Review of National Memory Assessment Services (MAS):

Identifying good practice examples and opportunities for improvement

LEEDS BECKETT UNIVERSITY

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Contents

Acknowledgements

We would like to thank the Lay Advisory Group (LAG) comprising people who have accessed memory assessment services and who have a diagnosis of dementia, Mild Cognitive Impairment (MCI) or another form of memory impairment or who support people who have. We would also like to thank all of our case study research sites and participants.

The project is also supported by a Steering Group (SG) comprised of the evaluation team, NHSE and NHSI representatives, Clinical Network representatives and staff working in roles in memory assessment or related services.

Glossary of Terms and Abbreviations

Memory Assessment Services (MAS) – Services that offer assessment for a formal diagnosis of dementia or Mild Cognitive Impairment

Cognitive Stimulation Therapy (CST) – A therapeutic limited formal intervention typically offered in groups

Post-diagnostic Support – formal support offered after the point of diagnosis

Occupational therapist (OT) - professional group who help people to adapt and support the performance of daily activities

Multidisciplinary Team (MDT) – Team comprising professionals from different areas of practice

Mild Cognitive Impairment (MCI) – a diagnostic category where people have difficulties with cognition and thinking abilities but can still undertake and maintain most daily activities

Foreword - The project Lay Advisory Group

Jill Bateson, Steve Bateson, David Gater, Tim Hough, Ann Lomax, Ruth Malkin, Ananga Moonesinghe, Joanna Moonesinghe and Jill O'Connell

Attending a Memory Assessment Service (MAS) can be a worrying time and, in our experience may not provide the kind of support someone might need. We wanted to take part in this project because it was a way that we could help to make the experience of attending a MAS better for others. While many people who access MAS are aged 65+, it is important to recognise there is no typical person who attends. We are all different people with different needs. We hope in the future memory assessment services will be inclusive and able to meet the needs of all who require their services.

Inclusion means doing things differently according to someone's need, to provide the same opportunity for everyone. It is not about providing one way of doing things that is designed to work for everyone. There have to be a range of options to suit the range of different people that come through services. This project is about ways to achieve this. The case studies in this report give examples of service providers who understand this and have worked towards providing different approaches to service provision and have adapted the tools and resources they have available to them, with the aim of being inclusive for people in the community they serve. They have been written by talking to people who are on the front-line delivering memory assessment services and people who have accessed these services.

We hope that through this report we can improve the MAS experience for all those who attend for assessment and diagnosis as well as their supporters. We want memory assessment services to provide timely access to diagnosis, an accurate diagnosis and then the intervention and support people require, at the time they require it. We hope this might prevent things getting worse for people when this might be avoided with the right support.

We have enjoyed working on this project. It has been important to us that our views have been listened to and that we have had a genuine input where we have shaped the content and messages you will read in this report.

In reading this report we ask people who provide and commission memory assessment services to review their service and ask themselves if it really meet the needs of everyone in their local community. We would encourage you to ask people in the community if there are barriers to accessing services and to work together on solutions to remove these. While there have been improvements in memory assessment service provision, we must acknowledge there is still a long way to go before everyone gets the quality of memory assessment, diagnosis and post-diagnostic support they need and deserve.

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

For many people who receive a diagnosis of dementia, their journey begins in memory clinics where assessment and diagnosis take place. Memory clinics are there to facilitate the diagnosis of dementia, with the ambition that, as a minimum, two thirds of people with dementia should receive a formal diagnosis and accompanying high quality post diagnostic support.

Many assessment services were disrupted by the COVID-19 pandemic, which meant they had to change the way that they worked and offered services. In many cases, this meant the adoption of new approaches and adopting technology to facilitate the delivery of services. In some cases, as explored in this report, this has permanently changed the way that memory clinics offer their services. Against this backdrop, it is known that variation in the way that memory services are delivered means that the experience of people accessing services often varies. Although less is understood about the impact of service variation on patient outcomes.

NHS England and Improvement commissioned Dr Sarah Jane Smith, Professor Claire Surr and their team at Leeds Beckett University to investigate how the pandemic has affected services, and services that offer innovative approaches to practice that can help NHS England meet the ambition to provide timely diagnosis and high-quality post diagnostic support. Examples of these innovative approaches are presented in the case studies in this report "Review of National Memory Assessment Services: Identifying good practice examples and opportunities for improvement".

Summary

Who should read this report?

This report is aimed at:

- People involved in commissioning and developing memory assessment services in England and Wales
- Managers and staff working in memory assessment services
- People interested in development and best practice in memory assessment services, including anyone involved in quality improvement, researchers, clinicians, people living with dementia and their families

What is the purpose of the report?

The report explores Memory Assessment Services (MAS) in England and Wales including:

- if/how the COVID-19 pandemic has affected services,
- some of the challenges that MAS are facing, and
- examples of innovative service delivery which address some of these challenges.

The report provides ideas to support ongoing practice development within MAS, with the aim of continual improvements in service delivery, increased dementia diagnosis rates and the provision of high-quality peri- and post-diagnostic support services.

What does the report include?

Findings from a national survey of MAS and case studies of good or innovative practice at 15 sites in England and Wales

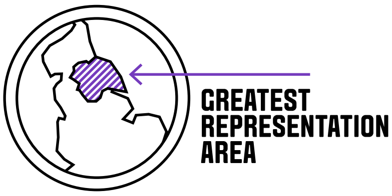
Who took part?

Responses from 40 MAS in England and nine from Wales were included in the analysis of the survey. Thirteen case studies were located in England and two in Wales.

Survey Findings

Respondents

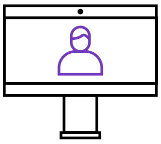
Respondents were from across England (n=40) and Wales (n=9) with the greatest representation from the North East and Yorkshire regions. Most worked in MAS located in Mental Health and Community Trusts, but some MAS were also based in acute trusts, primary care or other organisations.

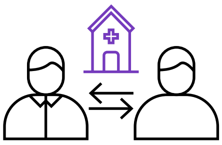


How MAS appointments are delivered

Very few MAS reported delivering their service using one mode of appointment, where this was reported this was by providing appointment visits in the patient’s own home. Most services used a mix of modes of appointment including telephone, video conferencing and in person at a hospital. Non-NHS settings and primary care were the least likely settings for appointments.

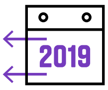
FREQUENT REPORTED MODALITIES





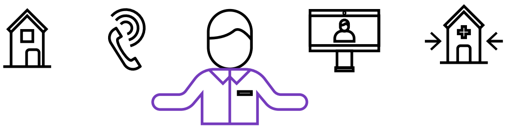
Of our respondents 78% said the current model of delivery was different to pre-COVID and 79% said the current model was how they planned to deliver the service moving forwards.

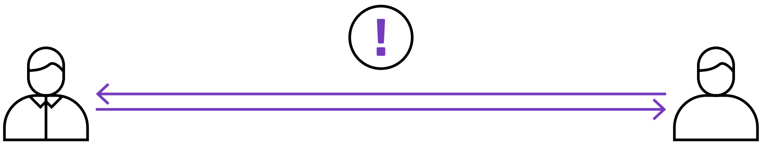
%78 DIFFERENT PRE-COVID



%79 SERVICE PLAN MOVING FORWARDS

For those who had changed their usual appointment setting or method since COVID, most indicated that they would retain blended approaches that offer optionality for patients.





There was recognition of the importance of offering face to face appointments.

> “We will continue to deliver face to face assessments as our standard care pathway. There will be opportunities for patients to choose remote/virtual consultations however patients have not preferred for this as yet. This could be due to working in a relatively deprived area where people do not have access to internet.”

Workforce

All MAS based in Mental Health and Community Trusts included Old Age Psychiatrists in their workforce, with a large majority of MAS also including or describing access to Registered Mental Health Nurses, Occupational Therapists, and Psychologists. Non-medical prescribers and healthcare assistants were also commonly employed staff groups.

REGISTERED MENTAL HEALTH NURSES

OCCUPATIONAL THERAPISTS

PSYCHOLOGISTS

NON-MEDICAL PRESCRIBERS & HEALTHCARE ASSISTANTS

Some staff groups were less frequently represented, including neurologists and neuropsychologists, dementia navigators, admiral nurses and Alzheimer's society outreach workers.

NEUROLOGISTS & NEUROPSYCHOLOGISTS

DEMENTIA NAVIGATORS

ADMIRAL NURSES

ALZHEIMER'S SOCIETY OUTREACH WORKERS

GAPS REPORTED BY **78%** OF RESPONDENTS

Gaps in the workforce were reported by 78% of respondents. Reported gaps related to general service capacity and resourcing, as well as the need to have more specialist staff to support for people with MCI, rarer dementia and provide post diagnostic support.

Services offered within MAS

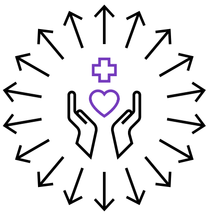
Most MAS were commissioned to offer assessment and diagnosis to those aged over 65, with the majority offering a diagnostic service to those under 65 too. Neuropsychology assessment, occupational therapy and cognitive stimulation therapy were offered by most services. Where patients needed to access specialist components of assessment, such as imaging or biomedical assessment, these were less frequently commissioned as part of the service but could be accessed via other parts of the NHS.

ASSESSMENT AND DIAGNOSIS OVER

65 YEARS OLD

DIAGNOSTIC SERVICE UNDER

SPECIALIST SUPPORT OFFERED ELSEWHERE



Post diagnostic support services (with the exception of Cognitive Stimulation Therapy) were less likely to be commissioned by the MAS but could be accessed via other providers. For example, information sessions or care co-ordinators. More specialist support, such as Admiral Nurses, were not commonly offered or accessible elsewhere.

When about gaps in current service commissioning 45% of MAS in England said they had gaps, 29% said there were no gaps and 26% were unsure. Reported gaps in commissioning related to support for MCI and less common forms of dementia and post diagnostic and carer support.

45% ✓ **29%** ✗ **26%** ?

Case Study Findings

We invited Memory Assessment Services (who completed the survey) to take part in a case study if their service had novel or innovative service design or delivery that could be shared with other MAS. This report shares examples of innovative service features that were present in our case study sites.

The service features are described below with examples from some of the key case study sites (full overview of sites provided in appendix 4):

Personalised Care Pathways

Site 1: Improving the diagnostic process by streamlining multidisciplinary team meetings and medical input working with local external services (GP & audiology)
Site 2: A team with specialist staff input commissioned to provide support from referral to end of life
Site 5: A psychology orientated assessment and diagnostic service with personalised pathways
Site 6: Rapid referral triage, specialist diagnostic pathways, and in-house health testing with CST

In several sites, personalised care pathways meant operating a tailored approach to referral into the service or triage systems (site 1, 5, 6). For example, site 6 provides telephone triage for anyone referred into the service within 24-hours. This operates seven-days a week. The information gathered at triage alongside the referral is used to determine whether a person is assessed via a Tier 1 routine pathway, or a Tier 2 pathway for more complex cases. Tier 2 includes neuropsychological assessment and MDT review. This triage is available 7-days a week as referrals are dealt with by nurses who cover both memory assessment and functional mental health problems.

> *"If we find that we identify risks within that conversation, where people need support within 24 hours, or even a couple of hours, depending on what it is, we are able to do that. And I think that's really important." (Nurse)*

Similarly, at site 5, the service offers different pathways that are based upon patient needs and presentation at screening.

> *"Clients we would sort of divide people up into different pathways depending on how they present. So from the most not for the most straightforward, the most kind of obvious. You know people that look like they've gotten established cognitive impairment or established dementia, but nobody has formally diagnosed them through to people that you may have comorbid major mental health difficulties may be considerably younger and may still be working. So we've we developed a number of different pathways." (Staff member one)*

The idea of the pathways ensures that people are not over or under assessed whilst ensuring that diagnostic accuracy is maintained.

> *"So it's making sure that we're giving the right type of assessment to the to the right, to the right clients so that the with the exception of the formulation pathway, the other pathways people get the same. Assessment process. But how much of which bits they get will depend on how much they need." (Staff member 1)*

Post diagnostic Support

Site 2: A team with specialist staff input commissioned to provide support from referral to end of life
Site 3: Providing tailored post-diagnostic support during the pandemic and beyond through adapted delivery of Cognitive Stimulation Therapy (CST) and other interventions
Site 4: Memory Hub and Younger Persons Memory Service with extended post-diagnostic support
Site 6: Rapid referral triage, specialist diagnostic pathways, and in-house health testing with CST
Site 11: Post-diagnostic support for people with dementia delivered by people with dementia and Promoting brain health in the local community
Site 12: Standalone MAS with specialist post-diagnostic primary care support
Site 14: MAS service with Specialist Occupational Therapy support

Half of the case studies featured innovative approaches to post-diagnostic support. In some cases, this referred to specific interventions such as cognitive stimulation therapy. For example, at site 6, due to COVID staff felt alternatives to face-to-face group CST were needed to prevent people newly diagnosed with dementia from becoming isolated and under-stimulated. They developed options for delivering CST to people in their own home by way of a cross-borough project set up by the MAS psychologists and working collaboratively with psychologists from another MAS service within the same Trust.

> *"[We were] very aware that, as the pandemic moved on and a lot of things had moved to online, that it was very much an issue around exclusion, digital exclusion, with older people predominantly. Maybe, many people within that*

> *group may not have… be able to access it. So, we are very mindful of that and the additional challenge of people with dementia as well. But we thought it would be worth giving it a go and seeing… and starting to develop a way of having conversations with people who were waiting for CST. About the idea and thinking about what support they would need to access the group online. And talking, also, to people who supported them, their families and carers, to see whether we could work together to enable them to access the group if they were interested." (Staff member 2).*

In other cases, innovative post-diagnostic support meant adopting an extended model of post-diagnostic support such as at case study site 2 where post-diagnostic support is offered until end of life. At site 2 the lifetime support includes a one-month post-diagnostic review, followed by six-monthly comprehensive reviews which can be increased in frequency where complexities exist/arise, until the person with dementia has stabilised. Reviews are undertaken by either an Assistant Practitioner or a nurse dependent on the complexity of needs. At least one review annually is conducted in the person's own home. The team includes occupational therapy and psychology staff who support diagnosis and post-diagnostic support. A lead practitioner and non-medical prescriber provide more intensive support for those with the most complex needs.

> *"It was the beginning of a relationship and that for us was critical, that it's not about being dumped with something and go away and sort out your affairs. … It's about, yes, this is something we're going to support you through and we will be following it up and you will be seeing [name] on a regular basis. So I think that's … absolutely critical. You need continuity and you need somebody that you can begin to build trust with because it's such an unknown territory at the beginning and you know it's pretty terrifying because you think. Where do I begin?" (Wife of someone diagnosed with dementia by the service – site 2)*

As in the above example, many of the reported cases rely on MDT approaches. For example, in site 12 a post-diagnosis support service within primary care was commissioned and is led by two GPs with a special interest in dementia. Both the memory assessment and post-diagnostic services work in collaboration with the Alzheimer's Society.

Support for MCI and Rarer Dementia

Site 4: Memory Hub and Younger Persons Memory Service with extended post-diagnostic support
Site 9: Research Active Memory Assessment Service with a One Stop Shop and Innovative Brain Health Assessment and Support

This was identified as a key theme present in two cases. Site 4 offers pre diagnostic support, diagnosis and post-diagnostic support for younger people with dementia for as long as required.

> *"I work with the younger person's memory service and if someone needs nursing input prior to diagnosis, that will be through the younger person's memory service, which is one of the reasons why there's not dementia name in the service because a lot of people referred to the service won't have dementia… And then when someone receives a diagnosis with dementia, then will remain within the younger person's memory service until they have no need for us or until they're 65" (Consultant Psychiatrist)*

This has also afforded the opportunity for re(de)diagnosis.

> *"there was a kind of natural point there to start looking at diagnoses again when you repeat cognitive tests. And then you look back and think, well, right over a period of years, this hasn't declined. This isn't really consistent with your diagnosis anymore…. I think that is quite unique to our service because we do follow people up long term even if there aren't major issues." (Consultant psychiatrist – Site 4)*

This was only possible because of the length of time people are followed up and has enabled staff to identify people who they may have expected to decline but have not. This approach may not be viable in services that do not offer an extensive follow up in this age group.

Site 9 had developed an innovative service improvement project for people presenting to services unlikely to meet the threshold for dementia (e.g. MCI or similar). In this project a consultant intercepted and reviewed referrals to the regional MAS, redirecting those likely to present as MCI or functional impairment to a brain health clinic.

> *"It's not a perfect system, people … who are MCI, stage, still get through to the other consultants and people who have dementia stage illnesses are still getting through to me… over the last three months (the clinic) taking about 20% of the referrals which works out, if you do it retrospectively, works out at about the rate at which MCI is diagnosed amongst all referrals." (Consultant Psychiatrist – site 9)*

After a comprehensive assessment within the brain health clinic, clients are offered feedback and follow up care based upon their individual need. The idea of the clinic is to address the gap in support that people with subjective cognitive impairment might experience, and recognise that tailored support can be offered with beneficial outcomes for this heterogeneous group.

Site 6 operates a specific MCI post-diagnostic pathway using funding provided by the Clinical Commissioning Group (CCG). This includes six group sessions that cover biopsychosocial advice to support the person to lead a healthy lifestyle and a workbook which provides advice and information related to the session content. People can receive the workbook even if they don't want to attend the group sessions.

> *"[The workbook includes] links to local resources that they can tap into so local exercise classes, …different voluntary organisations etc. People have found that useful, and … reiterates healthy living, health promotion, exercise, and … we … if someone wanted to give up smoking we can sign post them to smoking cessation or alcohol reduction teams. So we feel like we're giving them something useful" (Service manager – site 6)*

The team have also been able to create a specific MCI register to ensure recall happens in a timely manner. This includes a six-monthly triage for those who are at high risk of conversion to dementia. If there has been a change the patient will come back in for assessment sooner.

Equity of Access

Site 1: Improving the diagnostic process by streamlining multidisciplinary team meetings and medical input working with local external services (GP & audiology)
Site 3: Providing tailored post-diagnostic support during the pandemic and beyond through adapted delivery of Cognitive Stimulation Therapy (CST) and other interventions
Site 7: Providing culturally tailored assessment and diagnosis
Site 10: Ensuring culturally appropriate assessment and diagnosis for people from the Somali community and at least 12-months of post-diagnostic support within the service

Examples of services that promoted equity of access included those that had adopted culturally appropriate practices. Site 7 was located in a city region with a high South Asian population. They noticed that members of this community were not being referred into the service at the same rate as white British people. When they did attend assessment, members of the South Asian community reported feeling the process was not culturally sensitive and staff reported difficulties administering the Addenbrookes cognitive assessment tool due to issues with language and the euro-centric nature of some of the questions. The service has worked with local GPs to dispel myths about dementia and to highlight the potential benefits of referring for/seeking a diagnosis. They undertook a project to develop a culturally appropriate version of the Addenbrookes which included revised questions and translation into Urdu and Hindi, and employ staff who speak some of the languages spoken in the local community so assessments can be conducted in their preferred language.

> *"I'd experienced that challenge as a practitioner when I was delivering the original form of the Addenbrookes. Even interpreters were saying, well, that that's not a fair tool. You're not giving this this person a fair chance to, to demonstrate their cognitive abilities. That often resulted in fairly uncomfortable sessions where the interpreter was attempting to help out the individual who was being assessed and … trying to rephrase." (Service Manager – site 7)*

Innovative examples of working with external services

Site 1: Improving the diagnostic process by streamlining multidisciplinary team meetings and medical input working with local external services (GP & audiology)
Site 6: Rapid referral triage, specialist diagnostic pathways, and in-house health testing with CST
Site 8: An approach to reducing assessment and diagnosis waiting lists with integration with primary care
Site 12: Standalone MAS with specialist post-diagnostic primary care support
Site 13: Nurse-led Memory Assessment Service located in primary care

Site 13 had worked with external services to develop a rapid scanning pathway. Unlike other MAS' who need to refer service users to local hospitals with long wait times for brain scans, the service had an innovative and bold scanning provision with very short waiting times. Both MRI and CT scans can be booked at the same time as the assessment appointment. The team also commissioned another more local scanning facility with longer wait times. This second service is more accessible by public transport and the more protracted wait times consider that not everyone will want a rapid service.

> *"Look at your scanning pathway and see if there's a possibility of doing that better as a kind of quick fairly, I mean, I'd say quick, easy win. I don't do the contracts [S1] knows about that stuff, but you know, it seems to me to be a common theme of and a source of frustration or you know, some services get around that by requesting that the GPs get the scans done before they come into the service." (GP – site 13)*

A further example of novel approaches to external working was seen in Site 14 in which the team established a relationship with Digital Technologies Wales and was able to loan equipment, for example, iPads and Echo Dots, to trial with their service users.

> *"How technology can advance somebody's independence, looking at different ways in which we can enable people to be independent rather than just looking at kind of not using technology...there's a perception there with older people, they'll be less likely to use technology, but our outcomes of that are very different." (OT assistant practitioner – Site 14)*

The team based their interventions around technology that is affordable and is often already in people's homes, or that can be easily purchased from websites such as Amazon.

Specialist staff

Site 2: A team with specialist staff input commissioned to provide support from referral to end of life
Site 5: A psychology orientated assessment and diagnostic service with personalised pathwayss
Site 7: Providing culturally tailored assessment and diagnosis
Site 14: MAS service with Specialist Occupational Therapy support

Site 14 provided an example of a service that utilises specialist staff for a large portion of their service provision. The MAS occupational therapy (OT) service is a new service that delivers evidence-based pre-diagnostic assessment and post-diagnostic intervention. Each case is discussed at weekly MDT meeting and service users are referred to the OT team on a needs-based basis. For service users in receipt of OT support, once the OT team have completed their intervention (on average 12 weeks but can be shorter or longer) the service user will be discharged but will remain on the wider MAS caseload. To assist other healthcare professionals (e.g. GP), the OT team conduct re-assessments to determine if there have been any changes to an individual's clinical or functional profile.

Location of memory services

Site 11: Post-diagnostic support for people with dementia delivered by people with dementia and Promoting brain health in the local community
Site 12: Standalone MAS with specialist post-diagnostic primary care support
Site 13: Nurse-led Memory Assessment Service located in primary care
Site 15: Rural Service, nurse led, personalised approach

The location of services featured in some of the cases, often alongside innovative workforce practices or approaches, as a means to increase diagnosis rates and/or the efficacy of post-diagnostic support. For example, in site 13 an innovative MAS nurse-led model was implemented. The service was reformed into a community service, operating out of primary care locations, and delivering home visits.

In site 11 the service had identified some localities across the area it serves which have low referral and dementia diagnosis rates. They considered ways they could be targeted to increase referrals from these areas. Public brain health sessions were suggested as a possible solution, and these were commissioned for delivery by a local charity.

> *"And the idea of the brain health sessions was to get down to grassroots. So we want [sessions] in supermarkets. We want them in libraries, in leisure centres. We were sort of saying, right, how do we get right down to ... a really basic level with people who are out shopping and, oh, let's talk about brain health. This is why it is important." (Service Manager)*

The intention of the sessions is to increase availability and accessibility of support, raise awareness of dementia and its symptoms, reduce stigma by getting people talking and promoting the importance of getting a timely diagnosis.

Summary and Recommendations

- Variation exists in the way that MAS are provided, and many changes to how services are delivered, made because of the COVID pandemic, have been retained and have generated opportunities to for services to streamline, refine and improve MAS pathways. MAS need to routinely (re)evaluate the design and delivery of their services to ensure they meet local needs and/or gaps in service provision.

- Examples of good and innovative practice are evident across features of service provision (e.g. post-diagnostic support, counselling), service structure (location of services, care pathways, accessibility), service workforce (use of GPs and specialists), and remit (supporting younger people, people with MCI or rarer dementia).

- Unmet local needs ranged from access to postdiagnosis services to developing services for recognised underserved communities. Meeting the needs of ethnically diverse communities is a recognised and evidenced gap in the MAS offer in the UK. This report presents examples of services adopting innovative local solutions designed to meet the needs of local ethnically diverse communities.

- We have identified the importance of adopting novel and innovative approaches that sit outside of 'typical' MAS models to address identified local need. Examples included the physical location of services or points of contact within the service pathway, including community-based public engagement events to increase diagnostic rates within specific communities.

- There were a number of commonly identified areas of local need that inform national priority areas for service development. These include post-diagnostic support and support for support for people with MCI, younger people, and rarer dementias. Our case studies series offer examples of successfully addressing these shortfalls, and examples of best practice where services and commissioners were able to work together flexibility to support innovative practice.

- To achieve continual improvement and innovation in MAS, commissioners need to work with service managers to identify local service needs and be willing commission innovative approaches that enable MAS services to address these needs.

Appendix 1 - National Survey Methods

A survey of Memory Assessment Services (MAS) was conducted to:

I. provide an overview of the range of service delivery models operating
II. to identify areas of need/concern
III. to identify innovative practice in MAS in England to inform case study selection (part 2) to share this as a foundation for ongoing service development and innovation.

Survey Design

The survey design was informed by the expert steering group, who identified 13 specific areas of practice identified as of particular interest (also reflected in a best practice development guide published in 2021). The survey sought to understand how MAS in England and Wales are designed/what their service looks like, to recognise areas of need, and to identify what they feel are features of good or innovative practice
Involves.

Questions focused on

- the service design
- the workforce
- the services the MAS is commissioned to deliver
- areas of need/concern
- areas of innovative practice

The survey was distributed via the NHS England Clinical Networks are involved with this project who maintain a list of MASs in their region and distributed the e-mail invite to their local list and was promoted via webinars upon dissemination of the project best practice report and via Improvement Cymru and the Royal College of Psychiatrists.

Appendix 2 - Survey Findings

Respondent Information

Respondents to the survey came from England and Wales. There were 88 responses in total, although 39 were removed for incompletion or representing duplicate responses. Forty responses from England and 9 from Wales were included in the analysis.

There was a broad geographical spread of respondents (see Figure 1) with the greatest representation from the North East and Yorkshire region, clustering in the locality of the research team.

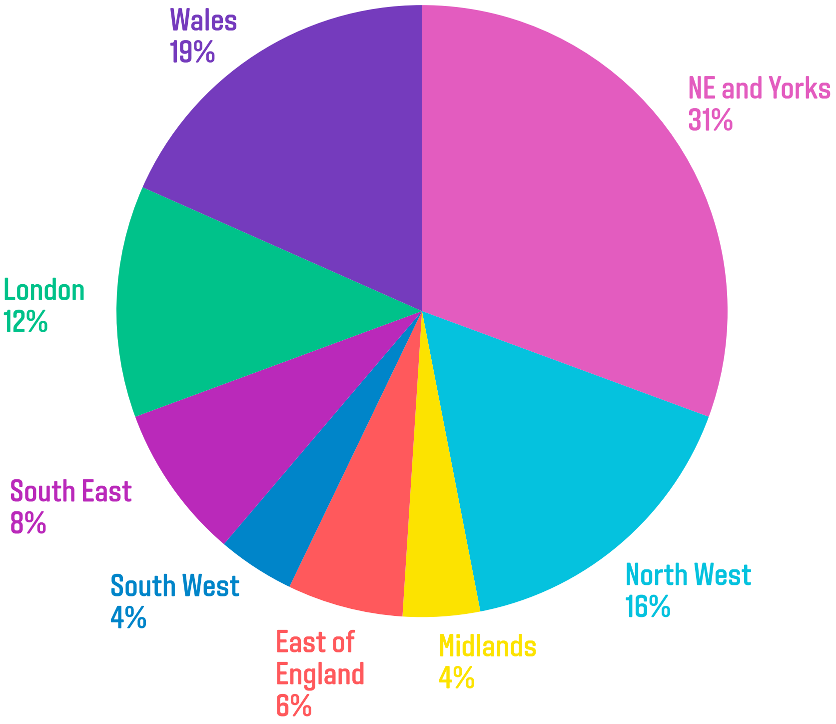


Figure 1: Respondents by Region

Service Design

In England, the majority of the respondents (77%) were reporting for an individual MAS rather than on behalf of all MAS within their organisation (e.g. Trust). In Wales about half were reporting for services within their organisation (see Table 2).

In England, 38% of the services that were reported were MAS that were embedded with Community Mental Health Teams (see Table 1 & 2). Most of the MAS services reported in the survey (62%) in England were stand alone services. In Wales, whilst fewer services were reported on overall, just over half of these (55%) were services embedded in Community Mental Health Teams.

Table 1: Location of MAS

Area	ICS/Health Board	Number of responses included in data analysis	Mental Health/ Community/ Care Trust	Acute NHS Trust	Other
North East and Yorkshire (n=15)	Humber, Coast and Vale	2	12	3	
	North East and North Cumbria	5			
	South Yorkshire and Bassetlaw	4			
	West Yorkshire and Harrogate	4			
North West (n=8)	Cheshire and Merseyside	1	8		
	Greater Manchester	6			
	Lancashire and South Cumbria	1			
Midlands (n=2)	Coventry and Warwickshire	1	2		
	Birmingham and Solihull	1			
East of England (n=3)	Hertfordshire and West Essex	2	3		
	Norfolk and Waveney	1			
South West (n=2)	Cornwall and the Isles of Scilly	1	2		
	Bristol, North Somerset and South Gloucestershire	1			
South East (n=4)	Kent and Medway	2	3		1(Social enterprise)
	Sussex	2			
London (n=6)	North Central London	2	6		
	North East London	1			
	South East London	2			
	South West London	1			
Wales (n=9)	Aneurin Bevan	1	4	4	1(unclear)
	Betsi Cadwaladr	2			
	Cardiff and Vale	2			
	Cwm Taf Morgannwg	1			
	Powys	2			
	Swansea Bay	1			

In England and Wales around half of services reported that they had a unified management structure for the MAS services in their organisation, with the other half reporting that each service had a different management structure (see Table 2).

Table 2: Structure of Services reported in the survey

Region	Type of service		Management structure			Reporting	
	Embedded	Stand-alone	Unified	Individual	Other	All	Single
North East and Yorkshire	4	11	6	9		5	10
North West	4	4	3	5			8
Midlands	1	1	2			2	
East of England	3			3			3
South West		2	2			2	
South East	2	2	3		1		4
London	1	5	3	3			6
England	**15 (38%)**	**25 (62%)**	**19 (48%)**	**20 (50%)**	**1 (2%)**	**9 (23%)**	**31 (77%)**
Wales	**5 (56%)**	**4 (44%)**	**5 (56%)**	**4 (44%)**		**4 (44%)**	**5 (56%)**

Format of MAS service appointments

The respondents were asked the about the format of their assessments and consultation appointments, as they were currently (December 2021) being delivered in their service(s).

Figure 2: An overview of the way that appointments are delivered (December 2021)

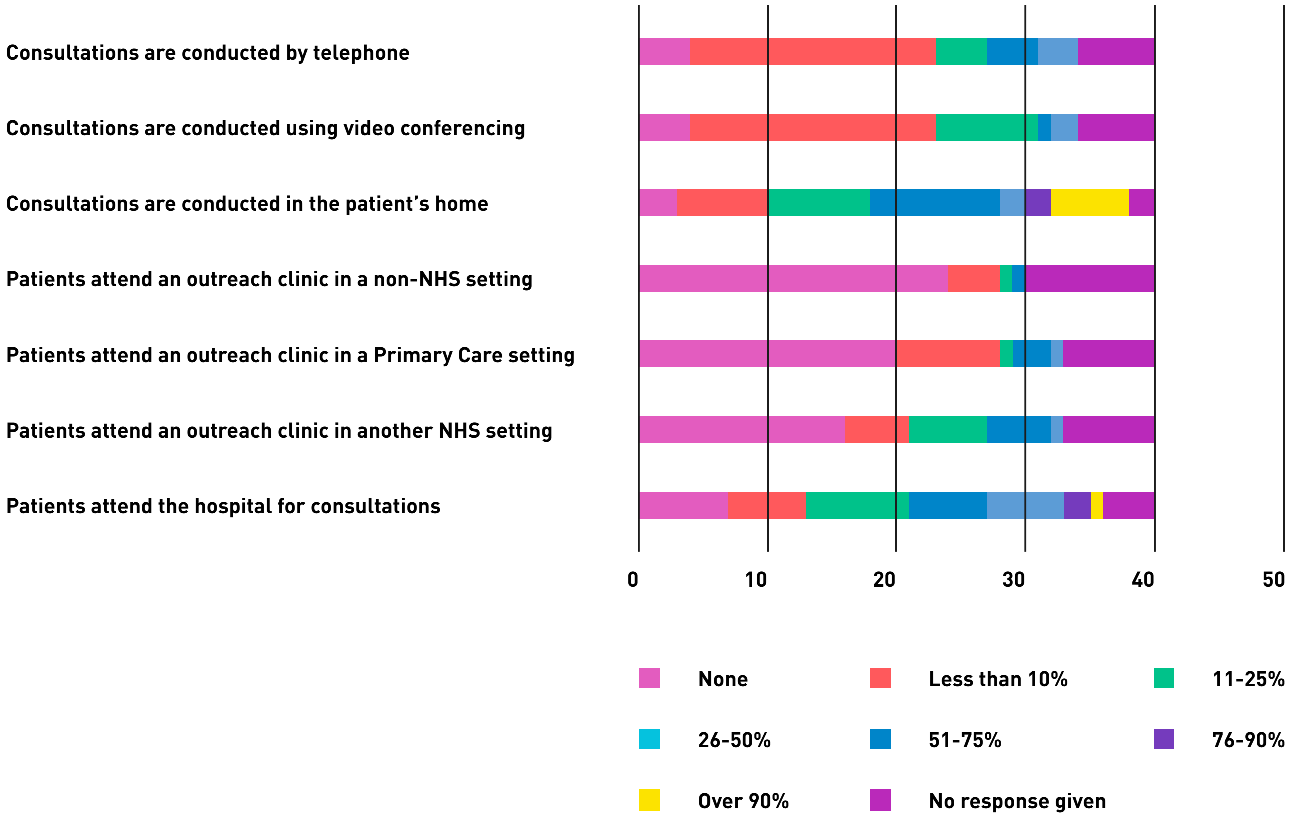


Figure 2 provides an overview of the format of MAS appointments at the point of the survey was completed (December 2021). Few services reported that appointments were delivered in a single modality. Where this was the case, (e.g., over 90% of services being delivered in one way) this tended to be using the patient's own home. Where a mix of modalities were being used, these included telephone, video conferencing and hospital as relatively common choices. It appeared that non-NHS settings and primary care were the least likely settings for appointments.

Participants were asked if they had any further comments on how appointments were delivered at the point of survey completion. These comments generally alluded to changes that had been made in response to the COVID crises, and the long-term adoption, or not, of these approaches.

Some respondents referred to the blended approaches they employ:

> *"The assessment is carried out face to face however, feedback of diagnosis has been delivered via telephone or video consultation"*
>
> *"Currently we are working a blended model of delivery where we use all means available to us to gather the information needed to arrive at a diagnosis and deliver this to the patient."*
>
> *"We are using a blended about of telephone, video and face to face appointments. Face to face appointments take place in a patient's home or in a clinic setting."*

For most respondents the approaches that had been adopted in COVID peak were still influencing practice, particularly with regards to adopting and retaining blended approaches.

> *"Capacity is increasing again as COVID eases and we are gradually doing more face to face and fewer remote/phone consultations. However, we have found phone and remote consultations can work well for some patients- especially for follow ups and when relatives living far away wish to participate in assessment - so we will move to a more varied model of assessment in future according to patient need"*

> *"Following the covid outbreak appointments are now and will continue to be offered, remotely via Microsoft teams, face to face at home or in clinic, or over the telephone. Where a telephone appointment is deemed appropriate and no other option available, outcomes are always discussed in the weekly multi-disciplinary team meeting to ensure enough information is available to go ahead with a diagnostic appointment or decide if further assessment is required at home. We have found the majority of our service users prefer to come to clinic for initial assessment."*

Both for some of those retaining a blended approach, and others, the gold standard remains face to face, and they are returning to this model where possible.

> *"During the pandemic we switched to largely remote consultations. We are now working towards face-to-face assessments and only offer remote assessments if clinically this is the best option for the patient. Feedback appointments remain largely remote- mostly telephone."*

Respondents were explicitly asked if the currently delivery model was different to the pre-COVID-19 model of delivery. In Wales, all respondents to this question indicated yes, in England two thirds said the model was different.

Table 3: Is the current model of delivery different to pre-COVID?

	No	Yes
England	10	28
Wales	0	7

A follow up question was asked for respondents to provide further information about how the model was different.

Some respondents indicated how COVID had interrupted or delayed service changes that were already in the pipeline or being implemented, affecting the planned implementation.

> *"Pre-COVID one part of the service was embedded in the CMHT. The decision had been made to make it a stand-alone service…but managed jointly with the already established MAS in the other half of the Trust which is commissioned by a different CCG. A model had been agreed pre-COVID for the new service but this had to be re visited due to the situation."*

> *"Pre-COVID the established stand-alone service had trialled an assessment to treatment model. This was recommenced recently however it was difficult to put into operation due to the number of assessments compared to the number of those able to diagnose. It became very dependent on medics and the skills of others were not used."*

> *"Pre-COVID the service had began to implement a "Market Place" event, bringing together services/agencies who can offer a service to those living with dementia. This is something we plan to grow and develop as soon as lifting of restrictions on service delivery are lifted."*

Other respondents referred to the impact on the adoption of technology for remote consultations and blended approaches. This mainly referred to the adoption of remote assessments, and how this has streamlined services and offered more in the way of patient preferences. Although some respondents note the increased use of technology this has been at the "cost' of reducing face to face contact, which is not regarded as favourable. Others indicated that this has "fast-tracked" the adoption of technologies more generally.

> *"Now patients are seen face to face for assessment, they are formulated via an MDT formulation and then feedback is via pre agreed format, i.e. telephone, video or face to face."*
> *"Pre covid remote assessments were practically 0%"*

> *"Pre-Covid, no assessments were carried out by phone or remotely. During the first, second, third waves of Covid most assessments were carried out remotely and by phone. We have now re-opened our clinic and are seeing most patients either in clinic or in home visit appointments, however, our team are now confident to offer remote and telephone assessments on rare occasions when it is needed"*
>
> *"Post Covid we are still delivering more services virtually if its clinically appropriate, we will continue to offer a range of venues and means of assessment as we have found some positive benefits to the use of technology"*
>
> *"Covid has fast tracked the use of virtual working"*
>
> *"During the majority of 2020 the referrals received were screened for telephone or video (depending on access) however as soon as we could and had the correct set up (PPE/distancing etc) we returned to face to face due to the greater quality of assessment."*
>
> *"The use of digital interventions has been useful and for some service users and their next of kin very much appreciated. the big change since covid is with our monitoring service. For people on dementia treatment we are commissioned to monitoring the medications 6 monthly. This was entirely completed by phone during Covid, we are now completing some clinic and home visits but it remains around 70% phone appointments "*

Some respondents referred to the temporary impact of COVID, and how that is returning to a pre-COVID model with no or minimal impact on their service model

> *"Assessment process has returned to Pre-Covid although screening process has been improved as structure modified during covid to identify suitability of remote assessment."*
>
> *"Staff have generally returned to their normal practice and preference which is to assess people in their home environment or within clinic."*

Respondents were asked if the current model reflected how they plan to deliver the service moving forwards. Most respondents in England and Wales indicated that the service that they described as currently operating was how they plan to deliver the service moving forwards, although a greater proportion of respondent in England (21%) said no, it wasn't how they plan to deliver the service, likely relating back to those services returning to a pre-COVID model of delivery.

Table 4: Is this how you plan to deliver the service going forward?

	No	Yes
England	8	30
Wales	1	5

Most respondents indicated that the elements of change that they will retain are the blended approaches that offer optionality for patients. However, there was recognition of the importance of offering face to face appointments.

"It's likely to be a mixture of remote and in person assessments"

"more face to face clinic appointments fewer phone and video ones- but there will still be some for follow ups and when patient prefers or for other needs e.g. when a relative who lives far away wishes to take part "

"Would aim for mixed offer of remote and face to face. All follow up work (if appropriate) would be conducted via telephone i.e., post-diagnostic appointments and shorter follow up consultation will also be carried out remotely."

"We have found that family members and carers tend to prefer telephone consultations as they are more convenient. Home visits have also been found to improve access to the service for people with mobility issues or those who are concerned about attending hospital appointments. Looking at developing model that incorporates different consultation modes dependant upon need"

"Given the success of remote consultation to expect remote to be a sustained offer within our service."

Others indicated a full return to a pre-COVID model was the preference of the staff or patients

> *"We plan to revert to a pre-COVID model."*
>
> *"We will continue to deliver face to face assessments as our standard care pathway. There will be opportunities for patients to choose remote/virtual consultations however patients have not preferred for this as yet. This could be due to working in a relatively deprived area where people do not have access to internet."*
>
> *"All our patients / relatives / carers have always been offered the flexibility / choice of where they wish to be seen. It is my observation that appointments carried out in the home setting are far more productive and beneficial to the patient as the assessor is able to see how things really are, also the individual is often more relaxed in the home environment."*

Memory Assessment Service Workforce

The survey was interested in the workforce and staff employed within the MAS described by the respondents. The survey asked respondents which staff groups were represented within their MAS, an overview of these staff groups is provided in figure 6. All MAS based in Mental Health and Community Trusts included Old Age Psychiatrists in their workforce, with a large majority also including Registered Mental Health Nurses, occupational therapists, and Psychologists. Non-medical prescribers and healthcare assistants were also commonly employed staff groups.

Table 5: Which staff disciplines have dedicated sessional time in your MAS?

	England			Wales		
	Mental Health/ Community/ Care Trust (34)	Acute NHS Trust (3)	Other (1)	Mental Health/ Community/ Care Trust (4)	Acute NHS Trust (2)	Other (1)
Old Age Psychiatrist	34	2	1	4	1	1
Neurologist	3	1	0	1	0	0
Geriatrician	0	0	0	0	1	0
Junior Doctor	20	2	0	0	0	0
Clinical Psychologist	29	1	0	3	1	1
Assistant Psychologist	18	1	0	1	1	0
Neuropsychologist	8	1	0	0	2	0
Occupational Therapist	27	2	1	4	2	1
Registered Nurse	9	0	1	1	1	0
Registered Mental Health Nurse	32	2	1	4	2	1
Advanced Nurse Practitioner	5	1	0	0	0	0
Non-Medical Prescriber	17	0	1	3	1	0
Dementia Navigator/ Coordinator	7	0	1	3	2	0
General Practitioner	1	0	1	0	1	0
Healthcare Assistant	16	2	0	3	1	1
Other role	14a	1b	1c	1d	0	1e

[a] Carer Support services, Alzheimer's Society, Social Worker, GPwER, QAP, support worker, Admin, Alzheimer's Society outreach worker, Administrator, Social Worker, Dementia Support Advisor, Social Worker, Admiral Nurses, Nurse Consultant, Social Workers, Occupational therapist assistant, Dementia advisor, Carer support worker
[b] Admiral nurses via Age UK
[c] GPwER
[d] Speech and language therapy
[e] Dementia advisor, Occupational therapy assistant practitioner

Some staff groups were less frequently represented, but still present in services, including neurologists and neuropsychologists, dementia navigators, and staff groups mentioned within the other category such as admiral nurses and Alzheimer's society outreach workers.

We went onto ask (respondents from England only) about the gaps or challenges in their current commissioned workforce model. We first asked if the respondent perceived there to be gaps in their workforce; 78% of respondents said "Yes", there were gaps. We then asked for details of the gaps and challenges in their workforce. The responses broadly fell into four categories.

First, some respondents indicated that the staffing issues were broadly related to limited general capacity and resourcing issues, or the need to have more specialist staff.

Referral volume vs staffing volume

> *"Assistant psychologists are brilliant at doing neuropsychological assessments under supervision from a psychologist in another team - but are hard to retain- which means there are gaps when one goes and another is coming. Ideally we would benefit from a full time qualified psychologist but service is not commissioned or funded to include this"*
>
> *"No Occupational Therapist/s. No Assistant Practitioners (1 Fixed Term post at present), No Health Care Assistants/ Support Workers. We do not have enough dedicated medic time into the service. There are not enough staff in general."*
>
> *"Occupational therapy and clinical psychologist provision are taken from existing CMHT resource so are limited in terms of capacity and availability"*

Many respondents to this question, when asked to provide detail, identified the need for staff who can provide specialist or rarer dementia support, this included MCI, young onset dementia and less common forms of dementia.

Support for MCI/rare dementia

> *"MCI work is not standard throughout the four localities, each medic will mange these caseloads differently"*
>
> *"We do not have a commissioned MCI pathway currently"*
>
> *"Pathway for people who have a suspected alcohol-related brain damage and are still actively drinking."*

Many respondents also identified needing more staff to enhance post-diagnostic support provision.

Post-diagnostic Support

> *"We would benefit from additional nurses and dementia navigators for post-diagnostic support as currently we cannot meet the need."*
>
> *"Patients with new dementia diagnosis could benefit from cognitive stimulation therapy and additional support. There can be a big gap for people after getting the diagnosis before their condition deteriorates to the point where the qualify for some of the other support services."*
>
> *"The current pathway does not provide ongoing care to patients who require longer term input following the diagnosis of dementia. As a result they are transferred to community mental health team. "*
>
> *"A challenge for us as service is that we are commissioned for one year of support post-diagnostic only. Given that we deliver support and care planning functions as well as medication functions (initiation to annual review), not being commissioned to hold support for life, is a challenge to us. A life long integrated clinical and support service would support patients and carers, as needs increase."*

Finally, some respondents indicated a key staffing issue was a reliance on services external to the MAS in providing key features of the service for diagnosis or support.

Challenges with Relying on External Services

> *"Extended wait for CT."*
>
> *"Getting the MRI scans back in time to meet the 12 week KPI"*
>
> *"CT scans should not be heavily relied on for diagnosis."*
>
> *"The service budget is significantly smaller (circa 100K) than the national average (2015 data) and we have evolved to develop relationships and pathways to access clinical expertise we require on a 'need based' approach. E.g. Complex Case Reviews with our neurology colleagues (average quarterly), NPA accessed via referral"*

Commissioned Services in MAS

In order to obtain a comprehensive overview of the MAS represented in our survey we requested respondents indicate which services they were commissioned to offer and deliver. An overview is presented in Figure 8. In the present survey, most MAS were commissioned to offer assessment and diagnosis to those over 65, with the majority offering a diagnostic service to those under 65 too. Neuropsychology assessment, occupational therapy and cognitive stimulation therapy were also offered by most services.

Table 5: Which staff disciplines have dedicated sessional time in your MAS?

Combined England and Wales	Commissioned as part of MAS	Available via the MAS but provided by another part of the NHS	Available via the MAS but delivered by a VCSE or other non-NHS partner	Unsure if available	Not available	Not reported
Memory assessment and dementia diagnoses for those aged 65+	42	1	0	1	0	5
Memory assessment and dementia diagnoses for younger people with dementia (under 65)	37	4	0	1	1	6
Neuropsychology assessment and input	35	6	0	1	1	6
Occupational Therapy assessment and input	34	4	0	1	4	6
Brain scanning (CT)	14	25	2	1	1	6
Brain scanning (MRI)	12	26	2	2	1	6
Brain scanning (PET)	10	26	1	2	3	7
Lumbar punctures for amyloid	3	13	1	7	15	10
Cognitive stimulation therapy (CST)	28	4	3	3	4	7
Dementia advisor/care co-ordinator	16	2	19	1	3	8
Dementia information sessions	22	2	13	1	4	7
Carer support	24	2	16	0	1	6
Advance care planning	22	1	7	1	9	9
Admiral nurse(s)	6	3	8	4	19	9
Other	9[f]	0	0	0	15[g]	25

[f] 12 week post-diagnostic review and care plan, START, Brainfood, Dementia clinical nurse specialists, Assistive technology occupational therapist, post-diagnostic support, social workers, Medication and Care Planning, 3rd sector support agencies
[g] Neuropsychology assessment

Where services referred to specialist components of assessment or diagnoses, such as imaging or biomedical assessment, these were less frequently commissioned as part of the service but could be accessed. Similarly, services that related to post-diagnostic support (outside of CST) were less likely to be commissioned, but in most cases could be accessed, for examples information sessions or care co-ordinators. More specialist support, such as admiral nurses, was not commonly offered or accessible elsewhere. This is reflected in the comments that respondents went on to give.

A follow-on question was asked (to respondents from England) about gaps in respondents current service commissioning. Of the 38 respondents to this question, 45% said they had gaps in the way the service is commissioned, 29% said there were no gaps and 26% were unsure. We asked respondents to provide further detail with regards to the gaps in service commissioning. There responses fell broadly into two categories; support for MCI and less common forms of dementia and Post-diagnostic Support & Carer Support.

Support for MCI and less common forms dementia

> *"Inadequate under 65s services, especially for non-neurodegenrative dementias (i.e. vascular and alcohol related brain injury)."*
>
> *"Specialised service for young onset dementia."*
>
> *"No specific service for early onset dementia."*
>
> *"No commissioned follow up for MCI patients, we are seeking to rectify this."*
>
> *"MCI"*
>
> *"Community and specialist services for people with YOD*
> *Rare dementia specialist services"*
>
> *"Assessment and post-diagnostic support pathway for Korsakoff's and alcohol related dementia "*

Post diagnostic Support & Carer Support

> *"Longer term follow-up is an issue. Currently, stable patients are discharged to the GP after 6 months, with referral back to the MAS when necessary. There are plans to increase support (e.g. Admiral Nurses) in the near future."*
>
> *"Admiral nurse service not across the whole trust"*
>
> *"Carers service not available across the whole trust"*
>
> *"Not a life long service support service yet commissioned to provide support planning post diagnosis but not Advanced Care Planning. All things that feel challenging given the nature of the diseases diagnosed and treatment."*

Finally, we asked respondents (from England) whether they had any plans in place for quality improvement over the coming 12 months. Most respondents (78%) indicated that they did, with 22% saying no or maybe.

In combination with their previous responses about the commissioned services they offer, this question was used to prioritise case study sites for phase 2, and can be described under three themes; streamlining and workforce recruitment, introducing new services and remodelling existing pathways.

Streamlining Workforce & recruitment

> *"Recruitment of NMP [Non-medical prescriber]"*
>
> *"Extending roles to increase number of diagnostic appointment"*
>
> *"Re-introduce ""floating consultant"" clinic so several staff can be supervised immediately after assessment and give patient diagnosis at first appointment"*

> *"We have trained our support workers to do phlebotomy and ECG's so that we can complete all outstanding investigations at the first appointment"*

Introducing new services or interventions

"Improve access to biomarkers"

"New business case to support MCI services"

"To embed the Market Place Events, to develop the post diagnosis care plan, we have put a business case together for an MCI pathway which we are hoping to get funding for in the future. we are about to register for MSNAP accreditation." "Our vision is to offer patients referred to MAS an initial assessment appointment at the point of the screening being completed within 24 hrs of receipt of the referral."

Remodelling existing Pathway

> *"Improving triage process to make it more consistent and clear"*
>
> *"Reducing DNA by admin and clinical staff working differently – e.g. phoning more rather than sending letters Reduce documentation e.g. reduce length of assessment letters "*
>
> *"Assistant Practitioner role typically review patients on six monthly basis and monitor change, offer education and advice and signpost to service. QI approach being utilised to create additional evidence based wellbeing plan for people living with dementia."*
>
> *"Developing of Pathway Lead structure, reviewing the current pathway and designing a virtual diagnostic clinic for the county to help streamline assessments"*

Appendix 3 – Case Study Series Methods

Aims of the case study series

The aim of the case studies was to identify, illustrate and share examples of good and innovative practice in local memory assessment service delivery. The case study format has been identified as an effective way to share experiences and learnings in an accessible way.

Design and Methods

Case study sites in England and Wales were identified based on responses that providers gave in the survey. Service providers and staff provided information about MAS services in the survey concerning their design and delivery. In the survey respondents' identified the specific services they were commissioned to deliver as well as innovative approaches to service delivery or development plans.

The following criteria were applied to the survey findings in order to select case study sites:

- Demonstrates at least one example of good or innovative practice.
- Delivers an example of good practice that is judged by SG and LAG members to be strong, significant, innovative and replicable in other situations.
- Represents a range of geographic locations/regions.
- Represents a range of delivery models.

Shortlisted sites were then discussed at our project steering group meeting and LAG meeting where consensus agreement indicated sites were approached to take part in the evaluation.

Data collection

At each site, the respondent to the survey was first approached to take part in the case study. Agreement to take part as a site was then obtained at the appropriate level. The initial respondent took responsibility for the identification of participants at each site, who comprised two groups
1) Staff
2) Service recipients, as set out below.

1. **People who have accessed memory assessment services or supported someone who has**

- accessed memory services in the last two years
- supported someone who has accessed memory services in the last two years
- experienced the focus of the case study
- able to provide information relevant to the focus of the case study
- have capacity to give informed consent
- able and willing to take part in a video conference or telephone interview

2. **Staff working in an MAS organisation, who have**

- worked at the MAS for at least four months and have experienced/been involved with delivery of the focus of the case study
- able to provide information relevant to the focus of the case study
- able and willing to take part in a video conference or telephone interview.

As many participants as were willing to take part were approached at each site.

Case Study Series Analysis

At each case study site, the interview transcripts were reviewed by researchers for key features and characteristics of good or innovative practice and compiled into a case study narrative that included quotations from participants to illustrate points. The key characteristics focused on the nature of service provision, key features of quality improvement projects, novelty in terms of workforce, service models or pathways and services targeted to specific user groups.
The case study characteristics were further grouped according to higher level service features. Some of these service features correspond to or address concerns identified in the survey, for which the case studies offer novel or innovative solutions or approaches. Appendix 4 provides an overview of the service features and corresponding cases. Examples of practice under each service feature from the case studies in the series follow.

Appendix 4 - Case Study Series

Case description	Location	Participant description	Service Features	Contact Details
Site 1: Improving the diagnostic process by streamlining multidisciplinary team meetings and medical input working with local external services (GP & audiology)	England	4 staff interviews,	Personalised care pathways Equity of Access Innovative/examples working with external services	Daniel Harwood Croydon Memory Service Daniel.Harwood@slam.nhs.uk
Site 2: A team with specialist staff input commissioned to provide support from referral to end of life	England	3 staff interviews 2 service users	Post-diagnostic support Personalised care pathways Specialist staff (e.g. occupational therapy/admiral nurses)	Bethany Campbell Camden Memory Service camdenmemoryservice@candi.nhs.uk
Site 3: Providing tailored post-diagnostic support during the pandemic and beyond through adapted delivery of Cognitive Stimulation Therapy (CST) and other interventions	England	3 staff interviews	Post-diagnostic support Equity of Access	Nicole Deenamode Islington memory and dementia navigator service islingtonmemoryservice@candi.nhs.uk
Site 4: Memory Hub and Younger Persons Memory Service with extended post diagnostic support	England	3 staff interviews 1 service user	Post-diagnostic support Support for MCI and rarer dementia	Susan Dodds Gateshead Specialist Memory Hub susan.dodds5@nhs.net
Site 5: A psychology orientated assessment and diagnostic service with personalised pathways	England	1 staff interview	Personalised care pathways Specialist staff (e.g. occupational therapy/admiral nurses)	Nikki Belsham Memory Assessment Service, BSMHFT nicola.belsham@nhs.net
Site 6: Rapid referral triage, specialist diagnostic pathways, and in-house health testing with CST	England	2 staff interviews	Post-diagnostic support Personalised care pathways Innovative/examples working with external services	Liz Carlise West Essex Specialist Dementia and Frailty Service liz.carlisle@nhs.net
Site 7: Providing culturally tailored assessment and diagnosis	England	2 staff interviews	Personalised care pathways Equity of Access Specialist staff (e.g. occupational therapy/admiral nurses)	Ambreen Kauser Bradford, Airewharfe & Craven Memory Assessment & Treatment Service Ambreen.Kauser@bdct.nhs.uk
Site 8: An approach to reducing assessment and diagnosis waiting lists with integration with primary care	England	1 staff interview	Innovative/examples working with external services	Zumer Jawaid WNW MAS Leeds zumerarif.jawaid@nhs.net Louise Chahal louise.chahal@nhs.net
Site 9: Research Active Memory Assessment Service with a One Stop Shop and Innovative Brain Health Assessment and Support	England	3 staff interviews	Support for MCI and rarer dementia	Ross Dunne Central Manchester MAS Ross.Dunne@gmmh.nhs.uk Tony Ellis Tony.Ellis@gmmh.nhs.uk
Site 10: Ensuring culturally appropriate assessment and diagnosis for people from the Somali community and at least 12-months of post-diagnostic support within the service	England	1 staff interview	Equity of Access	Dr Louise Mahon South Manchester Later Life MATS Louise.Mahon@gmmh.nhs.uk
Site 11: Post-diagnostic support for people with dementia delivered by people with dementia and Promoting brain health in the local community	England	2 staff interviews	Post-diagnostic support Location of memory services (e.g. Primary Care, community)	Alison Couch Hull and East Riding MAS acouch@nhs.net
Site 12: Standalone MAS with specialist post-diagnostic primary care support	England	2 staff interviews	Post-diagnostic support Innovative/examples working with external services Location of memory services (e.g. Primary Care, community)	Vanessa Loftus Kingston MAS vanessa.loftus@swlstg.nhs.uk
Site 13: Nurse-led Memory Assessment Service located in primary care	England	Group interview with 3 staff 1 staff interview	Innovative/examples working with external services Location of memory services (e.g. Primary Care, community)	Jason Willcox Brighton and Hove MAS jason.willcox@nhs.net
Site 14: MAS service with Specialist Occupational Therapy support	Wales	3 staff interviews	Location of memory services (e.g. Primary Care, community)	Zoe Williams MAS CTMUHB Zoe.williams@wales.nhs.uk
Site 15: Rural Service, nurse led, personalised approach	Wales	1 staff interview 1 service user	Location of memory services (e.g. Primary Care, community)	Louise Peters Radnorshire MAS Powys lhb louise.peters2@wales.nhs.uk

Appendix 5 - Case study series descriptions

Site 1 – Improving the diagnostic process by streamlining multidisciplinary team meetings and medical input working with local external services (GP & audiology)

Summary

The site has revised its MDT meetings to improve efficiency without impacting the quality of diagnosis. MDT meetings reviewed every patient and were long, unstructured and not felt to be a good use of time. However, the staff did not want to risk missing things. The team implemented a traffic light system, only discussing amber and red patients who were most complex, using a devised template of information to present about each patient. Green patients are all reviewed by a consultant outside the meeting. This has halved meeting times and allowed more discussion time for complex cases. The service has introduced joint neurology and MAS MDTs, training and support of geriatricians, and joint working with GPs to improve the appropriateness of referrals and avoid duplication of effort. The team are praised for their person-centred and human approach, for example, they have introduced an innovative system for individuals with hearing impairments.

The service provides early assessment, treatment and care for people who are experiencing memory problems that may be due to dementia. The service helps people with the first signs of memory problems to aid health and independence. Memory practitioners (nurses and OT) assess and make a preliminary dementia diagnosis with complex/differential cases being discussed in multidisciplinary team meetings (MDT). All diagnoses are reviewed and confirmed by a part-time consultant before feeding back diagnosis to the person with dementia. The service is commissioned to provide limited support to individuals post-diagnosis, at which point they are referred to their GP. However, the service will keep people on their caseload who have been prescribed dementia medication to monitor their progress until they are satisfied that the treatment is effective and stable before referring them back to the GP.

What led to you developing the service in this way?

Originally, every single patient who had had an initial assessment during the previous week was presented and discussed in the MDT, which meant that the meeting was long and tended to overrun. The patient presentations were often unstructured. Staff hadn't had any training or guidance about how to do the MDT presentations and the meeting was not looked forward to by staff. People felt they were wasting time sitting there, not participating or learning.

> *"There was often not enough time to talk about the more complex, high-risk patients because we were spending too much time discussing people who you know were reasonably straightforward and didn't necessarily need to be discussed at the team meeting." (Consultant)*

The issue was raised at a service development meeting and there was a consensus amongst the staff that it was too long, but also some apprehension about changing the process.

> *"If we weren't going to allow people to present all the information and then we might miss things, and how we how we were we going to keep it safe if we cut the time down, so that there was there was some of the anxiety at the time". (Consultant)*

Historically, the team would receive a high number of referrals, some of which were of poor quality or inappropriate for the MAS pathway. This led to long waiting lists which were exacerbated by a high number of DNAs. There were also very weak relationships between the MAS and other healthcare services and the team were unclear about other teams' remits which caused friction. This led to the changes described in the service overview below.

What does the service offer?

Changed MDT meeting template

The team devised a template which outlined the key points to be discussed at the MDT. The consultant highlighted specific areas to talk about which were often left out before (e.g. drugs and alcohol and ensuring staff understood guidance around alcohol units etc.; questions to ask to diagnose Parkinson's disease dementia and Lewy body dementia. Staff were encouraged to state what they thought the diagnosis is during the MDT and the team ensured correct ICD 10 codes are used.

> *"I was often having to ask a lot of questions to see whether the person had Parkinson's disease or Lewy body disease, and I became aware that the staff were kind of aware of that but weren't specifically asking the questions about level of consciousness and sleep disturbance and falls and hallucinations and so on. So again, we kind of formalized a bit of a checklist to say you need to ask these questions of people and you know present them in the meeting if they're positive. So, a template with some specific things, the DLB symptoms and the alcohol". (Consultant)*

A traffic light system was also implemented (red – complex, amber – complicated, green – straightforward) to help streamline the process and indicate which cases are a priority for discussion at MDT.

> *"Each patient was colour coded, so when the practitioner had seen them, they said right Mrs. So and so is red because she's complex. She's high risk. There are safeguarding issues and the diagnosis is unclear. Mr So and so is a green because it's fairly straightforward. We know it's fairly clear what the diagnosis is. There's no major risk. So, the agreement we had is that the "reds" and the "ambers", the people where they were complexity and uncertainty about the diagnosis, would be discussed at the team meeting". (Consultant)*

The consultant now goes through all patients, including those marked as green (i.e. non-complicated), outside of the meeting to confirm the diagnosis, acting as a safety net for staff.

> *"The team meeting certainly feels more structured and safer. I don't have a worry that we're missing people, or, you know, people are slipping through the net. There's a kind of safety net with the spreadsheet, and we can revisit it the next week if things aren't picked up". (Consultant)*

Upskilling clinical staff

Intertwined with these changes was upskilling/supervising staff in both knowledge (the way training is provided has now changed and is usually staff led and all staff have protected time), skills (e.g. IT), and confidence (evidenced through service user feedback) to be able to independently make a diagnosis and to take a holistic approach to their cases.

As a result of the changed structure and staff training the MDT meeting has been halved in time and this means staff have more time to focus on their patients.

> *"It's cut it drastically from about 2.5 to 3 hours to 1.5 hours. If that. Sometimes we're not even there 1.5 hours. So that has made such a difference 'cause then you can actually use the other time to then follow up what needs to be done from the outcome of that meeting for the patients…some people have gone on to now go and do home visit straight after 'cause they they've got that time to do that". (Team Leader)*

Nursing staff also found that discussing complex cases in depth meant more informal learning opportunities.

> *"I mean, for me it was. It was a massive sort of learning experience because I was picking up so much about the other complex cases that were coming that the that me and my colleagues were bringing. I could learn so much from what the team and what [consultant] and the other doctor were recommending for those complex cases. So that's sort of helped in rather than just like going through a checklist". –(Nurse)*

Historically, staff did not feel well supported by the medical team and the service does not have a full-time consultant which can leave staff feeling unsafe. The MDT meeting changes allowed the team to have more time so they can work better and more effectively as a team as well as have stronger working relationships.

> *"Well, you know some services the size of [S5] will have a full-time consultant in them but some don't. Everywhere is different, isn't it? So if you've only got 2 days of a consultant and half that time…in that team, I'm seeing patients. That means I really got a day or less by the time you take out the MDT to deal with all the patients they're seeing. So , I need them to. I need to be able to delegate and I need to be able to have certain levels of expectation, but also they need to know that they can always contact me if they are worried. (Consultant)*

Identifying staff expertise and formal and informal learning opportunities

Individual learning needs are important, and the team never make assumptions about what others know. Having leads on certain topics (e.g. physical health, digital services, research) can provide the team with a first point of contact when they have a question.

> *"What I'm sort of picking up now 'cause I've got to know the staff a lot better is individuals learning needs, and so you know I can see that for some people they're really up on top of things, and you know that's fine. But others kind of struggle with certain areas, and I think some of the areas I'm finding that people struggle with a bit are, uhm, the physical health issues and but that's so that is a solvable problem because one of the nurses who's joined us has got a background in physical nursing, physical health nursing and used to work in a substance misuse services used to*

> *doing physical stuff there. So she is going to be our kind of physical health lead and do some training on that kind of things". (Consultant)*

Supervision and protected time for staff training are valued. The training sessions are usually set up by staff in areas they would like to develop. This sense of ownership has helped with training engagement.

> *"A couple weeks ago one of my colleagues had set that up because she was unclear about licenses and dementia and driving and how we navigate and negotiate that. So again, that was really useful. So, I think the fact that you know again the teaching sessions don't, it doesn't just fall to the manager to try and organize things that are going to educate people. It's a sort of joint enterprise really where, where we all know we can bring something that's important to us or particularly on our mind at that time to give that to share with the rest of the team that information". (Nurse)*

Holistic approach and working in partnership

The team aim to take a holistic and person-centred approach to care and appreciate that both mental and physical health are important in dementia care.

> *"And also she'd noticed quite a lot of physical things which were due, due to stress actually. He was treated for hypertension…He certainly flushed. And she noticed he was sweating. I didn't notice that actually…And he was breathless at times…So she suggested a chest X Ray, ECG, and blood tests if we hadn't had them done." (Carer)*

They also understand that GP service is variable and that some service users may be unaware of what physical health checks they should be receiving. The team support service users in this area of care by advising what they should be asking their GP and writing supportive letters.

> *"General practice is very variable over the borough and some of the poorer parts of the borough don't have brilliant primary care services, so people are falling through the net in terms of their physical health monitoring, vascular risk factors, and so on. It's not something we can just sort of leave to the GPs to get on with. We have to take a little bit of responsibility and at least give the GP some guidance. We can't do it all ourselves, of course, but we need to be thinking about it and giving patients and relatives a care plan saying look, you know, you do need to have your blood pressure checked every year. You do need to have your blood sugar checks however many times and then just give people a bit of guidance on that. It's work in progress". (Consultant)*

Assessment for individuals with hearing impairment

The OT team identified that assessments were being cancelled because service users had hearing issues and were struggling to engage. The MAS would refer the individual to audiology and would only see them again after they had been prescribed hearing aids. OT was aware of the link between dementia and hearing impairments and with the protracted waiting times for audiology services they knew that people would deteriorate

> *"That it's called a hearing device and it's like earphones, the old-style earphones you just put them in and then the clinician has a mic which is linked to the earphones and you can adjust the volume and the tone. And that usually enables the person to hear well enough to do the assessment…it just seemed really unfair on them that they were missing out on a timely diagnosis just because of their hearing…so we recently purchased two of these devices". (OT)*

What are the challenges of this model and how have you overcome these?

Improvement of the MAS interface and joint working with other services

There are issues around the service being in a big borough and there are lots of different teams, making the care pathways quite complicated. Historically, there were high numbers of referrals, some of which were not suitable for the MAS. The team have worked with neurologists, geriatricians, and the neuro-rehabilitation team at general hospitals to encourage better joint working. Initiatives over the last 18 months include a neurology/MAS MDT once a month, MAS consultant-led supervision to geriatric medicine doctors, and the development of a new neuro-rehab pathway. The team also promote good working relationships with general psychiatry and with physician colleagues to encourage them to ask for advice rather than referring for a full assessment and to provide ad hoc advice to the complex care team regarding dementia and drugs.

> *"It has an impact on the patient in terms of their waiting times, inappropriate referrals, or us not be able to give the best that we could give 'cause of poor referrals coming through. So, working jointly with GPs, putting a name to the face of the memory service, what we do, how we do it. You know we were going around doing that meeting, networking with facilitators and meeting with GPS just to just have a better, more fluid way of working for both patients and for the for the both services". (Team Leader)*

Knowing how other teams work reduces staff friction and benefits patient experience as the MAS staff can explain how other pathways work.

> *"You know when when referrals aren't being processed as fast as we'd like them for like follow ups and scans that kind of thing. PET scans have been very slow and then you get to understand the limitations they're working under and why it's taking so long. And then you can explain to the client group why they've been waiting X amount of months for this. Whereas before we just were in the dark. So those conversations are important. They're important to manage". (OT)*

What do you think the benefits are of what your service is offering?

Staff are more confident in making assessments and the team has a streamlined process which provides an efficient service for people who are accessing it. The stronger relationships between the MAS and other health services mean they can offer service users a better support system, offering aids or other information which they were previously unaware of. This also benefits the clinicians as they feel better supported in caring for service users who have mental and physical health co-morbidities.

The changes enable the MAS to focus on providing high quality person centred care including consistency with staff throughout the client journey

> *"We had the same nurse the whole time... A very good thing because she built a rapport with us, you know, just she spoke to us, I think she spoke to us once on the phone before we went in for the assessment and so we were expecting to meet her there and she greeted us as if she, you know, we were recognised and known sort of thing. And then she kept us in, in touch with what was going on because after, after the assessment, after the memory assessment, she discussed it with the consultant psychiatrist". (Carer)*

It was also reported that having a human touch, displaying empathy, and treating service users with respect were valued.

> *"Yes, she was very good. Yes, very human and very worldly. So she was aware of, you know, what we were going through as well as what it meant for him and treated him with great respect". (Carer)*

Site 2 - A team with specialist staff input commissioned to provide support from referral to end of life

Summary

The site has been commissioned to provide ongoing support to people through to end of life, following a dementia diagnosis. This includes a 1-month post-diagnostic review, followed by six-monthly comprehensive review which can be increased in frequency where complexities exist/arise, until the person with dementia has stabilised. Reviews are undertaken by either an Assistant Practitioner or a nurse dependent on the complexity of needs. At least one review annually is conducted in the person's own home. The team includes occupational therapy and psychology staff who support diagnosis and post-diagnostic support. A lead practitioner and non-medical prescriber provide more intensive support for those with the most complex needs. This model means people with dementia and their family continue to be supported by a specialist team post-diagnosis.

What led up to you developing the service in this way?

Previously the MAS was primarily a medic-led diagnostic service, with some additional Nursing and OT support for those diagnosed with dementia including reviewing medication on a 6-monthly basis. People who were not prescribed medication or had this stopped were discharged. Then in 2015 the Clinical Commissioning Group undertook a review of dementia service provision and identified diagnosis rates were good, but that service users were requesting greater post-diagnostic support. This was seen to be a priority area and there was some discussion about whether this should be provided by the third sector or the NHS. The service put forward a bid to provide the post-diagnostic support through increasing the number of assistant practitioners (Band 4) and more psychology time so they could offer a diagnosis to end-of-life service. The proposed service was commissioned, and the model of delivery was changed immediately in April 2016. The service has continued to develop and grow in the period since. The service is funded through the ageing well funding stream, with this innovative approach to commissioning was achieved through good relationships between commissioners and senior MAS clinicians that allowed the initial conversations to happen and commissioners who were bold in providing more for their population of people with dementia. It is not subject to review, but is part of the ongoing funding the services receives to operate.

What does the service offer?

People referred to the service see a doctor in the first instance. There is no waiting list currently, so they are seen within 4 weeks sometimes sooner. Most people accessing the service will be given their general diagnosis of dementia, if appropriate, at that initial appointment. Scans are accessed after this, where necessary, to determine dementia sub-type or where the doctor feels they are needed to confirm a dementia diagnosis. People with a dementia diagnosis who are started on medication are referred to a non-medical prescriber in the service who starts medication and follows up until the person is stable, at which point the GP takes over the medication management and they move into the review system within the MAS.

Ongoing review based on needs

The review system offers on-going post-diagnostic review and support and the type of review depends on the complexity of the case. People who have complex needs for example due to behaviours such as sexual disinhibition, aggression, severe hallucinations or if there are complex carer dynamics, are referred onto a nurse within the service. The nurse will follow them up on average every three-months, but can see people more frequently if required to work with them through a crisis or to solve a particular issue.

The less-complex cases are referred onto one of the 6 assistant practitioners who offer everyone a 1-month review from the point of diagnosis and from then a six-monthly review. The one-month reviews have arisen from an identified clinical need.

> *"We offer a one month review because we found that a lot of questions and a lot of concerns came up at the diagnosis giving that weren't quite answered. Therefore we follow them up after one month to able to kind of answer those questions and we also have particular areas that we cover such as research such as their home environment and things. These kind of elements that maybe have not been picked up or seen in the diagnostic part." (Staff member 01)*

The six-monthly reviews are comprehensive including cognition, medication compliance, appetite, sleep, mood, symptoms such as hallucinations, how they manage day-to-day tasks such as shopping and cooking, carer stress, support and needs and any care packages they have in place etc. They aim to conduct at least one review a year in the person's home, the other is usually via telephone. Where needs or concerns are identified the assistant practitioners are able to provide advice and can signpost the person and their carer to relevant services and support as required.

> *"I really do like that approach of considering the carer because … including them in the post-diagnostic support I think is a really good way to prevent carer breakdown as well." (Staff member 06)*

Where complexities arise they can refer to the nurses within the team to follow up until they have restabilized. If a person or their carer needs support before their next 6-monthly follow up they can contact the service for support. This is offered via a duty system if the named worker isn't available. People being supported by the service therefore always have someone they can contact if they need to. There is specialist knowledge within the team to provide appropriate advice and support or signpost on to other services.

> *"When I get in contact with them, I'm able to iron out any sort of creases that they've been having in the past few months. And then to remind them that … we're here to help, to support them. …A lot of the service users family get in contact with me via email or they'll call me, and ask certain questions. And then then I'll help as much as I can. And if I'm not able to help, then I've got my supervisor who's a nurse and then the consultants as well." (Staff member 02)*

The MAS discharges people from their caseload if they move into a care home and may refer them to a care home liaison team dependant on need.

Ability to access specialist post-diagnostic support at the right time

The service has recently appointed a Senior Nurse Specialist to work alongside the non-medical prescriber and who can provide more intensive support to people who require more complex intervention than the Band 6 Nursing roles. They are therefore able to offer a comprehensive step-up, step-down model for everyone under their care.

There are also a multi-disciplinary team of clinicians who can provide input via a referral system. The OT undertakes pre- and post-diagnostic assessments and provides advice on cognitive-based issues, for example assistive technologies. The two psychologists conduct pre-diagnostic neuropsychological assessments and provide one-to-one support for carers post-diagnostically where there are complex relationships or needs. They also offer advice to and work with the nurses to support people with more complex needs.
The assistant psychologists offer post-diagnostic cognitive stimulation therapy to people with dementia and the Strategies for Relatives (START) intervention for carers. There is a robust assessment and referral criteria established so referrals are appropriate and staffing resources are used appropriately.

> *I'm always very confident people on our waiting list are actually people that can benefit from psychology and that has really paid off. It's quite rare that I get to assessment and then I'm like oh, actually this wasn't an appropriate referral, which then enormously reduces the amount of people and makes it feasible for only two psychologists in a service of ..thousands of people in our cases. So that is very important. (Staff member 5)*

Building local expertise and relationships

The nurse and assistant practitioner caseloads are split across boroughs, so they follow-up the same people and also develop expertise around support available within their locality. This also means they can develop good relationships with GPs and other health professionals such as district nurses across their local area as well as charitable and community organisations who offer post-diagnostic support services. The third sector provision locally was identified as important in providing post-diagnostic services that the MAS did not.

> *"So a lot of what we, [assistant practitioner refer to, … would be for example Age UK [in our local area] is a really good service, …in terms of what they support [they provide] because they do things like day centres and … counselling for dementia, … … well being services, so befriending services, they support a lot with financial support, care needs, planning, support for the carers as well… [name] Carers is a is another really good one and that's support specifically for the carers. They have a dementia group every Wednesday." (Staff member 06)*

What are the challenges of this model and how have you overcome these?

The numbers on the caseload are a challenge at approximately 170-180 for the Assistant Practitioners and around 60-70 for nurses. They manage this through having targets of people to contact each week, limiting the numbers of times they attempt to contact people for their 6-montly review, prioritisation of individuals during busy periods and setting boundaries around their role as a cognitive advice and support service for example by not undertaking care co-ordination or helping to sort out care packages. They signpost and refer onto appropriate support as required and the good local relationships help with this. It has also helped to separate out the staff who undertake diagnosis and then a referral system onto those who undertake post-diagnostic support or the specialist services such as OT and psychology.

> *"And I think that the element of this also those boundaries between what we do and what we don't do. It's really key for your staff to know what they do and then what they don't do." (Staff member 01)*
>
> *"I think you in order to really deliver on patient care, but also, you know, managing the numbers you've just got to be very efficient. You've got to be careful with your time. You've got to be organized. And we do have targets, you know. They're not strict targets. But I think in terms of keeping on top of our caseload, we do have to set ourselves targets in order to make sure that we're delivering to the patients that we make a commitment to." (Staff member 04)*

Getting a service like this commissioned initially can be a challenge. The service was helped by a local CCG [Clinical Commissioning Group] which had a focus on dementia and improving post-diagnostic care and who were open to commissioning new service models that might address this.

> *"I think we've shown it as successful, and it's doable. If you've got the right backing." (Staff member 01)*

Assistant practitioners find that engaging some people diagnosed with dementia or getting in contact with family carers to arrange reviews can be a challenge. They have to accept not everyone wants to accept a diagnosis or engage with e service. They approach this by attempting to make contact at each review point and re-trying at the next point to see if the person's wishes to engage have changed. They can also refer the person on to adult social care for assessment and support if there are any concerns about well-being or safety.

What do you think the benefits are of what your service is offering?

Benefits identified are across a number of areas:

- Continuity of care for people diagnosed with dementia and carers

  "Service users can build up some sort of relationship with the professionals and therefore feel like they're receiving personalized advice or guidance, information and support really. So it's not just, a kind of drop in and drop out kind of service." (Staff member 04)

  "We had good service, they kept in touch with us … They called us in every so often and we'd have a meeting with a young lady up in the building in the top floor. And she discussed things with us and was there anything we needed. Or could she do this? Could she do that, you know?" (Husband of someone diagnosed with dementia by the service)

  "It was the beginning of a relationship and that for us was critical, that it's not about being dumped with something and go away and sort out your affairs. … It's about, yes, this is something we're going to support you through and we will be following it up and you will be seeing [name] on a regular basis. So I think that's … absolutely critical. You need continuity and you need somebody that you can begin to build trust with because it's such an unknown territory at the beginning and you know it's pretty terrifying because you think. Where do I begin?" (Wife of someone diagnosed with dementia by the service)

- Ability to access specialist advice and support easily and quickly when needed

  "I think it's helpful for them and comforting for them to know that there's someone on the phone that they can either call or they can or I can go round to see them at home. I think it gives them confidence in the journey." (Staff member 02)

"They connected us into the alcohol support service because [husband] loved his Guinness and he used to love going to our local pub which is, something he's done all his life, but he didn't know how many pints he drunk. and so he would have too much and that was very distressing. The man came to the house and we talked together about strategies we might use to help [husband]. [Husband] was involved in that conversation." (Wife of someone diagnosed with dementia by the service)

"Maybe that is a good thing about having larger caseloads because we are exposed to such a range of, ... different inquiries or concerns or questions or situations, and therefore I've been involved in discovering lots of new services ... for older adults that I can now just pick out like that if I see someone else with a similar problem or concern." (Staff member 04)

"We had an MDT (multi-disciplinary team meeting) case the other day there from an Albanian background and someone from the team was able to suggest an Albanian carer support group that we could then signpost the family to." (Staff member 06)

"We had an MDT (multi-disciplinary team meeting) case the other day there from an Albanian background and someone from the team was able to suggest an Albanian carer support group that we could then signpost the family to." (Staff member 06)

- Better local integration of services particularly for post-diagnostic support.

"I think the benefits of it has been the greater integration between ourselves and the wider health and social care community .. of what we know other services do, but also that other services know what we do ... We've also raised the awareness of what a memory service can do, so the GPs are much more much more willing and able to refer to us than what we were seeing before" (Staff member 01)

Site 3 - Providing tailored post-diagnostic support during the pandemic and beyond through adapted delivery of Cognitive Stimulation Therapy (CST) and other interventions

Summary

This service is commissioned to deliver dementia assessment, diagnostic and post-diagnostic support through to end of life. The service offers extensive post-diagnostic support including offering CST in a range of modalities, including for people living at home to prevent isolation, and START carer support.

What led to you developing the service in this way?

Providing for a densely populated inner-city area, with a very diverse population, this site usually delivers Cognitive Stimulation Therapy (CST) face-to-face in groups at local day centres. However, lockdowns and the requirements for social distancing during the Covid-19 pandemic meant this could not continue.

Staff felt alternatives to face-to-face group CST were needed to prevent people newly diagnosed with dementia from becoming isolated and under-stimulated. They therefore looked to develop options for delivering CST to people in their own home. A cross-borough project was set up by psychologists, working collaboratively with other psychologists from another MAS service within the same Trust

> *"[We were] very aware that, as the pandemic moved on and a lot of things had moved to online, that it was very much an issue around exclusion, digital exclusion, with older people predominantly. Maybe, many people within that group may not have... be able to access it. So, we are very mindful of that and the additional challenge of people with dementia as well. But we thought it would be worth giving it a go and seeing... and starting to develop a way of having conversations with people who were waiting for CST. About the idea and thinking about what support they would need to access the group online. And talking, also, to people who supported them, their families and carers, to see whether we could work together to enable them to access the group if they were interested." (Staff member 2).*

A range of possible and accessible CST solutions were identified, these included:

- Virtual CST groups (VCST) run using video-conferencing software
- One-to-one CST via phone calls and later in person and
- Supporter-led CST inspired by Individual CST (Yates et al., 2015) through providing family and carers with a pack of resources, referred to as CST at home, which they could do at home with the person they care for. .

To support these services work was undertaken to develop and print CST at home packs to post out for people to work from. Based on standard face-to-face group CST, these packs included elements such as session plans and a booklet of activities such as looking at maps, reminiscing about holidays and talking about music. The packs were developed in consultation with the developer of CST, Professor Aimee Spector (Spector et al., 2003) and the publishers of the CST manuals, Hawker Publications (Yates et al. 2015).

What does the service offer?

Cognitive Stimulation Therapy (CST)

The service offers CST in a range of modalities. At the time of writing, which reflected on the pandemic period CST options included waiting for face-to-face group CST to resume, trying a virtual CST group or their supporter/carer accessing the CST at home packs. Out of 171 people that were contacted around half opted for one of the options to access CST at home.

Virtual group CST

Virtual CST comprised/comprises ten weekly sessions of 45 minutes each. These involve approximately four people living with dementia, their supporter/s, if available, and two assistant psychologists acting as facilitators. Groups were formed based on people's cognitive abilities.

CST at home

Those opting to do CST at home are provided with CST at home packs. These are based on a similar approach to the CST groups, containing ten sessions and ten different activities a supporter could facilitate at home. The service also made a short video giving an introduction to CST and how to do this at home, which was posted on the Trust's YouTube channel and the link can be emailed to the supporter. There is also guidance where the person's first language isn't English and on adapting the activities and materials to be culturally appropriate. Both of these resources were co-developed with supporters of people with dementia. The team offers a follow-up phone call after 4-5 weeks to answer any questions, offer additional support and gain feedback from supporters.

Telephone CST

Those people who were more socially isolated, without access to technology and without a supporter can be offered telephone-based one to one CST. People are sent a different booklet containing activities and worked through these with an assistant psychologist over the phone. These were sessions selected or developed from bringing together sessions from the group CST programme offered by the service. As soon as COVID-19 restrictions allowed some of these individual sessions were run in-person in the person's own home.

START Carers' support

The service also offers the STrAtegies for RelaTives (START) intervention, which is an evidence-based, eight session psycho-educational intervention for carers of people with dementia. It has been found to help reduce the risk of carers/supporters developing depression. The service took part in the initial research on the intervention. START is delivered predominantly by two assistant psychologists under supervision in the team. Supporters report the benefits they see from attending the intervention.

> *"... the memory team also got me involved with the START programme, which also taught me how to better take care of, of mum, and deal with my own personal guilt and stuff with leaving her and all the rest of it. That was amazing. And I got a CD on meditation and oh my days! I seriously... I was literally... my hair was falling out at the beginning of dealing with mum. But then, after the session, I had eight sessions of that and while mom was doing her sessions, after that, my hair isn't falling out anymore and I feel... I feel less anxious and angry and frustrated with myself."*
> *(Supporter)*

What are the challenges and how did you overcome these?

There were some challenges experienced in delivering the CST options at home by both staff and people with dementia. Individual CST via telephone included the large time commitment from staff, and the approach was found to be less suitable for people with moderate cognitive impairment associated with their dementia and those with hearing loss.

> *"[our participants are] older and so with that comes hearing loss and, they can't hear you very well. They have a cognitive impairment and we're talking about things that aren't normal,. A normal conversation might be from their family maybe, ringing up and saying. "Do you want me to get you something from Asda?" We're not having that conversation and they can't put a face to the name. They are all very difficult things to do on the phone."*
> *Staff member 1*

The supporter-led approach meant was that personalisation wasn't possible. So, each person received the same pack. However, the service did offer guidance on how to adapt the activities and materials to fit the interests, background and needs of the person they care for. Also, not every person had a supporter with the time and space to be able to support them. Another potential drawback was that it could be putting more demand on family and supporters.

Challenges for the video conferencing groups included that some people didn't have access to the technology required, in the form of laptops or smart phones. Ohers didn't have someone available to support them in setting it up. Unfamiliarity with the technology sometimes made it hard to operate and a particular challenge when experiencing memory loss. Following the conversation on a screen was difficult for some people and, as a consequence, supporters and session facilitators felt they spoke more than would have been ideal. Another issue was the sessions' timings which, at 2pm, were when some people's supporters were at work and so couldn't support them. There were also time-consuming technical issues to contend with.

> *"And then you've got this tiny screen. This person might have poor eyesight, they have dementia, and sometimes they wouldn't be able to use the camera. And so it would be really, really challenging for them to get those, those cues that we all need to know when it's your turn to speak. So yeah, that that's definitely one of the challenges of VCST, I think."*
> *(Staff member 3).*

> *"It would be beneficial if someone was with mom while she was attending the online meetings, because if you're not physically with someone, this is very new for someone of her age, especially with her memory. This isn't new for me. I mean, everyone does this now. But for her to know that they were not talking to her, they were talking to someone else doesn't really work with her particular Alzheimer's. So it was challenging." (Supporter)*

The assistant psychologists involved have written a brief article about their experience of delivering CST during the pandemic (contact details provided in appendix 4)

What are the benefits of service?

A number of overall benefits were identified for the CST services. The benefits included preventing isolation and under-stimulation by enabling continued access to CST and to connect with another person, or people at a time when connections to others were limited. CST at home was also felt to increase accessibility and inclusivity for some people who were unable to access to face-to-face groups due to mobility issues, lack of support or low income.

> *"So, the problem of CST is always how you make it equal for everyone and how you get... some groups of our population come to groups more than others. And getting people can sometimes be difficult. But, by sending it to their home, that's opened up the doors to people who maybe can't access.... even mobility wise, can't get out the house. We've restarted our groups again, but we're also going to keep up the CST at home for people that can't come to the group. So to try to, open it up to a larger population, .. that's been really good" Staff member 1.*

Individual CST with a staff member worked well for some people because the initial delivery by telephone used a medium older people are familiar with and which was accessible to them. The later sessions in people's own homes were felt to work even better for delivering a positive experience and reducing social isolation. It could also allow tailoring to the specific individual and an opportunity for people to open up about how they were feeling.

> *"So we did a there's a CST session that's themed around music and I did one session with somebody who was a really big Queen fan, but she is incredibly socially isolated and she has a range of physical health problems that mean she can't access technology, and she's very lonely. And so building in Queen numbers into the session was just really, really wonderful and allowed us to do a bit of Multi sensory stuff, a little bit of physical movement. It just really, really brightened her and she's someone who also has a diagnosis of depression. And she went on to talk about how when she's feeling low, she would think back to dancing to Queen. And it was just really, really touching. And I think because it because it happened in that one to one ... You know in a CST group, you'd be aiming to tailor as much as you can, but because it was one to one, it allowed that kind of vulnerable exploration about what it meant to her and, really tailoring it to what she wanted. It was a very lovely session." (Staff member 3)*

Supporter-led sessions also reported positive experiences. The flexibility of being able to do sessions whenever a supporter was free was welcomed. The positive effects on people with dementia were also noted.

> *"The feedback has been really positive. So family members have really liked having this thing that they can do. And obviously they keep it [the CST at home pack], so it's then something that can go back to time and time again." Staff member 1.*

> *"I was given some suggestions about just talking with her [mum]. And I realised that, the singing with her, and the talking about it, really helps her come out of herself. And it actually brings up her mood." Supporter.*

Although challenging, video conferencing did have benefits for people who otherwise would not have seen human faces or interacted during the lockdown periods. Still being able to access CST support provided opportunities for engagement and well-being.

> *"...being able to talk to people and hear other people, and just that... this is her interaction because she doesn't leave [the house]. So, actually having that interaction with other people who were like her and people who understood and didn't get frustrated with her. That was good." Supporter.*

> *"Because I was sitting there and she was remembering stuff, all the different kinds of foods that my nanny used to, my grandmother used to make. And it was just it, there was a genuine smile on her face. And when she was talking about those old memories, and then I don't know, there was sometimes a question or something. And it made her think of a song and she started singing a song. I mean, it's a really good service. It's amazing." (Supporter)*

The service is planning to continue to offer a range of CST options in future. This will include face-to-face groups, which have now resumed, supporter-led CST at home packs and will continue to consider offering one to one sessions where clinically needed. People will be able to indicate what suits them best.

> *"It would be nice to think that something virtual could be offered to people who were unable to physically come, you know, to groups for whatever reason. And I think there is something to be said for the difficulty in reaching people that are also at quite a late stage of their illness." (Staff member 3).*

Advice for other services wanting to explore options for people to do CST at home includes screening people at point of referral about their CST delivery preferences. This could help reduce the staff resources needed to phone people offering the service and screen them for suitability. Also, to work closely in developing materials with the originator of CST, ensuring copyright etc. This service was asked to keep the materials they developed as a within-service resource, separate approaches would need to be made. Additional budget needs to be allocated to print the materials but there should be no training costs as psychologists are already trained to deliver the material.

> *"Other advice would be to see it as a bit of an opportunity to tailor your working to individuals. Because you're kind of committed to a degree of flexibility, I think, when you slightly reinvent something. And I think there is opportunity there to meet the needs of people more specifically." Staff member 3.*

Site 4 - Memory Hub and Younger Persons Memory Service with extended post-diagnostic support

Summary

The Memory Assessment Service at this site incorporates a dedicated younger persons memory service that provides post-diagnostic support for as long as required, and a memory Hub that is responsible for providing long term post-diagnostic support. People over 65 are offered a standard memory assessment service route in which the diagnostic service is located in the Community Mental Health Team, with access to the memory Hub for post-diagnostic support.

At this site, regardless of age all persons receiving a diagnosis of dementia are referred onto the memory Hub for support.

> *"the cognitive assessments are done through local community mental health teams, so all referrals from GP for people over 65, whether it's for functional mental health problems like depression, bipolar disorder, psychosis or whether it's for cognitive assessment, just go to the same team and then they have an assessment within that team and the diagnosis is given within that team. This is for over 65s, and then those people if they get a diagnosis of dementia get a referral through to the memory hub and the memory hub is the sort of Post-diagnostic support and treatment and ongoing follow...so we start the medications, the nursing team delivers the.. post-diagnostic stuff that doesn't happen in the in the first interview where a diagnosis is given, so all the stuff about lasting power of attorney and you know the information about the diagnosis and lots of time for people to ask questions." (Consultant Psychiatrist)*

For people receiving a diagnosis over the age of 65 the memory Hub is able to offer support for at least 6 months, and sometimes up to a year or longer depending on the individual need

> *"The length of the service varies… think six months is a sort of minimum that that you'll be offered with the hub and then people who have more complex problems. So maybe they have psychosis, maybe they have mood problems, there's behavioural disturbance as part of their dementia, they can be followed up more long term. It could be that the sort of carer support if the carer's struggling and things, so you know if there's a clinical need they can be followed up indefinitely then by the by the memory Hub." (Consultant Psychiatrist)*

The model for people with suspected dementia at a younger age is slightly different, this service offers pre diagnostic support, diagnosis and post-diagnostic support for as long as required.

> *"I work with the younger person's memory service and if someone needs nursing input prior to diagnosis, that will be through the younger person's memory service, which is one of the reasons why there's not dementia name in the service because a lot of people referred to the service won't have dementia. Most of the people referred to the service probably don't have dementia. And then when someone receives a diagnosis with dementia, then will remain within the younger person's memory service. And really they remain within the service until they have no need for us or until they're 65" (Consultant Psychiatrist)*

The service also supports people with diagnosis of Parkinson's where cognitive impairment may be present, with access to advice and support through geriatrician led multidisciplinary team meetings:

> *"they [within Parkinson's service MDT meetings] talk about someone with hallucinations and I think, you know what, I think I should just see that person, then they can refer directly through to me or if they're already under one of our services, I'll just make an appointment to see them. And similarly, the other way around. If they feel oh, I think this is more than the MDT can manage, you know, more than a conversation can deal with then I can refer through to them for assessment" (Consultant Psychiatrist)*

What led up to you developing the service in this way?

Developing a Hub for Post-diagnostic dementia support

The Hub for dementia support has changed significantly in the last five years, and has evolved from a day hospital model.

> *"It looks very different now, so this service used to be just the old day hospital model and they were gradually closed down throughout the nationwide. So we evolved into a memory service. So we, the old day hospital was for functional patients and organic so then. The functional patients moved onto the community health teams some were discharged, and we focused on organic patients and then it just evolved from there." (Service Manager)*

The service has developed to offer post-diagnostic support that is responsive to patient need in the community for as long as it takes for people to become stable prior to discharge to Primary Care.

Supporting people with Parkinson's dementia and Lewy Body Dementia

The service has been supporting people with Parkinson's disease via the Parkinson's disease team since 2019. This was initiated when the consultant with a special interested in this area (interviewed here), came into post

> *" when you when you're in appointed as a consultant quite often there be something the job… that that that fits your interest. And so for me that was really interesting thing to do for I think it came from our service rather than the geriatricians. The geriatricians were very enthusiastic I think I think it was it came sort of from us as our idea". (Consultant Psychiatrist)*

The region also has a strong culture of interest in supporting people with LBD, clinically and from a research perspective.

> *"we've got a bit of a heritage here of the dementia with Lewy bodies research. So I was trained here by [professor], who's a DLB researcher for many year and so the level of awareness here of DLB I think is much higher than other areas of the country…and I think that goes not just for our trust, but really the whole [region] because [city] has been a bit of a centre for DLB research and so many of the doctors that are working here like me have come through training with people who have special interest in DLB research. So I think we're sort of hyper aware. Of DLB and as a result, the nurses I think are probably much more knowledgeable than the average region in in terms of DLB as well." (Consultant Psychiatrist)*

What does the service offer?

Person centred post-diagnostic support via the support Hub

The service offers longer term post-diagnostic support which is an MSNAP accredited service. The service prides itself on a person centred approach from the first point of contact, with patients being triaged by the service manager within days of referral. This approach has been seen to reduce DNA rates and prepare patients for their first appointment.

> *"So..it's me who makes that first contact with service users just really to engage with them, find out sort of what they're remembered from the appointment with the consultant cause it's life changing, isn't it? Getting a diagnosis like that do they understand the reason for the referral of the happy for that. So we're gaining consent, that sort of thing. So we do that and then we bring patients in for treatment and post-diagnostic support, and we offer CST therapy as well… if you look at our DNA rate it is very low… People turn up for their appointments and they know what to expect, we give them information. And I think that's good practice. And then when we went through accreditation, I was really praised for that. You know, half an hour with a family right at the beginning, but it saves a lot of work overall…In fact people, if they don't turn in for an appointment, it's usually because they have been admitted to hospital or, you know or something like that. So I am proud of that. So I'll put a little bit of work in at the beginning and I think it just allows service users to ask any questions that hopefully I can answer that we're gonna talk about the pathway and what do we expect from this." (Service Manager)*

The Hub is also offering a drop in surgery for patients, which will aim to bring together a range of post-diagnostic support resources into one place for patients and their carers to access on an ad hoc basis.

> *"for post-diagnostic support, we work with the Citizens Advice.. we're…having a surgery here, like we called it a drop in. That's not a drop in really because we will have to plan it, but we're setting up some joint work and where they can use our service as a base…dementia advice workers come in can do their job from here as well. But also we can invite people to come in just to have those face to face discussions with them. So it might be around finances that sort of thing. Other dementia advice worker will go out to people's homes but just thought would be great to have everything under one roof where people can just call in. We're working with the Age UK…so they're gonna come along to this surgery as well and talk about day provision in [town] for patients that come in cause probably like everywhere day provision just closed down didn't throughout the pandemic. But there's new things shooting up everywhere…we'll work closely with occupational therapy. And they've actually got some technical instructors who go out and just look at the gaps, look and see what's what's new out there, and they set up a directory and give us that, which is really helpful… We'll work closely with psychology. They are there on site." (Service Manager)*

Younger Persons Memory Service

The younger persons memory service offers a specialist approach for people who have suspected dementia at a younger age. All elements of the service are mindful of the fact that a diagnosis of dementia for younger people has different and sometimes more complex implications. The staff at the service are prepared and mindful of this, both in terms of the approach to diagnosis (i.e. offering pre diagnostic counselling) and the need to provide unlimited support thereafter.

> *"People have, you know, people have sexual relationships at this age. They sometimes have young kids. They can have mortgages. They've been working. So it's a very, very different. Although it's, you know, it's the same diagnosis, it impacts so differently. And I think that's where the unlimited time service really is of a benefit to our patients and service users" (Staff member)*

It is also important to the service that the post-diagnostic support offered is age appropriate. For this reason, specific and tailored support is offered.

> *"Because one of the things that we know that the patients need is that peer support, especially when it hits them at an early age and we know how important and how imperative that peer support is and it's one of the things particularly we find that the men struggle with. So at the minute we do offer peer support in the terms of lunch groups and a coffee group monthly, and we're developing a men's group at the minute, but we're looking to expand that to bring in carers in as well and having that on the unit where we can look at sort of sessions around LPA and get speakers in to do a little bit of educational work, but then also have that peer support following it, but it gives them that that glue to talk to each other without the main focus being sort of the negative sides of the diagnosis." (Staff member)*

The service has also considered the location of the services that they offer and reach out into the community to build patients confidence with activities of daily living as a priority.

> *"The chances are they don't want to be sitting making decoupage and knitting and you know, doing older activities, but it's about finding things that are stimulating for them and making sure they've still got the confidence to go out, you know, so we work with patients in the community and we'll take them out and help them develop skills with confidence in using buses if they've lost the driving licence and making sure with it you know that change is isn't as hard as what they were anticipating and tried to make that transition a little bit easier, you know." (Staff member)*

Specialist support for Parkinson's disease dementia and Lewy Body Dementia

The service offers specialist assessment and support for people with PDD and LDB. This is enabled by close working between the professionals involved in peoples care, which may be invisible to the care recipients themselves, but means that their care is informed by the specialist memory service.

> *"I think what we have you know is we have an easy line of communication between old age psychiatry and geriatricians where we can discuss complex cases…So it's kind of support around the decision making process, the clinical decision making process because as I say, the person themselves probably won't notice…. So it's so it's not so much that there's a different kind of process for the patient, it's more that we have a sort of open and continuous line of communication between us …" (consultant psychiatrist)*

The old age psychiatrist also attends the geriatrician meetings, so that they can identify and provide feedback on cases directly.

> *"I don't want to oversell it too much. You know it's a sort of once monthly meeting, it's not kind of you know been a reorganization of our service or anything like that. But I think when you have open lines of communication it is more than the meeting. You get emails then so I I know who to email to ask for a bit of advice. They email me for a bit of advice" (consultant psychiatrist)*

In reality for the patient this results in more informed care and potentially fewer hospital appointments.

> *"One less visit to the hospital for people and their carers and again quicker responses because you're not waiting to see a new person." (consultant psychiatrist)*

This can also mean that individuals with these diagnosis are offered Specific and tailored support for PDD and DLB via the memory HUB.

> *"if you have dementia with Lewy bodies, you do get a longer duration of care so we tend to keep people with dementia with Lewy bodies under our care. And the reason for that is simply that the complexity of the disease usually means that people have ongoing problems and even if they don't have a current problem, there's a high likelihood they'll encounter a problem. You know, so the discharging them is not the best way to care for them." (consultant psychiatrist)*

The region continues to be well known and well established for DLB research, participating in large scale studies:

> *"I think is it as a sort of health ecosystem in in the [region]. I I think the expertise that's there in [city] filters out to the region and and we know this because the [study 3] was a big NIHR grant. I wasn't involved in it, but it was. It was led from [city] and [city 2] and it looked at diagnostic rates for dementia with Lewy bodies in the [region] and the [city 2] region and the diagnostic rates are higher here and you know, there was evidence from the project they suggested that was because people…follow the diagnostic criteria more closely here…we benefit from research that occurs here and there is a much greater awareness of DLB than other regions, and I think that's really true of us as an individual service because the memory hub was led by [professor] for a lot of years and in the he was involved in the setting up with the memory hub. So I think his knowledge and DLB research really filtered through the rest of the team as well." (consultant psychiatrist)*

Revisiting Diagnosis

Under the umbrella of the younger persons memory service, there has been an initiative to revisit patients' diagnosis when the clinical profile is suggestive or has features that indicate the patient may not meet the criteria for a diagnosis of dementia.

> *"there was a kind of natural point there to start looking at diagnoses again when you repeat cognitive tests. And then you look back and think, well, right over a period of years, this hasn't declined. This isn't really consistent with your diagnosis anymore…. I think that is quite unique to our service because we do follow people up long term even if there aren't major issues." (consultant psychiatrist)*

This is only possible because of the length of time people are followed and has enabled staff to identify people who they may have expected to decline, but haven't. this approach may not be viable in services that do not offer an extensive follow up in this age group.

> *"If you discharge to the GP, I don't see how you're ever going to identify those people because they're not having problems. So they're not, it's highly unlikely they're going to come and say, I want to re-diagnosis because I don't think my cognitive decline is consistent with my diagnosis." (consultant psychiatrist)*

Nonetheless, setting this process up has been challenging and staff have recognised that the process of this follow up has, and will not be, easy for individuals and their families.

> *"It's really psychologically challenging for people and their carers. You know, we don't come to clinic and say I don't think you've got the right diagnosis we say. You know, we're just looking at there's not being a lot of decline in, in, in your memory tests over the last few years and you know for someone with, say, it's Alzheimer's disease for someone with Alzheimer's disease we'd expect things to be getting worse a bit quicker. And we we're just wondering whether maybe we should think about doing a bit of a reassessment of your diagnosis and maybe having another look at that. And then leave it with him. And if they don't want the re-diagnosis, absolutely no problem. You know that that's completely fine. And but if they're happy to, then we'll do a re-diagnosis. And because it's so. Psychologically challenging for people, we really, really don't want to get it wrong" (consultant psychiatrist)*

In practice, the reassessment involves all of the functional and cognitive tests that were offered at baseline, in addition to repeat structural or functional imaging.

> *"And then in those really tricky cases. We have the option to refer to the Cognitive neurology clinic in in [city] that can do and give another opinion firstly but also they have access to CSF biomarkers which can pretty conclusively rule out Alzheimer's disease." (consultant psychiatrist)*

If a re-diagnosis is indicted, and the person does not have dementia, there is a very careful process to ensure that the patient is aware of the implications of the re-diagnosis, for example, that they will be discharged from the service. They are also made aware of the positive implications.

> *"For instance, one person wanted to reapply for the driving license, and obviously much better for them not having a diagnosis of dementia and then after the re-diagnosis, we'll sort of offer for the their nurse, maybe to meet with them again a month later and have a bit of a chat about things. If they're really struggling with it, then a psychologist can give input over that time as well. And then once we feel that kind of that has been dealt with and they're sort of adjusting to the to the re-diagnosis, you know, and have adjusted, we can then discharge from the service." (consultant psychiatrist)*

In terms of the frequency of re-diagnosis, the staff reported that it may seem like they are following a lot of people up, but that this could be misleading.

> *" So it feels like it's very common in our service, but that's because, you know, sadly people with dementia have reduced life expectancy. People who don't have dementia don't have reduced life expectancy, so if you follow people up over a long period of time, your people without dementia hang around for years and years and years and years and years, and sadly, our people with dementia unfortunately die over a period of time. So we actually ended up having a reasonable number of people in our case load who had a re-diagnosis and as a result, I'm just really interested in the process now because it is a really challenging process, but it's quite rewarding as well if you're able to do it right and people can kind of change their outlook on life a little bit" (consultant psychiatrist)*

At present there are no specified pathways for re-diagnosis, so the learning from this team may be valuable for other services seeking to offer reassessment or re-diagnosis.

> *"Because it was in [the best practice guidance] and I was just really pleased to see it your guidelines because it was something, it's something that I think is really, really off the radar of the vast majority of services and if we think about our older people in the memory hub which you know is a fantastic service and you know is providing much more input than most services in the region and nationally, but the people who are stable are discharged and they'll be the people who have been misdiagnosed. And a misdiagnosis is not about a medical mistake by anyone. You know, it's just the degree of accuracy we have in our diagnosis is 80, 90%. If you're good. And so there just will be people who are misdiagnosed." (consultant psychiatrist)*

What are the challenges of this model and how have you overcome these?

Support for younger people due to COVID

The COVID-19 pandemic has impacted the way that the younger persons memory service is offered and run.

> *"we had a day treatment service and we had a small community outreach service. Because of COVID we've had to change the way that we work. So what happened was that there was the suspension of the day treatment service where patients would come in... What we've what we've actually found is that the service users have been so resilient and the changes we've made have empowered them and the carers to feel that they can manage without that service, and so we've changed into more of a community service supporting them and that's working. The nurses do the majority of the outreach and we have a support worker who can sort of parachute in and deliver interventions that that have been led by the nurse. So at the minute, that's how we're running. Not back to a full day treatment service, but to shift into something where we can offer courses and bespoke sessions to, and almost offer that peer support but in a more structured environment." (Staff member)*

As a result the post-diagnostic support has shifted toward outreach in the community, a model that is, at present, working well.

Barriers to the provision of long term post-diagnostic support in the memory Hub

When the Hub was set up there was an aspiration to offer lifelong support for people, in a way that mirrored the Parkinson's disease service.

> *"We had support from [professor] who has just recently left the trust. Unfortunately, he was really like the steering sort of person who took that forward, he had a vision, he really wanted a lifelong model for everyone. And we did try that within the first couple of years. But we're just very quickly created a bottleneck where referrals were flying in and we had nowhere to move people to. So really, it took a probably a year of fighting with consultants really to say, look, you know, we're gonna have to stop referrals if you don't let us transfer back to primary care. They wanted some sort of the service on par with the Parkinson's service you know like a lifelong model and I can totally get that and I like to think what I would feel like if I was a service user or a relative of course I would like to be under the umbrella of a memory service but we just couldn't do that." (Service Manager)*

As a compromise the service now offers extended post-diagnostic support (in comparison to many other service models), and only transfers back to primary care when patients are stable.

> *"So we compromised and we only we only transfer back to primary care if things are stable. So if things, if families feel well supported, things are in place, there's no gaps at that point we would but wouldn't transfer someone if we envisage sort of issues straight away" (Service Manager)*

What do you think the benefits are of what your service is offering?

Benefits identified are across a number of areas:

- Person centred extended post-diagnostic support

  "Oh definitely ongoing as well. I mean, it's not just, you know, obviously clearly it's not just a place you go and you know you like you go and see the consultant and you may not see them again. But with this, or for a while. But with this like very, very much you know sort of an ongoing appointment, telephone calls. Even with the medication, they're not just gonna say oh, you get it from the doctor, they do it all there. Your medication has to be, you know, each time we go Dad will get the next lot of medication and it provided everything's fine and everything is to, you know, it's is going well and then they monitor everything and they just seem as if they take it off your hands. They take charge of it all you know. So that's nice. That's nice. Just to know that there there's someone there. Who's giving that service and who's. And they're very friendly, very, very friendly, lovely, lovely people." (Relative of patient)

- Streamlined cohesive service for people with Parkinson's dementia and Lewy Body dementia

  "I think it's responsiveness. You know having a quick answer to the questions when they arise because of the person who's just seen the individual with the LBD or PD, you know they have identified a problem and instead of you know a referral going through it's a quick email to someone and you get a response sometimes the same day and things are resolved very quickly for that person. And also then that has a knock on in terms of kind of the efficiency of our service and you know increasing availability of appointments for other things if we have to deal with things without necessarily always needing a another person to see someone because inevitably there's a repetition of a lot of the assessments that have already been done by the other team. so where we can have that input, I think it's about kind of speed of response and efficiency for the services." (Consultant Psychiatrist)

Site 5 - A psychology orientated assessment and diagnostic service with personalised pathways

Summary

This service, which came into operation in 2010, has been commissioned to deliver assessment and diagnosis of suspected dementia. The memory assessment service is a lifespan service to which people are referred from primary or secondary care. After referral patients are screened and allocated to a pathway depending on their presentation to make sure that the assessment process meets their specific needs. The service consists of healthcare professionals, including senior practitioners (Registered Mental Health Nurses or Occupational Therapists by background) and Clinical Psychologists. They carry out detailed assessments with the Service Users and the families. Additional specialist assessment such as Occupational Therapy or neuropsychological assessment may be required. The assessments are discussed with the medic and outcome, or diagnosis reached. The diagnosis is generally fed back to the service user by the member of the team that did the assessment. The service is not commissioned to offer post-diagnostic support but does refer on to other services for cognitive stimulation therapy, pharmacological treatments and intervention and support. Patients are discharged from the service with a detailed care plan.

What led up to you developing the service in this way?

The service has been operating across a large geographical predominantly urban region since 2010 and has an annual referral rate of around 2800 patients.

The service model prior to this comprised a memory service (in the region) operating out of five different Community Mental Health Teams (CMHTs), each doing slightly different things. This raised some issues with the service provision:

> *"So there are there are five CMHTs throughout [site 10], all of which at the time were doing obviously a mix you know. Predominantly urgent CMHT you know CMHT work. So yeah, people with men- older people with memory, with mental health difficulties that needed urgent responses and then they were trying to fit in their memory assessments at the same time. And obviously every time you know, something urgent came in the non the non-urgent memory assessment got bumped down the line. There was also no consistency so I think. The quality, the accuracy of the diagnostic work was variable." (Staff member 01)*

This inconsistency, in combination with low diagnostic rates highlighted at a national level in 2009, informed the need to commission the service differently. The structure has developed over time, but the key ethos was to develop a standalone assessment service with a centralised operational structure and clinical governance. The main object is to provide detailed assessment without issues with care coordination or prioritising urgent care, enabling a consistency of approach.

> *"it's driven up quality accuracy and we've always been very much from the outset about putting the person at the heart of." (Staff member 01)*

Since the centralisation of the standalone MAS it has developed as a service. At the outset it was a service for people over 65 but has since taken responsibility for assessments for younger people too. This has helped address the longer wait that younger people with memory problems were typically experiencing.

A further unique feature of the service is the assessment and delivering the diagnosis are typically carried out by non-medic staff; the psychologists and senior practitioners. The service was specifically commissioned to operate in this way.

> *"Only a very small proportion of people see a medic. You know, lots of services where you have memory, kind of clinicians that will go and collect all the assessment information and then take it to the to the psychiatrist who then delivers the, who goes over and delivers the diagnosis. Having just met the person where you know. And that's probably again one of the reasons around that was one of the commissioning changes because I think the trust was scared, they will become bankrupt if everybody saw a medic because of the sheer volume of people coming through." (Staff member 01)*

What does the service offer?

The service offers specialist memory assessment and diagnosis. Once referred into the service patients are seen by senior practitioners that are either mental health nurses or occupational therapists by background who do the assessment and see people throughout the assessment process. Once screened patients are triaged into the appropriate assessment pathway, after which the same person that conducted the assessment will see then for the diagnosis.

> *"The person that saw them to do the assessment would then see them to … deliver the diagnosis back to them to ensure continuity. 'cause you don't want a stranger that you've never met turning up and delivering a life changing diagnosis to you…*
> *We do we revisit at the beginning of the feedback session what they want to know, have they changed their minds, that they still want to be told the diagnosis or the outcome of the assessment? Do they still want their loved one to know? And obviously some people change their mind one way or the other. "(Staff member 01)*

Triage and specific assessment pathway

The service offers different pathways that are based upon patient needs and presentation at screening.

> *"Clients we would sort of divide people up into different pathways depending on how they present. So from the most not for the most straightforward, the most kind of obvious. You know people that look like they've gotten established cognitive impairment or established dementia, but nobody has formally diagnosed them through to people that you may have comorbid major mental health difficulties may be considerably younger and may still be working. So we've we developed a number of different pathways." (Staff member 01)*

There are broadly four different pathways

1. a pathway for non complex pathway for people presenting with established cognitive impairment or established dementia
2. a mainstream pathway typically for older people "in their 60s, seventies, possibly in their 80s that had memory problems for a while, but it it's not it's a fairly early stage and it may or may not be a dementia"
3. a psychology pathway for complex presentations
4. a formulation pathway, "for people where they're highly unlikely to have a neurodegenerative condition but are complaining of a memory problem" where difficulties may be related to low level mental health problems

The idea of the pathways is making sure that people are not over or under assessed whilst ensuring that diagnostic accuracy is maintained.

> *"So it's making sure that we're giving the right type of assessment to the to the right, to the right clients so that the with the exception of the formulation pathway, the other pathways people get the same. Assessment process. But how much of which bits they get will depend on how much they need."*
> *(Staff member 01)*

Pre-diagnostic counselling

Everyone entering the service will be offered pre-assessment counselling. The goal of this is to ensure that, at a basic level, everybody understands why they have been referred to the service. The pre assessment counselling includes an overview of what the potential outcomes of the assessment might be:

> *"So what you know, different causes of memory difficulties or cognitive difficulties, but also to make sure that people are prepared that one of the outcomes might be a diagnosis of dementia. So we're up front from the outset." (Staff member 01)*

The counselling will also cover the potential implications of getting a diagnosis of dementia, for example the requirement to notify the DVLA if people are driving, as well as the benefits of knowing a diagnosis such as treatment options. At this point the clinician will ask the person if they would want to know about a diagnosis if they have one. At this point the client also has the opportunity to decline to have an assessment.

The process of pre assessment counselling in this service is not a defined period or appointment time.

> *"Now that can take 10 minutes, it can take an hour or couple of hours. It might be that people need to go away and think about it. It's basically what the client. Yeah. And the family wants and primarily the client. So if somebody wants an assessment, then what we would do… I think when we when we have the conversations, I think people then decide at that point in time whether they want to go forward. So we would give people the opportunity to think about it. But if they generally speaking, I think.. At that point, people may feel that they're not ready and can opt out, and*

> *we would tend to discharge them. We we are able to. So if if within six months they change their mind, they can come directly back to the service. That's the trust standard...I think having people opting out at the point of pre assessment counselling shows that it's working that actually you're not forcing somebody into something that they're not ready for." (Staff member 01)*

Enhanced diagnostic accuracy with neuropsychological input

The service is a psychology orientated service with the opportunity for detailed neuropsychological assessment in some pathways. For all pathways the assessment involves a detailed clinical history from the client and or informant according to a very clear and diagnostically driven clinical assessment form. The form is deigned to facilitate an accurate etiological diagnosis

> *"So there are specific questions looking at Alzheimer's disease, Vascular dementia, Lewy body dementia, FTD, frontal temporal dementia. So you've kind of you're picking. So if you were to follow the form accurately, it should hopefully mean that you've collected sufficient information to be clear about changes in cognitive domains. So memory language, Visuospatial changes, personality changes, executive functioning changes, et cetera, et cetera.*
> *But to also rule out other things like mental health issues, physical health problems, and so on. And then there are specific questions targeting Lewy body dementia and behavioural variant FTD. So making sure that we collect an accurate amount of information. And it's done like a conversation. In terms of, you know that this is a semi structured interview." (Staff member 01)*

In most pathways, if possible, this would be followed by cognitive testing, such as the Addenbrookes Cognitive Examination III, neuroimaging, and potentially questionnaires regarding activities of daily living for the family.
For the majority of people, that would be the assessment completed. However, for other people a more detailed neuropsychological assessment may be required. Because the service is psychology orientated there are no additional waiting times for this- some people require a neuro psych assessment, and some people require a psychological assessment – both of which can be offered quicky in the service

> *"What impacts is somebody's anxiety or trauma or depression having on their functioning? And it may be that they need more detailed functional assessment. So we have OTs within the service that can do an OT assessment or or formal AMPS assessments [assessment of motor and process skills]." (Staff member 01)*

For very few people in the service even after this a diagnosis may not be possible.

> *"If at that point then you know that it's the information is not sufficient to make a diagnosis it may be that the person sees one of them, one of the medics in clinic, but currently speaking I would say that only about 5% if that of of our clients that we see a medic in clinic." (Staff member 01)*

Post-diagnostic support

The service is not commissioned to offer post-diagnostic support although they can access cognitive stimulation Therapy and are also able to refer directly into ancillary support

> *"everyone gets offered a dementia advisor if they want one. So we make referrals for that. Currently we are running a virtual cognitive stimulation therapy group. Uhm, pre COVID there was a you know, face to face groups and a number of different ones, but obviously they've been paused and so the only one we're able to offer at the moment is Cognitive Stimulationnd that's virtually" (Staff member 01)*

The service refers on for initiation of treatment where appreciate and can refer directly for *"social services support if the person needs a care package and then admiral nurse support for family carers"*

Everybody is offered the opportunity to participate in research or to be to be on the research database.

Having been through the service all of the information is compiled in a support plan that is sent to the individual and their GP *"depending on what's been agreed they're either kept within the mental health trust. So for continuation of prescribing or if there were other care needs or they're discharged back to the GP at that point".*

What are the challenges of this model and how have you overcome these?

One of the key features of the model is that the assessment and diagnosis in the service is primarily conducted by non-medic trained staff. This has required a bespoke model of training to enable this approach to work and be sustainable

> *"I'm there as a psychologist. I'm very proud of what we've undertaken specific additional training in house with one of our psychiatrists to become independent diagnosers of dementia. So there's three of us that are kind of can make independent diagnosis of dementia, so it's not everyone has to be to go through a medic 'cause I think that's doing it helps with. Sort of the speed and the throughput of seeing people. So I can see somebody and diagnose them rather than needing to run it by. Uhm yeah a medic. It helps to support the team. So I think that's the one of the things I think that's been a really good development." (Staff member 01)*

There is also a competency framework that is associated with the training to "to ensure that staff are competent before they are let loose on clients". To ensure the validity of this approach the service has engaged with a number of audits on accuracy of assessments.

The audits have also examined the accuracy of assessments when they are conducted in different modalities. This has been prompted by the COVID pandemic which, for this service, promoted a number of assessments to be conducted by telephone.

> *"Once we started the telephone assessment, we did an audit to look at the accuracy of diagnosis and compared it with face to face diagnosis and the accuracy came out pretty much like the same. So irrespective of what modality of assessment you get, you come out with a an accurate diagnosis. We audited it in terms of patient satisfaction in, people were surprised. At how thorough it was. Some people even preferred sort of telephone and video assessments because they could be done in the comfort of their home own home. Uh, so we're keeping a blended approach." (Staff member 01)*

What do you think the benefits are of what your service is offering?

Benefits identified are across a number of areas:

- Non-medical staff trained to deliver a diagnosis

  "Nurses and OTs, psychologists are perfectly capable of sensitively delivering a diagnosis and perhaps tending to, you know, deliver it in a more straightforward way than some sometimes other colleagues might do." (Staff member 01)

- Specific pathways designed to meet client's assessment needs
- In house training and organisational development

  "Between us we developed the idiot proof clinical assessment form. So you know. And so it was a lot of supervision and case presentations around that I suppose upskilling us in terms of, you know not, I mean we can, yeah, as psychologist cognitive domains and you know and how the bits of that part of the brain yeah, those things work. But just to think more about differential diagnosis. What to be. You know where you could come unstuck because you missed something. And we've got very clear kind of diagnostic guidelines we've developed and on the basis of the kind of the formal ones... How to make how clear to make an etiological diagnosis, which we've obviously what we've shared with the team and it started to permeate across the Community mental health teams, which still do memory assessments because of the risk. So we're trying to upskill and improve the quality across the whole of the organization as well." (Staff member 01)

- Providing diagnosis for working-age people

  "so when we first started, it was a service for people over the age of 65 and within a couple of years. So we had a separate working age dementia service in [site 10]. So we took over the. So the memory assessment service took over the assessments for younger people. So again that had the same centralized kind of structure."

Site 6 – Rapid referral triage, specialist diagnostic pathways, and in-house health testing with CST

Summary

The site provides telephone triage for anyone referred into the service within 24-hours. This operates 7-days a week. The information gathered at triage alongside the referral is used to determine whether a person is assessed via the Tier 1 routine pathway, or Tier 2 pathway for more complex cases. Tier Two includes neuropsychological assessment and MDT review. This helps ensure people are assessed appropriately and can receive a timely diagnosis as well as appropriate peri-diagnostic support. To reduce the waiting times for diagnosis and being able to commence dementia medications the service is able to conduct blood tests and ECGs in-house for patients who do not have these in place. These are carried out by trained nurses and support workers from the service.

Post-diagnostically the service has embraced technology to delivery Cognitive Stimulation Therapy (CST) prompted by work during the pandemic. This includes use of technology in face-to-face group sessions, continued delivery of virtual group CST and a developing interactive life-story project. The service has developed a specialist Mild Cognitive Impairment (MCI) pathway which includes six group sessions and a workbook, with the aim of improving the experience of those diagnosed with MCI and increasing attendance at recall assessments. The programme focusses on a healthy lifestyle and signposts to local exercise classes and voluntary organisations who can provide advice and support. To improve access to post-diagnostic support for those living in care homes and improve dementia diagnosis recording the service has a project to match care home records of residents with dementia compared to Quality Outcomes Framework (QOF) recorded diagnoses. QOF registers will be updated where appropriate and streamlined formal diagnosis offered to care home residents with suspected dementia but without a current diagnosis.

This memory assessment service is part of a wider NHS service that offers both mental health and community services. The team offers an assessment, diagnosis and treatment pathway for people of any age with dementia as well as those over the age of 75 who have functional mental health presentations.

What led to you developing the service in this way?

The service provides both a routine and more specialised assessment pathway dependant on the needs of the person accessing the service. The development of a more in-depth pathway was initially driven by work of one of the consultants who wanted to include in-depth, specialist neurological assessment within the service's offer. The service was also getting increasing referrals for younger people (aged under 65) who needed more specialist review. Therefore, the service evolved to provide these services.

What does the service offer and what are the benefits and challenges?

A single point of access and two-tier assessment pathway

The service offers memory assessment services. The pathway involves referral to the service via their GP via a single point of access and then an initial telephone triage call is made to the person and/or their carer/supporter within 24-hours by a nurse. The call is used to collect any further information not included in the GP referral covering current presentation, physical health and activities of daily living. This triage is available 7-days a week as referrals dealt with by the nurses cover both memory assessment and functional mental health problems.

> *"If we find that we identify risks within that conversation, where people need support within 24 hours, or even a couple of hours, depending on what it is, we are able to do that. And I think that's really important." (Nurse)*

This initial triage assessment reassures the family that their referral has been sent and is being processed and gives them an opportunity to discuss how they are feeling and coping and for the specialist nurses to provide pre-diagnostic support. They can also signpost to other services such as social care or pass the referral onto a more appropriate service (such as social care) where the referral is inappropriate or it is not related to seeking a dementia diagnosis.

> *"So for example, they're saying they're having a problem with continence or ... at night they're not finding the toilet we'll say "Oh well, have you left a light on in the corridor? You know, that sort of thing. "Have they put signs up?" It's those things that would make a real change to them just for the interim" (Nurse)*

Further benefits include the person being referred to the service and their supporters having the contact details for the service, so they do not need to go back through their GP if they have any queries about the referral. Triage assessment also means the service can ask who will attend the MAS appointment with the person and if there are days/times to avoid for appointments and who copies of the appointment letter should be sent to. This can help to reduce non-attendance.

Based on the assessed complexity or specialised nature of the diagnosis that will be required people either pass through the Tier 1 routine pathway (approx. 70% of patients) or Tier 2, which is for more specialised assessments such as potentially rarer types of dementia, and those under age 65. Anyone who receives a diagnosis of mild cognitive impairment (MCI) or subjective cognitive impairment (SCI) and who require ongoing annual review are also reviewed under the Tier 2 pathway. Every referral and triage assessment is reviewed at a Multi-disciplinary Team (MDT) meeting who decides on which pathway a person will pass through. Every referral will go to an MDT meeting within a week of receipt.

The Tier 1 pathway involves initial assessment with a Junior doctor, the information gained from the assessments is then discussed with a consultant in supervision. The consultant then sees the patient for a disclosure appointment and puts together a care plan for post-diagnostic care including assessing eligibility for medication and cognitive stimulation therapy (CST). The service has a large number of junior doctors and so the service aims to offer an average six-week referral to diagnosis period, although this can be delayed by getting timely scans.

> *"We attract junior doctors that want to come and have placements with us, it's actually very good training for the junior doctors to do that... those really robust mental health and dementia assessments. So they get something out of it, which is why we attract such a lot of junior doctors" (Service manager)*

In Tier 2, patients receive more comprehensive tests including a neuropsychological battery of tests, conducted by a psychologist. During this time the consultant will gain a background history from the carer/supporter attending with the person. The case is then discussed in the Tier 2 multi-disciplinary team meetings and a diagnosis determined. Following a disclosure consultation those with a dementia diagnosis go onto the usual dementia pathway for post-diagnostic support. Those with MCI or SCI are placed on a register for regular review.

One challenge of this model can be resource. The service receives up to 60 referrals a week and triage phone calls can take between 20 minutes to an hour for more complex cases or where someone needs support. Approximately 80% of the referrals that come in are for memory assessments. There are three nurses and one full time and one part-time administrator working on the triage team. Usually this is manageable but can become challenging if a high volume of referrals come in at the same time. In such cases the team prioritise who to contact based on the information in the referral. They may also not complete write up of triage assessments immediately and will hand-over verbally in the MDT meeting if necessary.

Specialist MCI pathway

Previously those who were given an MCI diagnosis just received an annual review and a booklet about MCI. Using funding provided by the Clinical Commissioning Group (CCG) the service have developed a specific MCI post-diagnostic pathway that includes six group sessions that cover biopsychosocial advice to support the person to lead a healthy lifestyle and a workbook which provides advice and information related to the session content. People can receive the workbook even if they don't want to attend the group sessions.

> *"[The workbook includes] links to local resources that they can tap into so local exercise classes, ...different voluntary organisations etc. People have found that useful, and ... reiterates healthy living, health promotion, exercise, and ... we ... if someone wanted to give up smoking we can sign post them to smoking cessation or alcohol reduction teams. So we feel like we're giving them something useful" (Service manager)*

The team have also been able to create a specific MCI register to ensure recall happens in a timely manner. This includes a six-monthly triage for those who are at high risk of conversion to dementia. If there has been a change the patient will come back in for assessment sooner.

The aim is that those on the MCI pathway will benefit from receiving some targeted support following their diagnosis and this will encourage them to attend for regular reassessment and those progressing onto dementia will be identified in a timely manner, to ensure earlier diagnosis.

> *"Historically people didn't want to come back and then ... they were missing out on that opportunity to have that diagnosis made. And then by the time they were coming back, they were ... more impaired.." (Service manager)*

The service hope this new MCI pathway will improve patient experience and engagement, prevent conversion by optimising the person's biopsychosocial wellbeing and where a patient is deteriorating pick these cases up sooner.

Providing medical tests and checks in house

Once a person receives a dementia diagnosis their suitability for dementia medication is assessed and this includes having an ECG. Being able to access ECGs was extremely difficult during the pandemic as these are usually conducted at the GP practice. The service addressed this by purchasing static ECG machines for each of the bases they work from and are purchasing three portable machines so these examinations can also be conducted in people's own homes. The nurses and support workers are all trained to carry out ECGs and so if a patient has not had one completed by the time of their disclosure appointment this saves time as it can be carried out immediately on-site and a decision about medication prescription made there and then.

> *"The thing is then we're chasing up the ECG result, whereas actually we've physically got it, ... and you're not waiting for the GP then to be passing information back. And equally we use System-One, which is [also used by] the GPs .... So we can upload it, and then it's there for everybody .... Then the only delay would be if we needed a cardiology opinion, for somebody who's identified on the ECG as having ... [a cardiac] abnormality" (Service manager)*

Nurses and support workers are also trained in phlebotomy (taking blood) so they can carry out any necessary blood tests that are missing at the point of referral rather than have to refer back to the GP. It also means referral onto other teams isn't always necessary for health-related concerns. For example, if a member of the memory assessment team is conducting a home visit and feels the person might have an infection, they are able to take bloods there and then rather than refer onto the district nurse.

> *"Everyone will have a kit in the back of their car and .. they can just take those bloods. They'll be self sufficient, they'll have urine testing kits in their cars. ...Blood pressure machines, ..Thermometers. Oximeters. They can go out and do a physical [examination] on that patient and it saves another professional having to go out or, having to wait for another professional to go out." (Service manager)*

The ability to conduct health-based checks within the team means people can receive their dementia diagnosis and receive a prescription for dementia medication, where appropriate, in a timely manner. It also means any concerns or crises can be dealt with immediately, without having to rely on other services.

> *"If you've got a patient who's in a crisis, even if it's a physical health crisis, actually, you've got a very small window of opportunity to intervene for that patient, waiting two days for someone [else] to go out and do some bloods, you could have missed that opportunity. Especially with our patients with dementia, who possibly get a urine infection, [can] become highly delirious, ... fall and end up in A and E, or we often see that they go off their food and their drink, they stop taking their medication. And of course if they're not taking their medication then how do you treat their urine infection?" (Service manager)*

Embracing technology as part of Cognitive Stimulation Therapy (CST) delivery

The service have been delivering CST groups for over ten years. They have developed this offering to include group and individual (carer led) (ICST) delivery, and this was adapted to virtual delivery via MS Teams during the COVID-19 pandemic when meeting in person was not possible. Where people did not have a carer who could support ICST and were not able to or did not wish to attend the virtual groups, ICST was offered by a staff member either in-person at a social distance and using PPE, or over the telephone. The service found that offering virtual groups was a preference for some people who might not otherwise have attended an in-person group and so are continuing to offer this alongside face-to-face delivery.

The course sessions draw a lot on video and interactive PowerPoint content for virtual delivery, some of which has been retained now face-to-face delivery has recommenced, as they find the content enhances delivery.

> *"Using sound clips, music clips, all of that has really helped, and why I'm saying all of this is because how we run our face to face groups now is probably more enhanced from what we've learned from using the technology. So we still use some of the PowerPoint bits. We still use the chair yoga, ...that's gone down really, really well. There's just so much there that we can use now that we've got [access to] the technology, we've all got laptops, we've got a projector. We've just invested in a television on wheels ." (Occupational Therapist)*

The service also had ambitions to expand their existing life story work, usually completed with people who had more complex needs, to include everyone that comes through their CST programme.

> *"Because they're the people at the right time that need to be thinking about things, ... putting things in place for later on and life stories are fabulous for that, capturing their memories while they can. What's important to them." (Occupational Therapist)*

Using the skills of a volunteer they have been able to offer some service users the opportunity to virtually develop an interactive life story book. This can be opened on a tablet or smartphone and contains embedded content such as videos and sound.

Participants also receive a paper copy. The service are growing their pool of volunteers who want to work on this project so they can expand who it is offered to.

Specialist training for support workers

The support workers visit people at home with the aim of building relationships with them and getting them to engage in support or meaningful activity. This can be part of monitoring the person's mental health, or to give carers a break. To help the support workers make the most of this time the service provided them with training on things that could help them use their time therapeutically and productively with the person. This included mindfulness, recognition of delirium, falls prevention, life history work etc.

> *"We got really, really good [feedback] from our support workers and they've really enjoyed it and they … appreciated the effort … because it was very much focused on them as support workers. It was something just for them and something outside mandatory training" (Service manager)*

The main challenges the service faced related to logistical issues such as organising sessions that all support workers could attend and identifying different outside speakers to run each session.

Ensuring care home residents have their dementia diagnosis recorded on the Quality Outcomes Framework (QOF) register

Since the pandemic the recorded dementia diagnosis rates have declined locally, in line with a similar picture nationally. The service feels that this may in part be related to people with dementia living in care homes not having their diagnosis formally recorded on the QOF register. This can be due to information not being transferred over if the person moves into the area to access a care home after being under the care of a different NHS Trust, or to care home residents not being able to access a formal diagnosis during the pandemic. They have received funding to support an assistant psychologist to check that residents living in specialist dementia residential, or nursing homes are identified on the QOF register as having dementia. They will then approach the care homes to identify residents with a formal dementia diagnosis to cross-reference against QOF registers or residents who care home staff feel may have dementia but where no formal diagnosis has been made. For those without a formal dementia diagnosis an appropriate diagnostic assessment can be conducted.

> *"…we would [complete] a more streamlined assessment because … [if] they've clearly got dementia and [are living] in a care home, …. we're not going to be [requiring imaging] as long as we've got a clear collateral history, … they're needing support in all activities of daily living, … they've clearly got a cognitive impairment, we would … formalise that diagnosis." (Service manager)*

This will ensure these residents can access appropriate post-diagnostic services and treatments that might benefit them, in addition to ensuring QOF records are up to date.

Site 7 - Providing culturally tailored assessment and diagnosis

Summary

This service is located in a city region with a high South Asian population. They noticed that members of this community were not being referred into the service at the same rate as white British people. When they did attend assessment members of the South Asian community reported feeling the process was not culturally sensitive and staff reported difficulties administering the Addenbrookes cognitive assessment tool due to issues with language and the euro-centric nature of some of the questions. The service have worked with local GPs to dispel myths about dementia and to highlight the potential benefits of referring for/seeking a diagnosis. They undertook a project to develop a culturally appropriate version of the Addenbrookes which included revised questions and translation into Urdu and Hindi. The service contracts out post-diagnostic support services and so commissions culturally specific services and is looking to expand this offer.

This service is commissioned to deliver assessment and diagnostic services. People are referred into the service by their GP. Assessment and diagnosis is conducted by the clinical team comprised of assistant psychologists, memory nurses and doctors. Once a person's diagnosis and, if appropriate, medication introduction is complete they are discharged to a dementia advisor provided by a national charity for a time limited period, after which they are discharged to GP. Dementia medication prescribing, and ongoing monitoring after discharge from the memory service is provided by the GP. There is an Admiral nursing service within one of the localities served by the memory assessment service, who can also provide post-diagnostic support for those with more complex needs.

What led to you developing the service in this way?

Originally the service was set up to deliver assessment and diagnosis consultations out of GP practices rather than people having to come into the specialist mental health settings owned by this service. We offered this out of 14 GP practices, and this resulted in good uptake and historical diagnosis rates at about 80%. Feedback was that the majority of people found the service local and accessible, but this was not the case for all members of the community, in particular the South Asian population. Members of this community were often not getting past GP referral.

> *"We did some work with the local University to capture people's experiences from the South Asian community of trying to, and of accessing memory services and ... the kind of feedback that we were getting is that often signs early signs of dementia were being dismissed as being generally part of the aging process. But also that there was nothing that could be done even if dementia was likely, and that, the service was perceived by GPs .. [as not] offering anything that was particularly culturally specific and that it wouldn't meet the needs of that population anyway. Which was uncomfortable for us to hear." (Service manager)*

When people from the South Asian community were entering the service the assessment process and in particular the cognitive assessments used were not felt to be appropriate or tailored to their culture or background.

> *"For those who came through the service, they talked about some of the assessment tools that we use, not being culturally specific enough. That we were asking questions that may not be either relevant or understood from a cultural perspective." (Service manager)*
>
> *"So whilst working with the South Asian population administering the Addenbrookes, I've found that I was excluding a lot of the items due to either was the language, educational background, the reading and writing abilities. And also we found with the females because they were mainly housewives within the South Asian culture, we ended up excluding most of it, to be honest with you. When in discussion with the consultants within the clinics, we found that [we were asking] whether it was valid to use it towards the diagnostics, because a lot of it was excluded." (Assistant Psychologist)*

What does the service offer/how did it develop its offer?

Working to dispel myths with GPs and the local community

The service staff went out to local GP practices to speak to staff, tell them about the service and what they could offer and to let them know memory assessment service staff were from diverse cultural backgrounds and had the language and cultural knowledge and skills to work with people from the South Asian community. They also talked about the benefits of timely diagnosis and the potential for treatment and post-diagnostic support.

> *"So that was the hearts and minds side of what we were attempting to do" (Service manager)*

Staff from the service also engaged in outreach work, for example attending primary care network meetings where they discussed cases with staff and provided guidance about appropriate referral. They also attended local well-being cafes and other groups specifically for the South Asian community so people could ask questions and understand what would happen if they did get referred to the service.

Developing a culturally relevant version of cognitive assessment tools

The service recruited an assistant psychologist researcher to help adapt and translate the Addenbrookes cognitive examination for use with the South Asian community, with permission from the copyright owners and in collaboration with a University. No culturally relevant version of that or any other cognitive assessments for the South Asian community existed. This process included working with the South Asian community and professionals to identify the problems with the current imagery, language and white-British political, historical references in it and make the questions more globally relevant. They also translated the assessment into Urdu and Hindi, which were the core languages the local community use.

> *"I'd experienced that challenge as a practitioner when I was delivering the original form of the Addenbrookes. Even interpreters were saying, well, that that's not a fair tool. You're not giving this this person a fair chance to, to demonstrate their cognitive abilities. That often resulted in fairly uncomfortable sessions where the interpreter was attempting to help out the individual who was being assessed and … trying to rephrase." (Service Manager)*

The cognitive assessments are also conducted in the person's native language either by a member of the memory assessment service team or via an interpreter. Staff have all received training on how to conduct and score the adapted version.

Signposting to culturally appropriate post-diagnostic services

Due to the large South Asian population in the locality of this service, there are available support services that are culturally appropriate to those from the South Asian community. The memory service contracts out its post-diagnostic support to local voluntary and charitable sector organisation and plans to widen this with a new tender in the next year or so, to include more culturally specific services.

> *"Community support agencies are often more culturally focused as well. So we've had the benefits of organizations like [name] who are very culturally focused and we can signpost people on to them as well, so that, that that makes a difference." (Service Manager)*

What are the challenges and how have you overcome them?

COVID-19 did disrupt the developing dialogue with GPs and the service are working to pick this activity up again. For example by recommencing attendance at primary care network meetings.

An additional challenge has been people questioning the validity of the adapted assessment. The service have addressed this by discussing the problems with the standard version of the tool and the advantages they have seen with the culturally adapted version.

> *"There have been often questions about the validity of the tools because we haven't put them to any form of validation process, we've simply. Made the amendments and we've evaluated the acceptability of those tools really in terms of whether it's been possible to complete the tools more than had previously been the case. And the evidence suggested that around 20 to 25% more of the tool was completed than had previously been the case with South Asian communities and that their scores were better as well. … and we've had new members of staff coming in. The first question often is well, is this validated? Are we allowed to use it? Is it OK? It's got to be more valid than the English version hasn't it?" (Service Manager)*

What do you think are the benefits are of what your service is offering?

The service is seeing more referrals from the South Asian community, and diagnosis rates are at about 50% of expected number, which while still behind those for the White British population represents an increase in about 30% from figures before this work. The experience people have when they do enter the service has also improved in terms of the cognitive assessment experience.

> *"I think they don't find as daunting, so they don't get anxious. So they kind of relaxed and at ease while doing it so and they're not distracted. So I would be like, we can't really relate to that. Let's skip that. So now they'll engage, they'll complete the whole assessment without feeling like gosh, we don't know that we should have known that or sometimes … tend to feel like they're stupid or not being able to answer… if they've had like an MCI and they want retesting in 12 months. They're more likely to then come back" (Assistant Psychologist)*

People using the service reported that the adapted cognitive testing is accessible to them.

> *"I liked the memory clinic, I found it easy to understand the language and you speaking slow which was good". (Person accessing service)*
>
> *"You being like me I found it good and comfortable, nice" (Person accessing service)*
>
> *"I felt very easy with you, was scared to come to clinic but now I feel really good". (Person accessing service)*
>
> *"I was worried about this and what will happen it was not bad at all". (Person accessing service)*
>
> *"The test was okay and I understand it because you speak like me". (Person accessing service)*
>
> *"If interpreter was here it would be more difficult". (Person accessing service)*

Supporters of people attending the service reported positive feelings about the service and relief that the assessment was being conducted in a culturally appropriate way.

> *"The best thing was you could speak Mirpuri". (Supporter)*
>
> *"I literally think it's made huge huge difference to the test she would have scored way less, she felt comfortable, she felt accepted and being herself". (Supporter)*
>
> *"A treasure an absolute asset having you, bilingual, I was able to leave her alone with you better accurate assessment able to communicate and know the culture" (Supporter)*
>
> *"The test was culturally understandable, and she could relate to it". (Supporter)*

MAS staff find that most people are able to complete the full cognitive assessment process.

> *"We find the only things that we will exclude would be, and that is probably a handful of people, the writing task or the reading task, because they've not been formally educated. It is mainly amongst the South Asian women who have had no formal education, they've not been to school, they have not learned how to read or write. But the other items they can actually relate to. And we don't exclude them like language comprehension, language naming. So they manage them as well as the fluency task, just to name a few." (Assistant Psychologist)*

Reading and writing-based tasks were reported to be a remaining challenge by some people attending the service and their supporters.

> *"The test was bit hard as I can't write". (Person accessing service)*
>
> *"Some things need changing like historical facts, anything to do with reading and writing an uneducated person would not know". (Supporter)*
>
> *"The test would need some adaptions for people who have not gone to school, like writing and reading". (Supporter)*

Peoples scores on the cognitive assessments are different than using the non-culturally adapted versions which makes diagnosis more accurate.

> *"Given that we've always had a phenomenon of people from South Asian communities generally turning up further down the cognitive decline pathway. And so doing so and then being more hampered by the tools as well may have. Resulted in not necessarily wrong diagnoses, but, maybe over-estimating the level of cognitive decline that people were experiencing at that time." (Service Manager)*

Site 8 - An approach to reducing assessment and diagnosis waiting lists with integration with primary care

Summary

This service had a large waiting list of people referred and awaiting assessment and diagnosis following ceasing of diagnostic services during the initial months of the COVID-19 pandemic. They adopted a time-limited, consultant-led solution including triage of referrals followed by telephone triage, allowing prioritisation of need. Remote assessment was not feasible for the majority of referred patients due to lack of access to the internet and technology, and to personal preference. Initially assessments were conducted by home visit, later moved to clinic-based appointments to increase the numbers that could be seen in a day. Assessment and diagnosis was completed in a single consultation by a consultant, with post-diagnostic support provided by a nurse. To reduce scanning burden on acute hospitals, GPs were asked not to refer for a scan on referral to MAS and a decision about need for a scan was made by the consultant at the assessment. This was a resource-intensive approach which was successful in reducing the waiting list, but which could not be sustained longer-term.

What led to you developing the service in this way?

Due to COVID-19, there was a large waiting list of people waiting for a memory assessment. The Memory Assessment Service (MAS) had stopped running altogether following COVID-19 for a number of months. All GP referrals were rejected for routine MAS from March 2020 onwards until September 2020. At this point, there were already around 160 people who had been referred and were waiting for assessment and the service knew there would be an influx of further referrals due to the period of closure.

> *"And bearing in mind that, memory assessment service was only one part of my job. I am not running that service five days a week, and similarly, the other consultant had ... different jobs and one of the jobs was memory assessment service. Essentially two consultants had to manage to see those people, and of course we have a team .... but it felt like a huge challenge." (Consultant)*

Prior to COVID-19 the memory assessment pathway was followed which dictated patients referred to the service, should be seen for an initial assessment within 8 weeks and within 12 weeks should have received a diagnosis. Referral to post-diagnostic support should occur within 2-weeks of diagnosis. GPs request scans and blood tests at the point of referral so these should hopefully be available to the memory assessment service in a timely manner.

There would usually be three clinical contacts with the patient: assessment usually by a nurse; diagnosis by a doctor; and a post-diagnostic appointment by a nurse again. The patient is then discharged from the diagnostic pathway, although may remain under the wider care of the service if they have additional needs e.g. the community mental health team. These benchmark timescales were the key performance indices (KPI) and were already a challenge for the service, and were often not met prior to COVID-19.

What did the service do?

Prioritisation based on need

A decision was made that anyone aged 70+ was considered vulnerable and should not be asked to come into a clinical setting to avoid face-to-face contact. They, therefore, were offered virtual assessments. This was particularly challenging in the context of the socially deprived local area where some people did not have a phone, many did not have internet access or IT equipment to carry out virtual consultations, or did not want to have an assessment and consultations carried out virtually.

> *"If you phone them up and give them the option, would you like to have face to face appointment or would you like to do it over a Zoom call or over Attend Anywhere [video-calling platforms], patients would say no [they preferred] face-to-face [assessments]. People were fed up ... and were desperate for a face-to-face contact, even if that meant [being seen] by a doctor or a nurse." (Consultant)*

Prioritisation for who should be seen was based upon need. The two consultants triaged everyone who had a referral using the local integrated care record (electronic care record where GP and NHS records can be seen by staff in both organisations), which allowed them to see if anyone was in the hospital or had passed away, and avoided having to contact individual GPs for information or re-referrals. Those who were identified as requiring a prioritised assessment were then triaged by telephone. When concerns were identified they were seen at home as soon as possible, because the clinical spaces remained closed. So, referrals were prioritised on a needs-led basis.

> *"We decided to start doing home visits between nurses, doctors, and all of us. We [identified] which could be seen by the nurses, which could be seen by the doctors. All of that, from September to December [2020], was a very [time-consuming] process because the maximum I could see in one day was 4. So even if I try my very best with the travel time, with the [time for] the whole assessment, I couldn't see more than four people in a day. You know, I could push to 5, but then that would mean maybe I'm not doing a good job. I'm not being as thorough as I would like to be." (Consultant)*

Reducing the number of clinical contacts and conducting appointments in clinical spaces

In January 2021, the service decided that the best way to reduce waiting lists and times for patients was to reduce the three clinical contacts to two, with doctors conducting the assessment and diagnosis in one consultation and then referring to nurses for post-diagnostic support. The service also made a strong case for being able to use clinic space for consultations to reduce travel time and be able to see more patients. A huge team effort was then made to reduce the waiting list.

> *"I think we all did; were doing [at least] two clinics a week, and other doctors, trainee doctors, and specialty doctors. You know, a lot of people were invested in getting rid of this waiting list which was compromising patient care and we got through all of them I think by the end of March, April something like that." (Consultant)*

Timing and number of scans

While the availability of scans for those referred prior to the pandemic was not a problem, getting timely scans for those referred after services had re-opened became a challenge. Acute hospitals were under intense pressure and had long waiting lists. To help ease the pressures the memory assessment service asked GPs not to request a scan straight away and that they would decide whether a scan was needed at the time of a person's assessment.

> *"And I think they were telling us that we were able to push back about 100 roughly or maybe [a greater] number of scans because of that, because if someone had a fall, for example, went in [city] Teaching hospital. They get a scan there, … which then means … that we don't need another scan. Whereas [the GP practice often doesn't] have time to check when the last scan was and … whether they …need [another] scan and also sometimes don't feel confident to make that decision, which can be made in the memory services." (Consultant)*

What are the challenges and how have you overcome them?

In addition to the challenges identified above and how these were addressed, reducing the diagnostic waiting list then created another, overwhelming waiting list for post-diagnostic support.

> *"Which meant that we had a huge waiting list for the post-diagnostic s [and] only a couple of memory nurses. [We] created a lot of work for [them]." (Consultant)*

While this approach did help to reduce the waiting lists quickly and was liked by the clinicians and patients, it was not a sustainable model to retain, and the service has now transitioned back to its usual pathway.

> *"Although this was a good way to get through [the waiting list] and see the patients who had been waiting, .. it wasn't cost effective. It was a very expensive use of resource. We had to get an extra doctor in with us, to help us out. We had to [employ additional] admin staff because there were a lot of paperwork, GP letters, … the general administrative stuff, …. chasing CT scans, booking appointments, and making sure that the people who didn't turn up … [were] plan[ned] for. So I think it's just not what the doctors did, it was everybody else who got invested in that." (Consultant)*

It was also very challenging to keep this model staffed because many of the staff were having to isolate for 10 days due to being in contact with people with COVID-19 as they were unable to see people face-to-face.

What do you think the benefits were of what your service offered?

The service did not feel that patients who experienced the two rather than three clinical contacts knew that this was different from what would usually be offered and neither did it affect their overall experience. Many were able to receive a diagnosis on the day of their assessment and about 56% of those attending an assessment, received their diagnosis within 12 weeks of re-opening the referrals.

> *"Overall patient perspective['s], it was positive. They didn't have to wait through, [a process of] seeing the doctor and [then] having another appointment [about] whether they've got dementia or not. I think it really helped them" (Consultant)*

The service has continued this approach of deciding if a patient requires a scan. This saves some resources but also avoids people having to attend another unnecessary scan.

Site 9 - Research Active Memory Assessment Service with a One Stop Shop and Innovative Brain Health Assessment and Support

Summary

The Memory Assessment Service sits within a Community Mental Health Team in an urban area in the North West. Referrals are made by primary care and include detailed physical health overview with dementia screening. The service adheres to a 12-week pathway and from referral most patients are seen within six weeks. Patients are typically seen by a nurse and then taken to a weekly MDT meeting. When additional information is required, the service also operates a One Stop Shop pathway – the purpose of which is to enable patients to have any further investigations such as scans in a dedicated clinic on one day. The service is also research active and has recently implemented a novel Brain Health Clinic and a 12 month post-diagnostic service.

What led up to you developing the service in this way?

One Stop Shop service

The One Stop Shop element of the service has been running for around 10 years, in various formats, with the idea of having a dedicated and streamlined approach to assessment.

> *"It's been around for about 10 years, probably. And we started doing it and it's had slightly different forms over the years, but yeah … it was getting the slots, the CT scan slots, that was the big win at the local hospital and getting their buy in. And then allowing them to be able to report on those scans with dementia in mind rather than there's, you know, reporting on the scan saying, well, there's no stroke which doesn't give us the detail. Yeah. And so that's been that. That was brilliant. And yeah, that was about 10 years ago." (Staff member 2)*

This element of the MAS has inevitably been affected by COVID during the time that it has been operational.

> *"in the in the one stop shop pre COVID there used to be a little bit more of a sort of a things happening on one day that's been affected by COVID, so we used to have the slot on Friday at for CT scan and we would use the X Ray Department or the ECG department at the same hospital so and also have a basic health screen by one of the junior doctors. So the client could have all of those investigations on one day and. Unfortunately, COVID put pay to that, but at the same time, our assistant practitioners also became skilled in providing ECG, which they can do in somebody's own home." (Staff member 2)*

Being a research active service

The service has become more research active through increasing engagement with research activity in the trust and has consultants operative within the service who are engaged with and leading on research projects. This has led to a change and a readiness for the service becoming research active.

> *"I think that's starting to filter through actually that you know we need to be research active,. And I and I contrast that in the talks to research passive … Research active is actually you talk to people about it. And you're not just saying, you know, sometimes we have people who would like to do research. It's we're a research active organization. Everybody who passes through our doors will be offered the chance to participate in research. That might be a questionnaire or it might be a randomized controlled trial. Is it OK if one of our research nurses gives you a ring in the next 10 days about this? That's a very different conversation too." Consultant Psychiatrist*

Staff are invested in the research process are equipped to understand and engage with projects:

> *"So we're probably we're at the stage now where when I talk to them about research, they don't run a mile. They're very interested in what the outcomes are. They're very interested in how it will benefit their patients" Consultant Psychiatrist*

Staff members report a consequent positive attitude and confidence in discussing research with clients to engagement with

> *"Yeah. Yeah, it's something that I've always found quite. I suppose working in the field that I do quite sort of a normal thing and it's just being able to explain it to people in a jargon free way and just explaining…I can discuss research with people that we see" (Staff member 2)*

What does the service offer?

Access to research

The memory assessment service is known to be research ready, and facilities research opportunities for clients coming into the services (as well as staff). Some of the staff are research active themselves and report presenting opportunities for clients to engage in research throughout their journey. The service also has good connections with the clinical research team in the trust, who play an active role in the multidisciplinary team meetings.

> *"at every point of contact really with the clients, they will be asked about research. So I sometimes broach it on initial assessment if it's. Appropriate to do so. And sometimes it's not, but sometimes it might just be. You know, something that I bring up. And at point of discussion within our MDT, we have a think about whether somebody might be suitable for a research project, so that can be then followed up. We also have one of the research team who accesses the minutes and sometimes joins us in those meetings to pick up people that are discussed .. And then the dementia support advisors again will offer more information and discuss again at their input. And so there's a number of ways where people can be encouraged or have discussions about research." (Staff member 2)*

The service also has research active nurses and consultants within the team, engendering a positive attitude toward research participation and opportunities

> *"There's also [consultant]] and his different [research] strand into the team and there's opportunities for us to engage in research. I'm currently involved in a research project to develop a cognitive assessment tool for people who are from Somalian heritage because we found that the cognitive assessment tools that we have available to us don't aren't appropriate. … We've developed, devised it a tool and we're in the process of trailing that at the moment. And so there are opportunities for us to actually get involved ourselves, which is nice. And yeah, we just got very close links with the research team" (staff member 2)*

That being said the staff are also mindful that research isn't for everyone

> *"It depends, and again, I wouldn't necessarily mention it at first appointment. Always. It would just depend on the on the person. And sometimes people bring it up and themselves and will say ohh you know, I know my memory's not very good. I'd be really interested to know if there are any you know is there any research, you know what research is going on at the moment and I've had a few of those recently actually. And that's not always the case. And sometimes people. Panic and think it's about drugs. Ohh. You're not gonna give me a? You're not gonna give me a tablet are you? That's that's what people's perception of research is. Oh, it's drugs. And it's about demystifying that a little bit and just sort of explaining all of those lots of different forms of research" (staff member 1)*

Innovative Brain Health Clinic

One of the consultants in the service has been pioneering a new clinic for people with a subjective cognitive impairment that is unlikely to meet the threshold for dementia. This clinic is fulfilling a known gap in memory service provision for people with functional cognitive impairment or mild cognitive impairment. The clinic intercepts at the point of referral from primary care to the memory assessment service.

At present the consultant running the clinic reviews the referrals and redirects those that are likely to present as MCI or functional impairment to the brain health clinic.

> *"It's not a perfect system, people … who are MCI, stage, still get through to the other consultants and people who have dementia stage illnesses are still getting through to me, but it's working mostly and at this stage I'm taking.. over the last three months taking about 20% of the referrals which I works out, if you do it retrospectively, works out at about the rate at which MCI is diagnosed amongst all referrals." (Consultant Psychiatrist)*

Individuals referred into the clinic are sent questionnaires to complete ahead of time regarding everyday functioning, sleep and mood. Once they come into the clinic they are also offered a full neuropsychological assessment, physical assessment, neuroimaging. Biomarkers will soon be introduced to the model. After a comprehensive assessment within the clinic, clients are offered feedback and follow up care based upon their individual need.

> *"There's nearly always something you can identify, though. There's alright, it's subjective cognitive impairment, but actually I'm looking at you walking down the hallway and you're a perfect sleep apnea candidate." (Consultant Psychiatrist)*

The clinic can then either provide support for the person within the clinic or refer on elsewhere in the trust for support for the specialist need that the assessment has identified. The idea of the clinic is to address the gap in support that people with subjective cognitive impairment might experience, and recognise that tailored support can be offered with beneficial outcomes for this heterogeneous group.

> *"And even if that's so called functional cognitive disorder, in other words, people who have a health anxiety or even might be classified as a sort of a neurological conversion disorder with respect to their memory. The process of understanding your brain, having it explained to you, having a normal scan explained to you. And hopefully down the line, have negative biomarkers... So that you can say these people not only did you not have Alzheimer's, but your neurofilament light shows you don't have any neurodegeneration." (Consultant Psychiatrist)*

This specialist clinic can ultimately reduce burden on traditional memory assessment services, so that people are not being referred in and undergoing assessment that may not be appropriate.

> *"Now what we know about these people is you [can] over investigate them. Obviously they remain dissatisfied, especially people with significant health anxieties...These people are [now] not getting seen twice. They're not getting referred from one memory clinic to another. They're not getting referred from one consultant to another. In fact, it's probably lower cost than getting seen by a nurse on a home visit and then getting seen by a consultant after being discussed in an MDT. I think it's probably cheaper than that." (Consultant Psychiatrist)*

The nature of the support that can be offered within the Brain Health Clinic does and will vary from person to person

> *"Certainly they're coming back after a scan. If they need a scan. If they come and they're after their testing, which is fed back immediately, it's very obvious this is anxiety, this is depression, then those people won't be followed up until that is adequately treated and they still have a cognitive problem. So I am sending those people back to the GP unless they express a desire to be seen in six months time. When would you next like to be seen? Would you like to go back to your GP, get treatment for this anxiety now that you've been reassured that you're in the normal range and all these tests? So. So the idea is to actually dig into that a little bit and make it a little bit more tailored and which I think will help." (Consultant Psychiatrist)*

One stop shop

The One Stop Shop approach offers streamlined service that is more convenient for patients by enabling patients to have the majority of their clinical in investigations in one day. An additional benefit is that it offers the MAS more control over the client experience and has reduced the rate of people not attending appointments.

> *"The driver was really kind of to reduce appointments, the number of appointments and reduce waiting times as well. That was a purpose of setting up the, the one stop shop. And also it allows the assistant practitioner can facilitate transport for clients who are without family or who have, you know, significant memory problems. And in terms of remembering appointments so she can facilitate people to get to the hospital for their scan. And that's reduced the number of DNAs that that happened. And she's been brilliant in terms of helping people to a) remember about the appointment and then b) to actually take some of them that would not be able to get there otherwise." (Staff member 1)*

Post Diagnostic Support

The service has recently changed the way on which it offers support to people after their diagnosis and introduced a 12 month post-diagnostic support service. The service includes support from nurses within the MAS, dementia support advisors and also includes support from the wider community mental health team should this be required.

> *"We have two dementia support advisors within the team and they would then arrange to see the person who was diagnosed with dementia. And also an appointment with the carer of that person with dementia and they would offer them. So they do an initial assessment and they would then see arrange to see them again. These are done face to face. They would arrange then to see the three month and six months and nine months and then at 12 months and at the end of the 12 months, if everything's fine, they would then be discharged back to the care of the GP. But should that person present with some concerns, maybe some challenges with behaviour, for example, throughout that 12 month period, then we would then again have a conversation within the MDT and then we would then consider moving that person into the community mental health team for care coordination, and yeah, for as long as they require, CMHT involvement."(staff member 1)*

What are the challenges of this model and how have you overcome these?

Innovative Brain Health Clinic

The Brain Health Clinic is an innovative model that has faced some challenges in getting up and running. It has been pioneered and developed as a service development initiative by and individual consultant, which has addressed a need but also presented challenges in terms of initiating the clinic, managing the patient intake, and sustainability.

> *"it's been interesting actually. So it started, I started in full force in January with a little bit of a break in February for some annual leave and things. And initially it was a trickle and what I was trying to do was interview everybody I picked out over the phone to do an Amsterdam ADL and a CDR and that was because it was only me doing it absolutely unsustainable. So that kind of collapsed and I realized that actually, you could probably get most of the information from the GP referral. And most GP referrals have some element of functional detail about it, i.e., this person is, you know, getting lost outside the house. OK, so dementia stage very likely. But this person has had concerns about their memory for the last six months, very likely MCI SCI stage." (Consultant Psychiatrist)*

The clinic is now increasing in the number of referrals it can take, whilst it remains managed at the individual consultant level.

> *"Over the last say 5 weeks 5 on Saturday I go through the referrals for the last seven days and email the teams and say I want to be allocated these patients that's been 8 patients a week 10 patients a week over the past several sort of four or five weeks. So I'm now booked up for several weeks in advance...I can really only see four people a day because it does take an hour and a half to two, two hours. By the time you written people up." (Consultant Psychiatrist)*

Managing the incoming referrals from several MAS services has also presented an issue to the implementation of the clinic. This is because practically all of the MAS are set up differently, in addition to a cultural or political consideration that comes with rerouting patients from one service to another.

> *"This has required a bit of coordination to say the least, and you know [area] is an absolute nightmare. It's 10 boroughs, two mental health trusts, and so we've got, I think, within the mental health trust we've got maybe 8 memory clinics, 8 independent memory clinics. All do things differently, different processes, different admin, different. Different politics, so, so that that was, that was really what November and December last year were about was kind of very slowly making sure I knew where the landmines were with all of these clinics so that I could make it clear to them I'm taking patients away from you. You don't have to see these people. Nurse doesn't have to see them consultant doesn't have to see them. I'll do all the work. I'll do all the admin" (Consultant Psychiatrist)*

Being Research Active

The journey to being a research active hasn't been easy and has sometimes been met with scepticism from staff. It was suggested that staff willingness to enter into being a research active service has been accelerated by the pandemic, which has essentially enhanced perceptions of the value of the research process.

> *"[there is] still probably some scepticism about commercial RCTs and things like that, you know? And. But yeah, I think that the unfortunately it is variable, so it's variable across 3 memory services and it's variable within each service. But the good ones are really good and really keen and I actually think that probably the pandemic has done quite a lot to lower, you know, non researchers fears about research because we went from no treatment for this illness to hang on a second. Nine months later, we've got a vaccine. And now it's in, you know, millions of millions of people and the sort of attitude towards science is alright, this." (Consultant Psychiatrist)*

What do you think the benefits are of what your service is offering?

The service offers benefits across a number of areas, as previously identified, namely:

- 12 month post-diagnostic support

The offer of a significant period of postdiagnosis support has been a recent change to the service but offers patients and extended and dedicated period of care that has been received favourably.

> *"It's quite new to the team, so we're in a little bit of a seeing how it works and it will be evaluated, yeah. But so far the feedback has been very, very positive from carers and family and say I think some of it is just that. You know feeling of ohh I'm not on my own. I there is somebody I can go to and that's the thrust of their feedback that we've had so far" (staff member 2)*

- Being research active

This offers the opportunity for patients to be involved in research, in line with NICE recommendations, but moreover offers the staff opportunities to take part in research projects and develop their research skills and confidence.

- Brain Health Clinic

The innovative Brain Health Clinic addresses a recognised need for patients referred into MAS who do not meet the criteria for dementia, but nonetheless present with unmet needs, that would have been previously unexplored and unaddressed

Site 10 - Ensuring culturally appropriate assessment and diagnosis for people from the Somali community and at least 12-months of post-diagnostic support within the service

Summary

This service offers at least 12-months of post-diagnostic support within the MAS, provided by Dementia Support Advisors (DSA's) who are proactively in contact, usually by telephone, with the person/their supporter at 3-, 6-, 9- and 12-months post diagnosis. This supports ongoing provision of information and support by staff with expertise in dementia at a time that is right for the person and their supporter(s) and encouraging them to access a network of appropriate post-diagnostic support ahead of discharge to GP. The service also have a project underway to develop a culturally appropriate cognitive assessment tool for use with members of the Somali community, where the older population may not have received any formal education and for whom many of the questions/tasks on current cognitive assents are inappropriate. This has involved working collaboratively with the local Somali community to identify problems with existing tools and to pilot and feedback on a new assessment tool. The tool is not yet ready for use in day-to-day practice but feedback to date suggests it is preferable to translated versions of existing cognitive assessments.

The service is one of three that operate across the city region, each run by a separate team but located within the same NHS Trust. It offers memory and assessment, diagnosis and then a minimum of 12-months of post-diagnostic support. Assessment and diagnosis usually involves referral via GP, followed by initial assessment at home by a nurse. This may take place over 1-2 visits. The person is also referred for a brain scan at this time if required. Assessments are then discussed at a Multi-disciplinary Team (MDT) meeting and if a dementia diagnosis is clear, it is then shared, if diagnosis is not clear the person will be referred for further assessments with psychology, occupational therapy and sometimes speech and language therapy.

What led up to you developing the service in this way?

At least 12-months of post-diagnostic support

The service has been looking at research evidence and feedback from people who have accessed their service about what they want. Based on this they agreed to offer at least 12-months of post-diagnostic support within the MAS service.

> *"Because what we were finding with some people is that initially when they were diagnosed with dementia that they would be offered lots of information and groups and support, and for some people that was just too early. They'd only just learned about the diagnosis [and were] still getting their head around it and trying to process it so. So for some of those people, it was just too much, too soon, so they would say no, no, I don't want any more information and support [at this time] and then some of those people would then be discharged." (Clinical Psychologist)*

This meant some people's information and post-diagnostic support needs were not consistently being met.

Culturally appropriate assessment

Psychologists from two of the city's services have been holding group supervision sessions for anyone working in MAS services across the city region. It is usually nurses who attend. They are an opportunity to share ideas and issues that come up and to learn from one another. One of the issues that was identified in this group was that referrals were being received for people from the Somali community, but that the usual cognitive assessments (i.e. the Addenbrookes Cognitive Examination - ACE) were not suitable.

> *"You know people in their 70s and 80s, that had come over to this country, a lot of those people have never really had any kind of formal education, so they couldn't read or write, they weren't used to holding a pen. Some of those tasks, even when they're supposed to be appropriate for other populations, they usually involve drawing, but this was quite an alien task for people. Asking people the date and their age often wasn't appropriate for that community. They don't use the Gregorian calendar, sometimes people wouldn't necessarily think about the days, it will be more around looking at their activities. They would organise their days and their time around what activities they were doing, [e.g., prayers and meals], rather than focusing on what the date was. That often meant it was more difficult [to reach] an accurate diagnosis. Sometimes it was more … a watch and wait to see whether people might decline over time and it would be an opportunity missed really. An opportunity for people potentially to get access to medication and nonpharmacological support and interventions that might help." (Psychologist)*

What does the service offer?

At least 12-months of post-diagnostic support

The post-diagnostic support offers pro-active contact from a Dementia Support Advisor (DSA) support advisor from the MAS at 3-, 6-, 9- and 12-months post-diagnosis. This is usually provided by telephone but can be done face-to-face if needed. The person with a dementia diagnosis and their family have the contact details of the DSA to be able to contact them if they have any questions or their needs change between reviews.

The service do find people's needs have changed over this time. For example, they may have become more accepting of to the diagnosis and be ready for more information about services and support, or a carer may be starting to struggle and may need referral for additional support. The aim is to signpost people onto relevant support services during this 12-months, so that they have a good network of support when they are discharged back to GP at 12-months if stable, or onto the Community Mental Health Team if they have ongoing needs.

Culturally appropriate assessment

The service is running a project conducted by a clinical psychologist, a nurse, an assistant psychologist and an interpreter, to develop a more culturally appropriate cognitive assessment for people from the Somali community. This involved speaking to people from the community, who were accessed via local mosques. They were asked about their understanding of dementia and to identify difficulties with the current assessment tools. An initial draft of the Manchester Somali Cognitive Assessment Tool (MSCAT) was developed and it was taken back to the Somali community to gain their thoughts on it.

The current phase of the project is looking at whether the tool is acceptable and suitable for people in the Somali community by testing it out with people who do not have dementia. Their ability to complete the tool is being compared to the ACE translated into Somali.

> *"That's followed by an interview. So asking them questions around the tool, around what they think the task was asking them to do, how difficult or easy the tasks were, whether they've got any suggestions to improve the translation, whether they think it's appropriate for Somali culture and whether they've got any suggestions to improve that. Generally getting their experience of completing the two different measures. We've got an assistant psychologist within our within our service now who is from Somalia, so she's been going out and doing the assessments with people and doing the interviews, then we've been getting those translated by our interpreter within our link worker service. She's [Assistant Psychologist] been noting down other things from the interviews as well around any items that weren't suitable to be administered to people and then reasons why, any other observations that she's making around how people were finding the assessments and how long it was taking." (Clinical Psychologist)*

Initial findings are that the ACE isn't suitable for the Somali population, translation of the ACE into Somali does not provide a viable solution to the issues with it and that people generally prefer completing the MSCAT. The next steps of the project are to make some revisions to the MSCAT tool based on learning to date, this includes translation into different Somali dialects and to pilot this with more participants without cognitive impairment to ensure all the tasks are ones you would expect someone without cognitive impairment to be able to complete. In future the service hope to trial the tool in a Somali population with cognitive impairment compared to one without to examine its ability to distinguish the two groups.

What are the challenges of this model and how have you overcome these?

At least 12-months of post-diagnostic support

Resourcing can be a challenge. The service have resourced this within their existing service by looking at how the existing time of their two Dementia Support Advisors (DSA's) in each locality was being used.

> *"So rather than the DSAs offering a lot of visits .. early on [after diagnosis], it's spreading that out ... over the year. And yeah, it had involved more, more visits from them, but it's been able to be managed within the resource that we've got within the teams." (Clinical Psychologist)*

Culturally appropriate assessment

There is no external funding for this project. It has been helpful that the Assistant Psychologist is from Somalia which has enabled the service to use her expertise and native language skills to conduct the field work within her job role. The service have paid for the translation of materials and the interviews. The project is well supported by the service managers and so staff have been released from other duties to work on this.

Finding enough participants from the Somali community is also a challenge and the project has taken longer than the service has initially thought in order to reach their initial ten participants, particularly people from the over 70 age group and those who have had little or no formal education.

What do you think the benefits are of what your service is offering?

At least 12-months of post-diagnostic support

The benefits are that people are able to access appropriate support and signposting to other services, provided by a team with expertise in dementia, for an ongoing period of time during which their needs may change.

> *"One of our Dementia Support Advisors (DSAs) fed back recently that she went to review a man living with dementia and his wife recently, I think it was about after six months and his wife is deaf. She was struggling with that carer role, but she really struggled to access any support. But with the DSA going in and finding out what their needs were, she could … give her that assistance that she needed to look at what services might be appropriate, what help and support they might need and then to give her that assistance in trying to get access to those. Rather than her just being left to try and figure that out by herself." (Clinical Psychologist)*

Culturally appropriate assessment

The project has not yet delivered a version of the MSCAT that can be used in day-to-day practice with members of the Somali community. It is hoped that when this is available it will ensure a more appropriate and accurate diagnostic experience and outcome for people, providing them with a timely diagnosis and access to appropriate post-diagnostic support.

Site 11 - Post-diagnostic support for people with dementia delivered by people with dementia and Promoting brain health in the local community

Summary

The MAS is based within a Mental Health Trust that covers a large geographic region. Previously the MAS services were located within the local Community Mental Health Teams. However, two years ago they were brought into one central team. This was to ensure parity of service across the region. MAS services are offered at three different sites across the region and clinics are also offered within or close to GP practices, meaning there maybe 6-8 clinic sites a month where assessments are offered.

Initial cognitive assessment and history taking is conducted by an Assistant Psychologist. This is passed to a specialist nurse and reviewed at a Multi-disciplinary Team (MDT) meeting who make a decision about whether a diagnosis can be made or whether more specialist assessment (e.g. neuro-psychological, occupational therapy, imaging) is needed. Following diagnosis the person and their family is referred onto appropriate support agencies and reviewed again at 3-months post-diagnosis, before their care is transferred to their GP. The local Alzheimer's Society are commissioned to provide some of the post-diagnostic support and their Dementia Advisors are the main point of contact once someone's care is passed back to their GP. Where possible their advisors are on-site when clinics and services were being provided by the MAS, to offer informal advice and support, support an integrated care pathway and create a feeling of a seamless service for people accessing the service. Within the East Riding area people are offered the Good Life with dementia Course at point of diagnosis.

What do you offer and what led to you develop the service in this way?

The 'Good Life with Dementia Course':Post-diagnostic support for people with dementia delivered by people with dementia

The Good Life with dementia' course is a post-diagnostic support group/course for people with dementia, this is designed and delivered by people with dementia

The Service Manager is an active member of the local dementia collaborative which consist of the NHS organisation, Clinical Commissioning Group, Local Authority and private and voluntary sector organisations. The Dementia Friendly Communities lead for the area invited a colleague in the only other UK city that is offering this course currently to share their work with the Dementia Collaborative. Members of this group agreed this was something they wanted to offer within the local area.

The training is jointly commissioned, by the MAS, local authority and clinical commissioning group. The MAS Service Manager had to make a case to the other services to obtain their financial buy-in. It is delivered by a voluntary sector organisation who coproduce dementia training courses. They have coproduced a course for people with dementia, developed and delivered by people with dementia. Groups run for up to ten people with dementia per group and three groups per year have been commissioned.

While only 30 people with dementia a year are able to attend the training programme this has led to other indirect benefits.

> *"The spin off though, is that they've [people with dementia who attended the training] created a peer support group for people, post diagnosis and so now you've got people hearing about the peer support group and saying, well, I haven't been through the training course, but can I come to the peer support group? And the answer is always yes. And so that group in its own right is growing as a peer support group for people in the area post diagnosis." (Service Manager)*

Promoting brain health in the local community

The service had identified that there are some localities across the area the MAS serves which have low referral and dementia diagnosis rates. They considered ways they could be targeted in increasing referrals from these areas and brain health sessions were suggested as a possible solution.

The local Alzheimer's Society is commissioned to deliver the brain health sessions, which are funded through COVID-19 recovery funding.

> *"And the idea of the brain health sessions was to get down to grassroots. So we want [sessions] in supermarkets. We want them in libraries, in leisure centres. We were sort of saying, right, how do we get right down to ... a really basic level with people who are out shopping and, oh, let's talk about brain health. This is why it is important." (Service Manager)*

The intention of the sessions is to increase availability and accessibility of support, raise awareness of dementia and its symptoms, reduce stigma by getting people talking and promoting the importance of getting a timely diagnosis.

> *"To work within the community be a visible presence at places where people wouldn't necessarily expect to come across that kind of advice, they wouldn't certainly go seeking it there necessarily. So like in your garden centres, in your supermarkets, in libraries. Building up those community connections, so that we could talk openly to people in the community about brain health and about our risk of dementia and talk about anyone who was worried about their memory and how they would then seek a diagnosis through the system." (Alzheimer's Society staff member)*

The service are focusing on the primary care networks (PCN) with the lowest diagnosis rates across the East Riding of Yorkshire. In those areas, they have worked with partners to agree locations where they can have 'pop up' sessions a number of times a month. These sessions are in community settings, supermarkets, garden centres, libraries, shopping areas and at community events. One tool that has proved useful is the Alzheimer's Society symptoms checklist. The service's Brain Health Advisor uses this to talk through possible symptoms of dementia, and support the person to complete the checklist themselves if they have concerns. They can then take the checklist with them to an appointment with their GP to support that conversation.

The service also work directly with GP surgeries. One example of this is their work with the Holderness PCN. Holderness have widely promoted the brain health sessions through their social media platforms and have invited the service's Dementia Support worker to have appointments with patients at the surgery on a weekly basis. They also pro-actively contact people on their patient register to make them aware of the support Alzheimer's Society offer including where and when the Brain Health sessions are taking place. Recently one of the social prescribers at the practice has been looking at how their patients could be better supported and enabled to have memory concerns investigated. This has resulted in a trial of the service's Brain Health worker completing the 6-CIT with a person who has worries about their memory. If they score 8 or more bloods can then be completed for the individual without the need for a GP appointment. Once the bloods are back a GP appointment then takes place. This means easier access to early support for people who are concerned about potential dementia symptoms and at least one less GP appointment for them at this practice.

What are the benefits and challenges of this model and how have you overcome any challenges?

Post-diagnostic support for people with dementia delivered by people with dementia
Peer support is proving to be invaluable to people who have received a dementia diagnosis.

> *"When it was COVID, they met online, but then there was just the loveliest thing, the first time they got [to] physically meet up together. They said, 'right, why don't we just meet on a local beach to us, and we'll walk our dogs. And if you don't have a dog, just come for a walk'. And it was so gorgeous. And the feedback that you got from that was, "It's the first time since my diagnosis that I just met with a group of people. And we just met, and chatted and were friends, but it just happened, that we happened to all have a diagnosis, but that wasn't important. What was important was that we met as a group of people, and I didn't feel like a person with dementia. I just felt like a normal person going out to meet with some normal other people and have a nice time." And so now they meet up and I think they do all sorts of things and we're just trying to arrange venues for them to meet that, can support." (Service Manager)*

The peer support group are helping the service with other initiatives in the area related to post-diagnostic support for people with dementia. For example, visiting a local leisure centre to feedback on how accessible the facilities are ahead of them providing swimming session for people with dementia. The group have also developed a booklet written by people with dementia, for people with dementia. Its production was funded by the local Rotary Club.

> *"So what we did was we created a booklet that was very, very user friendly and we had about 300 of them printed, but we also have a PDF version as well. All [the printed versions] have gone. They all went immediately and [we keep getting requests] "can we have some more?". That has ... spread by word of mouth. Some GPs know about it purely because they've had this booklet." (Service Manager)*

The biggest challenge has been finding the funding to commission the training course for people with dementia. The service manager had to proactively request joint funding from the other commissioning organisations to be able to provide this.

In order to get the GP practices to support the model the Alzheimer's society have worked closely with one of the social prescribers to promote speedier access to appointments with GP's for those people presenting with memory concerns.

Promoting brain health in the local community

The events run to date have seen good attendance, supported by GP practices. The brain health sessions were launched during Dementia Action week (takes place annually in May in England).

> *"With the theme for Dementia Action Week being [the importance of a] diagnosis, and … myth busting, everything just slotted in really nicely. We had huge turnouts at some of our venues for advice because one of the GP services on the list of the lower referrals, we've developed a really strong relationship with… They've promoted our community events to the point where there were people waiting, queuing for the worker to arrive so that they could…. We've never seen anything like it before, honestly, so it's absolutely fabulous we've got that opportunity to use that post to really talk to people within the community where they feel comfortable. It's not that we're … just cold calling or, … approaching people." (Alzheimer's Society staff member)*

One challenge is that the brain health worker post is currently only funded for 12-months. The service is working to secure additional funding to extend the post. The service hope that tracking the impact of work in specific local areas, to referrals from GP practices in that area, will provide an evidence-base for further funding.

Site 12 – Standalone MAS with specialist post-diagnostic primary care support

Summary

Originally, the MAS was embedded within the Community Mental Health Team (CMHT). The team identified that a high number of MAS clinics were often being cancelled as consultants would be called away to administer mental health act assessments for people in crisis. This meant waiting lists were high and patient satisfaction was low. The team also recognised that even though they were a MAS they did not have a dementia-friendly status, the clinic environment was quite hostile, and parking was stressful. The team are striving to change this for their service users. The team have secured funding so administration staff can phone people the day before their appointment to reduce the number of DNAs. A post-diagnosis support service within primary care was commissioned and is led by two GPs with a special interest in dementia. Both the memory assessment and post-diagnostic services work in collaboration with the Alzheimer's Society.

The service provides specialist assessment, diagnosis and treatment for people who are worried about their memory. They accept referrals for people younger than 75 where memory is the primary concern. They also assess and treat people who already have a diagnosis of dementia and who may have additional mental health symptoms. Referrals usually come from the GP but can also be made by other healthcare professionals. The MAS is made up of a multi-disciplinary team including, one consultant in old age psychiatry, a support worker, three memory nurses, one psychologist, and one occupational therapist.

Once a referral is picked up, it is assessed for appropriateness and administration staff check that all relevant information has been gathered (e.g. bloods, personal history). The referral will then be passed to a nurse who organises an appointment to see a clinician (90% of the time this will be a nurse with the consultant taking a supported advisory liaison role) and discussed in MDT. Everyone who accesses the service will receive an assessment and a care/support plan. After a diagnosis has been made, people are discharged to the primary care Dementia Support Service, led by two GPs with a special interest in dementia. This service provides annual reviews and, if needed, 6 monthly reviews for more complex cases. They are also referred to the Alzheimer's society for post diagnosis counselling and support.

What led up to you developing the service in this way?

Originally, the MAS was embedded within the Community Mental Health Team (CMHT). The team identified that a high number of MAS clinics were often being cancelled as consultants would be called away to administer mental health act assessments for people in crisis. This meant waiting lists were high and patient satisfaction was low.

The team also recognised that even though they were a MAS they did not have a dementia-friendly status and the clinic environment was quite hostile. This led them to change the aesthetics of the MAS clinic. Service users would consistently complain about the parking. The hospital is quite small and the car park was redesigned so there were a lot of electric, disabled and parent and child parking spaces, meaning public use spaces are in high demand.

Money was invested into primary care by the commissioners and the Dementia Support Service was introduced. Rather than the MAS keeping all service users on their caseload post-diagnosis, they refer them to the Dementia Support Service which is run by two GPs with a special interest in dementia. Unlike neighbouring boroughs, this means the MAS does not have large ongoing caseloads.

What does the service offer?

A standalone MAS with strong working relationships with parallel departments

In the last 18 months, the team decided to create a separate MAS with one dedicated consultant.

> *"[The clinic is] working so much better by just having a nominated consultant rather than having the distractions of mental health act assessments, which would mean we had to keep cancelling clinics so often. So actually, having that, you know, pure dedicated consultant to the service is only making it improve, actually both kind of quantitatively with our data, but also with our feedback from the patients and the service users." (Consultant)*

The service has built strong working relationships with other departments and highlighted the need to build both academic and clinical links.

> *"We have an academic program on a Thursday morning and so we have a usually a case presented by a junior doctor and then an external speaker. So just having that relationship starting somewhere is not bad. Good to get a neurologist to come and speak at your academic program and then that could forge a relationship."*

The MAS team felt that they made a lot of referrals to other parallel services but they didn't have any rapport with them.

> *"So, we're sitting there talking about referrals to the falls service and have no clue about who runs the falls service and what they're about. So, we invite them to come and join us [at the MDT] and then we just got into a regular pattern."*

The team now make a conscious effort to fully understand the processes surrounding onward referrals from the perspective of the service users so they can answer any questions. They also emphasise that the service user should remain at the centre of all clinical decisions and conversations.

> *"The managers find out you're wanting to have a meeting with another clinician across a different organization that you'll get a bit like oh, who pays and who's this. And that's not in our scope of work. And it's just it's so unhelpful. But that's kind of how this sort of silo thinking across acute care, primary care, mental health becomes. So, I think those challenges often get broken down if you remember the patient in the middle and you make clinical connections." (GP)*

Relationships with Alzheimer's Society and Dementia Friends

The Alzheimer's Society holds a contract with the local CCG to provide certain services to the area. The MAS service has an 'in-house' Alzheimer's Society staff member every Tuesday. Tuesday is the busiest clinic day which works well as when someone receives a diagnosis of dementia they can be directly introduced to the Alzheimer's Society.

> *"Our Alzheimer's society lady that comes in on a Tuesday, she comes for the first half an hour of MDT meeting. Every week pretty much, she will say, I've just seen this lady you might discharge, or she's on your caseload and she's really poorly. And I saw somebody urgently last Wednesday because [colleague L] discussed somebody in the meeting, and she's not even clinically or medically trained. So, it's another pair of eyes. You know, out there on the patients that that can bring them back to you." (Consultant)*

The Alzheimer's Society also supports the post-diagnostic Dementia Support Service.

> *"So, at the moment the format of the clinic is me one day a week, my colleague one day a week and in the room next to me, the one day a week we have the Dementia Advisor from the Alzheimer's Society. So literally on site at the time when I've seen the person and done the assessment, I walk them into the room next door and I can kind of go [colleague R], this lady doesn't yet have her, I don't know, council tax reduction [or] I think she's probably due a carers assessment, so she can kind of help work in her links and, you know, advice around different things that she might be able to help with." (GP)*

During the pandemic, the MAS consultant was invited to speak at some Dementia Friends seminars, leading to the development of a serendipitous relationship. The MAS and Dementia Friends are now collaborating on a project to make the MAS clinic more dementia friendly.

> *"And actually, the more we started to look at the clinic, the more hostile we realized it was, you know. They all loved the pink, big, comfy chairs. But actually, you know, the walls are covered with paper, literally with out of date, A4 pieces of paper about, you know, how you use alcohol hand gel and wearing a mask or not wearing a mask and how confusing all of these messages were."*

The team are going to change the outdoor signage to the MAS clinic to make it clearer. An interior designer has agreed to donate some time to look at colour schemes and to build a library to store information booklets and a nurse is creating a dementia-friendly garden.

> *"And at least it's in a nice environment and they're getting these, you know, big Alzheimer's Society hug." (Consultant)*

A key aspect of this work was ensuring they invited everybody to be part of the process and talking with colleagues who have experience in running similar projects.

> *"So, we're gonna meet remotely every month now to get to get everybody on board and ideas and to start making some plans really and getting them costings and seeing whether we can apply for charitable funding and things like that." (Consultant)*

Dedicated Parking

The team are in conversations with the Hospital Estate team to acquire two nominated MAS spaces.

> *"So that they can come and not have to come in, like almost having a panic attack because they've been walking around trying to find a space and a parking machine." (Consultant)*

Dementia Support Service within primary care

The service is in the process of establishing an official contracted monthly supervision group for local GPs in the Dementia Support Service. This supervision started as an unofficial quarterly meeting where the MAS Consultant and two GPs would meet to discuss patients of interest.

> *"I have a special interest in dementia. So that's where my link in with the memory service really came about. While I was doing my postgraduate certificate, I worked on, not employed by, but I worked having experience in sitting in with the memory service locally, which was really, really helpful. My direct supervisor was actually there." (GP)*

The system has been trialled over the last two years to support GPs and to offer clinical advice to improve action time for dementia intervention. The MAS will send a discharge summary to the Dementia Support Service.

> *"For me, I think it's better because I think keeping hundreds and hundreds of people on forever that are stable with medication, who are obviously going to get worse, I don't think it's very useful use of time in a specialist service. I think you know, I think in primary care is in more sensible place." (Consultant)*

Offering support to GPs on more complex cases.

> *"But it also is those informal links that have been incredibly useful. So, if I've got a stumbling block or I'm not quite sure about something, then [MAS Consultant] been really good about me just being able to e-mail through with that query and we kind of have that nice flexibility going forward. So, I guess my role with the MAS has been about training and development. So, they've very much helped me learn and develop my skills." (GP)*

What are the challenges and how have you overcome them?

Resistance to change

The service found that some people were resistive to the proposed aesthetic changes to the clinic or they did not take the project seriously. The team found that gaining support from high-level management helped change people's minds and now most are supportive and have asked for advice on how to implement changes in their clinics.

Increasing staff morale

When the MAS was integrated with the CMHT, staff morale was lower. Now the services have separated, staff can commit themselves to one service and can be fully invested. It is hoped that this will help with the retention of staff as they will feel less burnt out.

> *"The morale has improved and you know, just on relationships have improved just because it feels like we're owning something really exciting rather than just in a hamster wheel of God help me. What time, when? When is it 5 o'clock kind of thing."*

Lack of support for MCI

The team acknowledged that they were seeing high cases of MCI diagnoses and that was little support for this population.

> *"And even actually the Alzheimer's [colleague L] is regularly told by her manager that she's not allowed to see people with MCI, but she regularly sits and says I really want to see this one. Yeah, somebody who's anxious with MCI, that's mum's had dementia and thinks she's gonna be seen in six months' time and get a diagnosis of dementia, which she might do. She's got a 30% percent chance."*

The team try to refer people to research projects.

> *"This might be dementia in six months, we'll see you for follow up. It's a bit empty, you know, doctoring. So, it's really nice to say, do you want to be part of a research project? And you know, it's amazing that the amount of people that say yes." (Consultant)*

They also provide visual explanations of the difference between MCI and dementia.

> *"So, if you're here, you've got normal memory testing normal ADL. If you're MCI, you've got impaired memory, but your ADLs are good. And if you've got, if you're here, you've got impaired cognitive testing and impaired ADL. And that's what the nurses use now. And patients regularly ask for a copy of this, and so we just have hordes of them."*

The post-diagnostic primary care team are also unable to accept referrals for MCI.

Non-Permanent funding and health inequalities

The post-diagnostic Dementia Support Services does not receive permanent funding. It was originally set up by the local dementia Commissioner and began with securing a one-off funding grant from the 'Better Care Fund'.

> *"We just keep getting recurrent funding so far year on year, so it's always a little bit precarious and I think that's just how all sorts of services work. Funding is always, always a challenge, isn't it? And I think until we know that we're more permanent, I think it's really hard to expand it too far. Equally the budget's just not there really." (GP)*

With their small team and limited funding, they acknowledge that there are health inequalities.

> *"So, I think it is really challenging because cost wise, we can't afford enough GP time to do an annual review for everyone with dementia in [Site 20]. So, at the moment, I have a cohort of patients, but I don't have all of them. We just can't afford it. So that kind of raises all sorts of inequalities about who and who is and who isn't. You know, we don't actually refuse any referrals but just through our capacity, we can't actively go out and make sure we've got them all." (GP)*

To try and mitigate these challenges they don't tend to prioritise people in care homes as these individuals usually have their care needs to be met by the staff in the home. The team highlight that prioritising patients is challenging and there are no fast or hard rules around this but they try to be pragmatic.

> *"I think any of the young onset, any of the frontal lobe, the progressive primary aphasias the, you know, the slightly less typical are much more likely to run into complex care needs earlier, aren't they? Whereas some of the more straightforward Alzheimer's could be a little bit more predictable can't it. I guess the other bit that adds into that is if they've got physical health frailty issues."*

The team are trying to plan how the service might be sustainable in the future and how best to use their funding.

> *"I think to be a more cost-effective service, what we may look to do is to have per PCN one allied health professional, be that a nurse with experience in dementia, be that a social worker, be that an OT. You know, whatever sort of team we put together so that someone in each PCN is going to do the majority of those annual reviews with a step-up service or a step in and out service to me, if there's medication queries and things that require my expertise." (GP)*

What do you think the benefits are of what your service is offering?

Dedicated and timely diagnosis

Service users now have a dedicated MAS team who can focus on dementia diagnosis and do not need to split their time between the CMHT.

As the service only has one part-time Consultant, the team have worked hard to upskill nurses so they have the confidence to make dementia diagnoses. The consultant has developed a framework they can follow to help with differential diagnosis and uses MDT meetings as a learning space.

> *"Whereas two years ago they were nowhere near doing that. They would have gone oh you diagnose her. Cause I'm not the doctor kind of thing. So that's really been a really amazing process as well. So, it's kind of giving them the confidence and the autonomy to be doing this so that the service continues to run. So that actually our dementia rates have gone from 60% to 100% because the patients are being given a diagnosis."*

Excellent relationships and partnership working

The team have worked hard to build strong working relationships with parallel services, the Alzheimer's Society and Dementia Friends. For example, a neurology opinion is readily available if necessary or a second opinion from another consultant when complex cases arise. The team are working hard to make clinic visits as easy and pleasant as possible. The Dementia Support Service provides annual check-ups on individuals discharged from the MAS.

Cognitive Stimulation Therapy

Cognitive stimulation therapy has recently been established within the trust which is very positive for MAS users. The service is led by a Psychologist who has been commissioned by the trust to run the therapy.

> *"So certainly, the patients say that they've been enjoying it. But you know that they feel it's just really important I think as well psychologically when someone's been given an MRI or a diagnosis of dementia to be able to actually give them something." (Consultant)*

Post-diagnosis Dementia Support Service within primary care

Once a diagnosis has been made, the individual is discharged from the MAS and is referred to the Dementia Support Service which is based within primary care. Within primary care, the individuals will receive an annual review or more frequent contact if needed. (GP)

> *"Follow up and see how they're getting on. Make tweaks if we need to change medication and really do a holistic assessment looking at their physical, psychological and mental health as well as carer assessment." (GP)*

Service users value seeing the same clinician post-diagnosis.

> *"I've just felt that the continuity was really important. The patients like the continuity. So I'm now seeing patients that I've seen for three or four years with their diagnosis." (GP)*

Site 13 – Nurse-led Memory Assessment Service located in primary care

Summary

The service was experiencing low Dementia Diagnosis Rates (DDR) and protracted waiting times for diagnosis (up to two years). To improve this, an innovative MAS nurse-led model was implemented. The service was reformed into a community service, operating out of primary care locations and delivering home visits. In 2017, the service mobilised a working group titled 'The MAS System Thinking – 2017' with the purpose of better understanding what their patients and support network needed and how they, as a service, might meet this need. The MAS is now a partnership, working in collaboration with the local NHS trust and third sector providers to provide integrated clinical care and social/psychological support from the point of referral, regardless of diagnosis. The service offers consistent and reliable support that is needs-based. They have a rapid brain scanning pathway so service users can receive a timely diagnosis.

The service offers an integrated care experience providing assessment, diagnosis, treatment, support, and advice for people with newly presented memory problems. The service is community-based, operating out of primary care locations and delivering home visits. Individuals are referred to the service by their GP. The assessment and diagnosis process are based on a nurse-led model with the support of part-time doctors. The service also has memory support workers who support service users through their entire MAS journey. The service was commissioned to provide 12 months of support post-diagnosis and then service users are referred back to their GP . However, if the person is on dementia medication, they stay open to the MAS for medication reviews, but the care planning responsibility would return to the GP. The service is also keeping individuals with a diagnosis of MCI on the caseload for 12 months and offering reassessments.

What led to you developing the service in this way?

The previous MAS service was experiencing low Dementia Diagnosis Rates (DDR) and protracted waiting times for diagnosis (up to two years).

> *"For me as a GP, you newly made the referral, there was gonna be a huge long wait for the patient, they're probably gonna deteriorate during that time and it kind of felt hopeless. So, I think a lot of the time GPs actually just didn't refer their patients because there was also that idea of what's the point, it's just going to upset them, and there's nothing that can be done." (GP)*

To improve this, an innovative MAS model was implemented. The service was reformed into a community service, operating out of primary care locations and delivering home visits, as well as introducing a nurse-led model of diagnosis.

[2] At the time the time the case study was conducted post-diagnostic support was limited to 12 months. The service has since been commissioned to offer lifelong support.

> *"There was a clear desire to move into the community setting to improve engagement, to reduce stigma of it being embedded in a mental health team, and to improve patient journeys." (Head of Dementia Provision and Innovation)*

The team felt that the service could provide better care and support.

> *"I think there was a big drive with the GP community, just feeling like these patients are getting really raw deal here. And we need to do something. We need to do it better." (GP)*

In 2017, the service mobilised a working group titled 'The MAS System Thinking – 2017' with the purpose of better understanding what their patients and support network needed and how they, as a service, might meet this need. The working group had the representation of every staffing group within the service and was centred around citizens (patient and carer). They also had ad-hoc representation from the CCG during the work. Over a four-month period, they undertook live observations of all service appointments delivered, case study reviews, pathway mapping, and patient and carer focus groups. The outcome resulted in a new service purpose that radically transformed the service through innovation and redesign and has anchored their decision-making ever since.

> *"Moving forward, I think if we had tried to do a number of the things without the systems thinking approach it would have not been as successful and I don't think it would have been sustained." (Head of Dementia Provision and Innovation)*

A primary driving factor in the service development was patient and carers' voices. To ensure these are always at the forefront of service delivery the team have introduced 'Patient Champions' who will influence future decisions.

The team took a proactive approach to the service development and still take practical steps to resolve issues.

> *"We don't shy away from gaps. We're not frightened of gaps. We actually find them, name them, and then think what we can do about them. And so, we don't sort of take that or that's not our job approach to a gap which you know you could see if you were a service that was struggling or weren't open to different ideas that could be a tempting way to go, wouldn't it. And I think we've never done that." (GP)*

Their trailblazing approach has allowed them to weave creative and effective pathways which work for the service and the service users.

> *"The memory support workers, they used to have quite a narrow remit when they were just employed sort of through the Alzheimer's Society. But now that we employ them directly, we can broaden their remit and they can support our patients in any way that we as a service feel that patients need that support rather than it being like, well, this is what we deliver and this is the model that we deliver along." (GP)*

What does the service offer?

An equitable and accessible service

With the knowledge that wait times for some specialist referrals can take up to nine months, the team worked hard to build relationships with other healthcare services so they can informally contact them to discuss their service users' needs. The team also identified that many services 'close their front doors' to individuals who partake in substance misuse or who are homeless. The service has worked really hard to reach out to these stigmatized and marginalized groups. They have changed their referral and assessment processes and often do assessments at the homeless support organisation in collaboration with a support worker.

> *"And you don't want to exclude them from something that might be helpful to them. And we know that the system then says if you have a dementia diagnosis, then that opens up doors as well in the local authority and housing." (Head of Dementia Provision and Innovation)*

While many MAS will discharge individuals with MCI, the present service will hold the individual on their caseload. They identified that there was an MCI support gap and individuals were being left to fend for themselves and navigate their way through the system. The team highlighted that MCI can be potentially scarier than receiving a dementia diagnosis, as it is not a definitive diagnosis.

> *"So, when they get a diagnosis of MCI, they'll have a care plan appointment the same as they would if they had a diagnosis of dementia. So that we can make sure that they are accessing the right support, let them know what is available and just ensure that they're getting that support that they need as well." (Lead Memory Support Worker)*

The team are also implementing a system thinking workstream to engage with the LGBTQ+ and South Asian community.

A supportive team culture

A strong team culture has been created centred on all the staff being there to help the service users. The team value service user relationships and try to create a safe environment from the very initial stages of the referral.

> *"From the people who answer the phones, who establish relationships sometimes with these patients and they will ask for them by name when they ring up or recognize their voice because they've had positive interaction with this particular person, and I think it does, you know, that's a really skilled thing to do, to make people feel safe right from the moment they pick up the phone and call this unknown service. So I think that's sort of, yeah, the culture that we've built together."*

Joined Up Working

Service user records are all electronic across the whole MAS pathway, meaning the service user does not need to retell their story each time they see a clinician.

> *"You all enter into one into one record that makes everyone's contact for that patient completely transparent and visible, and it allows us to communicate easily with each other. Whether you're working in primary care at home, in the patient's home, all of that helps us so." (Head of Dementia Provision and Innovation)*

The team have developed their own templates within SystemOne which have been transformative for their clinical practice.

> *"A good example of this can be evidenced in our Assessment and MDT templates that were created out of the foundations of the ICD-10 Diagnostic Criteria for dementia. Not only has this mitigated quality of assessment depending upon clinician, but also supported induction and training for newer members of the team." (Head of Dementia Provision and Innovation)*

Integrated clinical care and social support

The MAS is a partnership, working in collaboration with the local NHS trust and third sector providers. Their community service has a workforce that has blended together clinicians across secondary and primary care with the addition of third sector workers within their support pathway. Given the partnership and workforce structure, they have good relationships with both primary and secondary care helping them to provide both clinical and support functions which are fully integrated under one service.

> *"It's the integrated nature of what we deliver. That we have a support team in house that ensures that we have this holistic view and we can meet needs because a lot of that psychosocial stuff, uh, clinical services don't have, well historically don't have that, and it's a post-diagnostic support service or it's a referral to the local authority." (Head of Dementia Provision and Innovation)*

Support from the point of referral, regardless of diagnosis

Originally, the system was set up so that support could only be offered after the service user had received a formal dementia diagnosis. The Systems Thinking project highlighted that service users and their families really wanted a system where they could access support at the point of referral. The service can now offer this which has been transformational.

> *"We know that people are on their journey with cognitive impairment and actually just might not meet a criteria and whether that's the same for, you know, a dementia diagnosis, whether it's a referral to a crisis team, if you don't meet a criteria doesn't mean you don't have needs. And when we looked at what the patients were asking for, it wasn't a diagnosis, it was support. So, 70% of the people that we spoke to and reviewed said that support was the priority for them. And I think we had some really painful case studies that we own and particularly one stands out in my mind was that after a year and a half of trying to assess and diagnose a patient because they were in and out of hospital and needed the extra time to and then when is it clinically appropriate to assess. We didn't have a meaningful conversation with them about what mattered most until we delivered the care plan, you know, and actually a year and a half down the line, that's an awfully long time. And I remembered the patient was, you know, pretty unwell and probably didn't have that many years ahead of them. So, a year and a half is a huge amount of time. And all they wanted was to move closer to their loved ones. And actually, we'd done nothing to help them." (Head of Dementia Provision and Innovation)*

Their dementia advisors became memory support workers in acknowledgement that some service users may not go on to receive a dementia diagnosis. The service now has meaningful conversations with every referred individual to ask what is important to them and to risk assess 'right at the front door', essentially allowing them to rapidly refer to specialist teams (e.g. OT) if needed.

From the first conversation, the service user is assigned a memory support worker who they can contact at any point.

> *"And then from there on we explained to them that that that person will be their memory support worker while they're being seen by the service. If they've got any questions, concerns, anything at all, they can call us at any point and we'll be here to support them. So they know that they've got someone that they can call. Particularly some people, you know, an assessment can be quite a worrying time for them. So they might even need just to call up a couple of days before to say I'm really worried. Could we just talk through it again?" (Lead Memory Support Worker)*

The team have a relatively low turnover of staff which makes this consistency feasible.

> *"I think a lot of it is because we we're not kind of hierarchical. So, for example, the doctors don't kind of look down on the rest of the staff or it's, you know, if we have a query or we have anything to input, the doctors are always open to listening to us. And same with the nurses and everyone just is on the same level and the respect for each other is there and I think we're all very, all of us our aim is to provide the best quality service to people and I think that's just what kind of binds us together. That we we've all got that same purpose and we all want to do the best so we work really well together." (Lead Memory Support Worker)*

Needs-based approach

The service utilises a needs-based approach, so service users only see the relevant healthcare professionals.

> *"You know not everyone needs to see a consultant and I think the nursing team are hugely experienced in that. So, you've got to have the quality in your team to do that and you've got to have the structure." (Head of Dementia Provision and Innovation)*

This protection of provisions means that service users most in need of specialist treatment can receive it.

> *"So, although we only have a consultant for half a day a week, that's a really valuable half day a week to some patients and it means that we don't have to refer on to secondary care colleagues with every unusual presentation or for confirmation of a diagnosis." (GP)*

Rapid scanning pathway

Unlike other MAS' who need to refer service users to local hospitals with long wait times for brain scans, the service has an innovative and bold scanning provision with very short waiting times. Both MRI and CT scans can be booked at the same time as the assessment appointment. The team also commissioned another more local scanning facility with longer wait times. This second service is more accessible by public transport and the more protracted wait times consider that not everyone will want a rapid service.

> *"Look at your scanning pathway and see if there's a possibility of doing that better as a kind of quick fairly, I mean, I'd say quick, easy win. I don't do the contracts [S1] knows about that stuff, but you know, it seems to me to be a common theme of and a source of frustration or you know, some services get around that by requesting that the GPs get the scans done before they come into the service." (GP)*

A step away from the traditional medical model

The team provide person-centred care by collating a detailed personal history of the service user, taking a practical and functional approach to aiding the individual to live their best life.

> *"Don't be afraid of stepping away from those traditional medical models of this is [S2] probably knows, you know, this is how you gather the history from a mental health perspective. You know, there is a very set pattern, but actually that didn't really, that wouldn't have worked for us and we just needed to shake it up and change it a bit."*

What are the challenges and how have you overcome them?

Introducing a new model is hard

The team described the model change as 'a leap of faith' to some degree as the method of working was something very unknown and new.

> *"So I think there was a feeling that something was needed and obviously this was quite a bold radical new step and actually [the organisation] had always been an organization that took bold, radical steps I think would be fair to say." (GP)*

The nurse-led model was attractive to staff although it was a different way of working.

> *"Although you know initially hadn't realized quite what that meant, it created quite a bit of anxiety with myself and [nurse colleague P], who was the other nurse at the time. How much responsibility we were gonna have, which had traditionally been given to doctors, but it was certainly an attraction for me." (Lead Nurse)*

The team found there was a stigma around the nurse-led model.

> *"There was a bit of disbelief within certain healthcare settings, or particularly consultants in different specialties, that you know a patient could go through the service and not see a consultant psychiatrist or a consultant neurologist for their diagnosis. And that was seen to be like oh, we're going to just reduce the quality of the diagnosis by not having that real expert at the helm." (GP)*

Through the creation of clear pathways and the development of working relationships with teams such as primary care, neurology, secondary care, and inpatient hospital teams the service is now well accepted and appreciated.

> *"GPs know when they refer to us that their patient will be seen. You know, there may be a bit of a wait, but it won't be a long wait. And you know, I think they do. I think we had a good reputation. I think they do trust us to look after these patients." (GP)*

Serendipitously, nurse-led models have become more popular in the past few years which makes their implementation a bit easier. The team also highlighted that to develop a service the team needed to embrace change and have the desire for complete transformation which can be challenging.

> *"We constantly evolve as well, I think don't be afraid of change." (GP)*

Ultimately, the team reported that the primary reasons the model worked were because they listened to their patients, their staff were highly skilled, and they built strong working relationships with 'the right people'.

> *"It was part of our system redesign...to put patients at the heart of what you're doing and have meaningful conversations with them. And if you do that together, whether you're a provider, whether you're multiple providers, if you're all doing that and on a journey, then you're more likely to share the understanding that will drive your change. It's not guaranteed, and you've got to have the right people and the right skills, but I think if you can bring Commissioners, providers, including staff and patients and go on that journey, then you're more likely to have something that's really impactful in terms of outcomes, the learning and then also the sustained change." (Head of Dementia Provision and Innovation)*

What do you think the benefits are of what your service is offering?

- The efficiency of the service has improved, and the team are now able to offer a more tailored approach to dementia diagnosis
- The service is responsive to feedback and proactive in making changes

The service collects feedback from service users and carers. Originally, there was a preconception that service users might not be able to answer questionnaires or more complex questions and it was noted that wider dementia services always tended to be focused on carer feedback.

The team worked hard to offer different methods of accessible feedback which has worked really successfully (e.g. focus groups, semi-structured interviews). Quality of life measures help the team to quantitively assess their service and provide data to commissioners. They also supported care planning conversations and are now embedded within the service and are a contractual reporting need.

The team spent time building connections with individuals such as commissioners, so that true change could be made in a timely fashion.

> *"And it was I was sort of quite incredulous for the first few years where, you know, we'd want to make changes to templates and they could be done, you know, almost instantly, you know, in our service. Coming from secondary care, you know, nothing would happen probably for years if you wanted to change something on a on a template." (Nurse)*

The MAS has a low staff turnover and high staff satisfaction due to being an organisation built on workers self management (a teal organisation)

> *"It's what was considered a teal organization. Yes, we have structures, but everyone has a voice. It's not hierarchical in that nature. So yes, [S3] and I have been service leads and everyone can contribute to decision making. When we have issues or problems, we seek advice and guidance from other members of the team. We're very clear that you know the accountability and responsibility will sit with us, but it doesn't mean that we have all the answers." (Head of Dementia Provision and Innovation)*

Site 14 –MAS service with Specialist Occupational Therapy support

Summary

The team identified a gap for a proactive service that helped people to remain as independent as possible during the early stages of dementia. The design of the innovative OT service has been built with people living with dementia and those who support them as well as scoping work and conversations with other national services. The service offers both pre- and post-diagnostic OT assessment and support for all who need it, whether or not the final diagnosis is dementia. The service can loan digital technology to people and work with them over several weeks to help them achieve their personal goals. They also take a holistic and person-centred approach to care offering practical (i.e. benefit advice) and physical (i.e. hearing) healthcare advice. Furthermore, the staff worked hard to find an outcome measure that was sensitive enough to detect subtle changes for the person living with dementia whilst also giving them the opportunity to accurately record their reflections. The AusTOMs was introduced and is working well for service users and staff.

The MAS occupational therapy (OT) service is a new provision that delivers evidence-based pre-diagnostic assessment and post-diagnostic intervention. The service is based within the wider MAS which sits within primary care. The team consists of four band 7 OTs, one of which is the team lead, and two band 4 OT assistant practitioners. Typically, the GP will refer to the service and a band 7 memory nurse will triage the referral and collate a personal history and cognitive profile. The case will then be discussed at a weekly MDT meeting. Service users are referred to the OT team on a needs-based basis. For service users in receipt of OT support, once the OT team have completed their intervention (on average 12 weeks but can be shorter or longer) the service user will be discharged but will remain on the wider MAS caseload. To assist other healthcare professionals (e.g. GP), the OT team conduct re-assessments to determine if there have been any changes to an individual's clinical or functional profile.

What led to you developing the service in this way?

Although the Welsh health board established dementia services for those who are more advanced in their journey (e.g. crisis team, social services, hospital ward-based support), there was a gap for a proactive service that helped people to remain as independent as possible during the early stages of dementia. The service model was arrived at following a collaboration with an OT who was completing their PhD who interviewed a wide range of service users who reported that they would prefer support from the point of diagnosis. Therefore, the design of the service has been built with people living with dementia and those who support them in mind. The updated service coincided with the development of the national dementia strategy. The post-diagnostic interventions that the service offers are designed for people during the early stages of dementia. Interventions include smart technology with the aim of enabling increased independence for tasks that are important to the individual.

> *"Across the UK, where we spoke with Scotland and Ireland and their models of post-diagnostic work was very much sitting with people early. Where you can still embed and learn new things and practice yourself or with minimal support, and with our staffing it was very much key that actually that person could take on board those strategies and really work with those strategies themselves." (Clinical Lead)*

What does the service offer?

A tailored service-user-led system

The development of the service was predicated on the principle that people living with dementia and their care partners have influence over service changes, rather than it being a tokenistic afterthought. This included having service users on the interview panel for new job roles. The team believe that one of the reasons they have been so successful is because they have worked so closely with service users.

> *"We've seen results quicker than what we would have expected because we've got it right." (Clinical Lead)*

From experience, the team found that focus groups did not work, potentially because of their population's age group and also because their geographical area is very large. There were already some established groups up and running so they utilised these for feedback.

> *"We do it in a more informal way than maybe we would have thought we would have done these things. But we find then we get true feedback from people. We've got rapport built with these people and they're more honest and they do give us good feedback." (Band 7 OT)*

The team are passionate about delivering person-centred and tailored care.

> *"So, every material that we've made has been made with that person, so we're just the facilitator of them deciding what the guide is rather than right, I need you to follow this. That's not theirs. That's something that's been prescribed rather than ownership of that's my guide. You just printed it out for me, is how it feels. We put a lot of work in behind the scenes, but that person doesn't need to know." (Clinical Lead)*

Pre- and post-diagnostic OT support

The service offers both pre- and post-diagnostic OT assessment and support for all who need it, whether or not the final diagnosis is dementia. The pre-diagnostic pathway takes a two-pronged approach (1) assessment and a timely diagnosis and (2) the development of a functional occupational profile. The team collects a history and description of the person's routines, interests and performance levels, considering the person as a whole. When the occupational profile is created, it focuses on strengths and changes being experienced and is not risk-focused. The benefits of this method are the person discusses their day with context, and it facilitates exploration of strengths, interests and roles.

> *"To support the consultant and the team, but also to help that person to understand where these changes have occurred, but also then what, what can we do about that." (Clinical Lead)*

Technology based post diagnostic support

The team established a relationship with Digital Technologies Wales and was able to loan equipment, for example, iPads and Echo Dots, to trial with their service users.

> *"How technology can advance somebody's independence, looking at different ways in which we can enable people to be independent rather than just looking at kind of not using technology…there's a perception there with older people, they'll be less likely to use technology, but our outcomes of that are very different." (OT assistant practitioner)*

The team based their interventions around technology that is affordable and is often already in people's homes, or that can be easily purchased from websites such as Amazon. The team will work with the individual over a number of weeks to help them achieve their personal goals.

> *"Some people don't take to it particularly, but the majority I would say, especially when we really consider what that patient, what their goal is, what they're trying to achieve, and how they want it to be integrated within their routine and their life, it's been amazing. It's really changed things for them."*

Holistic support

Service users really benefited from the OT spending time with both the person living with dementia but also the carer. Carers appreciated that although their loved one was the OT's main priority as the patient, they would still spend time listening and supporting them.

Because I did speak to the occupational therapist a fortnight ago or more, more probably because she was phoning to make sure I'm still happy to go ahead with this. And I was having a bad day so she was ages on the phone just chatting with me and giving me information and giving me sort of a bit of help. (Carer)

They also valued the practical advice that was provided.

> *"She's advised these different things that we might be, but we could apply for things like the rate reduction, which I wasn't aware of. You know, if you're not on benefits, if you've worked all your life, you don't know what's out there. Once you're in, it leads to other things." (Carer)*

The team take a holistic and person-centred approach to care, not just focusing on dementia symptoms.

> *"So he's also a bit deaf as well. Yeah. So she referred me to a lady in the [hospital 2], which is further down the valley, she said. Speak to her. So there were. There were lots of different things that probably helped us in ways we didn't even realize we were being helped with." (Carer)*

Connections and projects

The team actively network with a wide range of organisations to find out more about what other services are doing and what research is taking place. For example, the team have established good connections with the Dementia Enabling Environment Project (DEEP) and they had just attended the Alzheimer's Disease International Conference. The staff also have allocated time to do project work.

> *"So, we tend to within our like annual reviews, our PDRs we tend to try and match people [staff] with projects that they're interested in...We're a close team, we do, you know, we try and link it in with kind of career development as well. So, the health board's getting something out of it as well and obviously we're sharing." (Band 7 OT)*

This is facilitated by the team having supportive management who really listens and understands the service.

A flexible approach

The team highlighted how one of the challenges of setting up and sustaining a service is that people's needs and expectations change and that it is important to keep having conversations with people throughout the entire process.

> *"The important part was continuing that journey because it's, it's that person's service who's accessing it at this time. So, we recognize that what people tell us from say 10 years ago may no longer be appropriate as to what services need to look like, but also in five years' time, our service may need to look different as well. So the challenge in the setting up was very much the speed that we could go at because it's quite easy to set a service up and say right, this is what we're delivering." (Clinical Lead)*

They also explained that you need to keep an open mind when it comes to service development.

> *"So, sometimes when you think right, OK, this is how we're gonna set it up and this is what it's gonna look like, people become rigid and unable to change and deviate from that as well. So, I think that's definitely important in, sometimes it's better not to know what you're gonna look like because you can look like what you need to look like." (Clinical Lead)*

Transparent outcome measures and monitoring - AusTOMs

For the pre-diagnostic pathway, the service worked hard to find an outcome measure that was sensitive enough to detect subtle changes for the person living with dementia whilst also giving them the opportunity to accurately record their reflections. The team were aware that some of their service users would have difficulties recalling things and had to take this into consideration, as well as acknowledging that dementia is a progressive condition and deterioration is normal. The AusTOMs was introduced and is administered at three, six and twelve months with a proportion of service users (staff capacity restricts the team from administering the AusTOMs at three time points with everyone).

> *"So, its therapist measured but within there it's very much linked to the person's goals. So, we worked with the author to have the paperwork changed so that the AusTOMs is still the AusTOMs so the validity is still there but we changed the paperwork so that people could write their goals with us and see the goals and measure with us." (Clinical Lead)*

The team also explained that gaining accurate evaluations of people's progress is challenging. For example, individuals can sometimes struggle with Likert scales and rating themselves so they tend to focus more on word-based feedback than quantitative scales.

> *"Recognizing from a therapy point of view that once someone becomes independent they quickly forget that that was a difficulty... You've got them confident you don't want to in that conversation bring them back to the fact that oh my gosh, can you believe I was having difficulty with the remote control?" (Clinical Lead)*

Implementing an effective outcome measure allows the team to evidence that the service is working efficiently and effectively which they can then present to commissioners for future funding.

What are the challenges and how have you overcome them?

Being a victim of success

The service covers four geographical areas. When the team did their scoping exercise to see which areas had unmet OT needs, only two came back saying they did. The team used this feedback to benchmark their staffing and resource requirements. Unfortunately, because of the success of the service, they are now oversubscribed and wait times can be long.

> *"In one of our areas that put in for no OT, we actually get two-thirds more referrals than we do in the other three areas... which is not sustainable and really does then impact on how we sort of manage going forward, what our success is." (Clinical Lead)*

Unlike other teams who may only have one appointment with the service user, the OT team usually have several longer appointments in order to build the functional profile so they really have to consider demand and capacity.

> *"You know, the advice that I would give is if you don't have information is to maybe don't pilot within that area when you start...be up and running and then extend...But we run the risk then of never getting the funding for the other two areas as well. So, it's there. There's no right or wrong way, and it's just about being mindful that actually there are risks to working in a particular field." (Clinical Lead)*

The team are in the planning stages of setting up group sessions which they hope will reduce waiting times.

Questions about where the funding had come from

The funding for the service came from the Welsh Government Dementia Action Plan grant scheme. However, there was a misconception among healthcare professionals that the money had been pulled from neighbouring services.

> *"This is not health board money. We haven't, you know, we know you need more nurses. We haven't pinched that money to offer this service." (Clinical Lead)*

To overcome this the team did lots of presentations and would highlight to colleagues that their funding comes from Welsh Government. The team were also transparent with service users and they now have patient representatives who meet with Welsh Government Officials about the service.

> *"So that empowers that person to know that actually our government under, the World Health Organization, drive for strategies that actually our government is, is proactive and trying to do something. And out of that comes the opportunity to have occupational therapy in, in your memory assessment service. So, we're very much trying to make that that political link as well."*

Not having direct links with social services

The team identified how it would be beneficial to bridge the gap between the primary care OT MAS and social services by employing a designated social worker within the team. Satff spend a significant amount of time signposting people to social services who then encounter barriers around referral streams or clinical diagnoses.

> *"It's a team upstairs. So, you know, we haven't actually physically met people...And we're like if we could just have a conversation around some of these issues, I'm sure, I'm sure it would be a lot easier. So, I think that is something that we need to look at working on and working together with because again we're, you know, we're all trying to achieve the same." (Band 7 OT)*

What do you think the benefits are of what your service is offering?

The service uses very subtle assessment and intervention techniques which truly respect the service users dignity.

> *"The Occupational Therapist nurse came to the house and did a very informal it was a lovely way of doing it in the house. No stress, no waiting around." (Carer)*

Also, as the support starts from the point of referral (i.e. pre-diagnostic), if an individual goes on to receive a diagnosis of MCI, they still have strategies to draw on. This is quite unique as many MAS do not provide interventional support for those diagnosed with MCI. The early and proactive nature of the service means that people can implement strategies to remain as independent as possible throughout their dementia journey. This obviously has an impact on whether people can remain at home and the level of care packages they might need.

Site 15 - Rural Service, nurse led, personalised approach

Summary

The memory service covers a large and very rural area (one of the largest counties in Wales). The service sits within the CMHT and is a consultant led service with a trained nurse whose role is the Dementia Coordinator managing the assessment and post-diagnostic support with part-time support from CPNs. There is no central office location and services are delivered via a range of clinic locations and home working. The service aims to deliver a personalised approach, providing home visits and ongoing individual contact as possible and appropriate.

What does the service offer?

Patients are referred to the service, which sits within a CMHT, by primary care where they are triaged by a consultant Multidisciplinary Team (MDT). Referrals of suspected dementia are dealt with by the dementia co ordinator who makes initial contact and does a pre-screen assessment, checking bloods, ECG and that a brain scan has been requested. The staff member is led by patient need in terms of conducting memory assessments in their homes or at one of several locations in the community that can be accessed by the service. Patients with a diagnoses are offered immediate post-diagnostic support within the service and also referred onto appropriate community connectors and services in the third sector, depending on need. Another significant factor is sourcing good third sector services to make referrals to which enables the staff member to focus on assessments. These services include occupational therapy, physiotherapy, speech and language therapy, continence services, social services and community connectors.

One of the clear benefits of the service is its relationships with the community. The dementia coordinator is highly knowledgeable about local services and is well placed to make referrals to formal or informal services.

> *"If I identify needs... which nine times out of 10 you can safely say there is a need identified, I refer onto another service. So that can either be for occupational therapy, it can be for physiotherapy, speech and language therapy, continence service, social services... our local, what we call community connectors and that's the... the third sector. Who I would say, if somebody was lonely and they needed company, or... is there a luncheon club they could attend or anything? Our community connectors are... I wouldn't be able to operate without them really. They are, like I say, they are my angels really..." Staff member*

Of the local services the staff member said

> *"if there isn't a service there they will do their darndest to try and provide one. Now they gave an example once of a gentleman he was forces you know ex forces and I think he might have had, ... a bit of PTSD ... and Socially he found it difficult to mix with people, but he really liked the garden. So basically cut a Long story short, they ... managed to find somebody who would become his befriender and with a common interest with gardening. And it goes from there."*

Patients are reviewed every 6-12 months by phone or in person and can contact the staff member by telephone at any time. People with an MCI diagnosis are kept on record and contacted once a year if this is their preference. There are around 400 people on the dashboard at any one time and four to eight new referrals a week.

Home visits

Where possible and appropriate the service aims to provide patients with the option of a face-to-face home visit rather than having to travel to a clinic. During Covid-19 pandemic lockdowns many other MAS services were forced to move to working over the telephone. Whilst this service did use the phone, some patients found this difficult. With the knowledge of how valuable home visits were, the staff member continued, wherever possible and permitted, to make home visits wearing PPE and standing in peoples' gardens and garages.

> *"The thing is, people will believe and... and they don't tell you a tale because they want to tell you a tale. They will 100% believe that they're fine. And that they are managing and that they are... [they say] "I still do this, and I still do that". And you get there and it's a completely different story."*

What are the challenges of this model and how have you overcome these?

This personalised model can represent a strong demand on staff resource. However, the staff member is practised at managing her workload effectively. Working from home she can plan home visits to cover certain areas to minimise travel time. The service once covered an even larger area, but when a second service was opened the area was divided and this made the workload more manageable. Pressures of potential staff overload are also eased as patients come to naturally, over time, need less 1-1 telephone contact.

> *"If I'm doing a review that can take an hour, so working out that four or five people is a lot in one day and obviously I wouldn't say, "oh, I'm gonna see somebody in [this village] and [other village] and then [another village]"… I try and stick to the [same] districts, areas in one day." (Staff member).*
>
> *"It naturally drops off as, well, because people come to terms with it. They realise that, you know, that life goes on, doesn't it?… I don't think you can lose really by monitoring people, you know. It's just putting your arm around them a little bit, isn't it?" (Staff member).*

What do you think the benefits are of what your service is offering?

Patient benefits have been identified as arising from the service's personal touch and home visits. By having face-to-face contact the staff member can pick up on any problems more easily in person. Patients, who may be isolated in a rural area and either reluctant or unable to attend a hospital or clinic, can still engage with the service and benefit from seeing a human face. Having an initial single point of contact provides security and continuity for patients, both before and after they are referred to the right support. Patients can also often be more relaxed in their own homes.

> *"I just think people need to feel you… you're human, aren't you? And they're human. And they need to know that they're not on their own … obviously, I make that clear that, 'cause I'm not Wonder Woman, I can't do everything, can I? But you know it's a point of contact, isn't it?" (Staff member).*
>
> *"I would like to see face-to-face consultations on everything. I think it's important. For instance [before retirement], if I wanted to see a new customer, I would not telephone the person. I would make an appointment to see them … you can't beat an initial, face-to-face contact." (Patient supporter).*

The main takeaway from this service's experience is that, where possible, providing patients with the option of a home visit or personal contact by telephone is very beneficial.

> *"It's a lifeline … You're not forgotten, that's the thing, you're not forgotten… She gave us her telephone number, and you can ring it any time of the day or night. And I have…. I mean, I'm 80, my wife's 79 and when you get that old being neglected is a killer. It drags people down. I've got friends, who are older than me, and they're not getting any attention at all. And I think that's dreadful." (Patient supporter).*