# Taking Memory Assessment Services (MAS) into the Future

A guide to supporting continuous development, improvement and innovation in memory assessment services







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# Taking Memory Assessment Services into the future

A guide to supporting continuous development, improvement and innovation in MAS

# Foreword - Professor Alistair Burns,

National Clinical Director for Dementia and Older People's Mental Health - NHS England and Improvement

Director of Manchester Institute for Collaborative Research on Ageing

# Professor of Old Age Psychiatry, University of Manchester

Improving the lives of people with dementia, their families and carers is a priority for NHS England. It is our ambition that, as a minimum, two thirds of people with dementia should receive a formal diagnosis and accompanying high quality post diagnostic support. A timely diagnosis and support are key aspects of improving the quality of care for people with dementia, their families, and carers. For many, assessments and diagnoses begin in memory clinics where they can have access to a multi-disciplinary team.

Everyone will be aware that the COVID-19 pandemic had a drastic impact on memory services. They needed to rapidly change the way in which they worked, and staff had to adapt quickly to develop new skills. Throughout this change in ways of working, the emphasis has always remained on the provision of personalised care, based on 'what matters' to people and how best to meet their individual needs.

The lens of the pandemic has facilitated the development of exceptional ideas and inspiration for how services can improve and innovate. To capture, showcase, and develop these ideas, NHS England and Improvement commissioned Professor Claire Surr and her team at Leeds Beckett University to investigate the latest, innovative practice in memory services and speak to the people who work in them and use them.

The outcome is this insightful and practical document: "A guide to supporting continuous development, improvement, and innovation in memory assessment services." Our aspiration is that by showcasing this good practice, it will inspire others and lead to lasting improvements in care for people with dementia, their families and their carers.

# Taking Memory Assessment Services into the future

A guide to supporting continuous development, improvement and innovation in MAS

# Foreword – Professor John Boulton

# Director Improvement Cymru / National Director of NHS Wales Quality Improvement and Patient Safety

There is a clear vision for Wales to be a dementia friendly nation that recognises the rights of people with dementia to feel valued and to live as independently as possible in their communities. The All Wales Dementia Care Standards sets the direction of travel for Memory Assessment Services to play their part in facilitating this vision, with a strong emphasis for services to consider accessibility, responsiveness, partnerships & relationships within the community supporting the person's journey. Memory Assessment Services play a pivotal role to ensure both positive experiences and outcomes are achieved for both the person and their supporter.

Opportunities at an early stage to provide effective Memory Assessment Services, delivering a timely diagnosis and subsequently key life enabling health and social care advice will enable the person to make sense of their situation. This provides time to consider current and future life plans, ensure access to risk reduction, advice, information and interventions, and promoting and enabling better health. Memory Assessment Services are key to supporting transition. The allocation of a named connector will enable the person to access advice and information including the right service and organisation, at the right time, by the right person to meet their future changing needs.

COVID-19 has presented huge challenges for the health and care system. During this time the NHS has demonstrated its ability to change rapidly, respond, innovate and improve to support the prevailing needs. Staff within our Memory Assessment Services have shown great dedication, resilience, strength and kindness, flexing and adapting their approaches to support our most vulnerable, under difficult circumstances. Now, whilst the pandemic isn't over, there is an increasing focus on how we continue to provide health and care in a safe, effective and efficient manner. This is clearly not without challenge and so it is imperative that we work collaboratively together, learning, improving and continuing to develop Memory Assessment Services, to deliver interventions that are even better than they were before.

Quality Improvement initiatives will be crucial in supporting delivery of memory services across England and Wales and ultimately increase dementia diagnosis rates and the provision of high quality peri- and post-diagnostic support services. All nations, organisations and partners, working together, by sharing innovation and improvements, will achieve better experiences and outcomes for people diagnosed with dementia and their supporters, which ultimately is what matters most.

# Introduction

Memory assessment services in England and Wales operate using a variety of models for service design and delivery. This guide to practice development and innovation in memory assessment services has been written with contributions from experts with experience of working, or supporting, practice in Memory Assessment Service (MAS) organisations across this spectrum and lay experts with experience of accessing memory assessment services themselves.

The guide is not designed to be an audit tool or to set standards for MAS, nor does it set expectations that individual MAS can aim to achieve all of the statements in all areas of practice. It is written as a guide to promote aspirational ideas for practice development and innovation for MAS operating across the spectrum of service models. Staff working in MAS can use it to support practice development projects and programmes in areas of focus for their services. It should be interpreted and applied in a way that is meaningful to each MAS. It is designed to complement national standards and programmes such as the Memory Services National Accreditation Programme (MSNAP)<sup>1</sup> and the All Wales Dementia Care Pathway of Standards<sup>2</sup>.

The aim of this guide is to encourage MAS to engage in ongoing practice development, founded on principles of aspiration and innovation, with the ultimate aims of continual improvements in service delivery across England and Wales and, ultimately, increased dementia diagnosis rates and the provision of high-quality peri- and post-diagnostic support services. We hope that people working in memory assessment services will find ideas and inspiration in its content.

# A note on terminology used in this guide

We have adopted a person-centred approach to language in this guide. Therefore, we have chosen to use the term 'person/people attending the service' rather than 'patient' throughout. This reflects the fact that not everyone who accesses a MAS will be given a diagnosis of dementia. Also, that many people who have received a dementia diagnosis identify terms such as 'patient' as terminology they prefer is not used to describe them, where possible<sup>3</sup>.

We have also used the word 'supporters' throughout to refer to people who provide support for a person who is accessing the MAS. This will include people who are carers but also a wider range of people, including family members and friends who may provide support. This terminology is inclusive of those who are a person's primary carer, but also acknowledges that not everyone who is providing support identifies themselves as a carer.

Throughout the guide we have predominantly used the term 'should' to provide a description of practice approaches to accompany each practice development and innovation statement. We have chosen to do this to reflect the non-mandatory goal, or aspirational, focussed nature of the practice we aim to promote.

<sup>1 &</sup>lt;u>www.rcpsych.ac.uk/docs/default-source/improving-care/ccqi/quality-networks/memory-clinics-msnap/msnap-</u> standards-6th-edition-2018.pdf?sfvrsn=d3a9bc94\_2

<sup>2 &</sup>lt;u>https://phw.nhs.wales/services-and-teams/improvement-cymru/news-and-blog/publications/dementia-standards/</u>

<sup>3 &</sup>lt;u>https://dementiavoices.org.uk/wp-content/uploads/2015/03/DEEP-Guide-Language.pdf</u>

# Taking Memory Assessment Services into the future A guide to supporting continuous development, improvement and innovation in MAS

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# **Taking Memory Assessment Services into the future**

A guide to supporting continuous development, improvement and innovation in MAS

# 1. Service values and ethos

The values and ethos that underpin a Memory Assessment Service (MAS) provide the foundation for all the work it does.

#### 1.1 A person-centred, value-based, mission statement

Does the mission statement place the needs of people attending the service and their supporters at its centre? The mission statement should be clear, understandable and practical in the sense that it can readily be applied to how the service and its staff operate.

Has the mission statement been co-produced with people attending the service, their supporters, staff and all key stakeholders? The mission statement should reflect the aims and values that stakeholders want and expect from their service

*Does the mission statement inform service design and delivery?* The service should be able to evidence concrete ways in which this has been applied.

Can staff describe how the mission statement is implemented in their own and their colleagues' day-to-day practice? This should apply to all staff, working in all roles.

Are all all people who attend the service aware of the mission statement and its implications for the service they will receive? People accessing the service should know how to raise concerns if they feel the service they receive, is not aligned to the mission statement.

### 1.2 A needs-led service

Does the MAS ask people attending the service and their supporters what they want and need and what matters most to them, at the point of access? This should be clearly recorded and used to inform their individual care pathway and reviewed regularly to ensure ongoing responsiveness to needs.

### Is the service needs support-focussed?

Support should be provided from the point of access and not at the point of diagnosis.

# Is the speed and timing of access through the service and its corresponding pathway components set by the person attending the service and their supporters?

People attending the service and their supporters should be aware of the care pathway and how they will progress through this. Timely access is that which is determined by the person attending the service and their supporters; recognising that some people may wish to proceed through the diagnostic process more, or less, rapidly than others. Speed of progress through the service should be flexible, balancing, as far as possible, the needs and wishes of the person and their supporter(s), taking into account any related levels of risk (e.g. driving, supporter needs) and any clinician concerns.

# Are people provided with a named professional who is responsible for their care (including supporting re-accessing the MAS if appropriate) from point of diagnosis to end of life?

People who receive a dementia diagnosis from the service should be provided with a single, named health or social care professional responsible for co-ordinating their care, as outlined in the National Institute for Health and Care Excellence (NICE) guidelines. How the relationship of care co-ordination interfaces with the MAS will depend on the commissioning model. The MAS should consider how well this works, particularly in relation to the post-diagnostic support experiences of people given a dementia diagnosis and their supporters, and ongoing access to MAS services, if required.

### 1.3 Personalised care that puts the person attending the service at the centre

Is there choice of how to attend appointments that takes into account personal preference and risk? People attending the MAS should be offered a choice about their preferred method for conducting their appointment from those provided by the service (this may include face-toface, phone and video call) and which are appropriate for the type of appointment.

### Is there an individualised approach to service delivery and postdiagnostic support including an individualised plan of care?

Each person attending the service should have an individualised plan of care, developed with them, that supports them to progress through the service pathway via a route and at a speed that takes into account their needs and wishes. The person attending the service should have access to this care plan.

# Is appropriate information gathered about the person attending the service and is this used to underpin individualised care?

The service should gather information about personal, cultural, communication and language preferences, relationships, support networks, life history, other health conditions, sensory impairments and other personal details that are important for providing an individualised service. This information should be used to tailor how the service is delivered (e.g. the service pathway, methods for providing appointments, types and formats of information provided and communication approaches adopted).

# Does the service design allow time for staff to build appropriate relationships with people attending the service and their supporters to deliver an individualised service?

Building of relationships should be seen as valuable and time for this allocated within service design and delivery. This should be achieved on an ongoing basis, while the person is under the care of the service.

#### 1.4 Needs and values led commissioning and design

#### Is service commissioning informed by the needs of people who may use the service within the population it serves?

Memory assessment services should be commissioned to meet the needs of the local population. Where a service is commissioned, commissioners should seek to understand the memory assessment and support needs of the population it serves (e.g. in terms of language, culture and other demographics), in order to define a person-centred, needs-led commissioning brief.

#### Is evidence from the MAS used to inform the commissioning brief or service design?

The MAS has an opportunity to provide information to inform future commissioning briefs, based upon their own ongoing service evaluation and review and their understanding of the local needs of people who will use the service and of those who support them. They should be well-positioned to identify gaps in current provision, or areas where there are risks associated with inequalities of access. A guide to supporting continuous development, improvement and innovation in MAS

# 2. Pathway

## 2.1 Equity of access

Equity of access underpins all aspects of the pathway and should be considered in relation to each area.

#### Are services provided by the MAS tailored to the needs of the local population?

The needs of the local population should determine the way services are designed and delivered. The MAS should conduct regular assessments to understand the needs within the local population and if and how they are being met by the service. This might include evaluation of available data and conducting consultations, these might be undertaken in partnership with local health, social care and Voluntary, Community and Social Enterprise (VCSE) organisations.

# Does the service identify and address potential barriers to access for people from under-served communities?

People from under-served communities (taking into account these communities will not all reflect protected characteristics) may experience difficulties or may access the MAS inconsistently or not at all. The MAS should actively identify and address barriers to access for people from under-served communities.

# Does the service consider and address potential barriers for access in other groups who may experience access inequities due to their socio-economic, living or support arrangements?

People in the following circumstances may face inequalities of access to the MAS or receipt of a dementia diagnosis: those who live alone, in a care home or assisted living facility; those who are homeless; those within the prison service; those who do not have access to a family member, friend or paid carer to support travel to, and attendance at, appointments; those who do not have access to digital technology or the internet. Their access to the MAS and/or a dementia diagnosis should be facilitated by the service.

### Is equity of access considered in relation to physical or sensory impairments or needs?

Many people who attend a MAS also experience a range of additional health conditions and comorbidities. These include physical and sensory impairments that can impact getting to a service and ability to engage with diagnostic assessments and post-diagnostic support. Their access to the MAS and/or a dementia diagnosis should be facilitated by the service.

### Does the service actively promote inclusivity and accessibility?

The MAS should actively promote of inclusivity and accessibility, for example by: conducting culturally appropriate assessments; ensuring under-served populations are represented in service promotional materials; good use of interpreting services (including leaflets); providing rainbow lanyards and LGBT+ posters; sensory adaptations (large print options, assisted listening devices). The service should follow the Accessible Information Standard and be able to provide information in a full range of formats including large print, Braille, Easy Words and Pictures. The service should retain the services of a British Sign Language (BSL) interpreting provider which is advertised in accessible formats to potential service users.

# Does the service actively reach out in ways tailored to individuals and communities who may experience inequalities of access, to understand their access and service needs?

Traditional methods of consultation and outreach may fail to reach under-represented communities or those who experience other reasons for inequality of access to services. The MAS should employ tailored methods of outreach to understand the needs of these individuals and communities to inform plans to support equality of access. This may include the need to access interpretation and translation services to support this work. It should involve collaboration with other organisations e.g. GPs/Clinical Commissioning Groups (CCGs), VCSEs, churches and mosques etc.

### 2.2 Service design and delivery

# Is the service model flexible in order to accommodate different needs of people who attend the service and their supporters?

Flexible service models should be able to accommodate and meet the potentially diverse needs of people attending the service and their supporters, within resources available, without this impacting the quality or choice of available services or support.

# Does the service ensure the same, and at least minimum level of service and outcomes of care, across all people accessing the service?

Service models should set an expected minimum level of service provision and outcomes across all components of the care pathway. This should include meeting any national or local standards for MAS. This should be achieved for every person attending the service and their supporter(s).

# Does the service ensure the same, and at least minimum level of service and outcomes, across all modalities of delivery?

Service models should set an expected minimum level of service provision and outcomes across all components of the care pathway. This should include meeting any national or local standards for the MAS. This should be achieved for every person attending the service and their supporters.

*Is the service able to effectively manage variability in service provision whilst maintaining standards of service?* The service should be set up in a way to be able to identify inconsistency and effectively manage variability to ensure a minimum level of service for all people accessing the service and their supporters.

## Does the service permit flexibility, based on clinical decision-making?

In some cases, guidelines, criteria or policies may determine what services and support individuals can access. However, clinicians may feel there are justifiable reasons for not sticking rigidly to these for some people attending the service. The MAS should accommodate this and support clinicians in appropriate clinical decision-making. If clinical decision making is routinely at odds with policies there should be a mechanism to raise this and review policy.

# 2.3 Service information

# Is there appropriate signposting to what the service can offer?

There should be clear information about the diagnostic process and the information and support the MAS and its partner organisations can offer. People attending the service should receive appropriate signposting and support, to assist them through the diagnostic process and to access the support they need, at the time(s) they need it.

# Is information easily understandable and available in multiple formats and languages?

It is important that information about the service and the memory assessment and diagnostic process provided to people attending the service, is easy to understand and is available in their preferred language or with access to a translator to assist understanding.

# *Is the way the service presents itself, and what it provides, communicated in a way that is sensitive to the population it serves?*

How a service is 'presented' to people who use it and their supporters, for example in appointment letters or information leaflets, may impact perception of the service and preferences for engaging with it. For example, the way information is presented may reduce or enhance stigma or reluctance to attend. Information should be presented in ways that encourage access by people from across the local community and reduce barriers to access.

# Are the information needs of the person attending the service and their supporters assessed and the right information provided at the right time for each?

The MAS should assess what information people attending the service and their supporters want or need at each point in their assessment pathway and ensure that it is provided. This includes ensuring the person is not overwhelmed with information they do not want yet. People attending the service and their supporters should have the opportunity to discuss the information provided and ask questions and seek clarification.

# 2.4 Supporter involvement and support

Is the support network of the person attending the service identified and considered in the diagnostic process and associated care planning? Support networks for people may be complex and it is important that the MAS understands who those attending the service are able to turn to, or not, within their support network and how the available support might impact their assessment and diagnostic journey.

# A guide to supporting continuous development, improvement and innovation in MAS

Is the person attending the service asked if, and to what degree, they would like a supporter involved in their diagnostic process? For example, for some people, having another person who receives copies of all correspondence, with permission, can help in managing the process and attending appointments. For others this would not be acceptable.

# Is a supporter included in providing information to support assessment (e.g. history taking, information about activities of daily living), with the permission of the person attending the service? Supporters are often able to provide information about the person's medical or life history that may be important to the diagnostic process. It is important that this information is not sought from the supporter at the exclusion of speaking to the person to gather information.

# Are supporters provided with appropriate information and support throughout the process, taking into account their individual needs?

Supporters are likely to need information and support, particularly if a diagnosis of dementia or another medical condition is confirmed. Their needs, including reasonable adjustments (e.g. for physical or sensory impairments), should be considered alongside those of the person attending the service.

# If appropriate, are supporters signposted to where they can access a formal Carer's Assessment?

Where appropriate, those acting in the role of primary carer should be signposted to where they

can access a formal carer's assessment and additional information, advice and support.

### 2.5 Referral - processes

## Are there a range of effective referral routes into the service?

Providing a range of referral routes into a MAS can improve accessibility. Referral only via a GP can create barriers to accessing the MAS. The service could operate an 'every contact counts' perspective which supports referral via any route. A self-referral should be offered (with appropriate triage). All routes should ensure timely entry into the MAS.

### Are there clear and consistent, locally developed and agreed, referral criteria?

Referral criteria should be clear and applicable to any referral route and should align with any national or local standards or guidelines. There should be clarity about what assessments and tests need to be obtained/conducted prior to referral and whose responsibility it is to initiate/fund these.

### Is there an aspirational waiting time for initial assessment following referral?

Local systems may choose to adopt an aspirational waiting time suited to their local needs or service. Decisions underpinning aspirational waiting times should be transparent and should consider the impact of any targets on the experiences of the person attending the service and their supporters and on staff ability to deliver a quality service.

# Are reasons for exceeding aspirational waiting times monitored and addressed where feasible?

Aspirational waiting times should be monitored and reasons for not meeting these understood, recognising not all will be within the power of the MAS to address. A flexible service that supports people attending the service to set their own pace through the diagnostic process may find, for example, that their waiting times are not achieved due to individual preference. In other cases, there may be changes to the system needed that can support a more rapid service delivery where this is desired by the person.

### Is there a strategy for managing waiting lists?

Services should have a strategy in place to manage waiting lists, and decisions around management should align to the service values and ethos, with considerations of equity of access. There should be a mechanism in place to ensure that patients at greater risk are prioritised and seen in a timely manner.

# Does the MAS operate a shared-care policy with primary care, with an option to re-access the service dependent on needs?

After being discharged from a MAS, people attending the service should, if appropriate, be able to re-access it at times of need (e.g. at a point of crisis for advice), without re-referral. People attending the service should be provided with information about where to access initial support on discharge, so they are able to access this if required in a timely way.

#### Is there a process for developing referral quality?

Services should have a process in place to clarify referral criteria and educate and support referrers in cases where referrals are not accepted by the MAS. In these cases, patients should be informed and supported appropriately.

# 2.6 Referral - preparation of the person attending the service

Are potential waiting times discussed with and explained to people attending the service at point of referral? It should be made clear to people attending the service at the point of referral, their likely waiting time to initial assessment. They should be provided with information and access to relevant support (including crisis signposting) from point of referral (this may be via the MAS or via external organisations).

# Is the person attending the service provided with information about what the assessment process will involve and how this will be conducted?

Going through a diagnostic process can be stressful and frightening. This may be lessened by ensuring people know what will happen, when and how<sup>4</sup>. They should be informed of this, in an accessible way and format at the start of their contact with the service and at appropriate timepoints thereafter. They should also be informed, in advance, of information the service will need such as a list of current medications. Where a person has sensory impairments that may impact the assessment process, these should be discussed, and provisions made to meet their access requirements.

# *Is the person attending the service prepared that they might receive a dementia diagnosis and asked how they want to know their diagnosis?*

While some people are concerned about symptoms and are looking for an explanation for these, not all people attending a MAS for assessment are ready, or open to, receiving a dementia diagnosis. Services should ensure the person attending the service is aware that the process may lead to a dementia diagnosis, through talking to them about this, and supporting them in the context of their needs and wishes. For example, it should be agreed at the start of the process: who will deliver their diagnosis (e.g. a nurse they have had regular contact with or a psychiatrist); who to share the outcome with (for example, who they want present, whether they want copies of letters sent to a supporter); and how they want to be informed. Where the person is not ready or open to receiving a dementia diagnosis, the MAS should work with them, with the aim of supporting them to a point of readiness by the end of the diagnostic process.

Are the practical support needs of people attending the service assessed and addressed? This might for example include reasonable adjustments and or appropriate support for attendance at appointments.

# *Is pre- peri- and post-diagnostic emotional support available to people attending the service and their supporters?*

Some people attending the service may wish to avail themselves of pre-assessment/diagnostic emotional support and where clinically indicated, counselling. Services should ensure emotional support is available and that all MAS staff have the skills and confidence to provide this. They should also be aware of wider local services who can provide ongoing support and be able to signpost people to them.

### 2.7 History taking

# *Is there a standardised, locally developed and agreed history taking document used for all assessments including collateral history?*

Thorough and consistent history-taking forms are a core component of an effective memory assessment process. The service should have standardised documents for history taking, which include personal, educational and employment history and other factors which may influence outcomes on cognitive tests or support and care planning needs. History taking should be a single process and people accessing the service should not need to provide a history multiple times.

*Is this conducted/completed in a consistent way to a quality standard, by staff who are appropriately trained?* Staff should be trained to use history taking documents and should conduct history-taking so that a standard quality of information is collected for all people attending the service.

Is the person attending the service and their supporters, where possible (if appropriate and with permission) included in history-taking to provide a rounded picture? The service should ensure flexibility in seeking input from a supporter, for example in history-taking with a relative who may be located at a distance.

### 2.8 Cognitive assessment

# Is an appropriate cognitive test used for the person attending the service considering their particular cultural, language and educational background?

Not all cognitive tests are appropriate for, or have been validated for use with, individuals of different cultural and educational backgrounds, English language familiarity or those with specific needs such as a learning disability or hearing or visual impairment. Tests should be selected on the basis of good evidence about their validity and based on the individual's background and needs.

Is an appropriate cognitive test used for the modality of assessment? Some tests cannot be delivered remotely, and others will have items that are not possible to administer remotely.

# *Is information about any previous cognitive assessments undertaken with the person attending the service, made available?*

Where cognitive assessments have been completed previously, information about these should be accessible within the person's care record. Subsequent tests should be evaluated in the context of previous results.

## Is reliability of outcome assured?

The cognitive test should be conducted in a manner that provides confidence in the validity of its result (see also points below regarding factors that may impact reliability).

#### Are sensory impairments optimised?

Sensory impairments may impact the validity of results so should be considered and optimised when conducting cognitive tests.

### Are adjustments available in respect of English language familiarity and literacy?

First language and literacy skills of the person attending the service should be considered on referral so they can be accommodated when conducting cognitive tests. Consideration of language and literacy skills should be included in cognitive test selection and in interpreting the results. For MAS in Wales, the cognitive assessment should be conducted in Welsh where the Welsh language is identified as the person's primary or preferred language. Provision for speakers of BSL should be considered.

# Are other impairments or needs of the person attending the service considered appropriately during assessment?

Other needs or impairments that should be considered include a learning disability, and some physical or mental health conditions.

# Are the results of the cognitive test considered in context of a holistic assessment?

Cognitive tests should never be used as the sole method for determining a dementia or other diagnosis. They should always be considered within the context of all other information collected as part of a holistic assessment.

### Where assessments are completed remotely how is a sense of connection and rapport established?

Rapport building is part of conducting a cognitive assessment but can be more difficult to achieve with some forms of consultation, in particular remote appointments. Connection and rapport building should be considered and built into the assessment process.

# If appropriate, is a detailed neuropsychological assessment available?

Neuropsychological assessment may be important in the diagnostic process for some people and access to a detailed assessment should be available when required.

# 2.9 Occupational Therapy (OT) assessment and post-diagnostic support

### Is an OT-based assessment available to aid diagnosis?

OT assessment should form part of a holistic multi-disciplinary team approach to memory assessment. It can be used to determine if and how a person's functional ability is affected by cognitive issues (e.g. memory, visuospatial, executive functioning). People accessing a MAS should have access to an OT assessment. Where a service does not include OT provision this should be sought from other parts of the NHS when required, ensuring this provision is skilled and specialises in older person's mental health. The impact of this on other parts of the NHS should be considered.

### Is an OT-based assessment offered post-diagnosis to promote independence and maximise function?

Post-diagnostic assessment and care planning can identify client-centred interventions (e.g. assistive technology, equipment provision, adaptation of the environment) and use goal setting to address issues that impact day-to-day functioning. This should be available to those who receive a dementia or other diagnosis where such input may be appropriate, either through the MAS or from other parts of the NHS, when required.

#### Are OT-led/supported interventions offered as part of the post-diagnostic support offer?

This may include programmes such as home-based memory and cognitive rehabilitation programmes, vocational rehabilitation, cognitive stimulation programmes, post-diagnostic support groups, environmental modifications and supported self-management. Where a service does not include OT provision this should be sought from other parts of the NHS, when required, ensuring this provision is skilled and specialises in older person's mental health. The impact of this on other parts of the NHS should be considered. Where interventions are commissioned, there should be a robust occupational focused learning and skills-based training for providers, along with clear pathways to access OT consultancy and advice, where needed.

### 2.10 Brain scanning<sup>5</sup>

### *Is the necessity of a scan assessed?*

The MAS should check whether previous scans are available that could be re-reported.

# *Is the timing of a scan considered in relation to the referral pathway?* Waiting for a scan should not present a barrier to accessing a MAS referral or access to support.

Is it clear who is responsible for referral for scanning and is this considered in relation to the referral process and access to a MAS? Where referral route is not via GP the referral route to scanning should be clearly defined.

*Is the modality of a scan considered and appropriate, in line with NICE guidelines?* NICE guidelines for scan modality should be followed.

Does the referral provide required detail for the appropriate scan to be undertaken? Scan referrals should clearly state the scan type, reason for request and any other information pertinent to conducting the scan appropriately.

Are structural, functional and other specialist scans available to all services and for all people attending the MAS? All imaging modalities recommended by NICE guidelines should be available to all services and people accessing them for cognitive assessment regionally.

Are high-quality reports on scans available to clinicians? Clinicians should be able to access a high-quality report to accompany any scans undertaken.

Does the diagnosing clinician have direct access to the scan images?<sup>6</sup> Reporting of the scan should also include access to the scan images for the MAS clinician. There should

- be a shared care record in place so clinicians can access all necessary information at point of need.
- 5 Services may wish to make reference to the following review

https://www.southeastclinicalnetworks.nhs.uk/wp-content/uploads/2020/12/Wessex-review-of-diagnostic-imagingfor-dementia.pdf\_

and webinar report <u>https://www.hampshirethamesvalleyclinicalnetworks.nhs.uk/wp-content/uploads/2020/10/</u> <u>Dementia-Imaging-Webinar-Report.pdf</u>

6 Having direct access to the scan images can be beneficial for the clinician and person receiving a diagnosis <u>https://www.alzheimers.org.uk/sites/default/files/2020-10/pathway\_report\_full\_final.pdf</u> *Is scanning practically accessible to all people attending the service?* People attending the service should be able to access the appropriate brain scans and this should not be restricted by practical issues such as physical impairments, transport or available support.

*Is timeliness of scanning accommodated within pathway design to optimise time to diagnosis?* There may be long waiting lists for scanning. Consideration should be given to when in the pathway a scanning referral is made and whether this supports a timely diagnosis?

*Is there a locally agreed pathway for reporting and escalating other urgent abnormalities?* There should be a clear route for reporting and escalating other non-dementia related abnormalities identified during scanning, onto the appropriate service in a timely manner.

# 2.11 Blood testing

#### Is blood testing included as part of locally agreed referral criteria?

Blood testing is a required component of the dementia diagnosis pathway, as indicated in NICE guidelines. Blood testing should be clearly indicated in locally agreed referral routes, including the timing of blood testing in the referral process.

Is it clear who is responsible for conducting required blood tests?

It should be clear who (e.g. GP, other referrer, MAS) is responsible for conducting required blood tests.

Is necessity of a blood test and time frame in relation to assessment considered?

Services should consider whether a blood test is necessary and whether the person attending the service has recently undertaken relevant blood tests that do not indicate re-testing.

Are any abnormalities identified and addressed by the appropriate clinician? It should be clear who should identify and address any identified abnormalities and ensure appropriate action.

### 2.12 Communicating a diagnosis

*Is there an aspirational waiting time between initial assessment and receiving a diagnosis or other outcome and what is the rationale for this?* The waiting time between initial assessment and receipt of diagnosis should be monitored.

Are the wishes of the person attending the service followed about how their diagnosis is communicated? The wishes of the person regarding diagnosis, should be established at the point of referral (see also section Referral – preparation of the person attending the service) and revisited again ahead of communicating a diagnosis to ensure they remain the same.

*Is consistency of diagnosis (dementia, Mild Cognitive Impairment (MCI) etc) across the service monitored and assured?* 

Dementia type should be diagnosed according to recognised diagnostic criteria and applied in a consistent way across the service, by all clinicians. Diagnosis should take into account all available evidence and have a clear rationale for a particular diagnosis provided. MDT discussions should take place regarding diagnosis of more complex cases.

# Is information about the diagnosis communicated to the person attending the service in an empathic way that can be understood, allowing for any questions at the time to be addressed?

A 'one-size-fits-all' approach to diagnosis should not be adopted. How information is provided to people attending the service and their supporters should be tailored to them and their needs and wishes. Time should be available for people attending the services and their supporters to ask any questions they may have. Anyone receiving a diagnosis should have this delivered empathically and to a consistent standard, no matter which clinician is delivering it.

### Is immediate emotional support provided following a diagnosis, where appropriate?

There should be provision within the service design and delivery for a person attending the service and their supporters to receive emotional support appropriate to their needs, immediately post-diagnosis.

#### Is a staged process to diagnosis offered?

Diagnosis should be seen as a staged process rather than a one-off appointment. Follow up conversations or appointments should be offered to allow people to have follow-up contact, ask questions and receive ongoing support. The person attending the service and their supporters should be encouraged to ask questions.

#### Is there an agreed, standardised, local way of reporting any diagnosis to the GP?

Services should have a standardised way of reporting the diagnosis to the GP (e.g. shared records or letter) that should include the required Read Codes to use within GP record systems. For MAS in Wales, services should be following guidance set in the current Welsh Government READ Code Circular.

Is the impact of the diagnosis for continuing with daily life activities discussed, including a risk assessment for continuing driving?

This may be raised prior to diagnosis if the clinician deems there to be a risk with continuing driving.

### 2.13 Prescribing and managing medications

Are appropriate medications offered to all people attending the service where their diagnosis of dementia sub-type, severity and clinical presentation indicates the prescribing of cognitive enhancing medications? All people attending the service who are eligible should be offered a prescription for cognitive enhancing medications.

# *Is there an appropriate review of co-existing health conditions to ensure safe prescribing of cognitive enhancing medications?*

This should include consideration of cardiac disease and pulse with further investigations for those if indicated, when prescribing Cholinesterase inhibitors, and assessment of renal function, when prescribing Memantine.

Are people attending the service and their supporters made fully aware of the potential benefits, limitations and side-effects of cognitive enhancing medications? Benefits, limitations, and potential side effects of cognitive enhancing medication should be discussed with the person attending the service and their supporter in a clear and understandable way, enabling them to make an informed decision about taking a medication.

*Is a full medication review conducted and is anticholinergic burden reviewed and considered?* This may include use of an anticholinergic burden checker/calculator and review of the appropriateness and dose of any antipsychotic or sedative medications.

### Are concerns regarding appropriateness of existing prescribed medications raised with the GP for further review?

There should be a clear process in place for raising concerns about the current medications of a person attending the service with their GP, and ensuring appropriate action is taken.

Is the capacity of the person with dementia to manage medications assessed to ensure appropriate support is put in place to assist them and/or their supporter where required? This may require liaison with community services including GP, domiciliary care agencies and community pharmacists.

*Is appropriate review conducted to assess the tolerability of and adherence to prescribed cognitive enhancing medications?* This should include side effects during titration and adherence to taking medications.

Is the GP informed of any newly prescribed medications and are any proposed medication changes discussed with the GP ahead of implementation where this is clinically necessary? There should be a clear and timely process for informing the GP of any

new medications prescribed or updates to prescriptions.

*Is there consistent and clear agreement about responsibility for ongoing prescription, monitoring/review and management of cognitive enhancing medication?* 

Services should ensure it is clear to the person attending the service and their GP who is responsible for ongoing prescription and monitoring of cognitive enhancing medications once final dose is established.

Are GPs able to seek expert input from the MAS on medication management for people who are or have been under the care of the MAS, where this responsibility is discharged to the GP? There should be a clear, direct mechanism for GPs to contact an expert within the MAS team for advice on medication prescription and ongoing management and oversight.

# 2.14 Peri- and post-diagnostic support

### Is support offered, or started, at point of referral in line with service ethos?

There should be provision of information/early support to people who are on the waiting list to access memory assessment services and their supporters. This should include an immediate assessment and triage process that identifies needs that cannot wait until the person has received a full initial assessment and/or diagnosis.

# Is the person attending the service and their supporters provided with appropriate information about their diagnosis and the support available locally?

People attending the service should be provided with clear, comprehensive and up-to-date information about the full range of local peri- and post-diagnostic services and support. This may be through signposting to a source such as dementia/care navigator for this information.

# Are people attending the service and their supporters directed to resources and peer support in a way that is equitable?

Access to resources and support may be impacted by the practical and social resources a person has available to them (e.g. help from family/friends, internet access, transport issues). Services should consider ensuring information and support is available in different formats (e.g. hard copy, on-line, in person).

# *Is the person attending the service signposted/referred to where they can access appropriate non-pharmacological interventions either through the MAS or external providers?*

This might include Cognitive Stimulation Therapy, specialist counselling, emotional support, peer support, rehabilitation and social prescribing. Signposting and referral should consider the person's individual interests, wants and needs and what matters to them most.

### Is personalised care support planning offered?

Future care plans and advance care planning should be discussed and offered. Advanced care planning may not be appropriate to undertake at the point of diagnosis. Information about who can undertake or support advance care planning when the person is ready, should be provided at point of diagnosis.

### Are physical health, sensory impairments and other comorbidities

*considered in terms of ongoing needs and support?* Personalised care planning should be holistic and consider the wider needs of the person attending the service and their supporters.

Is quality of life, what matters most to the person and living well with dementia the primary focus of personalised care support planning? Personalised care planning should focus on understanding and supporting the person to achieve/maintain what matters most to them.

# *Is the person attending the service referred to a named person who will support them and their /support network through their journey with a dementia diagnosis?*

There should be a named person and organisation who takes on the role of ongoing support upon discharge from the MAS to end of life. This might, for example, be a Dementia Care Navigator or Co-ordinator, Admiral Nurse or other health or social care professional. The details of the named person and organisation should be recorded by the MAS (and GP for services in Wales).

Is there an agreed pathway for people attending the service to access appropriate referral for, or provision of treatment/support and follow-up (where this is considered clinically appropriate) for those with a diagnosis of a non-dementia condition e.g. depression? If a person is given a diagnosis of a non-dementia condition, there should be an appropriate referral and support pathway to ensure their needs are appropriately met. Is there provision of support and follow-up (where clinically appropriate) for those where no diagnosis or a nondementia cognitive impairment (e.g. Mild Cognitive Impairment, Subjective Cognitive Impairment) is given? Services should have a strategy in place for supporting these individuals. They should be provided with information about brain health and dementia risk reduction along with support for concerns and worries about memory.

Where the dementia diagnosis is uncertain/unclear or where dementia does not progress as expected, is appropriate review conducted and the diagnosis revisited? Sometimes diagnoses are uncertain, or a dementia diagnosis may not progress as clinically expected. There should be a process for review and revisiting of a diagnosis in such cases to ensure people do not live with an incorrect diagnosis.

# 3. Research opportunities

Are opportunities to take part in research offered and are people attending the service and their supporters directed to relevant local studies and to Join Dementia Research, if they receive a dementia diagnosis and are interested in taking part in dementia related research? Services should have a clear and consistent process for discussing research opportunities with a person

with dementia and where relevant their supporter. Information about Join Dementia Research should be provided. They should be asked about consent for contact for research at their initial assessment.

## Is the service research active?

The service should take part in research either as a participating site or staff working in the service may develop and lead research. The service should contribute to the evidence base in service improvement.

Are staff actively encouraged and supported to conduct or take part in research? The service should offer opportunities for all members of the service team to be involved in research if they wish.

Is there a named staff member who is responsible for increasing research activity and encouraging people attending the service and their supporters to get involved with research? There should be a named lead for increasing research activity in the MAS. There should be a named person responsible for speaking to people accessing the service and their supporters about research and encouraging/supporting participation in studies.

# 4. Co-ordination and/or integration with Primary Care Networks

Is there clarity about roles and responsibilities of the MAS and GP for the ongoing monitoring and care of people attending the service who are diagnosed with dementia or another cognitive impairment? The roles and responsibilities of the MAS and GP in ongoing monitoring and support should be clear to the MAS, GP, person accessing the service and their supporters, including how this might change over time.

*Is a shared care and partnerships model operated?* Services should have a well-defined and effective shared care and partnerships model in place.

Does the MAS input to the Primary Care Network and wider community-based support and services and decision-making within the local healthcare economy? Is there clarity about the MAS position within the overall care pathway?

The MAS should operate within a wider local healthcare economy. The MAS should be outward looking and connected to and inputting relevant expertise to the Primary Care Network and services and decision-making within the local healthcare economy.

Does the service provide appropriate advice, consultancy, input and support to primary care practitioners to manage the day-to-day care of people with dementia?

GPs and other primary care practitioners should be able to access support and advice from MAS staff (e.g. for the prescription and monitoring of dementia related medications, annual reviews, medications reviews). They should be made aware of this and the mechanisms/routes to access.

Are care plans produced as part of MAS services able to be accessed, co-ordinated and implemented in primary care?

Services should have effective mechanisms for sharing personalised care plans with colleagues in primary care. Information within these plans should support GPs to co-ordinate and implement them.

# 5. Partnerships

# *Is the service active in developing local partnerships with commissioned services relevant to the journey through the service?*

Local partnerships should be developed with relevant organisations, which may include clinical teams within the NHS and/or social care (e.g. learning disabilities or drug and alcohol services), VCSE, and other NHS Trusts. Partnerships should ensure a smooth journey through the service and the best possible care.

Is coordinated care with other provider agencies considered and implemented?

People with dementia may have multiple appointments across health and other care services. These can duplicate effort and increase the burden for the person and their supporters. Care should be co-ordinated across services to minimise the numbers of appointments, tests and journeys and to support management of other comorbidities in the context of a dementia diagnosis.

# Is data sharing effectively facilitated between organisations so that appropriate information is shared and people attending the service and their supporters to not have to re-repeat information provision? Local data sharing arrangements should be in place so that important medical and personal history, accessible information requirements, and clinical information is shared

across relevant services and accessible to all clinicians involved a person's care.

# Are gaps in partnership working identified and appropriate relationships that can facilitate effective collaboration developed?

Services should have a mechanism for reviewing local partnerships in the context of the journey through the service and identifying gaps or where improvements could be made. The importance of developing collaborative relationships should be recognised to ensure effective, high-guality and efficient care delivery.

### Does the service build appropriate partnerships and relationships with local communities whose population it serves?

Services should actively engage with and build partnerships and relationships with individuals and organisations that support the local community.

# Taking Memory Assessment Services into the future

A guide to supporting continuous development, improvement and innovation in MAS

# 6. Staff development and support

### 6.1 Ongoing professional development

Are appropriate opportunities for ongoing professional development offered to all staff to ensure they have the appropriate skills, knowledge and expertise to undertake their role effectively? This should be offered to all staff working in the service, including those in clinical and non-clinical roles.

# Are there an appropriate range of education and training opportunities, both

formal and informal, available to suit different learning needs?

Staff development opportunities should include a range of provision that can meet the needs of staff with different learning styles and needs. This should be reviewed regularly to ensure it meets staff needs.

# Is available training and education aligned to current best practice, including ensuring

the voice of people attending services and their supporters is represented?

The design, delivery and commissioning of training and education should follow best-practice guidance (for example those identified in the What Works? Study<sup>7</sup>). Training should include the perspectives of people attending memory assessment services, people with dementia and their supporters.

# Is there an ethos of a 'learning environment' where education, training and ongoing professional development

are prioritised, valued for all professional groups at all levels and sharing of learning is encouraged? Services should value learning and the sharing of this across the staff team. Staff learning and development should be recognised as important for all staff and as underpinning high quality service delivery. The implementation of education and training into practice should be seen as a central outcome of learning and development activity and supported by service managers.

### Is dementia training at an appropriate level statutory/mandatory for all staff?

The dementia education/training available should align to appropriate national frameworks (e.g. in England the Dementia Training Standards Framework<sup>8</sup> in Wales the Good Work Framework<sup>9</sup>). It should be mandatory for all staff.

# Are clinical staff aware of Continuing Professional Development opportunities and frameworks and supported to avail of these?

Staff should be encouraged to regularly consider their current/ongoing education, training and wider development needs and be made aware of and supported to access relevant education, training and other development opportunities.

Are administrative and other non-clinical staff supported to access dementia-specific training and development? Staff in non-clinical roles should be supported and encouraged to attend dementia training that is relevant to them and their role.

# Do all members of the team feel supported and able to access

appropriate development opportunities and support? Services should review whether staff feel their learning and development needs are being met and ensure that access to training and development opportunities is equitable.

### Is regular clinical supervision or similar offered to all staff working in the service?

All staff working in the service should have access to regular clinical supervision or other regular support as relevant to their role. This should be seen as a positive and useful experience. For services in Wales, in regions where there is limited or inconsistent support and supervision due to workforce challenges, there should be a partnership arrangement with other regions to access this.

Does the MAS offer opportunities for training and development to clinicians and other staff working in the wider support network supporting the assessment, diagnosis and post-diagnostic support pathway? MAS teams have extensive dementia expertise. They should make this available by offering training and development opportunities to organisations and staff in the wider local health, social care and voluntary sector network, who have a wider role in the dementia referral, assessment, diagnosis and post-diagnostic support pathway. This should be regularly reviewed to examine and address gaps in local needs.

- 7 <u>https://www.leedsbeckett.ac.uk/research/centre-for-dementia-research/what-works/</u>
- 8 https://skillsforhealth.org.uk/info-hub/dementia-2015-updated-2018/
- 9 <u>https://socialcare.wales/cms\_assets/file-uploads/Good-Work-Dementia-Learning-And-Development-Framework.pdf</u>

### 6.2 Teamworking

*Is the role and skill mix of the team considered in the context of the service design and delivery?* This may include service roles but also potentially language skills, for example in areas with diverse populations.

Does the service adopt a team-based approach, shared values and agreed ways of working where the input and expertise of all members are recognised and valued? Services should recognise and value the expertise that all members of the team bring to service delivery. This should be reviewed regularly to ensure staff feel included and valued and that all expertise and contributions are sought and recognised.

Is there an MDT approach to service delivery which ensures people attending the service and their supporters have appropriate input from, and access to, clinicians across a range of roles as required (e.g. OT, psychology) to inform the formulation and interventions/support needed? Decisions within the service should be informed by an MDT comprised of individuals with an appropriate range of expertise. Where specific expertise is not available within the commissioned MAS team this should be sought as required.

# Are all members of the team able to contribute to service design, evaluation or to suggest new approaches to working?

Services should have mechanisms for consulting with all staff in order to continually evaluate the service and how it is delivered. Where a need for service change is identified there should be effective mechanisms for consultation with and engagement of all staff. All staff should feel able to contribute ideas.

# 7. Quality assurance and evidence-based and innovative service delivery

*Does the service have a practice development and continuous improvement ethos?* Practice development should be a valued core component of activity for the service. There should be strategies developed to ensure this takes place.

# Does the service have internal quality assurance and practice development

structures that feed into Trust-wide clinical governance processes? Services should use internal quality assurance and Trust-wide clinical governance processes to support ongoing quality assurance and practice development.

*Is regular evaluation of the service conducted and are learning points identified and acted upon?* Services should have a regular cycle of service evaluation that seeks to identify good practices, points of learning, areas for improvement and mechanisms for addressing these.

*Is there a process of audit and evaluation to quality assure the diagnostic output of the service?* Diagnostic quality should be monitored, reported and any concerns addressed. Services should evaluate performance regarding diagnosis of particular dementia types versus known epidemiology.

Are people attending the service representative of the demographics of the local area? Services should monitor local demographics and whether people referred to the service and those who go on to receive a dementia diagnosis, reflect the local population. Any discrepancies between expected and actual demographics should be acted upon

Does the service seek feedback from people attending the service and their supporters about their experiences and ways to improve service delivery and quality? Is this acted upon? Services should actively seek feedback from people attending the service and their supporters, using methods that ensure equitable ability for all to provide feedback. People attending the service and their supporters should be informed about how the service has acted on feedback.

### Are 'Did Not Attends' (DNAs) evaluated?

The service should evaluate the numbers of DNAs and, where possible, determine the reasons for this. This information should be acted upon to reduce DNAs. Reasons for DNAs and late arrivals for appointments can include accessibility issues such as the need for text message reminders of appointments, ensuring people are able to hear their named being called for their appointments and issues with navigating transport and buildings.

# Does the team utilise evidence-based practice? How do they stay in touch with current developments in memory assessment service practice?

Services should actively engage with evidence on current best practice. There should be an ethos within the service of valuing and supporting evidence-based practice. Staff should be provided with appropriate support, skills and resources to remain up-todate with current developments in MAS memory assessment service practice.

*Is information from service evaluation and feedback from those attending the service and their supporters, translated into service development, redesign or innovation?* Information from service evaluation and feedback should be translated into service development or innovation.

# Are people attending the service and their supporters encouraged to contribute to service design and ongoing development?

Service evaluation or redesign should include active participation of people attending the service and their supporters throughout the process. They should be supported to participate in meaningful ways and their input valued.

# Are all staff encouraged to feedback ideas for service development?

Service evaluation or redesign should include active participation of all staff throughout the process. All staff, in all roles, should be encouraged to participate and their input valued.

# Is innovative practice encouraged?

Services should have an ethos that values innovation and be willing to take risks to innovate and continually improve.

# Are new practices introduced and their impact/effectiveness evaluated?

Innovations and practice changes should be implemented in a considered way, including a clear plan for evaluation of impact. Evaluations should be reviewed and used by the service and shared beyond the service to influence wider practices in memory assessment services.