

Memory and Cognition Clinic Guidelines

National Service Guidelines for Specialised Dementia and Cognitive Decline Assessment Services in Australia

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Disclaimer: This document provides general guidance based on expert consensus and latest evidence. The clinician's judgement and the client's personal preferences should always be considered when following these Guidelines.



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Memory and Cognition Clinic Guidelines

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Executive summary

Memory and Cognition Clinics (hereafter: MC Clinics) were introduced in Australia in the early 1980s to offer multidisciplinary and specialised assessment of dementia and cognitive decline. They are internationally recognised as the gold-standard for comprehensive dementia assessment and are particularly recommended for people with a complex symptom presentation or a younger disease onset.

There exists substantial variation in the service delivery scope and organisational structure of Australian MC Clinics. This depends on several factors, including the funding model and geographical location of the MC Clinic. For example, in Victoria, MC Clinics were established under the Victorian Department of Health's Health Independence Program in the early 1990s. This centralised approach is not mirrored in other Australian states and territories. Consequently, considerable variability exists in the operational and assessment processes applied at Australian MC Clinics.

To address this variability, ADNeT has developed the first national service Guidelines for MC Clinics that are based on the overarching principles of person-centred care, equity, and respect. The Guidelines provide consensus-based, best-service recommendations for MC Clinics. These recommendations were developed in consultation with researchers, health professionals and Lived Experience Experts, and cover the following areas: pre-assessment considerations, modes of assessment, referral, the clinical interview and diagnostic work-up, neuropsychological assessment, diagnostic biomarkers, case conferencing and communication of diagnosis.

The Guidelines identify common standards for post-diagnostic support and care that should ideally be provided by MC Clinics. The lack of clear post-diagnostic care pathways for people who have recently been diagnosed with dementia is evident in Australia. During the development of these Guidelines, stakeholders agreed that MC Clinics could play an important role in supporting a person after their diagnosis. It was acknowledged that in many cases, a lack of funding impedes the provision of post-diagnostic services. The sections within these Guidelines titled 'Feedback and follow-up' (Section 12) and 'Support, advice, and care after the

diagnosis' (Section 13) outline the minimum post-diagnostic support a MC Clinic should provide, as well as aspirational criteria that may require increased funding.

Following the publication of these Guidelines, a monitoring and quality improvement pilot program will be conducted by the ADNeT-Memory Clinics initiative. A sample of Clinics from across Australia will be recruited to participate in the program, which will incorporate a process of self-assessment, review, and quality improvement.

Overall, these Guidelines aim to ensure that all Australian MC Clinics provide the highest quality of assessment and post-diagnostic care to people with cognitive decline and dementia.

Glossary of Terms

Term	Definition
Allied Health	University qualified health professionals specialised in a particular area that help to prevent, diagnose, and treat impairments and diseases, but who are not part of the medical, dental or nursing profession (e.g., dietitian-nutritionists, exercise physiologists, occupational therapists, physiotherapists, psychologists, social workers and speech pathologists).
Australian Dementia Network (ADNeT) Clinical Quality Registry	A mechanism employed for monitoring and enhancing the quality of healthcare delivered to people diagnosed with either dementia or mild cognitive impairment through the collection, analysis, and reporting of relevant demographic and clinical data.
Biomarkers	Molecules, genes and their derived products that could be found in body fluids or tissues (e.g., cerebrospinal fluid and blood) and are signs of a biological process or a disease. Deficit or accumulation of some of these components is associated with dementia.
Blood-based biomarkers	Proteins (e.g., beta amyloid, tau protein, neurofilament light etc) or other molecules which can be found in blood and are signs of the disease process. Their abnormal quantities inform the presence of a disease or the risk of developing it in the future.
Capacity	A legal concept which describes client's awareness and understanding of their situation, actions, and consequences of said actions, and the ability to make informed decisions regarding any of the assessments and diagnostic procedures based on their understanding.
Care-plan	A written document developed by Memory and Cognition Clinic staff that contains information related to the client's diagnosis, disease management, and the post-diagnostic support recommendations. The care-plan is based on the completed assessments and the needs and wishes of the client and their family/carer (if applicable).
Carer/Care partner	A paid or unpaid person who provides care and assistance with activities of daily living to the client, to whom they may or may not have a family relation.

Case conference	A meeting between the health professionals involved in an assessment to discuss diagnosis, care-plan, and strategies for post-diagnostic care.
Client	A person with cognitive complaints presenting to a Memory and Cognition Clinic for assessment and support.
Clinical Quality Indicator	A specifically defined, measurable item that provide an indication of the quality of care.
Delphi method	A method commonly used to obtain expert opinion on topics that are not subject to empirical research (e.g., agreement on methods, guidelines, and definitions by experts in the field).
DSM-5	Fifth edition of the Diagnostic and Statistical Manual of Mental Disorders, published by the American Psychiatric Association. DSM-5 classes dementia as a 'major neurocognitive disorder' (although retained the term dementia in parentheses) and recognises the earlier stage of cognitive decline as 'mild neurocognitive disorder' (which is similar to the commonly used term 'mild cognitive impairment' [MCI]).
Feedback session	The appointment during which the diagnosis is communicated to the person who had been assessed at the Memory and Cognition Clinic, and the first discussion of post-diagnostic care-planning takes place.
Follow-up session	The appointment during which assessment of the status of the care-plan or referral plan occurs.
Informant	A family member or carer that provides information about the client.
Lived Experience Expert	A person with lived experience of dementia and their care partners, who provided expert input to the Guidelines.
Memory and Cognition Clinic	A multidisciplinary, specialist assessment service for dementia and cognitive decline. The multidisciplinary team may be employed within the Clinic or engaged via established referral networks.
Memory and Cognition Clinic clinicians	Health professionals working at a Memory and Cognition Clinic.
Multidisciplinary team	A multidisciplinary team is comprised of three or more health professionals of different disciplines, who work collaboratively and cooperatively to address multiple aspects of a client's assessment and care needs.

Post-diagnostic support	Support and advice provided to clients after the diagnosis that enables them to better understand, adjust to and live well with the diagnosis. It includes education and support, a care-plan, and evidence-based programs and interventions provided either at the clinic or via referral to external services.
Practice points	These recommendations represent aspirational criteria that might not apply to every Memory and Cognition Clinic, or criteria that may not currently be feasible given the high variability in staffing and financial resources of Memory and Cognition Clinics. A detailed overview of the strength of recommendations can be found in the section titled 'How to use the Guidelines'.
Recommendation	Recommendations that achieved high rates of agreement from health professionals and Lived Experience Experts during the development of these Guidelines. They represent additional criteria deemed to further increase the quality of Memory and Cognition Clinics. A detailed overview of the strength of recommendations can be found in the section titled 'How to use the Guidelines'.
Roving service	A clinical service that operates at different locations to offer easily accessible specialist services in mostly regional and remote areas.
Strong recommendation	Recommendations that achieved the highest level of agreement from health professionals and Lived Experience Experts during the development of these Guidelines. They represent the fundamentals of a good Memory and Cognition Clinic. A detailed overview of the strength of recommendations can be found in the section titled 'How to use the Guidelines'.
Telehealth	A means of administering clinical care remotely using mediums such as the telephone, videoconferencing, or text-based internet messaging.

Abbreviations

Abbreviation	Explanation
ACAT	Aged Care Assessment Team
ADNeT	Australian Dementia Network
AI	Associate Investigator
APD	Accredited Practising Dietitian
BPSD	Behavioural and Psychological Symptoms of Dementia
CDAMS	Cognitive Dementia and Memory Service
CSF	Cerebrospinal fluid
CI	Clinical Investigator
СТ	Computer Tomography
DSM-5	Diagnostic and Statistical Manual of Mental Disorders, 5 th edition
GP	General Practitioner
IADL	Instrumental Activities of Daily Living
LGBTQIA+	Lesbian, Gay, Bisexual, Transgender, Queer, Intersex, and Asexual and other non-cis gendered identities
MCI	Mild Cognitive Impairment
MRI	Magnetic Resonance Imaging
MSNAP	Memory Service National Accreditation Programme
NHMRC	National Health and Medical Research Council
NNIDR	National Health and Medical Research Council's National Institute for Dementia Research
PET	Positron Emission Tomography
РР	Practice Point
R	Recommendation
SR	Strong Recommendation

Introduction

<u>Scope</u>

These Guidelines were developed to establish national service recommendations for Australian Memory and Cognition Clinics. For these Guidelines, a MC Clinic is defined as a multidisciplinary, specialist assessment service for dementia and cognitive decline. The multidisciplinary team may either be employed within the clinic or engaged via established and timely referral networks.

It is acknowledged that dementia is diagnosed in multiple clinical settings, including hospitals, private specialist clinics, memory clinics, general practices, community health services and residential care. The first Australian Clinical Guidelines and Principles of Care for People with Dementia recommends a referral to 'memory assessment specialists or services for a comprehensive assessment' to all people with a suspected diagnosis of dementia (recommendation 25)¹. Multidisciplinary, dedicated MC Clinics are internationally regarded as the gold-standard for a comprehensive dementia assessment. These Guidelines are aimed at all existing MC Clinic models and settings in Australia, including metropolitan and regional, public and private, hospital-based, and community/primary care-based, and research clinics.

Rationale and aims of the Guidelines

There are currently no national service guidelines that seek to standardise and harmonise the clinical practice and diagnostic processes across Australian MC Clinics. Harmonisation of service delivery and practices is important to:

- 1) ensure equity of access to care,
- 2) communicate expected standards of care, and
- 3) assist with the development and expansion of services to meet international standards.

Thus, the primary aim of these Guidelines is to foster best-practice and standardisation of services.

Nature of the Guidelines

The proposed Guidelines represent the consensus of a group of stakeholders, including:

- 1) Australian health professionals working at specialised dementia assessment services,
- 2) Leading national dementia experts, and
- 3) People with the lived experience of dementia and their care partners.

Importantly, these Guidelines represent 'ideal' or best-practice service provision. Consequently, it is not expected that all MC Clinics would currently meet every recommendation. The Guidelines also cover the seven major Clinical Quality Indicators (CQIs) which were developed following a separate scoping review and a modified Delphi process for the ADNeT Registry². CQIs are specifically defined, measurable items which provide an indication of the quality of patient care³. They are used to assess health care processes and outcomes, and to monitor, evaluate, benchmark, and improve the quality of patient care and interventions that impact patient outcomes⁴. The CQIs support the ADNeT Registry in its aim of collecting and analysing data to monitor and enhance the quality of care for Australians diagnosed with either dementia or MCI.

Further to the quality assurance work performed by the ADNeT Registry, these Guidelines aim to provide a basis on which barriers and opportunities for further service development or improvement can be identified, quantified, and reported. To facilitate this process, a monitoring and quality improvement pilot program will be developed and launched following the publication of these Guidelines.

The Guidelines should always be used in the context of the overarching principles that guide every assessment (outlined below).

Overarching principles

A) This document offers general recommendations for MC Clinics. All services should provide person-centred assessment, care and intervention that is tailored to each client's unique needs.

B) MC Clinics should strive to ensure equal access to assessment, care, and interventions for all people with a suspected dementia or cognitive decline irrespective of their

gender, age, ethnicity, sexual orientation, intellectual ability, as well as developmental, socioeconomic, cultural, and linguistic background.

C) MC Clinics should ensure that each client is treated with respect. Each clinician should acknowledge and respects the client's wishes, recognising that every individual has a unique experience of dementia or cognitive decline and will be affected differently.

Intended users

These Guidelines are intended for all medical specialists, nurses, aged care workers, and allied health professionals with expertise in dementia, who are regularly involved in the assessment and care of people with cognitive decline and dementia as part of a specialist, multidisciplinary team. They are also applicable to clinic managers and administrators.

Clinical population

The clinical population covered in the Guidelines is people with cognitive decline or dementia and their care partners. It extends to people living in Residential Aged Care, Nursing Homes, Assisted Living and Retirement villages who may need a specialised, multidisciplinary assessment.

Please note that cognitive impairments that are neurodevelopmental, stable after an acute brain insult, or in association with a primary psychiatric disorder (such as traumatic brain injury, schizophrenia, bipolar disorder, depression, etc.) are **not covered** in these Guidelines. Each Clinic should utilise its discretion regarding the circumstances in which such individuals may be assessed and supported.

The Guidelines recognise the distinct and diverse needs of Aboriginal and Torres Strait Islander people, people with a culturally and linguistically diverse (CALD) background, people with an intellectual disability, and the Lesbian, Gay, Bisexual, Transgender, Questioning/Queer, Intersex, Asexual and other non-cisgender (LGBTQIA+) community. It is important to highlight that all Guidelines equally apply to these groups. However, to ensure that their specific needs are sufficiently addressed, the ADNeT-Memory Clinics team will be conducting further scoping work for these groups to expand the next iteration of the Guidelines.

Background

Dementia currently affects approximately between 386,200 and 472,000 people in Australia⁵. In the coming decades, the prevalence is projected to grow exponentially due to the increasing ageing population. Dementia is the single greatest cause of disability in older Australians and the second leading cause of death in Australians. It constitutes a major healthcare, psychological, societal, and economic burden⁶. The rising incidence of dementia highlights the need for tools and systems to support earlier diagnosis and interventions⁷.

Dementia care is varied and inconsistent across Australia, with significant heterogeneity in service accessibility, diagnostic processes, assessment procedures, and effectiveness of clinical care⁸⁻¹⁰. Additionally, dementia is currently diagnosed in several settings outside of MC Clinics, including general practices, hospitals, private specialist practices (e.g., geriatricians, old age psychiatrists, neurologists), community health services, and in residential care¹¹. The lack of a clear diagnostic pathway and access to information and support often leads to delays in the diagnostic process. Early stages of the disease, young onset dementia, and dementia types other than Alzheimer's disease are particularly likely to receive a delayed diagnostic and care outcomes in early and complex symptom presentations, evidence supports a multidisciplinary, specialist approach¹³. The Australian Clinical Practice Guidelines and Principles of Care for People with Dementia particularly recommend referral to comprehensive memory services for dementia diagnosis¹.

MC Clinics are specialised multidisciplinary services established for the comprehensive assessment of patients with dementia and cognitive decline. The number of MC Clinics has continuously increased since their first appearance in Australia in the 1980s. However, MC Clinics significantly differ in their organisation, funding, staffing, diagnostic protocols, and levels of service across the country^{8,10}. Patients living in rural and remote Australia do not have easy access to specialist services and multidisciplinary teams¹⁴. Their care needs are often inadequately addressed by the current models of care, and delivering standardised, consistent services nation-wide remains a significant challenge.

Most MC Clinics, like the state-funded Cognitive Decline and Memory Services (CDAMS) in Victoria, are explicitly commissioned to focus on diagnostic assessment with little to no funding

for post-diagnostic care. Australian health service data shows that there are no clear postdiagnostic referral pathways. Specialists and primary care services involved in the ongoing care of people with dementia display little collaboration or awareness of available programs. Accordingly, the patients' access to appropriate health service information, support, and interventions is impeded¹⁵. Given the specialist knowledge of MC Clinic clinicians and their close relationship to research, MC Clinics are ideally positioned to offer broader dementia health education, non-pharmacological interventions, and referrals to existing post-diagnostic support programs. However, to optimise their service provision, MC Clinics would require further funding, coupled with greater harmonisation and agreement on service standards.

Over the past decade, various publications have been released in Australia to improve the quality of dementia assessment and care, in particular the above-mentioned Clinical Practice Guidelines and Principles of Care for People with Dementia¹ and the Cognitive Dementia and Memory Service Best Practice Guidelines: Service Guidelines for Victorian Cognitive Dementia and Memory Services¹⁶. While these publications have sought to improve the quality and consistency of care, there is no nationally consistent guideline or accompanying auditing framework. To meet the healthcare needs of the growing cohort of people with dementia and cognitive decline, boosting multidisciplinary collaboration and establishing networks between MC Clinics and primary healthcare services, aged care, dementia, and other relevant support services is crucial⁷.

The ADNeT 'Memory and Cognition Clinic Guidelines: National Service Guidelines for Specialised Dementia and Cognitive Decline Assessment Services in Australia' is an attempt to provide a coordinated approach to circumvent the key barriers highlighted above. It is published with an overarching view to optimise care quality, support continuity of care, and improve patient outcomes and quality of life. The Guidelines aim to bring about greater harmonisation of MC Clinic procedures, including the diagnostic standards and post-diagnostic support pathways. This will endeavour to offer services that are best equipped to provide consistent, evidence-based, and high-quality care to all patients, regardless of their geographic location and socio-economic circumstances.

An auditing framework, which is currently under development, will be published after the Guidelines. It will provide an overview on how far Australian MC Clinics are able to implement

these Guidelines. This data will be valuable to identify resource needs and service gaps and could be used to inform policy changes.

Approach to developing the Guidelines

<u>Overview</u>

The Guideline recommendations have been developed based on a literature review and extensive consultation with a range of relevant stakeholders.

Literature review

Published literature pertinent to memory services and dementia care was thoroughly reviewed. This included the previously published guidelines:

- UK Memory Service National Accreditation Programme (MSNAP) Standards for Memory Services (Abhayaratne et al., 2020);
- Clinical Practice Guidelines and Principles of Care for People with Dementia (NHMRC Partnership Centre for Dealing with Cognitive and Related Functional Decline in Older People, 2016);
- Cognitive Dementia and Memory Service (CDAMS) Best Practice Guidelines (Victorian Department of Health, 2013).

The review focused on publications after the 2016 'Clinical Practice Guidelines and Principles of Care for People with Dementia' comprehensive systematic literature review. This ensured that the Guidelines represent the already agreed-upon practice standards, as well as recent developments in dementia assessment and post-diagnostic care.

Stakeholder consultation

The Delphi method is commonly used to obtain expert opinion on topics that are not subject to empirical research (e.g., agreement on methods, guidelines, and definitions by experts in the field). Delphi methods employ questionnaires to gather expert opinion, interspersed with rounds of feedback, until consensus is reached on all items¹⁸.

Four (4) rounds of alternating input (in the form of questionnaires) and feedback (in the form of questionnaires and consensus meetings) were conducted with the stakeholder groups. The

development of the Guidelines employed two separate processes based on the input of the target groups:

- 1) Health Professionals working in MC Clinic settings;
- 2) Lived Experience Experts

Sub-dividing the Delphi process allowed the tailoring of materials to each stakeholder group to ensure that their input was used most effectively. The two processes were then consolidated in the final stage of the developmental process (see Figure 1).

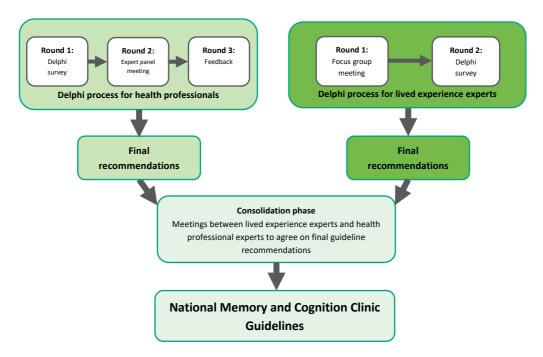


Figure 1: Parallel Delphi processes to obtain feedback from health professionals and Lived Experience Experts.

Health Professional Delphi Process

Based on the literature review, an online questionnaire was developed and administered in Round 1 of the Health Professional consultation process. Information was obtained on the current clinical landscape of Australian MC Clinics and the clinicians' opinions on ideal practices. This assisted in identifying gaps in current clinical practice. The questionnaire targeted topics related to the definition of a MC Clinic, their organisational structure (e.g., clients' profile, waiting times), assessment procedures (e.g., assessment protocols, diagnostic decision making) and post-diagnostic care (e.g., follow-up appointments, cognitive interventions). The questionnaire was distributed through the ADNeT's wide professional network, Dementia Australia, and the Queensland state-wide Dementia Network. A total of 100 responses were received.

Since the full complexity of each topic could not be covered by a questionnaire, the items were further discussed during the Round 2 Expert Panel meetings which involved 25 national experts from the existing ADNeT professional network. These experts came from six different states (NSW, QLD, SA, TAS, VIC, and WA) and covered a variety of professions including geriatricians, psychologists, neurologists, neuroscientists, general practitioners, registered nurses, and a range of allied health professionals. Two three-hour virtual meetings were conducted.

Based on the results of Rounds 1 and 2 and a complementary literature review, an initial list of service Guidelines was developed. Round 3 involved a feedback survey, which sought feedback on all recommendations and agreement on the previously contentious items. This survey was distributed to participants who completed the Round 1 survey and consented to be involved in Round 3.

Lived Experience Experts Delphi Process

In a parallel Delphi process, input was obtained from Lived Experience Experts. In Round 1, 13 Lived Experience Experts were invited to one 90-minute virtual Focus Group meeting. Some Lived Experience Experts had previously been engaged in the NNIDR-Community and Consumer Involvement Reference Group (CCIRG). Others were recruited through Dementia Australia and within the network of the ADNeT Consumer Involvement Officer. The participants discussed their assessment experience, the way the diagnosis was communicated to them, and the support they received in the year post-diagnosis. They were further questioned about how their experience could have been improved.

Based on these discussions, 24 potential recommendations regarding the assessment process, post-assessment feedback, and ongoing post-diagnostic support were formulated. The recommendations were reviewed by the Focus Group members and embedded in a questionnaire that constituted Round 2 of the Lived Experience Experts Delphi process. With the help of Dementia Australia and Alzheimer's Western Australia, the survey was distributed across Australia. The survey was completed by 73 participants. Recommendations that reached 70% agreement were incorporated into the preliminary Guidelines.

Unlike the Health Professional Delphi, the Lived Experience Experts process did not involve a subsequent feedback round, as the participants were able to provide sufficient input during Round 1. This was followed by a high level of agreement on all items during Round 2. Overarching approval of these recommendations took place during the final Consensus and Consolidation Meetings.

Final Consensus and Consolidation Meetings

The last Delphi round comprised two 90-minute consolidation meetings, the purpose of which was to reach agreement on a final list of Guidelines among all stakeholders. The meetings were attended by the Expert Panel members from Round 2, Lived Experience Experts from Round 1, and the ADNeT-Memory Clinics research team. Any items that remained contentious following the meeting were reworked and sent back to all stakeholders via short REDCap polls. The feedback from the meetings and the polls was implemented to form the final set of Guidelines.

How to use the Guidelines

Recommendation Types

The full set of Guidelines represents broad consensus on the ideal practices of a MC Clinic. It is unlikely that every service would be able to meet every recommendation. The recommendations are categorised to facilitate the implementation of the Guidelines into clinical practice. The categories are as follows:

Recommendation Type	Definition
	These recommendations represent the fundamentals of a good Memory and Cognition Clinic.
Strong recommendation (SR)	They achieved the highest level of agreement (>70% of responses were within the "high agreement" rating on the Likert scale) during the Delphi Process.
	It is expected that all Memory and Cognition Clinics would be able to meet these recommendations, independent of their location and financial resources.
	These recommendations represent criteria that further increase the quality of a Memory and Cognition Clinic.
Recommendation (R)	These recommendations achieved a moderate to high level of agreement (>70% of responses were between "medium" and "high agreement" ratings on the Likert Scale).
	It is expected that most Memory and Cognition Clinics would be able to meet these recommendations if sufficient resources were available.
Practice point (PP)	These recommendations represent <u>mostly aspirational</u> <u>criteria</u> . They might not apply to each clinic or might be currently unfeasible given the highly variable staffing and financial resources of Australian Clinics.

All recommendations that were developed during the Delphi process of people with the lived experience of dementia and their care partners are marked with an asterisk (*).

Some recommendations include a *guidance* statement to provide further information on how a particular criterion could be implemented into clinical practice.

Guidelines Distribution

The Guidelines will be distributed through the ADNeT newsletter. They will also be available for download and in the online format on the ADNeT– Memory Clinics webpage:

https://www.australiandementianetwork.org.au/initiatives/memory-clinics-network/

Implementation and Evaluation Plan

Broad implementation of the Guidelines is crucial to achieve an overall improvement and a greater harmonisation of MC Clinics. Following publication of the Guidelines, a pilot monitoring and quality improvement program will be conducted by the ADNeT-Memory Clinics team. At least one (1) MC Clinic from each state and territory will be engaged to pilot the self-review process.

The pilot program will include a mix of government and privately funded MC Clinics, located in metropolitan or regional areas. The sample will include MC Clinics with a multidisciplinary team and those that utilise an established referral network to offer multidisciplinary assessments and interventions.

Following the recruitment phase, an online training session will be conducted for the participating pilot Clinics. This will provide Clinic staff with additional information about the purpose of the pilot program, its methodology, the self-assessment and quality improvement frameworks, and the reporting process that ADNeT will use.

The pilot Clinics will then undertake a self-assessment process using an online framework. For each Guideline, Clinics will be asked to report the extent to which it has been achieved using one of four pre-determined indicators: achieved / in progress / not achieved / not applicable. The framework will also allow the Clinics to upload relevant documentation as evidence of their adherence to the recommendations (or progress toward meeting).

If a Clinic is unable to meet a recommendation or deems it not applicable, they will be asked to provide a reason. This information will assist ADNeT to identify barriers to service delivery within the MC Clinic setting and discuss opportunities for future improvement. The framework will also incorporate a quality improvement section. ADNeT will aim to review Clinics based on these planned improvements approximately one-year after completion of the initial selfassessment process.

The Clinics will be supported throughout the pilot program by staff from the ADNeT-Memory Clinics initiative. When the data has been collated and reviewed by ADNeT, an online meeting will be convened with the pilot Clinics to share the initial findings. This meeting will also allow for discussion about adjustments to the Guidelines, as well as the accompanying audit methodology and tools. A summary report will be prepared and disseminated to each pilot Clinic and an overarching evaluation report will be published by ADNeT. Following the pilot program, a nation-wide roll out of a monitoring and quality improvement program for all MC Clinics is planned.

National map of cognitive decline assessment services

The ADNeT-Memory Clinics Initiative has launched a national map of various cognitive decline assessment services, including Memory and Cognition Clinics, solo private practitioners, and neuropsychology clinics. The purpose of the map is to facilitate access to specialised dementia assessment services and to establish a national network with linkages between infrastructures. Since its launch, the map has become a useful tool for health professionals, GPs, and the general public. The map can be found on the ADNeT-Memory Clinics webpage:

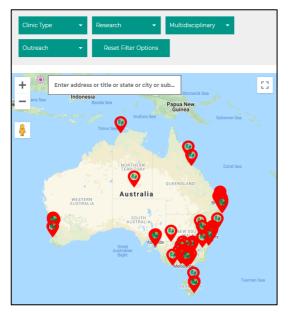


Figure 2: ADNeT national map

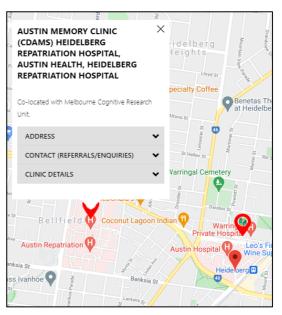


Figure 3: Detailed view of clinic's information

The map can be accessed on the ADNeT website at:

https://www.australiandementianetwork.org.au/initiatives/memory-clinics-network/

Section 1

Main functions of a Memory and Cognition Clinic

Key points

- Memory and Cognition Clinic provides:
 - o specialist multidisciplinary assessment
 - general and evidence-based support after diagnosis
 - o education on dementia

We have an opportunity to state what we ideally want for best practice, rather than being constrained by current resources.

- Delphi Panel Health Professional



Main functions of a Memory and Cognition Clinic		
Number	Standard/Criterion	Level
1.1	A specialised Memory and Cognition Clinic is characterised by several r functions that make it distinct from other services that provide assess dementia and cognitive decline (e.g., GP services).	
1.1.1	• The clinic offers specialist assessment of dementia and cognitive decline.	SR
1.1.2	• The clinic employs a multidisciplinary team. Guidance: When required, a comprehensive and multidisciplinary assessment may be offered either via 1) the multidisciplinary team employed within the clinic, or 2) cross-referrals within the established referral networks (e.g., neuropsychologists, nurses, allied health professionals) in the local catchment area.	SR
1.1.3	 The service is able to provide general advice and support after the diagnosis, as well as post-diagnostic support in the form of evidence-based programs, either at the clinic or via timely referral to other services and allied health support. Guidance: Please refer to Section 13 "Support and advice" for further guidance around the provision of post-diagnostic care. 	R
1.1.4	• The service offers education on dementia to general practitioners and the general public.	PP

SR (Strong recommendation) – fundamentals of a good Memory and Cognition Clinic

R (Recommendation) – criteria that further increase the quality of a Memory and Cognition Clinic PP (Practice Point) – aspirational criteria

Section 2



Key point

• Face-to-face and Telehealth modes of assessments are offered



What about rural and remote people? There isn't always access to public or private clinics in the cities, some people can't afford travel.

– Person living with dementia



	Modes of assessment	
Number	Standard/Criterion	Level
2.1	Memory and Cognition Clinic offers different modes of appointments their services as accessible as possible:	s to make
2.1.1	Face-to-face appointments	SR
2.1.2	• Appointments via Telehealth* Guidance: Lived Experience Experts particularly endorse this option when they cannot get to the clinic easily. Telehealth includes telephone, videoconferencing or other communication media that permit remote assessments and care.	SR*
2.1.3	 A roving clinical service Guidance: A roving clinic describes a clinical service that operates at different locations to offer easily accessible specialist services in mostly regional and remote areas. Memory and Cognition Clinic is encouraged to consider how to improve their service accessibility for people in the regional and remote areas within their catchment area It is suggested that a face-to-face appointment with a client in the regional or remote area is followed-up with a Telehealth appointment, if possible and appropriate. 	R

SR (Strong recommendation) – fundamentals of a good Memory and Cognition Clinic

R (Recommendation) – criteria that further increase the quality of a Memory and Cognition Clinic

^{(*) –} criteria particularly endorsed by people with lived experience of dementia and their care partners

Section 3



Key points

- A referral from a GP or other health professional is preferred
- Prioritisation of referrals is encouraged
- An initial assessment should be conducted within no more than:
 - o 30 days of receipt of the referral for high-priority clients
 - o 90 days for routine-priority clients

Need to allow self-referrals – we can't deny any people. But good to get a GP involved to allow a feedback loop.

– Delphi Panel Health Professional



	Referral process	
Number	Standard/Criterion	Level
3.1	Memory and Cognition Clinic has clear guidelines for accepting referrals and a framework for prioritising the accepted referrals. Guidance: For example, clinics may choose to decline a referral if the cognitive problems are clearly within the context of a psychiatric disorder, non-progressive brain disease with no evidence of decline, traumatic brain injury and/or alcohol dependence, etc.	R

Referral process		
Number	Standard/Criterion	Level
3.2	Referrals to Memory and Cognition Clinic can be accepted from multiple	e sources:
3.2.1	• GP or a medical specialist Guidance: This is the preferred referral source.	SR
3.2.2	• Self-referrals Guidance: The GP's endorsement of the self-referral or general involvement of the GP should be encouraged to ensure ongoing support after the Memory and Cognition Clinic assessment.	R
3.2.3	• Other health professionals Guidance: This may include, but is not limited to, nurse practitioners, allied health and the Aged Care Assessment Team (ACAT).	R

SR (Strong recommendation) – fundamentals of a good Memory and Cognition Clinic

R (Recommendation) – criteria that further increase the quality of a Memory and Cognition Clinic

	Referral process		
Number	Standard/Criterion	Level	
3.3	A highly specialised Memory and Cognition Clinic assessment is only wa under specific circumstances.		
	Triggers for a Memory and Cognition Clinic assessment include:		
	Guidance: Generally, a Memory and Cognition Clinic assessment would not be indicated for clients who have received a prior dementia diagnosis and for whon their dementia has progressed well past the early/mild stage, their dementio subtype was considered clear, and for which there are no novel referral questions		
	Clients who present with non-dementia related cognitive decline (e.g., which can be clearly associated with an acute stroke or traumatic brain injury) may be referred on to a different diagnostic service.		
	However, accepting these clients is left up to the discretion of the Me Cognition Clinic.	mory and	
3.3.1	• A client presents with a potential diagnosis of young onset dementia.	SR	
3.3.2	• A differential diagnosis of dementia (e.g., specific syndrome) is required.	SR	
3.3.3	• A client shows a complex symptom presentation.	SR	
3.3.4	 Longitudinal tracking of cognitive problems at potentially prodromal stages of dementia/MCI is required. 	SR	
3.3.5	• A client presents with behavioural and/or personality changes. Guidance: This includes behavioural and psychological symptoms of dementia (BPSD) such as, but not restricted to depressive symptoms, anxiety, apathy, agitation, sleep problems, psychosis irritability, and wandering.	SR	

SR (Strong recommendation) – fundamentals of a good Memory and Cognition Clinic

3.3.6	• There is evidence of risk factors for dementia in the presence of subjective cognitive complaints.	SR
	Guidance: Examples of risk factors may include a strong family history of dementia, diabetes, history of smoking, heavy alcohol use or other substance use.	
3.3.7	• There is evidence for rapid cognitive decline.	SR
3.3.8	 A client presents with progressive cognitive problems and / or progressive cognitive problems are reported by a family member, care partner or other informant close to the client. Guidance: This may include subjective memory complaints. 	R

	Referral process	
Number	Standard/Criterion	Level
3.4	To adequately process a referral, Memory and Cognition Clinic ensur- relevant information is received, including:	res that all
	Guidance: This includes information that is required to assess the appro of a referral, as well as prioritisation. The information can be received fr sources, including the referring health professional, client, and care par	om various
3.4.1	Demographic information	SR
3.4.2	• Client's preferred spoken language, language abilities, and the need for an interpreter	SR
3.4.3	Main symptoms	SR
3.4.4	• Progression of symptoms (e.g., rapid decline, no decline noticed)	SR
3.4.5	Medical and psychiatric history	SR
3.4.6	A list of current medications	SR

SR (Strong recommendation) – fundamentals of a good Memory and Cognition Clinic

R (Recommendation) – criteria that further increase the quality of a Memory and Cognition Clinic

3.4.7	Family history	R
3.4.8	Presence of behavioural and/or psychological symptoms	R
	Guidance: This includes BPSD such as, but not restricted to depressive symptoms, anxiety, apathy, agitation, sleep problems, irritability, and wandering.	
3.4.9	Blood test results	R
	Guidance: Core blood tests are undertaken <u>ideally</u> within 3 months or <u>within a maximum</u> of 12 months prior to referral or at the time of the diagnosis.	
	This also forms a Clinical Quality Indicator for the ADNeT Clinical Quality Registry.	
3.4.10	Imaging results	R
	Guidance: Structural neuroimaging is completed <u>ideally</u> within 3 months or <u>within a maximum</u> of 12 months prior to referral or at the time of the diagnosis.	
	This also forms a Clinical Quality Indicator for the ADNeT Clinical Quality Registry.	
3.4.11	Reports by other specialists or previous investigations	R
3.4.12	Information about safety concerns for the client or family/carer	R
3.4.13	Results of cognitive screening	РР
3.4.14	Information regarding the clients support network	РР
	Guidance: This may include information about the client's living situation (e.g., living alone, home care), as well as information about the actual and potential carer burden.	

R (Recommendation) – criteria that further increase the quality of a Memory and Cognition Clinic PP (Practice Point) – aspirational criteria

3.4.15	• Hearing status Guidance: This includes information about the need for hearing aids or other hearing impairments that might affect the assessment.	PP
3.4.16	• Vision Guidance: This includes information about the need for glasses or other visual impairments that might affect the assessment.	PP

PP (Practice Point) – aspirational criteria

	Referral process	
Number	Standard/Criterion	Level
3.5	Memory and Cognition Clinic is encouraged to prioritise the referrals th to optimise the case flow.	ey receive
	Under the following circumstance a referral is regarded as "high priorit	y":
	Guidance: Any of the criteria from 3.5.1 to 3.5.7 in isolation could be a sufficient to define the client as "high priority". The precise criteria for priority client" are up to the discretion of the Memory and Cognition of and may change depending on evolving circumstances and the capac clinic. Conversely, the definition of a "routine priority" client may similar	or a "high- Clinic staff city of the
3.5.1	• Safety concerns in the current living situation (for client or family/carer)	SR
3.5.2	Suspected self-neglect or abuse	SR
3.5.3	• Clients who care for others (e.g., parents of young children, carers of a person with disability, etc.)	SR
3.5.4	Rapid cognitive decline	SR
3.5.5	Significant carer burden and stress	SR
3.5.6	• Other safety concerns (e.g., driving, depression symptoms)	SR
3.5.7	Clients with a suspected diagnosis of young onset dementia	SR

SR (Strong recommendation) – fundamentals of a good Memory and Cognition Clinic

	Referral process
Number	Standard/Criterion Level
3.6	Memory and Cognition Clinic ensures timely access to assessment and diagnosis.

For high priority clients, Memory and Cognition Clinic provides an initial appointment:

3.6.1	• Within 30 days of referral* Guidance: Lived Experience Experts highlighted that an appointment should be provided within a month after they first contact the Memory and Cognition Clinic.	SR*
3.6.2	Ideally, within 14 days of referral	РР

For routine priority clients, Memory and Cognition Clinic provides an initial appointment:

3.6.3	Within 90 days of referral	SR
	This also forms a Clinical Quality Indicator for the ADNeT Clinical Quality Registry.	
3.6.4	Within 60 days of referral	R
3.6.5	• <u>Ideally</u> , within 45 days of referral	PP

SR (Strong recommendation) – fundamentals of a good Memory and Cognition Clinic

R (Recommendation) – criteria that further increase the quality of a Memory and Cognition Clinic PP (Practice Point) – aspirational criteria

^{(*) -} criteria particularly endorsed by people with lived experience of dementia and their care partners



Key points

- Before the assessment, written information is provided on:
 - O the type, purpose, and duration of the assessment
 - O waiting times
 - O costs
 - O general information relating to the assessment

As a patient, we need an option of support material between initial call and meeting. Three months is ages to wait when you are worried and scared!

– Person living with dementia



	Prior to the assessment	
Number	Standard/Criterion	Level
4.1	Prior to the assessment, Memory and Cognition Clinic provides information about the assessment process to their clients. * This information includes:	s written
4 1 1		CD#
4.1.1	 Types and purpose of the assessment 	SR*
4.1.2	Waiting times	SR*
	Guidance: If a booking has not been made, the Memory and Cognition Clinic staff should provide approximate waiting times to the clients with a brief explanation of potential delays. Staff members should emphasise to the clients that the waiting times depend on a variety of factors, and, thus, can vary from the suggested ones.	
4.1.3	Assessment costs and duration	SR*
4.1.4	 General information relevant to the appointment Guidance: This includes information about: The names of staff members the client will see on the day Location and parking or public transport access (e.g., map) What to bring for the appointment (especially glasses, hearing aids, and medication) 	SR*
4.2	Memory and Cognition Clinic supports clients and care partners de waiting time for an initial assessment, if required.	uring the
4.2.1	• Memory and Cognition Clinic can provide a referral to an experienced counsellor in case the client or care partner expresses distress during the waiting time for the initial assessment and requires support.	SR*

SR (Strong recommendation) – fundamentals of a good Memory and Cognition Clinic

^{(*) -} criteria particularly endorsed by people with lived experience of dementia and their care partners



Key points

- The clinical interview is conducted to identify client's needs, hopes, and wishes
- Relevant information is obtained about the client to inform the diagnosis and the post-diagnostic care-plan



	Initial clinical interview	
Number	Standard/Criterion	Level
5.1	Memory and Cognition Clinic ensures that a clinical interview is conduc	ted.
5.1.1	 Memory and Cognition Clinic staff arrange an interview with the client to identify their needs, hopes, and wishes for the Memory and Cognition Clinic assessment independently from others (e.g., separate interview from the carer). Guidance: This should not occur if the client declines the opportunity and wishes for their carer/informant to remain with them for the duration of the interview. 	SR
5.1.2	 Memory and Cognition Clinic staff arrange an interview with someone who knows the client well (informant). Guidance: This only occurs if the client consents to the clinic staff speaking with the informant, who was preferably identified by the client. This interview should also identify the family's/carer's hopes and wishes for the Memory and Cognition Clinic assessment. 	SR

	Initial clinical interview	
Number	Standard/Criterion	Level
5.2	The clinical interview is conducted to obtain relevant information about to inform the diagnosis and the post-diagnostic care-plan. Topics for the initial clinical interview include:	the client
5.2.1	• Demographic information Guidance: This includes information about the client's place of birth, spoken languages, education, relationship status, and employment.	SR
5.2.2	• Detail of the nature, onset, and progress of cognitive complaints	SR

SR (Strong recommendation) – fundamentals of a good Memory and Cognition Clinic

5.2.3	• Medical and psychiatric history Guidance: Details of conditions associated with cognitive impairment are particularly pertinent. This may include but is not limited to vascular risk factors, head injury, neurological disorders, depression, and thyroid abnormalities.	SR
5.2.4	• Possible risk factors Guidance: Examples of risk factors may include a strong family history of dementia, diabetes, history of smoking, and heavy alcohol or other substance use.	SR
5.2.5	• Presence of depression or anxiety symptoms Guidance: Where possible, an assessment of depression should be completed using a standard screening tool in addition to the clinical interview.	SR
5.2.6	 Presence of psychotic symptoms including hallucinations and delusions Guidance: It is also recommended to screen for the presence of other BPSD such as, but not restricted to, apathy, agitation, irritability, and wandering. 	SR
5.2.7	• Sleep disturbance Guidance: Where possible, a sleep assessment should be completed using a standard screening tool in addition to the clinical interview.	SR
5.2.8	• Nutrition/diet Guidance: Where possible, a malnutrition risk assessment should be completed using a standard screening tool and, if indicated, a referral made to a dietitian-nutritionist with expertise in dementia and preferably an Accredited Practising Dietitian (APD).	SR
5.2.9	Mobility and falls	SR

SR (Strong recommendation) – fundamentals of a good Memory and Cognition Clinic

5.2.10	Current medications	SR
	Guidance: Staff is generally encouraged to confirm the information on current medications provided at the time of referral and obtain any missing information. Staff is further encouraged to discuss the ability to manage medications safely and review the use of any dosing aids.	
5.2.11	• Family history Guidance: Particularly relevant is the family history of mental health issues, neurological disorders, dementia, as well as the corresponding ages of onset.	SR
5.2.12	Client's social support	SR
5.2.13	Client's everyday functioning	SR
5.2.14	Driving	SR
5.2.15	Legal issues	SR
	Guidance: This point pertains only to potential legal issues that may influence the assessment and the post-diagnostic care-plan. Informed consent should be sought for the assessment and development of a care-plan and, if needed, the capacity of the client with regard to this should be tested (see 7.2.8). Clinic staff should enquire about the presence of a current substitute decision maker. Other forms of capacity, including testamentary capacity, would generally not be assessed during the clinical interview.	
5.2.16	Advance care-plans	R
5.2.17	Physical activity engagement and routine	R

SR (Strong recommendation) – fundamentals of a good Memory and Cognition Clinic

R (Recommendation) – criteria that further increase the quality of a Memory and Cognition Clinic



Key point

- Memory and Cognition Clinic offers a holistic diagnostic work-up, including assessing multiple cognitive domains and IADLs, and utilises neuroimaging results in formulating the diagnosis
 - Organise the full range of assessment, diagnostic, therapeutic, and rehabilitation services to accommodate the needs of people with different types and severities of dementia, as well as the needs of their carers and families.

- Person living with dementia



	Diagnostic work-up	
Number	Standard/Criterion	Level
6.1	Memory and Cognition Clinic offers a holistic diagnostic work-up.	
6.1.1	 Multiple cognitive domains are tested. Guidance: Cognitive testing needs to be tailored to the client's cultural and educational backgrounds and to their presenting symptoms. Assessments by a neuropsychologist should be considered as required (see section 7.2 for further guidance around the circumstances that may warrant a neuropsychological assessment). Assessments by additional allied health professionals (e.g., Speech Pathologists) should be considered as required. This also forms a Clinical Quality Indicator for the ADNET Clinical Quality Registry. 	SR
6.1.2	 A person's ability to undertake personal and instrumental activities of daily living (IADL) are assessed. Guidance: Under some circumstances, an occupational therapist with expertise in dementia is consulted to conduct a standardised performance-based assessment to clarify domains and extent of functional impairment. These circumstances include but are not limited to 1) a client presenting with mild functional impairment and good cognitive test scores; 2) reliable information on the client's IADL not being available. This also forms a Clinical Quality Indicator for the ADNeT Clinical Quality Registry. 	SR
6.1.3	• Result of all investigations including neuroimaging is considered when making the diagnosis.	SR

SR (Strong recommendation) – fundamentals of a good Memory and Cognition Clinic

2 Neuropsychological assessment

Key points

- Neuropsychological services should be made available within the clinic or via established referral pathways
- Neuropsychological testing will not be required in all circumstances

Neuropsychology is not always readily available in all settings in Australia either - alas!! Would be great to have more access all around.

– Delphi Panel Health Professional



	Neuropsychological assessment	
Number	Standard/Criterion	Level
7.1	Memory and Cognition Clinic is able to offer neuropsychological servente clinic or via established referral pathways to an accessible, available service. The following neuropsychological services are made available:	
7.1.1	• Specialised neuropsychological assessment for diagnosis Guidance: This includes but is not limited to the assessment of multiple cognitive domains, as well as mood, behaviour, sleep, and everyday functioning.	SR
7.1.2	• Behavioural assessments Guidance: While specialised neuropsychological assessment includes a general assessment of behaviour changes via questionnaires and/or clinical interview, a behavioural assessment is a more detailed, individualised breakdown of the client's BPSD including contexts, triggers, consequences (such as the A-B-C model of Antecedent, Behaviour, Consequence). A behavioural assessment informs post- diagnostic intervention strategies with individualised recommendations and education for the client, family, carers, and allied health professionals.	SR
7.1.3	• Non-pharmacological post-diagnostic support Guidance: This may include evidence-based cognitive interventions and cognitive or memory strategies.	R

SR (Strong recommendation) – fundamentals of a good Memory and Cognition Clinic

R (Recommendation) – criteria that further increase the quality of a Memory and Cognition Clinic

	Neuropsychological assessment	
Number	Standard/Criterion	Level
7.2	Neuropsychological services may not be required for every client.	
	It is suggested that neuropsychological testing is undertaken in the circumstances:	following
7.2.1	• Where there is diagnostic uncertainty or for the purpose of differential diagnosis	SR
7.2.2	• If a client presents with complex or unusual symptom pattern	SR
7.2.3	• In the presence of functional decline despite 'normal' scores on gross screening tools, especially if the client has a high level of education	SR
7.2.4	• If a client presents with pronounced speech and language difficulties (e.g., suspected primary progressive aphasia)	SR
	Guidance: In many cases, speech pathology diagnostic assessment should be preferred over neuropsychological testing. Consultation with a speech-language pathologist is generally encouraged when a client presents with significant language difficulties.	
	Speech Pathology diagnostic assessment should, therefore, be particularly considered when a detailed testing of language functions (e.g., semantic, phonological, syntactic functioning) is required; for differential diagnosis; in the presence of re-emerging motor speech vs. phonological difficulties, or social communication changes and eating/swallowing/hyperorality changes.	
7.2.5	• If a client presents with suspected young onset dementia	SR
	Guidance: Young onset dementia is defined here as a diagnosis of dementia in clients under the age of 65. It may have highly varied and complex symptom presentation that does not necessarily include memory decline.	

SR (Strong recommendation) – fundamentals of a good Memory and Cognition Clinic

-		
7.2.6	 If there is a need to understand the cognitive profile to inform treatment and management Guidance: This may include determining whether decline in cognitive domains (such as memory, executive functioning, or language) is sufficient to interfere with the client's adherence to treatment or compromise the likely success of treatment. A detailed neuropsychological profile may be informative regarding the client's cognitive strengths and weaknesses, which in turn can inform management plans. 	SR
7.2.7	• If a client presents with pronounced behavioural changes Guidance: This may include apathy, suspected behavioural variant frontotemporal dementia, etc.	SR
7.2.8	 If there is a need to conduct a specific capacity assessment (e.g., capacity to make informed decisions on finances, treatment, careplan, placements into residential aged care) Guidance: This standard refers to situations where more information about cognitive abilities would be beneficial to determine the client's capacity for these specific forms of capacity. 	SR
7.2.9	• If a client presents with subtle cognitive changes Guidance: This may include subjective cognitive complaints and mild cognitive impairment. In this instance, neuropsychological assessment may be required, as it is more sensitive to subtle changes in cognition than cognitive screening measures.	SR

SR (Strong recommendation) – fundamentals of a good Memory and Cognition Clinic

Diagnostic biomarkers

Key points

- Evaluation of diagnostic biomarkers might become part of the diagnostic work-up once resources and expertise become available. This includes:
 - o positron emission tomography (PET)
 - o lumbar puncture
 - o genetic testing
 - o blood-based biomarkers

Blood-based biomarkers of AD have the potential to be a game changer for the development of effective AD treatments.¹⁹

- Schindler & Bateman (2021), p.27



	Diagnostic biomarkers	
Number	Standard/Criterion	Level
8.1	If appropriate resources and expertise are available, Memory and Cogni includes the evaluation of diagnostic biomarkers to provide the most diagnosis.	
8.1.1	 Where there is diagnostic uncertainty and/or detailed diagnostic information is required, advanced neuroimaging, e.g., Positron Emission Tomography (PET) is conducted. Guidance: To be considered based on out-of-pocket costs for the client, expertise of staff, and access. 	PP
8.1.2	• Lumbar puncture is undertaken for more complex cases, including the use of CSF markers of amyloid and tau pathology.	РР
8.1.3	• Testing of common genetic polymorphisms and/or mutations associated with dementia onset and/or progression can be conducted where considered to provide additional diagnostic value.	РР
Note	Once the validity and prognostic utility have been demonstrated for a clinics and appropriate training is provided to clinicians, obtaining blo biomarkers may form part of the diagnostic work-up.	

PP (Practice Point) – aspirational criteria

හි Case-conference

Key points

- A case-conference is conducted:
 - o at a minimum, for complex cases with an unsure diagnosis
 - o ideally, for every client
- The assessment results, diagnosis, and care-plan are discussed

We should prioritise case-conference towards complex or atypical cases. "Complex cases" doesn't necessarily mean in the diagnostic sense – could be that the client lacks support, or there are safety concerns, making the case 'complex'.

– Delphi Panel Health Professional



	Case-conference	
Number	Standard/Criterion	Level
9.1	On completion of all assessment procedures, Memory and Cognition Cli to conduct an interdisciplinary case conference that includes all avail members involved in a particular assessment, including leave replacem Interdisciplinary case-conferences are conducted:	able team
9.1.1	For complex cases with an unclear diagnosis	SR
9.1.2	For every client	R

	Case-conference	
Number	Standard/Criterion	Level
9.2	A case conference may be conducted at different time points:	
9.2.1	After the initial assessment	SR
9.2.2	After the follow-up session, as required	R

	Case-conference	
Number	Standard/Criterion	Level
9.3	During the case-conference the assessment results, diagnosis, and car discussed.	e-plan are
	Specific topics for discussion include:	
9.3.1	• Assessment results (e.g., cognitive test results)	SR
9.3.2	Imaging results	SR
9.3.3	Consensus diagnosis	SR

SR (Strong recommendation) – fundamentals of a good Memory and Cognition Clinic

R (Recommendation) – criteria that further increase the quality of a Memory and Cognition Clinic

SR (Strong recommendation) – fundamentals of a good Memory and Cognition Clinic

9.3.4	Medical prognosis	SR
9.3.5	Early support	SR
	<i>Guidance: The immediate support needs of the client and care partner should be identified during the case-conference.</i>	
9.3.6	Client's strengths, weaknesses, and available resources	SR
9.3.7	Possible care strategies for the client	SR
9.3.8	Pharmacological intervention options	SR
9.3.9	Risk factor modification	SR
9.3.10	Driving capabilities	SR
9.3.11	Risk of abuse	SR
9.3.12	Counselling needs	SR
9.3.13	Education needs	SR
9.3.14	• Suitability for pharmacological and non-pharmacological research studies	SR
9.3.15	Cognitive intervention options	SR
9.3.16	Legal and financial capabilities	SR



Key points

- The diagnosis is communicated in a timely, empathetic, and understandable manner
- The terms 'dementia' and 'mild cognitive impairment' are used

When you are the one sitting there not understanding what they [clinicians] are talking about, it can be overwhelming. A lot of the time you don't know what questions to ask. Clinicians should ask questions about how much information is sinking in. You might need a few appointments to make it all sink in.

- Person living with dementia



	Communicating the diagnosis	
Number	Standard/Criterion	Level
10.1	Memory and Cognition Clinic clinicians communicate the diagnosis ir empathic, and easily understandable manner.	n a timely,
10.1.1	 Memory and Cognition Clinic clinicians inform the client of the diagnosis as soon as all the investigations are completed * Guidance: Dementia Lived Experience Experts especially stressed the importance of providing the information in both verbal <u>and</u> written forms. 	SR*
10.1.2	 When communicating the diagnosis, the preferred terms are "dementia" and "mild cognitive impairment". Guidance: Stakeholders involved in the Delphi process preferred the use of these terms, as opposed to the DSM-5 "major and minor cognitive disorder". If known, communicating the dementia subtype is encouraged. 	SR
10.1.3	• If the diagnosis of dementia is uncertain, clients are given an easy- to-understand written explanation of the results and the next steps. *	SR*
10.1.4	 Memory and Cognition Clinic offers a lay person summary of the client's test result reports.* Guidance: This would ideally include scan reports, neuropsychological reports, biomarker analyses, etc. A copy of the test results reports may be provided to the client upon request. 	SR*

SR (Strong recommendation) – fundamentals of a good Memory and Cognition Clinic

^{(*) -} criteria particularly endorsed by people with lived experience of dementia and their care partners

10.1.5 • The appointment during which the diagnosis is communicated SR* is long enough for the client to process the information and ask questions.*

Guidance: The length and format of the appointment(s) should be determined based on the clinical judgement and may vary according to the client's preference. Clinicians should consider providing an opportunity for a break within the appointment or offering an additional appointment to continue discussing the diagnosis where required, especially if the client seems confused or distressed. More recommendations about the feedback session during which the diagnosis is communicated can be found in section 12 "Feedback and Follow-up".

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Dignity, consent, capacity, and confidentiality

Key point

• Client's wishes regarding confidentially are respected

We have a duty of care to reduce stigma and raise awareness – we need to talk about positives of a diagnosis and how this can improve the quality of life.

– Delphi Process Health Professional



	Dignity, consent, capacity, and confidentiality	
Number	Standard/Criterion	Level
11.1	Memory and Cognition Clinic ensures that the client's wishes regaced confidentiality of their diagnosis are respected.	arding the
11.1.1	• The assessing clinician confirms if the client wishes to know the diagnosis.	SR
	<i>Guidance: The client should be informed about the benefits of learning their diagnosis, including how their quality of life may be improved.</i>	
11.1.2	• If a client does not wish to know the diagnosis, the medical practitioner and other Memory and Cognition Clinic staff respect that wish as much as possible.	SR
	Guidance: Wherever possible, clinicians should seek to understand the client's preference and act in accordance with it. If the client <u>does not</u> wish to know their diagnosis, clinicians should use their clinical judgement to determine whether the client's family/care partner should be informed of the diagnosis, considering factors such as autonomy, capacity, confidentiality, and risk/safety.	
	The clinician should aim to provide education to reduce the stigma of the diagnosis and outline the benefits of knowing the diagnosis to ensure that the client receives the required support.	
11.1.3	• The assessing clinician asks the client if and with whom the outcome of the assessments should be shared.	SR
11.1.4	• If the client does not have capacity to decide whether to receive their diagnosis, the decision of their proxy decision maker (known as a Person Responsible in most states) should be respected and further discussed over time.	SR
	Guidance: Where possible, the clinician should provide education to outline the benefits of knowing the diagnosis.	

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ກົ້ Feedback and follow-up

Key points

- At a minimum, one feedback and one follow-up session are provided in a timely fashion after the diagnosis is formulated
- Clients with dementia are followed-up at least once every 12 months
- Clients with MCI are followed-up at least once every 12-18 months

We felt we were left to fend for ourselves after our final appointment. We also had to wait quite a long time for follow-up appointments, which was distressing for my husband.

- Carer of a person living with dementia



	Feedback and follow-up	
Number	Standard/Criterion	Level
12.1	Following the completion of all assessments and diagnosis formulation and Cognition Clinic organises the feedback and post-feedback follow-u in the following fashion:	
	Guidance: Recommendations for the follow-up sessions apply after a d dementia or MCI classification is established and may apply for cl subjective cognitive complaints, if required (e.g., monitoring risk factors	lients with
12.1.1	 A separate feedback session to communicate or discuss the diagnosis, start on the care-plan, and organise a care coordinator (if available)* Guidance: In some cases, two shorter feedback sessions may be necessary to allow sufficient time for the client to process the diagnosis. Please refer to Section 10 for more guidance. 	SR*
12.1.2	• A minimum of one post-feedback follow-up session to assess the status of the care or referral plan's implementation*	SR*
12.1.3	• If necessary, at least one additional follow-up session to provide further support and to monitor and adjust the care-plan	R

Feedback and follow-up		
Number	Standard/Criterion	Level
12.2	The clinical specialist who assessed the client has a leading role in the initial post-diagnostic process (i.e., feedback session and care-plan development).	SR
	Guidance: This may include medical specialist, nurses, and allied health professionals.	

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^{(*) –} criteria particularly endorsed by people with lived experience of dementia and their care partners

Feedback and follow-up					
Number	er Standard/Criterion				
12.3	Memory and Cognition Clinic ensures timely scheduling of the session(s).	feedback			
12.3.1	 The feedback session is conducted as soon as possible after the final diagnostic assessment. Guidance: Ideally, a feedback session is conducted within 4 weeks of the initial assessment, provided that all assessments have been completed and the results of all investigations are received. 	SR			

Feedback and follow-up				
Number	Standard/Criterion	Level		
12.4	The feedback session during which the diagnosis is communicated attended by all relevant parties. This includes the assessing clinicians and the client and may also in following:			
12.4.1	• Support person or care partner (with client's consent)	SR		
12.4.2	Allied health professionals	R		

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	Feedback and follow-up	
Number	Standard/Criterion	Level
12.5	Memory and Cognition Clinic offers follow-up sessions to evaluate t progression and care-plan implementation.	he client's
12.5.1	 Memory and Cognition Clinic follows up all clients with a diagnosis of dementia at least once every 12 months and thereafter based on the client's need for review. Guidance: Follow-ups should be based on the client's needs. Ideally, they are offered within the 12 months after the diagnosis, particularly if the client cannot be followed-up and supported by other clinical services. Clinics with limited resources, who are unable to offer follow-up sessions for all clients with an established dementia diagnosis, should ensure an appropriate follow-up mechanism by linking the client into 	R
	appropriate services.	
12.5.2	 Memory and Cognition Clinic follows up all clients with a diagnosis of MCI at least once every 12-18 months based on the clinical judgement and thereafter based on the client's need for review. This also forms a Clinical Quality Indicator for the ADNeT Clinical Quality Registry. 	R

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A Support, advice, and care after the diagnosis

Key point:

- The client receives all relevant information to enable them to better understand, adjust to, and live well with the diagnosis
 - We have an opportunity to state what we ideally want for best practice rather than being constrained by current resources... If post-diagnostic support was available in memory clinics, it would help to drive this through to the community.
 - Delphi Panel Health Professionals



Support, advice, and care after the diagnosis

Definition

Directly after the diagnosis, Memory and Cognition Clinic provides support and advice to enable clients to better understand, adjust to, and live well with the diagnosis. This includes:

- 1) Educating the client about their diagnosis or opportunities for risk reduction with the aim of reducing stigma;
- 2) Developing a clear post-diagnostic care-plan;
- 3) Providing information about and referring to support services with dementia expertise, depending on their diagnosis and need (e.g., Dementia Australia, legal services, social worker, relevant community health services);
- 4) Providing or referring to evidence-based programs and interventions.

The following tables outlines services and items that should be ideally:

- 1) Discussed with the client;
- 2) Provided at the clinic; or
- 3) Offered via referral to external services.

Support, advice, and care after the diagnosis			
Number	Standard/Criterion	Level	
13.1	Memory and Cognition Clinic ensures that the client receives a information post-diagnosis and assists with developing the care-plan.	ll relevant	
13.1.1	 Memory and Cognition Clinic provides written post-diagnostic support recommendations to the client, the client's GP, the referring medical practitioner (if other than the GP) and the post-diagnostic support service(s), as applicable. * Guidance: If a client was not referred by a GP, Memory and Cognition Clinic should encourage the client to involve a GP to ensure ongoing support after the Memory and Cognition Clinic assessment. 	SR*	

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13.1.2	• The client, their care partner(s), and all assessing clinicians (e.g., medical practitioner, neuropsychologist) are actively involved in the client's care-planning.	SR
13.1.3	 For clients with MCI or early signs of dementia, Memory and Cognition Clinic provides personalised risk reduction information to the client, GP, or other referring medical practitioner, if required. Guidance: Such information may also be provided to clients with subjective cognitive complaints, if required. 	PP
13.1.4	 Memory and Cognition Clinic provides support and advice to clients they did not initially assess and diagnose. Guidance: This may apply to clients with a recent diagnosis, who, for example, have recently moved into the catchment area and seek advice on ongoing support or were unable to access relevant advice and information about local post-diagnostic supports. 	PP
13.1.5	 Memory and Cognition Clinic assures the client and their family/care partner(s) that further advice and assistance can be sought after the discharge. Guidance: For example, this may include information about local support services with dementia expertise. 	PP

Support, advice, and care after the diagnosis				
Number	Standard/Criterion	Level		
13.2	Memory and Cognition Clinic facilitates the care-plan implementation.			
13.2.1	• Memory and Cognition Clinic has active relationships with relevant support services to refer as appropriate (e.g., support group for carers).	SR		
13.2.2	• Memory and Cognition Clinic offers follow-up phone calls to assist the client with the care-plan implementation. *	R*		

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	Support, advice, and care after the diagnosis	
Number	Standard/ Criterion	Level
13.3	<u>Where appropriate</u> , directly after the diagnosis, Memory and Cogniprovides advice, information, and support regarding the following issue	
13.3.1	• Education about dementia (e.g., psychoeducation) provided to the client, family, and carers*	SR*
13.3.2	Carer support*	SR*
13.3.3	Beneficial lifestyle changes*	SR*
13.3.4	Behaviour management interventions	SR
13.3.5	Risk reduction	SR
13.3.6	Management of safety concerns	SR
13.3.7	• Written personalised strategies to help the client live with dementia day-to-day (e.g., use of calendars, medication boxes, and phone reminders)*	SR*
13.3.8	• Involvement in research and clinical trials (where appropriate)	SR*
13.3.9	• Recruitment into the ADNeT Clinical Quality Registry (for eligible clients)	SR
	Guidance: This only applies for Memory and Cognition Clinics that participate in the ADNeT Clinical Quality Registry. Further information: https://www.australiandementianetwork.org.au/initiatives/clinical- quality-registry/	

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	Support, advice, and care after the diagnosis					
Number	Standard/Criterion	Level				
13.4	If Memory and Cognition Clinic is unable to provide more detailed post-di support (e.g., due to a lack of resources), it refers clients to relevant, a and timely services with dementia expertise. Where appropriate, these services include:					
13.4.1	 Provision of psychological support (e.g., management of depression/anxiety) * 	SR*				
13.4.2	• Nursing Support <i>Guidance</i> : This may include care coordination.	SR				
13.4.3	Occupational therapy	SR				
13.4.4	Speech and language therapy					
13.4.5	 Group based programs focused on improving well-being (e.g., Day Centres with leisure activities, Meeting Centre Support Programs, etc.)* 					
13.4.6	Dietetic advice					
	Guidance: Provided by a dietitian with expertise in dementia, preferably an Accredited Practising Dietitian (APD).					
13.4.7	• Exercise programs <i>Guidance: Provided by an exercise physiologist or physiotherapist with</i> <i>expertise in dementia.</i>	R				
13.4.8	• Provision of interventions for poor sleep-wake functioning (e.g., Cognitive Behaviour Therapy, sleep hygiene, interventions to treat obstructive sleep apnoea)	R				
13.4.9	Home-based multidisciplinary reablement programs	R				

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13.4.10	• Evidence-based cognitive interventions (e.g., computerised or memory strategy training) via face-to-face appointments or via Telehealth	РР
	<i>Guidance: Dementia Lived Experience Experts particularly endorse the option of Telehealth, if they cannot get to the service easily.</i>	

Support, advice, and care after the diagnosis					
Number	Standard/Criterion	Level			
13.5	<u>Where appropriate</u> , Memory and Cognition Clinic connects client following services, after the diagnosis is communicated:	ts to the			
13.5.1	Driving assessments	SR			
13.5.2	Dementia Australia	SR			
13.5.3	Community Care Services*	SR*			
13.5.4	Legal and financial counselling	R			

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R (Recommendation) – criteria that further increase the quality of a Memory and Cognition Clinic PP (Practice Point) – aspirational criteria

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Pharmacological support

Key point

• Memory and Cognition Clinic offers a medication review and provide access to pharmacological interventions, if required



Pharmacological support					
Number	Standard/Criterion	Level			
14.1	Where appropriate, Memory and Cognition Clinic provides a pharmacological treatments.	advice on			
	This may include the following elements:				
14.1.1	• Medication review (e.g., where medications may potentially contribute to cognitive impairment)	SR			
14.1.2	Dementia specific medications				
14.1.3	• Pharmacological interventions for BPSD Guidance: BPSD include but are not restricted to depressive symptoms, anxiety, apathy, agitation, sleep problems, psychosis, irritability, and wandering.	R			

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R (Recommendation) – criteria that further increase the quality of a Memory and Cognition Clinic

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Notes:		



Australian Dementia Network REGISTRY. CLINICS. TRIALS.



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