rated scales, 4)
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17 8 clinician-rated scales, 5) measures of subjective cognitive concern, 6) computerised
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19 9 cognitive tests, 7) standardised pen-and-paper neuropsychological measures. Within the
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21 10 'neuropsychological measures' category, we further distinguished between standardised
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23 11 neuropsychological batteries and individual tests in nine cognitive domains (premorbid
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25 12 ability, processing speed, attention and working memory, memory, language, visuo-spatial
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27 13 abilities, executive functions, social cognition and effort). For each category, the survey listed
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29 14 commonly used test instruments determined by experienced neuropsychologists (NK, SN).
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31 15 Respondents rated on a 5-point Likert scale how often they used each test instrument in
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33 16 their everyday clinical practice. Under 'other' the respondents were able to add up to five test
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35 17 additional instruments they currently use to ensure that we captured all instruments that
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37 18 were not originally considered. Options to skip this component of the survey were available
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39 19 to those respondents who did not conduct clinical assessments (e.g., dedicated coordinators
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41 20 of Memory Clinics).

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43 21 The third part of the survey asked if respondents offered any form of cognitive
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45 22 intervention to their clients. If the response was no, respondents were asked to provide
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47 23 reasons; if yes, they were asked to provide further details about the methods. We provided a
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49 24 list of possible intervention types and asked them to select all that apply. The options
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51 25 included: computerised testing; memory strategy training; psychoeducation; independent
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53 26 completion (exercise material); input to rehabilitation with other clinicians and involvement of
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55 27 family, friends and caregivers. Furthermore, we asked in which frequency this intervention
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was provided. A copy of the full survey can be acquired from the corresponding author upon request.

Patient and Public Involvement

The design of this survey was based on previous national and international memory clinic surveys^{6,8,9} to ensure a comparability of results. We further received input from expert clinicians and researchers within the Australian Dementia Network Team. Questions were added, deleted and adjusted according to their feedback. As the survey was specific to current clinical practices with a particular focus on cognitive and neuropsychological assessment tools, the involvement of people living with dementia and/or cognitive decline in the design of this specific survey was not warranted. The dissemination of the survey was supported by the national professional associations “The Australia and New Zealand Society for Geriatric Medicine (ANZSGM)” and “The Royal Australian and New Zealand College of Psychiatrists (RANZCP)” as well as Dementia Australia to increase our outreach and involve as many members of the target population as possible. Some of the participants of this survey were informed about the results of this survey during ADNeT-Memory Clinic meetings and/or national conferences. A link to the published results paper will be provided to all respondents that provided contact details in their survey response.

Data analysis

All survey responses were recorded and saved in Qualtrics and the data later exported into Excel. One member of the ADNeT-MC team (IM) de-identified the data and assigned a unique study ID to each response. Identifiable information (e.g., profession, clinic location) was coded and comments that contained identifiable information were separated from the response sheet and securely saved. Only anonymised data were used for the analyses presented in this paper. All statistical analyses were carried out with IBM SPSS Statistics, version 25. We conducted descriptive analyses to provide an overview of the variety of clinical settings and assessment tools that were reported by clinicians and clinical

1 coordinators across Australia. To compare categorical variables of different groups we
2 performed a Chi-Square test. When the skewness of continuous data was within the
3 recommended range of – 1 and 1, we performed parametric tests (e.g., t-test), when the
4 data was skewed, we performed non-parametric tests (e.g., Mann-Whitney U). Spearman
5 correlations were used to investigate associations between skewed continuous data.

7 **RESULTS**

8 **Respondents**

9 Between May and August 2019, we obtained 318 responses. We excluded responses from
10 163 who did not complete the survey (e.g., some data provided but did not press the
11 “complete button” at the end) as well as data from 5 respondents who accidentally
12 completed the survey multiple times. Consequently, 150 individual responses, with
13 representation from each of the Australian states and territories, were included. By matching
14 addresses, postcodes and other identifiable information the respondents voluntarily provided
15 (e.g., name of clinic), we were able to identify responses from 90 different Memory Clinic
16 services.

18 [FIGURE 1 – near here]

20 The majority of responses were from Victoria and New South Wales, reflecting a
21 large number of Memory Clinics located in the two most populated states (see Figure 1).
22 Unsurprisingly, the highest density of Memory Clinics was found in metropolitan areas
23 (68.4% of respondents). Most of the respondents were employed in public clinics (82.8%),
24 compared to 17.2% employed in private clinics.

25 While most respondents identified as geriatricians (42.7%) and neuropsychologists
26 (23.3%), we also received responses from occupational therapists (7.4%), neurologists
27 (6.7%), psychiatrists (5.3%), registered nurses (3.3%), speech pathologists (2.0%), clinical

psychologists (1.3%), social workers (1.3%), pharmacists (0.6%), trainee doctors (3.3%) and clinical coordinators who are not involved in any clinical work (2.7%).

Organisational Aspects

Overall, 38 respondents from 38 different Memory Clinics reported that they fulfil the duties of a clinical coordinator or manager at their clinic site. Eighteen of these services voluntarily identified as a Memory Clinic or CDAMS while the remaining services identified as geriatric services (mostly private), cognitive and memory assessment services or did not provide clear information. Responses from all Australian states and territories were represented in this sample.

Table 1 summarises the main results from the survey regarding the clinics' general organisational aspects. The table shows the overall responses as well as the results split for metropolitan versus regional, and public versus private clinics.

Table 1: Result summary – general organisational structures

	all	metropolitan	regional	public	private
Respondents (n)	38	24	14	26	12
Clinic Type					
public	26	17	9	/	/
private	12	7	5	/	/
Service area					
1 community	14 (37%)	11 (46%)	3 (21%)	10 (38%)	4 (33%)
> 1 community	24 (63%)	13 (54%)	11 (79%)	16 (62%)	8 (67%)
Frequency (n=38)					
< 1x week	4 (10%)	1 (4%)	3 (21%)	3 (12%)	1 (8%)
1x week	6 (16%)	5 (21%)	1 (7%)	6 (23%)	0
>1x week	28 (74%)	18 (75%)	10 (71%)	17 (45%)	11 (92%)
Waiting Times (n=37)	9.9 weeks (± 9.7)	10.4 weeks (± 10.3)	9 weeks (± 8.6)	11.9 weeks* (± 10.8)	5.3 weeks* (± 3.1)
Waiting Times Range	3 days – 12 months	3 days – 12 months	1 week – 9 months	2 weeks – 12 months	1 week – 10 weeks
Average EFT per Clinic (n=34)	2.4 (± 3.2)	3.1 (± 4.0)	1.4 (± 1.2)	2.7 (± 3.5)	1.6 (± 2.4)
EFT Range	0.1 EFT – 14.0 EFT	0.1 EFT – 14.0 EFT	0.2 EFT – 3.6 EFT	0.1 EFT – 14.0 EFT	0.2 EFT – 8.0 EFT
Average number new patients per each clinic day (n=38)	3.3 (± 2.4)	3.2 (± 2.6)	3.5 (± 2.1)	3.1 (± 2.1)	3.7 (± 3.0)
Number of new patients per each clinic day - Range	1 - 11	1 - 11	1 - 8	1 - 10	1 - 11

Follow-ups conducted – yes/no (n=38)	37 (97%)	24 (100%)	13 (93%)	25 (96%)	12 (100%)
Average number of follow-up patients per each clinic day (n=37)	4.2 (± 3.3)	4.4 (± 2.9)	3.7 (± 4.1)	4.5 (± 3.8)	3.5 (± 2.0)
Number of follow-up patients per each clinic day - Range	1 - 16	1 - 12	1 - 16	1 - 16	1 - 8
Proportion of patients from an indigenous background (n=25, who assess people with an indigenous background)					
≤5%	22 (88%)	12 (92%)	10 (83%)	16 (84%)	6 (100%)
> 5% - 10%	2 (8%)	1 (8%)	1 (8%)	2 (11%)	0
>10%	1 (4%)	0 (0%)	1 (8%)	1 (5%)	0
Proportions of patients from a CALD background (n=38)					
≤10%	24 (63%)	11 (46%)	13 (93%)	14 (54%)	10 (84%)
> 10% - 20%	3 (8%)	3 (13%)	1 (7%)	3 (12%)	1 (8%)
>20% - 30%	2 (5%)	2 (8%)	0 (0%)	2 (8%)	0
>30% - 40%	1 (3%)	1 (4%)	0 (0%)	1 (4%)	0
>40% - 50%	5 (13%)	5 (21%)	0 (0%)	4 (15%)	1 (8%)
>50%	2 (5%)	2 (8%)	0 (0%)	2 (8%)	0
Main source of referrals					
GP	35 (92%)	22 (92%)	13 (92%)	24 (92%)	11 (92%)
Other (Neurologist, Geriatrician)	3 (8%)	2 (8%)	1 (8%)	2 (8%)	1 (8%)
Main source of funding					
State-health funds	19 (50%)	12 (50%)	7 (50%)	19 (73%)^	0
Patient charges/ Medicare	9 (23%)	7 (29%)	2 (14%)	1 (4%)	8 (67%)
State funds +patient charges	3 (8%)	3 (13%)	0	3 (12%)	0
commonwealth	1 (3%)	0	1 (7%)	1 (4%)	0
State-health funding + other	1 (3%)	1 (4%)	0	1 (4%)	0
Patient charges + other	5 (13%)	1 (4%)	4 (29%)	1 (4%)	4 (33%)

T-test and Chi-Square were used to compare metropolitan vs regional and public vs private services for each variable. Only significant differences are highlighted in the table.

* significant public vs private Memory Clinics (Mann-Whitney-U, p=.031)

^ significant difference according to Chi-squared test comparison (Chi-square; p<.001)

Community = defined catchment area; Frequency = indicates how often a clinic is operating; CALD = culturally and linguistically diverse; GP = general practitioner; Medicare = Australian public health fund

We observed no statistically significant differences between metropolitan and regional clinics for any of the reported organisational aspects we surveyed (see Table 1). A comparison of public and private Memory Clinics, unsurprisingly, revealed a significant difference in the clinics' funding sources (Chi-square= 30.18, $p<.001$). We would like to note that each clinic was always assigned to both features, 'metropolitan/regional' and 'private/public'. Despite our proportions were relatively balanced (e.g., 29% of metropolitan clinics and 36% of

1 regional were private), this overlap in the data may have influenced our analysis. Given the
2 overall small sample size, it can therefore be assumed that only strong associations will
3 have reached significance.

4 Seventy-three percent of public clinics report some support from state health funds
5 while the private services mainly rely on patient charges and rebates from the Australian
6 public health insurance Medicare. Funding support is also commonly supplemented by
7 research funds, commonwealth funding, support from the department of veteran affairs,
8 donated time of their staff members or rural workforce support.

9 In terms of waiting times, overall, the average reported waiting time for an initial
10 assessment was 9.9 weeks (SD= 9.7; median = 7 weeks). However, substantial variability
11 was observed, ranging from less than one week to about 12 months waiting time. Some
12 clinics also reported that they follow a triaging procedure to reduce the waiting times for
13 urgent cases. We observed a difference in the waiting times reported by private (mean: 5.3,
14 SD:3.1) and public clinics (mean: 11.9, SD: 10.8; $p_{\text{Mann-Whitney-U}}=.031$).

15 Most clinics reported that they run services at least once per week or more often (see
16 Table 1). Very few clinics, mostly in regional areas, ran less frequently. Thirty-four
17 respondents (89%) reported on their clinic's staffing. The mean allocation per clinic was 2.4
18 (SD= 3.2) effective-full time (EFT) positions (range: 0.1 EFT to 14.0 EFT). No significant
19 correlation was found between the clinics' EFT and waiting time (Spearman's $r=.288$,
20 $p=.104$).

21 Few differences were observed in terms of the representation of the various
22 professions in public versus private, and metropolitan versus regional Memory Clinics
23 (Appendix A). Specifically, private clinics reported lower EFTs for a dedicated clinical
24 coordinator (mean EFT: 0.01; $p_{\text{Mann-Whitney-U}}=.020$) than public clinics (mean EFT: 0.32) and
25 metropolitan Memory Clinics reported a higher average EFT for trainee doctors (mean EFT:
26 0.35) compared to regional clinics (mean EFT: 0.01; $p_{\text{Mann-Whitney-U}}=.038$).

27 Almost all clinics (97%) reported that follow-up assessments/ reviews form part of
28 their standard services. These follow-ups are mostly conducted on an ad hoc basis, and the

1 frequency may differ from case to case (e.g., after 6 months, after 12 months). In a number
2 of clinics, follow-ups were predominantly scheduled for people initially diagnosed with mild
3 cognitive impairment (MCI). On a regular clinic day an average of 3.3 (SD= 2.4) new patients
4 and 4.2 (SD= 3.3) follow-up patients are assessed (see Table 1). All clinics reported seeing
5 patients from cultural and linguistically diverse (CALD) backgrounds. In some cases, CALD
6 patients were reported to represent up to 50% of the clinic's case load. While a wide variety
7 of languages were reported (e.g., Cantonese, Arabic, Spanish, Maltese) for CALD clients,
8 the most commonly represented languages were Italian, Greek and Mandarin. Twenty-five
9 clinics (66%) reported that they regularly assessed patients with an indigenous background
10 but only three clinics reported this proportion to be larger than 5%.

11 General Practitioners were the most common referral source for 35 (92%) Memory
12 Clinics. The remaining three clinics reported that most of their referrals come from a
13 Neurologist or a Geriatrician.

14
15 **Clinical Assessments**

16 One of the main aims of this survey was to identify the most commonly used clinical
17 assessment tools across Australian Memory Clinic clinicians. The 141 clinicians who
18 responded to this part of the survey, represented 14 different professions, with the majority
19 being geriatricians (42%) or neuropsychologists (24%). The types of assessments carried
20 out by different professionals are presented in Figure 2. Using a Chi-Square test, a
21 significant difference was only observed for neuropsychological testing (chi-square= 75.06,
22 $p<.001$). Post-hoc testing using the Fisher-exact test showed that neuropsychological tests
23 were most commonly conducted by trained Neuropsychologists ($z=7.47$, $p<.001$). However,
24 clinicians from other professions (e.g., Neurologists, Psychiatrists, Speech Pathologist) also
25 reported the use of neuropsychological tests (see Figure 2).

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[FIGURE 2 – near here]

Overall, the respondents reported the use of more than 100 different test instruments across all assessment types and cognitive domains. Table 2 summarises the most commonly used test instruments across different assessment types in a routine dementia assessment, while Table 3 summarises the top three neuropsychological test instruments reported for each cognitive domain included in our survey. Both tables display the percentage of respondents at each frequency of test use on a 5-point Likert Scale (1=always; 5=rarely/never) and the mean Likert Scale ratings (smaller mean represents more frequent test use). The tables also display the total number of respondents who reported using of any of the listed tools within a specific assessment type or within a cognitive domain.

One hundred and twenty-six respondents (90%) reported the use of self-reports. Within this category, most clinicians (122, 97%) reported the use of a variety of depression and anxiety scales (e.g., Geriatric Depression Scale, Depression Anxiety Stress Scales; see Table 2), while only 43 of the 126 respondents (34%) reported the use of sleep scales (e.g., Epworth Sleepiness Scale, Pittsburgh Sleep Quality Index). Nevertheless, those 43 respondents reported a relatively frequent use of the Epworth Sleepiness Scale (see Table 2), so that it was identified as one of the top 3 self-reported measures. Compared to the self-reported measures, clinician rated measures (30%) or formal assessments of subjective cognitive concerns (14%) were only reported by a relatively low proportion of respondents (see Table 2/ Figure 3). Respondents reported that they assess domains like *language*, *executive function* or *processing speed* 'most of the time' during their routine assessment. In contrast, even the most popular test instruments assessing domains like *social cognition* and *effort* were on average only used 'sometimes' (see Table 3).

[FIGURE 3 - near here]

Table 2: Three most commonly used general mood, sleep, self and informant rated and clinical/ cognitive assessment tools

		Percentage of respondents					
		always (1)	most of the time (2)	about half the time (3)	sometimes (4)	rarely/ never (5)	mean rating (SD)
Self-report (n=126)							
1	GDS -15	15.9	32.5	15.1	17.5	19.0	2.9 (1.4)
2	DASS-21	6.3	11.1	7.9	16.7	57.9	4.1 (1.3)
3	Epworth Sleepiness Scale	0.8	3.2	1.6	32.0	62.4	4.5 (0.8)
Informant-rated measures (=77)							
1	IQCODE	20.8	13.0	5.2	24.7	36.4	3.4 (1.6)
2	CBI-R	5.2	5.2	2.6	16.9	70.1	4.4 (1.1)
3	Zarit Burden	9.1	5.2	0	9.1	76.6	4.4 (1.3)
Clinician-rated measures (n=42)							
1	Clinical Dementia Rating	7.3	22.0	2.4	29.3	39.0	3.7 (1.4)
2	Neuropsychiatric Inventory	11.9	14.3	11.9	19.0	42.9	3.7 (1.5)
3	Hamilton Depression Rating	2.4	2.4	0	9.8	85.4	4.7 (0.8)
Subjective cognitive concerns (n=19)							
1	IQCODE	31.6	5.3	5.3	42.1	15.38	3.0 (1.6)
2	ECog (Self)	0	5.3	0	5.3	89.5	4.8 (0.7)
3	ECog (informant)	0	5.3	0	0	94.7	4.8 (0.7)
Cognitive Screening (n=141)							
1	Clock drawing	39.7	31.2	8.5	9.9	10.6	2.2 (1.3)
2	MMSE	34.0	36.9	6.4	8.5	14.2	2.3 (1.4)
3	MoCA	7.8	18.4	13.5	34.0	26.2	3.5 (1.3)

GDS= Geriatric Depression Scale; DASS= Depression Anxiety Stress Scale; IQCOE= Informant Questionnaire on Cognitive Decline in the Elderly; CBI-R= Cambridge behavioural Inventory-revised; ECog= Measurement of Everyday Cognition; MMSE= Mini-mental State Examination; MoCA= Montreal Cognitive Assessment

Table 3: Three most commonly used neuropsychological test instruments for each cognitive domain

		Percentage of respondents					
		always (1)	most of the time (2)	about half the time (3)	sometimes (4)	rarely/ never (5)	mean rating (SD)
Premorbid Function (n=44)							
1	TOPF	15.9	34.1	6.8	9.1	34.1	3.1 (1.6)
2	WAIS-IV Vocabulary	4.5	15.9	6.8	18.2	54.2	4.0 (1.4)
3	NART	6.8	2.3	6.8	11.4	72.7	4.4 (1.2)
Processing Speed (n=51)							
1	Trail Making A	35.3	39.2	7.8	15.7	2.0	2.1 (1.1)
2	WAIS-IV Coding	17.6	29.4	5.9	19.6	27.5	3.1 (1.5)
3	WAIS-IV Symbol Search	13.7	19.6	9.8	21.6	35.3	3.1 (1.5)
Attention/ Working Memory (n=48)							
1	Digit Span (2 subtests)	33.3	16.7	2.1	12.5	35.4	3.0 (1.8)
2	Digit Span (3 subtests)	14.6	25.0	4.2	20.8	35.4	3.4 (1.5)
3	TEA	0	2.1	6.3	14.6	77.1	4.5 (1.1)
Memory (n=47)							
1	WMS-IV Logical Memory	29.8	23.4	12.8	6.4	27.7	2.8 (1.6)
2	Rey Complex Figure (30min delay)	21.3	21.3	8.5	17.0	31.9	3.2 (1.6)
3	WMS-IV Visual Reproduction	17.0	21.3	12.8	17.01	31.9	3.3 (1.5)
Language (n=54)							
1	Category Fluency (Animals)	46.3	33.3	7.4	7.4	5.6	1.9 (1.2)
2	COWAT (FAS)	42.6	20.4	7.4	7.4	22.2	2.5 (1.6)
3	Boston Naming (60 items)	16.7	27.8	13.0	20.4	22.2	3.0 (1.4)
Visuo-spatial abilities (n=57)							
1	Clock drawing	40.4	33.3	5.3	12.3	8.8	2.2 (1.3)

2	Rey Complex Figure (copy)	33.3	33.3	3.5	8.8	21.1	2.5 (1.5)
3	Cube copying/drawing	26.3	31.6	5.3	21.1	15.8	2.7 (1.5)
Executive function (n=54)							
1	Trail Making B	29.6	44.4	7.4	13.0	5.6	2.2 (1.2)
2	WAIS-IV Similarities	29.6	24.1	7.4	9.3	29.6	2.9 (1.7)
3	Stroop (D-KEFS)	7.4	11.1	3.7	16.7	61.1	4.1 (1.3)
Social Cognition (n=8)							
1	Reading the Mind in the Eyes	0	0	12.5	62.5	25.0	4.1 (0.6)
2	The Awareness of Social Interference Test	0	0	12.5	37.5	50.0	4.4 (0.7)
3	Facial Expression of Emotion/ Ekman Faces	0	0	0	12.5	87.5	4.9 (0.4)
Effort (n=30)							
1	WAIS-IV embedded measure - reliable digit span	0	16.7	6.7	36.7	40.0	4.0 (1.1)
2	WAIS-IV embedded measure logical Memory - delayed recognition	0	10.0	13.3	33.3	43.3	4.1 (1.0)
3	Advanced Clinical Solutions – word choice	0	10.0	13.3	30.0	46.7	4.1 (1.0)

TOPF= Test of Premorbid Function; WAIS= Wechsler Adult Intelligence Scale; NART= national Adult Reading Test; TEA= Test of Everyday Attention; WMS= Wechsler Memory Scale; COWAT= Controlled Oral Word Association Test; D-KEFS= Delis-Kaplan Executive Function System

1 A comparison of the test use of clinicians from metropolitan and regional Memory
2 Clinics showed that self-reported measures were more commonly used in metropolitan
3 clinics (see full table in Appendix B: chi-square= 4.59, $p=.032$). Moreover, we observed that
4 the “NART” (National Adult Reading Test), was more frequently used by clinicians from
5 metropolitan than regional areas ($t= -2.21$, $p=.032$) and the test “WAIS-IV embedded
6 measure: reliable digit span” was more frequently reported by clinicians from public than
7 private clinics ($t= -2.80$, $p=.010$, see full table in Appendix B).

8 Only 10 respondents (7%) reported the use of computerised assessment tools, and
9 these were used infrequently. The “Q-Interactive” test was the most commonly used (mean
10 rating= 3.9, SD=1.7) followed by the computerised “Wisconsin Card Sorting Test” (mean
11 rating= 4.3, SD=1.1).

12 13 **Cognitive Interventions**

14 Only 46 (31%) from 34 different identifiable Memory Clinics (38%) reported that they offer
15 any form of cognitive intervention. No differences were found between respondents working
16 for public or private (chi-square= 0.003, $p =.956$) and metropolitan or regional Memory
17 Clinics (chi-square= 0.07, $p =.791$). Not all clinicians that work for the same Memory Clinic,
18 reported that they are able to provide cognitive interventions. Hence, we concentrated our
19 analysis on the individual response level and did not provide further clinic-based analysis.

20 Most respondents who offer cognitive intervention reported the use of a combination
21 of different cognitive interventions, with a mix of *psychoeducation*, *involvement of family*
22 *members* and *input to rehabilitation* being the most commonly reported combination (33%).
23 Moreover, 89% of clinicians (41 out 46) reported that they conduct an individualised rather
24 than a standardised approach. The overall data further suggests that there is a significant
25 difference in the provision of *memory strategy training* by profession (chi-square= 16.87, p
26 $=.018$). However, pairwise comparisons of all professions post-hoc (using Bonferroni
27 correction) did not identify which specific professions differ from each other. Interestingly,
28 more than half (52%) of the respondents who offer interventions are only able to provide one

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3 1 session. Only 7 out of the 46 respondents (15.2%) reported that they can provide more than
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5 2 5 sessions of cognitive intervention to their patients. Respondents who do not provide
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7 3 cognitive intervention reported a lack of resources, often accompanied by a lack of
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9 4 appropriate training as the most common reason for not offering cognitive interventions.
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14 6 **DISCUSSION**

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16 7 This survey provides an updated overview of the current clinical situation of Memory Clinics
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18 8 across Australia. It further identified the most commonly used assessment tools, which
19
20 9 marks an important first step in ADNeT’s effort to harmonise and improve standards of
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22 10 diagnostic procedures across Australian Memory Clinics.
23

24 11 Our survey included a substantially larger number of respondents than previous
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26 12 Memory Clinic surveys in Australia⁸ or internationally^{6,11}. We broadened our target group to
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28 13 all clinicians involved in the specialised assessment of dementia and cognitive decline and
29
30 14 identified responses from 90 different Memory Clinic services. This broad recruitment
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32 15 approach provided a more comprehensive overview of current clinical practices in the
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34 16 specialised assessment of people with dementia and cognitive decline across Australia.
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37 17 The survey confirmed the large heterogeneity in the organisational aspects (e.g.,
38
39 18 staffing, number of patients, waiting times) of Memory Clinic services across Australia,
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41 19 previously reported in the national survey from 2009⁸. Similar variability in Memory Clinic
42
43 20 services has been observed in the Netherlands, Ireland, the UK, Israel and New Zealand
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45 21 and greater harmonisation has been internationally endorsed^{6,9,11,13,15}.
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47 22 Previous surveys^{6,8} identified relatively long waiting times for an initial assessment
48
49 23 and understaffing as the main issues that may compromise a timely and accurate dementia
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51 24 diagnosis in a Memory Clinic setting. Woodward and Woodward⁸ reported an average of 10
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53 25 weeks waiting time in their first Australian survey. Our results suggest that the waiting time
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55 26 remained largely unchanged over the past 10 years (average waiting time = 9.9 weeks).
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57 27 However, waiting times also greatly varied between services. The services with the shortest
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59 28 and the longest waiting time were both operating in metropolitan areas at relatively high
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frequency (4-5x a week). The clinic with the shortest waiting time was a private service and with one of the largest staff numbers in our survey. However, over all respondents, no meaningful relationship between staffing and waiting times was observed. The UK National Health Service's *Implementation guide and resource pack for dementia care*²⁶ recommends a maximum waiting time of six weeks to diagnosis as the minimum standard for Memory Clinics. Our survey showed that only 43% of cognitive assessment services would be able to offer an initial assessment within 6 weeks, with the majority falling short of this, most likely due to understaffing. Time to initial diagnosis was not assessed in our survey and should be added to future Memory Clinic surveys.

Indeed, staffing varied largely across Memory Clinics. Our survey results suggest that the average EFT increased from 1.7 EFT reported in 2009⁸ to 2.4 EFT. In an international comparison, however, this staffing allocation is still comparatively low (e.g., Ireland⁶: 3.4 EFT). A clinical coordinator position to handle general administration issues was included in only 44% of services. It can be assumed that clinicians in the remaining services must fulfil administrative duties in parallel to their clinical work. This is likely to affect the clinicians' capacity to see more clients for assessment and could potentially add to the delay in establishing a dementia diagnosis.

The composition of Memory Clinics teams varied widely between clinics, a finding also observed internationally^{6,9,11}. The majority of clinics reported the employment of geriatricians (76%). A similar percentage of geriatrician involvement was reported by the latest Memory Clinic survey in the Netherlands⁹. With 73%, geriatricians were one of the professions frequently involved in Memory Clinic assessments. Moreover, Gruters et al.⁹ report an even stronger involvement of Neurologists (81%) and Psychologists (94%). The distribution of professions that responded to our survey differed substantially (Psychologists: 24.6%; Neurologists: 6.7%). Higher involvement rates for Neurologists and Psychologists were also reported in Memory Clinic surveys in the British Isles¹¹ and Israel¹³, while a distribution similar to the one we observed was reported for Memory Clinics in Ireland⁶ and New Zealand¹⁵. The distribution of professions reported in this study matches previous

1 results of Woodward and Woodward⁸, who also reported a strong involvement of
2 geriatricians and seems therefore representative for the Australian Memory Clinic landscape.
3 However, our results may have been influenced by our participation call in the regular
4 newsletter of Australia's largest geriatric society (ANZSGM), while we were unable to use a
5 similar dissemination strategy through other professional associations (e.g., Australia and
6 New Zealand Association of Neurologists). Importantly, our survey showed that only a small
7 number of clinics include allied health professionals like occupational therapists (24%) or
8 speech pathologists (12%). A similar observation was made in the Irish Memory Clinics
9 survey⁶ and Israel¹³. We expect this would inevitably restrict post-diagnostic care options
10 provided by these services and should be further assessed.

11 To gain a very broad overview of the post-diagnostic support the Memory Clinics are
12 able to provide themselves, all respondents were asked if their clinic offered any form of
13 cognitive intervention. Our survey showed that less than a third of respondents (30%)
14 reported that they offer cognitive interventions with the majority only offering a single
15 session. In comparison, a recent survey conducted across Memory Services in the
16 Netherlands showed that 72% offer psychosocial interventions. A more detailed evaluation
17 study would be required identify which type cognitive intervention would be most effective
18 and should be recommended. The survey results presented in this paper cannot contribute
19 to this discussion. Nevertheless, we would like to argue that, due to its high specialisation,
20 Memory Clinics would be generally well equipped for the provision of high-quality and
21 evidence-based cognitive interventions. As outlined in the current Australian 'Clinical
22 Practice Guidelines and Principles of Care for People with Dementia'²⁴, Memory Clinics are
23 also encouraged to focus on the diagnostic assessment. Consequently, most of the
24 Australian clinics reported a lack of funding or adequate training to offer more complex
25 diagnostic support. This may be one possible reason why post-diagnostic support provided
26 by Memory Clinics has not been shown to be more effective than general practitioner
27 services²⁷. Importantly, we did observe that almost all Memory Clinics (97%) are able to offer
28 a follow-up appointment. Unfortunately, we did not obtain more detailed information about

the nature of these appointments. While post-diagnostic support (e.g., medication review) might be provided during such a follow-up session, they may also serve a mainly diagnostic purpose (e.g., performance changes, transition between dementia syndromes, for MCI: establishment of a dementia diagnosis). If and how Memory Clinics could be involved more actively in post-diagnostic support is part of a larger discussion about the goals and purpose of Memory Clinics^{6,28}. In Australia, ADNeT as well as other projects²⁹ have been commissioned to address this issue in due course.

There appears to be international agreement on the main components of a comprehensive assessment of dementia and cognitive decline including family and medical history, blood tests and structural neuroimaging, yet notably cognitive assessment protocols remain variable^{6,9,11}. Our survey results made a similar observation. We identified more than 100 cognitive test instruments that clinicians use at least 'sometimes' in their assessments. Some agreement was observed in the use of cognitive screens, with the MMSE and clock drawing test being the most commonly used test tools^{9,13,15}.

Based on our survey results, we identified the three most commonly used tests across the major cognitive domains (e.g., attention, language, memory) and types (e.g., self-report, informant-rated, see Table 2 and 3). This forms the basis for the development of a harmonised neuropsychological test protocol. Such a protocol would provide a minimum data set that would be uniform across Memory Clinics, thereby enabling comparison of practices and outcomes across clinics, the pooling of patient data for joint examination, and the ready recruitment nationally for clinical trials. A core minimum dataset does not constrain any clinic if there is a wish or need to expand the assessment to meet client and/or service needs.

LIMITATIONS

We aimed to reach as many Australian clinicians who conduct specialised dementia assessments in Australia as possible, to gain a representative overview of current clinical practice across the country. Hence, we used a broad Memory Clinic definition and allowed

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2
3 1 for anonymous responses which have been previously reported to be beneficial for large
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5 2 response rates³⁰. Due to the anonymity of respondents we were unable to follow-up with
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7 3 individual respondents to clarify their responses and to ensure the best possible data quality.
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9 4 All respondents were asked to answer the questions to the best of their knowledge, and we
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11 5 have no reason to believe that the quality of our data was greatly impacted by this
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13 6 procedure. Nevertheless, it is possible that individual respondents interpreted some
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15 7 questions differently which may have increased the variability in our data. To balance this
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17 8 potential impact, we discussed outliers in the data and statistically controlled for outliers
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19 9 (e.g., run statistical analyses with and without outlier data in the sample) to ensure that only
20
21 10 robust results are reported.

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23
24 11 This survey also aimed to capture how many Australian Memory Clinic clinicians can
25
26 12 offer some form of cognitive intervention. It is important to acknowledge that some of the
27
28 13 interventions that were reported, can be included in a standard assessment sessions (e.g.,
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30 14 involvement of family members), while others require a separate appointment (e.g., memory
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32 15 strategy training) that would require additional staff and funding. Similarly, our study showed
33
34 16 that a large percentage of respondents is able to offer a follow-up session to their clients.
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36 17 However, these may be mainly diagnostic to track the client's performance or used to
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38 18 provide post-diagnostic support. A more detailed analysis of the post-diagnostic support that
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40 19 is offered and the resources required to provide it was unfortunately outside the scope of this
41
42 20 survey and should be considered for future scoping surveys. Nevertheless, our results show
43
44 21 that the provision of non-pharmacological cognitive interventions is not part of the standard
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46 22 services Memory Clinic clinicians are able to provide. Ways to include Memory Clinics into
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48 23 post-diagnostic care should be explored.

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54 25 **CONCLUSION**

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56 26 This national survey of Memory Clinics in Australia presents a picture of considerable
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58 27 heterogeneity in assessment procedures, while identifying some common elements that can
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60 28 be the basis of future harmonisation of practices. While the Memory Clinics have expanded

1 since the previous survey a decade earlier, the service largely remains a diagnostic one with
2 only few clinicians who are able to offer cognitive interventions. With the rapid ageing of the
3 population, the demand for Memory Clinics is growing. This survey is the first step toward an
4 effort to develop standards for Memory Clinic assessments and post-diagnostic care such
5 that each individual with cognitive deficits can receive prompt state-of-the-art assessment
6 and care.

7 All ADNeT initiatives work closely together to achieve these improvements. The
8 ADNeT clinical quality registry will monitor the ongoing improvements of Memory Clinics
9 procedures through regular feedback and benchmarked outcome measures. Harmonised
10 diagnostic procedures that map onto common research outcomes across Memory Clinics
11 also facilitates translation of research findings into practice and the clients' participation in
12 research. Memory Clinics will be an important entry point into clinical trials as new drugs and
13 therapies are developed with national support through ADNeT-Trials.

14 To further the harmonisation of Memory Clinics procedures, we will employ Delphi-
15 methods, including expert opinions from of clinicians, researchers, people living with
16 dementia and carers from all Australian states and territories to develop national best-
17 practice standards. Furthermore, the survey results confirm the need for better resourcing of
18 Memory Clinics and cognitive assessment services to further support early diagnosis of
19 dementia and cognitive decline by increasing staff levels to match international standards.
20 With projections of exponentially increasing numbers of people who will develop dementia in
21 the next decades, it is essential that Memory Services are well-equipped in terms of funding
22 and best practices to provide early diagnosis and evidence-based post-diagnostic care.

23
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1
2
3 1 their networks. We also want to thank all members of the Australian Dementia Network for
4
5 2 their support and ongoing collaboration (see Appendix C for a full collaborators list).
6
7 3
8
9 4 **Contributors:** I.M. designed study method and data collection tools, organised and
10
11 5 facilitated data collection, cleaned, analysed and interpreted the data and drafted and
12
13 6 revised the paper. N.A.K. designed the study method and data collection tool, interpreted the
14
15 7 data and revised the manuscript for intellectual content. MY.O. made major contribution to
16
17 8 the design of the data collection and reviewed the manuscript. J.D.C. made major
18
19 9 contributions to the analyses and interpretation of the data and revised the manuscript for
20
21 10 intellectual content. S.L.N. and P.S.S. designed and conceptualised the study and its
22
23 11 methods, interpreted the data, and revised the manuscript for intellectual content. All authors
24
25 12 read and approved the final manuscript.
26
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28
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30
31 15 **Competing interests:** Non declared
32
33 16 **Patient and public involvement:** We included expert Memory Clinic clinicians in the design
34
35 17 and reporting of this research. Patients were not involved in the design or conduct or
36
37 18 reporting or dissemination of this research.
38
39 19 **Patient consent for publication:** Not required
40
41 20 **Ethics approval:** The conduct of this study was approved by UNSW’s Human Research
42
43 21 Ethics Approval Panel (HREAP) D: Biomedical (reference: HC190221). The participants’
44
45 22 consent was requested before the start of the survey.
46
47 23 **Data sharing statement:** A copy of the survey and the de-identified dataset analysed for the
48
49 24 current study are available from the corresponding author on reasonable request.
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Figure Legends

Figure 1: Panel A – National distribution of respondents in percent; Panel B – National distribution of individual respondents

Figure 2: Types of assessments conducted by clinicians of different professions.

Note: Other = GP; administration staff, social worker, geriatric advanced trainee, geriatric registrar

Figure 3: Three most commonly used general mood, sleep, self and informant rated and clinical assessment tools

Note: GDS= Geriatric Depression Scale; DASS= Depression Anxiety Stress Scale; IQCODE= Informant Questionnaire on Cognitive Decline in the Elderly; CBI-R= Cambridge Behavioural Inventory-revised; ECog= Measurement of Everyday Cognition; MMSE= Mini-mental State Examination; MoCA= Montreal Cognitive Assessment

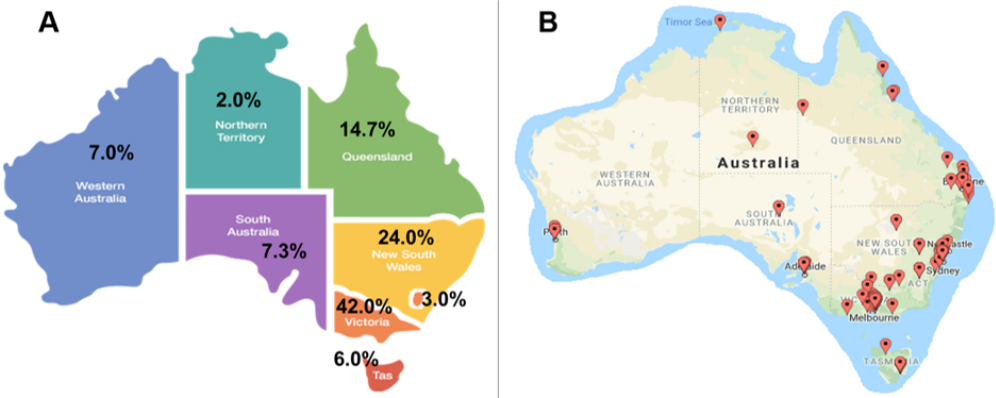


Figure 1: Panel A - National distribution of respondents in percent; Panel B –National distribution of individual respondents

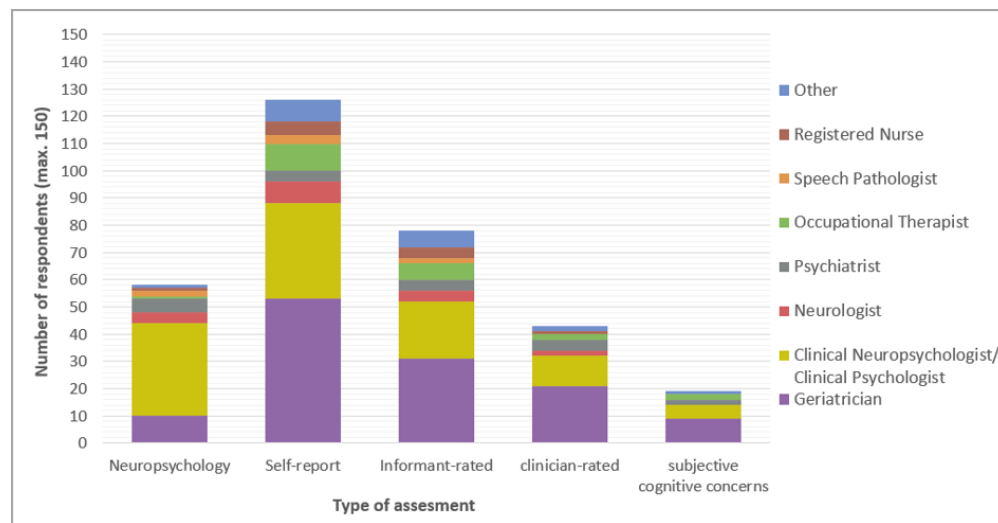


Figure 2: Types of assessments conducted by clinicians of different professions. Note: Other = GP; administration staff, social worker, geriatric advanced Trainee, Geriatric Registrar

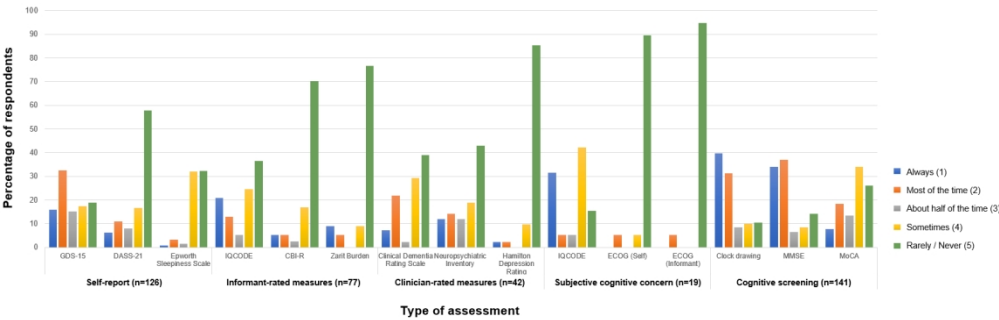


Figure 3: Three most commonly used general mood, sleep, self and informant rated and clinical assessment tools. Note: GDS= Geriatric Depression Scale; DASS= Depression Anxiety Stress Scale; IQCODE= Informant Questionnaire on Cognitive Decline in the Elderly; CBI-R= Cambridge Behavioural Inventory-revised; ECog= Measurement of Everyday Cognition; MMSE= Mini-mental State Examination; MoCA= Montreal Cognitive Assessment

Appendix A

Profession	# of clinics ^x (%) (max.: 34)	Mean EFT (SD)	Public Mean EFT (SD)	Private Mean EFT (SD)	metropolitan Mean EFT (SD)	regional Mean EFT (SD)	public vs private – <i>p</i> [^]	metropolitan vs regional <i>p</i> [^]
Geriatrician	26 (76%)	1.23 (2.14)	0.77 (1.71)	1.41 (2.51)	1.33 (2.45)	0.39 (0.03)	.163	.274
Clinical coordinator ⁺	15 (44%)	0.52 (0.34)	0.32 (0.37)	0.01 (0.03)	0.24 (0.35)	0.24 (0.35)	.020*	.986
Clinical Neuropsychologist	13 (38%)	0.69 (0.59)	0.32 (0.54)	0.11 (0.33)	0.34 (0.55)	0.16 (0.41)	.140	.180
Trainee doctor	10 (29%)	0.68 (1.52)	0.28 (0.49)	0	0.35 (1.13)	0.01 (0.03)	.072	.038*
Registered nurse	9 (26%)	0.78 (0.54)	0.28 (0.49)	0	0.17 (0.33)	0.26 (0.57)	.120	.849
Occupational Therapists	8 (24%)	0.81 (0.59)	0.26 (0.50)	0	0.28 (0.55)	0.06 (0.17)	.163	.377
Social worker	8 (24%)	0.23 (0.16)	0.08 (0.14)	0	0.07 (0.12)	0.04 (0.13)	.154	.199
Psychiatrist	6 (18%)	0.28 (0.36)	0.07 (0.20)	0	0.07 (0.22)	0.01 (0.05)	.298	.416
Clinical Psychologist	4 (12%)	0.63 (0.40)	0.10 (0.27)	0	0.03 (0.08)	0.14 (0.34)	.489	.416
Speech Pathologist	4 (12%)	0.16 (0.16)	0.03 (0.08)	0	0.01 (0.03)	0.03 (0.11)	.489	.743
Neurologist	3 (9%)	0.20 (0.10)	0.02 (0.07)	0	0.03 (0.08)	0	.618	.478
Rehabilitation Physician	1 (3%)	0.30	n/a	n/a	n/a	n/a	n/a	n/a
Aged Care Physician	1 (3%)	0.30	n/a	n/a	n/a	n/a	n/a	n/a
Consultant Physician	1 (3%)	0.20	n/a	n/a	n/a	n/a	n/a	n/a
General Practitioner	1 (3%)	0.20	n/a	n/a	n/a	n/a	n/a	n/a

EFT = effective full time (1.0 = 35 hours/ week).

^x # of clinics who reported that this profession is part of their team

⁺ paid time uniquely dedicated to clinic administration tasks

[^] Mann-Whitney-U test used due to skewed data

* significant *p* value, *p* < .05

Appendix B

	All	metro- politan	regional	Chi-square (p)/ t (p)^	public	private	Chi-square (p)/ t (p)^
All respondents involved in clinical assessments (n)	140	99	41		116	24	
Self-reported measures	90%	92%	80%	4.59 (.03)*	90%	83%	1.07 (.30)
1) GDS (15 items)	2.9 (1.4)^	3.0 (1.4)	2.9 (1.4)	0.13 (.90)	2.9 (1.4)	3.2 (1.4)	0.95 (.35)
2) DASS (21 items)	4.1 (1.3)	4.2 (1.2)	3.7 (1.6)	1.70 (.10)	4.1 (1.3)	4.1 (1.4)	0.07 (.94)
3) Epworth Sleepiness Scale	4.5 (0.8)	4.5 (0.8)	4.5 (0.7)	0.12 (.90)	4.5 (0.7)	4.5 (0.9)	-0.40 (.70)
Informant-rated measures	55%	51%	66%	1.51 (.22)	56%	50%	0.38 (.54)
1) IQCODE	3.4 (1.6)	3.6 (1.6)	3.1 (1.6)	1.34 (.19)	3.4 (1.6)	3.6 (1.3)	0.45 (.66)
2) CBI-R	4.4 (1.1)	4.4 (1.1)	4.4 (1.1)	-0.08 (.93)	4.4 (1.2)	4.8 (0.6)	1.71 (.10)
3) Zarit Burden	4.4 (1.3)	4.2 (1.4)	4.7 (1.0)	-1.49 (.14)	4.3 (1.3)	4.8 (0.9)	1.42 (.17)
Clinician-rated measures	30%	29%	32%	0.02 (.90)	29%	33%	0.09 (.76)
1) Clinical Dementia Rating	3.7 (1.4)	3.8 (1.3)	3.6 (1.6)	0.33 (.74)	3.7 (1.4)	3.6 (1.5)	-0.27 (.80)
2) Neuropsychiatric Inventory	3.7 (1.5)	3.5 (1.5)	4.2 (1.3)	-1.56 (.13)	3.6 (1.6)	4.1 (0.6)	1.60 (.12)
3) Hamilton Depression Rating	4.7 (0.8)	4.7 (0.9)	4.8 (0.4)	-0.70 (.50)	4.7 (0.9)	4.7 (0.5)	-0.9 (.93)
Subjective Cognitive Concerns	14%	13%	15%	0.04 (.85)	14%	13%	0.03 (.85)
1) IQCODE	3.0 (1.6)	3.2 (1.7)	2.8 (1.5)	0.42 (.68)	2.9 (1.7)	3.7 (0.58)	1.35 (.21)
2) ECog (Self)	4.8 (0.7)	4.7 (0.9)	5.0 (0.0)	-1.30 (.22)	4.8 (0.8)	5.0 (0)	1.29 (.22)
3) ECog (Informant)	4.8 (0.7)	4.8 (0.8)	5.0 (0.0)	-0.67 (.51)	4.8 (0.8)	5.0 (0)	1.00 (.33)
Cognitive Screening	99%	99%	100%	0.04 (.84)	100%	100%	0.99 (.32)
1) Clock drawing	2.2 (1.3)	2.1 (1.3)	2.4 (1.5)	-1.22 (.22)	2.2 (1.3)	2.4 (1.6)	0.70 (.49)
2) MMSE	2.3 (1.4)	2.2 (1.3)	2.7 (1.6)	-1.87 (.07)	2.3 (1.4)	2.6 (1.5)	1.11 (.28)
3) MoCA	3.5 (1.3)	3.6 (1.3)	3.4 (1.4)	0.50 (.62)	3.5 (1.2)	3.5 (1.5)	-0.26 (.80)
Neuropsychological Measures							
	All	metro- politan	regional	Chi-square (p)/ t (p)^	public	private	Chi-square (p)/ t (p)^
n	59	42	17		51	8	
Premorbid function	76%	79%	71%	0.20 (.65)	76%	75%	0.35 (.55)
1) TOPF	3.1 (1.6)	3.2 (1.5)	2.6 (1.7)	1.19 (.25)	3.1 (1.6)	2.8 (1.5)	-0.41 (.69)
2) WAIS-IV Vocabulary	4.0 (1.4)	4.2 (1.2)	3.3 (1.6)	1.90 (.08)	4.0 (1.4)	3.7 (1.5)	-0.51 (.63)
3) NART	4.4 (1.2)	4.3 (1.3)	4.8 (0.4)	-2.21 (.03)*	4.5 (1.1)	3.8 (1.6)	-1.01 (.36)
Processing Speed	86%	90%	76%	2.03 (.16)	86%	88%	0.01 (.93)
1) Trail Making A	2.1 (1.1)	2.2 (1.2)	1.9 (0.9)	0.76 (.45)	2.0 (1.1)	2.6 (1.4)	1.0 (.35)
2) WAIS-IV Coding	3.1 (1.5)	3.1 (1.6)	3.1 (1.5)	0.06 (.95)	3.1 (1.5)	3.0 (1.6)	-0.17 (.86)
3) WAIS-IV Symbol Search	3.1 (1.5)	3.6 (1.5)	3.1 (1.5)	1.05 (.31)	3.5 (1.5)	3.1 (1.8)	-0.51 (.63)
Attention/ Working Memory	81%	83%	76%	0.78 (.54)	80%	87%	0.23 (.63)
1) Digit span (2 subtests)	3.0 (1.8)	3.1 (1.8)	2.9 (1.8)	0.36 (.72)	3.0 (1.8)	3.3 (1.9)	0.44 (.67)
2) Digit span (3 subtests)	3.4 (1.5)	3.3 (1.6)	3.5 (1.5)	-0.45 (.66)	3.5 (1.5)	2.6 (1.7)	-1.36 (.21)

3) TEA	4.5 (1.1)	4.8 (0.6)	4.2 (1.0)	2.05 (.06)	4.6 (0.7)	4.9 (0.4)	1.22 (.24)
Memory	80%	83%	71%	1.21 (.27)	80%	75%	0.12 (.73)
1) WMS-IV Logical Memory	2.8 (1.6)	2.9 (1.6)	2.5 (1.6)	0.71 (.49)	2.9 (1.7)	2.3 (1.2)	-0.93 (.38)
2) Rey Complex figure (30min)	3.2 (1.6)	3.0 (1.6)	3.8 (1.4)	-1.62 (.12)	3.2 (1.6)	3.3 (1.9)	0.23 (.82)
3) WMS-IV Visual Reproduction	3.3 (1.5)	3.4 (1.6)	2.8 (1.4)	1.17 (.25)	3.3 (1.6)	3.0 (1.4)	-0.47 (.66)
Language	92%	93%	88%	0.33 (.56)	90%	100%	0.86 (.36)
1) Category Fluency (Animals)	1.9 (1.2)	1.8 (1.1)	2.3 (1.3)	-1.46 (.16)	1.9 (1.1)	2.1 (1.4)	0.46 (.66)
2) COWAT (FAS)	2.5 (1.6)	2.3 (1.6)	2.8 (1.7)	-0.92 (.37)	2.4 (1.6)	2.6 (1.7)	0.30 (.77)
3) Boston Naming (60items)	3.0 (1.4)	2.8 (1.4)	3.7 (1.3)	-2.34 (.03)*	3.0 (1.4)	3.4 (1.8)	0.60 (.56)
Visuo-spatial	97%	98%	94%	0.45 (.50)	96%	100%	0.33 (.57)
1) Clock drawing	2.2 (1.3)	2.1 (1.3)	2.4 (1.4)	-0.74 (.46)	2.0 (1.2)	2.9 (1.8)	1.26 (.24)
2) Rey Complex figure (copy)	2.5 (1.5)	2.3 (1.5)	3.0 (1.6)	-1.45 (.16)	2.5 (1.6)	2.6 (1.6)	0.22 (.83)
3) Cube copying/ drawing)	2.7 (1.5)	2.7 (1.5)	2.6 (1.4)	0.20 (.84)	2.7 (1.5)	2.8 (1.5)	0.14 (.90)
Executive Function	92%	90%	94%	0.21 (.65)	90%	100%	0.86 (.36)
1) Trail Making B	2.2 (1.2)	2.2 (1.1)	2.3 (1.3)	-0.41 (.68)	2.2 (1.2)	2.1 (1.3)	-0.20 (.85)
2) WAIS-IV Similarities	2.9 (1.7)	2.8 (1.6)	3.1 (1.7)	-0.59 (.56)	2.8 (1.7)	3.0 (1.8)	0.26 (.80)
3) Stroop (DKEFS)	4.1 (1.3)	4.2 (1.4)	4.0 (1.2)	0.49 (.63)	4.2 (1.3)	3.6 (1.7)	-0.95 (.37)
Social Cognition	14%	12%	18%	0.34 (.56)	16%	0	1.45 (.23)
1) Reading the Mind in the Eyes	4.1 (0.6)	4.0 (0.7)	4.3 (0.6)	-0.73 (.50)	4.1 (0.6)	n/a	n/a
2) The Awareness of Social Interference Test	4.4 (0.7)	4.6 (0.5)	4.0 (1.0)	0.96 (.42)	4.4 (0.7)	n/a	n/a
3) Facial Expressions of Emotion / Ekman Faces	4.9 (0.4)	4.8 (0.4)	5.0 (0)	-1.00 (.37)	4.9 (0.4)	n/a	n/a
Effort	51%	48%	59%	0.61 (.44)	51%	50%	0.00 (.96)
1) WAIS-IV embedded measure reliable digit span	4.0 (1.1)	4.3 (0.9)	3.4 (1.3)	2.03 (.06)	4.2 (1.0)	2.8 (1.0)	-2.8 (.05)*
2) WAIS-IV embedded measure logical Memory, delayed recognition	4.1 (1.0)	4.3 (0.9)	3.8 (1.1)	1.09 (.29)	4.2 (0.9)	3.8 (1.5)	-0.52 (.63)
3) Advanced Clinical Solutions – word choice	4.1 (1.0)	4.3 (0.9)	3.8 (1.1)	1.21 (.25)	4.3 (0.8)	3.0 (1.4)	-1.80 (.16)

^ the values refer to the mean rating on the Likert Scale (1=always; 2=most of the time; 3=about half the time; 4=sometimes; 5=never/rarely)

^^ chi-square applies for nominal data describing if assessments of a particular type were conducted (highlighted in green) / t-tests were performed for to determine differences in test use across different clinical settings

* highlights a significant difference $p < .05$

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Appendix C

ADNeT Chief Investigators	
ADNeT Chief Investigators	Principal Institution
Christopher Rowe	The University of Melbourne
Perminder Sachdev	University of New South Wales
Sharon Naismith	University of Sydney
Michael Breakspear	The Council of the Queensland Institute of Medical Research
Henry Brodaty	University of New South Wales
Kaarin Anstey	Neuroscience Research Australia
Ralph Martins	Macquarie University
Stephanie Ward	University of New South Wales
James Vickers	University of Tasmania
Colin Masters	The University of Melbourne

ADNeT Associate Investigators	
ADNeT Associate Investigators	Principal Institution
Peter Schofield	Neuroscience Research Australia
Rob Grenfell	The Council of the Queensland Institute of Medical Research
Susan Kurrle	University of Sydney
Elizabeth Beattie	Queensland University of Technology
Ashley Bush	Florey Institute of Neuroscience and Mental Health
Maria Crotty	Flinders University
Annette Dobson	University of Queensland
Leon Flicker	University of Western Australia
Paul Maruff	The University of Melbourne
John McNeil	Monash University
Peter Nestor	University of Queensland
Olivier Salvado	University of Queensland
Susannah Ahern	Monash University

Revised Standards for Quality Improvement Reporting Excellence (SQUIRE 2.0)
September 15, 2015

Text Section and Item Name	Section or Item Description
Notes to authors	<ul style="list-style-type: none"> • The SQUIRE guidelines provide a framework for reporting new knowledge about how to improve healthcare • The SQUIRE guidelines are intended for reports that describe system level work to improve the quality, safety, and value of healthcare, and used methods to establish that observed outcomes were due to the intervention(s). • A range of approaches exists for improving healthcare. SQUIRE may be adapted for reporting any of these. • Authors should consider every SQUIRE item, but it may be inappropriate or unnecessary to include every SQUIRE element in a particular manuscript. • The SQUIRE Glossary contains definitions of many of the key words in SQUIRE. • The Explanation and Elaboration document provides specific examples of well-written SQUIRE items, and an in-depth explanation of each item. • Please cite SQUIRE when it is used to write a manuscript.
Title and Abstract	
1. Title	Indicate that the manuscript concerns an initiative to improve healthcare (broadly defined to include the quality, safety, effectiveness, patient-centeredness, timeliness, cost, efficiency, and equity of healthcare)
2. Abstract	<ol style="list-style-type: none"> Provide adequate information to aid in searching and indexing Summarize all key information from various sections of the text using the abstract format of the intended publication or a structured summary such as: background, local problem, methods, interventions, results, conclusions
Introduction	<i>Why did you start?</i>
3. Problem Description	Nature and significance of the local problem
4. Available knowledge	Summary of what is currently known about the problem , including relevant previous studies

5. Rationale	Informal or formal frameworks, models, concepts, and/or theories used to explain the problem , any reasons or assumptions that were used to develop the intervention(s) , and reasons why the intervention(s) was expected to work
6. Specific aims	Purpose of the project and of this report
Methods	<i>What did you do?</i>
7. Context	Contextual elements considered important at the outset of introducing the intervention(s)
8. Intervention(s)	a. Description of the intervention(s) in sufficient detail that others could reproduce it b. Specifics of the team involved in the work
9. Study of the Intervention(s)	a. Approach chosen for assessing the impact of the intervention(s) b. Approach used to establish whether the observed outcomes were due to the intervention(s)
10. Measures	a. Measures chosen for studying processes and outcomes of the intervention(s) , including rationale for choosing them, their operational definitions, and their validity and reliability b. Description of the approach to the ongoing assessment of contextual elements that contributed to the success, failure, efficiency, and cost c. Methods employed for assessing completeness and accuracy of data
11. Analysis	a. Qualitative and quantitative methods used to draw inferences from the data b. Methods for understanding variation within the data, including the effects of time as a variable
12. Ethical Considerations	Ethical aspects of implementing and studying the intervention(s) and how they were addressed, including, but not limited to, formal ethics review and potential conflict(s) of interest
Results	<i>What did you find?</i>
13. Results	a. Initial steps of the intervention(s) and their evolution over time (e.g., time-line diagram, flow chart, or table), including modifications made to the intervention during the project b. Details of the process measures and outcome c. Contextual elements that interacted with the intervention(s) d. Observed associations between outcomes, interventions, and relevant contextual elements e. Unintended consequences such as unexpected benefits, problems, failures, or costs associated with the intervention(s) . f. Details about missing data
Discussion	<i>What does it mean?</i>
14. Summary	a. Key findings, including relevance to the rationale and specific aims b. Particular strengths of the project

15. Interpretation	<ul style="list-style-type: none"> a. Nature of the association between the intervention(s) and the outcomes b. Comparison of results with findings from other publications c. Impact of the project on people and systems d. Reasons for any differences between observed and anticipated outcomes, including the influence of context e. Costs and strategic trade-offs, including opportunity costs
16. Limitations	<ul style="list-style-type: none"> a. Limits to the generalizability of the work b. Factors that might have limited internal validity such as confounding, bias, or imprecision in the design, methods, measurement, or analysis c. Efforts made to minimize and adjust for limitations
17. Conclusions	<ul style="list-style-type: none"> a. Usefulness of the work b. Sustainability c. Potential for spread to other contexts d. Implications for practice and for further study in the field e. Suggested next steps
Other information	
18. Funding	Sources of funding that supported this work. Role, if any, of the funding organization in the design, implementation, interpretation, and reporting

Table 2. Glossary of key terms used in SQUIRE 2.0. This Glossary provides the intended meaning of selected words and phrases as they are used in the SQUIRE 2.0 Guidelines. They may, and often do, have different meanings in other disciplines, situations, and settings.

Assumptions

Reasons for choosing the activities and tools used to bring about changes in healthcare services at the [system](#) level.

Context

Physical and sociocultural makeup of the local environment (for example, external environmental factors, organizational dynamics, collaboration, resources, leadership, and the like), and the interpretation of these factors (“sense-making”) by the healthcare delivery professionals, patients, and caregivers that can affect the effectiveness and [generalizability](#) of [intervention\(s\)](#).

Ethical aspects

The value of [system](#)-level [initiatives](#) relative to their potential for harm, burden, and cost to the stakeholders. Potential harms particularly associated with efforts to improve the quality, safety, and value of healthcare services include [opportunity costs](#), invasion of privacy, and staff distress resulting from disclosure of poor performance.

Generalizability

The likelihood that the [intervention\(s\)](#) in a particular report would produce similar results in other settings, situations, or environments (also referred to as external validity).

Healthcare improvement

Any systematic effort intended to raise the quality, safety, and value of healthcare services, usually done at the [system](#) level. We encourage the use of this phrase rather than “quality improvement,” which often refers to more narrowly defined approaches.

Inferences

The meaning of findings or data, as interpreted by the stakeholders in healthcare services – improvers, healthcare delivery professionals, and/or patients and families

Initiative

A broad term that can refer to organization-wide programs, narrowly focused projects, or the details of specific interventions (for example, planning, execution, and assessment)

Internal validity

Demonstrable, credible evidence for efficacy (meaningful impact or change) resulting from introduction of a specific intervention into a particular healthcare [system](#).

Intervention(s)

The specific activities and tools introduced into a healthcare [system](#) with the aim of changing its performance for the better. Complete description of an intervention includes its inputs, internal activities, and outputs (in the form of a logic model, for example), and the mechanism(s) by which these components are expected to produce changes in a [system’s](#) performance.

Opportunity costs

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3 Loss of the ability to perform other tasks or meet other responsibilities resulting from the diversion
4 of resources needed to introduce, test, or sustain a particular [improvement](#) initiative
5

6 7 **Problem**

8 Meaningful disruption, failure, inadequacy, distress, confusion or other dysfunction in a healthcare
9 service delivery [system](#) that adversely affects patients, staff, or the [system](#) as a whole, or that
10 prevents care from reaching its full potential
11

12 13 **Process**

14 The routines and other activities through which healthcare services are delivered
15

16 17 **Rationale**

18 Explanation of why particular [intervention\(s\)](#) were chosen and why it was expected to work, be
19 sustainable, and be replicable elsewhere.
20

21 22 **Systems**

23 The interrelated structures, people, [processes](#), and activities that together create healthcare services
24 for and with individual patients and populations. For example, systems exist from the personal self-
25 care system of a patient, to the individual provider-patient dyad system, to the microsystem, to the
26 macrosystem, and all the way to the market/social/insurance system. These levels are nested within
27 each other.
28

29 30 **Theory or theories**

31 Any “reason-giving” account that asserts causal relationships between variables (causal theory) or
32 that makes sense of an otherwise obscure [process](#) or situation (explanatory theory). Theories come
33 in many forms, and serve different purposes in the phases of [improvement](#) work. It is important to
34 be explicit and well-founded about any informal and formal theory (or theories) that are used.
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Organisational aspects and assessment practices of Australian Memory Clinics: An Australian Dementia Network (ADNet) survey

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Organisational aspects and assessment practices of Australian Memory Clinics: An Australian Dementia Network (ADNeT) survey

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Abstract

Objectives: Conducting a national survey of clinicians and administrators from specialised dementia assessment services (Memory Clinics) in Australia to examine their current organisational aspects and assessment procedures and inform clinical tool harmonisation as part of the Australian Dementia Network (ADNeT) – Memory Clinics project.

Design: A cross-sectional survey.

Setting: Public and private Memory Clinics across Australia

Participants: 150 individual clinicians completed the survey between May and August 2019. Responses could be given anonymously. Most clinics were publicly funded services (83.2%) and in metropolitan regions (70.9%).

Outcome measures: Descriptive data on organisational aspects of Memory Clinics (e.g., waiting times, staffing); the three most commonly used assessment tools per assessment type (e.g., self-report) and cognitive domain (e.g., attention).

Results: Since the last national survey in 2009, the number of Memory Clinics across Australia has increased substantially but considerable variability has remained with respect to funding structure, staffing and assessment procedures. The average clinic employed 2.4 effective full-time staff (EFT; range 0.14 to 14.0). The reported waiting time for an initial assessment ranged from 1 week to 12 months with a median of 7 weeks. While most clinics (97%) offered follow-up assessments for their clients, only a few (31%) offered any form of cognitive intervention. We identified over 100 different cognitive assessment tools that were utilised at least ‘sometimes’, with widespread use of well-established core screening tools and a subset of common neuropsychological tests.

Conclusion: This paper presents a current snapshot of Australian Memory Clinics, showing considerable heterogeneity with some common core elements. These results will inform the development of national Memory Clinic guidelines. Furthermore, our data make a valuable contribution to the international comparison of clinical practice standards, and advocates for greater harmonisation to ensure high-quality dementia care.

Strengths and limitations of this study

- Our study is the first national Memory Clinics survey that presents responses from all Australian states.
- A broad definition of 'Memory Clinic' was used to include all clinicians specialising in dementia diagnosis to gain a broad overview of current clinical practice
- The survey presents a comprehensive list of the most commonly used cognitive assessment tools that can inform the development of a national Memory Clinics guidelines for harmonisation of assessment tools.
- While several strategies were used to identify Memory Clinics across the country, the survey cannot be considered to be exhaustive.

INTRODUCTION

About 459,000 Australians are currently living with dementia and the numbers are expected to increase dramatically over the next 30 years¹. Nevertheless, Australia is currently lacking clear diagnostic pathways for people with dementia and cognitive decline, which may delay an early diagnosis^{2,3}. A diagnosis can be made in a number of ways, for example through a GP, incidentally in a hospital or in a specialised assessment service or Memory Clinic².

Since the late 1980s, Memory Clinics have been an integral part of Australia’s dementia care services^{4,5} and have repeatedly been recommended as the best services to obtain an early diagnosis of dementia^{2,3}. Despite such recommendations, there is no consensus definition of a Memory Clinic and no published national or international agreement on the composition, services and standards of Memory Clinics⁶. Memory Clinics are most commonly described as multidisciplinary medical assessment centres that are highly specialised for the diagnostic work-up of cognitive decline and dementia⁷. Memory Clinic surveys from six different countries (Australia⁸, Ireland⁶, Netherlands^{9,10}, British Isles¹¹ and England in particular¹², Israel^{13,14} and New Zealand¹⁵) also showed considerable heterogeneity in the diagnostic protocols that were used. Such variability was attributed to many factors including differences in the Memory Clinics’ organisational structure, the area they service (regional vs. metropolitan), the funding received by clinics, the composition and level of staffing and the frequency of clinical services. The lack of evidence-based guidelines at the time may have also contributed to the variability. Interestingly, studies from England^{16,17} and the Netherlands^{18,19} that evaluated the economic aspects of a Memory Clinic reported mixed results with regard to the cost-effectiveness of multi-disciplinary Memory Clinic services. Despite all studies showed an advantage in the clinical outcomes of a multi-disciplinary Memory Clinic (e.g., measured by various quality of life indices), Memory Clinic services were associated with substantially higher costs.

The first Australian survey of Memory Clinics in 2009⁸ provided the first benchmark data for international comparison. The 2009 survey reported results from 16 Memory Clinics located in 5 Australian states (Victoria: 8 clinics, New South Wales: 4 clinics, South

1 Australia: 2 clinics, Queensland: 1 clinic and Western Australia: 1 clinic). The results showed
2 a comparatively long average waiting time of 10 weeks prior to the initial assessment. For
3 example, a survey of English memory assessment services reported that 73% of the 80
4 surveyed services are able to provide an initial appointment in 6 weeks or less¹². Moreover,
5 Australian Memory Clinics reported a relatively low average effective full time (EFT) staff
6 allocation of 1.7 EFT, compared to the average Memory Clinic staffing in other countries
7 (e.g., Ireland: 3.4 EFT⁶; England: 9.9 EFT¹²). They also reported differences in the
8 assessment protocols used across Memory Clinics though with relative agreement in the use
9 of blood tests, imaging and the Mini Mental State Examination (MMSE) as a cognitive
10 screen⁸. Cost-effectiveness measures have not been assessed.

11 Importantly, it has been argued that a large variability in organisational structures and
12 assessment procedures may contribute to delays in diagnosis, reduce accuracy and impede
13 the provision of early interventions^{2,20}. The benefits of harmonised diagnostic procedures for
14 clinical practice and dementia research are undeniable²¹. A harmonised assessment
15 protocol has the potential to boost collaboration between different Memory Clinics and
16 between clinicians, community dementia care services and researchers. Greater
17 harmonisation would also be required to implement national best practice standards and
18 thereby improve the quality of diagnosis and care throughout the country².

19 The call for greater harmonisation of diagnostic methods and processes has sparked
20 a number of international initiatives, for example in the United Kingdom (Memory Services
21 National Accreditation Program [MSNAP])²², the United States (National Alzheimer's
22 Coordinating Centres [NACC])²³ and the Netherlands⁹. In 2018, Australia followed this
23 international movement and supported the establishment of the Australian Dementia
24 Network (ADNeT), funded through the Australian NNIDR Boosting Dementia Research
25 Fund¹. ADNeT incorporates three main components - Clinical Quality Registry, Screening

¹ provided by the National Health and Medical Research Council (NHMRC) – National Institute for Dementia Research (NNIDR)

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3 1 and Trials and Memory Clinics - to improve the quality and accessibility of dementia care
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5 2 services across Australia.

7 3 ADNeT-Memory Clinics (ADNeT-MC) set out to establish a national network of
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9 4 clinicians and dementia care services to boost multidisciplinary collaboration, to harmonise
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11 5 diagnostic standards and develop clear pathways for post-diagnostic care and support.
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13 6 Given this new national initiative the current survey is important to assess baseline Memory
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15 7 Clinic practices and evaluated the resources available to deliver their services. Since the
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17 8 publication of the last national Memory Clinics survey in 2009⁸, best practice guidelines for
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19 9 the state-funded Cognitive, Dementia and Memory Services (CDAMS) in Victoria⁴ as well as
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21 10 clinical practice guidelines and principles of care for people with dementia²⁴ have been
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23 11 published and potentially changed clinical practice compared to 10 years ago. Hence, an
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25 12 updated national Memory Clinics survey is warranted.

28 13 The main aim of this survey was to obtain current information about the variety of
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30 14 assessment procedures used in Australian Memory Clinics and to determine the most
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32 15 commonly used cognitive and neuropsychological test instruments. These results will be
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34 16 important to establish harmonised assessment protocols that are feasible for clinicians from
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36 17 different states and Memory Clinic settings. Moreover, the survey obtained some basic
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38 18 benchmark information to present a comparative update on some of the organisational data
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40 19 reported in the previous survey⁸ (e.g., staffing, funding) in a larger sample of Memory Clinics
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42 20 and to evaluate differences between public and private as well as metropolitan and regional
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44 21 clinics where it is appropriate.

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48
49 23 **METHODS**

51 24 **Sample and Setting**

53 25 Due to the lack of a consensus definition of Memory Clinics, potential participants for this
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55 26 survey included any clinician or coordinator who self-identified as working for a specialised
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57 27 diagnostic assessment service for dementia. This was done to avoid missing out on
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59 28 responses of dedicated cognitive assessment services that do not identify as a Memory

1 Clinic and other specialised clinicians. Using this broad definition of a Memory Clinic we will,
2 in the following, refer to the services that responded to our survey as “Memory Clinic” or just
3 “clinic”. We used various recruitment strategies including the use of already established
4 contacts (e.g., official contact list of state-funded Cognitive Dementia and Memory Services
5 [CDAMS] in Victoria) and recommendations from professional networks. Hence, this group
6 of potential participants was previously known to the ADNeT research team. We sent a
7 single invitation to participate in the survey but no reminder email. We also advertised our
8 study in professional associations (esp., Australian and New Zealand Society for Geriatric
9 Medicine [ANZSGM] and the Royal Australian and New Zealand College of Psychiatrists
10 [RANZCP]) to increase our outreach and disseminate the survey to colleagues that were
11 unknown to the immediate ADNeT-Memory Clinics research Team. Due to our broad
12 distribution strategies it is difficult to estimate how many potential participants received the
13 survey link. All respondents were able to remain anonymous or to provide voluntary
14 identifiable information if they wished to be contacted again for future projects and
15 information about ADNeT.

17 **Survey and Procedure**

18 A Clinical Assessment Harmonisation survey was developed in Qualtrics²⁵. All potential
19 respondents were required to read the Participant Information Sheet and Consent form and
20 provide consent to their participation before they were able to start the survey (HREC No:
21 HC190221). Respondents were not obliged to provide any personal information (e.g., name,
22 contact address) but had the opportunity to do so, if they wished to be added to our ADNeT
23 contact list. Participants who did not wish to be contacted again, were also able to express
24 that at the end of the survey.

25 The survey comprised three main parts. The first part was directed at clinical
26 coordinators and clinicians involved in the operational management of a clinic. Here, the
27 respondents were asked to give details about the specific organisational structure of their
28 clinic: staffing (e.g., average EFT per profession and clinic), clinical activity (e.g., frequency

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3 1 of clinical assessments, waiting times, regulations for follow-ups), characteristics of the
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5 2 clinical population (e.g., proportion of indigenous and non-English speaking population) and
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7 3 funding support. Any respondent who was not involved in administrative tasks was able to
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9 4 skip this section of the survey.

11 5 The second part of the survey contained questions about the clinical and cognitive
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13 6 assessment tools used by the individual clinicians. Here, we investigated seven sub-
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15 7 categories: 1) cognitive screening tools, 2) self-reported scales, 3) informant-rated scales, 4)
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17 8 clinician-rated scales, 5) measures of subjective cognitive concern, 6) computerised
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19 9 cognitive tests, 7) standardised pen-and-paper neuropsychological measures. Within the
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21 10 'neuropsychological measures' category, we further distinguished between standardised
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23 11 neuropsychological batteries and individual tests in nine cognitive domains (premorbid
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25 12 ability, processing speed, attention and working memory, memory, language, visuo-spatial
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27 13 abilities, executive functions, social cognition and effort). For each category, the survey listed
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29 14 commonly used test instruments determined by experienced neuropsychologists (NK, SN).
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31 15 Respondents rated on a 5-point Likert scale how often they used each test instrument in
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33 16 their everyday clinical practice. Under 'other' the respondents were able to add up to five test
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35 17 additional instruments they currently use to ensure that we captured all instruments that
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37 18 were not originally considered. Options to skip this component of the survey were available
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39 19 to those respondents who did not conduct clinical assessments (e.g., dedicated coordinators
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41 20 of Memory Clinics). As some of the listed neuropsychological test instruments can only be
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43 21 conducted by trained neuropsychologists, we also compared the test use of
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45 22 neuropsychologists and non-neuropsychologists across cognitive domains.

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47 23 The third part of the survey asked if respondents offered any form of cognitive
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49 24 intervention to their clients. If the response was no, respondents were asked to provide
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51 25 reasons; if yes, they were asked to provide further details about the methods. We provided a
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53 26 list of possible intervention types and asked them to select all that apply. The options
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55 27 included: computerised testing; memory strategy training; psychoeducation; independent
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57 28 completion (exercise material); input to rehabilitation with other clinicians and involvement of

1 family, friends and caregivers. Furthermore, we asked in which frequency this intervention
2 was provided. A copy of the full survey can be acquired from the corresponding author upon
3 request.

4 5 **Patient and Public Involvement**

6 The design of this survey was based on previous national and international memory clinic
7 surveys^{6,8,9} to ensure a comparability of results. We further received input from expert
8 clinicians and researchers within the Australian Dementia Network Team. Questions were
9 added, deleted, and adjusted according to their feedback. As the survey was specific to
10 current clinical practices with a particular focus on cognitive and neuropsychological
11 assessment tools, people living with dementia and/or cognitive decline were not involved in
12 the design of this specific survey. The dissemination of the survey was supported by the
13 national professional associations “The Australia and New Zealand Society for Geriatric
14 Medicine (ANZSGM)” and “The Royal Australian and New Zealand College of Psychiatrists
15 (RANZCP)” as well as Dementia Australia to increase our outreach and involve as many
16 members of the target population as possible. Some of the participants of this survey were
17 informed about the results of this survey during ADNeT-Memory Clinic meetings and/or
18 national conferences. A link to the published results paper will be provided to all respondents
19 that provided contact details in their survey response.

20 21 **Data analysis**

22 All survey responses were recorded and saved in Qualtrics and the data later exported into
23 Excel. One member of the ADNeT-MC team (IM) de-identified the data and assigned a
24 unique study ID to each response. Identifiable information (e.g., profession, clinic location)
25 was coded and comments that contained identifiable information were separated from the
26 response sheet and securely saved. Only anonymised data were used for the analyses
27 presented in this paper. All statistical analyses were carried out with IBM SPSS Statistics,
28 version 25. We conducted descriptive analyses to provide an overview of the variety of

1 clinical settings and assessment tools that were reported by clinicians and clinical
2 coordinators across Australia. To compare categorical variables of different groups we
3 performed a Chi-Square test. When the skewness of continuous data was within the
4 recommended range of – 1 and 1, we performed parametric tests (e.g., t-test), when the
5 data was skewed, we performed non-parametric tests (e.g., Mann-Whitney U). Spearman
6 correlations were used to investigate associations between skewed continuous data.

7
8 **RESULTS**

9 **Respondents**

10 Between May and August 2019, we obtained 318 responses. We excluded responses from
11 163 who did not complete the survey (e.g., some data provided but did not press the
12 “complete button” at the end) as well as data from 5 respondents who accidentally
13 completed the survey multiple times. Consequently, 150 individual responses, with
14 representation from each of the Australian states and territories, were included. By matching
15 addresses, postcodes and other identifiable information the respondents voluntarily provided
16 (e.g., name of clinic), we were able to identify responses from 90 different Memory Clinic
17 services.

18
19 [FIGURE 1 – near here]
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21 The majority of responses were from Victoria and New South Wales, reflecting a
22 large number of Memory Clinics located in the two most populated states (see Figure 1).
23 Unsurprisingly, the highest density of Memory Clinics was found in metropolitan areas
24 (68.4% of respondents). Most of the respondents were employed in public clinics (82.8%),
25 compared to 17.2% employed in private clinics.

26 While most respondents identified as geriatricians (42.7%) and neuropsychologists
27 (23.3%), we also received responses from occupational therapists (7.4%), neurologists
28 (6.7%), psychiatrists (5.3%), registered nurses (3.3%), speech pathologists (2.0%), clinical

psychologists (1.3%), social workers (1.3%), pharmacists (0.6%), trainee doctors (3.3%) and clinical coordinators who are not involved in any clinical work (2.7%).

Organisational Aspects

Overall, 38 respondents from 38 different Memory Clinics reported that they fulfil the duties of a clinical coordinator or manager at their clinic site. Eighteen of these services voluntarily identified as a Memory Clinic or CDAMS while the remaining services identified as geriatric services (mostly private), cognitive and memory assessment services or did not provide clear information. Responses from all Australian states and territories were represented in this sample.

Table 1 summarises the main results from the survey regarding the clinics' general organisational aspects. The table shows the overall responses as well as the results split for metropolitan versus regional, and public versus private clinics.

Table 1: Result summary – general organisational structures

	all	metropolitan	regional	public	private
Respondents (n)	38	24	14	26	12
Clinic Type					
public	26	17	9	/	/
private	12	7	5	/	/
Service area					
1 community	14 (37%)	11 (46%)	3 (21%)	10 (38%)	4 (33%)
> 1 community	24 (63%)	13 (54%)	11 (79%)	16 (62%)	8 (67%)
Frequency (n=38)					
< 1x week	4 (10%)	1 (4%)	3 (21%)	3 (12%)	1 (8%)
1x week	6 (16%)	5 (21%)	1 (7%)	6 (23%)	0
>1x week	28 (74%)	18 (75%)	10 (71%)	17 (45%)	11 (92%)
Waiting Times (n=37)	9.9 weeks (± 9.7)	10.4 weeks (± 10.3)	9 weeks (± 8.6)	11.9 weeks* (± 10.8)	5.3 weeks* (± 3.1)
Waiting Times Range	3 days – 12 months	3 days – 12 months	1 week – 9 months	2 weeks – 12 months	1 week – 10 weeks
Average EFT per Clinic (n=34)	2.4 (± 3.2)	3.1 (± 4.0)	1.4 (± 1.2)	2.7 (± 3.5)	1.6 (± 2.4)
EFT Range	0.1 EFT – 14.0 EFT	0.1 EFT – 14.0 EFT	0.2 EFT – 3.6 EFT	0.1 EFT – 14.0 EFT	0.2 EFT – 8.0 EFT
Average number new patients per each clinic day (n=38)	3.3 (± 2.4)	3.2 (± 2.6)	3.5 (± 2.1)	3.1 (± 2.1)	3.7 (± 3.0)
Number of new patients per each clinic day - Range	1 - 11	1 - 11	1 - 8	1 - 10	1 - 11

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Follow-ups conducted – yes/no (n=38)	37 (97%)	24 (100%)	13 (93%)	25 (96%)	12 (100%)
Average number of follow-up patients per each clinic day (n=37)	4.2 (± 3.3)	4.4 (± 2.9)	3.7 (± 4.1)	4.5 (± 3.8)	3.5 (± 2.0)
Number of follow-up patients per each clinic day - Range	1 - 16	1 - 12	1 - 16	1 - 16	1 - 8
Proportion of patients from an indigenous background (n=25, who assess people with an indigenous background)					
≤5%	22 (88%)	12 (92%)	10 (83%)	16 (84%)	6 (100%)
> 5% - 10%	2 (8%)	1 (8%)	1 (8%)	2 (11%)	0
>10%	1 (4%)	0 (0%)	1 (8%)	1 (5%)	0
Proportions of patients from a CALD background (n=38)					
≤10%	24 (63%)	11 (46%)	13 (93%)	14 (54%)	10 (84%)
> 10% - 20%	3 (8%)	3 (13%)	1 (7%)	3 (12%)	1 (8%)
>20% - 30%	2 (5%)	2 (8%)	0 (0%)	2 (8%)	0
>30% - 40%	1 (3%)	1 (4%)	0 (0%)	1 (4%)	0
>40% - 50%	5 (13%)	5 (21%)	0 (0%)	4 (15%)	1 (8%)
>50%	2 (5%)	2 (8%)	0 (0%)	2 (8%)	0
Main source of referrals					
GP	35 (92%)	22 (92%)	13 (92%)	24 (92%)	11 (92%)
Other (Neurologist, Geriatrician)	3 (8%)	2 (8%)	1 (8%)	2 (8%)	1 (8%)
Main source of funding					
State-health funds	19 (50%)	12 (50%)	7 (50%)	19 (73%)^	0
Patient charges/ Medicare	9 (23%)	7 (29%)	2 (14%)	1 (4%)	8 (67%)
State funds +patient charges	3 (8%)	3 (13%)	0	3 (12%)	0
commonwealth	1 (3%)	0	1 (7%)	1 (4%)	0
State-health funding + other	1 (3%)	1 (4%)	0	1 (4%)	0
Patient charges + other	5 (13%)	1 (4%)	4 (29%)	1 (4%)	4 (33%)

T-test and Chi-Square were used to compare metropolitan vs regional and public vs private services for each variable. Only significant differences are highlighted in the table.

* significant public vs private Memory Clinics (Mann-Whitney-U, p=.031)
^ significant difference according to Chi-squared test comparison (Chi-square; p<.001)

Community = defined catchment area; Frequency = indicates how often a clinic is operating; CALD = culturally and linguistically diverse; GP = general practitioner; Medicare = Australian public health fund

We observed no statistically significant differences between metropolitan and regional clinics for any of the reported organisational aspects we surveyed (see Table 1). A comparison of public and private Memory Clinics, unsurprisingly, revealed a significant difference in the clinics' funding sources (Chi-square= 30.18, p<.001). We would like to note that each clinic was always assigned to both features, 'metropolitan/regional' and 'private/public'. Despite our proportions were relatively balanced (e.g.,29% of metropolitan clinics and 36% of

1 regional were private), this overlap in the data may have influenced our analysis. Given the
2 overall small sample size, it can therefore be assumed that only strong associations will
3 have reached significance.

4 Seventy-three percent of public clinics report some support from state health funds
5 while the private services mainly rely on patient charges and rebates from the Australian
6 public health insurance Medicare. Funding support is also commonly supplemented by
7 research funds, commonwealth funding, support from the department of veteran affairs,
8 donated time of their staff members or rural workforce support.

9 In terms of waiting times, overall, the average reported waiting time for an initial
10 assessment was 9.9 weeks (SD= 9.7; median = 7 weeks). However, substantial variability
11 was observed, ranging from less than one week to about 12 months waiting time. Some
12 clinics also reported that they follow a triaging procedure to reduce the waiting times for
13 urgent cases. We observed a difference in the waiting times reported by private (mean: 5.3,
14 SD:3.1) and public clinics (mean: 11.9, SD: 10.8; $p_{\text{Mann-Whitney-U}}=.031$).

15 Most clinics reported that they run services at least once per week or more often (see
16 Table 1). Very few clinics, mostly in regional areas, ran less frequently. Thirty-four
17 respondents (89%) reported on their clinic's staffing. The mean allocation per clinic was 2.4
18 (SD= 3.2) effective-full time (EFT) positions (range: 0.1 EFT to 14.0 EFT). No significant
19 correlation was found between the clinics' EFT and waiting time (Spearman's $r=.288$,
20 $p=.104$).

21 Few differences were observed in terms of the representation of the various
22 professions in public versus private, and metropolitan versus regional Memory Clinics
23 (Appendix A). Specifically, private clinics reported lower EFTs for a dedicated clinical
24 coordinator (mean EFT: 0.01; $p_{\text{Mann-Whitney-U}}=.020$) than public clinics (mean EFT: 0.32) and
25 metropolitan Memory Clinics reported a higher average EFT for trainee doctors (mean EFT:
26 0.35) compared to regional clinics (mean EFT: 0.01; $p_{\text{Mann-Whitney-U}}=.038$).

27 Almost all clinics (97%) reported that follow-up assessments/ reviews form part of
28 their standard services. These follow-ups are mostly conducted on an ad hoc basis, and the

1 frequency may differ from case to case (e.g., after 6 months, after 12 months). In a number
2 of clinics, follow-ups were predominantly scheduled for people initially diagnosed with mild
3 cognitive impairment (MCI). On a regular clinic day an average of 3.3 (SD= 2.4) new patients
4 and 4.2 (SD= 3.3) follow-up patients are assessed (see Table 1). All clinics reported seeing
5 patients from cultural and linguistically diverse (CALD) backgrounds. In some cases, CALD
6 patients were reported to represent up to 50% of the clinic's case load. While a wide variety
7 of languages were reported (e.g., Cantonese, Arabic, Spanish, Maltese) for CALD clients,
8 the most commonly represented languages were Italian, Greek and Mandarin. Twenty-five
9 clinics (66%) reported that they regularly assessed patients with an indigenous background
10 but only three clinics reported this proportion to be larger than 5%.

11 General practitioners were the most common referral source for 35 (92%) Memory
12 Clinics. The remaining three clinics reported that most of their referrals come from a
13 neurologist or a geriatrician.

14
15 **Clinical Assessments**

16 One of the main aims of this survey was to identify the most commonly used clinical
17 assessment tools across Australian Memory Clinic clinicians. The 141 clinicians who
18 responded to this part of the survey, represented 14 different professions, with the majority
19 being geriatricians (42%) or neuropsychologists (24%). The types of assessments carried
20 out by different professionals are presented in Figure 2. Using a Chi-Square test, a
21 significant difference was only observed for neuropsychological testing (chi-square= 75.06,
22 $p<.001$). Post-hoc testing using the Fisher-exact test showed that neuropsychological tests
23 were most commonly conducted by trained neuropsychologists ($z=7.47$, $p<.001$). However,
24 clinicians from other professions (e.g., neurologists, psychiatrists, speech pathologist) also
25 reported the use of neuropsychological tests (see Figure 2).

[FIGURE 2 – near here]

Overall, the respondents reported the use of more than 100 different test instruments across all assessment types and cognitive domains. The most commonly used test instruments are displayed in Table 2 and 3. Both tables display the percentage of respondents at each frequency of test use on a 5-point Likert Scale (1=always; 5=rarely/never) and the mean Likert Scale ratings (smaller mean represents more frequent test use). The tables also display the total number of respondents who reported using of any of the listed tools within a specific assessment type or within a cognitive domain.

In specific, Table 2 summarises the most commonly used test instruments across different assessment types in a routine dementia assessment. One hundred and twenty-six respondents (90%) reported the use of self-reports. Within this category, most clinicians (122, 97%) reported the use of a variety of depression and anxiety scales (e.g., Geriatric Depression Scale, Depression Anxiety Stress Scales; see Table 2), while only 43 of the 126 respondents (34%) reported the use of sleep scales (e.g., Epworth Sleepiness Scale, Pittsburgh Sleep Quality Index). Nevertheless, those 43 respondents reported a relatively frequent use of the Epworth Sleepiness Scale (see Table 2), so that it was identified as one of the top 3 self-reported measures. Compared to the self-reported measures, clinician rated measures (30%) or formal assessments of subjective cognitive concerns (14%) were only reported by a relatively low proportion of respondents (see Table 2/ Figure 3). A comparison of the test use of clinicians from metropolitan and regional Memory Clinics showed that self-reported measures were more commonly used in metropolitan clinics (see full table in Appendix B: chi-square= 4.59, $p=.032$).

[FIGURE 3 - near here]

Table 3 summarises the top three neuropsychological test instruments reported for each cognitive domain included in our survey.

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Table 2: Three most commonly used general mood, sleep, self and informant rated and clinical/ cognitive assessment tools

		Percentage of respondents					
		always (1)	most of the time (2)	about half the time (3)	sometimes (4)	rarely/ never (5)	mean rating (SD)
Self-report (n=126)							
1	GDS -15	15.9	32.5	15.1	17.5	19.0	2.9 (1.4)
2	DASS-21	6.3	11.1	7.9	16.7	57.9	4.1 (1.3)
3	Epworth Sleepiness Scale	0.8	3.2	1.6	32.0	62.4	4.5 (0.8)
Informant-rated measures (=77)							
1	IQCODE	20.8	13.0	5.2	24.7	36.4	3.4 (1.6)
2	CBI-R	5.2	5.2	2.6	16.9	70.1	4.4 (1.1)
3	Zarit Burden	9.1	5.2	0	9.1	76.6	4.4 (1.3)
Clinician-rated measures (n=42)							
1	Clinical Dementia Rating	7.3	22.0	2.4	29.3	39.0	3.7 (1.4)
2	Neuropsychiatric Inventory	11.9	14.3	11.9	19.0	42.9	3.7 (1.5)
3	Hamilton Depression Rating	2.4	2.4	0	9.8	85.4	4.7 (0.8)
Subjective cognitive concerns (n=19)							
1	IQCODE	31.6	5.3	5.3	42.1	15.38	3.0 (1.6)
2	ECog (Self)	0	5.3	0	5.3	89.5	4.8 (0.7)
3	ECog (informant)	0	5.3	0	0	94.7	4.8 (0.7)
Cognitive Screening (n=141)							
1	Clock drawing	39.7	31.2	8.5	9.9	10.6	2.2 (1.3)
2	MMSE	34.0	36.9	6.4	8.5	14.2	2.3 (1.4)
3	MoCA	7.8	18.4	13.5	34.0	26.2	3.5 (1.3)

GDS= Geriatric Depression Scale; DASS= Depression Anxiety Stress Scale; IQCOE= Informant Questionnaire on Cognitive Decline in the Elderly; CBI-R= Cambridge behavioural Inventory-revised; ECog= Measurement of Everyday Cognition; MMSE= Mini-mental State Examination; MoCA= Montreal Cognitive Assessment

Table 3: Three most commonly used neuropsychological test instruments for each cognitive domain

		Percentage of respondents					NP vs non-NP+ (p-value)	
		always (1)	most of the time (2)	about half the time (3)	sometimes (4)	rarely/ never (5)		overall mean rating (SD)
Premorbid Function (n=44/ Neuropsychologists= 33 [75%])								
1	TOPF*	15.9	34.1	6.8	9.1	34.1	3.1 (1.6)	p<.001
2	WAIS-IV Vocabulary	4.5	15.9	6.8	18.2	54.2	4.0 (1.4)	p=.162
3	NART	6.8	2.3	6.8	11.4	72.7	4.4 (1.2)	p=.065
Processing Speed (n=51 / Neuropsychologists= 34 [67%])								
1	Trail Making A	35.3	39.2	7.8	15.7	2.0	2.1 (1.1)	p=.392
2	WAIS-IV Coding*	17.6	29.4	5.9	19.6	27.5	3.1 (1.5)	p<.001
3	WAIS-IV Symbol Search*	13.7	19.6	9.8	21.6	35.3	3.1 (1.5)	p<.001
Attention/ Working Memory (n=48 / Neuropsychologists = 34 [75%])								
1	Digit Span (2 subtests)	33.3	16.7	2.1	12.5	35.4	3.0 (1.8)	p=1.00
2	Digit Span (3 subtests)*	14.6	25.0	4.2	20.8	35.4	3.4 (1.5)	p<.001
3	TEA	0	2.1	6.3	14.6	77.1	4.5 (1.1)	p=.169
Memory (n=47 / Neuropsychologists= 34 [72%])								
1	WMS-IV Logical Memory*	29.8	23.4	12.8	6.4	27.7	2.8 (1.6)	p=.006
2	Rey Complex Figure (30min delay)	21.3	21.3	8.5	17.0	31.9	3.2 (1.6)	p=.251
3	WMS-IV Visual Reproduction*	17.0	21.3	12.8	17.01	31.9	3.3 (1.5)	p<.001
Language (n=54/ Neuropsychologists = 34 [63%])								
1	Category Fluency (Animals)	46.3	33.3	7.4	7.4	5.6	1.9 (1.2)	p=.903
2	COWAT (FAS)*	42.6	20.4	7.4	7.4	22.2	2.5 (1.6)	p<.001
3	Boston Naming (60 items)*	16.7	27.8	13.0	20.4	22.2	3.0 (1.4)	p=.030
Visuo-spatial abilities (n=57 / Neuropsychologists = 34 [60%])								
1	Clock drawing^	40.4	33.3	5.3	12.3	8.8	2.2 (1.3)	p=.001
2	Rey Complex Figure* (copy)	33.3	33.3	3.5	8.8	21.1	2.5 (1.5)	p<.001

3	Cube copying/drawing^	26.3	31.6	5.3	21.1	15.8	2.7 (1.5)	<i>p</i> =.002
Executive function (n=54 / Neuropsychologists = 34 [63%])								
1	Trail Making B	29.6	44.4	7.4	13.0	5.6	2.2 (1.2)	<i>p</i> =.183
2	WAIS-IV Similarities*	29.6	24.1	7.4	9.3	29.6	2.9 (1.7)	<i>p</i> <.001
3	Stroop (D-KEFS)*	7.4	11.1	3.7	16.7	61.1	4.1 (1.3)	<i>p</i> =.019
Social Cognition (n=8 / Neuropsychologists = 4 [50%])								
1	Reading the Mind in the Eyes	0	0	12.5	62.5	25.0	4.1 (0.6)	<i>p</i> =.624
2	The Awareness of Social Interference Test	0	0	12.5	37.5	50.0	4.4 (0.7)	<i>p</i> =.674
3	Facial Expression of Emotion/ Ekman Faces	0	0	0	12.5	87.5	4.9 (0.4)	<i>p</i> =.391
Effort (n=30 / Neuropsychologists= 27 [90%])								
1	WAIS-IV embedded measure - reliable digit span	0	16.7	6.7	36.7	40.0	4.0 (1.1)	<i>p</i> =.136
2	WAIS-IV embedded measure logical Memory - delayed recognition*	0	10.0	13.3	33.3	43.3	4.1 (1.0)	<i>p</i> <.001
3	Advanced Clinical Solutions – word choice*	0	10.0	13.3	30.0	46.7	4.1 (1.0)	<i>p</i> <.001

TOPF= Test of Premorbid Function; WAIS= Wechsler Adult Intelligence Scale; NART= national Adult Reading Test; TEA= Test of Everyday Attention; WMS= Wechsler Memory Scale; COWAT= Controlled Oral Word Association Test; D-KEFS= Delis-Kaplan Executive Function System / NP vs non-NP[†]= t-test comparison of test use of neuropsychologist versus non-neuropsychologists / * significantly more often used by neuropsychologists / ^ significantly more often used by non-neuropsychologists

As mentioned earlier, testing of different cognitive domains was mostly carried out by trained neuropsychologist. Indeed, many of the tests summarised in Table 3 require a specific neuropsychological training. For the readers information, we listed the number and percentage of respondents for this part of this survey who identified as neuropsychologist and compared the test use of neuropsychologists and non-neuropsychologists. The p-values of this comparison are displayed in Table 3. Overall, respondents reported that they assess domains like *language*, *executive function* or *processing speed* 'most of the time' during their routine assessment. In contrast, even the most popular test instruments assessing domains like *social cognition* and *effort* were on average only used 'sometimes' (see Table 3).

Unsurprisingly, subtests of neuropsychological test batteries (WMS and WAIS, see Table 3) and or other specific test that require a training (TOPF, see Table 3) are significantly more often used by neuropsychologist (see Table 3) as non-neuropsychologists would not be qualified to conduct them. A stark difference in the test use of neuropsychologist and non-neuropsychologist can be observed in the domain 'visuo-spatial' abilities. Neuropsychologist use the "Rey complex figure" test more often than non-Neuropsychologists ($t=-4.6$, $p<.001$), who, in contrast, use the "Clock drawing" ($t=3.6$, $p=.001$) and "Cube copying/ drawing" ($t=3.2$, $p=.002$) more often to assess visuo-spatial abilities. Moreover, we observed that the "NART" (National Adult Reading Test), was more frequently used by clinicians from metropolitan than regional areas ($t= -2.21$, $p=.032$) and the test "WAIS-IV embedded measure: reliable digit span" was more frequently reported by clinicians from public than private clinics ($t= -2.80$, $p=.010$, see full table in Appendix B).

Only 10 respondents (7%) reported the use of computerised assessment tools, and these were used infrequently. The "Q-Interactive" test was the most commonly used (mean rating= 3.9, SD=1.7) followed by the computerised "Wisconsin Card Sorting Test" (mean rating= 4.3, SD=1.1).

Cognitive Interventions

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3 1 Only 46 (31%) from 34 different identifiable Memory Clinics (38%) reported that they offer
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5 2 any form of cognitive intervention. The majority of respondents who offer cognitive
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7 3 interventions identified as neuropsychologist (n=16/ 35%), geriatricians (n=13/ 28%) or
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9 4 occupational therapists (n=7/ 15%). Other professions were psychologists, psychiatrists,
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11 5 neurologists, speech pathologists and registered nurses. No differences were found between
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13 6 respondents working for public or private (chi-square= 0.003, $p =.956$) and metropolitan or
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15 7 regional Memory Clinics (chi-square= 0.07, $p =.791$). Not all clinicians that work for the same
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17 8 Memory Clinic, reported that they are able to provide cognitive interventions. Hence, we
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19 9 concentrated our analysis on the individual response level and did not provide further clinic-
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21 10 based analysis.

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24 11 Most respondents who offer cognitive intervention reported the use of a combination
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26 12 of different cognitive interventions, with a mix of *psychoeducation*, *involvement of family*
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28 13 *members* and *input to rehabilitation* being the most commonly reported combination (33%).
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30 14 Moreover, 89% of clinicians (41 out 46) reported that they conduct an individualised rather
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32 15 than a standardised approach. The overall data further suggests that there is a significant
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34 16 difference in the provision of *memory strategy training* by profession (chi-square= 16.87, p
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36 17 $=.018$). However, pairwise comparisons of all professions post-hoc (using Bonferroni
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38 18 correction) did not identify which specific professions differ from each other. Interestingly,
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40 19 more than half (52%) of the respondents who offer interventions are only able to provide one
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42 20 session. Only 7 out of the 46 respondents (15.2%) reported that they can provide more than
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44 21 5 sessions of cognitive intervention to their patients. Respondents who do not provide
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46 22 cognitive intervention reported a lack of resources, often accompanied by a lack of
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48 23 appropriate training as the most common reason for not offering cognitive interventions.

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DISCUSSION

56 26 This survey provides an updated overview of the current clinical situation of Memory Clinics
57 27 across Australia. It further identified the most commonly used assessment tools, which

marks an important first step in ADNeT's effort to harmonise and improve standards of diagnostic procedures across Australian Memory Clinics.

Our survey included a substantially larger number of respondents than previous Memory Clinic surveys in Australia⁸ or internationally^{6,11}. We broadened our target group to all clinicians involved in the specialised assessment of dementia and cognitive decline and identified responses from 90 different Memory Clinic services. This broad recruitment approach provided a more comprehensive overview of current clinical practices in the specialised assessment of people with dementia and cognitive decline across Australia.

The survey confirmed the large heterogeneity in the organisational aspects (e.g., staffing, number of patients, waiting times) of Memory Clinic services across Australia, previously reported in the national survey from 2009⁸. Similar variability in Memory Clinic services has been observed in the Netherlands, Ireland, the UK, Israel and New Zealand and greater harmonisation has been internationally endorsed^{6,9,11,13,15}.

Previous surveys^{6,8} identified relatively long waiting times for an initial assessment and understaffing as the main issues that may compromise a timely and accurate dementia diagnosis in a Memory Clinic setting. Woodward and Woodward⁸ reported an average of 10 weeks waiting time in their first Australian survey. Our results suggest that the waiting time remained largely unchanged over the past 10 years (average waiting time = 9.9 weeks). However, waiting times also greatly varied between services. The services with the shortest and the longest waiting time were both operating in metropolitan areas at relatively high frequency (4-5x a week). The clinic with the shortest waiting time was a private service and with one of the largest staff numbers in our survey. However, over all respondents, no meaningful relationship between staffing and waiting times was observed. The UK National Health Service's *Implementation guide and resource pack for dementia care*²⁶ recommends a maximum waiting time of six weeks to diagnosis as the minimum standard for Memory Clinics. Our survey showed that only 43% of cognitive assessment services would be able to offer an initial assessment within 6 weeks, with the majority falling short of this, most likely

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3 1 due to understaffing. Time to initial diagnosis was not assessed in our survey and should be
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5 2 added to future Memory Clinic surveys.
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7 3 Indeed, staffing varied largely across Memory Clinics. Our survey results suggest
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9 4 that the average EFT increased from 1.7 EFT reported in 2009⁸ to 2.4 EFT. In an
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11 5 international comparison, however, this staffing allocation is still comparatively low (e.g.,
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13 6 Ireland⁶: 3.4 EFT). A clinical coordinator position to handle general administration issues
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15 7 was included in only 44% of services. It can be assumed that clinicians in the remaining
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17 8 services must fulfil administrative duties in parallel to their clinical work. This is likely to affect
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19 9 the clinicians' capacity to see more clients for assessment and could potentially add to the
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22 10 delay in establishing a dementia diagnosis.
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24 11 The composition of Memory Clinics teams varied widely between clinics, a finding
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26 12 also observed internationally^{6,9,11}. The majority of clinics reported the employment of
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28 13 geriatricians (76%). A similar percentage of geriatrician involvement was reported by the
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30 14 latest Memory Clinic survey in the Netherlands⁹. With 73%, geriatricians were one of the
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32 15 professions frequently involved in Memory Clinic assessments. Moreover, Gruters et al.⁹
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34 16 report an even stronger involvement of neurologists (81%) and psychologists (94%). The
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36 17 distribution of professions that responded to our survey differed substantially (psychologists:
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38 18 24.6%; neurologists: 6.7%). Higher involvement rates for neurologists and psychologists
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40 19 were also reported in Memory Clinic surveys in the British Isles¹¹ and Israel¹³, while a
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42 20 distribution similar to the one we observed was reported for Memory Clinics in Ireland⁶ and
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44 21 New Zealand¹⁵. The distribution of professions reported in this study matches previous
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46 22 results of Woodward and Woodward⁸, who also reported a strong involvement of
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48 23 geriatricians and seems therefore representative for the Australian Memory Clinic landscape.
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50 24 However, our results may have been influenced by our participation call in the regular
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52 25 newsletter of Australia's largest geriatric society (ANZSGM), while we were unable to use a
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54 26 similar dissemination strategy through other professional associations (e.g., Australia and
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56 27 New Zealand Association of Neurologists). Importantly, our survey showed that only a small
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58 28 number of clinics include allied health professionals like occupational therapists (24%) or
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1 speech pathologists (12%). A similar observation was made in the Irish Memory Clinics
2 survey⁶ and Israel¹³. We expect this would inevitably restrict post-diagnostic care options
3 provided by these services and should be further assessed.

4 To gain a first idea of interventions the Memory Clinics are able to provide
5 themselves, all respondents were asked if their clinic offered any form of cognitive
6 intervention. Our survey showed that less than a third of respondents (30%) reported that
7 they offer cognitive interventions with the majority only offering a single session. In
8 comparison, a recent survey conducted across Memory Services in the Netherlands showed
9 that 72% offer some form of psychosocial interventions including cognitive interventions. A
10 more detailed evaluation study would be required identify which type cognitive intervention
11 would be most effective and should be recommended. The survey results presented in this
12 paper cannot contribute to this discussion. Nevertheless, we would like to argue that, due to
13 its high specialisation, Memory Clinics would be generally well equipped for the provision of
14 high-quality and evidence-based cognitive interventions. As outlined in the current Australian
15 'Clinical Practice Guidelines and Principles of Care for People with Dementia'²⁴, Memory
16 Clinics are also encouraged to focus on the diagnostic assessment. Consequently, most of
17 the Australian clinics reported a lack of funding or adequate training to offer more complex
18 post-diagnostic support. This may be one possible reason why post-diagnostic support
19 provided by Memory Clinics has not been shown to be more effective than general
20 practitioner services²⁷. Importantly, we did observe that almost all Memory Clinics (97%) are
21 able to offer a follow-up appointment. Unfortunately, obtaining more detailed information
22 about the content of these appointments or any other types of interventions that may be
23 provided (e.g., pharmacological, life-style counselling) was outside the scope of this survey.
24 In how far Memory Clinics are currently and could generally be involved in a holistic and
25 long-lasting post-diagnostic support is part of a larger discussion about the goals and
26 purpose of Memory Clinics^{6,28}. In Australia, ADNeT as well as other projects²⁹ have been
27 commissioned to address this issue in due course.

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3 1 There appears to be international agreement on the main components of a
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5 2 comprehensive assessment of dementia and cognitive decline including family and medical
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7 3 history, blood tests and structural neuroimaging, yet notably cognitive assessment protocols
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9 4 remain variable^{6,9,11}. Our survey results made a similar observation. We identified more than
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11 5 100 cognitive test instruments that clinicians use at least 'sometimes' in their assessments.
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13 6 Some agreement was observed in the use of cognitive screens, with the MMSE and clock
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15 7 drawing test being the most commonly used test tools^{9,13,15}.

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18 8 Based on our survey results, we identified the three most commonly used tests
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20 9 across the major cognitive domains (e.g., attention, language, memory) and types (e.g., self-
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22 10 report, informant-rated, see Table 2 and 3). This forms the basis for the development of a
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24 11 harmonised neuropsychological test protocol. Such a protocol would provide a minimum
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26 12 data set that would be uniform across Memory Clinics, thereby enabling comparison of
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28 13 practices and outcomes across clinics, the pooling of patient data for joint examination, and
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30 14 the ready recruitment nationally for clinical trials. A core minimum dataset does not constrain
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32 15 any clinic if there is a wish or need to expand the assessment to meet client and/or service
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34 16 needs.

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39 18 **LIMITATIONS**

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41 19 We aimed to reach as many Australian clinicians who conduct specialised dementia
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43 20 assessments in Australia as possible, to gain a representative overview of current clinical
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45 21 practice across the country. Hence, we used a broad Memory Clinic definition and allowed
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47 22 for anonymous responses which have been previously reported to be beneficial for large
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49 23 response rates³⁰. Due to the anonymity of respondents we were unable to follow-up with
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51 24 individual respondents to clarify their responses and to ensure the best possible data quality.
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53 25 All respondents were asked to answer the questions to the best of their knowledge, and we
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55 26 have no reason to believe that the quality of our data was greatly impacted by this
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57 27 procedure. Nevertheless, it is possible that individual respondents interpreted some
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59 28 questions differently which may have increased the variability in our data. To balance this

potential impact, we discussed outliers in the data and statistically controlled for outliers (e.g., run statistical analyses with and without outlier data in the sample) to ensure that only robust results are reported.

This survey also aimed to capture how many Australian Memory Clinic clinicians can offer some form of cognitive intervention. It is important to acknowledge that some of the interventions that were reported, can be included in a standard assessment sessions (e.g., involvement of family members), while others require a separate appointment (e.g., memory strategy training) that would require additional staff and funding. Other types of interventions were also not included in this survey that predominantly focused on assessment tools and procedures. Moreover, our study showed that a large percentage of respondents is able to offer a follow-up session to their clients. However, the exact post-diagnostic support that is provided within these follow-up sessions was not investigated in this survey. A more detailed analysis of the post-diagnostic support that is offered and the resources required to provide it was unfortunately outside the scope of this survey and should be considered for future scoping surveys. Nevertheless, our results show that the provision of non-pharmacological cognitive interventions is not part of the standard services Memory Clinic clinicians are able to provide. Ways to include Memory Clinics into a holistic post-diagnostic care should be explored.

CONCLUSION

Since the last national Memory Clinics survey in Australia services have expanded noticeably and with the rapidly ageing of the population, the demand for Memory Clinics is still growing. Our survey results present a picture of considerable heterogeneity in assessment procedures, while identifying some common elements that can be the basis of future harmonisation of practices. This survey is the first step toward an effort to develop standards for Memory Clinic assessments and post-diagnostic care such that each individual with cognitive deficits can receive prompt state-of-the-art assessment and care.

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1 All ADNeT initiatives work closely together to achieve these improvements. The
2 ADNeT clinical quality registry will monitor the ongoing improvements of Memory Clinics
3 procedures through regular feedback and benchmarked outcome measures. Harmonised
4 diagnostic procedures that map onto common research outcomes across Memory Clinics
5 also facilitates translation of research findings into practice and the clients' participation in
6 research. Memory Clinics will be an important entry point into clinical trials as new drugs and
7 therapies are developed with national support through ADNeT-Trials.

8 To further the harmonisation of Memory Clinics procedures, we will employ Delphi-
9 methods, including expert opinions from of clinicians, researchers, people living with
10 dementia and carers from all Australian states and territories to develop national best-
11 practice standards. Furthermore, the survey results confirm the need for better resourcing of
12 Memory Clinics and cognitive assessment services to further support early diagnosis of
13 dementia and cognitive decline by increasing staff levels to match international standards.
14 With projections of exponentially increasing numbers of people who will develop dementia in
15 the next decades, it is essential that Memory Services are well-equipped in terms of funding
16 and best practices to provide early diagnosis and evidence-based post-diagnostic care.

17
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24
25 **Contributors:** I.M. designed study method and data collection tools, organised and
26 facilitated data collection, cleaned, analysed and interpreted the data and drafted and
27 revised the paper. N.A.K. designed the study method and data collection tool, interpreted the
28 data and revised the manuscript for intellectual content. MY.O. made major contribution to

1 the design of the data collection and reviewed the manuscript. J.D.C. made major
2 contributions to the analyses and interpretation of the data and revised the manuscript for
3 intellectual content. S.L.N. and P.S.S. designed and conceptualised the study and its
4 methods, interpreted the data, and revised the manuscript for intellectual content. All authors
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11 reporting or dissemination of this research.

12 **Patient consent for publication:** Not required

13 **Ethics approval:** The conduct of this study was approved by UNSW's Human Research
14 Ethics Approval Panel (HREAP) D: Biomedical (reference: HC190221). The participants'
15 consent was requested before the start of the survey.

16 **Data sharing statement:** A copy of the survey and the de-identified dataset analysed for the
17 current study are available from the corresponding author on reasonable request.

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Figure Legends

Figure 1: Panel A – National distribution of respondents in percent; Panel B – National distribution of individual respondents

Figure 2: Types of assessments conducted by clinicians of different professions.

Note: Other = GP; administration staff, social worker, geriatric advanced trainee, geriatric registrar

Figure 3: Three most commonly used general mood, sleep, self and informant rated and clinical assessment tools

Note: GDS= Geriatric Depression Scale; DASS= Depression Anxiety Stress Scale; IQCODE= Informant Questionnaire on Cognitive Decline in the Elderly; CBI-R= Cambridge Behavioural Inventory-revised; ECog= Measurement of Everyday Cognition; MMSE= Mini-mental State Examination; MoCA= Montreal Cognitive Assessment

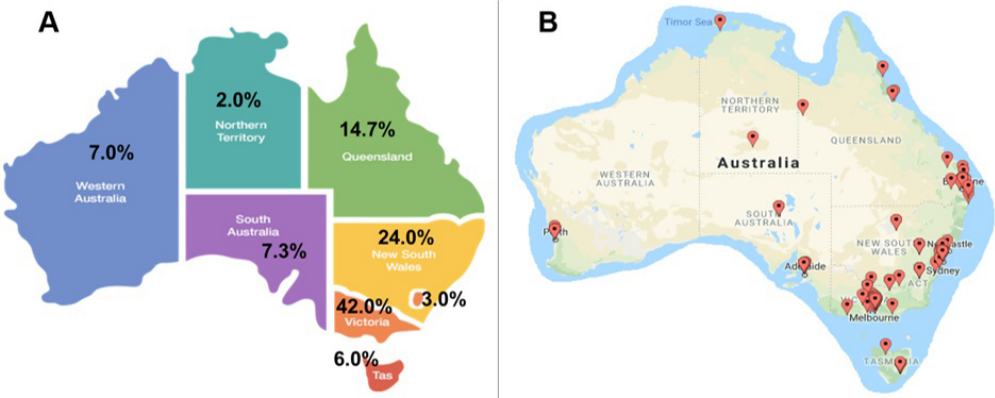


Figure 1: Panel A - National distribution of respondents in percent; Panel B - National distribution of individual respondents

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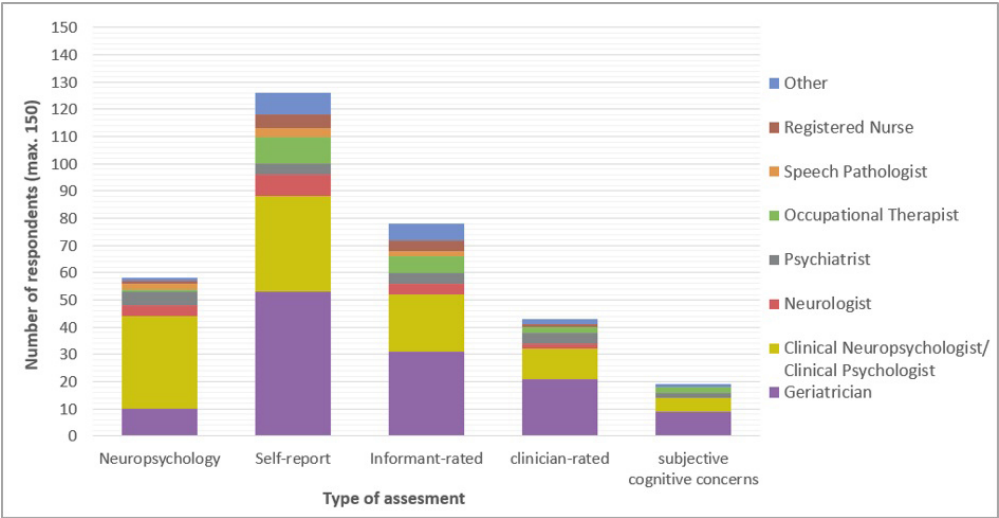


Figure 2: Types of assessments conducted by clinicians of different professions. Note: Other = GP; administration staff, social worker, geriatric advanced trainee, geriatric registrar

79x41mm (300 x 300 DPI)

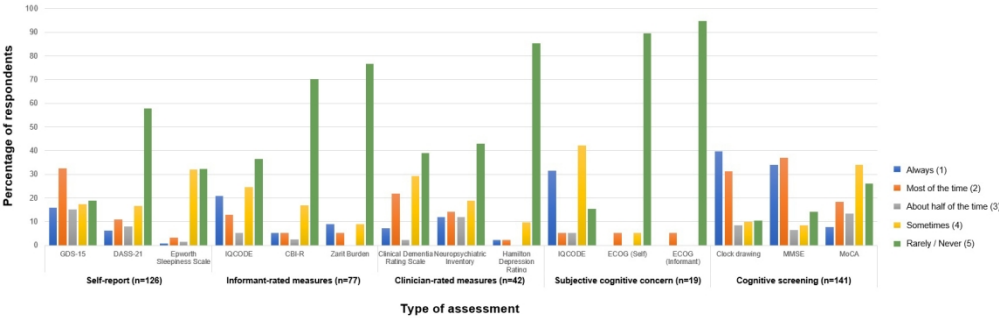


Figure 3: Three most commonly used general mood, sleep, self and informant rated and clinical assessment tools. Note: GDS=Geriatric Depression Scale; DASS= Depression Anxiety Stress Scale; IQCODE= Informant Questionnaire on Cognitive Decline in the Elderly; CBI-R= Cambridge Behavioural Inventory-revised; ECog= Measurement of Everyday Cognition; MMSE= Mini-mental State Examination; MoCA= Montreal Cognitive Assessment

144x47mm (300 x 300 DPI)

Appendix A

Profession	# of clinics ^x (%) (max.: 34)	Mean EFT (SD)	Public Mean EFT (SD)	Private Mean EFT (SD)	metropolitan Mean EFT (SD)	regional Mean EFT (SD)	public vs private – <i>p</i> [^]	metropolitan vs regional <i>p</i> [^]
Geriatrician	26 (76%)	1.23 (2.14)	0.77 (1.71)	1.41 (2.51)	1.33 (2.45)	0.39 (0.03)	.163	.274
Clinical coordinator ⁺	15 (44%)	0.52 (0.34)	0.32 (0.37)	0.01 (0.03)	0.24 (0.35)	0.24 (0.35)	.020*	.986
Clinical Neuropsychologist	13 (38%)	0.69 (0.59)	0.32 (0.54)	0.11 (0.33)	0.34 (0.55)	0.16 (0.41)	.140	.180
Trainee doctor	10 (29%)	0.68 (1.52)	0.28 (0.49)	0	0.35 (1.13)	0.01 (0.03)	.072	.038*
Registered nurse	9 (26%)	0.78 (0.54)	0.28 (0.49)	0	0.17 (0.33)	0.26 (0.57)	.120	.849
Occupational Therapists	8 (24%)	0.81 (0.59)	0.26 (0.50)	0	0.28 (0.55)	0.06 (0.17)	.163	.377
Social worker	8 (24%)	0.23 (0.16)	0.08 (0.14)	0	0.07 (0.12)	0.04 (0.13)	.154	.199
Psychiatrist	6 (18%)	0.28 (0.36)	0.07 (0.20)	0	0.07 (0.22)	0.01 (0.05)	.298	.416
Clinical Psychologist	4 (12%)	0.63 (0.40)	0.10 (0.27)	0	0.03 (0.08)	0.14 (0.34)	.489	.416
Speech Pathologist	4 (12%)	0.16 (0.16)	0.03 (0.08)	0	0.01 (0.03)	0.03 (0.11)	.489	.743
Neurologist	3 (9%)	0.20 (0.10)	0.02 (0.07)	0	0.03 (0.08)	0	.618	.478
Rehabilitation Physician	1 (3%)	0.30	n/a	n/a	n/a	n/a	n/a	n/a
Aged Care Physician	1 (3%)	0.30	n/a	n/a	n/a	n/a	n/a	n/a
Consultant Physician	1 (3%)	0.20	n/a	n/a	n/a	n/a	n/a	n/a
General Practitioner	1 (3%)	0.20	n/a	n/a	n/a	n/a	n/a	n/a

EFT = effective full time (1.0 = 35 hours/ week).

^x # of clinics who reported that this profession is part of their team

⁺ paid time uniquely dedicated to clinic administration tasks

[^] Mann-Whitney-U test used due to skewed data

* significant *p* value, *p*<.05

Appendix B

	All	metro- politan	regional	Chi-square (p)/ t (p)^	public	private	Chi-square (p)/ t (p)^
All respondents involved in clinical assessments (n)	140	99	41		116	24	
Self-reported measures	90%	92%	80%	4.59 (.03)*	90%	83%	1.07 (.30)
1) GDS (15 items)	2.9 (1.4)^	3.0 (1.4)	2.9 (1.4)	0.13 (.90)	2.9 (1.4)	3.2 (1.4)	0.95 (.35)
2) DASS (21 items)	4.1 (1.3)	4.2 (1.2)	3.7 (1.6)	1.70 (.10)	4.1 (1.3)	4.1 (1.4)	0.07 (.94)
3) Epworth Sleepiness Scale	4.5 (0.8)	4.5 (0.8)	4.5 (0.7)	0.12 (.90)	4.5 (0.7)	4.5 (0.9)	-0.40 (.70)
Informant-rated measures	55%	51%	66%	1.51 (.22)	56%	50%	0.38 (.54)
1) IQCODE	3.4 (1.6)	3.6 (1.6)	3.1 (1.6)	1.34 (.19)	3.4 (1.6)	3.6 (1.3)	0.45 (.66)
2) CBI-R	4.4 (1.1)	4.4 (1.1)	4.4 (1.1)	-0.08 (.93)	4.4 (1.2)	4.8 (0.6)	1.71 (.10)
3) Zarit Burden	4.4 (1.3)	4.2 (1.4)	4.7 (1.0)	-1.49 (.14)	4.3 (1.3)	4.8 (0.9)	1.42 (.17)
Clinician-rated measures	30%	29%	32%	0.02 (.90)	29%	33%	0.09 (.76)
1) Clinical Dementia Rating	3.7 (1.4)	3.8 (1.3)	3.6 (1.6)	0.33 (.74)	3.7 (1.4)	3.6 (1.5)	-0.27 (.80)
2) Neuropsychiatric Inventory	3.7 (1.5)	3.5 (1.5)	4.2 (1.3)	-1.56 (.13)	3.6 (1.6)	4.1 (0.6)	1.60 (.12)
3) Hamilton Depression Rating	4.7 (0.8)	4.7 (0.9)	4.8 (0.4)	-0.70 (.50)	4.7 (0.9)	4.7 (0.5)	-0.9 (.93)
Subjective Cognitive Concerns	14%	13%	15%	0.04 (.85)	14%	13%	0.03 (.85)
1) IQCODE	3.0 (1.6)	3.2 (1.7)	2.8 (1.5)	0.42 (.68)	2.9 (1.7)	3.7 (0.58)	1.35 (.21)
2) ECog (Self)	4.8 (0.7)	4.7 (0.9)	5.0 (0.0)	-1.30 (.22)	4.8 (0.8)	5.0 (0)	1.29 (.22)
3) ECog (Informant)	4.8 (0.7)	4.8 (0.8)	5.0 (0.0)	-0.67 (.51)	4.8 (0.8)	5.0 (0)	1.00 (.33)
Cognitive Screening	99%	99%	100%	0.04 (.84)	100%	100%	0.99 (.32)
1) Clock drawing	2.2 (1.3)	2.1 (1.3)	2.4 (1.5)	-1.22 (.22)	2.2 (1.3)	2.4 (1.6)	0.70 (.49)
2) MMSE	2.3 (1.4)	2.2 (1.3)	2.7 (1.6)	-1.87 (.07)	2.3 (1.4)	2.6 (1.5)	1.11 (.28)
3) MoCA	3.5 (1.3)	3.6 (1.3)	3.4 (1.4)	0.50 (.62)	3.5 (1.2)	3.5 (1.5)	-0.26 (.80)
Neuropsychological Measures							
	All	metro- politan	regional	Chi-square (p)/ t (p)^	public	private	Chi-square (p)/ t (p)^
n	59	42	17		51	8	
Premorbid function	76%	79%	71%	0.20 (.65)	76%	75%	0.35 (.55)
1) TOPF	3.1 (1.6)	3.2 (1.5)	2.6 (1.7)	1.19 (.25)	3.1 (1.6)	2.8 (1.5)	-0.41 (.69)
2) WAIS-IV Vocabulary	4.0 (1.4)	4.2 (1.2)	3.3 (1.6)	1.90 (.08)	4.0 (1.4)	3.7 (1.5)	-0.51 (.63)
3) NART	4.4 (1.2)	4.3 (1.3)	4.8 (0.4)	-2.21 (.03)*	4.5 (1.1)	3.8 (1.6)	-1.01 (.36)
Processing Speed	86%	90%	76%	2.03 (.16)	86%	88%	0.01 (.93)
1) Trail Making A	2.1 (1.1)	2.2 (1.2)	1.9 (0.9)	0.76 (.45)	2.0 (1.1)	2.6 (1.4)	1.0 (.35)
2) WAIS-IV Coding	3.1 (1.5)	3.1 (1.6)	3.1 (1.5)	0.06 (.95)	3.1 (1.5)	3.0 (1.6)	-0.17 (.86)
3) WAIS-IV Symbol Search	3.1 (1.5)	3.6 (1.5)	3.1 (1.5)	1.05 (.31)	3.5 (1.5)	3.1 (1.8)	-0.51 (.63)
Attention/ Working Memory	81%	83%	76%	0.78 (.54)	80%	87%	0.23 (.63)
1) Digit span (2 subtests)	3.0 (1.8)	3.1 (1.8)	2.9 (1.8)	0.36 (.72)	3.0 (1.8)	3.3 (1.9)	0.44 (.67)
2) Digit span (3 subtests)	3.4 (1.5)	3.3 (1.6)	3.5 (1.5)	-0.45 (.66)	3.5 (1.5)	2.6 (1.7)	-1.36 (.21)

3) TEA	4.5 (1.1)	4.8 (0.6)	4.2 (1.0)	2.05 (.06)	4.6 (0.7)	4.9 (0.4)	1.22 (.24)
Memory	80%	83%	71%	1.21 (.27)	80%	75%	0.12 (.73)
1) WMS-IV Logical Memory	2.8 (1.6)	2.9 (1.6)	2.5 (1.6)	0.71 (.49)	2.9 (1.7)	2.3 (1.2)	-0.93 (.38)
2) Rey Complex figure (30min)	3.2 (1.6)	3.0 (1.6)	3.8 (1.4)	-1.62 (.12)	3.2 (1.6)	3.3 (1.9)	0.23 (.82)
3) WMS-IV Visual Reproduction	3.3 (1.5)	3.4 (1.6)	2.8 (1.4)	1.17 (.25)	3.3 (1.6)	3.0 (1.4)	-0.47 (.66)
Language	92%	93%	88%	0.33 (.56)	90%	100%	0.86 (.36)
1) Category Fluency (Animals)	1.9 (1.2)	1.8 (1.1)	2.3 (1.3)	-1.46 (.16)	1.9 (1.1)	2.1 (1.4)	0.46 (.66)
2) COWAT (FAS)	2.5 (1.6)	2.3 (1.6)	2.8 (1.7)	-0.92 (.37)	2.4 (1.6)	2.6 (1.7)	0.30 (.77)
3) Boston Naming (60items)	3.0 (1.4)	2.8 (1.4)	3.7 (1.3)	-2.34 (.03)*	3.0 (1.4)	3.4 (1.8)	0.60 (.56)
Visuo-spatial	97%	98%	94%	0.45 (.50)	96%	100%	0.33 (.57)
1) Clock drawing	2.2 (1.3)	2.1 (1.3)	2.4 (1.4)	-0.74 (.46)	2.0 (1.2)	2.9 (1.8)	1.26 (.24)
2) Rey Complex figure (copy)	2.5 (1.5)	2.3 (1.5)	3.0 (1.6)	-1.45 (.16)	2.5 (1.6)	2.6 (1.6)	0.22 (.83)
3) Cube copying/ drawing)	2.7 (1.5)	2.7 (1.5)	2.6 (1.4)	0.20 (.84)	2.7 (1.5)	2.8 (1.5)	0.14 (.90)
Executive Function	92%	90%	94%	0.21 (.65)	90%	100%	0.86 (.36)
1) Trail Making B	2.2 (1.2)	2.2 (1.1)	2.3 (1.3)	-0.41 (.68)	2.2 (1.2)	2.1 (1.3)	-0.20 (.85)
2) WAIS-IV Similarities	2.9 (1.7)	2.8 (1.6)	3.1 (1.7)	-0.59 (.56)	2.8 (1.7)	3.0 (1.8)	0.26 (.80)
3) Stroop (DKEFS)	4.1 (1.3)	4.2 (1.4)	4.0 (1.2)	0.49 (.63)	4.2 (1.3)	3.6 (1.7)	-0.95 (.37)
Social Cognition	14%	12%	18%	0.34 (.56)	16%	0	1.45 (.23)
1) Reading the Mind in the Eyes	4.1 (0.6)	4.0 (0.7)	4.3 (0.6)	-0.73 (.50)	4.1 (0.6)	n/a	n/a
2) The Awareness of Social Interference Test	4.4 (0.7)	4.6 (0.5)	4.0 (1.0)	0.96 (.42)	4.4 (0.7)	n/a	n/a
3) Facial Expressions of Emotion / Ekman Faces	4.9 (0.4)	4.8 (0.4)	5.0 (0)	-1.00 (.37)	4.9 (0.4)	n/a	n/a
Effort	51%	48%	59%	0.61 (.44)	51%	50%	0.00 (.96)
1) WAIS-IV embedded measure reliable digit span	4.0 (1.1)	4.3 (0.9)	3.4 (1.3)	2.03 (.06)	4.2 (1.0)	2.8 (1.0)	-2.8 (.05)*
2) WAIS-IV embedded measure logical Memory, delayed recognition	4.1 (1.0)	4.3 (0.9)	3.8 (1.1)	1.09 (.29)	4.2 (0.9)	3.8 (1.5)	-0.52 (.63)
3) Advanced Clinical Solutions – word choice	4.1 (1.0)	4.3 (0.9)	3.8 (1.1)	1.21 (.25)	4.3 (0.8)	3.0 (1.4)	-1.80 (.16)

^ the values refer to the mean rating on the Likert Scale (1=always; 2=most of the time; 3=about half the time; 4=sometimes; 5=never/rarely)

^^ chi-square applies for nominal data describing if assessments of a particular type were conducted (highlighted in green) / t-tests were performed for to determine differences in test use across different clinical settings

* highlights a significant difference $p < .05$

Appendix C

ADNeT Chief Investigators	
ADNeT Chief Investigators	Principal Institution
Christopher Rowe	The University of Melbourne
Perminder Sachdev	University of New South Wales
Sharon Naismith	University of Sydney
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Henry Brodaty	University of New South Wales
Kaarin Anstey	Neuroscience Research Australia
Ralph Martins	Macquarie University
Stephanie Ward	University of New South Wales
James Vickers	University of Tasmania
Colin Masters	The University of Melbourne

ADNeT Associate Investigators	
ADNeT Associate Investigators	Principal Institution
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Rob Grenfell	The Council of the Queensland Institute of Medical Research
Susan Kurrle	University of Sydney
Elizabeth Beattie	Queensland University of Technology
Ashley Bush	Florey Institute of Neuroscience and Mental Health
Maria Crotty	Flinders University
Annette Dobson	University of Queensland
Leon Flicker	University of Western Australia
Paul Maruff	The University of Melbourne
John McNeil	Monash University
Peter Nestor	University of Queensland
Olivier Salvado	University of Queensland
Susannah Ahern	Monash University

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Revised Standards for Quality Improvement Reporting Excellence (SQUIRE 2.0)
September 15, 2015

Text Section and Item Name	Section or Item Description
Notes to authors	<ul style="list-style-type: none">• The SQUIRE guidelines provide a framework for reporting new knowledge about how to improve healthcare• The SQUIRE guidelines are intended for reports that describe system level work to improve the quality, safety, and value of healthcare, and used methods to establish that observed outcomes were due to the intervention(s).• A range of approaches exists for improving healthcare. SQUIRE may be adapted for reporting any of these.• Authors should consider every SQUIRE item, but it may be inappropriate or unnecessary to include every SQUIRE element in a particular manuscript.• The SQUIRE Glossary contains definitions of many of the key words in SQUIRE.• The Explanation and Elaboration document provides specific examples of well-written SQUIRE items, and an in-depth explanation of each item.• Please cite SQUIRE when it is used to write a manuscript.
Title and Abstract	
1. Title	Indicate that the manuscript concerns an initiative to improve healthcare (broadly defined to include the quality, safety, effectiveness, patient-centeredness, timeliness, cost, efficiency, and equity of healthcare)
2. Abstract	<ol style="list-style-type: none">Provide adequate information to aid in searching and indexingSummarize all key information from various sections of the text using the abstract format of the intended publication or a structured summary such as: background, local problem, methods, interventions, results, conclusions
Introduction	<i>Why did you start?</i>
3. Problem Description	Nature and significance of the local problem
4. Available knowledge	Summary of what is currently known about the problem , including relevant previous studies

5. Rationale	Informal or formal frameworks, models, concepts, and/or theories used to explain the problem , any reasons or assumptions that were used to develop the intervention(s) , and reasons why the intervention(s) was expected to work
6. Specific aims	Purpose of the project and of this report
Methods	<i>What did you do?</i>
7. Context	Contextual elements considered important at the outset of introducing the intervention(s)
8. Intervention(s)	a. Description of the intervention(s) in sufficient detail that others could reproduce it b. Specifics of the team involved in the work
9. Study of the Intervention(s)	a. Approach chosen for assessing the impact of the intervention(s) b. Approach used to establish whether the observed outcomes were due to the intervention(s)
10. Measures	a. Measures chosen for studying processes and outcomes of the intervention(s) , including rationale for choosing them, their operational definitions, and their validity and reliability b. Description of the approach to the ongoing assessment of contextual elements that contributed to the success, failure, efficiency, and cost c. Methods employed for assessing completeness and accuracy of data
11. Analysis	a. Qualitative and quantitative methods used to draw inferences from the data b. Methods for understanding variation within the data, including the effects of time as a variable
12. Ethical Considerations	Ethical aspects of implementing and studying the intervention(s) and how they were addressed, including, but not limited to, formal ethics review and potential conflict(s) of interest
Results	<i>What did you find?</i>
13. Results	a. Initial steps of the intervention(s) and their evolution over time (e.g., time-line diagram, flow chart, or table), including modifications made to the intervention during the project b. Details of the process measures and outcome c. Contextual elements that interacted with the intervention(s) d. Observed associations between outcomes, interventions, and relevant contextual elements e. Unintended consequences such as unexpected benefits, problems, failures, or costs associated with the intervention(s) . f. Details about missing data
Discussion	<i>What does it mean?</i>
14. Summary	a. Key findings, including relevance to the rationale and specific aims b. Particular strengths of the project

15. Interpretation	<ul style="list-style-type: none">a. Nature of the association between the intervention(s) and the outcomesb. Comparison of results with findings from other publicationsc. Impact of the project on people and systemsd. Reasons for any differences between observed and anticipated outcomes, including the influence of contexte. Costs and strategic trade-offs, including opportunity costs
16. Limitations	<ul style="list-style-type: none">a. Limits to the generalizability of the workb. Factors that might have limited internal validity such as confounding, bias, or imprecision in the design, methods, measurement, or analysisc. Efforts made to minimize and adjust for limitations
17. Conclusions	<ul style="list-style-type: none">a. Usefulness of the workb. Sustainabilityc. Potential for spread to other contextsd. Implications for practice and for further study in the fielde. Suggested next steps
Other information	
18. Funding	Sources of funding that supported this work. Role, if any, of the funding organization in the design, implementation, interpretation, and reporting

Table 2. Glossary of key terms used in SQUIRE 2.0. This Glossary provides the intended meaning of selected words and phrases as they are used in the SQUIRE 2.0 Guidelines. They may, and often do, have different meanings in other disciplines, situations, and settings.

Assumptions

Reasons for choosing the activities and tools used to bring about changes in healthcare services at the [system](#) level.

Context

Physical and sociocultural makeup of the local environment (for example, external environmental factors, organizational dynamics, collaboration, resources, leadership, and the like), and the interpretation of these factors (“sense-making”) by the healthcare delivery professionals, patients, and caregivers that can affect the effectiveness and [generalizability](#) of [intervention\(s\)](#).

Ethical aspects

The value of [system](#)-level [initiatives](#) relative to their potential for harm, burden, and cost to the stakeholders. Potential harms particularly associated with efforts to improve the quality, safety, and value of healthcare services include [opportunity costs](#), invasion of privacy, and staff distress resulting from disclosure of poor performance.

Generalizability

The likelihood that the [intervention\(s\)](#) in a particular report would produce similar results in other settings, situations, or environments (also referred to as external validity).

Healthcare improvement

Any systematic effort intended to raise the quality, safety, and value of healthcare services, usually done at the [system](#) level. We encourage the use of this phrase rather than “quality improvement,” which often refers to more narrowly defined approaches.

Inferences

The meaning of findings or data, as interpreted by the stakeholders in healthcare services – improvers, healthcare delivery professionals, and/or patients and families

Initiative

A broad term that can refer to organization-wide programs, narrowly focused projects, or the details of specific interventions (for example, planning, execution, and assessment)

Internal validity

Demonstrable, credible evidence for efficacy (meaningful impact or change) resulting from introduction of a specific intervention into a particular healthcare [system](#).

Intervention(s)

The specific activities and tools introduced into a healthcare [system](#) with the aim of changing its performance for the better. Complete description of an intervention includes its inputs, internal activities, and outputs (in the form of a logic model, for example), and the mechanism(s) by which these components are expected to produce changes in a [system's](#) performance.

Opportunity costs

Loss of the ability to perform other tasks or meet other responsibilities resulting from the diversion of resources needed to introduce, test, or sustain a particular [improvement](#) initiative

Problem

Meaningful disruption, failure, inadequacy, distress, confusion or other dysfunction in a healthcare service delivery [system](#) that adversely affects patients, staff, or the [system](#) as a whole, or that prevents care from reaching its full potential

Process

The routines and other activities through which healthcare services are delivered

Rationale

Explanation of why particular [intervention\(s\)](#) were chosen and why it was expected to work, be sustainable, and be replicable elsewhere.

Systems

The interrelated structures, people, [processes](#), and activities that together create healthcare services for and with individual patients and populations. For example, systems exist from the personal self-care system of a patient, to the individual provider-patient dyad system, to the microsystem, to the macrosystem, and all the way to the market/social/insurance system. These levels are nested within each other.

Theory or theories

Any “reason-giving” account that asserts causal relationships between variables (causal theory) or that makes sense of an otherwise obscure [process](#) or situation (explanatory theory). Theories come in many forms, and serve different purposes in the phases of [improvement](#) work. It is important to be explicit and well-founded about any informal and formal theory (or theories) that are used.