Understanding dementia memory services across London

NHS

London Clinical Networks

May 2016

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Summary / Key findings	Recommendations	Audit results	Conclusion / Next steps	Appendices

Table of contents

| Summary / Key findings	Recommendations	Audit results	Conclusion / Next steps	Appendices

Executive summary | Key findings

The London Dementia Clinical Network effective diagnosis work stream carried out a clinical audit to provide a baseline picture and review memory services across London. Eight of the London memory services took part in the audit.

Key findings
Patient demographics
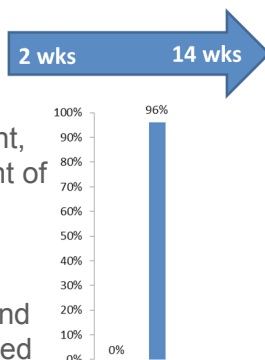Of those patients with a diagnosis of dementia:
» 48% live at home alone
» 43% have a named carer
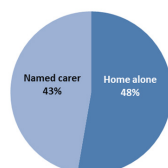
Referral and assessment
» The average wait to be seen ranged from 2 to 14 weeks.
» There was significant variation in practice on home assessment, ranging from zero to 96 per cent of patients first seen at home.

Investigations
» There was mixed practice around the percentage of people referred for scans and the modality of imaging requested.
» There was variation in waiting times for scans, ranging from 28 to 95 per cent of patients having a CT scan within 30 days of their assessment date.

Diagnosis
» The proportion of referred patients who received a diagnosis of dementia ranged from 37 to 96 per cent.
» The average wait from date referral received to date of diagnosis ranged from 4 to 19 weeks.
» There was significant variation in the type of dementia diagnosed.

Treatment
» Access to cognitive stimulation therapy was limited and varied.
» The number of patients being involved in clinical research discussions was low.

Post diagnosis support
There is variation in the number of patients referred to a dementia advisor.

Conclusion
The audit reveals substantial variation between services. Access to timely assessment, imaging, neuropsychology and post diagnosis interventions is very variable. Diagnoses vary widely from service to service although this is based on relatively small numbers of patients. Patients are generally not being asked about participation in research.

Next steps
Based on the audit result, several recommendations have been produced to improve practice and reduce variation. These will be disseminated via the London Memory Assessment Network. The audit will be repeated in late 2016. All memory services in London will be encouraged to take part. The audit parameters will be refined without losing impact. Round two data will remain anonymised, but will be shared with commissioners to cement buy in and resourcing.

Executive summary | Recommendations

Following the feedback session with members of the participating services and review of the results by the *Effective diagnosis* work stream, the Dementia Clinical Network has issued the following recommendations to memory services in London in preparation for round two of the audit.

» **Services should aim to assess all new patients within six weeks of referral** as proposed in the Prime Minister's Challenge on Dementia 2020.

» In order to reduce delays, **services should consider seeing patients even if full blood tests have not been completed in primary care**.

» **Services should review their contracts with their imaging provider**(s) to ensure that they have access to both CT and MRI and that scans will be performed and the report made available within four to six weeks of request.

» **Services should explore how they can obtain access to their imaging provider's PACS system** so that scans can be viewed directly.

» **Services should consider establishing a regular meeting with a neuroradiologist** to review scans (eg monthly or quarterly). Services could join together to hold a regional meeting. Inviting the regional neurologist(s) with a specialist interest in cognition is recommended.

» **Services should offer all older patients a falls risk assessment.** An example of a brief tool is provided in *Appendix 5*.

» **Services should monitor whether patients have been referred for cognitive stimulation therapy** and record the reason(s) why this isn't available or taken up.

» **Services should establish a mechanism for recording patients' consent to be contacted about research** and provide information about Join Dementia Research.

» **Services should ensure that all staff are aware of the local dementia advisor or navigator service**.

Summary / Key findings	Recommendations	Audit results	Conclusion / Next steps	Appendices

Introduction

Clinical Networks were established to provide clinical expertise and leadership to drive commissioning decision making, reduce variation and direct service improvements. They serve to bring providers, commissioners and patients together to create alignment around programmes of work to improve patient care. Clinical directors lead each network, along with associated clinical leadership groups.

Effective diagnosis was identified as a priority area, in line with national priorities and the Network's stakeholders. A timely, accurate and impactful diagnosis results in more effective dementia care and support.

The London Memory Assessment Network was formed in 2014 as a project of the effective diagnosis work stream. The network aims to:
» Share best practice in clinical care and service design
» Provide continuing professional development (CPD) and learning opportunities that are not readily available elsewhere
» Reduce variation in care and improve quality.

Through expert consensus in the effective diagnosis working group and stakeholder discussions with memory services, data fields for a proposed pan-London memory service audit was generated. The aim of the audit is to allow memory services to benchmark their patient pathway and clinical outcomes against similar services, and to understand capacity across the region.

Rationale

A memory service is defined as a multidisciplinary team that assesses and diagnoses dementia and may provide psychosocial interventions for dementia[1].

The *Establishment of memory services* report[2] states that a memory assessment service should be able to:
» Offer home based assessment when requested
» Give pre and post-diagnostic counselling
» Make the diagnosis of dementia accessing specialist psychometric assessments and timely brain imaging where necessary
» Explain the diagnosis
» Give information about prognosis and options for care
» Provide advice and support
» Provide pharmacological treatment of dementia;
» Follow-up and review patients.

There are 32 memory services in London providing assessment, diagnosis and treatment of dementia. Some services provide follow-up care (eg to monitor medication) and support for the person with dementia and their family and carers.

Scope
The audit invited participation from all memory services in London. Tertiary cognitive services were not included.

Aim of the audit
» Assess delivery of memory services against a set of 'best practice' standards derived from NICE guidance and strategic clinical network aspirations.
» Allow memory services to benchmark their patient pathway and clinical outcomes against similar services and to understand capacity across the region.
» To reveal variations between services to guide improved practice.

1. *English national memory clinics audit report*.
Royal College of Psychiatrists (2013). *Link*
2. *Establishment of memory services: Results of a survey of PCTs*.
NHS Information Centre (2011). *Link*

Method

Dataset development

The effective diagnosis working group was established in early 2014. The group consists of primary and secondary care clinicians, memory service managers and commissioners. The group reviewed existing standards, e.g. NICE guidance, national frameworks, available status reports on memory services and best practice and agreed a manageable patient level dataset. In the development of the dataset there was input from memory services. (*For membership of the working group, see Appendix 2.*)

Dataset structure

The dataset consisted of items on the following areas:

» Organisational
» Patient demographics
» Referral
» Assessment and investigation
» Diagnosis
» Treatment
» Follow-up

(*See Appendix 3 for the full dataset.*)

Identifying eligible memory services in London

Services were contacted through the following means:

» The names and contact details of current clinical and service team leads were identified.
» Clinical leads and service leads were sent a letter via email outlining the purpose of the audit and inviting the service to participate. (*See Appendix 4.*)

Services were given a period of 10 weeks to complete and return.

Sampling frame

Consecutive, new undiagnosed patients referred to the memory service from 1 January 2015 onwards, until a minimum of 50 per service was reached.

Results

Response rate

Eight out of 32 memory services in London responded, representing a response rate of 25 per cent. Services are anonymised throughout the report.

Service 8 submitted data only on patients who progressed to a diagnosis of dementia.

Excluded patients

Some services misinterpreted the sampling frame and submitted data only for patients who were seen, instead of all referrals whether seen or not. Therefore to achieve consistency and allow comparison between services, the following patients were excluded from the analysis:

» Patients already known to service (eg returning for follow up appointments)
» New referrals that did not attend the first memory service appointment
» New referrals that cancelled the first memory service appointment
» New referrals that were not seen by the memory service and instead referred to tertiary centres.

There were 34 patients excluded from the audit.

Organisational data items

The audit included four organisational data items:

» The organisation providing the memory service

» Whether the memory service is accredited by the Memory Service National Accreditation Programme (MSNAP).

» Whether the memory service is integrated with a consultant geriatrician and/or consultant neurologist.

» Whether the memory service provides home assessments.

Accreditation

The Memory Services National Accreditation Programme works with services to assure and improve the quality of memory services for people with memory problems/dementia and their carers. MSNAP is an initiative of the Royal College of Psychiatrists Centre for Quality Improvement. In London, 11 memory services are MSNAP accredited, three services are affiliated and two are in review stage.

Table 1: Organisational data item results

Memory service	Organisation providing service	MSNAP accredited	Integrated clinic (geriatrician +/- neurologist)	Home visit service provided
Service 1	Mental Health Trust	Yes	No	Yes
Service 2	Mental Health Trust	Affiliated	No	Yes
Service 3	Mental Health Trust	No	No	Yes
Service 4	Mental Health Trust	Yes	No	Yes
Service 5	Mental Health Trust	No	No	Yes
Service 6	Mental Health Trust	No	Yes, with a geriatrician	Yes
Service 7	Mental Health Trust	No	Yes, with a geriatrician	Yes
Service 8	Mental Health Trust	Yes	Yes, with a geriatrician	Yes

Patient demographics

The audit included the following patient demographic information:

» Age at referral

» Gender

» Ethnicity

» Usual place of residence.

Data was also collected on whether the person:

» Lives alone

» Has a named carer

» Required advocacy and interpretation services.

Table 2: Referral summary

Memory service	Number of patients	Total male	Total female	Median age at referral	% of patients under 65 years
Service 1	50	15	35	80	10%
Service 2	27	11	16	82	0%
Service 3	45	16	29	82	11%
Service 4	22	5	17	82	0%
Service 5	45	18	27	82	9%
Service 6	43	25	18	74	23%
Service 7	35	14	21	79	14%
Service 8	28	8	20	82	0%

| Summary / Key findings | Recommendations | Audit results | Conclusion / Next steps | Appendices |

Gender
In 2015 it was estimated that 61 per cent of people with dementia in the UK are women and 39 per cent are men[3]. This is likely to reflect the fact that women live longer than men and age is the biggest known risk factor for the condition. Apart from Service 6, a greater number of referrals were female. *(See Table 2, page 7.)*

Age
The median age at referral for the majority of services was 79 to 82 years. The median age for Service 6 was 74 years. Service 6 also had a higher number of referrals under 65 years when compared to all other services. Of all referrals under 65 years, 70 per cent were male. *(See Table 2, page 7.)*

Ethnicity
London is a diverse city. The Office of National Statistics reports that 40 per cent of Londoners (more than 3.2 million) are from black, Asian and minority ethnic groups[4]. A similar proportion was reported in the audit, as an average across the services reported that 35 per cent of patients referred were of black, Asian and minority ethnic background. *(See Figure 1.)*

Figure 1: Percentage of BAME referrals
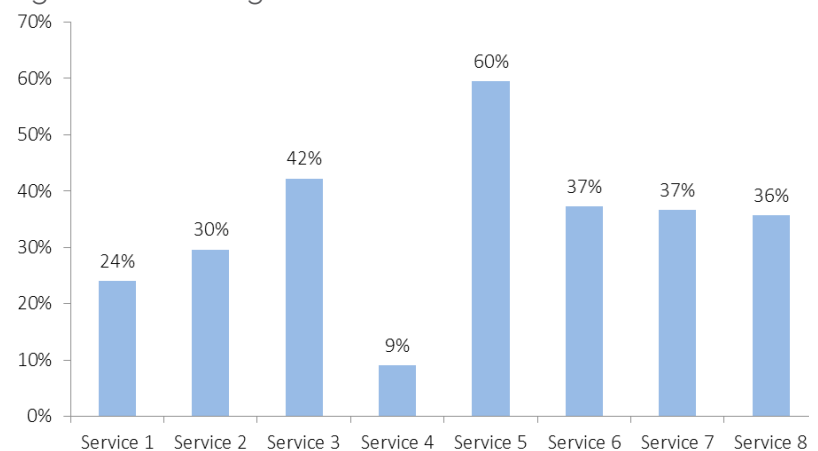
Usual place of residence
The audit captured the usual place of residence. The percentage of referrals with (a) a diagnosis of dementia; and (b) living at home. Data was not provided from Service 7. In four services, more than 50 per cent of patients with an eventual dementia diagnosis live at home alone. The majority of patients living in sheltered accommodation live alone.

Out of the total audit sample, 48 per cent of patients with a diagnosis of dementia live at home alone. Of those patients, 43 per cent have a named carer. For Service 8, 76 per cent of patients with a dementia diagnosis live at home alone and only 11 per cent of those patients have a named carer.

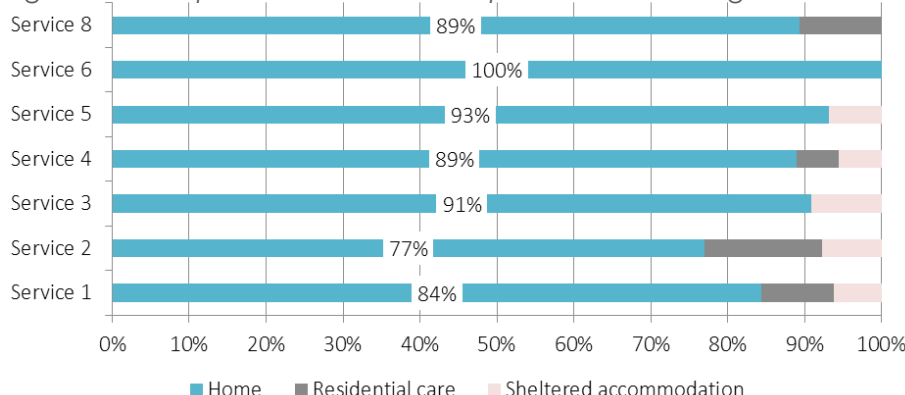Figure 2: Usual place of residence for patients with a diagnosis of dementia

Table 3: Percentage of patients with a diagnosis of dementia living alone

Memory service	Alone at home	Alone who have a named carer
Service 1	63%	47%
Service 2	20%	50%
Service 3	50%	50%
Service 4	44%	43%
Service 5	52%	71%
Service 6	17%	66%
Service 8	76%	11%

Referral

Waiting time to be seen from referral

The audit captured waiting times from GP referral date to the date first seen for initial assessment. *(See Figure 3.)*

In March 2012 the Prime Minister launched a dementia challenge to deliver improvement in health care, create dementia friendly communities and boost dementia research. One of the government's key aspirations is that by 2020 in every part of the country people with dementia have equal access to diagnosis as for other conditions, with an expectation that all patients are seen for an initial assessment within six weeks following referral from a GP.

Results show significant variation in access to be seen across the eight services. For Service 6, the average wait to be seen was 14 weeks. Of those referrals with a wait time to be seen greater than six weeks, 70 per cent of the delay was due to a lack of service capacity. For Service 7, the average wait was slightly less (10 weeks). The reason for delay was not captured. All referrals for Service 2 (100 per cent) were seen within six weeks, with an average wait of three weeks. For those referrals not seen within six weeks by services 1 and 8, the reason for delay was mainly not captured. The delays in services 3, 4 and 5 were largely attributed to patient choice or delay.

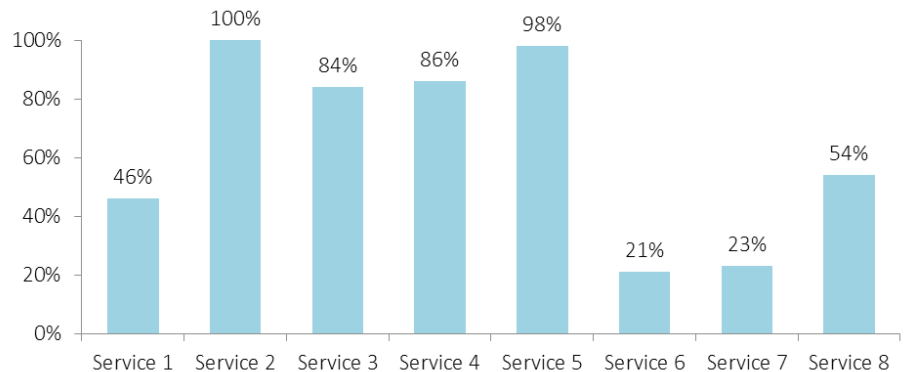*Figure 3: Percentage of all referrals seen within six weeks from GP referral date*

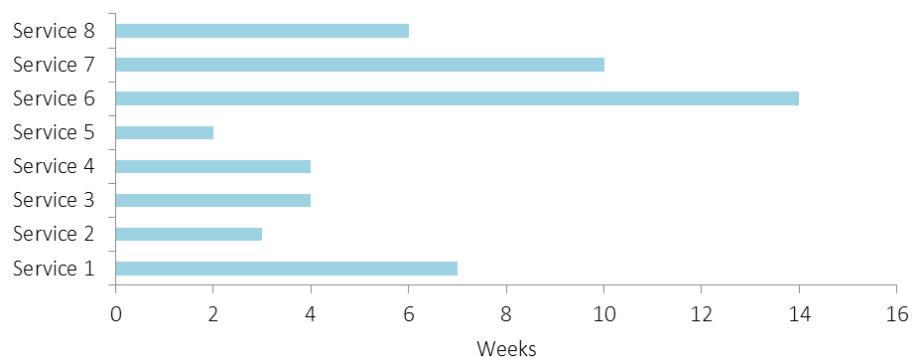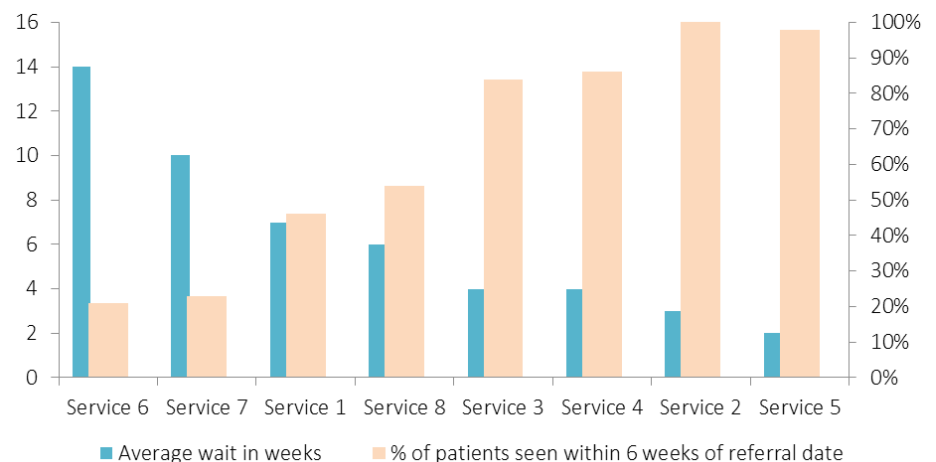*Figure 4: Average wait in weeks to be seen following referral*

Figure 5: Composite: Average wait in weeks against percentage of patients seen within six weeks of referral date

Place of assessment

Figure 6: Place of assessment

Figure 6 shows the percentage of home based assessments. There is clearly significant variation in practice. For example, services 1, 3 and 5 offer home based assessment for all referrals. Services 4 and 6 offer home assessment primarily to patients who are unable to travel. NICE does not provide specific guidance on the preferred location
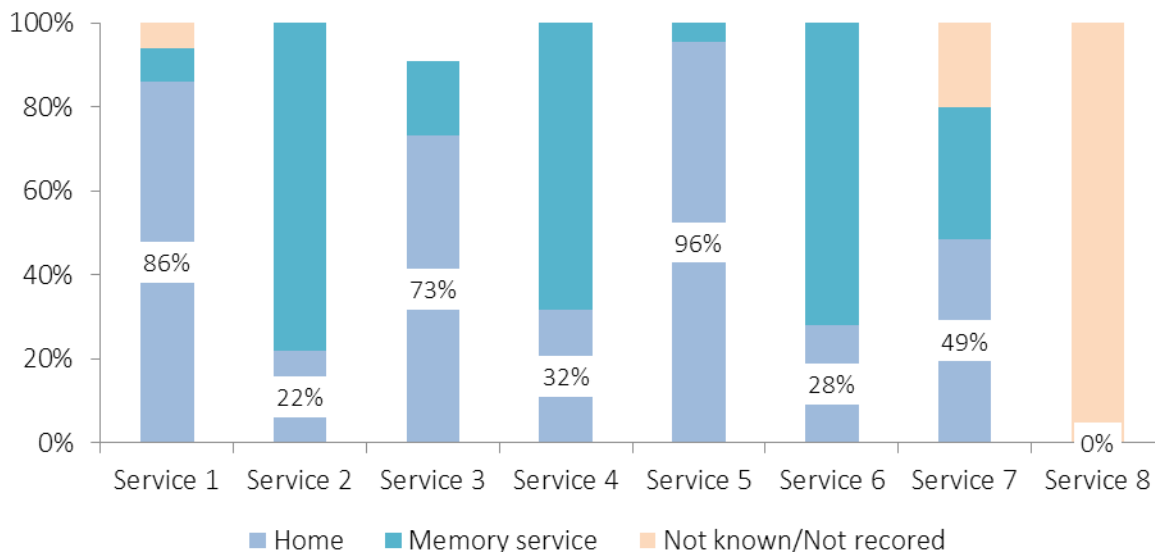
of dementia assessment (NICE 2006). Potential advantages of home assessment include the availability of additional information about the level of risk within the home and the person's functional level. The number of missed appointments (DNA's) is also less for services which offer home assessment. Home assessments are less time efficient because travel time for clinical staff is required and staff might not perform home visits alone. However, in this audit there was no clear relationship between waiting time and place of assessment.

Initial investigation

The National Institute for Health and Care Clinical Excellence (NICE) clinical guideline on dementia advises that a basic dementia screen should be performed at the time of presentation, usually within primary care. Part of this screen includes routine haematology, biochemistry tests, thyroid function tests and serum vitamin B12 and folate levels. *Table 4* shows the percentage of correct blood tests performed and whether the result was available on the date of the first assessment. It is unclear whether

Table 4: Availability of blood test results

	Blood test result available		% available blood test result and correct (NICE) blood test carried out (GP organised)	% available blood test result and correct (NICE) blood test carried out (service organised)
	Yes	No		
Service 1	74%	26%	89%	67%
Service 2	78%	22%	90%	N/A
Service 3	78%	22%	79%	100%
Service 4	95%	5%	100%	100%
Service 5	78%	22%	100%	N/A
Service 6	51%	49%	91%	N/A
Service 7	100%	0%	100%	N/A
Service 8	100%	0%	100%	N/A

an incorrect blood test or the unavailability of the blood test result led to a delay in patients being seen by the memory service. However, it is of note that several services achieved short waiting times despite not always having access to blood test results.

Assessment and investigations
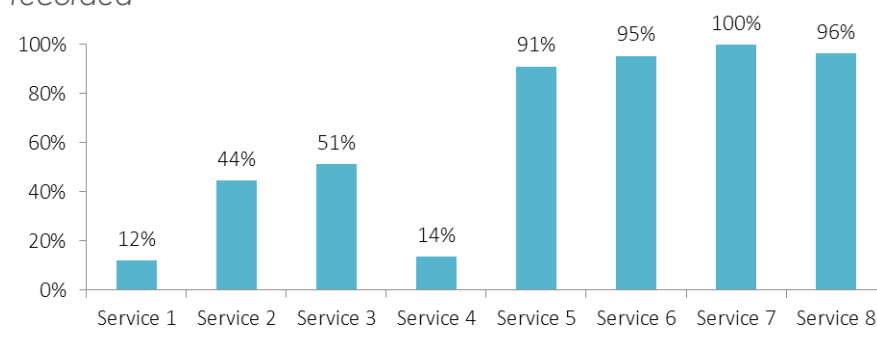
History taking

It was agreed to audit the following history taking items:

- » Adherence with medication
- » Smoking
- » Social/personal circumstances and preferences
- » Medical co-morbidities
- » Impairments of vision, hearing and mobility
- » Psychiatric/behavioural features
- » Risk assessment
- » Carer assessment (including burden, health, function)
- » Alcohol consumption

For each history item the selection option was, *yes*, *no*, *not applicable* or *not clear from notes*. *Figure 7* shows the percentage of patients being asked history on all the agreed items. The result is based on *yes* and *not applicable* responses.
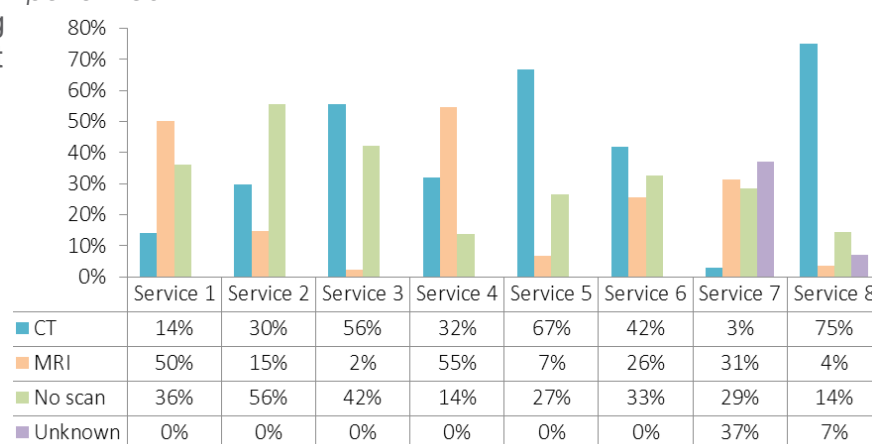
Imaging

NICE clinical guidance on dementia provides guidance on structural imaging. Magnetic resonance imaging (MRI) is the preferred modality to assist with diagnosis, although computed tomography (CT) scanning can be used. The guideline also indicates that imaging may not always be needed in those patients presenting with moderate to severe dementia, if the diagnosis is already clear.

There was mixed practice regarding brain imaging, with some services scanning the vast majority of referred patients. There was also inconsistency in the choice of imaging modality which is likely driven by local availability and preference. (*See Figure 8. Appendix 1* has further data on referrals with a diagnosis of dementia and the use of imaging.)

Future audits should capture whether patients have had a recent brain scan elsewhere such that further imaging was not required.

Figure 7: Patients in whom all history items were recorded

Service 1	Service 2	Service 3	Service 4	Service 5	Service 6	Service 7	Service 8
12%	44%	51%	14%	91%	95%	100%	96%

Figure 8: Percentage of all referrals having structural imaging performed

	Service 1	Service 2	Service 3	Service 4	Service 5	Service 6	Service 7	Service 8
CT	14%	30%	56%	32%	67%	42%	3%	75%
MRI	50%	15%	2%	55%	7%	26%	31%	4%
No scan	36%	56%	42%	14%	27%	33%	29%	14%
Unknown	0%	0%	0%	0%	0%	0%	37%	7%

Imaging access

A factor supporting people with dementia receiving a timely diagnosis is prompt access to imaging. There is currently no national guideline on waiting times for imaging. The audit looked at a 30 day waiting time from assessment date to imaging date.

Table 5: Percentage of CT and MRI scans carried out within 30 days of assessment date

	Percentage of CT scans within 30 days of assessment date		Percentage of MRI scans within 30 days of assessment date	
Service 1	71% (n=5)	2x data not provided	56% (n=14)	1x data not provided
Service 2	25% (n=8)		0% (n=2)	1x data not provided
Service 3	28% (n=25)		100% (n=1)	
Service 4	86% (n=7)	1x data not provided	100% (n=12)	
Service 5	23% (n=30)	3x data nor provided	100% (n=3)	
Service 6	50% (n=18)	3x data not provided	0% (n=11)	3x data not provided
Service 7	Imaging data not provided		Imaging data not provided	
Service 8	95% (n=21)	1x data not provided	100% (n=1)	

Results show variation in waiting times for scans. Services 3 and 8 referred a similar number of patients for a CT scan, yet access was markedly different. Only 28 per cent of patients had a scan within 30 days of their assessment date for Service 3, compared to 95 per cent of patients for Service 8.

Referral to neuropsychology services

The NICE clinical guideline for dementia specifies that formal neuropsychological testing should form part of the assessment stage in cases of mild or questionable dementia. *Figure 9* shows the percentage of referrals referred for neuropsychological assessment.

Figure 9: The percentage of referrals referred for neuropsychological assessment
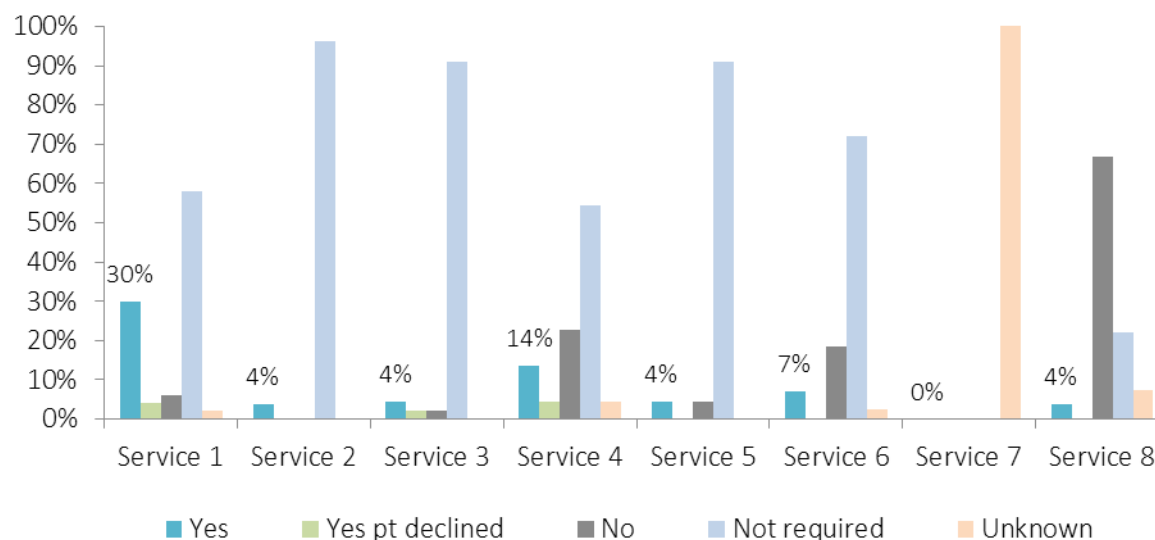
Diagnosis

Referral to diagnosis waiting time

The average wait in weeks from the date the referral was received to the date of diagnosis is shown in *Figure 10*. Results show marked variation across the services. Service 2 reported 54 per cent of patients diagnosed without the use of imaging *(see Appendix 1, figure 1)*. This service has the shortest waiting time at four weeks, compared to 19 weeks at Service 6. Data was not provided by Service 7.

Dementia diagnosis - over 65 years

The following graph shows the percentage of referrals over 65 years where a diagnosis of dementia was made during the audit period. Service 8 is not included in the graph as all the data submitted was on referrals with an eventual dementia diagnosis. Referral conversion rates range from 37 per cent (Service 7) to 96 per cent (Service 2).

Future audits should ensure a larger sample size of 50 patients as a minimum per memory service.

Figure 10: Average wait in weeks to be seen and average wait in weeks from date referral received to date of diagnosis (all referrals)
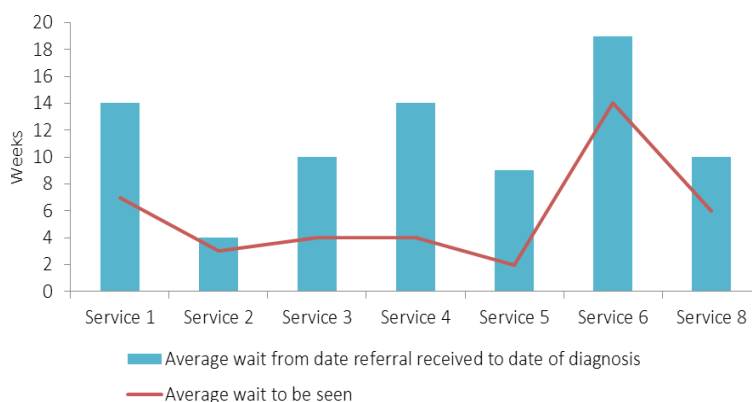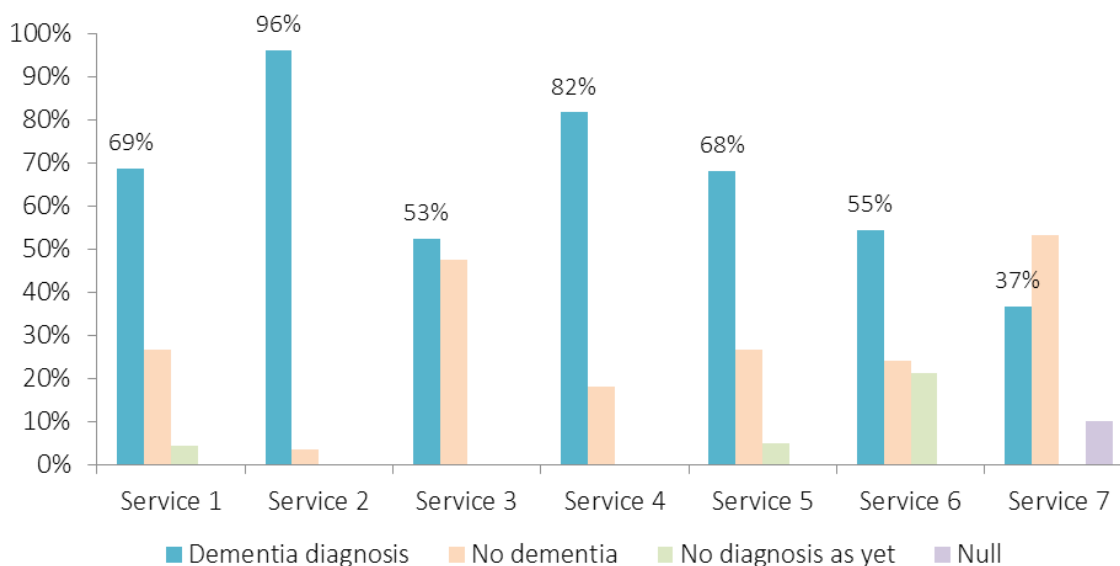

Average wait from date referral received to date of diagnosis
Average wait to be seen

Figure 11: Percentage of referrals diagnosed with dementia (65+ years)

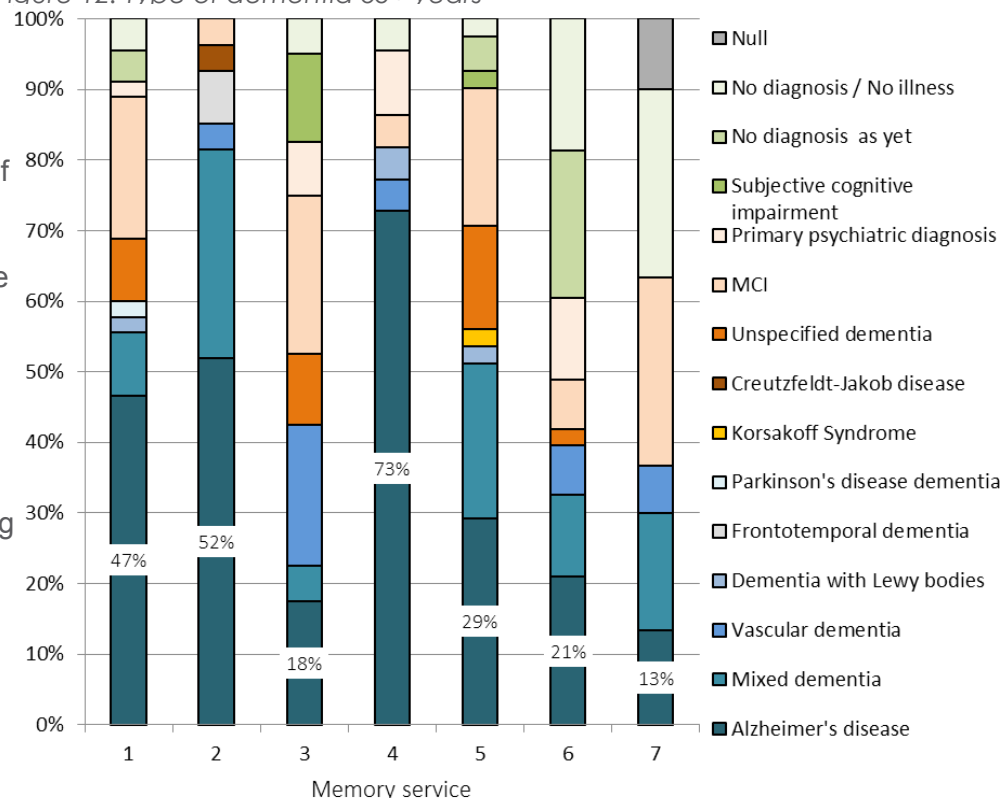Dementia diagnosis · No dementia · No diagnosis as yet · Null

Diagnosis breakdown

The audit captured information on the final diagnosis. As Alzheimer's disease is the most common cause of dementia, it would be reasonable see services diagnosing a higher number of these cases.

Results show significant variation in the type of dementia diagnosed. However, the number of diagnosed dementia patients per service is too small to be representative.

The diagnosis of mild cognitive impairment varied considerably, ranging from 2 per cent of patients (Service 2) to 27 per cent (Service 7). (*See Figure 12.*) Service 8 has not been included for comparison as submitted data was only for new referrals receiving a dementia diagnosis.

Data on disease stage and ethnicity can be found in Appendix 1, section 2.

Figure 12: Type of dementia 65+ years

Legend:
- Null
- No diagnosis / No illness
- No diagnosis as yet
- Subjective cognitive impairment
- Primary psychiatric diagnosis
- MCI
- Unspecified dementia
- Creutzfeldt-Jakob disease
- Korsakoff Syndrome
- Parkinson's disease dementia
- Frontotemporal dementia
- Dementia with Lewy bodies
- Vascular dementia
- Mixed dementia
- Alzheimer's disease

Young onset dementia

Dementia is 'young onset' when it affects people of working age, usually defined as those under the age of 65 years. Ten per cent of referrals across all services were aged under 65, whereas 2 per cent of the total numbers of patients diagnosed with dementia were under 65, a much lower conversion rate than for older people.

Table 6 shows the number of referrals under 65 years old for each service and the subsequent number diagnosed with dementia.

Table 6: Referrals aged under 65 years old

Memory service	Number of referrals under 65 years	Total diagnosed with dementia	Type of dementia
Service 1	5 (n=50)	1	Alzheimer's disease
Service 2	0	N/A	
Service 3	5 (n=45)	1	Vascular dementia
Service 4	0	N/A	
Service 5	4 (n=45)	1	Unspecified dementia
Service 6	10 (n=43)	0	(1x no diagnosis as yet)
Service 7	5 (n=35)	1	Mixed dementia
Service 8	0	N/A	

Prevalence rates for young onset dementia in black and minority ethnic groups are higher than for the population as a whole[5]. Of the four patients aged under 65 years with a diagnosis of dementia, three were of BME background.

Carer assessment and support

The [NICE clinical guideline for dementia](#) advises health care managers to offer carers an assessment of needs and support so that they feel able to cope with their caring responsibilities and to have a life alongside caring. This is also a national priority, confirmed in the [Prime Minister's Challenge on Dementia 2020](#).

Data on the number of patients diagnosed with dementia who have a named carer were collected.

The percentage of carers having a carer assessment carried out is shown in *Figure 13*. Results range from 60 per cent of carers receiving an assessment of needs and support (Service 3), to 100 per cent (services 6 and 8). *Figure 14* provides data on the percentage of carers who had an assessment of needs and accepted further support. Data could not be determined for a number of cases. Further audits should redefine the carer assessment data item and capture information on the service(s) available for carers.

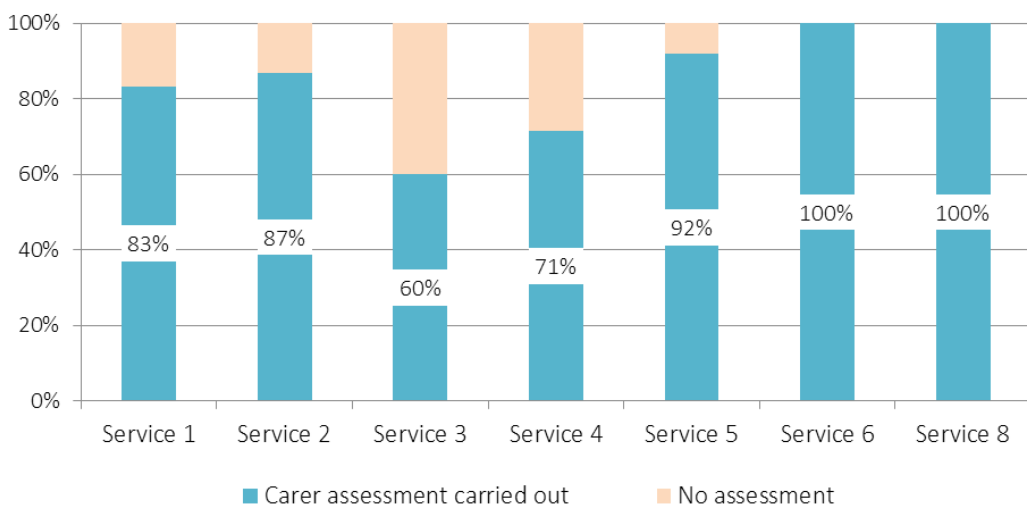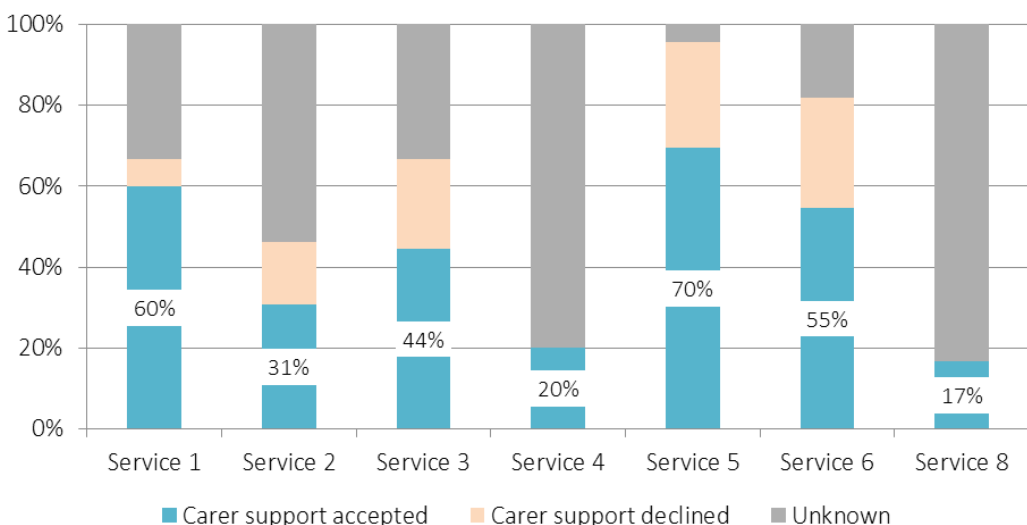*Figure 13: Percentage of patients with a named carer who received a carer assessment*

Figure 14: Percentage of carers who had an assessment of needs and went on to accept further support
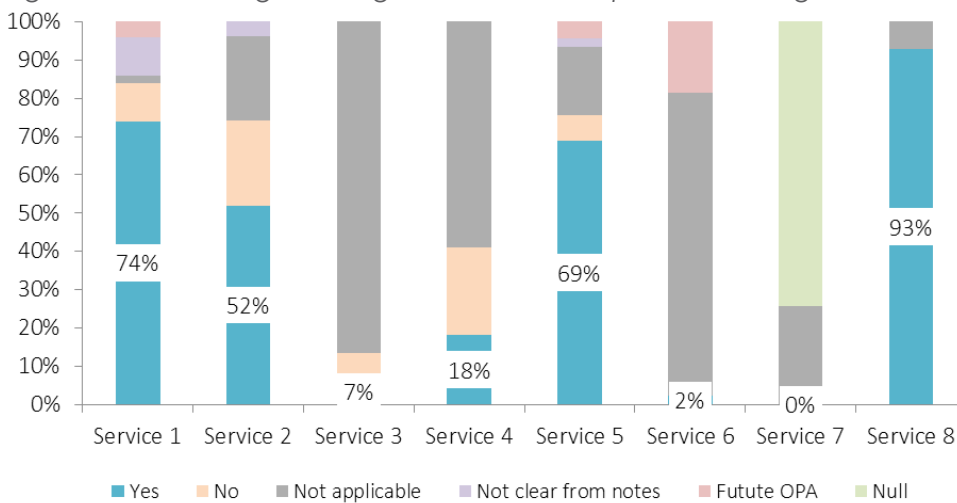
Falls assessment

Having dementia may increase the likelihood of falling[6]. Falls and fractures have been reported to be the most common reason for people with dementia to be admitted to hospital[7]. It was agreed to audit evidence of a falls risk assessment at the point of diagnosis.

Figure 15: Percentage of diagnosed dementia patients having a falls risk assessment

Legend: Yes, No, Not applicable, Not clear from notes, Futute OPA, Null

Services 3, 4 and 6 reported more than half of patients as 'not applicable' for a falls risk assessment. It may be that services answered whether the patient had experienced a recent fall. Future audit should define this data item more clearly and capture reason information on 'not applicable' responses.

Treatment

Cognitive stimulation therapy

The NICE clinical guideline for dementia recommends people with mild-to-moderate dementia of all types should be given the opportunity to participate in a structured group cognitive stimulation programme irrespective of any drug prescribed. *Figure 16* shows the percentage of diagnosed patients referred for cognitive stimulation therapy. (Data on pharmacological interventions can be found in *Appendix 1*, section 3.)
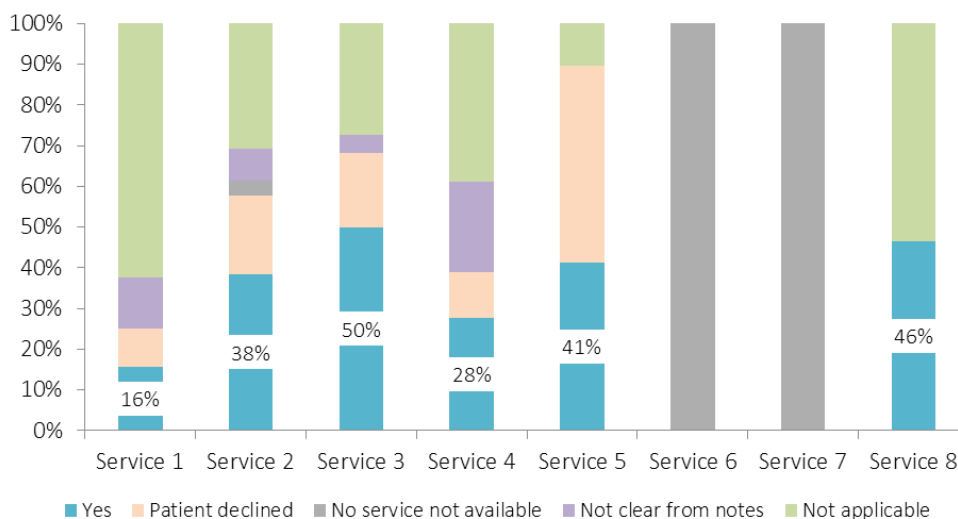
Figure 16: Percentage of diagnosed patients referred for cognitive stimulation therapy.

Legend: Yes, Patient declined, No service not available, Not clear from notes, Not applicable

6. *Alzheimer's Society. Link*
7. *Counting the cost: Caring for people with dementia on hospital wards*. Alzheimer's Society (2009). *Link*

Future audits should capture the reason why cognitive stimulation therapy was declined by the patient or not applicable. Access to free hospital transport may be a common reason for limited uptake.

Dementia research

Nationally, there were 13,583 people with dementia involved in research studies in 2013/14 (4.5 per cent of people in England living with dementia)[8]. Encouraging people with dementia to take part in research studies is key to identify medical advances that can help people living with the condition now, as well as helping to prevent people from developing dementia in the future.

Join Dementia Research (JDR) was launched in 2015 by the National Institute for Health Research (NIHR), Alzheimer's Research UK and Alzheimer's Society to increase the numbers of people participating in research. JDR allows people to register their interest in participating in dementia research to be matched with suitable studies.

There is variation across the services in the number of patients being involved in clinical research discussions, from 0 per cent (Service 2) to 56 per cent (Service 4).

Table 7: The percentage of diagnosed patients involved in clinical research discussions

Memory service	No. of patients with a dementia diagnosis	% of diagnosed patients consented for research	% of diagnosed patients who declined research
Service 1	32	25%	19%
Service 2	26	0%	0%
Service 3	22	5%	0%
Service 4	18	28%	28%
Service 5	29	34%	7%
Service 6	18	13%*	27%*
Service 7	12	Null	Null
Service 8	28	4%	0%

* Note: Although 18 patients in total had a diagnosis of dementia in Service 6, responses regarding research were not recorded for three patients.

Follow-up

It was agreed to audit the first follow-up. This was defined as a longer face to face appointment at which the patient and their carer could expect to receive verbal or written information on the pathway of follow-up care, key contacts, what to do in a crisis and social care support. There would also be a review of anti-dementia medication if relevant.

Figure 17 shows the percentage of diagnosed patients that had a longer face-to-face follow-up appointment following their diagnosis and received verbal or written information as listed above.

Figure 17: Percentage of diagnosed patients receiving verbal or written information on; the pathway of follow-up care, key contacts, what to do in a crisis and social care support
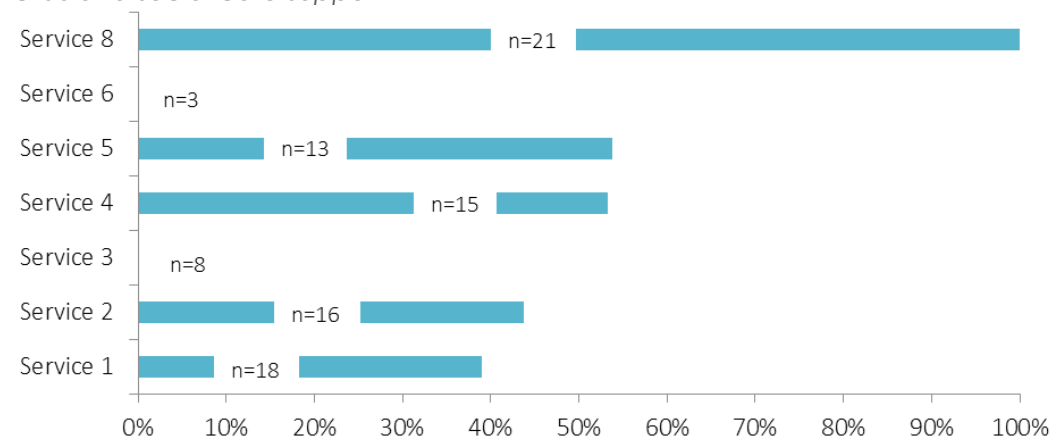
8. *Dementia: A state of the nation report on dementia care and support in England.* Department of Health (2013). *Link*

Third sector – Dementia Advisors or Navigators

Enabling easy direct access to a contact who can signpost and facilitate health and social care input throughout life with dementia is one of the objectives in the National Dementia Strategy (2009). The dementia advisor role is considered a delivery mechanism of this objective.

Dementia advisors are usually provided by third sector organisations for people with dementia to access local information about services and sources of support. The dementia advisor can be viewed as a care co-ordinator or navigator providing support after a diagnosis in the form of advice and facilitating easier access to relevant care and support services.

Figure 18: Percentage of diagnosed patients referred to a dementia advisor or navigator for support
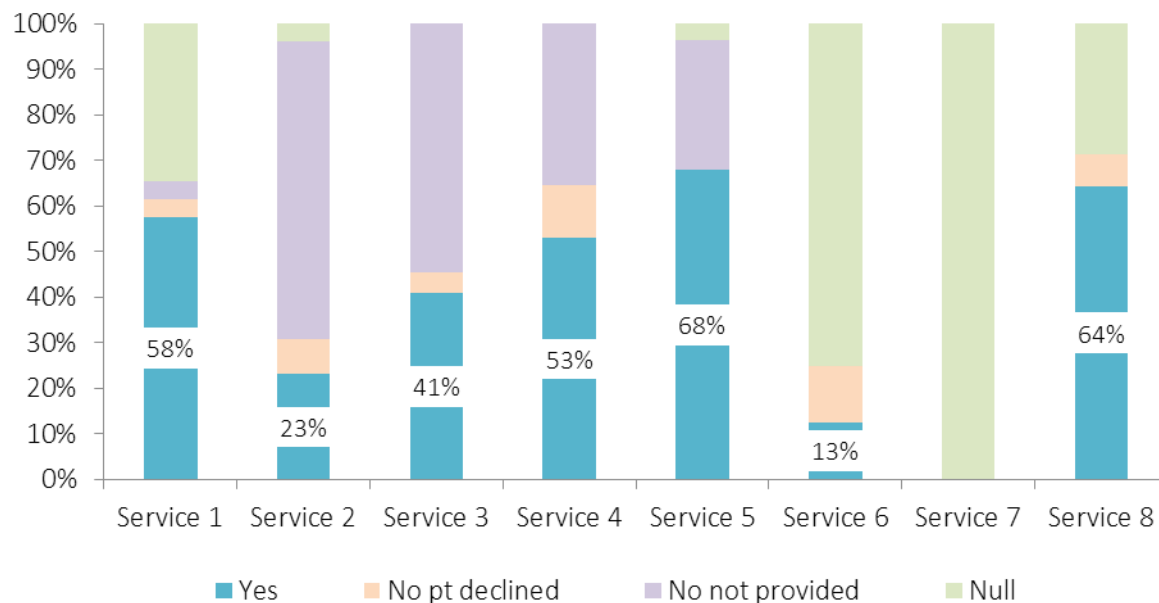
Legend: Yes | No pt declined | No not provided | Null

Conclusion

The audit reveals substantial variation between services and will hopefully prompt self-reflection by participating and non-participating memory services. Access to timely assessment, imaging, neuropsychology and post diagnosis interventions is very variable. Diagnoses vary widely from service to service although this does not necessarily indicate diagnostic bias given the relatively small number of patients audited. Patients are generally not being approached about research.

Next steps

The eight services who took part in the audit were invited to come together to discuss the data in detail. Team members from five services attended to provide further information on the structure of their memory service, such as staff provision, infrastructure, imaging pathways, treatment and follow-up procedures, protocols and standards and the use of electronic systems and databases.

Members shared practice on carer and post-diagnosis support. Tools (such as brief validated falls risk assessment forms) will be shared with the memory assessment network.

Discussion also triggered services to think about improving both paper and electronic documentation, for example, recording discussions on cognitive stimulation therapy and clinical research and whether these were accepted by patients.

Working with the Memory Assessment Network, the *Effective diagnosis* working group will develop clear guidance as to how to streamline the memory service pathway in order to reduce variation in access.

> Round two of the audit is scheduled for late 2016. All memory services in London will be encouraged to take part. The audit parameters will be refined without losing impact. Round two data will remain anonymised, but will be shared with commissioners to cement buy in and resourcing.

Recommendations

Following the feedback session with members of the participating services and review of the results by the *Effective diagnosis* work stream, the Dementia Clinical Network has issued the following recommendations to memory services in London in preparation for round two of the audit.

» **Services should aim to assess all new patients within six weeks of referral** as proposed in the Prime Minister's Challenge on Dementia 2020.

» In order to reduce delays, **services should consider seeing patients even if full blood tests have not been completed in primary care**.

» **Services should review their contracts with their imaging provider**(s) to ensure that they have access to both CT and MRI and that scans will be performed and the report made available within four to six weeks of request.

» **Services should explore how they can obtain access to their imaging provider's PACS system** so that scans can be viewed directly.

» **Services should consider establishing a regular meeting with a neuroradiologist** to review scans (eg monthly or quarterly). Services could join together to hold a regional meeting. Inviting the regional neurologist(s) with a specialist interest in cognition is recommended.

» **Services should offer all older patients a falls risk assessment.** An example of a brief tool is provided in appendix 5.

» **Services should monitor whether patients have been referred for cognitive stimulation therapy** and record the reason(s) why this isn't available or taken up.

» **Services should establish a mechanism for recording patients' consent to be contacted about research** and provide information about Join Dementia Research.

» **Services should ensure that all staff are aware of the local dementia advisor or navigator service**.

Appendix 1 | Additional data

Section 1: Imaging

Figure 1 shows the percentage of diagnosed patients where no imaging was needed. Service 2 reported 15 per cent of diagnosed patients living in a care home. Information on previous imaging performed prior to the referral date was not captured. Both of these factors may have contributed to results.

Figure 1: Percentage of diagnosed dementia referrals where a diagnosis was made without imaging
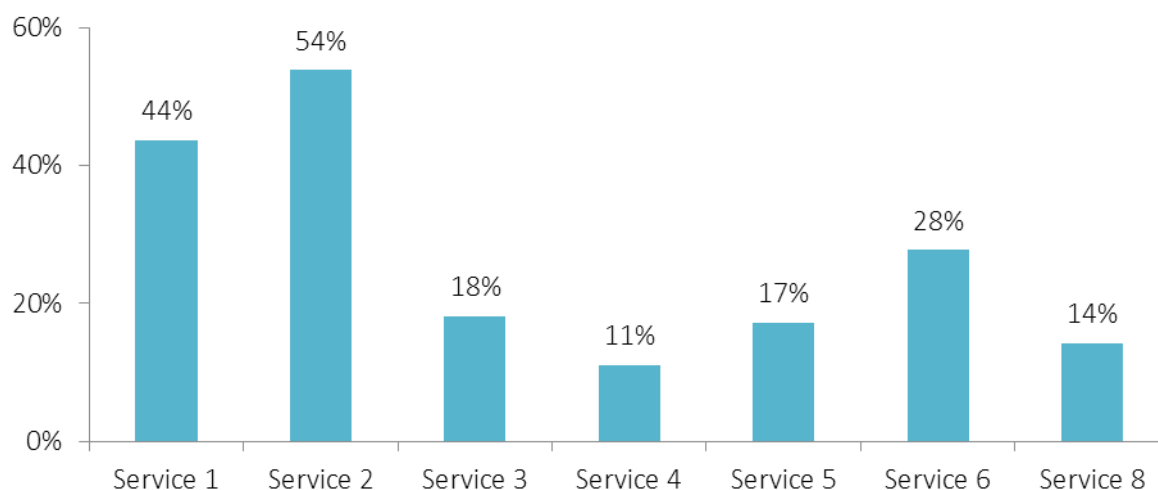

Table 1: Breakdown of dementia diagnosis and no required imaging.

|	Alzheimer's disease	Mixed dementia	Unspecified dementia	Vascular dementia
Service 1	36%	50%	100%	N/A
Service 2	50%	63%	N/A	100%
Service 3	0%	0%	50%	22%
Service 4	13%	N/A	N/A	0%
Service 5	8%	22%	29%	N/A
Service 6	22%	40%	100%	100%
Service 7	(unable to calculate)	(unable to calculate)	N/A	50%
Service 8	29%	(unable to calculate)	N/A	0%

Appendix 1 | Additional data

Section 2: Stage of dementia and ethnicity

The stage of disease was provided for the majority of patients. Figure 2 shows the stage of Alzheimer's disease at diagnosis.

Figure 2: Stage of Alzheimer's disease at diagnosis
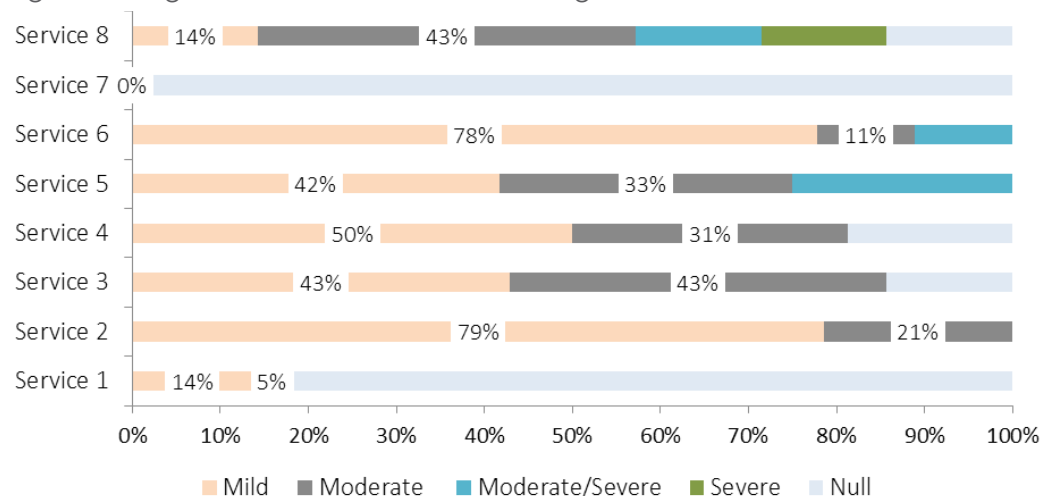
Improving the diagnosis of dementia for people of black, Asian, and minority ethnic origin groups has been set as a national priority by 2020 as evidence shows diagnosis rates are particular poor. Figure 3 shows ethnicity and stage of Alzheimer's disease. The majority of British and non-white British patients diagnosed with Alzheimer's disease were diagnosed as mild and moderate stage disease. However, 16 per cent of non-white British patients with a diagnosis of Alzheimer's disease were staged as moderate to severe and severe, compared to 0 per cent of British patients.
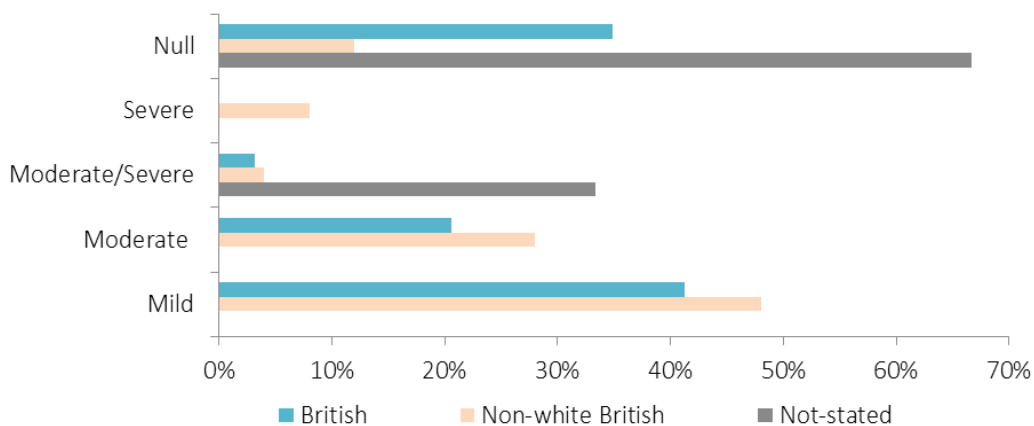

Figure 3: Ethnicity and stage of Alzheimer's disease (all patients)
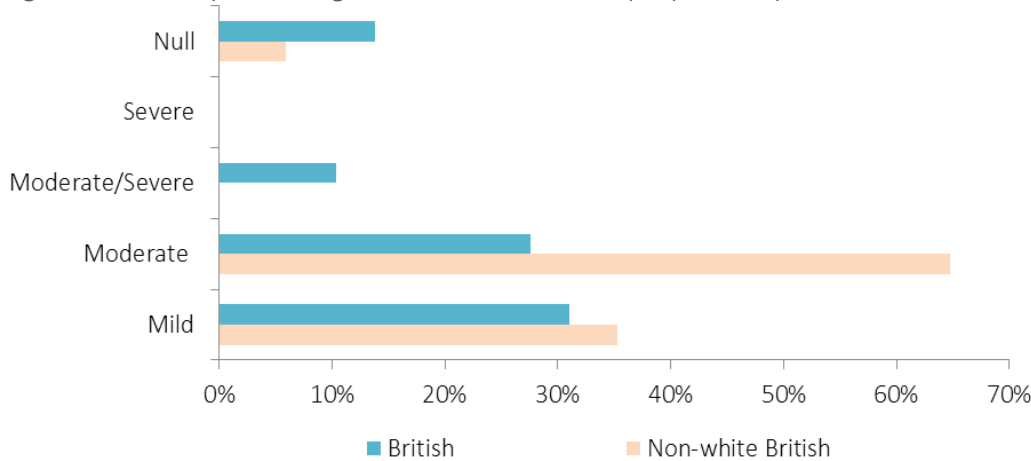
Appendix 1 | Additional data

For nearly a third of patients, information on the stage of disease was not provided. Sixty-five per cent of non-white British ethnicity group were diagnosed with moderate stage mixed dementia, compared to 28 per cent of white British ethnicity group. See figure 4.
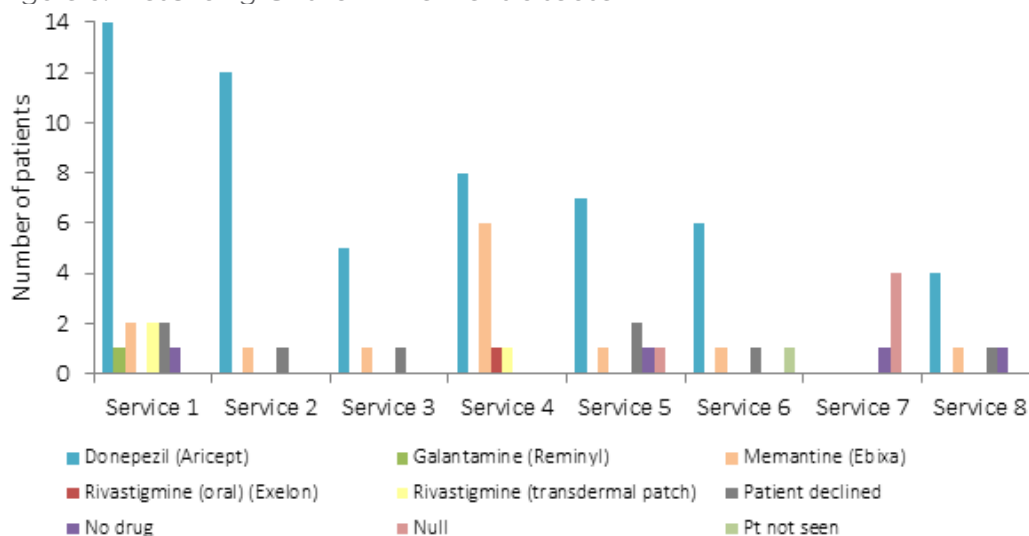
Figure 4: Ethnicity and stage of mixed dementia (all patients)

Section 3: Pharmacological interventions

The audit collected information on prescription of acetylcholinesterase inhibitors (CEIs) and memantine. The NICE clinical guideline for dementia recommends three CEIs, (donepezil, galantamine and rivastigmine) as options for managing mild to moderate Alzheimer's disease. Memantine is recommended as an option for managing Alzheimer's disease for people with severe Alzheimer's disease or with moderate Alzheimer's disease who are intolerant or have a contradiction to CEI inhibitors. For all services, donepezil was prescribed more frequently.

Figure 5: Prescribing CEIs for Alzheimer's disease

Appendix 2 | Effective diagnosis working group members

Name	Role	Organisation
Dr Nerida Burnie	General Practitioner	NHS Kingston CCG
Dr Lucy Carter	General Practitioner	NHS City and Hackney CCG
Sue Dyson	Service Manager	Barnet, Enfield and Haringey Mental Health NHS Trust
Ruth Evans	Senior Project Manager	London Dementia Clinical Network
Dr Mike Gill	Interim Associate Medical Director (Whipps Cross Hospital)	Barts Health NHS Trust
Dr Daniel Harwood	London Dementia Clinical Director Consultant Psychiatrist and Associate Clinical Director Inpatient Liaison and Specialist Care Services /	London Dementia Strategic Clinical Network South London and Maudsley NHS Foundation Trust
Dr Jeremy Isaacs	Consultant Neurologist and Effective Diagnosis Clinical Lead for the London Dementia Strategic Clinical Network	St George's University Hospitals NHS Foundation Trust
Dr Suzanne Joels	Consultant Psychiatrist	Camden & Islington NHS Foundation Trust
Dr Jonathan Kennedy	Consultant Neurologist	Royal Free London NHS Foundation Trust
Dr Robert Lawrence	Consultant Psychiatrist	South West London and St George's Mental Health NHS Trust
Jonathan Mason	Service Director for Older People's Services in Kingston and Richmond	South West London and St George's Mental Health NHS Trust
Dr Belinda McCall	Consultant in Elderly Medicine	Lewisham and Greenwich NHS Trust
Dr Sujoy Mukherjee	Consultant Psychiatrist	West London Mental Health NHS Trust
Katie Nichol	Project Manager	Dementia and Diabetes Clinical Networks
Helen O'Kelly	Assistant Lead	Mental Health, Dementia and Neuroscience Clinical Networks
Dr Cianan O'Sullivan	Consultant Physician in Elderly and General Medicine	Homerton University Hospital NHS Foundation Trust
Dr Roisin Purcell	Consultant Physician in Geriatric Medicine	Barts Health NHS Trust
Janice Richards	Senior Commissioning Manager	NHS Waltham Forest CCG
Geoff Sherlock	Chief Officer Adult Social Care	London Borough of Redbridge
Helen Souris	Clinical Team Manager – Islington Memory Service	Camden & Islington NHS Foundation Trust

Summary / Key findings	Recommendations	Audit results	Conclusion / Next steps	Appendices

Appendix 3 | Dataset

Data was captured through an excel spreadsheet. The following information outlines the content of the dataset.
Please provide answers to the following questions using the blue space provided, either by selecting an option or by providing detail.

1	MSNAP accredited: (please select)
2	Organisation providing memory service: (please select)
3	Do you run clinics in conjunction with (please select)
4	Do you offer a home visit service (please select)

Patient demographics

5	Age at referral
6	Gender
7	Ethnicity (see ethnicity codes on sheet 2, select code)
8	Usual place of residence
9	Does the person live alone
10	Was advocacy and interpretation needed
11	Does the person have a named carer

Referral

12	Referred by
13	Date referral received
14	Date seen for initial assessment (please state if not seen)
16	Reason for delay
15	Place of assessment
17	Blood test result available
18	Correct blood test carried out as per NICE guidance

Assessment and Investigations

19	Standardised cognition test carried out
20	CT
21	CT scan within 30 days of assessment
22	Reason for delay
23	MRI
24	MRI scan within 30 days of assessment
25	Reason for delay
26	Referred to neuropsychology services
27	Was there evidence of history taking on the following:
27 (1)	Social / personal circumstances and preferences
27 (2)	Impairments of vision, hearing and mobility
27 (3)	Medical co-morbidities
27 (4)	Psychiatric / behavioural features
27 (5)	Risk assessment
27 (6)	Carer assessment (including burden, health, function)
27 (7)	Alcohol consumption
27 (8)	Adherence with medication
27 (9)	Smoking

Summary / Key findings	Recommendations	Audit results	Conclusion / Next steps	Appendices

Appendix 3 | Dataset

Diagnosis
28   Recorded diagnosis (see diagnosis code on sheet 3)
29   Date diagnosis given to patient and carer
30   Stage of dementia at diagnosis
31   Was there evidence of written information given to the patient at or soon after the diagnosis in an appropriate format
32   Was the carer offered and referred for carer support
33   Was there evidence of assessment / signposting to the following services:
33 (1) Fire safety check
33 (2) Adult social care assessment
33 (3) Occupational therapy assessment
33 (4) Speech and language therapy assessment
33 (5) Psychological intervention other than CST
33 (4) Bathing assessment
33 (5) Falls risk
33 (6) Telecare services
33 (7) Local support services

Treatment
34   Referred for cognitive stimulation therapy (CST)
35   Dementia drug prescribed
36   Which dementia drug prescribed
37   Consent taken to be contacted for research

Follow-up
38   "Date of 1st detailed post diagnosis face-to-face follow-up appointment
        (See 'follow-up' sheet 4 for definition)"
39   Was the treatment continued after 1st detailed follow-up
40   Is there third sector involvement at this stage e.g. Dementia advisor
41   Is there evidence of correspondence to the GP which includes information on the following:
41 (1) The pathway of follow-up care
41 (2) Medication review
41 (3) What to do in a crisis
41 (4) Key contacts
41 (5) Social care support
42   If started on medication, place of medication review

Appendix 4 | Audit participation invite letter

15 July 2015

Dear colleague,

RE: Participation in a London-wide memory service audit

I am writing on behalf of the London Dementia Clinical Network (CN) to seek your participation in an audit relating to the quality of memory services in London. Those who have been directly engaged in or following the work of the memory assessment network will be aware that we agreed to create a pan-London dataset to allow memory services to benchmark their patient pathway and clinical outcomes against similar services, and to understand capacity across the region. At all stages in the development of the audit we have had input from memory services. Thank you to those who have contributed to this work. The dataset has been agreed through expert consensus in the effective diagnosis working group, where primary and secondary care clinicians, service leads and commissioners are represented. We have tried to strike a balance between brevity and detail.

We have agreed the following sampling frame:

Consecutive new undiagnosed patients referred to the memory service from 1st January 2015 onwards, until a minimum of 50 per service is reached.

I hope your service will take part in this audit. We will undertake to have the results presented at the memory assessment network meeting on the morning of Wednesday 4th November 2015.
Please email your completed spread sheet to Katie Nichol, Project Manager for the dementia strategic clinical network *katienichol@nhs.net* by Friday, 25 September 2015.

We look forward to receiving your response, and thank you for participating in this important work. We do not underestimate the effort required to abstract data from patient records, but I am confident that as a community of practice and as individual services we will benefit greatly from this process. I am very grateful for your time and commitment.

Yours sincerely,

Dr Dan Harwood
Clinical Director
London Dementia Clinical Network
Email: Daniel.Harwood@slam.nhs.uk

Dr Jeremy Isaacs
Clinical Lead for Effective Diagnosis
London Dementia Clinical Network
Email: Jeremy.Isaacs@nhs.uk

Appendix 5 | Falls risk assessment tool

Example falls risk assessment

If questions 1, 2 and 3 are "yes", with no obvious mechanical explanation for the fall (eg uneven pavement), and question 4 is "no", a referral to the falls service is indicated.

1. Has the patient fallen in the past year?	Yes [ ]	No [ ] *Proceed to question 3*
1a. How often has the patient fallen?	State frequency:	
1b. What were the circumstances (frequency, context and characteristics of the fall(s)?	Describe:	
2. Has the patient sustained injuries?	Yes [ ]	No [ ]
2a. Describe injuries sustained.	Describe:	
3. Is the patient worried about falling?	Yes [ ]	No [ ]
4. Has the patient had an assessment by the falls service?	Yes [ ]	No [ ]