



Australian
Dementia Network
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Memory and Cognition Clinic Guidelines

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

Version 2/2024



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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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Contributing Key Stakeholders

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Executive Summary

Memory and Cognition Clinics (hereafter: MC clinics or clinic) 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.

In 2021, ADNeT published the first national service Guidelines for MC clinics to address this variability. The Guidelines are based on the overarching principles of person-centred care, equity, and respect and provide consensus-based, best-service Standards for MC clinics. Standards were developed in consultation with researchers, health professionals and people with the lived experience of dementia and MCI, 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 the 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 Guidelines sections regarding, communicating the diagnosis, follow-up processes support, advice, and care after

the diagnosis (Sections 09 - 11) outline the minimum post-diagnostic support a MC clinic should provide, as well as aspirational criteria that may require increased funding.

This updated second iteration of the Guidelines also includes best-service Standards for the assessment and post-diagnostic support of MC clinic clients with Intellectual Disabilities and from a Culturally and Linguistically Diverse Backgrounds (Sections 12 and 13). These two sections were added after extensive consultation work with clinical experts as well as people with the lived experience.

Since the initial publication of these Guidelines in 2021, a monitoring and quality improvement pilot program (MQIPP) was developed and conducted by the ADNeT-Memory Clinics initiative between 2022 and 2023. A total of seven MC clinics participated in the pilot program, partaking in a process of self-assessment, review, and quality improvement. The feedback received during the pilot program has shaped this second Guidelines version. Key changes include the removal of secondary Standards and their integration as additional information and advice, which greatly increases conciseness and focus on the main service Standards. Many Standards have further been reworded for clarity. A summary of all changes that were made to this second Guidelines version can be accessed on the ADNeT website: <https://www.australiandementianetwork.org.au/initiatives/memory-clinics-network/adnet-memory-and-cognition-clinic-guidelines/>

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/support person(s) (if applicable).

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).
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 support person 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 Standards 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

	<p>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’.</p>
Recommendation	<p>Standards 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’.</p>
Roving service	<p>A clinical service that operates at different locations to offer easily accessible specialist services in mostly regional and remote areas.</p>
Strong recommendation	<p>Standards 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’.</p>
Support person	<p>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. Sometimes also referred to as ‘care partner’.</p>
Telehealth	<p>A means of administering clinical care remotely using mediums such as the telephone, videoconferencing, or text-based internet messaging.</p>

Abbreviations

Abbreviation	Explanation
AD	Alzheimer’s disease
ADNeT	Australian Dementia Network
CALD	Culturally and Linguistically Diverse
CDAMS	Cognitive Dementia and Memory Service
CQI	Clinical Quality Indicator
DS	Down Syndrome
ESR	Erythrocyte sedimentation rate
GP	General Practitioner
iADL	Instrumental Activities of Daily Living
ID	Intellectual Disability
MCI	Mild Cognitive Impairment
MRI	Magnetic Resonance Imaging
MSNAP	Memory Service National Accreditation Programme
MQIPP	Monitoring and Quality Improvement Pilot Program
NDIS	National Disability Insurance Scheme
NHMRC	National Health and Medical Research Council
NNIDR	National Health and Medical Research Council’s National Institute for Dementia Research
pADL	Personal Activities of Daily Living
PET	Positron Emission Tomography – also included ‘FDG-PET’: fludeoxyglucose-18 - Positron Emission Tomography
PP	Practice Point
R	Recommendation
SR	Strong Recommendation

Introduction

Scope

These Guidelines were developed to establish national service recommendations for Australian MC clinics. For the purpose of 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

These are the first 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 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, the Guidelines represent ideal service provision. Consequently, it is not expected that all MC clinics would currently meet every Standard. The Guidelines also cover all 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.

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

Overarching Principles

1. 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.
2. 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, socio-economic, cultural, and linguistic background.

3. 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 of interest to clinic managers and administrators and maybe used to inform dementia specific health care policies.

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.) or alcohol or substance misuse are not specifically 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, and people with an intellectual disability. It is important to highlight that all Standards equally apply to these groups.

After extensive consultations with clinical experts and people with the lived experience of dementia from CALD backgrounds and people with intellectual disabilities, specific Guidelines sections have been developed (see Sections 12 and 13) to complement the general Standards included in Sections 1 to 11. The ADNeT-Memory Clinics team plan to

consult with Aboriginal and Torres Strait Islander People to develop Standards which are specific to their clinical assessment and care needs in the future.

Background

Dementia currently affects approximately about 401,300 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 diagnosis and are often underdiagnosed in primary care settings^{9,12}. To achieve better 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*, first published in 2016, particularly recommend referral to comprehensive memory services for dementia diagnosis¹. Work on an updated version of these Guidelines will commence in 2024.

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}. People 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 care¹⁵. Some fully funded Dementia Support Programs are available through Dementia Australia or Dementia Support Australia (for behaviour specific support), but referral rates from MC clinic are anecdotally low. Specialists and primary care services involved in the ongoing assessment and ongoing care of people with dementia display little awareness of available programs. Accordingly, the patients' access to appropriate health service information, support, and interventions is impeded¹⁶. 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 Dementia*¹ and the *Cognitive Dementia and Memory Service Best Practice Guidelines: Service Guidelines for Victorian Cognitive Dementia and Memory Services*¹⁵. 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 crucial^{7,8}.

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. They are 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.

In 2022/2023, an auditing framework has been piloted in seven clinics across Australia. The next step will be to amend the program and implement a training, auditing and accreditation system to accompany the Guidelines.

Approach to Developing the Guidelines

Overview

The Guidelines has 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*¹⁷;
- *Clinical Practice Guidelines and Principles of Care for People with Dementia*¹;
- *Cognitive Dementia and Memory Service (CDAMS) Best Practice Guidelines*¹⁵.

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 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).

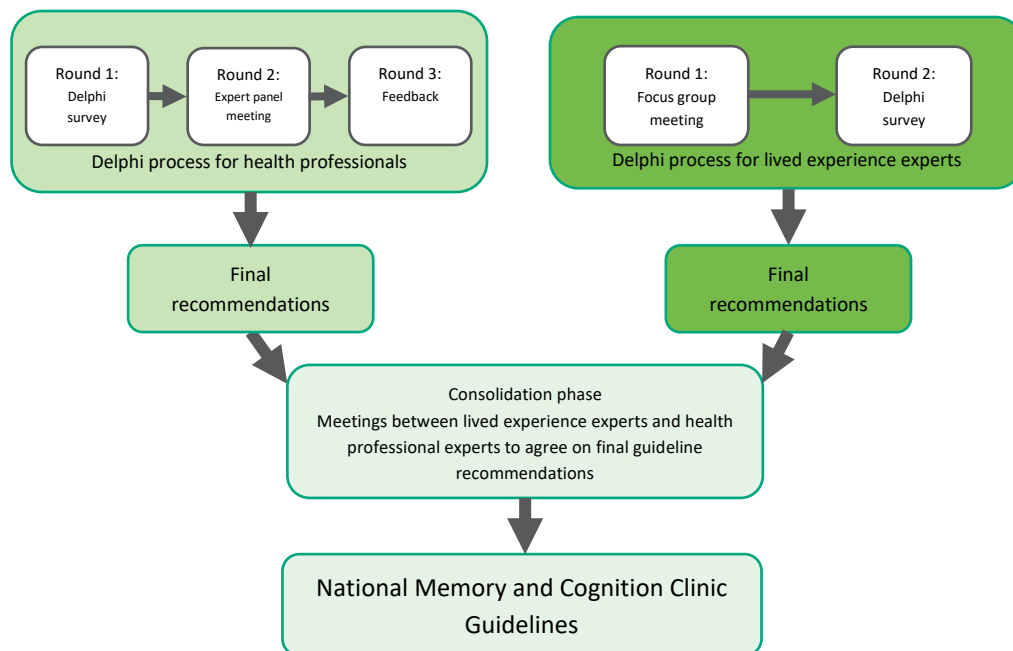


Figure 1: Parallel Delphi processes to obtain feedback from health professionals and Lived Experience Experts.

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. Results of the survey have been published¹⁹.

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 Standards was developed. Round 3 involved a feedback survey, which sought feedback on all Standards 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.

People with the Lived Experience Delphi Process

In a parallel Delphi process, input was obtained from people with the lived experience of dementia. In Round 1, 13 persons were invited to one 90-minute virtual Focus Group meeting. Some people with the lived experience had previously been engaged in the NNIDR-Community and Consumer Involvement Reference Group. 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 Standards regarding the assessment process, post-assessment feedback, and ongoing post-diagnostic support were formulated. The Standards were reviewed by the focus group members and embedded in a questionnaire that

constituted Round 2 of the people with the lived experience of dementia 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. Standards that reached 70% agreement were incorporated into the preliminary Guidelines.

Unlike the health professional Delphi, the process for those with lived experience 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.

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, people with the lived experience 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 Standards represent broad consensus on the ideal practices of a MC clinic. It is unlikely that every service would be able to meet every Standard. The Standards are categorised to facilitate the implementation of the Guidelines into clinical practice. The categories are as follows:

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

All Standards 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 additional information providing suggestions or guidance how a particular Standard could be implemented into clinical practice are also provided within the document.

Guidelines Version 2

Based on the results of the MQIPP and the feedback received from health professionals and other guideline users (e.g., policy makers), Version 2 of the Guidelines was developed. Some Standards have been reworded to increase clarity and ease of implementation. Lists of topics that clinicians should discuss with their clients, information that should be obtained and other details, which have previously been included as individual Standards, are now summarised as guidance points. This was done to highlight the higher-level service Standards which are of greater importance and apply to all MC clinics.

National Map of Cognitive Decline Assessment Services

The ADNeT-Memory Clinics Initiative maintains a national map of various cognitive decline assessment services, including MC 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 is regularly updated and can be accessed on the ADNeT website at:

<https://www.australiandementianetwork.org.au/initiatives/memory-clinics-network/find-a-clinic-or-service/>

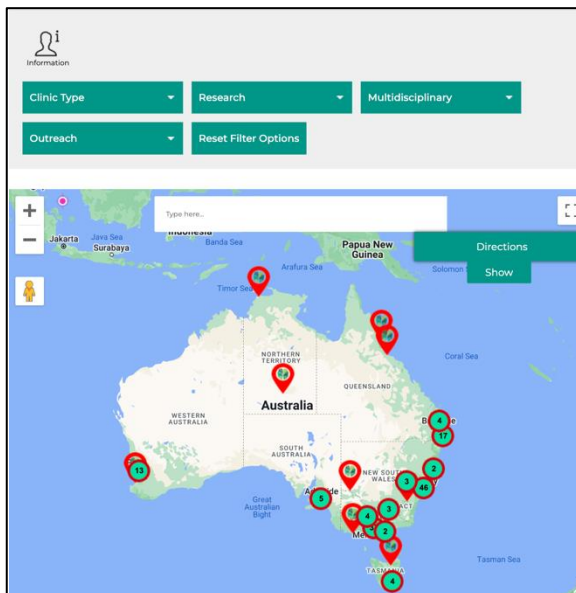


Figure 2: ADNeT national map

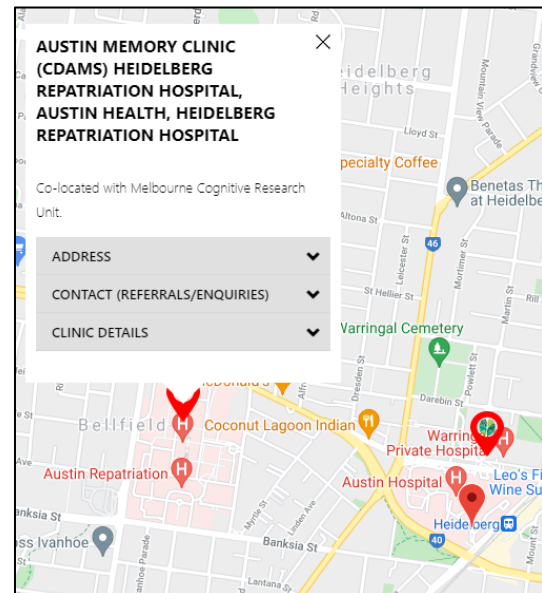


Figure 3: Detailed view of a clinic's information

Memory and Cognition Clinic Guidelines

Definition of a Memory and Cognition Clinic

At a minimum, a **Memory and Cognition Clinic**:

- provides a specialised and holistic assessment of dementia and cognitive decline;
- has access to a multidisciplinary team of medical specialists, nurses, allied health workers and other relevant support workers (e.g., social worker) either employed within the clinic or accessible via established referral pathways within the catchment area; and
- provides general advice, support and referrals after the diagnosis to ensure a timely and successful implementation of a care plan (e.g., government funded post-diagnostic care through Dementia Australia).

Some Memory and Cognition Clinics may also:

- provide post-diagnostic support in the form of evidence-based pharmacological and non-pharmacological programs (e.g., cognitive interventions, reablement); and
- offer education on dementia to general practitioners and the general public.

Section 1 – Modes of assessment

Face-to-face appointments are considered the default for all MC clinics. Clinics should be able to offer other modes of assessment to clients who cannot easily attend the service (e.g., to frail or immobile to attend the clinic, living in regional and remote areas).

Number	Standard	Level
1	The clinic offers assessments via telehealth.	SR*
2	The clinic offers outreach services to clients residing in regional and remote communities in the catchment area.	PP

* Standard particularly endorsed by people with the lived experience

Section 2 – Referral and Intake

Most MC clinics will require a referral before being able to arrange an appointment. This is required to access Medicare Benefits Schedule reimbursement and ensures ongoing post-diagnostic care by the referring physician. Clinics may choose to decline a referral if symptoms show no evidence of cognitive decline that may be consistent with a diagnosis of dementia and mild cognitive impairment (i.e., symptoms are consistent with either a psychiatric disorder, traumatic brain injury, alcohol dependence, ongoing substance misuse). It will be expected that the referrer highlights any potential issues regarding the patients’ capacity to consent in the referral. For practical reasons, the patient’s assent to the assessment should be assumed when they attend voluntarily cooperate with the assessment process.

Number	Standard	Level
3	The clinic follows clear guidelines for accepting referrals.	R
4	The clinic follows a framework for prioritising referrals based on clinical need.	R
5	The clinic ensures that all information that is required to assess the appropriateness and priority of a referral is received.	SR
6	Referrals from general practitioners and other medical specialists are accepted.	SR
7	Referrals from other relevant health professionals (e.g., allied health and the aged care assessment team) and self-referrals can be accepted if appropriate and assessment costs are covered.	R
8	For high priority clients an assessment appointment is offered within 30 days from referral.	SR*
9	For routine priority clients an assessment appointment is offered within 90 days from referral.	SR*
10	The clinic follows up with clients who have not attended an appointment / assessment.	R

* Standard particularly endorsed by people with the lived experience

Additional Guidance

Standard 3: All clients presenting with progressive cognitive problems and / or progressive cognitive problems may be accepted. Referrals should be particularly considered in the following circumstances:

- Client presents with a potential diagnosis of younger onset dementia.
- Differential diagnosis of dementia (e.g., specific syndrome) is required.
- Client shows a complex symptom presentation.
- Longitudinal tracking of cognitive problems at potentially prodromal stages of dementia/MCI is required.
- Client presents with behavioural and/or personality changes.
- There is evidence of risk factors for dementia in the presence of subjective cognitive complaints.
- There is evidence of rapid cognitive decline.

Standard 4: Under the following circumstances a referral may be deemed “high priority”:

- Safety concerns in the current living situation (for client or family/carer).
- Suspected self-neglect or abuse.
- Clients who care for others (e.g., parents of young children, carers of a person with disability, etc.).
- Rapid cognitive decline.
- Significant carer burden and/or stress.
- Other safety concerns (e.g., driving, depression symptoms).
- Clients with a suspected diagnosis of young onset dementia.

Standard 5: Clinics are encouraged to use a referral template to standardise information intake. The template could request the following information:

- Whether the person has a proxy decision maker
- Demographic information
- Preferred language, language abilities and the need for an interpreter
- Main symptoms
- Progression of symptoms
- Relevant medical and psychiatric history
- Current medications
- Family history
- Behavioural and psychological symptoms
- Blood test results (ADNeT Registry CQI)
- Imaging results (ADNeT Registry CQI)
- Reports by other specialists or previous investigations
- Results of cognitive screening

- Information regarding the client's support network, such as their living situation, and carer burden
- Hearing status, including information about the need for hearing aids
- Vision status, including information about the need for glasses

Missing information should be obtained at the time of the clinical assessment or via follow-up with the referring physician.

Section 3 – Prior to the assessment

Peopled with lived experience that participated in the Delphi process specifically emphasised the need to receive **verbal and written** information about the upcoming assessment. Pre-assessment information (e.g., regarding expected wait times) may also be provided to the referring physician.

Number	Standard	Level
11	Prior to the assessment, the clinic provides the client with verbal and written information to confirm and prepare the patient for the appointment	SR*
12	The clinic can provide a referral to an experienced counsellor if the client or care partner expresses distress during the waiting time for the initial assessment and requires support.	R*

* Standard particularly endorsed by people with the lived experience

Additional Guidance

Standard 11: information the clinic may wish to provide prior to the assessment:

- Waiting times, if the booking is yet to be made, and explanation of potential delays
- Explanation of assessment procedures, costs and duration
- What to bring to the appointment
- Information on who can accompany the patient
- Information on how to access the service (e.g., parking or public transport information)
- Name and job title of the person they will see
- Clinic's contact information

Standard 12: A referral to Dementia Australia and the National Helpline may be considered, for clients seeking dementia specific support during their waiting time for a MC clinic assessment.

Section 4 – Initial Clinical Interview

A clinical interview is conducted in the beginning of the assessment. With the client’s consent a support person would ideally attend the clinical interview to provide additional information where required.

Number	Standard	Level
13	A clinical interview is conducted with the client to obtain relevant information that inform the diagnosis and post-diagnostic care planning.	SR
14	The client is offered the opportunity for a clinical interview without the presence of the care partner to identify their needs, hopes, and wishes for the assessment.	R
15	With the client’s permission, the clinic arranges an interview with someone who knows the client well (informant) to obtain additional information on the client and identify the informant’s hopes, wishes and expectations for the assessment.	SR

Additional Guidance

Standard 13: Topics for the initial clinical interview include:

- Demographic information
- Nature, onset, and progress of cognitive complaints
- Medical and psychiatric history, particularly conditions associated with cognitive impairment, and possible risk factors
- Family history (particularly of mental health and neurological disorders)
- Presence of depression or anxiety (where necessary, assessment of depression should be completed using a standard screening tool)
- Presence of psychotic symptoms including hallucinations and delusions
- Sleep disturbance (where necessary, a sleep assessment should be completed using a standard screening tool)
- Nutrition/diet (where necessary, a malnutrition risk assessment should be completed using a standard screening tool and a referral made to an Accredited Practising Dietitian with expertise in dementia)
- Mobility and falls
- Current medications
- Client’s social supports
- Client’s everyday functioning

- Driving
- Physical activity levels and routine
- Legal issues that may influence the assessment and the presence of a substitute decision maker (informed consent should be sought prior to the assessment)
- Advanced care plans

Standard 15: a separate interview without the presence of the client should be offered (e.g., via a later telephone appointment, on the way out during a home visit) if required. Requirement for a separate interview is best judged based on the attending clinician's clinical experience.

Section 5 – Diagnostic work-up

Diagnostic assessment should go beyond a brief cognitive screen. Cognitive tests need to be tailored to the client’s cultural and educational backgrounds and their presenting symptoms.

Number	Standard	Level
16	Patients receive a comprehensive, evidence-based assessment including a physical health review and an assessment of multiple cognitive domains.	SR
17	Service has access to assessment tools to meet the needs of the people using the service	R
18	A person’s ability to undertake personal (pADL) and instrumental activities of daily living (iADL) are assessed.	SR
19	For clients that exhibit significant behavioural and psychological changes as symptoms of dementia, timely access to a specialised behavioural assessments and behaviour management planning is made available.	R
20	Neuroimaging results are obtained to assist with the diagnosis.	SR
21	The assessment includes the consideration of blood test results in accordance with clinical need	SR

Additional Guidance:

Standard 17: including access to cultural and language appropriate test tools as test tools for people with intellectual disabilities and other special needs (e.g., reading difficulties, sensory impairments).

Standard 19: In case behaviour management cannot be provided in-house, health professionals should support clients and care partners to access external services (e.g., specialised Old-Age-Psychiatrists, Dementia Support Australia).

Standard 20: Computer Tomography imaging is recommended as diagnostic minimum (ADNeT Registry CQI). Other imaging techniques including MRI and FDG-PET scan should be considered based on need.

Standard 21: This might include: erythrocyte sedimentation rate (ESR) or C-reactive protein-routine haematology, full blood count-biochemistry tests (including urea and electrolytes, calcium, glucose, and renal and liver function)-thyroid function tests-serum

vitamin B12 and folate levels-simple urinalysis (available on referral)-lipid profile/
cholesterol-syphilis serology and HIV.

Section 6 – Neuropsychological assessment

The clinic is ideally able to offer neuropsychological services within the clinic. Alternatively, referral pathways to an accessible service that can provide a timely assessment should be established. Neuropsychological services may not be required for every client and are most frequently used when there is diagnostic uncertainty or when the client presents with a complex or unusual symptom pattern. Neuropsychological assessment is more sensitive to subtle changes in cognition than brief cognitive testing and could thus assist with forming a diagnosis when the client presents with subtle cognitive changes in the early stages of the disease.

Additional speech pathology assessments should be considered when a detailed testing of language functions (e.g., semantic, phonological, and 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.

Number	Standard	Level
22	The clinic can provide access to a clinical neuropsychologist for a specialised neuropsychology assessment.	SR
23	The clinic has guidelines for determining which clients require neuropsychological assessments.	R

Additional Guidance

Standard 23: Neuropsychological testing is generally recommended in the following circumstances:

- Where there is diagnostic uncertainty
- For differential diagnosis purposes
- If a client presents with complex or unusual symptoms
- If a client presents with subtle cognitive changes
- In the presence of functional decline despite ‘normal’ scores on gross screening tools, especially if the client has a high level of education
- If a client presents with pronounced speech and language difficulties (e.g., suspected primary progressive aphasia)
- If a client presents with suspected young onset dementia
- If there is a need to understand the cognitive profile to inform treatment and management (this may include determining whether decline in cognitive domains is sufficient to interfere with the client’s adherence to treatment or compromise its success)
- If a client presents with pronounced behavioural changes.

Section 7 – Diagnostic biomarkers

Research and clinical applications for diagnostic biomarkers in the assessment of dementia are constantly evolving. Once the validity and prognostic utility have been demonstrated for Australian clinics and appropriate training is provided to clinicians, obtaining blood-based biomarkers may form part of the diagnostic work-up. These services should be considered based on out-of-pocket costs for the client, expertise of staff, and access.

Number	Standard	Level
24	Where there is diagnostic uncertainty and/or detailed diagnostic information is required, advanced neuroimaging, e.g., Positron Emission Tomography (PET) is conducted.	PP
25	Lumbar puncture is undertaken for more complex cases, including the use of cerebrospinal fluid markers of amyloid and tau pathology.	PP
26	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.	PP

Section 8 – Case-conference

Case conferences are conducted to confirm a client’s diagnosis as well as the post-diagnostic care recommendations within the assessment team. The client’s referring physician may be invited to attend a case conference if it would be beneficial to the post-diagnostic care planning or required due to other circumstances and feasible.

Number	Standard	Level
27	An interdisciplinary case-conference is conducted for complex cases with an unclear diagnosis after the initial assessment.	SR
28	A multidisciplinary team discussion with all clinicians who were involved in the assessment of a client is conducted.	R

Additional Guidance

Standard 27: During the case-conference the assessment results, diagnosis, and care plan are discussed. Other topics for discussion should include:

- Client’s and carer’s immediate support and counselling needs
- Risk factor modifications
- Risk of abuse
- Possible care strategies for the client
- Pharmacological intervention options, if appropriate
- Cognitive intervention options
- Legal and financial capabilities
- Enduring power of attorney and will
- Driving capacity

Standard 28: Multi-disciplinary team meetings or discussions may also be conducted for review clients when input from multiple disciplines was sought.

Section 9 – Communicating the diagnosis

Clinicians are encouraged to schedule the feedback session during which the diagnosis and care plan are communicated as soon as possible after the final assessment results have been received. During the Delphi process, people with lived experience of dementia highlighted that the feedback session must be long enough for the client to process the information and ask questions. Here, the length and format of the appointment(s) should be determined based on the clinical judgement and may vary according to the client’s preferences and needs. 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. Additionally, there is a need to harmonise the terminology employed during the feedback session. Stakeholders involved in the Delphi process preferred the terms “dementia” and “mild cognitive impairment” as opposed to DSM-5 “major and minor cognitive disorder”. If known, communicating the dementia subtype (verbally and written along with some explanations of the implications of this diagnosis is encouraged.

Number	Standard	Level
29	The clinic conducts a feedback session to communicate and discuss the diagnosis and care plan.	SR
30	The clinic has a protocol around who attends the feedback session to ensure ideal support for the client and care partner.	R
31	The assessing clinician confirms if the client wishes to know the diagnosis.	SR
32	Where the diagnosis is not communicated to the client, the reasons are clearly documented.	R
33	The assessing clinician confirms with the client if and with whom the outcome of the assessments should be shared.	SR
34	Clients and their support person(s) (with client’s consent) are given verbal and written information about their diagnosis in easy-to-understand language.	SR*
35	Clients and their support person(s) (with client’s consent) are given verbal and written information about the post-diagnostic care plan in easy-to-understand language.	SR*

* Standard particularly endorsed by people with the lived experience

Additional Guidance:

Standard 29: In case of a very clear diagnosis, communicating the diagnosis at the end of the assessment session may be a suitable option. The clinicians should ensure that sufficient support of the client and support person is provided to help them understand the diagnosis and plan for the necessary next steps.

Standard 32: It is recommended that the client is informed about the benefits of knowing their diagnosis, including how their quality of life may be improved.

Section 10 – Review Appointments

Recommendations for the review appointments apply after a diagnosis of dementia or MCI classification is established and may apply for clients with subjective cognitive complaints, if required (e.g., to monitor risk factors). Clinics that are unable to offer a review for all clients with an established dementia diagnosis should ensure an appropriate review mechanism is in place, e.g., linking the client into appropriate services.

Number	Standard	Level
36	The clinic conducts a minimum of one review appointment for all clients diagnosed with MCI to assess the status of the care or referral plan's implementation.	SR*
37	The clinic conducts a minimum of one review appointment for all clients diagnosed with dementia to assess the status of the care or referral plan's implementation.	R*
38	The clinic conducts an additional review appointment to provide further support and to monitor and adjust the care plan.	R
39	The clinic conducts follow-up phone calls within the first 8 weeks after the diagnosis was communicated to assist the client with the care plan implementation.	R*

* Standard particularly endorsed by people with the lived experience

Additional Guidance:

Standard 36: Clients with a diagnosis of MCI should be followed up at least once within the 12-18 months after the diagnosis (ADNeT Registry CQI). Thereafter, clients should be followed up based on their need for review.

Standard 37: Clients with a diagnosis of dementia should be followed up at least once within the 12 months after the diagnosis.

Section 11 – Support, advice, and care after the diagnosis

Directly after the diagnosis, the clinic provides support and advice to enable clients to better understand, adjust to and live well with the diagnosis. The same assessing clinician should lead the initial post-diagnostic support, which involves:

1. Educating the client about their diagnosis with the aim of reducing stigma and outline opportunities for risk reduction where appropriate;
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.

Number	Standard	Level
40	Directly after the diagnosis, the clinic provides the client and their support person(s) with advice and information about beneficial lifestyle changes, written personalised strategies to help the client live well with dementia day-to-day, and access to education about dementia.	SR*
41	Written post-diagnostic support recommendations are provided to the client, their support person(s), the client's GP/referrer and any relevant post-diagnostic support services.	SR*
42	Where required, the clinic provides advice and written information on available carer support services to the client's support person(s).	R*
43	Where required, the clinic provides advice and written information on behavioural management interventions and management of safety concerns.	R
44	The clinic has a documented directory of easily accessible post-diagnostic support services to which they can refer the client.	R
45	If the clinic is unable to offer post-diagnostic support directly, it refers the client to relevant and easily accessible post-diagnostic support services provided by specialists with dementia expertise, such as: <ul style="list-style-type: none"> • Psychological support services • Nursing support/Care coordination • Occupational therapy 	SR*

Number	Standard	Level
	<ul style="list-style-type: none"> • Speech and language therapy • Group-based programs focused on improving well-being • Dietetic advice • Exercise programs • Interventions for poor sleep-wake functioning • Home-based multidisciplinary reablement programs • Evidence-based cognitive interventions 	
46	The clinic connects the client to Dementia Australia.	SR*
47	Where required, the clinic connects clients to social and legal support services.	R*
48	The clinic has documented guidelines to assist clinicians in informing clients about managing issues around driving.	R
49	The clinic discusses and refers eligible clients to research and clinical trials.	SR
50	The clinic recruits eligible clients to the ADNeT Clinical Quality Registry.	SR
51	The clinic offers medication review (e.g., where medications may potentially contribute to cognitive impairment).	SR
52	Where medically indicated the clinic prescribes dementia specific medications.	R
53	The clinic offers advice on pharmacological interventions for behavioural and psychological symptoms of dementia.	R
54	Memory and Cognition Clinic provides support and advice to clients they did not initially assess and diagnose.	PP
55	For clients with MCI, early signs of dementia or subjective cognitive complaints (where necessary), the clinic provides personalised risk reduction information to the client and their GP/referring medical practitioner.	PP
56	The clinic assures the client and their family/care partner(s) that further advice and assistance can be sought after the discharge.	PP

* Standard particularly endorsed by people with the lived experience

Additional Guidance:

Standard 48: The internal guidelines could assist the identification of the driving status, give information about driving assessments and informs clinicians about their responsibilities if a client is non-compliant.

Standard 52: Please refer to the Clinical Practice Guidelines and Principles of Care for People with Dementia for further information (https://cdpc.sydney.edu.au/wp-content/uploads/2019/06/CDPC-Dementia-Guidelines_WEB.pdf). Some clinicians may prefer to recommend the prescription of dementia-specific medication to the GP to ensure correct ongoing medication management rather than prescribing the medication themselves.

Standard 54: 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.

Section 12 – Clients with intellectual disabilities

This section outlines additional Standards for the assessment of people with an intellectual disability (ID). All Standards included in Sections 1-11 still apply to these clients.

An ID is a neurodevelopmental condition characterised by impairments in intellectual and adaptive functioning in the conceptual, social and practical skills domains²⁰. The most common genetic cause of ID is Down syndrome (DS).

Research has shown that people with ID are at higher risk of dementia than people without ID. Alzheimer’s disease is the most commonly diagnosed form of dementia in people with DS²¹. Moreover, people with ID (particularly DS) show a much earlier onset of dementia symptoms, with cognitive decline observed as early as 40 years of age^{20,21}. There is less research on dementia in non-DS related ID, however, studies have suggested this population has a higher risk for dementia which presents about 10 years earlier and with a more rapid rate of cognitive decline than in the general population²¹.

Making a diagnosis of dementia with a person with ID is likely to be more difficult than a person without a pre-existing disability. Currently, the pathway to securing a comprehensive dementia assessment for clients with ID is fragmented, as is the pathway to ID-appropriate and quality care. It is acknowledged that specialised training is required to conduct a comprehensive assessment of clients with ID. Memory and Cognition Clinics are strongly encouraged to explore professional development opportunities in this area. Specialised centres that can conduct dementia assessments of people with ID are rare. Those that do exist have long waiting lists. Therefore, we encourage Memory and Cognition Clinics to accept and prioritise referrals from people with ID in the same manner as for all other referrals, that is, based on the individual’s need for an assessment. Importantly, people with ID of any age can access the Memory and Cognition Clinic.

Referral and Intake		
Number	Standard	Level
57	The clinic considers a referral from a person with ID based on the individual assessment need, regardless of the person’s age (i.e., ID clients are accepted at a younger age than may typically be seen at the clinic).	SR
58	The clinic arranges a phone call with the client and/or the client’s primary support person to clarify pre-assessment information (e.g., special needs).	SR

59	The clinic obtains comprehensive, longitudinal health data about the client, keeping in mind that changes in behaviour and functioning may represent underlying cognitive decline.	SR
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Prior to the Assessment

Number	Standard	Level
60	The clinic provides written information about the forthcoming assessment to the client and their support person(s) in Easy-Read format which ideally includes visual prompts. <i>Note:</i> Refer to Section 4 for the information that should be provided prior to the assessment.	R
61	The clinic adapts their environment as much as possible to the client's individual needs.	R

Assessment

Number	Standard	Level
62	The clinic has a clear protocol for assessing clients with ID.	R

Case-conference

Number	Standard	Level
63	The clinic includes the client's GP in the interdisciplinary case-conference to ensure optimal post-diagnostic care planning. <i>Note:</i> MBS reimbursement is available For GPs attending an interdisciplinary case conference (MBS items: 735 to 758).	R

Communicating the diagnosis

Number	Standard	Level
64	Clinicians address the client directly when communicating the diagnosis and the outcomes of the assessment.	SR

65	When communicating the diagnosis, clinicians should not use any jargon or long words, present information clearly in an easy-to-understand manner and at an appropriate speed.	SR
66	Clinicians use pictorial aids and provide written information about the assessment outcomes and diagnosis in an Easy Read format.	R

Support and advice after the diagnosis

Number	Standard	Level
67	The clinic staff identify all relevant healthcare providers and support workers and, with the consent of the client and primary support person, provide them with copies of the outcome report.	SR
68	The clinic staff prepare a letter of support addressed to the National Disability Insurance Scheme (NDIS) to inform of new diagnoses and any care need changes, particularly to support ageing in place if this is the patient and support person(s)'s preference.	R
69	The clinic arranges a minimum of two follow-up appointments to monitor the client's symptoms and care needs.	R
70	The clinic provides written care recommendations that clearly outline the next steps to the primary support person and the client in an Easy-Read format.	R
71	The clinic is able to refer the client to relevant and easily accessible support services that have expertise in working with clients with ID.	R

Additional guidance:

Standard 57: MC clinics should be aware of the following information:

- A change in behaviour and functional decline of the client with ID may serve as the main trigger for a MC clinic referral.
- New onset health-related issues (e.g., appearance of seizures, which is associated with the onset of AD in persons with DS) could also prompt a referral.
- Early onset of symptoms (e.g., in the 40s and 50s) is common in this population.
- Rapid decline may be expected in some cases and the presence of rapid decline should be confirmed with the referrer, if not explicitly stated in the referral.

Standard 58: Issues to clarify in a pre-assessment phone call may include:

- Who is involved to support decision making, including who is providing consent for the assessment and care decisions;
- The client's capacity to engage with medical assessments;
- What reasonable adjustments need to be made to tailor the clinic environment and assessment to individual needs and preferences (e.g., wheelchair access, client's preferred communication method and aids that are required, etc);
- Whether the client is able to undertake routine medical investigations as part of the workup (such as blood tests and neuroimaging). The clinic should then make reasonable adjustments to support this (e.g., offering a pre-medication to assist with reducing anxiety associated with medical procedures);
- Who will be able to provide longitudinal health data on the client.

Standard 60: It is important that the clinic communicates any changes and cancellations of appointments with sufficient notice to prepare the client for a change in schedule.

Standard 61: An assessment in the patient's home or another highly familiar environment should be considered and may be preferred. If a clinic appointment is required, adjusting the clinic environment to the clients' needs may involve:

- Ensuring that sufficient space is available (many clients with ID might bring multiple support people to the appointment)
- Offering a quiet and low stimulus waiting and assessment area
- Ensuring that the client's preferred communication method is available
- Organising an appointment that is longer than usual, with the option to include one or several breaks, or to split over two or more sessions

Standard 62: The assessment of a client with ID should ideally include:

- Screening and assessment tools appropriate for the evaluation of possible dementia in clients with ID.
- A comprehensive interview with someone who knows the client well to understand the client's baseline level of functioning and any perceived changes in behaviour and function.

Guidance: It is important to organise an interview with someone who has known the client for a long period of time. If this is not possible during this assessment, it is important to seek this information prior to or after the appointment. If a support person/carer has only assumed their role recently, they are unlikely to be the best person to provide a comprehensive picture of the client's longitudinal level of functioning.

- Tasks and tests that the client was previously able to complete as indicated in the medical records.

Additionally, clinic staff should be aware of the following information:

- Additional functional assessments and appointments might be required, depending on the client's needs.
- Involvement of an occupational therapist for the comprehensive functional assessment is encouraged.
- The involvement of other allied health professionals is encouraged based on the client's need (e.g., speech pathologist: changes in communication ability or swallowing assessment; physiotherapist: changes in mobility and gait; neuropsychologist: comprehensive cognitive assessment to assist with diagnostic clarification).

Standards 67 – 71: Clinicians should take extra precautions when prescribing or recommending medications to clients with ID, due to potentially higher risk of side-effects, and higher rates of co-occurring physical health conditions.

Section 13 – Clients from culturally and linguistically diverse backgrounds

This section provides additional Standards to aid clinicians when working with clients from culturally and linguistically diverse backgrounds (CALD). All Standards included in Sections 1 to 11 still apply.

Clinicians should be aware that people from CALD backgrounds tend to use Memory and Cognition Clinics less and later. The reasons for this may include language and cultural barriers, stigma and limited knowledge about dementia and available services. Clinicians are encouraged to reflect on any cultural and gender biases that may influence the assessment process and provision of post-diagnostic care. This includes potential biases the clinician might have, as well as biases of CALD clients and support person(s) around dementia and/or medical care. Clinicians should also note that CALD clients may lose English and native language proficiency as cognitive decline progresses.

Clinician professional development/ clinic environment		
Number	Standard	Level
72	All clinicians undergo cultural competency training.	PP
73	Clinics with a high proportion of CALD referrals work with cross-cultural workers relevant to their client demographics.	R

Prior to the assessment		
Number	Standard	Level
74	The clinic arranges a phone call with the client or their primary support person(s) to clarify the following information: <ul style="list-style-type: none"> • English language proficiency, literacy, and the need and preferences for an interpreter; and • Preferred spoken language and cultural considerations. 	SR
75	The clinic provides verbal and written information about the assessment in the preferred language of the client and primary support person(s). An interpreter is made available when required.	R

Assessment		
Number	Standard	Level
76	From the start of the assessment process, the clinic offers access to professional interpreting services for clients who prefer the support of an interpreter.	SR
77	Clinicians prepare an assessment battery that is appropriate for the client's CALD background that takes into consideration the relevance of materials to their culture and education.	SR

Communicating the diagnosis		
Number	Standard	Level
78	The clinic provides the client and their support person(s) with written information about the diagnosis, education on dementia, and the care plan in the preferred language of the client.	R

Support and advice after the diagnosis		
Number	Standard	Level
79	<p>The clinic ensures that clients who received a diagnosis of dementia are referred to culturally specific organisations and services, with the client's approval. The client's approval should be obtained prior to a referral being made.</p> <p><i>Note: Some clients might prefer a non-culturally specific service in case they are concerned that they may personally know somebody who is providing the service.</i></p>	R

Additional Guidance:

Standard 76: MC Clinic clinicians should be aware of the following information:

- Clinicians who are native, proficient speakers of the client's primary language may conduct the assessment in this language.
- Preference is given to in-person rather than over-the-phone interpreter services. Additional time should be allowed for the completion of an assessment that requires an interpreter. The interpreter's professional opinion about the client's skills in their

native language should also be considered (e.g., fluency, vocabulary, and appropriateness).

The following points should be considered when working with interpreters:

- Interpreters are given copies of screening tests and forms for collateral information that need to be translated when they arrive for the assessment.
- Interpreters are briefed prior to the assessment (suggestion: 15 minutes for initial routine assessments and 30 minutes for neuropsychological assessments).
- The interpreters should be briefed on the questions that the client will be asked and the tasks they will be required to complete during the assessment. Any relevant clinical information should also be communicated to the interpreter prior to the assessment. The interpreter should be advised not to answer the question for the client during cognitive testing.
- Some tasks (e.g., word lists) are translated in full prior to the assessment.
- Unless the client requests a different interpreter, the same interpreter is used for the initial assessment and the feedback session.

Standard 75: For further recommendations on culturally appropriate dementia assessment tools please refer to the Clinical Practice Guidelines and Principles of Care for People with Dementia for further information ([https://cdpc.sydney.edu.au/wp-content/uploads/2019/06/CDPC-Dementia-Guidelines WEB.pdf](https://cdpc.sydney.edu.au/wp-content/uploads/2019/06/CDPC-Dementia-Guidelines_WEB.pdf)) and resources published by the National Ageing Research Institute.

Standard 76: MC Clinic clinicians should be aware of the following information:

- Clinicians should use the interpreter to talk directly to the client rather than relying on the client's support person(s) to accurately relay relevant information onto the client in their spoken language. This includes communicating the diagnosis via the interpreter, unless otherwise preferred by the client.
- Written information about the diagnosis, education on dementia and the care plan should be pre-translated prior to the appointment by a professional translation service. Use of visual aids might be helpful when delivering the diagnosis. When this information is not available on the day of the appointment, it should be translated and mailed to the patient at a later stage.

References

1. Guideline Adaption Committee. Clinical Practice Guidelines and Principles of Care for People with Dementia. Sydney: NHMRC Partnership Centre for Dealing with Cognitive and Related Functional Decline in Older People; 2016.
2. Ayton D, Gardam M, Ward S, Brodaty H, Pritchard E, Earnest A, et al. How Can Quality of Dementia Care Be Measured? The Development of Clinical Quality Indicators for an Australian Pilot Dementia Registry. *J Alzheimers Dis.* 2020;75(3):923–36.
3. Campbell S, Braspenning J, Hutchinson A, Marshall M. Research methods used in developing and applying quality indicators in primary care. *Qual Saf Health Care.* 2002 Dec;11(4):358–64.
4. Mainz J. Defining and classifying clinical indicators for quality improvement. *Int J Qual Health Care.* 2003 Dec;15(6):523–30.
5. Australian Institute of Health and Welfare. Dementia in Australia - Prevalence of dementia [Internet]. 2024. Available from: <https://www.aihw.gov.au/reports/dementia/dementia-in-australia/contents/population-health-impacts-of-dementia/prevalence-of-dementia>
6. Australian Institute of Health and Welfare. Dementia in Australia: 2021 - Summary report. 2021 [cited 2022 Nov 10]; Available from: <https://www.aihw.gov.au/reports/dementia/dementia-in-australia-2021-summary/overview>
7. Speechly CM, Bridges-Webb C, Passmore E. The pathway to dementia diagnosis. *Med J Aust* [Internet]. 2008 Nov 3 [cited 2022 Nov 10];189(9). Available from: <https://www.mja.com.au/journal/2008/189/9/pathway-dementia-diagnosis>
8. Mehrani I, Kochan NA, Ong MY, Crawford JD, Naismith SL, Sachdev PS. Organisational aspects and assessment practices of Australian memory clinics: an Australian Dementia Network (ADNeT) Survey. *BMJ Open.* 2021 Feb 1;11(2):e038624.
9. Ng NSQ, Ayton D, Workman B, Ward SA. Understanding diagnostic settings and carer experiences for dementia diagnosis in Australia. *Intern Med J.* 2021 Jul;51(7):1126–35.
10. Woodward MC, Woodward E. A national survey of memory clinics in Australia. *International Psychogeriatrics.* 2009 Aug;21(4):696–702.
11. Ng NSQ, Ward SA, Ng NSQ, Ward SA. Diagnosis of dementia in Australia: a narrative review of services and models of care. *Aust Health Review.* 2019;43(4):415–24.
12. Loi SM, Goh AMY, Mocellin R, Malpas CB, Parker S, Eratne D, et al. Time to diagnosis in younger-onset dementia and the impact of a specialist diagnostic service. *International Psychogeriatrics.* 2022 Apr;34(4):367–75.
13. Luce A, McKeith I, Swann A, Daniel S, O'Brien J. How do memory clinics compare with traditional old age psychiatry services? *International Journal of Geriatric Psychiatry.* 2001;16(9):837–45.
14. Bauer M, Fetherstonhaugh D, Blackberry I, Farmer J, Wilding C. Identifying support needs to improve rural dementia services for people with dementia and their carers: A consultation study in Victoria, Australia. *Aust J Rural Health.* 2019 Feb;27(1):22–7.
15. Department of Health. Victoria A. Cognitive Dementia and Memory Service Best Practice Guidelines [Internet]. State of Victoria, Department of Health; 2013 [cited 2022 Nov 4]. Available from: <https://www.health.vic.gov.au/publications/cognitive-dementia-and-memory-service-best-practice-guidelines>

16. Low LF. Why Australia urgently needs post-diagnostic support and treatment for dementia. *Australian Journal of Dementia Care*. 2019;8(6):30–2.
17. Abhayaratne C, Blanchard E, Cartwright V, Grealley S. MSNAP Fifth National Report - Data from 2017/18 [Internet]. London, England; 2019. Report No.: CCQI 325. Available from: www.rcpsych.ac.uk/MSNAP
18. Hsu CC, Sandford B. The Delphi Technique: Making Sense of Consensus. *Practical Assessment, Research, and Evaluation* [Internet]. 2019 Nov 23;12(1). Available from: <https://scholarworks.umass.edu/pare/vol12/iss1/10>
19. Naismith SL, Michaelian JC, Low LF, Arsenova V, Mehrani I, Fyfe K, et al. Characterising Australian memory clinics: current practice and service needs informing national service guidelines. *BMC Geriatrics*. 2022 Jul 14;22(1):578.
20. Elliott-King J, Shaw S, Bandelow S, Devshi R, Kassam S, Hogervorst E. A critical literature review of the effectiveness of various instruments in the diagnosis of dementia in adults with intellectual disabilities. *Alzheimers Dement (Amst)*. 2016 Jun 30;4:126–48.
21. Evans E, Trollor J. *Dementia in people with Intellectual Disability: Guidelines for Australian GPs*. UNSW; 2018.



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