Greater Manchester Integrated Care Partnership

Greater Manchester Pathways to Dementia Diagnosis and Post Diagnostic Support

June 2024

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Introduction

"One in two of us will be directly affected by dementia in our lifetime, either by caring for someone with the condition, developing it ourselves or both" [1]

Dementia United is the dementia programme for Greater Manchester NHS, part of Greater Manchester Integrated Care Partnership. We work alongside clinicians, charities, localities, professionals, those living with dementia, families, friends, and care partners to make our region the best place to live if you have or are caring for someone with dementia.

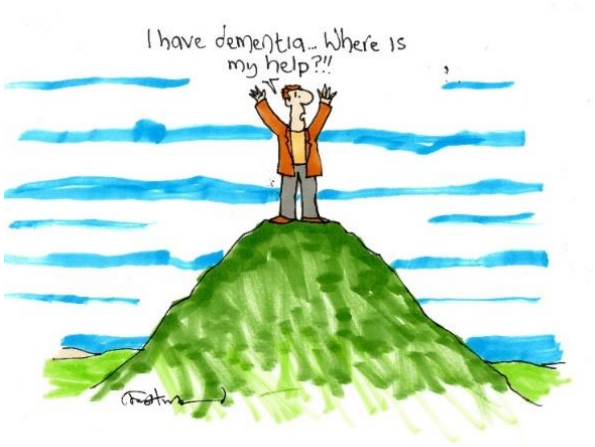
This is the report of one of Dementia United's multi agency project groups, which worked together to map the diagnostic pathways and initial post diagnostic support offer across Greater Manchester, as part of a project to improve the quality and experience of being diagnosed with dementia. This report includes an in-depth appreciative enquiry on service delivery models across the different localities.

Improving the quality and experience of dementia diagnosis is one of many projects that form Dementia United's delivery plan, which can be found at https://dementia-united.org.uk/wp-content/uploads/sites/4/2023/09/Dementia-and-Brain-Health-Delivery-Plan-2023-to-2025.pdf.

For clarity, within this document and workstream, the diagnostic pathway refers to the process of accessing an assessment, receiving a diagnosis, and accessing initial post-diagnostic support.

"The main driver for a dementia diagnosis is that it facilitates access to care and support that enables people to manage and live well with a complex condition. Driving up diagnostic rates without investing in post-diagnosis support results in people with dementia feeling unsupported after their diagnosis" [2]

[1] www.alzheimersresearchuk.org/wp-content/uploads/2023/08/Tipping-Point-Report.pdf
[2] www.alzheimers.org.uk/sites/default/files/2022-07/left-to-cope-alone-after-diagnosis-report.pdf



Cartoon by Tony Husband

Although Greater Manchester has a higher dementia diagnosis rate than the national average, improvement is still required. Dementia United recognise that the dementia diagnosis rate does not necessarily reflect the quality and experience of diagnosis and this project is therefore adopting a wider focus.

"Dementia is currently diagnosed far too late, with most people waiting years to seek a formal diagnosis. One in three people with dementia never receive a diagnosis at all" [3]

The All-Party Parliamentary Group on Dementia recently released a report 'Raising the barriers: An action plan to tackle regional variation in dementia diagnosis in England'[4]. This report highlights that 90% of people say they benefitted from a diagnosis but there is a postcode lottery on whether you will get a timely, accurate and quality dementia diagnosis. The group also call for more equitable access to post diagnostic support across England, with a named professional to coordinate a person's dementia journey. It's known that memory assessment services and post-diagnostic support services are commissioned differently in each locality of Greater Manchester, though different service models have not previously been explored.

3 www.alzheimersresearchuk.org/wp-content/uploads/2023/08/Tipping-Point-Report.pdf
4 www.alzheimers.org.uk/sites/default/files/2023-10/Raising%20the%20Barriers.pdf

There is also recognition nationally that dementia services have been "routinely underfunded"[5] and the Alzheimer's Society[6] and Alzheimer's Research UK[7] have both called for investment in diagnosis and dementia pathways. The 2023 Alzheimer's Society report 'Improving access to a timely and accurate diagnosis of dementia in England, Wales and Northern Ireland'[8] advocates for better funded dementia pathways that deliver effective care, support, intervention, and treatments for all those living with dementia.

Dementia United has worked with partners to produce the Greater Manchester Dementia and Brain Health Quality Standards[9], which include the following standards for diagnosis and post diagnostic support:

- Everyone can access an assessment and be considered for a formal diagnosis of dementia. Specific action may be required to support diverse populations to access an assessment and services should be culturally accessible.

- Dementia pathways are in place in each locality, including post diagnostic support. Post diagnostic support includes access to pharmacological and non-pharmacological interventions and meets the needs of diverse communities, including those with young onset or rarer forms of dementia.

The development of the Greater Manchester Integrated Care Partnership offers increased opportunities for innovation and shared learning across Greater Manchester. This work aligns fully with the vision of the Greater Manchester Integrated Care Partnership strategy 2023 – 2028[10] to share best practice effectively within a culture of collaboration, to reduce unwarranted variation, and to drive improvement.

It's recognised that this work does not explore the challenges faced by people from marginalised communities and those with rarer forms of dementia, including young onset, when accessing the dementia diagnosis pathway. Future analysis of these challenges will be built into the next phase of work.

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5 www.alzheimers.org.uk/sites/default/files/2023-05/alzheimers-society-improving-access-timely-accurate-diagnosis-england-wales-full-report_0.pdf
6 www.alzheimers.org.uk/sites/default/files/2023-05/alzheimers-society-improving-access-timely-accurate-diagnosis-england-wales-full-report_0.pdf
7 www.alzheimersresearchuk.org/wp-content/uploads/2023/08/Tipping-Point-Report.pdf
8 www.alzheimers.org.uk/sites/default/files/2023-05/alzheimers-society-improving-access-timely-accurate-diagnosis-england-wales-full-report_0.pdf
9 www.dementia-united.org.uk/wp-content/uploads/sites/4/2024/05/Greater-Manchester-Dementia-and-Brain-Health-Quality-Standards-2024-Long-Version.pdf
10 www.gmintegratedcare.org.uk/greatermanchester-icp/icp-strategy/

Background and policy context

The NHS England 'well pathway for dementia'[11] was developed several years ago and outlines the key areas for dementia support: preventing well, diagnosing well, supporting well, living well, and dying well. Dementia is a life-limiting condition and people living with dementia are likely to access multiple points in the wider health and social care system.

The dementia care pathway implementation guidance suggests memory assessment services may be configured in a range of ways[12]:

- Cognitive neurology clinics or neurology services.
- Geriatric or old age medicine clinics/services, through acute (medical) trusts.
- GP-led clinics/services supported by specialist advice and assessment from one or more of the services above.
- Integrated services, with co-location and/ or joint working between one or more of the providers above.
- Via secondary mental health care providers, either as stand-alone memory clinics or services, or integrated with older adult community mental health services.

However, this guidance document does not propose best practice service models to deliver support in each area of the dementia pathway and has "little guidance on how best to set up services and deliver quality care post-diagnosis"[13].

Leeds Beckett University Centre for Dementia Research were commissioned to outline different models of service delivery across England and Wales, and to share good and innovative practice. Their recent 'Review of national memory assessment services report'[14] notes the need to routinely evaluate the delivery of services to ensure they meet local needs and the importance of adapting novel approaches that sit outside of 'typical' memory assessment service models to meet these local needs.

[11] www.england.nhs.uk/mentalhealth/wp-content/uploads/sites/29/2016/03/dementia-well-pathway.pdf
[12] www.rcpsych.ac.uk/docs/default-source/improving-care/nccmh/dementia/nccmh-dementia-care-pathway-full-implementation-guidance.pdf?sfvrsn=cdef189d_8#:~:text=The%20dementia%20care%20pathway%20introduced,post%2Ddiagnostic%20support%20and%20treatment
[13] www.alzheimers.org.uk/sites/default/files/2020-10/pathway_report_full_final.pdf
[14] www.leedsbeckett.ac.uk/-/media/files/research/dementia/des01567_mas_long_report-and-guidelines_digital.pdf

The report suggests that innovative approaches should be explored around the physical location of services and meeting the needs of ethnically diverse communities, with "commissioners working with service managers to identify local service needs and be willing to commission innovative approaches that enable memory assessment service services to address these needs". A previous report[15] provides questions to drive innovation within memory assessment services and these have been considered within this report.

NICE guidance outlines key standards for assessment and support for people living with dementia, including the provision of a named health or social care professional who is responsible for co-ordinating their care[16]. Within Greater Manchester, as well as nationally, this responsibility is largely deferred to GPs with no provision for a specialist practitioner to support people affected by dementia.

The Memory Services National Accreditation Programme (MSNAP) provides a set of standards for memory assessment services to evaluate against[17]. Tameside memory service, Central Manchester, and North Manchester services are currently accredited by MSNAP, and Wigan and South Manchester services are in the process of gaining accreditation. It's noted there is a subscription cost of £2,300 +VAT per year to enter this programme.

There is no nationally endorsed model of service delivery for post diagnostic support, though MSNAP standards offer guidance for memory assessment services. Dementia United fully endorse post diagnostic support including both pharmacological and non-pharmacological interventions, with a need to ensure post diagnostic support offers within memory assessment services do not become limited to the initiation and titration of medication. It is recognised that post diagnostic support needs are individual, and that one approach will not suit all, so services should be responsive to individual need in line with personalised care principles.

Work is required from all areas of the Greater Manchester system to ensure that people given a diagnosis of dementia are supported. Dementia is a life-limiting condition and support should therefore be available from the point of diagnosis to end of life, supporting people to live as well as possible with their condition, in line with palliative care principles.

[15] www.leedsbeckett.ac.uk/-/media/files/research/dementia/taking-memory-assessment-services-into-future-web.pdf
[16] www.nice.org.uk/guidance/ng97
[17] www.rcpsych.ac.uk/docs/default-source/improving-care/ccqi/quality-networks/memory-clinics-msnap/msnap-standards---8th-edition-(2022).pdf?sfvrsn=d8341549_2

Unmet post diagnostic support need ***"increases the risk of adverse, costly and detrimental outcomes such as hospitalisation, carer breakdown and more rapid admittance to care homes for people affected by dementia"*** [18].

In contrast, good post diagnostic support care increases quality of life, enables care planning (including advance care planning), delays the need for costly residential care, and avoids unnecessary hospital admissions[19].

Dementia United recognise that this work has taken place as new treatments for dementia are being developed and significant change will be required within the system should the National Institute for Health and Care Excellence (NICE) issue guidance around disease-modifying treatments.

Staffing issues were reported by 78% of respondents to the Leeds Beckett study, which collected data in December 2021[20], and the Alzheimer's Society survey in 2022 found 71% of respondents reported workforce challenges as a barrier to ensuring people receive a timely diagnosis[21]. Staffing challenges are reflected in informal feedback from services across Greater Manchester, though this was not explored within this process.

Greater Manchester overview

Greater Manchester includes ten localities: Bury, Bolton, Manchester, Oldham, Rochdale, Salford, Stockport, Tameside, Trafford, and Wigan. Manchester locality has three memory assessment services, but they have been considered as one service following discussion with the relevant Service Manager.

Memory assessment services in Bolton, Manchester, Salford, Trafford, and Wigan are delivered by Greater Manchester Mental Health NHS Foundation Trust.

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[18] www.alzheimers.org.uk/about-us/policy-and-influencing/our-position-key-dementia-challenges/diagnosis

[19] www.rcpsych.ac.uk/docs/default-source/improving-care/nccmh/dementia/nccmh-dementia-care-pathway-full-implementation-guidance.pdf?sfvrsn=cdef189d_8#:~:text=The%20dementia%20care%20pathway%20introduced,post%2Ddiagnostic%20support%20and%20treatment

[20] www.leedsbeckett.ac.uk/-/media/files/research/dementia/des01567_mas_long_report-and-guidelines_digital.pdf

[21] www.alzheimers.org.uk/sites/default/files/2023-05/alzheimers-society-improving-access-timely-accurate-diagnosis-england-wales-full-report_0.pdf

Memory assessment services in Oldham, Rochdale, Stockport, and Tameside are delivered by Pennine Care NHS Foundation Trust.

Bury has a unique model in Greater Manchester as most people are diagnosed with dementia by their GP and there is no separate memory assessment service. Complex cases are referred for an old age psychiatrist review in an outpatient mental health clinic (delivered by Pennine Care NHS Foundation Trust) for further assessment and diagnosis.

There are five Voluntary, Community and Social Enterprise (VCSE) organisations commissioned to provide post diagnostic support within Greater Manchester:

- Alzheimer's Society in Bury, Oldham, Rochdale, Stockport, Tameside, and Wigan.
- Age UK Salford.
- Age UK Trafford.
- Bolton Dementia Support.
- Together Dementia Support in Manchester and North Trafford.

For the purposes of this report, 'commissioned' relates to agreements between the above organisations and the locality, or on a Greater Manchester basis, to provide dementia services as per a contracted arrangement. It is noted that the commissioning arrangements for each organisation/locality have not been explored in depth.

There are many additional VCSE organisations that provide support, beyond the commissioned offer provided by the organisations above. These services are often reliant on short-term funding arrangements, such as grants. The role of hospices in Greater Manchester in developing dementia support offers within their palliative care services is also recognised by Dementia United, and this is being further explored within the dementia palliative and end of life care project group.

Process

Improving the quality and experience of dementia diagnosis is one of the projects within Dementia United's delivery plan and a collaborative project group has been developed with engagement from across Greater Manchester. There are representatives from the acute trusts, Alzheimer's Society, local authorities, mental health trusts, people with lived experience, and VCSE organisations within these meetings.

In addition to information gained through the meetings, all Greater Manchester memory assessment services and commissioned VCSE organisations were requested to complete a data gathering spreadsheet. Further information has been sought by the Dementia United team as required, and feedback has also been gathered from members of the Dementia Carers Expert Reference Group and Dementia United Locality Implementation Forum.

Findings

Staffing

Each memory assessment service in Greater Manchester has a different staffing model. The table provides an overview of roles provided within services, but please note this does not indicate a whole time equivalent post is in place and there may be more or less than one member of staff within this role.

The MSNAP minimum standards state that a memory assessment service should "consist of a medical practitioner and a multidisciplinary team consisting of at least two other professions"[22]. Apart from Bury, services in Greater Manchester meet this minimum standard.

The information for Bury refers to the old age psychiatry outpatient clinic offer as there is no separate memory assessment service, though it is noted most dementia diagnoses in Bury are formulated and delivered within primary care. Vacancy information has been given where provided at the time of information gathering.

	Bury	Bolton	Manchester	Oldham	Rochdale	Salford	Stockport	Tameside	Trafford	Wigan
Admiral Nurse			✓							
Advanced Clinical Practitioner		✓					✓ Trainee	✓ Trainee		

[22] www.rcpsych.ac.uk/docs/default-source/improving-care/ccqi/quality-networks/memory-clinics-msnap/msnap-standards---8th-edition-(2022).pdf?sfvrsn=d8341549_2 p.18

	Bury	Bolton	Manchester	Oldham	Rochdale	Salford	Stockport	Tameside	Trafford	Wigan
Assistant Psychologist		✓	✓	✓ vacancy		✓		✓		
Assistant Practitioner			✓							
Carer Support Worker		✓								
Clinical Psychologist		✓	✓	✓ vacancy	✓	✓ vacancy			✓ vacancy	
Community Psychiatric Nurse		✓	✓	✓	✓	✓	✓	✓	✓	✓
Consultant Psychiatrist	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Dementia Support Advisor			✓			✓				
Non-Medical Prescriber			✓						✓	
Occupational Therapist		✓	✓	✓	✓	✓	✓	✓	✓	✓ Generic role
Psychiatrist	✓		✓	✓ vacancy		✓	✓		✓	✓
Speech and Language Therapist			✓				✓			
Support Worker	✓	✓	✓		✓	✓	✓	✓		✓
Senior Practitioner		✓	✓	✓		✓				✓
Team Manager		✓	✓	✓	✓	✓	✓	✓	✓	✓
Admin		✓	✓	✓	✓	✓	✓	✓	✓	✓

Please see Appendix 2 for a summary of the roles included above.

The staffing provision (whole time equivalent) for each role varies significantly across services.

It's noted that Manchester and Wigan memory assessment services sit within the older adult community mental health team (called LLAMS in Wigan), with staffing split across memory assessment and the community mental health offer. It's therefore difficult to accurately note the number of staff within the memory assessment pathway in these services.

It's also noted that Consultant Psychiatrists are often covering other community mental health services, or inpatient mental health services, as well as memory assessment, with difficulties accurately attributing time allocated to each service (given the nature of crisis work). The provision for Consultant Psychiatrists ranges from access via outpatient clinic only in Bury to 3.0 whole time equivalent consultant cover for both memory assessment and Community Mental Health Teams (CMHTs) in Wigan.

	Bury	Bolton	Manchester	Oldham	Rochdale	Salford	Stockport	Tameside	Trafford	Wigan
Consultant Psychiatrist	Via outpatient clinic only	0.6	2.0 (also cover CMHT)	3.0 (7 session)	2.0	2.0	2.0	0.3	2.0 (also cover CMHT)	3.0 (also cover CMHT)

The provision for Community Psychiatric Nurses ranges from no provision in Bury to 9.0 whole time equivalent in Salford. Manchester services have a higher whole time equivalent of nurses within the team, but this provision includes community mental health team support as well as memory assessment.

	Bury	Bolton	Manchester	Oldham	Rochdale	Salford	Stockport	Tameside	Trafford	Wigan
Community Psychiatric Nurse	0	4.8	9.6 (also cover CMHT)	4.6	2.0	9.0	4.5	1.2	3.4	11.16 (also cover CMHT)

The provision for Occupational Therapists (who deliver occupational therapy intervention) ranges from no provision in Bury and Wigan to 2.0 whole time equivalent in Salford. In Wigan Occupational Therapists works in a generic role across CMHT but occupational therapy specific work is included within their job plan.

	Bury	Bolton	Manchester	Oldham	Rochdale	Salford	Stockport	Tameside	Trafford	Wigan
Occupational Therapist	0	1.8	2.0 (also cover CMHT)	0.6	1.0	2.0	0.5	1.0	0.6 (0.2 generic role)	5.07 (also cover CMHT)

The provision for Clinical Psychologists ranges from no provision in Bury, Stockport, and Tameside, to 2.0 whole time equivalent in Salford. It's noted that Oldham and Trafford currently have vacant Clinical Psychologist posts.

	Bury	Bolton	Manchester	Oldham	Rochdale	Salford	Stockport	Tameside	Trafford	Wigan
Clinical Psychologist	0	1.55	0.6 – 1.0 (also cover CMHT)	0.8 (vacant post)	0.2	2.0 (1.0 vacant post)	0	0	1.0 (vacant post)	1.8

The Leeds Beckett study found an Admiral Nurse in one service of those that responded (48 respondents) so this support does not appear widespread nationally. An Admiral Nurse is based within each Manchester community mental health team (of which the memory assessment pathway is part) and their support is available for people following their diagnosis. This provision is not available elsewhere though admiral nurses are employed at other points in the system in some, but not all, localities.

Tameside memory assessment service have a trainee Advanced Clinical Practitioner within the team and another trainee is due to commence training in Stockport.

Referral routes

In Bury, GPs complete most dementia assessments and diagnoses, with no team within mental health services commissioned specifically to provide memory assessment. If a GP in Bury feels further assessment is required, for example if rarer forms of dementia are suspected, a person can be referred for an outpatient appointment with an old age psychiatrist. It's also possible to refer to the Cerebral Function Unit for further assessment. The pathways and links between GPs in Bury and the Cerebral Function Unit were not explored within this work.

The Bury model does not therefore follow NICE guidance (2018), which recommends

people are referred to a specialist dementia diagnostic service if reversible causes of cognitive decline have been investigated and dementia is still suspected[23]. The dementia care pathway implementation guidance suggests memory assessment services may be configured via GP-led clinics supported by specialist assessment from cognitive neurology clinics or neurology services and/or geriatric or old age medicine clinics/services, through acute (medical) trusts[24]. This is not in place in Bury.

Most referrals to memory assessment services are received from GPs, in line with NHS guidance to seek a GP appointment if a person is concerned about their memory[25]. Self-referrals are only accepted to one service (Wigan) and these referrals account for approximately 1% of all referrals to the service. GPs are requested to complete a blood screen if this has not already been completed for those who self-refer to the service.

Direct referrals are accepted from acute hospitals in Manchester, Tameside, Trafford, and Wigan, though the pathways are not clear to all parties in some localities and these pathways do not appear to be well established within many acute hospitals. It's recognised that acute hospitals are often required to refer to different localities for ongoing assessment so clear pathways are required.

Referral routes to memory assessment services are summarised below:

	Bury	Bolton	Manchester	Oldham	Rochdale	Salford	Stockport	Tameside	Trafford	Wigan
Acute hospital settings	N/A		✓			✓		✓	✓	✓
Community services e.g. geriatricians	N/A					✓	✓		✓	✓
GP referral	N/A	✓	✓	✓	✓	✓	✓	✓	✓	✓
Other older adult mental health teams	N/A				✓	✓	✓			✓
Self-referral	N/A									✓

[23] www.nice.org.uk/guidance/ng97
[24] www.rcpsych.ac.uk/docs/default-source/improving-care/nccmh/dementia/nccmh-dementia-care-pathway-full-implementation-guidance.pdf?sfvrsn=cdef189d_8#:~:text=The%20dementia%20care%20pathway%20introduced,post%2Ddiagnostic%20support%20and%20treatment
[25] www.nhs.uk/conditions/dementia/symptoms-and-diagnosis/diagnosis/

NICE guidance recommends practitioners in non-specialist settings complete an initial assessment including a history, physical examination, blood tests, and validated brief structured cognitive assessment, such as the 6-item Cognitive Impairment Test (6CIT)[26]. This information is requested from referrers by most memory assessment services, though referrers are not requested to complete a brief structured cognitive assessment in Trafford.

Information requested by memory assessment services

	Bury	Bolton	Manchester	Oldham	Rochdale	Salford	Stockport	Tameside	Trafford	Wigan
Reason for referral / history	N/A	✓		✓	✓	✓	✓	✓	✓	✓
Recent blood tests	N/A	✓	✓	✓	✓	✓	✓	✓	✓	✓
Brief cognitive screen	N/A	✓	✓	✓	✓	✓	✓	✓		✓
Medical history	N/A	✓		✓	✓	✓		✓		
Current medication	N/A	✓		✓	✓	✓			✓	
Six month history of concerns	N/A			✓	✓	✓				
ECG	N/A						✓	✓		

Within Pennine Care NHS Foundation Trust, referrals are directed to a single point of entry team who triage all referrals to older adult mental health services and forward relevant referrals to the memory assessment service. Further triage by the team manager also takes place in Oldham and Rochdale. Within Greater Manchester Mental Health NHS Foundation Trust services, referrals are sent directly to the relevant team where they are triaged by practitioners within the team.

Referrals can be declined at this point, with a letter to the GP sent by all services where a referral is not accepted for initial assessment. The person referred only receives a letter advising their referral has been declined in Manchester, Stockport, and Wigan.

[26] www.nice.org.uk/guidance/ng97

Pre-assessment

Trafford is the only locality to offer pre-assessment support, via a commissioned VCSE organisation (Age UK Trafford). Anyone accepted for an initial memory assessment is referred to Age UK Trafford via an opt out scheme and are then contacted by this organisation to discuss support available.

The Dementia Change Action Network has created a website and printable resource for people who are waiting for a memory assessment, in recognition of the increased waiting times across the UK[27]. This is a useful resource and has been shared with services to provide information to those people accepted for initial assessment by memory assessment services in Greater Manchester.

Initial assessment

There is flexibility to be seen in a requested place (home or clinic) within all services.

Initial assessment venue

	Bury	Bolton	Manchester	Oldham	Rochdale	Salford	Stockport	Tameside	Trafford	Wigan
Mostly home			✓	✓			✓		✓	✓
Mostly clinic	✓	✓			✓	✓		✓		

Other than in Bury, initial assessments are generally completed by a mental health practitioner, who is most often a Community Psychiatric Nurse but may also be an Occupational Therapist. Initial assessments by a Consultant Psychiatrist are requested within some services, where a more complex presentation is identified at triage, commonly suspected young onset dementia or rarer forms of dementia.

[27] www.nextsteps.org.uk/

Staff involved in the initial assessment

	Bury	Bolton	Manchester	Oldham	Rochdale	Salford	Stockport	Tameside	Trafford	Wigan
Mental Health practitioner (nurse or OT)		✓	✓	✓	✓	✓	✓	✓	✓	✓
Consultant psychiatrist	✓ via outpatients	✓ if indicated	✓ if indicated							
Speech and language therapist							✓			
Assistant practitioner (ACE-III only)						✓				
Advanced nurse practitioner		✓								
Advanced clinical practitioner								✓		

The MSNAP minimum standards state an initial assessment should include[28]:

- Basic dementia screen and blood tests in accordance with clinical need.
- A comprehensive, evidence-based assessment including mental health and medication, psychosocial and psychological needs, strengths and areas for development, and suicide risk.
- A cognitive assessment (formal cognitive testing using a standardised assessment) and mental state examination.
- Interview with someone who knows the person well, where possible.
- A physical health review.

Assessments included within the initial assessment

	Bury	Bolton	Manchester	Oldham	Rochdale	Salford	Stockport	Tameside	Trafford	Wigan
Initial pro-forma (local document)		✓	✓	✓	✓	✓	✓	✓	✓	✓
ACE-III		✓	✓	✓	✓	✓	✓	✓	✓	✓

[28] www.rcpsych.ac.uk/docs/default-source/improving-care/ccqi/quality-networks/memory-clinics-msnap/msnap-standards---8th-edition-(2022).pdf?sfvrsn=d8341549_2 p.9

	Bury	Bolton	Manchester	Oldham	Rochdale	Salford	Stockport	Tameside	Trafford	Wigan
MOCA	✓			✓	✓	✓			✓	
RUDAS (where indicated)		✓		✓	✓	✓		✓	✓	
GDS						✓ Where indicated		✓ Where indicated	✓	
HADS								✓ Where indicated		
GAD-7			✓					✓ Where indicated		
PHQ-9			✓							
ADL checklist			✓							
Risk screen/ assessment		✓	✓	✓	✓	✓	✓	✓	✓	✓
Carer questionnaire								✓	✓	
Frontal assessment battery								✓		
Driving assessment form				✓						
KOLT			✓							

Please see Appendix 1 for a summary of the assessments listed above.

Pennine Care NHS Foundation Trust have recently introduced a standardised initial assessment document that has been adopted by all memory assessment services. Within Greater Manchester Mental Health NHS Foundation Trust, equivalent documents have been developed within localities with no standardisation across the trust. In Bury, a history is taken by a GP as part of the assessment but there is no standardised form within the GP record system for recording the information gathered.

An “appropriate cognitive and assessment of functional abilities” is recommended within the implementation guidance for the dementia well pathway[29]. All services in Greater Manchester complete a standardised cognitive assessment and questions about function are included within the locally developed initial assessments, but not all services are completing an assessment of functional abilities. An interview with someone who knows the person well is completed in all services, where possible.

It's noted that the ADAPT South Asian Dementia Pathway includes the ACE-III, Montreal Cognitive Assessment (MOCA) and the Rowland Universal Dementia Assessment Scale (RUDAS), and these assessments are used by services in Greater Manchester.

Further assessment

Brain imaging

Structural imaging is recommended to “rule out reversible causes of cognitive decline and to assist with subtype diagnosis, unless dementia is well established and the subtype is clear”[30], and MSNAP minimum standards state there should be timely access to brain imaging (if clinically required)[31]. Guidance regarding imaging, including what imaging may be required and when, has been developed in other areas of the country[32].

There is little consistency regarding access to brain imaging in Greater Manchester:

	Bury	Bolton	Manchester	Oldham	Rochdale	Salford	Stockport	Tameside	Trafford	Wigan
MRI scan request prior to initial assessment	✓ via GP			✓	✓		✓	✓		

[29] www.rcpsych.ac.uk/docs/default-source/improving-care/nccmh/dementia/nccmh-dementia-care-pathway-full-implementation-
[30] www.nice.org.uk/guidance/ng97
[31] www.rcpsych.ac.uk/docs/default-source/improving-care/ccqi/quality-networks/memory-clinics-msnap/msnap-standards---8th-edition-(2022).pdf?sfvrsn=d8341549_2
[32] www.rcpsych.ac.uk/docs/default-source/members/faculties/old-age/neuroimaging-for-dementia---guidance-from-london-dementia-clinical-network.pdf?sfvrsn=1d1bcbe5_6#:~:text=Specialist%20imaging%20should%20only%20be,CIT%20SPECT%20(DAT%20scan).

	Bury	Bolton	Manchester	Oldham	Rochdale	Salford	Stockport	Tameside	Trafford	Wigan
CT scan request prior to initial assessment				✓ if MRI contraindicated	✓ if MRI contraindicated		✓			✓
Request following psychiatrist review of initial assessment			✓			✓				
MRI scan request following initial assessment		✓			✓ if not possible prior					
Request following psychiatrist appointment	✓								✓	✓

All services advised that additional scans, or a referral to the Cerebral Function Unit, would be considered if rarer forms or young onset dementia was suspected following initial assessment/psychiatry review.

Given the extent of variation across services, further exploration of the use of brain imaging is indicated. Access to imaging records and documentation completed in acute hospitals has also been raised as an issue for some memory assessment services.

Neuropsychology assessment and assessment of occupational functioning

NICE guidance suggests considering neuropsychological testing if it's unclear whether the person has cognitive impairment, whether their cognitive impairment is caused by dementia, or what the correct subtype diagnosis is[33]. The MSNAP minimum standards state the memory assessment service should have "access to in-depth assessment of occupational functioning and neuropsychological assessment as required (e.g., for young onset dementia, complex or abnormal presentations)"[34].

[33] www.nice.org.uk/guidance/ng97
[34] www.rcpsych.ac.uk/docs/default-source/improving-care/ccqi/quality-networks/memory-clinics-msnap/msnap-standards---8th-edition-(2022).pdf?sfvrsn=d8341549_2 p.10

There is variable access to neuropsychology and occupational therapy assessment across Greater Manchester:

	Bury	Bolton	Manchester	Oldham	Rochdale	Salford	Stockport	Tameside	Trafford	Wigan
Neuropsychology		✓	✓		✓	✓		✓	✓ vacancy	✓
Assessment of occupational functioning		✓	✓	✓		✓	✓	✓	✓	✓

Bury, Oldham, and Stockport services noted they would refer people to the Cerebral Function Unit if it was felt neuropsychological testing was required. The Cerebral Function Unit is a cognitive neurology clinic run by an interdisciplinary team of neurologists, neuropsychologists, neuropsychiatrists, and researchers based at Salford Royal Hospital[35]. The unit receives referrals from across the North West region.

Speech and Language Therapy

Manchester, Oldham and Stockport memory assessment services have access to specialist Speech and Language Therapists for complex presentations.

Diagnosis

The majority of diagnoses are made and delivered by Consultant Psychiatrists across Greater Manchester, though different models are developing in some localities.

Staff involved in delivering diagnosis

	Bury	Bolton	Manchester	Oldham	Rochdale	Salford	Stockport	Tameside	Trafford	Wigan
GP	✓									
Consultant psychiatrist	✓	✓	✓ where needed	✓	✓	✓	✓	✓	✓	✓
Psychiatrist						✓				

[35] www.cfu.org.uk/our-clinical-service/

	Bury	Bolton	Manchester	Oldham	Rochdale	Salford	Stockport	Tameside	Trafford	Wigan
Community psychiatric nurse			✓		Nurse sits in appointment	✓	✓			✓
Occupational therapist						✓				✓
Advanced clinical practitioner							✓	✓ current trainee		
Advanced nurse practitioner		✓								
Clinical psychologist						✓				

Manchester, Salford, Stockport, and Wigan have a blended model of diagnosis where staff who have completed the initial assessment discuss this with the consultant psychiatrist and deliver the diagnosis to the person (where possible). In Tameside, a trainee Advanced Clinical Practitioner is now in post and will be completing diagnoses following training, and a trainee Advanced Clinical Practitioner has also recently started in Stockport. An Advanced Nurse Practitioner is in post in Bolton and has a role in diagnosis.

Services where blended models are in place described pathways for assessment and diagnosis, with more complex cases (people with suspected younger onset and rarer forms of dementia) generally referred for consultant psychiatry review at the point of referral. This reflects feedback from services who contributed to the Leeds Beckett report, with pathways starting at the point of triage in several services[36].

Consideration should also be given to the role of other disciplines diagnosing dementia, recognising skills and experience beyond psychiatry. The role of Geriatricians within acute settings and outpatient clinics, who have specialist skills and training, should be explored further.

A diagnosis is given both at home or in a clinic environment, with consideration of personal preference.

[36] www.leedsbeckett.ac.uk/-/media/files/research/dementia/des01567_mas_long_report-and-guidelines_digital.pdf

Where no diagnosis is found, a person is discharged back to the GP by all services (please see the section below regarding mild cognitive impairment).

Memory assessment services are currently sharing diagnoses with GPs using ICD-10 codes. Primary care use SNOMED codes within this coding process so it's suspected that this may be creating issues around the accuracy of coding. A further piece of work is required to align ICD-10 codes to SNOMED codes for diagnosis, with consideration of memory assessment services using both codes on diagnosis letters that are shared with GPs. Trafford have recently implemented changes in this regard, and this will be explored further within the project group. Coding issues are not unique to Greater Manchester and a national programme of work was planned to explore this further, but this is currently on hold.

Initial post diagnostic support

In Bury and Trafford, all non-pharmacological post diagnostic support is provided by a VCSE organisation, whilst in all other areas the memory assessment services offer a degree of non-pharmacological post diagnostic support.

Post diagnostic support provided by memory assessment services.

	Bury	Bolton	Manchester	Oldham	Rochdale	Salford	Stockport	Tameside	Trafford	Wigan
Admiral nurse			✓							
Follow up telephone call							✓			
Referral to commissioned VSCE organisation	✓			✓ Dementia Advisor sits in clinic	✓ Dementia Advisor sits in clinic			✓	✓	✓
Referral to other services			✓					✓		

	Bury	Bolton	Manchester	Oldham	Rochdale	Salford	Stockport	Tameside	Trafford	Wigan
Information pack		✓	✓			✓		✓		
Internal dementia support advisor		✓	✓ 1 year follow up			✓				
Cognitive stimulation therapy		✓ via OT		✓ via OT	✓ via OT	✓		✓ via day unit pathway		✓
Occupational therapy		✓	✓ if driving only	✓	✓	✓	✓	✓ via day unit pathway		
Psychology		✓ group offer	✓	✓ vacancy (0.2)	✓ vacancy (0.2)	✓				✓
Education /support group		✓		✓ via OT	✓ via OT	✓ via psychology		✓ via day unit pathway		✓
Carer education group					✓ via OT			✓ via day unit pathway		✓
Carer support				✓	✓ via OT	✓				✓ via psychology
Medication titration	✓			✓	✓ limited cases	✓	✓	✓	✓	✓
Drop in				✓ With VCSE						
Care plan										

NICE guidance recommends carers should be offered a psychoeducation and skills training intervention[37] to promote cognition, independence, and well-being. There is however no guidance as to which service/organisation should offer this intervention, and at what point this should be offered. Rochdale, Tameside and Wigan memory assessment services provide this intervention as part of their post diagnostic support. It's noted that Empowered Conversations provide a carer education and support offer across Greater Manchester, but this is not commissioned within any locality.

MSNAP minimum standards also state that people living with dementia should have access to cognitive stimulation therapy [38]. Not all memory assessment services provide

[37] www.nice.org.uk/guidance/ng97
[38] www.rcpsych.ac.uk/docs/default-source/improving-care/ccqi/quality-networks/memory-clinics-msnap/msnap-standards---8th-edition-(2022).pdf?sfvrsn=d8341549_2 p.11

cognitive stimulation therapy intervention.

The minimum standards state services should provide or can signpost/ refer on to services that will offer information, advice, and support to assess and manage pharmacological treatment[39]. All services are providing or referring on to support around pharmacological management, as recommended by MSNAP.

Finally, the minimum standards also state services should provide or can signpost/ refer on to dementia advisor and support services for patients and carers (including Admiral Nurses, dementia navigators, or other specialist practitioners) [40]. An offer is available within each locality.

It's important to note that, whilst a service offer may exist in a locality, further information is required to explore if every person who receives a diagnosis of dementia is referred for this support and the impact of this support on those who access it. Quantitative data is therefore required regarding people who are referred for post diagnostic support (where this is provided internally with the memory assessment service and externally), as well as qualitative data around the experience of this support. For example, a recent Healthwatch report found that less than half (48%) of whose who completed the survey had been referred for post diagnostic support in Bury[41]. The report notes that referrals were "ad hoc and there were no consistent actions taken around advice and support at point of diagnosis". It's noted that work is taking place in Bury to improve pathways and service offer, and it's likely that this issue is not exclusive to Bury.

Onward post diagnostic support

Informal feedback and the Bury Healthwatch report indicate that not everyone who receives a diagnosis of dementia is referred to the locally commissioned VCSE organisation for ongoing post diagnostic support, though this offer is available in each locality. Further exploration of this is indicated.

The requirement for a named care co-ordinator also falls to GPs, rather than specialist dementia practitioners. This is a concern given the progressive and life-limiting nature

[39] www.rcpsych.ac.uk/docs/default-source/improving-care/ccqi/quality-networks/memory-clinics-msnap/msnap-standards---8th-edition-(2022).pdf?sfvrsn=d8341549_2 p.11
[40] www.rcpsych.ac.uk/docs/default-source/improving-care/ccqi/quality-networks/memory-clinics-msnap/msnap-standards---8th-edition-(2022).pdf?sfvrsn=d8341549_2 p.11
[41] www.healthwatchbury.co.uk/sites/healthwatchbury.co.uk/files/Dementia%20report%20V1.1%2003-02-23.pdf

of the condition, and the costs to the both the person and the wider system where adequate post diagnostic support is not provided.

The VCSE organisations commissioned to provide dementia support in Greater Manchester offer the following interventions:

	Bury	Bolton	Manchester	Oldham	Rochdale	Salford	Stockport	Tameside	Trafford	Wigan
Dementia advisor	✓	✓			✓		✓	✓	✓	✓
Dementia café		✓	✓			✓				✓
Singing for the Brain					✓		✓		✓	
Singing for the Brain (virtual offer)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Carer information & support group		✓	✓		✓		✓			
Drop-in clinic (with memory assessment service)							✓			
Activity groups			✓ charge			✓ charge			✓ North Trafford via TDS	
Home visits		✓	✓ charge							

It's recognised that there are many VCSE organisations who are not commissioned by statutory bodies but continue to offer dementia support. It has not been possible to map all support available across Greater Manchester within this work, but this should be considered further within localities. The ongoing challenges around funding of VCSE organisations are noted and this requires further exploration at a Greater Manchester system level.

Annual dementia review

Everyone who is diagnosed with dementia should receive an annual dementia review within primary care, under the requirements of the Quality Outcomes Framework[42]. This is an essential element of post diagnostic support, given the potential to identify new needs and to signpost/refer people living with dementia and their carers to additional

[42] www.england.nhs.uk/publication/quality-and-outcomes-framework-guidance-for-2023-24/

support services. However, available data shows that approximately a quarter of people living with dementia in Greater Manchester did not have an annual review in 2022/23[43].

There are proof of concept pilots in progress in Bury and Tameside to implement a digitised dementia wellbeing plan for people living with dementia, which offers additional opportunities for regular review following a diagnosis of dementia. The learning from these pilots will be shared across Greater Manchester when available.

The above suggests there is an opportunity for greater integration and partnership working between primary care, memory assessment services, and VCSE organisations, in line with Greater Manchester's Integrated Care Partnership strategy[44].

Mild Cognitive Impairment

Mild Cognitive Impairment (MCI) describes memory and thinking problems that are mild but still noticeable. Research has found that having Mild Cognitive Impairment can raise the risk of developing dementia in future, but this depends on the underlying cause[45]. There's currently no guidance from NICE related to MCI.

Interventions offered by memory assessment services following a diagnosis of Mild Cognitive Impairment

	Bury	Bolton	Manchester	Oldham	Rochdale	Salford	Stockport	Tameside	Trafford	Wigan
Discharge to GP	✓	✓	✓		✓		✓	✓	✓	
6-month nurse review				✓	✓ if indicated		✓ if indicated			✓
2-year review pathway						✓				
Mild cognitive impairment information pack						✓			✓	

[43] www.fingertips.phe.org.uk/search/dementia%20care%20plan
[44] www.gmintegratedcare.org.uk/greatermanchester-icp/icp-strategy/
[45] www.alzheimersresearchuk.org/dementia-information/types-of-dementia/mild-cognitive-impairment/

	Bury	Bolton	Manchester	Oldham	Rochdale	Salford	Stockport	Tameside	Trafford	Wigan
Commissioned VCSE offer									✓	
Occupational therapy									✓ if inidcated	✓ if inidcated
Psychology										✓ if inidcated
Be Well clinic								✓		
Memory skills / information group			✓					✓		
Refer to brain health clinic			✓							

A review of people given a diagnosis of Mild Cognitive Impairment is therefore completed by memory assessment services in half of the ten localities of Greater Manchester.

Data

Dementia data is available from various data sources and Dementia United are currently working with business intelligence colleagues to develop a Greater Manchester dementia data dashboard. Currently data is collected by both mental health trusts, including numbers of people waiting for initial assessment, wait times from referral to initial assessment, and wait times from referral to diagnosis. It's intended that this information will be available within the dementia data dashboard in future. There is an ongoing project around Greater Manchester dementia data.

The All-Party Parliamentary Group on dementia have called for a national Dementia Observatory to be created to facilitate robust data collection[46], which Dementia United support.

Experience of diagnosis

Feedback is not currently routinely gathered about the experiences of people recently diagnosed with dementia in Greater Manchester, as well as carers and loved ones. Friends and Family Tests can be used within the mental health trusts that provide

[46] www.alzheimers.org.uk/sites/default/files/2023-10/Raising%20the%20Barriers.pdf

memory assessment services, but this is not specific for experiences of diagnosis and so other opportunities are being explored. It's hoped that Dementia United can collaborate with Healthwatch to gather this information as part of wider views on dementia services within Greater Manchester.

Training

Training for all practitioners who complete initial assessments, diagnose, and deliver diagnoses is crucial to ensure a quality experience for the person given a diagnosis. This was not the focus of this work but is an area that requires further development across Greater Manchester. Several localities have developed informal training/development activities and there is likely learning to be shared across Greater Manchester from this work.

One of the objectives of Dementia United's project to improve the quality and experience of dementia diagnosis is to develop guidance for practitioners when delivering a diagnosis. This also links to the importance of discussing dementia as a life limiting condition, where one can still live well, throughout the dementia pathway.

Spotlight on innovation

There are many examples of good practice and innovation across Greater Manchester, often developed by passionate staff in response to local need. Some examples include:

- Healthy Hyde primary care network (Tameside) have developed a dementia case management service, offering a lifelong service to people within a diagnosis of dementia. This post diagnostic service is led by two dementia nurse case managers, alongside a care navigator.
- Age UK Trafford offer pre-diagnostic support for people who are referred for an assessment with Trafford memory assessment team. This is an opt out service, so everyone offered an initial assessment by the team is referred to Age UK Trafford, unless they decline this service.
- Central Manchester mental health services (GMMH) offer a pilot brain health clinic for people diagnosed with mild cognitive impairment. This includes review by a consultant psychiatrist and additional investigations, as well as support from a brain health care navigator.
- Empowered Conversations provide communication courses for family carers of people living with dementia, as well as training for staff. Courses are currently

available free of charge to carers in Greater Manchester, due to lottery funding, but this service is not commissioned in any locality.

- Pennine Care NHS Foundation Trust have a transformation programme around memory assessment services. This includes the development of standardised assessment documentation on PARIS (electronic record system).
- The Bolton quality contract includes additional targets for primary care related to people living with dementia and carers.
- Oldham have developed a Dementia Hub based at Dr Kershaw's Hospice, including a drop in for anyone affected by dementia in Oldham.
- The Alzheimer's Society Sahara team offer support for South Asian people affected by dementia across Greater Manchester.
- Willow Wood Hospice in Tameside provide a dementia support service, including a dementia café and dementia carers support group.

Key Findings

1. There is no nationally determined gold standard operating model for memory assessment services, though NICE guidance[47] and the MSNAP[48] provide standards for practice. Most memory assessment services in Greater Manchester are not accredited by MSNAP.
2. There is variation across many aspects of the diagnostic pathways in Greater Manchester, including in staffing provision, assessments offered, use of brain imaging, and delivery of diagnosis models.
3. There is no nationally endorsed model of service delivery for post diagnostic support, though the MSNAP standards offer guidance for post diagnostic support to be offered within memory assessment services. Each memory assessment service in Greater Manchester provides a different post diagnostic support offer and each locality has a different commissioned VCSE post diagnostic support offer.
4. Innovation has developed within memory assessment services and commissioned VCSE organisations in response to local need.

Staffing

5. It's difficult to clearly define staffing resource for memory assessment services located within a wider community mental health team offer, which is important given

[47] www.nice.org.uk/guidance/ng97
[48] www.rcpsych.ac.uk/docs/default-source/improving-care/ccqi/quality-networks/memory-clinics-msnap/msnap-standards---8th-edition-(2022).pdf?sfvrsn=d8341549_2

the ongoing transformation of community mental health services.

6. Consultant psychiatrist clinical time and leadership varies across memory assessment services. The impact on service delivery was not explored within this work, but the potential for a significant impact is noted given the current diagnostic model in most services is consultant led.

Referral pathways and assessment

7. Bury has a unique model as most people are diagnosed by GPs and there is no separate memory assessment service. This model does not follow NICE guidance, which recommends people are "referred to a specialist dementia diagnostic service if reversible causes of cognitive decline have been investigated and dementia is still suspected"[49].
8. Referral pathways between acute hospitals and memory assessment services are not well established in all localities. This leads to further delay for people who have been thoroughly assessed by skilled practitioners in hospitals to access further assessment through a memory assessment service. This also places increased burden on primary care to follow up referrals, and potential missed opportunities to offer memory assessment and post diagnostic support.
9. Only one locality offers pre-diagnostic support, via a commissioned VCSE organisation.
10. Pennine Care NHS Foundation Trust have recently introduced a standardised initial assessment document that has been adopted by all memory assessment services. Initial assessment documents have been developed by local services in Greater Manchester Mental Health NHS Foundation Trust with no standardisation across the Trust.
11. The Addenbrookes Cognitive Examination III (ACE-III) is used by all memory assessment services, but not used in Bury where the Montreal Cognitive Assessment (MOCA) is used.
12. The use of brain imaging is variable across services and requested at different points in the diagnostic pathway.
13. Staff are not employed/in post to complete neuropsychology assessment and assessment of occupational functioning within all memory assessment services, though access to these assessments are minimum standards within the MSNAP standards[50]. It's noted that services can refer to the Cerebral Function Unit for further neuropsychology assessment, but this results in additional delays for the

[49] www.nice.org.uk/guidance/ng97
[50] www.rcpsych.ac.uk/docs/default-source/improving-care/ccqi/quality-networks/memory-clinics-msnap/msnap-standards---8th-edition-(2022).pdf?sfvrsn=d8341549_2 p.10

person under assessment.

Diagnosis

14. Within memory assessment services, most diagnoses of dementia are formulated by psychiatrists / consultant psychiatrists, though three services have developed/are developing pathways for advanced nurse practitioners and advanced clinical practitioners to diagnose dementia. There has been little sharing of knowledge and learning around this process across services and organisations to date.
15. Blended models of delivering diagnosis are in place in several memory assessment services (where diagnoses are discussed with a psychiatrist / consultant psychiatrist and delivered by a mental health practitioner). There has been little sharing of knowledge and learning around the development of new models across services and organisations to date.
16. Different coding systems are used by memory assessment services (ICD-10) and primary care services (SNOMED). This may lead to people not being correctly recorded as having a dementia diagnosis within primary care, with implications for follow on care as well as local dementia diagnosis rates.

Post diagnostic support

17. Unmet post diagnostic support need "increases the risk of adverse, costly and detrimental outcomes such as hospitalisation, carer breakdown and more rapid admittance to care homes for people affected by dementia"[51]. In contrast, good post diagnostic support care increases quality of life, enables care planning (including advance care planning), delays the need for costly residential care, and avoids unnecessary hospital admissions[52].
18. NICE guidance[53] and MSNAP standards[54] recommend both pharmacological and non-pharmacological support is included within a post diagnostic support offer.
19. VCSE organisations provide all non-pharmacological post diagnostic support in two localities.
20. In two memory assessment services, a dementia advisor from the local

[51] www.alzheimers.org.uk/about-us/policy-and-influencing/our-position-key-dementia-challenges/diagnosis
[52] www.rcpsych.ac.uk/docs/default-source/improving-care/nccmh/dementia/nccmh-dementia-care-pathway-full-implementation-guidance.pdf?sfvrsn=cdef189d_8#:~:text=The%20dementia%20care%20pathway%20introduced,post%2Ddiagnostic%20support%20and%20treatment
[53] www.nice.org.uk/guidance/ng97
[54] www.rcpsych.ac.uk/docs/default-source/improving-care/ccqi/quality-networks/memory-clinics-msnap/msnap-standards---8th-edition-(2022).pdf?sfvrsn=d8341549_2

commissioned VCSE organisation sits within clinic and a person diagnosed with dementia is seen immediately following their diagnostic appointment.

21. Carer education and training is recommended in NICE guidance[55]. An offer is available in three memory assessment services in Greater Manchester. There is a VCSE organisation carer education offer available across all localities, but this is not currently commissioned in Greater Manchester.
22. Cognitive stimulation therapy intervention is a minimum standard within MSNAP[56], but this is not offered by all memory assessment services.
23. VCSE organisations are commissioned in each locality to provide post diagnostic dementia support. However, an opt out referral process is only in place in one locality. The numbers of people referred to their local VCSE organisation was not explored within this work, but this requires further consideration.
24. The capacity of commissioned VCSE organisations to provide support has not been explored within this work, though concerns around a lack of capacity due to funding arrangements have been raised informally and waiting lists for services have been reported.
25. The NICE guidance[57] requirement for a named care co-ordinator falls to GPs, rather than specialist dementia practitioners. This is of note given the progressive and life-limiting nature of the condition, and the costs to the both the person and the wider system, where adequate post diagnostic support is not provided.
26. Admiral nurses are employed to offer post diagnostic support via memory assessment services in one locality.
27. An annual dementia review is a key component of post diagnostic support and is currently available via primary care, though data indicates an annual dementia review is not completed for every person living with dementia in Greater Manchester.
28. There are proof of concept pilots in progress in Bury and Tameside to implement a digitised dementia wellbeing plan for people living with dementia, which offers additional opportunities for regular review following a diagnosis of dementia. The learning from these pilots will be shared across Greater Manchester when available.

Marginalised communities and people with rarer forms of dementia

29. This work has not explored specific pathways for people from marginalised communities and people with rarer forms of dementia, including young onset dementia. The unique needs of these populations are recognised and Dementia United have recently started a project around young onset and rarer forms of

[55] www.nice.org.uk/guidance/ng97
[56] www.rcpsych.ac.uk/docs/default-source/improving-care/ccqi/quality-networks/memory-clinics-msnap/msnap-standards---8th-edition-(2022).pdf?sfvrsn=d8341549_2
[57] www.nice.org.uk/guidance/ng97

dementia.

Mild cognitive impairment

30. Review of people given a diagnosis of mild cognitive impairment is completed by memory assessment services in half of the ten localities of Greater Manchester.

Data

31. Further data is required on various aspects of the assessment and diagnostic process, as well as post diagnostic support, to establish a clear baseline and measure change.

Recommendations

1. These findings should be reviewed and considered by the Greater Manchester system, including health, social care and VCSE partners.
2. A greater focus on post diagnostic support, both non-pharmacological and pharmacological, is required across the system.
3. Consideration should be given to whether MSNAP accreditation should be sought for all memory assessment services in Greater Manchester. This would provide a level of assurance that minimum standards are met across all localities.
4. The provision of memory assessment services, as well as ongoing dementia support, must be fully considered within the transformation of community mental health services.
5. Engagement with the improving quality and experience of dementia diagnosis project should be supported across the wider system as an opportunity to share knowledge and learning across services and organisations.

Staffing

6. Further exploration of the impact of consultant psychiatrist provision on diagnostic wait times is indicated. It's noted that Pennine Care NHS Foundation Trust have started this work within their services.
7. It's important that the staffing resource for memory assessment services is clearly defined where this service is provided within wider community mental health teams, particularly in the context of the transformation of community mental health services.

8. The role of geriatricians, neurologists, and other professionals with specialist skills and training in dementia should be further explored within local dementia diagnosis pathways and post diagnostic support offers.
9. An analysis of training needs for all staff working in memory assessment services should be completed, with additional training developed/sourced where indicated. Opportunities to share training resources between services and organisations should be explored.

Referral pathways and assessment

10. A more in-depth review of the Bury model is indicated given the model does not follow NICE guidance, but their dementia diagnosis rate is consistently one of the highest in Greater Manchester.
11. In the absence of pre-assessment support in nine localities, links to the Dementia Change Network next steps website[58] should be shared with people who are waiting for assessment. Consideration should be given to provision of pre-assessment support across Greater Manchester.
12. Referral pathways from acute hospitals to memory assessment services should be in place across Greater Manchester to ensure appropriate referrals of people in hospital.
13. Learning from Pennine Care's experience of implementing a standardised initial assessment across all memory assessment services should be shared across Greater Manchester, with consideration of whether this reduces unwarranted variation.
14. Further exploration of cognitive assessments used within initial assessments is indicated.
15. Further exploration of the use of brain imaging is indicated. Consideration should be given to the development of Greater Manchester focused guidance.
16. Access to neuropsychology assessment and assessment of occupational functioning should be available within each memory assessment service, in line with the MSNAP minimum standards. Where clinicians are not available within a service, clear pathways and referral criteria for alternative services should be developed to ensure appropriate access where indicated.

Diagnosis

17. Where blended models of diagnosis formulation and delivery are developed, clear pathways should be in place within memory assessment services. Sharing learning

[58] www.nextsteps.org.uk/

across services and organisations will be key to driving innovation in this area.

18. It's vital that training for staff is developed to support best practice where blended models of diagnosis are in place.
19. Memory assessment services should use relevant SNOMED codes in correspondence with primary care to ensure accurate diagnoses are recorded across all systems.

Post diagnostic support

20. Both non-pharmacological and pharmacological support should be included within post diagnostic support offers in Greater Manchester.
21. There are opportunities for greater integration between statutory and VCSE organisations across Greater Manchester, which should be explored within localities. Practitioners within memory assessment services should be aware of the remit and function of relevant commissioned VCSE organisations, with representation of VCSE organisations in multi-disciplinary teams where appropriate.
22. Consideration should be given to a commissioned carer education offer across Greater Manchester, to meet NICE guidance, if it's not possible to deliver this within local memory assessment services.
23. An opt out model for referral to commissioned VCSE organisations should be explored by localities, to ensure everyone given a dementia diagnosis is able to access this support. This should include consideration of dementia advisors contacting a person in a timely manner following their diagnostic appointment.
24. Further exploration of the capacity of locally commissioned VCSE organisations is indicated.
25. Opportunities to develop roles within primary care to offer increased post diagnostic support for people living with dementia should be explored. The provision of specialist dementia practitioners within primary care in Hyde is an example of innovative practice.
26. Admiral nurse provision, roles, and referral routes across Greater Manchester should be further explored.
27. Learning from current proof of concept pilots to implement a digitised dementia wellbeing plan for people living with dementia and a care navigation offer should be shared across Greater Manchester, when available.

Marginalised communities and people with rarer forms of dementia

28. Further work is required to explore pathways for people from marginalised communities and those with rarer forms of dementia, including young onset. It would

be beneficial to explore referrals to the Cerebral Function Unit within this work.

Mild cognitive impairment

29. Further exploration of the offer for people given a diagnosis of mild cognitive impairment is indicated.

Data

30. A dementia data dashboard is now in development and data relevant to dementia diagnosis and post diagnostic support should be included within this dashboard. Indicators beyond the dementia diagnosis rate need to be considered when exploring the quality and experience of dementia diagnosis and post diagnostic support.

Conclusion

This work has been completed as part of a project to improve the quality and experience of dementia diagnosis in Greater Manchester, one of the projects within the Greater Manchester Dementia and Brain Health Delivery Plan 2023-25.

The findings of this work highlight the variation in dementia diagnostic pathways across Greater Manchester, including in terms of initial post diagnostic support following diagnosis. This reflects the national picture as there is no nationally endorsed model for memory assessment services or the delivery of post diagnostic support. However, MSNAP provides standards for memory assessment services and this, combined with NICE guidance, provides useful guidance for good practice which has been considered within this work.

The recommendations resulting from this work cannot be implemented by one programme or organisation; change is required across the Greater Manchester system to improve the quality and experience of dementia diagnosis. The response to the variation identified through this work is now to identify areas of good practice and develop a vision for the future. It must also be recognised that new treatments may soon be approved by NICE, which will require further widespread change across all aspects of the system.

The recommendations of this report are therefore a combination of suggestions to improve the quality and experience of dementia diagnosis within the constraints of the

current system, and a call to further investigate and develop new ways of working. A greater focus on sharing innovation across services and organisations is required to promote best practice in dementia diagnosis and post diagnostic support across Greater Manchester, as well as moving towards true integration of health, social and VCSE organisations.

Dementia United will continue to work with all partners in our vision to make Greater Manchester the best place to live for all those affected by dementia.

Appendix 1: Glossary of key terms

ACE-III	Addenbrooks Cognitive Examination III This is one assessment that can be used to identify cognitive impairment. The five cognitive domains assessed are: attention, memory, fluency, language, and visuospatial processing.
Acute hospitals	Hospitals providing assessment and treatment for severe injury, period of illness, urgent medical condition, or to recover from surgery.
ADAPT South Asian Dementia Pathway	This online toolkit was developed as part of a study involving collaboration between universities, organisations, and people with lived experience. More information can be found at https://raceequalityfoundation.org.uk/adapt/.
ADL Checklist	Activities of Daily Living Checklist Activities of daily living are tasks completed on a day to day basis, such as bathing, meal preparation, and shopping. A checklist can be used to identify areas of difficulty.
All-Party Parliamentary Group on Dementia	This group is a cross party group of MPs and Peers with an interest in dementia, run in partnership with Alzheimer's Society. The group's aim is to influence legislation and policy making to improve the lives of people affected by dementia. The group meets several times a year and also conducts enquiries.
Annual dementia review	A face to face review of a dementia care plan, taking place within primary care.
Assessment of occupational functioning	An assessment of how a person is performing within occupations (day to day tasks). This is completed by an Occupational Therapist.
Brain health	Brain health is an approach to ensure the potential gains from reducing the risk of developing dementia are maximised. Brain health is about more than just dementia, with a focus on modifiable risk factors and determinants of healthy ageing.

Brain/structural imaging	Brain imaging can be used alongside other tests as part of the assessment process. There are a range of different scans that may be used. Brain imaging shows any damage that has occurred in the brain that can cause different symptoms.
Cerebral Function Unit	The Cerebral Function Unit is a regional clinical service for the investigation, diagnosis and care of early-onset and rare neurodegenerative dementias. It is a cognitive neurology clinic run by an interdisciplinary team, located at Salford Royal Hospital and part of Manchester Centre for Clinical Neurosciences.
Community Mental Health Team (CMHT)	Community Mental Health Teams support people with mental health problems living in the community, and their carers. The multidisciplinary team often includes Community Psychiatric Nurses, Occupational Therapists, Psychiatrists, and Social Workers.
Cognitive Stimulation Therapy (CST)	CST sessions are intended for people with mild to moderate dementia and aim to improve wellbeing and cognitive function. CST usually takes place in a group, with 14 sessions including a range of activities and discussions.
CT scan	Computerised Topography (CT) scans involve a series of x-rays taken from different angles of the head to produce images of a person's brain. CT scans are the most common type of brain scan used in dementia diagnosis.
Dementia	Dementia is a group of symptoms. It's caused by different diseases that damage the brain. Symptoms include memory loss, confusion and needing help with daily tasks, problems with language and understanding, and changes in behaviour. Symptoms are progressive and dementia is a life-limiting condition.
Dementia diagnosis rate	This indicator reports the rate of persons aged 65 and over with a recorded diagnosis of dementia per person estimated to have dementia given the characteristics of the population. NHS England agreed a national ambition of a Dementia

	Diagnosis Rate (DDR) of 66.7%.
Disease modifying treatments	These treatments alter the course or duration of a disease. There are currently several disease modifying treatments (DMTs) for dementia in late stage clinical trials.
Diverse populations/communities	Culturally diverse communities are groups of people with common cultural backgrounds, ethnic origins, cultural heritages, linguistic and/or religious backgrounds.
ECG	An electrocardiogram (ECG) is a test that records the electrical activity of the heart, including the rate and rhythm.
Friends and Family Tests	The NHS Friends and Family Test (FFT) was created to help service providers and commissioners understand whether patients are happy with the service provided.
Frontal assessment battery	A cognitive test that incorporates several clinical assessments to screen for frontotemporal dementia.
GDS	The Geriatric Depression Scale (GDS) is a self-report measure of depression in older adults.
HADS	The Hospital Anxiety and Depression Scale (HADS) is a self-report rating scale designed to measure anxiety and depression.
ICD-10 codes	The International Classification of Diseases, Tenth Revision (ICD-10) is a system used to classify and code all diagnoses, symptoms and procedures.
KOLT	The Kendrick Object Learning Test (KOLT) is a brief test of memory function.
Memory assessment service	Secondary care service that provides assessment and diagnosis of dementia.
MSNAP	The Memory Services National Accreditation Programme (MSNAP) provided by the Royal College of Psychiatrists.
Mild Cognitive	Memory and thinking problems that are mild but still

Impairment (MCI)	noticeable.
MOCA	Montreal Cognitive Assessment (MOCA) is a cognitive screening tool.
MRI scan	Magnetic Resonance Imaging (MRI) scans use a strong magnet and radio waves to produce detailed images of inside the body.
NICE	The National Institute for Health and Care Excellence (NICE) provides national guidance and advice to improve health and social care.
Neuropsychological assessment	This looks at a range of different brain functions including attention and concentration, memory, visual perception, language and problem solving skills.
Non-pharmacological interventions	Interventions that do not involve the use of medication.
Palliative care principles	Palliative care is defined by the World Health Organisation as an approach that improves the quality of life of patients and their families who are facing problems associated with life-limited illness, usually progressive.
Pharmacological interventions	Interventions that involve the use of medication.
PHQ-9	The Patient Health Questionnaire-9 (PHQ-9) is an instrument for screening and measuring depression.
Post-diagnostic support	Post-diagnostic support is an “umbrella term encompassing the variety of official and information services and information aimed at promoting the health, social, and psychological wellbeing of people with dementia and their carers after diagnosis” (Alzheimer’s International, 2022).
Psychiatry outpatient clinic	Outpatient treatments are those provided for people living in the community (who are not in hospital). A Psychiatrist provides appointments for people either at a clinical site or in the person’s home, and the group of appointments is referred to as a clinic.

Quality Outcomes Framework	This framework for primary care includes disease prevalence and quality achievement rates and measures. It is developed by NHS England.
Rarer forms of dementia	Most people living with dementia have Alzheimer's disease or vascular dementia, though there are many other diseases and conditions that cause dementia. The rarer forms include frontotemporal dementia (FTD), posterior cortical atrophy (PCA), and primary progressive aphasia (PPA).
RUDAS	The Rowland Universal Dementia Assessment Scale (RUDAS) is a multicultural cognitive assessment scale.
SNOMED codes	A structured clinical vocabulary for use in an electronic health record used to capture clinical information.
Unwarranted variation	Variation exists in the way healthcare services are provided. At times this variation is justified in response to population need. Unwarranted variation is that which cannot be explained by patient need or specific patient or population preferences.
VCSE organisation	Voluntary, Community and Social Enterprise (VCSE) organisations are a diverse range of organisations that operate for the greater good of society, for example charities, community groups, and nonprofit organisations.
Whole time equivalent (WTE)	Total contracted hours as a multiple of full time contracted hours (37.5 hours per week). For example 1.0 WTE is equal to 37.5 hours per week and 0.6 WTE is equal to 22.5 hours per week.
Young onset dementia	When a person develops dementia before the age of 65, this is known as young onset dementia.
6-item Cognitive Impairment Test (6CIT)	A dementia screening tool.

Please see Appendix 2 for a summary of practitioner roles.

Appendix 2: Summary of roles

Admin	Administrative staff that provide administrative and secretarial support.
Admiral Nurse	Specialist dementia nurses that provide support for families affected by all forms of dementia.
Advanced Clinical Practitioner	Healthcare professionals, educated to Master's level or equivalent, with the skills and knowledge to allow them to take on expanded roles and scope of practice.
Advanced Nurse Practitioner	Registered nurses who have completed extra training and qualification to be able to clinically assess, diagnose, refer, and treat patients.
Assistant Practitioner	Experienced staff working in support roles, alongside registered healthcare professionals.
Assistant Psychologist	Staff working in a psychology support role to provide clinical support to patients, supervised by a psychologist.
Carer Support Worker	Staff working a support role to support carers both practically and emotionally.
Clinical Psychologist	Work with individuals as well as teams and organisations to develop and support psychological practice. Trained to work with individuals, families and groups experiencing psychological distress or behavioural problems which disrupt their everyday functioning and wellbeing.
Community Psychiatric Nurse	Nurses who work outside hospitals and visit clients in their own homes, outpatient departments or GP surgeries. Use medical knowledge and interpersonal skills to support patients and administer medication.
Consultant Psychiatrist	An experienced Psychiatrist who has completed additional training to become a Consultant Psychiatrist.

Dementia Advisor / Dementia Support Advisor	Support staff providing information, practical advice, and emotional support for people living with dementia and their carers.
Non-Medical Prescriber	Non-medical healthcare professionals who have completed additional training to allow them to prescribe medication for patients.
Occupational Therapist	Qualified professionals who help people have difficulties carrying out day to day activities because of a disability, illness, trauma, ageing, and a range of long term conditions.
Psychiatrist	A medically qualified doctor who has chosen to specialise in psychiatry, which is a medical field concerned with the diagnosis, treatment and prevention of mental health conditions.
Senior Practitioner	Experienced practitioners who supervise others and may have managerial responsibilities.
Speech and Language Therapist	Qualified staff who provide treatment, support and care for people who have difficulties with communication, eating, drinking and swallowing.
Support Worker	Staff working in a support role, alongside registered professionals.
Team Manager	Oversee the operational management of the team.