

# The 2019 national memory service audit

Authors:

Laura Cook; Clinical Programme Lead

Helen Souris; Clinical Project Manager

Jeremy Isaacs; Clinical Director

Dementia Clinical Network, NHS England  
and Improvement (London Region)

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## Background

It is estimated that there are about 700 000 people living with dementia in England. Due to demographic ageing, this figure is expected to grow, making dementia one of the biggest challenges facing the health and social care system. The Prime Minister's Challenge on Dementia 2020<sup>1</sup> emphasises the importance of timely diagnosis, high quality care and research participation. The government's 2018/2019 mandate to NHS England also sets an expectation to improve the quality of care and support for people with dementia.<sup>2</sup> In 2018, the National Collaborating Centre for Mental Health published the Dementia Care Pathway which sets a national goal to increase the number of people being diagnosed with dementia and starting treatment within six weeks of a referral.<sup>3</sup>

Although dementia diagnosis rates for Clinical Commissioning Groups (CCGs) in England are published monthly by NHS Digital, limited data on memory service performance is available.

In 2015, the London Dementia Clinical Network completed a pilot audit of eight London memory services.<sup>4</sup> Using the pilot audit as a template, a best practice clinical dataset was developed by an expert reference group comprising of primary and secondary care clinicians, memory service managers and commissioners. The group reviewed existing standards, e.g. Memory Services National Accreditation Programme (MSNAP) standards and National Institute for Health and Care Excellence (NICE) guidance.

In 2016, ten London memory services participated in round one of the London audit, contributing data on 590 patients.<sup>5</sup> Variation was noted in neuroimaging practice, neuropsychology referrals, diagnosis subtype, non-dementia diagnoses, waiting times and post-diagnostic support.

Findings from the audit were used to initiate service improvement projects:

1. Streamlining memory service pathways: London memory services were offered a clinical pathway mapping meeting using value stream mapping principles and lean methodology to identify efficiency opportunities. A guidance document on streamlining pathways was published [here](#).
2. Implementing NICE guidelines: clinical advice meetings were held with CCGs to support implementation of the new guideline.
3. Non-dementia pathways: a working group was established to develop advice for primary care and memory services in assessing and managing patients with mild to moderate depression and/or anxiety, cognitive concerns in the context of alcohol misuse, mild cognitive impairment (MCI) and functional cognitive disorder. A guidance document was published [here](#)
4. Neuroimaging guidance: a [guidance document](#) was developed to help memory service clinicians decide which patients should be scanned and which imaging modality to choose.

To review the effectiveness of the above service improvement projects, memory services were invited to complete a second round of the audit. The dataset was updated to reflect changes from the revised NICE dementia guideline<sup>6</sup> published in June 2018 and learning from round one of the audit. In 2019, 20 London services participated in the second London audit contributing to data on 988 patients.<sup>7</sup>

Due to the success of the London memory service audit, the London Dementia Clinical Network decided to open the 2019 audit to services nationally.

## Methods

NHS England/Improvement regional Dementia Clinical Networks were invited to participate in the audit. Participating regions contacted memory services in their region to offer participation. Services were asked to complete the audit tool which consisted of organisational questions and a case note audit of 50 consecutively seen patients from 1<sup>st</sup> January 2019. Data was submitted between May and September 2019. Regional analysis was completed and various local events and webinars were held.

National analysis of data was completed by the London Dementia Clinical Network. Memory services that participated in the audit and other key stakeholders were invited to a one-day meeting in London on 30<sup>th</sup> January 2020 to share and discuss the findings and consider next steps including quality improvement projects.

## Results

Five regions of NHS England/Improvement participated in the audit: North East and Yorkshire and Humber, East of England, West Midlands, London and the South East. In total, 85 services participated in the audit contributing to data on 3978 patients. One service did not provide data on the organisational questions.

49% of the services were MSNAP accredited, 92% were part of a Mental Health Trust and 95% saw patients under the age of 65.

## Demographics

	Overall	Service variation
Mean age	79 Range 30-102	74 - 83
Percentage of patients under the age of 65	7%	0% - 22%
Percentage of patients who were female	57%	35% - 84%
Percentage of patients who lived alone	36%	13% - 62%
Percentage of patients who required an interpreter	4%	0% - 27%
Of those who required an interpreter, the percentage that was provided by family	31%	0% - 100%

Table 1: Demographics

Ethnicity was not stated in 6% of cases. 87% of patients were White British or Irish, 4% Asian, 4% White other, 2% Black, 1% Mixed ethnicity and 1% other. The proportion of people from a BAME group varied between services from 0% to 42%.

Most referrals (94%) came from a GP.

### Opportunities for joint working

18% and 20% of services had no opportunity for joint working with neurology or geriatrics respectively and where joint working was in place it was usually ad hoc advice. 30% of services had no opportunity for joint working with neuroradiology.

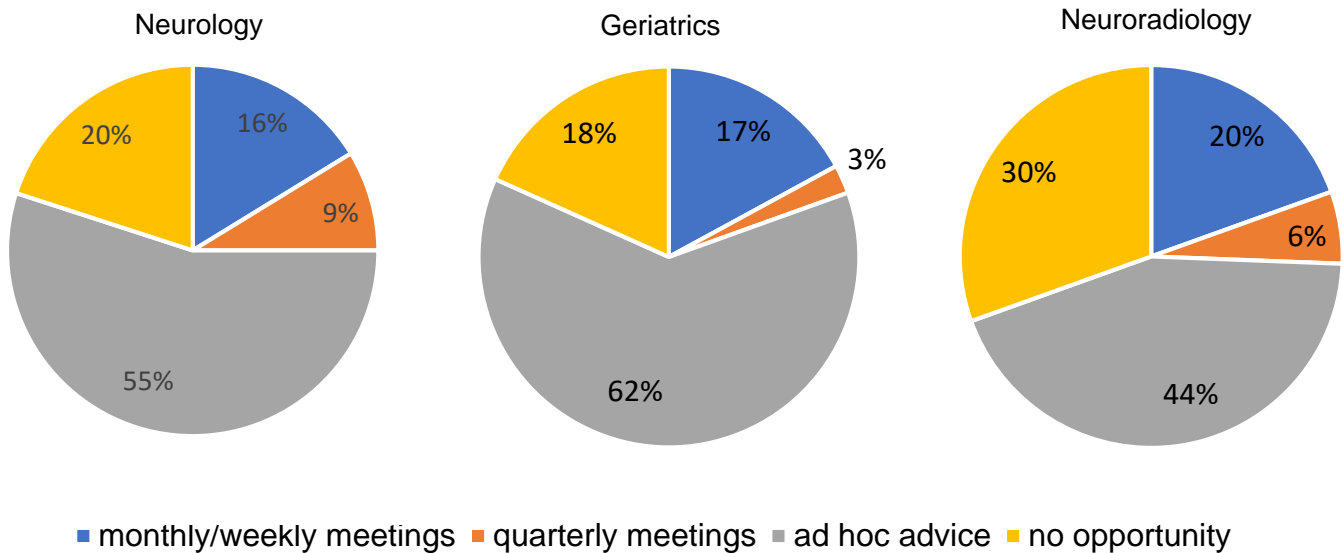


Figure 1: Joint working opportunities

### Alcohol and smoking

Alcohol consumption was not documented in 20% of cases. Where it was documented, 7% of patients reported consuming more than 14 units per week.

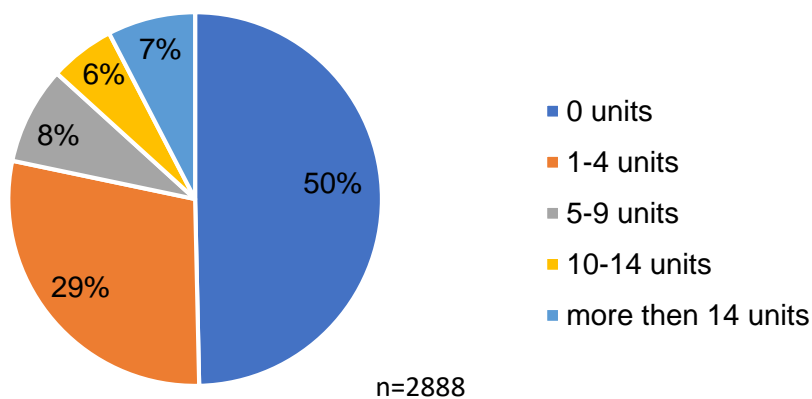


Figure 2: Alcohol intake

Of the patients who reported consuming more than 14 units per week, 52% were diagnosed with dementia, compared with 66% of patients who reported consuming less than 14 units. 10% of people diagnosed with dementia who reported consuming more than 14 units were diagnosed with an alcohol-related subtype.

Smoking status was documented in 19% of cases varying from 0% to 67% per service. Where smoking status was documented 9% of patients were smokers varying from 0% to 35% per service.

### Assessment location

Overall, 58% of patients were seen in clinic for their initial assessment (as opposed to their usual place of residence). This varied from 0% to 100% between services.

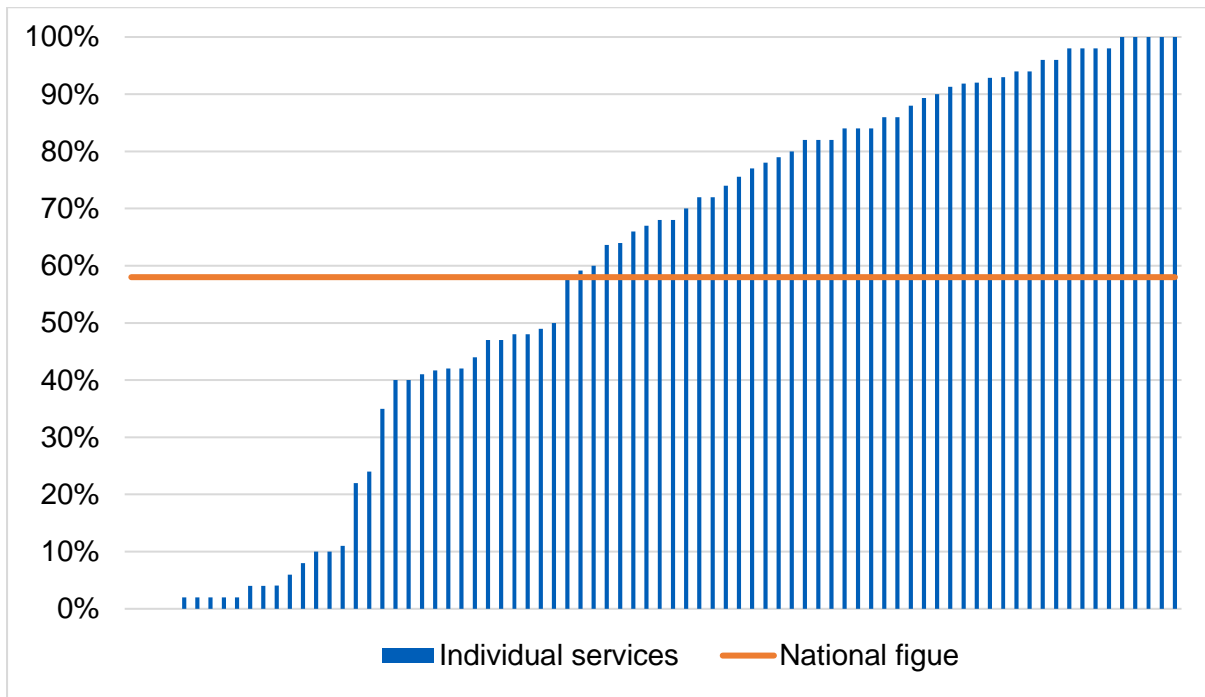
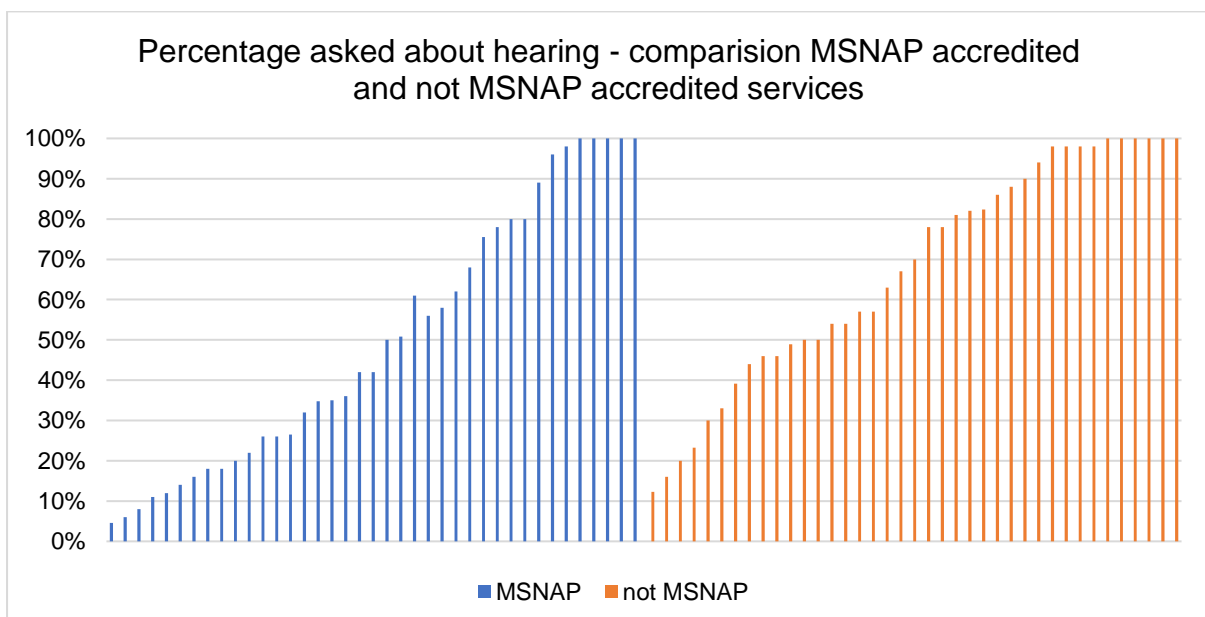


Figure 3: Percentage seen in clinic

### Falls, vision and hearing

71% of patients were asked about falls varying from 6% to 100% per service.

Overall, 57% of patients were asked about their hearing and 61% about their vision, varying between services from 5% to 100%. Only 61% of people diagnosed with MCI were asked about their hearing. The percentage of people asked about vision and hearing was similar for services who were and were not MSNAP accredited.



## Diagnostic neuropsychology

Overall, 11% of patients were referred for diagnostic neuropsychology, eight services did not refer any patients and two services reported that all patients were referred for diagnostic neuropsychology.

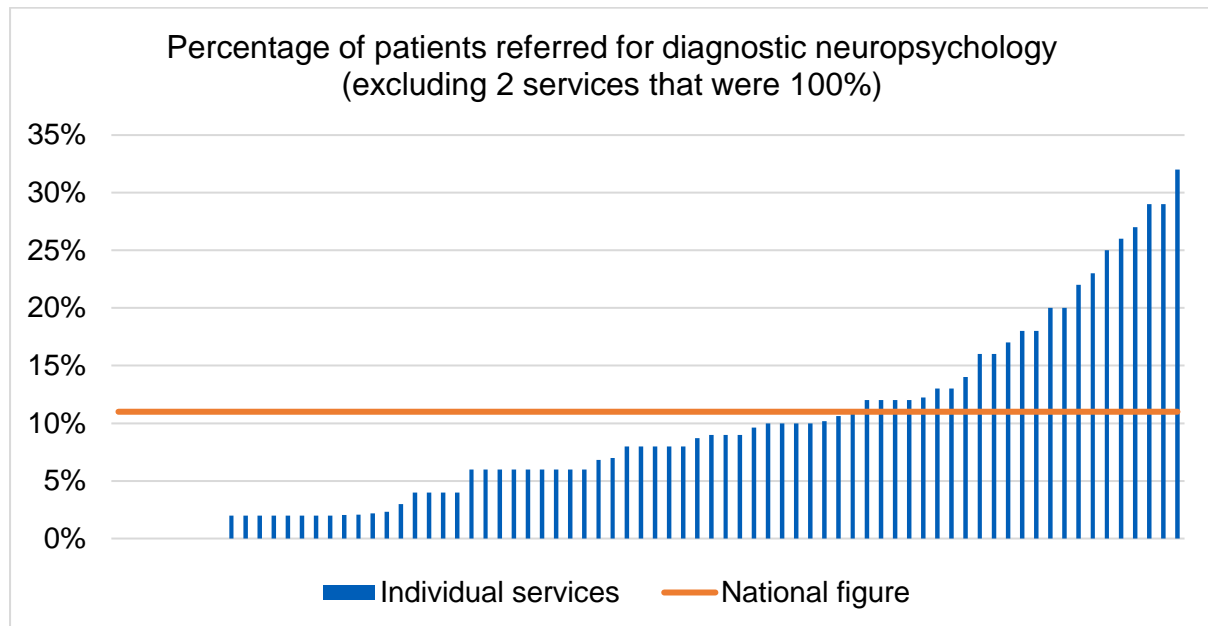


Figure 4: Percentage referred for diagnostic neuropsychology

## Neuroimaging – MRI and CT scans

Only 40% of services could view brain scans. 76% of services stated that scans were reported by neuroradiologists.

Overall, 12% of patients had previously had a scan and 4% refused a scan. 26% of services offered a scan to everyone who had not have previously had one. Overall, 15% of patients were deemed not to require a scan, this varied from 0% to 92% per service.

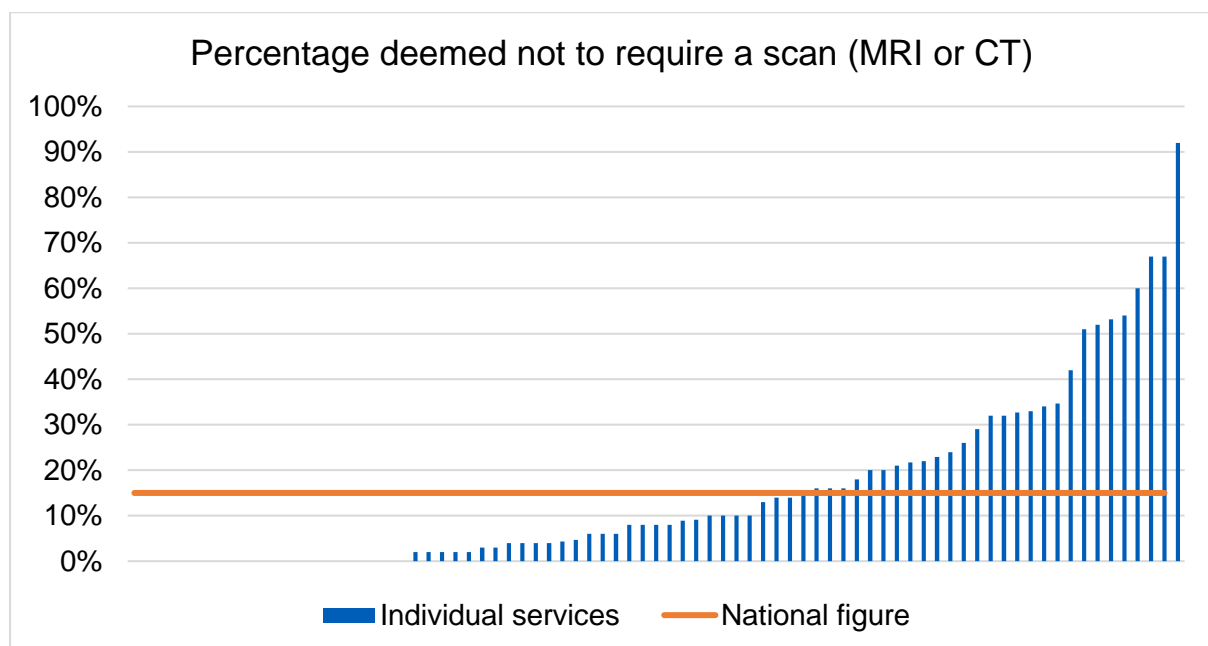


Figure 5: Percentage deemed not to require a scan

Overall, 26% of patients had an MRI scan rather than a CT scan; this varied from 0% to 93% between services. In 8 services none of the patients who had a scan had an MRI scan.

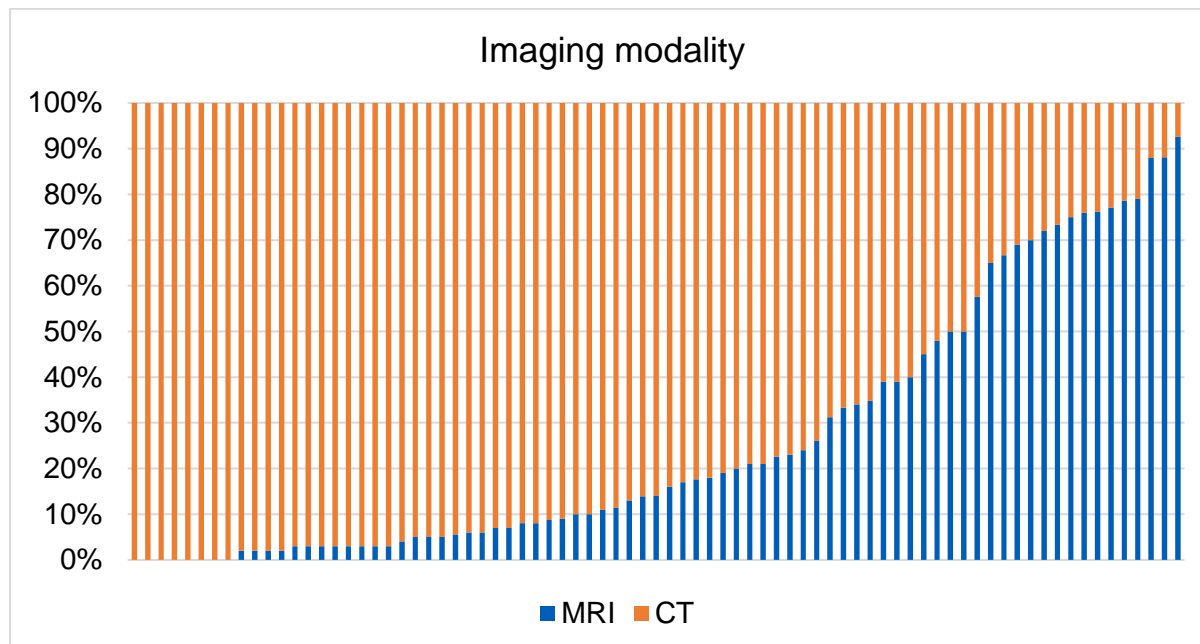


Figure 6: MRI or CT scan

On average people waited 5 weeks for an MRI scan and 5 weeks for a CT scan.

### Specialist investigations

87% of services told us that they could refer patients for DAT scans, 77% for PET scans and 56% for CSF examination. However, in the case note audit, only 2% of patients were referred for one or more of these specialist investigations.

49 patients had a DAT scan, of whom most (46) were over the age of 65, and 37 were diagnosed with dementia. Of those diagnosed with dementia, 38% were diagnosed with dementia with Lewy bodies, 19% with Alzheimer’s Disease, 14% with mixed dementia and 14% with Parkinson’s Disease dementia.

Of all the patients diagnosed with dementia with Lewy bodies, 31% had a DAT scan, and of all the patients diagnosed with Parkinson’s disease dementia, 11% had a DAT scan.

29 patients had a PET scan, of whom 22 were over the age of 65; 4 people were diagnosed with MCI and 13 with dementia; 7 with Alzheimer’s disease, 2 with vascular dementia 1 with frontotemporal dementia, 1 with mixed dementia, 1 with alcohol-related dementia and 1 with unspecified dementia.

4 patients had CSF examination, 2 of whom also had a PET scan. All patients undergoing CSF examination were over the age of 65. Two of the 4 patients who had CSF examination were diagnosed with dementia; 1 with Alzheimer’s disease, and 1 with unspecified dementia.



## Diagnosis under the age of 65

53% of services reported having a named lead for young onset dementia.

Of the 3,978 case notes audited, 271 (7%) were patients under the age of 65. Overall, 23% of patients seen under the age of 65 were diagnosed with dementia and 17% with MCI.

Subtype breakdown in patients aged <65

Alzheimer's disease	37%
Vascular dementia	19%
Alcohol-related dementia	12%
Unspecified dementia	9%
Other dementia	7%
Mixed dementia	7%
Frontotemporal dementia	7%
Parkinson's disease dementia	2%
Dementia with Lewy bodies	No patients

Table 2: Under 65 dementia subtype

Of the patients aged under 65 who were not diagnosed with dementia, 40% of cases had "no diagnosis given", 22% were diagnosed with MCI, 15% with a primary psychiatric diagnosis and 6% with functional cognitive disorder.

## Diagnosis – 65 years and over

Overall, 67% of patients aged 65 and over were diagnosed with dementia; this varied from 22% to 100% per service. Overall, 17% were diagnosed with MCI, varying from 0% to 47% per service.

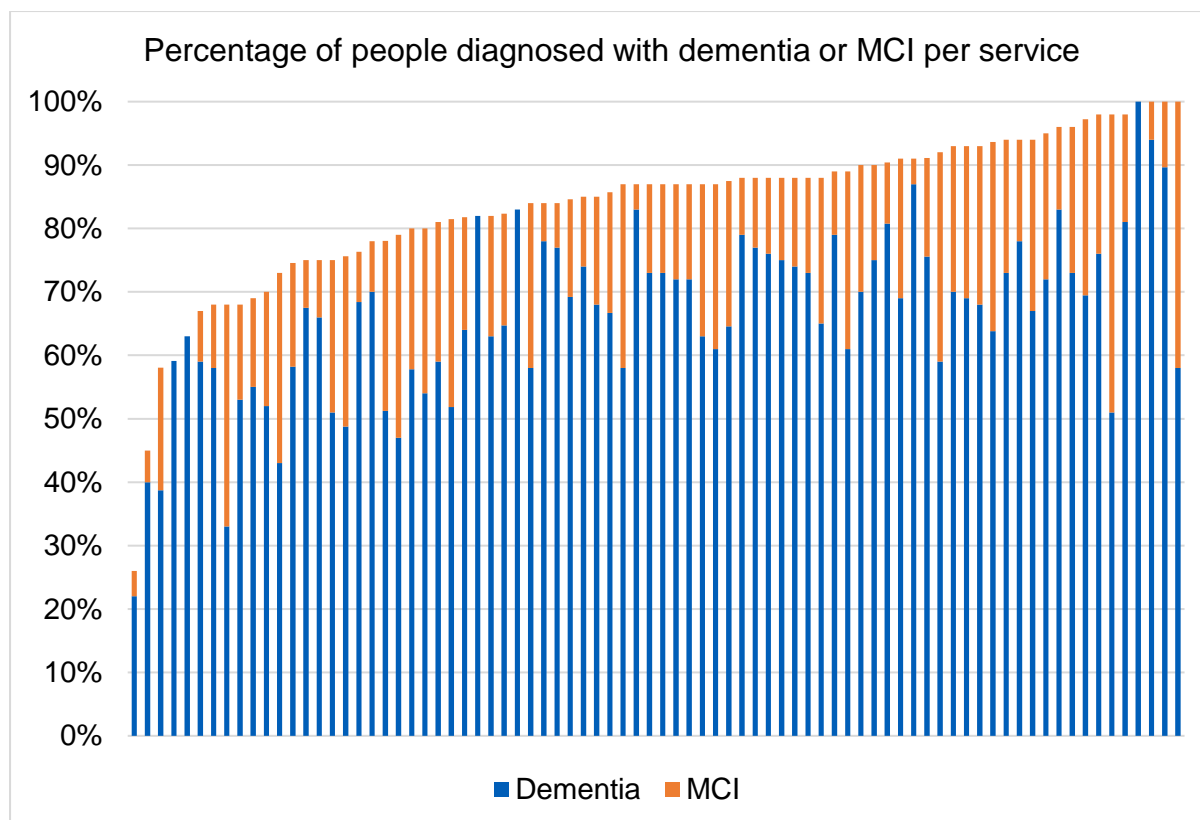


Figure 7: 65 and over dementia and MCI diagnosis

Dementia subtype diagnosis in patients aged 65 and over

Dementia subtype diagnosis	Overall percentage	Service variation	Expected prevalence <sup>8</sup>
Alzheimer's disease	46%	7% - 82%	62%
Mixed dementia	25%	0% - 80%	10%
Vascular dementia	17%	0% - 43%	17%
Unspecified dementia	6%	0% - 50%	<3%
Parkinson's disease dementia	3%		2%
Dementia with Lewy bodies	2%		4%
Other dementia	1%		Other 3%
Alcohol-related dementia	0.4%		<3%
Frontotemporal dementia	0.3%		2%

Table 3: 65 and over dementia subtype

Overall, 71% of patients aged 65 and over were diagnosed with Alzheimer's Disease or mixed dementia and therefore would be considered for cholinesterase inhibitors. This varied from 19% to 95% per service.

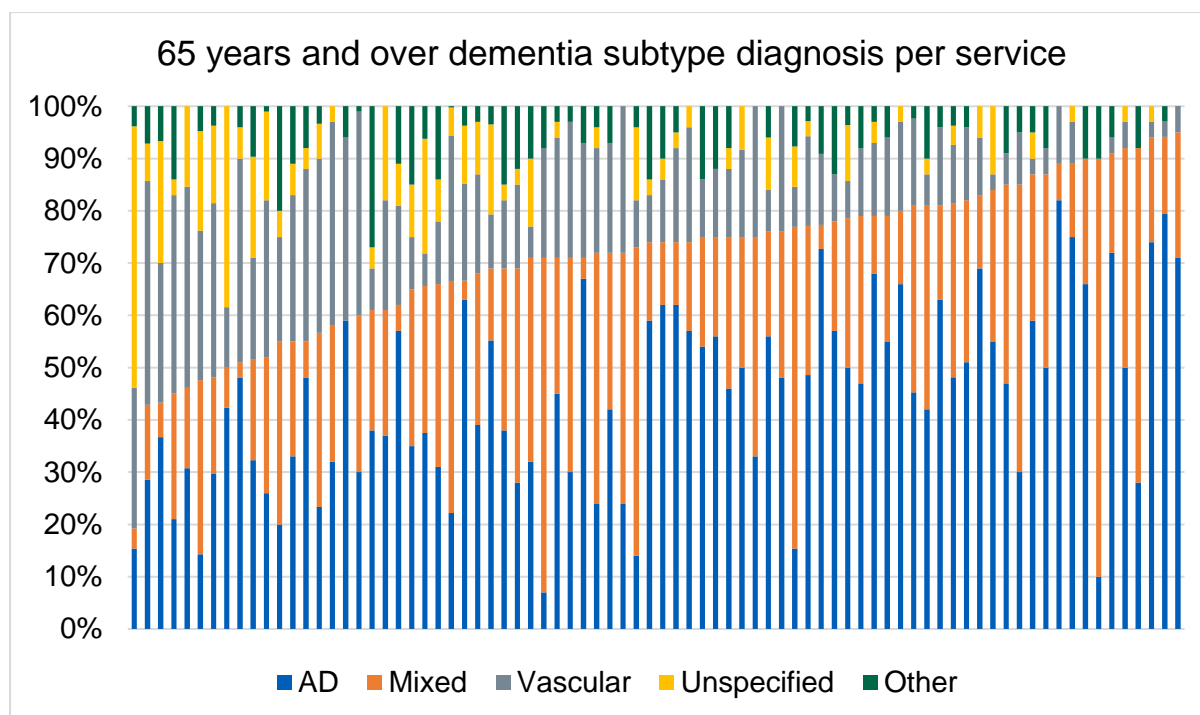


Figure 8: 65 and over dementia subtype diagnosis

Of the 1,121 patients aged 65 and over who were not diagnosed with dementia, 52% were diagnosed with MCI and 5% with a primary psychiatric diagnosis. In 12% of cases 'other' was recorded and 28% of cases were recorded as 'no diagnosis given'.

## Waiting times

The mean waiting time from referral to diagnosis was 13 weeks and varied between services from 3 weeks to 34 weeks. Overall, 26% of patients were diagnosed within 6 weeks of referral varying from 0% to 87% per service.

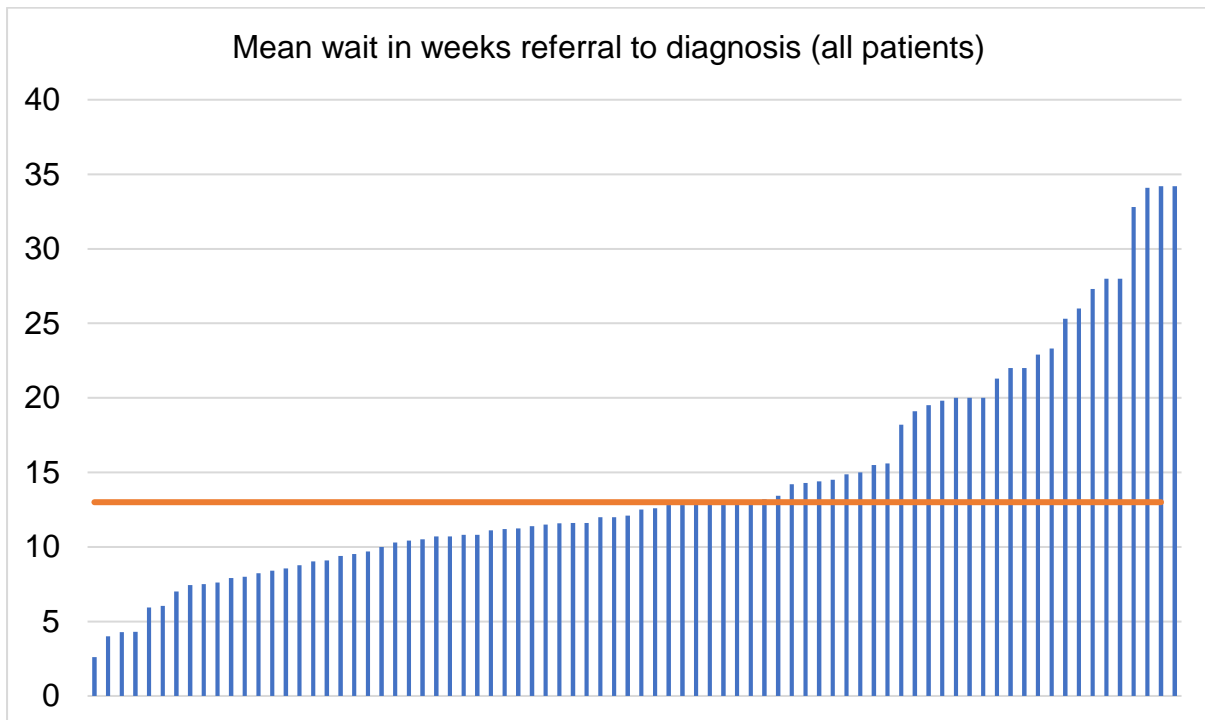


Figure 9 Average waiting times

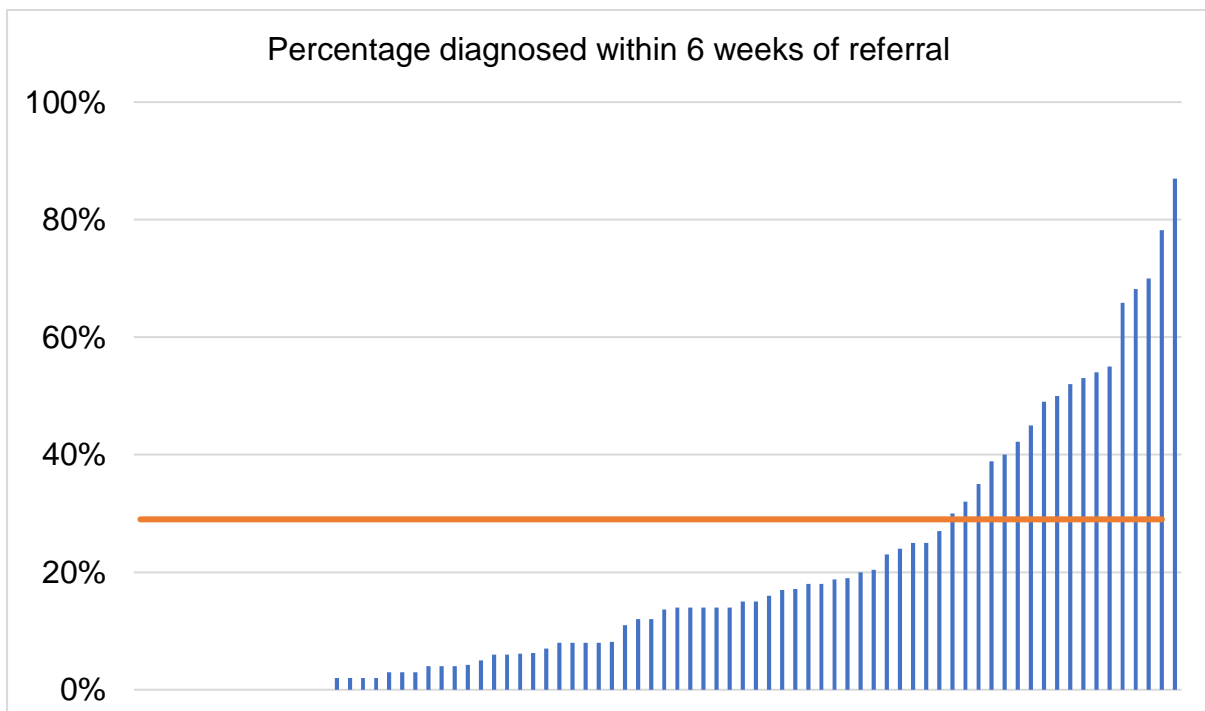


Figure 10 Percentage diagnosed within 6 weeks

## Waiting times young onset dementia

	Aged under 65	Aged 65 and over
Mean wait in weeks from referral to diagnosis (all cases)	13.0	13.0
Mean wait in weeks from referral to diagnosis people diagnosed with dementia or MCI	11.5	13.0
Mean wait in weeks from referral to diagnosis people diagnosed with dementia	12.0	13.4

## Medication

1,785 patients were diagnosed with either Alzheimer's disease, Parkinson's disease dementia, mixed dementia or dementia with Lewy bodies and could therefore be considered for anti-dementia medication. Overall, 83% of patients were offered medication varying from 0% to 100% per service. Most patients (90%) accepted medication.

Of the patients prescribed medication; 76% of patients were prescribed a cholinesterase inhibitor, 23% memantine and 1% both. Of the patients prescribed a cholinesterase inhibitor 90% were prescribed donepezil varying from 43% to 100% per service.

37% of services told us that they requested an ECG for all patients prior to prescribing a cholinesterase inhibitor.

## Cognitive stimulation therapy

25% of services did not provide or were unable to refer to another service for cognitive stimulation therapy (CST). In those services that were able to provide or refer on, 54% of people diagnosed with dementia were deemed not appropriate for CST. Of the 46% who were offered CST, around half (54%) accepted.

In the services that were able to provide or refer on, the percentage of people offered CST varied from 0% (where all patients were deemed not appropriate) to 100%. Of the people offered CST the percentage who declined varied from 0% to 100%.

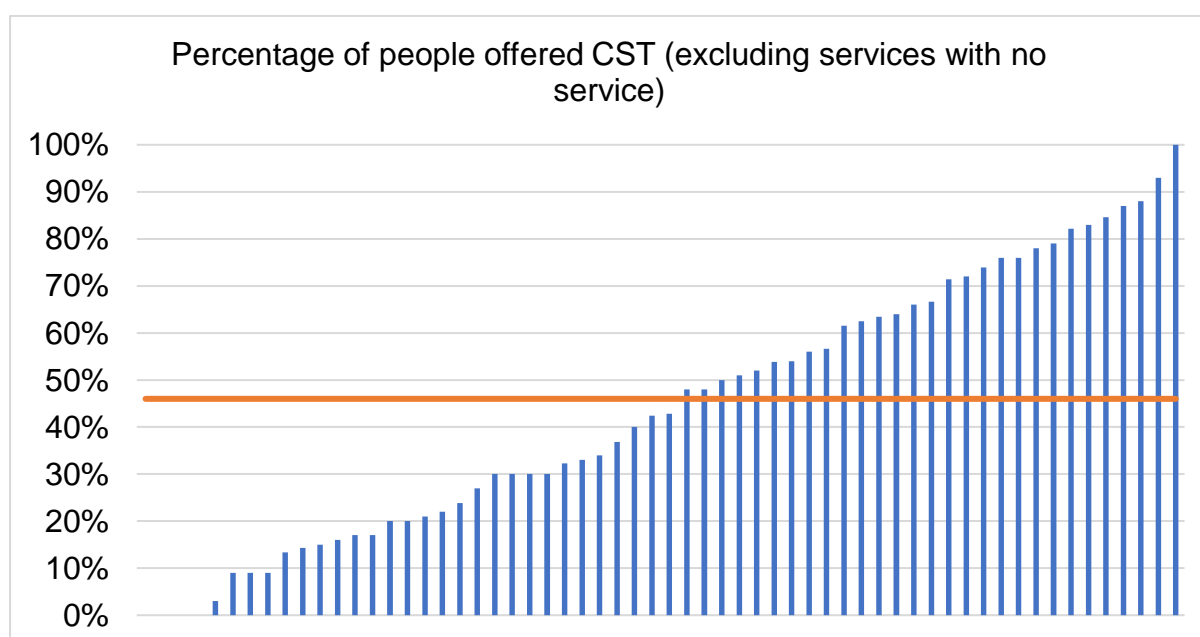


Figure 11 Percentage offered CST

### Dementia advisor type service

Overall, 81% of people diagnosed with dementia were offered a dementia advisor type service; this varied from 0% to 100% between services

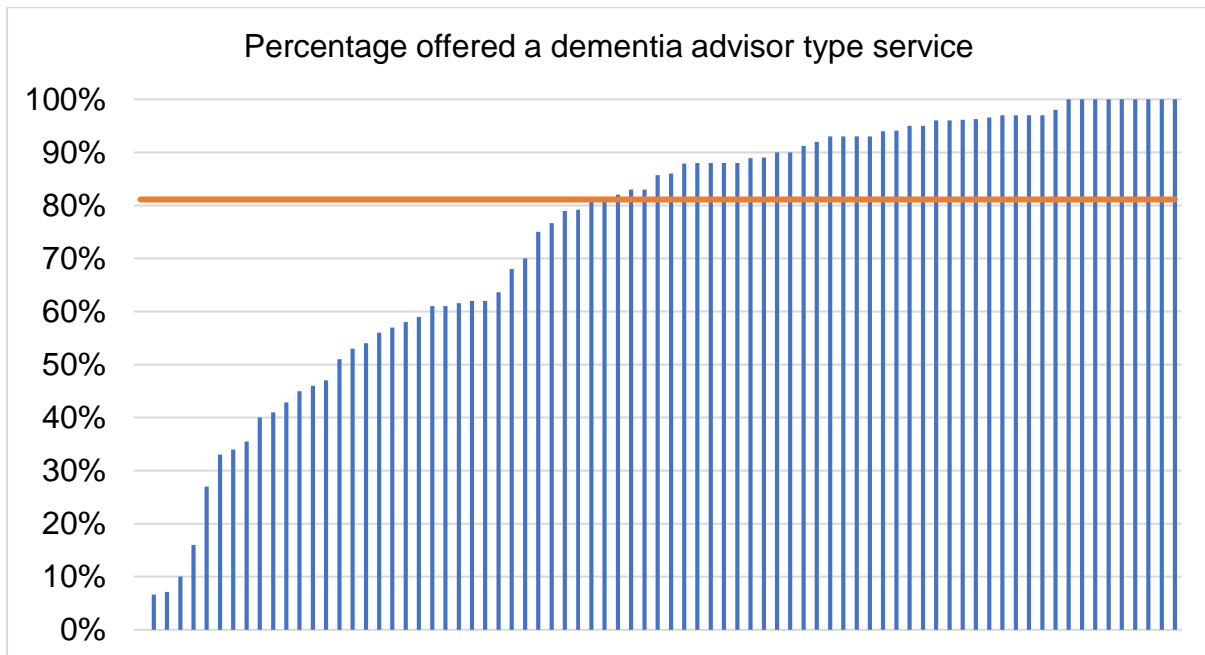


Figure 12 Percentage offered dementia advisor type service

### Carers psychoeducation

26% of services were unable to provide or refer on for carer psychoeducation.

Of the services that did, in 45% of cases it was deemed inappropriate. The percentage of patients where carers psychoeducation was offered varied between services from 0% (where it was deemed inappropriate in all cases) to 100%; overall, 27% declined the service.

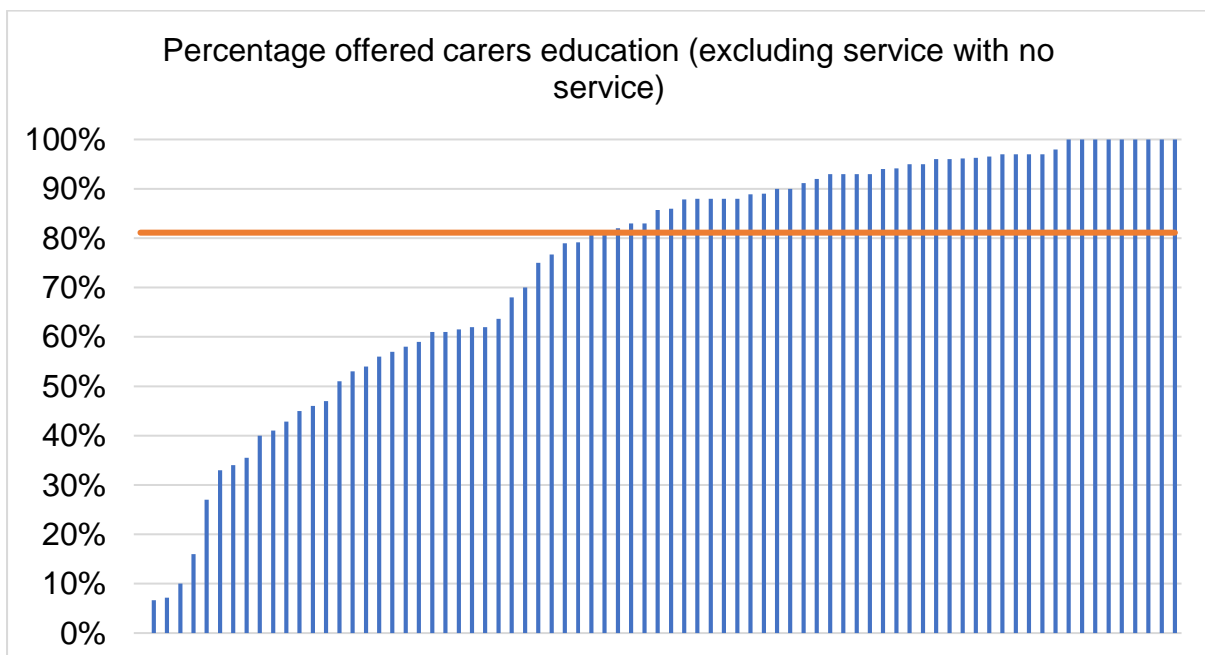


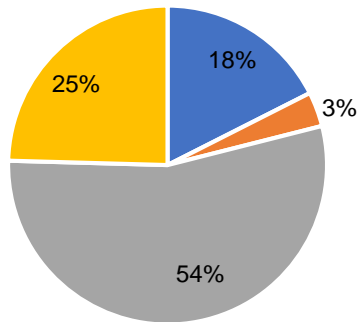
Figure 13 Percentage offered carers psychoeducation

### Post diagnostic support – young onset dementia

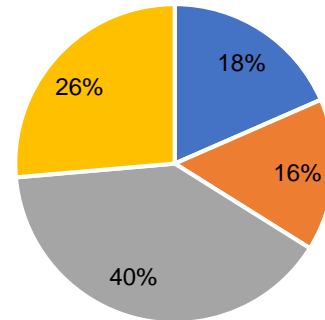
77% of people diagnosed with young onset dementia were offered a dementia advisor, compared to 80% of people over the age of 65.

Overall, more people over the age of 65 were offered CST (34% vs 21%). Of the people offered CST, older people were more likely to decline the service (16% vs 3% in the under 65s).

CST - young onset dementia (all services)



CST - aged 65 and over (all services)

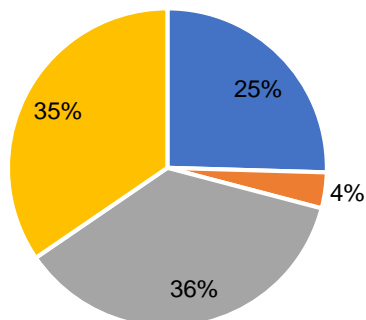


■ Yes accepted ■ Declined ■ Not appropriate ■ No service

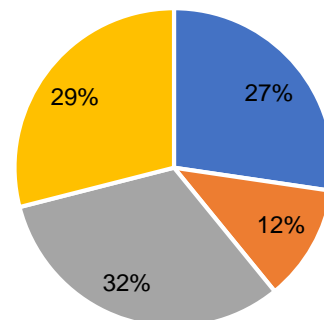
Figure 14 CST young onset dementia

Overall, more carers of older people with dementia were offered psychoeducation (39% vs 29%). Younger carers were less likely to refuse the service (4% versus 12% in the over 65s).

Carers psychoeducation - young onset dementia (all services)



Carers psychoeducation - aged 65 and over (all services)



■ Yes accepted ■ Declined ■ Not appropriate ■ No service

Figure 15 Carer psychoeducation young onset dementia

## Research

81% of services had a named research lead. Overall, 36% of people with dementia were offered consent to contact for research; this varied from 0% to 97% per service.

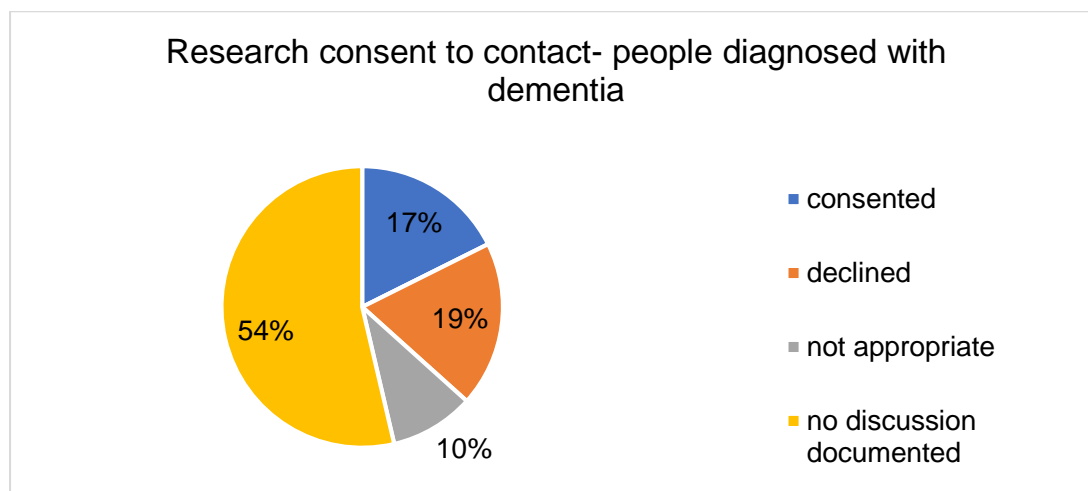


Figure 16 Research – consent to contact

## READ codes

One third of services did not include READ codes on correspondence to primary care. In other services the percentage of cases where coding was included varied from 3% to 100%.

## Event discussions and feedback

110 people attended the meeting on 30<sup>th</sup> January 2020. The day included several opportunities for table discussions and networking. Key discussions included:

### Assessment

The importance of joint working with related specialties and how this could be facilitated remotely, for example by using skype or a similar application.

There were differing views on whether clinic appointments or home visits were more advantageous. Some clinicians noted that they have been unable to increase the number of clinic visits due to a lack of space.

The responsibility for performing hearing and vision assessments was discussed; whether this should be the role of primary care prior to referral or part of memory service physical health checks. Some services said that being involved in MSNAP had improved this as it is one of the standards.

Variation in criteria for requesting neuropsychological assessment and in the banding of the psychology staff who perform the assessments.

Variation in the memory service pathways was also highlighted, e.g. one stop shop models versus multiple assessment appointments. From the audit data it appears that 23% of people were diagnosed at their initial assessment.

### *Investigations*

There was significant variation and a lack of consensus with regards to ECG practice prior to prescribing cholinesterase inhibitors.

There is variation in the commissioning of scans and some pathways require GPs to request scans prior to memory service assessment. Clinical concerns were raised about services that scan very few patients, services that scan everyone, poor quality of reports, some services not having access to MRI scans and services not being able to view scans. Scan waiting times were highlighted as a key barrier to meeting the 6-week pathway.

### *Diagnosis*

MCI diagnosis was a key area of debate. Discussion included the accuracy of diagnosis, whether it is being used as a 'holding' diagnosis and the risk of people with MCI falling through a gap if there is no standardised model of MCI follow-up. One service uses neuropsychology assessment to highlight those with MCI who are more likely to progress to dementia.

There was discussion around why the FTD diagnosis numbers were low; e.g. because there are fewer treatment options, people being diagnosed elsewhere or being misdiagnosed with another subtype initially. The need for training in FTD diagnosis was noted. Some of these concerns might also apply to Dementia with Lewy bodies.

### *Post-diagnostic support*

The offer of post-diagnostic interventions was felt to be largely dependent on knowledge and attitude of commissioners and many services were unable to provide them. Specific issues regarding provision for younger people were noted.

Difficulties providing CST included insufficient staffing levels leading to waiting lists and the need for transport services to bring people to/from the sessions. Some attendees felt it was better for the voluntary sector to deliver CST. The need for better carer psychoeducation pathways with additional input for those with complex needs was noted. Running group sessions, providing videos and running sessions at the same time as CST groups were possible solutions that were discussed.

Some of the barriers to taking consent to contact for research were that it was dependent on local research activity and enthusiasm; there was a perception in some services that it takes too long to have these discussions. Attendees noted that it would be useful to have advice on how to tailor research conversations to facilitate consent and generate enthusiasm for engagement.



## Discussion

This audit has demonstrated marked variation in almost every aspect of the memory service pathway, from assessment practices, to the choice of investigations, to the final diagnosis and access to treatment and support.

To our knowledge, this is the first national memory service case note audit in England. There are around 215 memory services in England; 85 participated in this voluntary audit. Services covered a reasonable geographical spread across England, although the Southwest and Northwest were not represented. Only half of the memory services that participated were MSNAP accredited, highlighting the importance of services who are not MSNAP accredited being able to access opportunities for audit, networking, sharing learning and quality improvement projects. Creating regional memory service forums (as in London) is a key consideration going forward.

The institutional questions highlighted a lack of joint working with other specialities. Around one in five services had no opportunity for joint working with neurology and geriatrics and nearly one in three services had no opportunity for joint working with neuroradiology. Where joint working was available it was often only ad hoc advice. The London Dementia Clinical Network recently completed a multidisciplinary meeting project with South West London STP,<sup>9</sup> which demonstrated the clinical effectiveness of regular meetings between neurology, neuroradiology and psychiatry to discuss clinical cases. Improving joint working with neurology, geriatrics and other services such as Parkinson's clinics was noted as an area for quality improvement. The use of technology to support remote meetings needs to be considered.

There is clearly no consensus on whether patients should be assessed at home or in clinic, which suggests that there isn't agreement on whether there is any clinical benefit from performing a domiciliary assessment in all cases. Once patient need is taken into consideration (e.g. people who are housebound needing a home visit), given the equipoise on the clinical advantages of home versus clinic, the decision should be based on cost/productivity considerations, which clearly favour clinic assessment. In some areas home visits are conducted by Community Mental Health Teams, and therefore not captured by this audit, which may account for some services having very high numbers of patients seen in clinic. If services choose to move to a clinic model, which may support a reduction in waiting times, then they should be supported by commissioners to have access to adequate clinic space.

Generally, more people are being asked about alcohol consumption, smoking and falls history than vision and hearing. Of note, only 61% of people with MCI were asked about their hearing, which is an important consideration due the importance of hearing aids for primary dementia prevention.<sup>10</sup> Asking about hearing and vision are MSNAP standards and services anecdotally reported that MSNAP accreditation had improved compliance, although the audit data suggested there was no difference in practice between services that were and were not MSNAP accredited. We are not aware of any national guidance on hearing and vision assessment in memory services and this was highlighted as an area for quality improvement.

Variation was noted in the percentage of people referred for diagnostic neuropsychology, suggestive of under provision in some services and possible over-referral in others. There also appears to be a lack of standardised criteria for which patients should be referred for diagnostic neuropsychology.

60% of memory services are unable to view brain images that they have requested, as they do not have access to PACS (picture archiving and communication system). Viewing brain images can support a diagnosis (including subtyping) as images can be re-interpreted alongside the patient's clinical features. Also, patients (and carers) often find it helpful to be shown their scan. Improving access to PACS was noted as a key area for quality improvement; local healthcare systems need to ensure access to PACS for Mental Health Trusts.

A quarter of services offered everyone a scan who had not previously had one, while some services are offering very few patients a scan. The NICE dementia guideline states that structural imaging should be offered to rule out reversible causes of cognitive decline and to assist with subtype diagnosis, unless dementia is well established and the subtype is clear.<sup>6</sup> Given the disadvantages of imaging; (e.g. discomfort, incidental findings), it would be a reasonable expectation that services may decide not to scan some of their patients.

The NICE dementia guideline does not specify whether CT or MRI is the preferred modality of investigation except in uncertain cases of vascular dementia, where MRI is favoured.<sup>6</sup> Therefore, services that use MRI as their default imaging modality may be subjecting patients to additional discomfort (claustrophobia, longer acquisition time, greater risk of finding incidental abnormalities) and incurring greater cost. Conversely, services that rarely or never use MRI may be missing opportunities to identify vascular pathology in patients where this is clinically relevant.

The NICE dementia guideline states that if the diagnosis of Alzheimer's disease is uncertain, clinicians should consider either cerebrospinal fluid examination (CSF) or FDG-PET.<sup>6</sup> Although 77% of memory services reported that they were able to refer patients for PET scans and 56% reported having access to CSF examination, the actual number of patients in the audit referred for these investigations was very low. Joint working with neurology and clear local or regional pathways will enable patients to access specialist investigations when required. Appropriate patient selection for biomarker tests is important. The NICE dementia guideline reminds us that CSF biomarkers lose specificity with increasing age. It is therefore notable that all of the patients who received CSF analysis were aged over 65. The purpose of biomarker-based investigations is to refine the sub-typing process. It is therefore interesting that several patients who underwent CSF or PET imaging were nevertheless diagnosed with mixed or unspecified dementia.

DaT scans have an important role in the diagnosis of dementia with Lewy bodies. However, their use in diagnosing Parkinson's disease dementia is not supported by current clinical guidelines. PDD is the presence of dementia in someone who has had motor features of PD for at least one year. In someone with an established diagnosis of PD, a DaTscan cannot determine whether the dementia is due to PD or another cause. Services where DaTscans are being performed in patients who are then diagnosed with PDD need to review their referral criteria to ensure that they are appropriate. Joint working with neurology is a good way to reduce unnecessary investigations.

Variation was noted in the percentage of people aged 65 and over who received a dementia or MCI diagnosis. This, and the discussions during the event, indicates a lack of consensus on the use of MCI as a diagnosis. This audit did not review conversion rates from MCI to dementia in different services, which could be considered for a future audit.

It appears that frontotemporal dementia is being under-diagnosed in both older and younger cohorts. Consensus documents suggest that the proportion of dementia in the over 65s due to FTD is 2%<sup>8</sup> compared to 0.3% in this audit. Data from younger cohorts suggests that FTD constitutes 30% of incident young-onset dementia<sup>11</sup> compared to 7% in this audit. This could be partially explained if FTD is diagnosed in other settings e.g. neurology clinics or community mental health teams, and patients bypass the initial memory service assessments covered by this audit. Underdiagnosis of FTD was a key area of discussion during the event, and clinicians reported that they would benefit from specific training in this area.

Marked variation between services was noted in dementia subtype diagnosis, which may indicate lack of adherence to standardised diagnostic criteria. The 2018 NICE guideline recommends that clinicians use validated criteria to guide clinical judgement.<sup>6</sup> A potential consequence of misdiagnosis is that people are not offered cholinesterase inhibitors as they are incorrectly diagnosed with for example, vascular dementia instead of mixed dementia or Alzheimer's disease. With the potential emergence of disease-modifying treatment, accurate subtyping will likely become even more important.

Among ageless services, half had a named lead for young onset dementia. Most people (77%) under the age of 65 who were seen did not have dementia. The most common non-dementia diagnosis was MCI followed by a primary psychiatric diagnosis. Services need to continue to implement effective non-dementia pathways<sup>12</sup> and ensure adequate triage processes and joint working with local IAPT services.

The National Collaborating Centre for Mental Health's Dementia Care Pathway was published in 2018<sup>3</sup> and recommended an increase in the number of people being diagnosed and starting treatment within 6 weeks of referral. This audit has shown that there is variation in waiting times; while some services are close to achieving the six-week ambition, in other services people are waiting on average over 6 months for a diagnosis. Memory services should consider how they can continue to streamline pathways to work towards this ambition, e.g. using value stream mapping methodology<sup>13</sup> to identify where efficiencies can be made according to "lean" principles. A guidance document on streamlining memory services was published by the London Dementia Clinical Network in 2017<sup>14</sup>, highlighting examples of efficient pathways from current practice. The audit has demonstrated that on average people are waiting 5 weeks for a brain scan, not including additional time for the scan report to be received. This needs to be addressed to ensure that imaging waiting times support the 6-week pathway. Management of DNAs was also highlighted as a key consideration to meeting the 6-week pathway.

Previous research has shown long waiting times for a diagnosis of young onset dementia.<sup>15</sup> This audit demonstrated similar waiting times for people aged under 65 and those aged 65 and over. It should be noted that the audit only measured time from referral to diagnosis, not from symptom onset to diagnosis. There were also proportionally more younger people where the diagnosis was stated as 'no diagnosis given' or there was a data omission; 28% of under 65s vs 13% in older people. Therefore, some younger people with dementia may have not received a diagnosis prior to the census point, which could have skewed waiting time results. It should also be noted that a large proportion of younger people seen in memory services likely have Functional Cognitive Disorder (FCD) and that a label of "no diagnosis" is a missed opportunity to provide appropriate advice and treatment for this condition.<sup>16</sup>

The NICE dementia guideline published in June 2018<sup>6</sup> recommends cognitive stimulation therapy, psychoeducation for carers and provision of care coordinators. It is clear from the audit that a significant number of patients and carers are not being offered CST and psychoeducation respectively, and there is wide variation between services. Access appears worse for people with young onset dementia. Commissioners should review current practice and service provision against the updated NICE guideline using the baseline assessment tool,<sup>17</sup> and consider opportunities to improve access to evidence-based post-diagnostic support, either in the memory service or in another setting e.g. voluntary sector, with specific consideration to the differing needs of people with young onset dementia.

For people diagnosed with dementia, there was no documented discussion about research participation in just over half of the cases audited. A standard script was suggested to support clinicians to have conversations about research, which might also reduce the perception of some clinicians that these conversations take too long.

READ Codes are a coded thesaurus of clinical terms and are currently used in the primary care system. Including READ codes on correspondence to primary care helps to ensure that the diagnosis is correctly recorded on the system. Standardising this information on GP letters was noted as a quality improvement project and this may also help to improve dementia diagnosis rates by ensuring accurate coding.

## Next Steps and key areas for quality improvement

There was a general consensus that the audit should be repeated, but further discussion is required on time frame, what data can be automatically pulled from electronic records and what time of year to complete the data. The audit tool should be updated to reflect the areas of improvement discussed e.g. making distinction between the 'no diagnosis given' field and a data omission clearer. The National Audit of Dementia hosted by the Royal College of Psychiatrists is planning a spotlight audit on memory services, which should incorporate the learning from this audit.

Key areas to be considered for national/local quality improvement projects

- Creating local memory service forums
- Improving joint working with neurology and geriatrics
- Establishing appropriate vision and hearing pathways
- Improving access to PACS
- Reducing the variation on the use of MCI as a diagnosis and auditing conversion rates to dementia (e.g. in MCI clinics)
- Creating a 'consent to contact' for research script
- Continue service improvement projects to improve waiting times
- Including standardised coding on clinic letters
- Specific training and education on frontotemporal dementia
- Minimising use of "no diagnosis" as an endpoint of memory service assessment, particularly in younger people, and improving awareness of Functional Cognitive Disorder.

The value of national case note audits that allow services to benchmark against each other, as well as against national standards, is well-established, with exemplars in stroke, cardiac surgery and hip fracture.<sup>18</sup> The National Audit of Dementia examines the care received by people with dementia in general hospitals; it has raised the profile of dementia care in the acute sector and encouraged hospital leaders to focus on raising standards.

We believe that memory services are ideally placed to benefit from a national audit. They are generally commissioned to provide a similar pathway i.e. from referral from primary care with symptoms suggestive of dementia to a diagnosis and initial treatment and support. Dementia remains a serious, life-limiting and much feared condition. It is vitally important that the diagnostic process is prompt, accurate and properly resourced while also being cost-effective. Access to NICE-approved post-diagnostic support should be an expectation, not a privilege. Given the widespread variation in diagnosis and care demonstrated by this audit, we hope that memory services and the regional clinical networks that support them will use our findings to prioritise their quality improvement projects and that a national re-audit will be possible after an agreed interval.

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