



English National Memory Clinics Audit Report

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An interactive map and copies of this report can be found on the website:

www.rcpsych.ac.uk/memoryclinicsaudit

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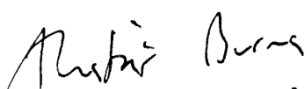
Foreword

It is a real privilege to have been asked to introduce the report of The Royal College of Psychiatrists' Centre for Quality Improvement Memory Clinic Audit. We know that around half of people with dementia do not have a formal diagnosis and memory services play a key part in improving this, allowing people with dementia, their families and carers to have access to the emotional, practical and financial support that a diagnosis can bring.

The main findings of the report are compelling and paint a unique national picture. Waiting times for assessment and diagnosis are five and eight weeks respectively, nearly half of people who were diagnosed at memory clinics were in the early stages (enabling access to post diagnostic support including anti-dementia medication in a timely manner), three quarters of memory clinics are asking about research and four times as many patients are being seen compared to the previous audit of two years ago. The summary recommendations are key: that any additional resources should be complementary to post diagnostic support; that more awareness raising is essential and; that linkage with research can be strengthened. The increased numbers of people coming to services lays down a challenge in exploring different ways of delivering high quality care.

I think the report puts memory services on a much firmer footing and in conjunction with the Memory Services National Accreditation Programme (MSNAP), shines a light on this crucial service.

I would like to thank all the organisations and individuals who took time to take part in the audit, to Sophie Hodge, Emma Hailey and Mike Crawford who have carried out a superb piece of work, and to colleagues from the Department of Health, NHS England and MSNAP who have supported the project.



Alistair Burns
National Clinical Director for Dementia
NHS England

Recommendations

Waiting times

The average waiting time for assessment is 5.20 weeks, and from the point of assessment to receiving a diagnosis the average wait is 8.36 weeks. The average waiting time for assessment is within the Memory Services National Accreditation Programme recommended standard of 6 weeks, which should be commended. However, there remain 24.3% of memory clinics outside the recommended waiting time which should be addressed. Additional resources should be considered to aid this problem, but it is crucial that resources are not diverted away from crucial post-diagnostic support and therapies in order to increase diagnostic rates.

Timely diagnosis

Nearly half of people diagnosed with dementia in the last year were in the early stages of the condition, which is an excellent result as early diagnosis enables planning for the future and increased efficacy of anti-dementia drugs. However there is still plenty of room for improvement. Memory clinics should consider their relationships with GPs and other referrers to ensure that they refer patients on at the earliest opportunity, at the same time as ensuring high quality, appropriate referrals. Awareness-raising work can be done in the community, and teams can consider making contact with hard-to-reach groups.

Research

73.0% of memory clinics ask people with dementia if they would like to be involved in research, and 84.3% had people from their clinic recruited to at least one research study in the last year; suggesting that although some clinics do not broach the subject directly with people with dementia, they are contacted through their clinic. It is encouraging to see that the majority of memory clinics are aware and involved in research. Clinics that do not currently recruit people with dementia to research studies could consider linking up with organisations such as the Dementias and Neurodegenerative Diseases Research Network (DeNDRoN) which helps memory clinics to connect with research studies, and in 2014 will launch a register for people who are interested in taking part in future research.

Patient numbers

Patient numbers have increased, at an estimate, almost four times since the 2010/11 audit, with memory clinics currently seeing an average of 1206.2 patients compared to 317 in 2010/11. There are several factors which could have contributed to this rise, but regardless of the reasons the rise in patient numbers should be taken seriously and plans should be made to deal with potential future increases.

Executive summary

An audit was conducted of memory clinics in England between July and September 2013.

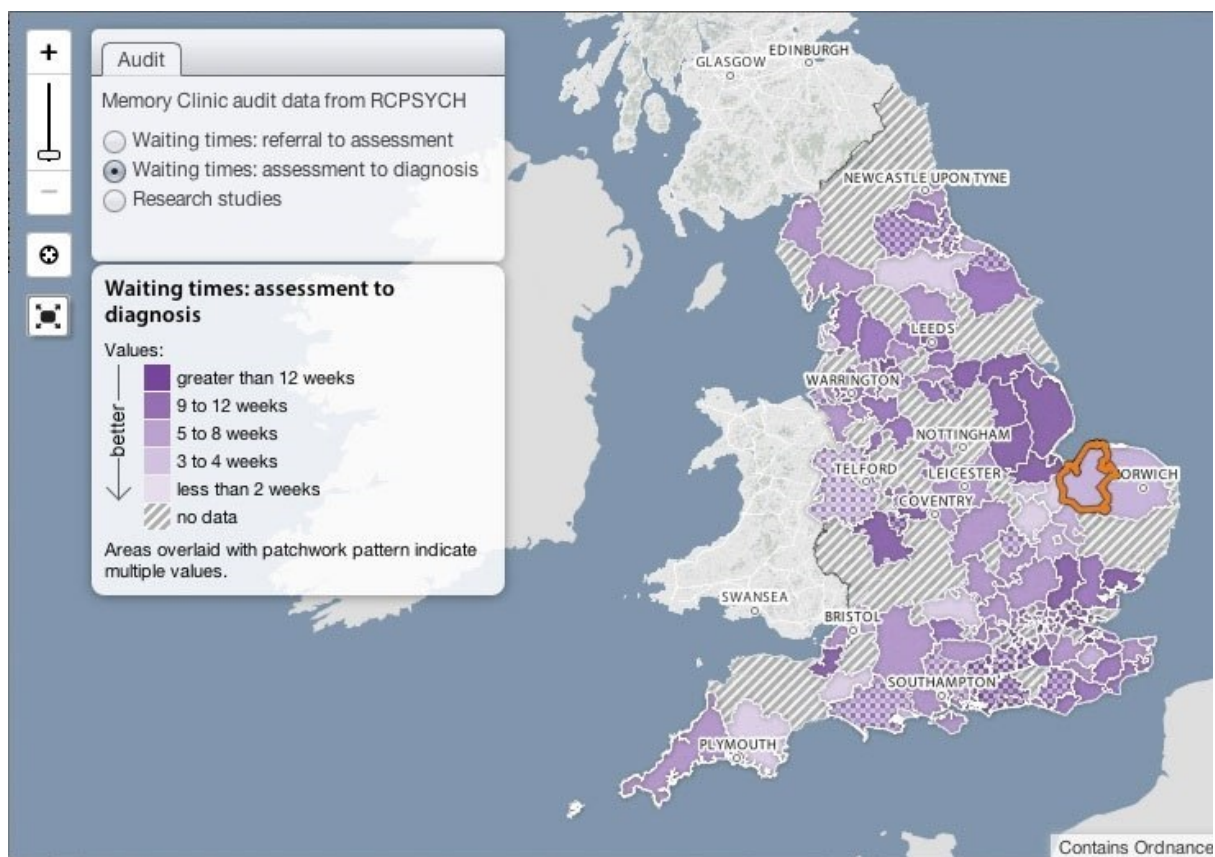
178 of 214 memory clinics in England responded, a response rate of **83%**.

Key findings

- **65.6%** memory clinics are provided as part of a **wider service** such as a CMHT-OP, as opposed to a stand-alone clinic.
- On average memory clinics cost **£622,621** each per year, but this figure varies widely.
- The average operating hours were **37.6 hours** per week
- Memory clinics can **assess a maximum** of 18.0 new patients each week, on average.
- In the last 12 months, memory clinics each **assessed** an average of **543.8** patients and **saw** an average of **1206.2** patients in total, a near fourfold increase since 2010/11.
- On average, people wait **5.20 weeks** from the point of referral to receiving their memory assessment, and an additional **8.36 weeks** from the point of having the assessment to receiving the diagnosis.
- **49.3%** people diagnosed with dementia over the last 12 months were in the **early stages** of the condition.
- **98.3%** of memory clinics can **initiate anti-dementia medication** and **97.8%** of clinics also **review medication**.
- **92.1%** of clinics provide **home-based assessments**.
- **73.6%** of clinics have access to **specialist post-diagnostic counselling**, **66.3%** have access to **Cognitive Stimulation Therapy**, **93.8%** provide access to **education and support for carers** and **62.9%** have access to **Life Story Work**.
- On average, each clinic provided **259.7** people with specialist post-diagnostic counselling, **53.7** people with Cognitive Stimulation Therapy, and **251.9** carers with education and support in the last 12 months.
- Involvement of people with dementia and carers in service improvement – people with dementia and carers are involved most often in giving **feedback on service quality**. Fewer than half of services involve them in the appointment of new staff, planning changes to service organisation, staff training and helping support other people with dementia/carers.
- **73.0%** of memory clinics ask people with dementia to register their interest in taking part in **research**.
- **33.7%** of memory clinics are members of the **Memory Services National Accreditation Programme**.

Please visit the online interactive map displaying waiting times, research involvement and MSNAP membership at the website:

www.rcpsych.ac.uk/memoryclinicsaudit



Introduction

In 2009, the Department of Health published *Living well with Dementia: A National Dementia Strategy*, which recommended that ‘new specialist services need to be commissioned to deliver good-quality early diagnosis and intervention,’ and went on to describe a community-based memory clinic which makes, and breaks, a diagnosis of dementia and provides, ‘directly appropriate treatment, information, care and support after diagnosis.’ £60million was attached to this Strategy with the aim of creating memory clinics, amongst other objectives.

In 2011 the NHS Information Centre published their report *Establishment of Memory Services - Results of a survey of Primary Care Trusts, final figures, 2011* which detailed the state of commissioned memory clinics in England in 2011, in support of the delivery of the National Dementia Strategy. An audit was conducted by requesting information from Primary Care Trusts. The report stated that there were 337 memory clinics in 2010/11 and estimated that there would be 443 by the end of the 2011/12 financial year. The audit also collected data on spending, aspects of service provision, and accreditation by the Memory Services National Accreditation Programme (MSNAP).

In 2012, the *Prime Minister’s Challenge on Dementia* was published to set out England’s aims with regards to dementia diagnosis and care. One of the key recommendations was to, ‘Ensure that memory clinics are established in all parts of the country and drive up the proportion of memory services that are accredited’.

This report aims to build on the findings from the NHS Information Centre report and provide an update on the progress of the Prime Minister’s Challenge.

Definition of a memory clinic

‘Memory clinics’ and ‘memory services’ were referred to interchangeably throughout the process in order to be as inclusive as possible. This was done deliberately because there is currently no agreement about what such services should be called and many would identify themselves as one but not the other. The following definition was used for the purpose of this survey:

“A memory clinic/service is defined as a multidisciplinary team (either NHS or private) that assesses and diagnoses dementia, and may provide psychosocial interventions for dementia. This can include Community Mental Health Teams for Older People.”

Method

Questionnaire development

The questionnaire included the same domains that were in the 2011 NHS Information Centre audit, as well as some additional questions. The Prime Minister's Challenge on Dementia advocated more dementia research, so services were asked to specify their involvement with research projects. In addition, a consultation group of memory service professionals, a person with dementia and a carer, was created to advise on the questionnaire and pilot its implementation. Additional questions were suggested by the group, including access to particular psychosocial interventions for people with dementia and carers. Refinements were made following a pilot phase and the questionnaire length was kept to a minimum to avoid overburdening services.

Identifying eligible services

A decision was made to attempt to contact memory clinics themselves, as there were a number of questions to be included in the questionnaire for which it was felt that memory clinics themselves would have access to the most accurate data.

Memory clinics have been difficult to locate as there is no national list, or a recognised moniker for such services (memory clinic; memory service; or cognitive disorders clinic; are some such titles). Services were contacted through the following means:

1. In 2012, the Royal College of Psychiatrists, at the request of the Department of Health, constructed the [Memory Services Register](#), and asked all memory clinics in the UK to complete a short form to attempt to identify how many services there were. The Register had 144 entries for England and these services were asked to complete the survey.
2. The 73 members of the [Memory Services National Accreditation Programme \(MSNAP\)](#) were contacted (some were also included on the Register).
3. An internet search using 'memory service' and 'memory clinic' search terms was conducted, and individual Trust websites were consulted in order to ensure that at least one service from each Trust was contacted. Community Mental Health Teams for Older People (CMHT-OPs) were also included in this search as many of them also provide the functions of a memory clinic.
4. Trust Clinical Audit Leads, Chief Executives and Medical Directors were contacted.

The identified contacts were emailed a link to a webpage with information and access to the online questionnaire, and asked to complete it.

Over 300 services were identified; after data collection any CMHT-OPs that had not responded were removed from the total as it was not clear whether they provided a memory clinic function. In total, including non-responding memory clinics, it is estimated that there are 214 memory clinics in England. This does not however tally with the

estimation of the NHS Information Centre report that there would be 443 memory clinics by 2012; this could be a result of organisational change, or there may have been clinics not captured by this audit.

Data collection

Data collection for the national memory clinics audit began on 5 July 2013 and ended on 20 September 2013, via an online questionnaire.

Data cleaning and quality

After data collection any extreme outliers and null responses were identified and the responder contacted to ask for clarification. Where no answer was received, the data were removed from the calculations.

Many of the questions were mandatory and responders were obliged to enter a response before they could complete the questionnaire. This caused an unforeseen problem where responders could not gain the information required and some answered '0'; therefore it was unclear which responses were truly zero and which were cases of incomplete data. An attempt was made to contact the responder for clarification; where none was given, some of the data was removed from calculations.

Some of the clinics also felt that data about funding was sensitive information and preferred not to provide this.

As part of data collection, responders were asked to state what source of information they mainly used in completing the questionnaire:

Table 1: Main source of information used when completing the questionnaire

Data that service already compiles	99 (55.6%)
Examination of records for the purpose of this audit	16 (9.0%)
Clinical impression based on experience of working in the service	63 (35.4%)

Results

Response rate

178 out of an estimated 214 memory clinics in England responded: a response rate of 83%. Memory clinics from 63 NHS Trusts completed the survey, and one private memory service.

Service type

Table 2: Types of memory clinic

Stand-alone memory clinic	54 (34.4%)
Part of a wider service (such as a CMHT-OP)	103 (65.6%)
Non-response	21

Just over a third of the services that responded were stand-alone memory clinics; many more were provided as part of a wider service.

Funding

Table 3: Memory clinic funding per year

Average funding per year	£622,621
Range	£25,000 - £5,000,000
Median	£445,685
Mode	£800,000
Non-response	66

As the non-response rate was so high, this data should be treated with caution. The NHS Information Centre report found that in 2008/9 each Trust spent an average of £486,000 on memory assessment services; in 2009/10 this rose to £551,700 and in 2010/11 it was £593,200. In 2010/11 there was an average of 3 memory clinics per Trust and therefore the average spend was £197,733 per service. The total here of £622,261 per memory clinic seems remarkably high and may have been skewed by poor data availability for this question (see *Data cleaning and quality*).

Capacity

In this section the survey asked about the number of hours the clinic operates, the maximum number of new patients that could be seen, and the actual number seen in each clinic.

Table 4: Memory clinic operating hours per week

Average	37.6
Range	4 – 77
Median	38
Mode	38
Non-response	2

The average, median and mode working hours reflect a standard working week, if it is assumed that the clinics operate between 7-8 hours a day Monday-Friday. 7.9% clinics open for more than 40 hours per week, operating what appears to be either extended weekday hours or a weekend service. Some memory clinics may provide a pathway to more intensive support services which can respond out-of-hours.

Table 5: Maximum number of new patients that can be assessed each week

Average	18.0
Range	2 – 102
Median	15
Mode	12
Non-response	1

Table 6: Total number of new patients that were assessed in the last 12 months

Average	543.8
Range	70 – 2,100
Median	445
Mode	400
Non-response	3

Table 7: Total number of patients who attended the clinic in the last 12 months (including new assessments)

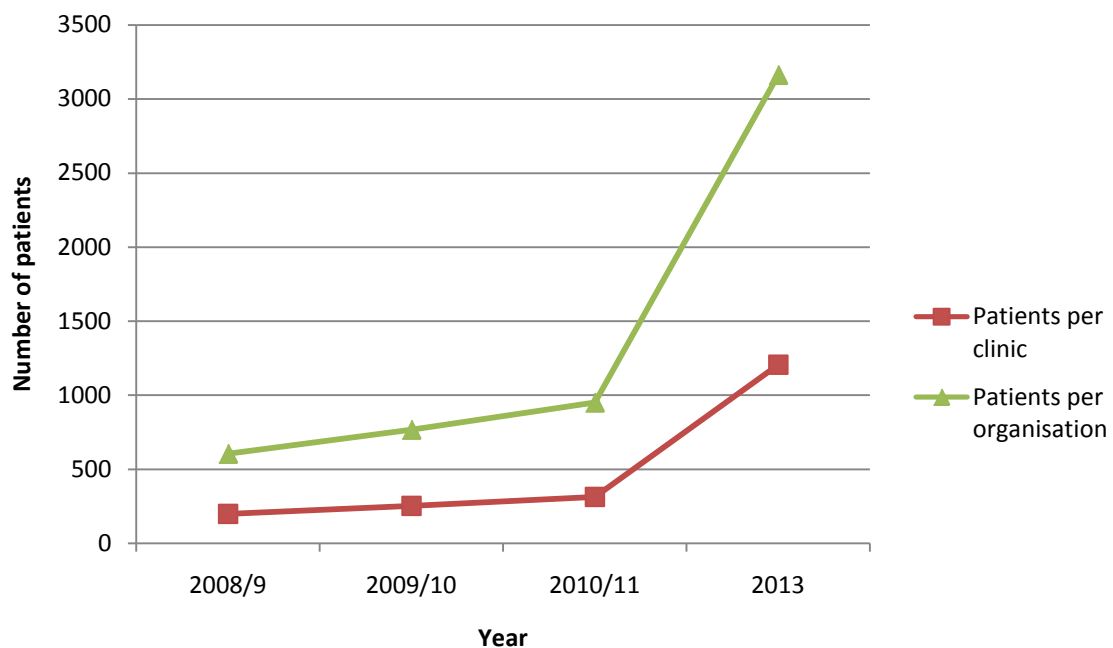
Average	1206.2
Range	81 – 7,802
Median	887
Mode	500
Non-response	9

On average, memory clinics each assessed 544 new patients and had a total of 1206.2 patients attending over the last year. However it can be seen from the ranges that these

figures vary hugely between clinics, with one clinic able to assess, at a maximum, 2 patients per week and 102 patients in another. It should be borne in mind that these services will serve different population sizes, which may explain some of the variance. In the NHS Information Centre report of 2011, it was recorded that there were 605 patients per organisation (Primary Care Trust) in 2008/9, rising to 767 in 2009/10 and 951 in 2010/11. It is more difficult to compare patients per organisation now as PCTs have been dissolved since the 2011 audit and we cannot be sure that the 2013 audit captured every memory clinic in each Trust. However if we accept this caveat, the 2013 audit captured 63 Trusts and one private memory service which equates to 3163 patients per organisation, as demonstrated in Figure 1.

Assuming 3 memory clinics per organisation across the 2008-2011 period, this equates to 202 patients per clinic in 2008/9, 256 in 2009/10 and 317 in 2010/11. The current figure of 1206 total patients per clinic in 2013 represents almost a fourfold rise in patient numbers.

Figure 1: Average number of patients accessing memory clinics per organisation (Trust) and memory clinic between 2008 and 2013



Waiting times

Table 8: Waiting time between memory clinic receipt of referral and the person starting their assessment

Average	5.20 weeks
Range	1 – 25 weeks
Median	4
Mode	4
Non-response	1

The standard set by the Memory Services National Accreditation Programme states that people should wait no more than 4-6 weeks between the receipt of referral and their first appointment. Despite the volume of patients seen for assessment, memory clinics are still on average meeting this target, although 24.3% memory services are still above 6 weeks waiting time, and the maximum waiting time is 25 weeks.

Figure 2: Number of weeks' wait between memory clinic receipt of referral and the person starting their assessment

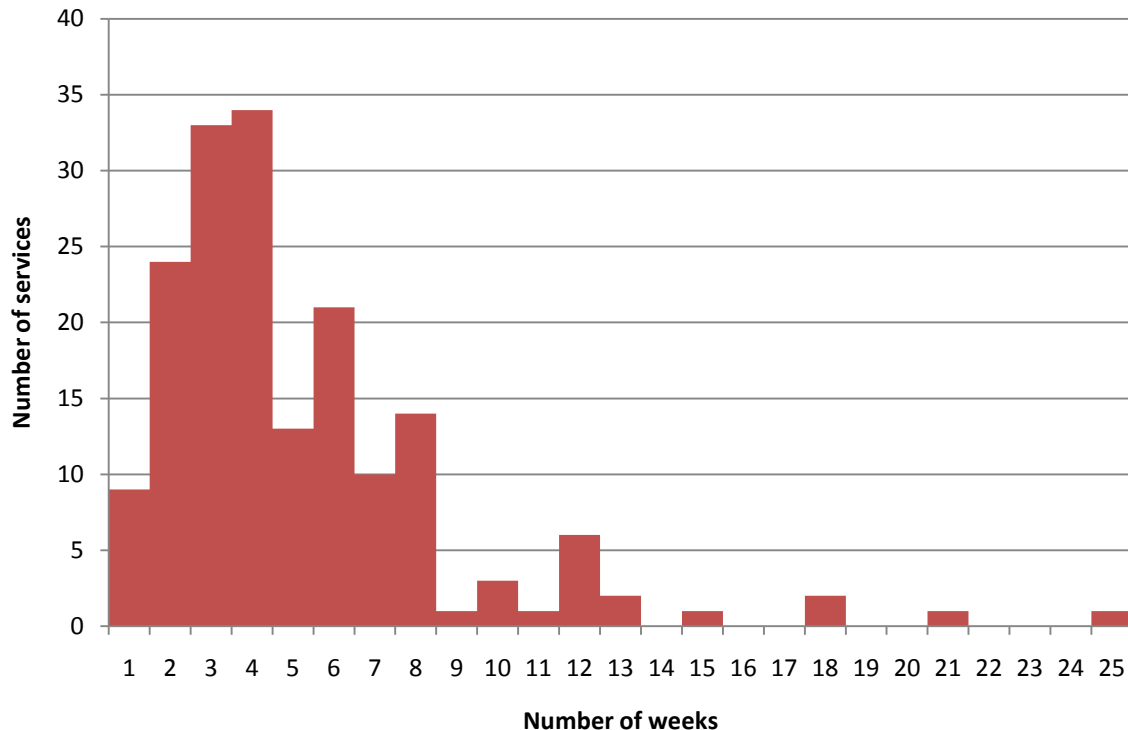
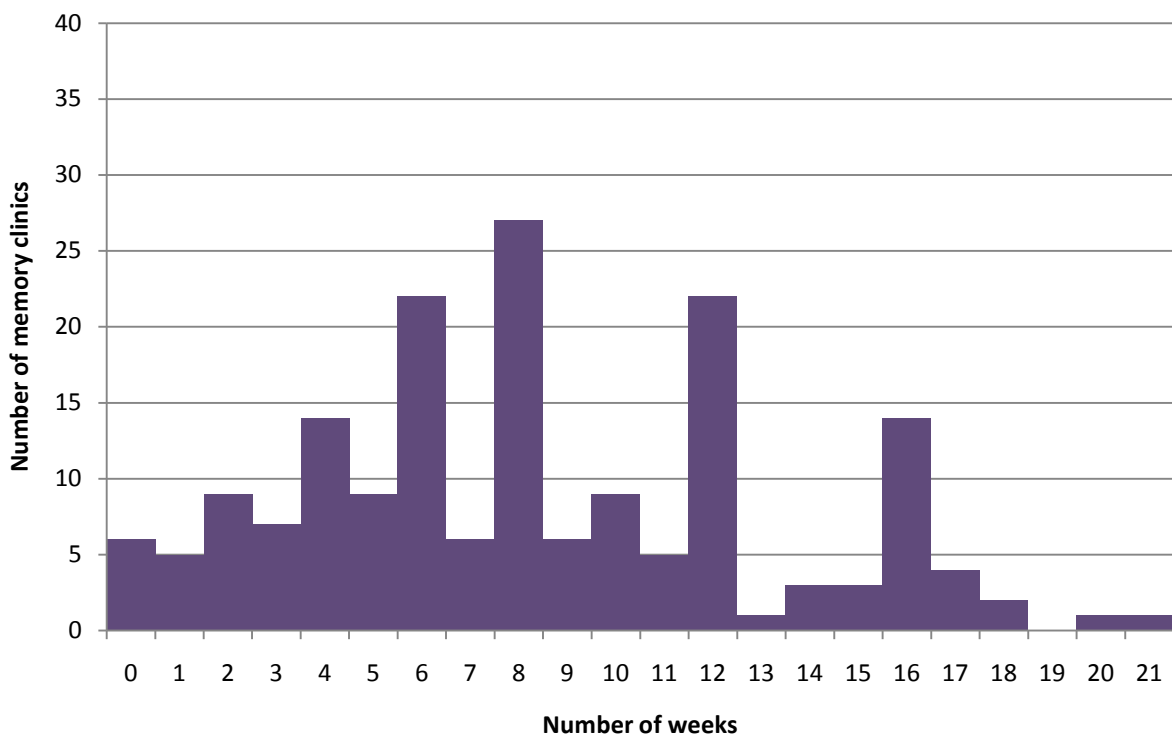


Table 9: Waiting time between assessment and receipt of diagnosis

Average	8.36 weeks
Range	0 – 21 weeks
Median	8
Mode	8
Non-response	1

The time between the assessment and diagnosis will often include receiving a brain scan, any additional tests needed (for example, specialist tests delivered by a psychologist, psychiatrist, occupational therapist, neurologist, geriatrician, etc.) and the wait for an appointment to deliver the diagnosis, which is most often done by the psychiatrist in the clinic. However it can be seen from Figure 3 that 6 clinics have no wait between assessment and diagnosis, suggesting that the diagnosis is usually delivered on the same day, without any additional appointments or tests.

Figure 3: Number of weeks' wait between the person's first assessment and receiving a diagnosis



The fact that there are peaks on the graph at 4, 6, 8, 12 and 16 weeks suggests that a number of clinics estimated these figures rather than relying on record-keeping. The data indicates that 35% of clinics mainly estimated their responses based on their impression of working in the service (see *Data cleaning and quality*).

Timely diagnosis

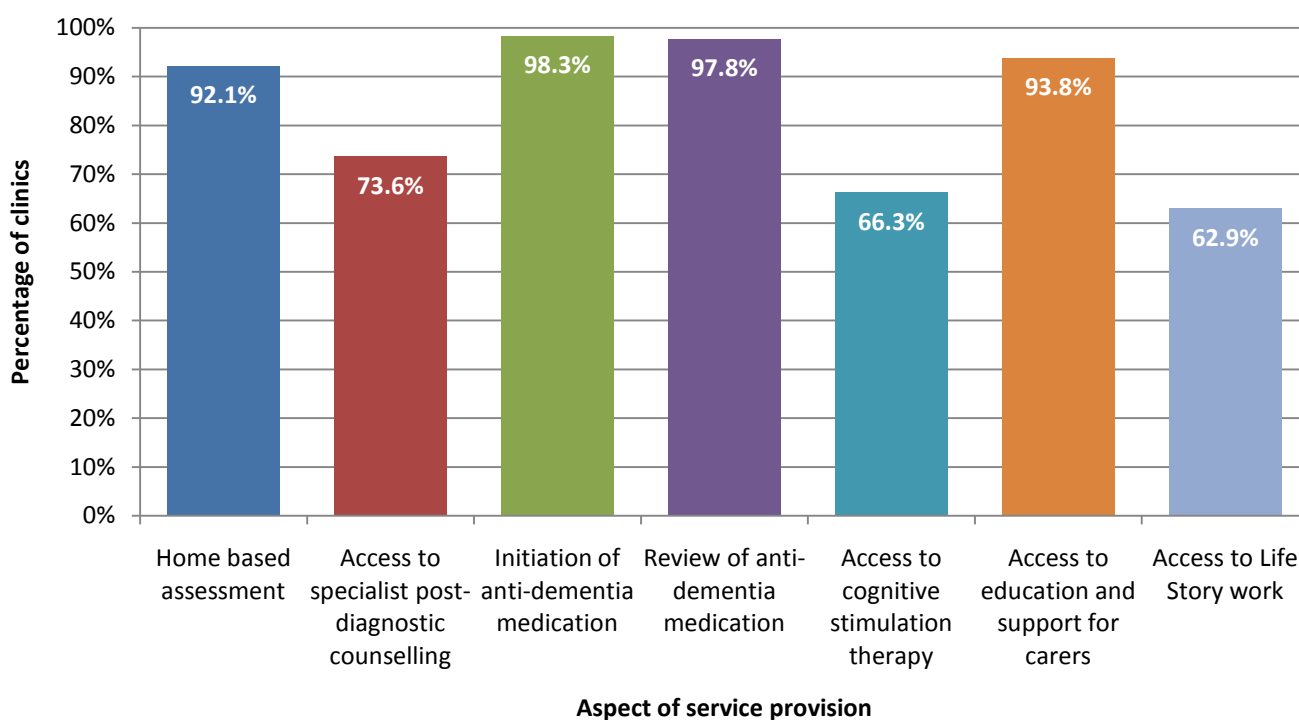
Table 10: Percentage of people diagnosed in the last 12 months who were diagnosed in the early stages of dementia (according to thresholds defined by the assessment tool used)

Average	49.3%
Range	4 – 100%
Median	50%
Mode	80%
Non-response	19

Almost half of diagnoses are given to those in the early stages of dementia, which is promising. Much work has been undertaken to raise public awareness of dementia, to de-stigmatise the condition, and to increase the number and quality of memory clinics over the last few years. This work is likely to have influenced how soon after noticing signs of dementia that people come forward for assessment. It is hoped that this proportion will increase further, allowing people early access to drugs which may slow down the progress of the disease and the opportunity to plan for the future whilst capacity is maintained.

Service provision

Figure 4: Percentage of memory clinics which provide various features of service provision



Almost all clinics provide initiation (98.3%) and review of anti-dementia medication (97.8%). In addition, the vast majority of clinics provide home-based assessments (92.1%) and access to education and support for carers of people with dementia (93.8%). Almost three quarters of clinics have access to specialist post-diagnostic counselling (73.6%) and approximately two thirds of clinics have access to Cognitive Stimulation Therapy (66.3%), a NICE recommended psychological intervention for dementia, and Life Story Work (62.9%). The NHS Information Centre report from 2011 noted that 88/119 Trusts provided all 8 of the aspects they recorded: home based assessment; counselling; specialised diagnostic equipment; provision of full explanation of diagnosis; provision of information on prognosis and care options; provision of advice and support; pharmacological treatment; and follow-up and review services. 9/119 Trusts provided none of these.

Table 11: Number of people who used specialist post-diagnostic counselling, per clinic, in the last 12 months

Average	259.7
Range	1 – 1451
Median	155
Mode	20
Non-response	77

The average number of people who used specialist post-diagnostic counselling (in services which provide it) in the last 12 months was 259.7, suggesting that this question was misinterpreted. Specialist post-diagnostic counselling should be provided by a trained counsellor, for people who have rarer diagnoses or a particularly adverse reaction to the diagnosis. It is likely that responders interpreted this as meaning providing general support and advice following a diagnosis, as it is unlikely that such a high number of people would need this kind of specialist counselling.

Table 12: Number of people who used Cognitive Stimulation Therapy, per clinic, in the last 12 months

Average	53.7
Range	0 – 500
Median	27.5
Mode	0
Non-response	60

Cognitive Stimulation Therapy is usually run as a group psychological intervention over a number of weeks and is designed to improve or maintain cognitive function. It is recommended by NICE and is included in the MSNAP standards.

Table 13: Number of people who used education and support for carers, per clinic, in the last 12 months

Average	251.9
Range	0 – 1977
Median	100
Mode	0
Non-response	8

A large proportion of care for people with dementia is provided by the informal family carer. It is therefore crucial to provide education for carers to enable them in their role, and support to ensure that carer burnout does not occur.

Involvement of people with dementia and carers in service development

The area with most involvement from people with dementia and carers (83.2%) is feedback on service quality, which is likely to be done by satisfaction survey. The area with least involvement is staff training, however one fifth (20.2%) of services do include people with dementia and carers. 50.0% of services involve people with dementia and carers in planning changes to service organisation and delivery, 47.2% involve them in helping support other people with dementia and carers and 20.8% of services involve them in the appointment of new staff.

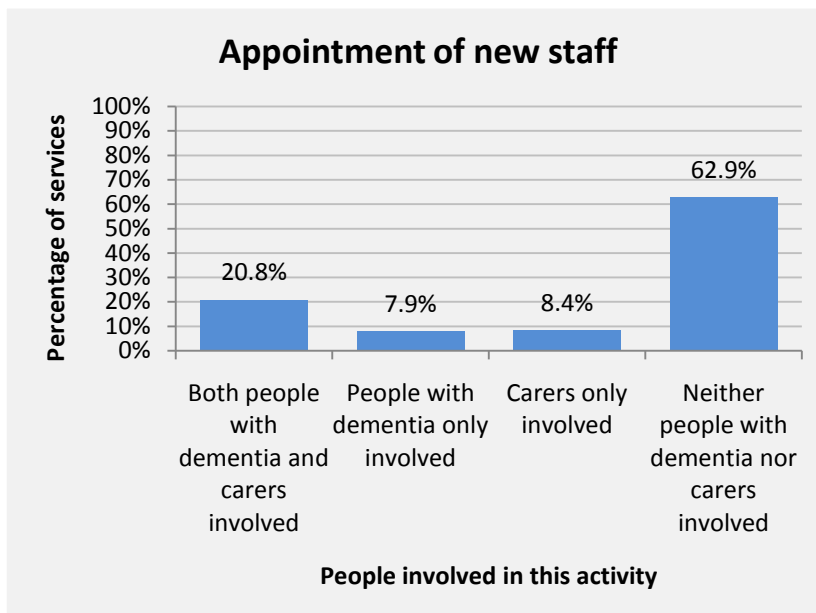


Figure 5: Percentage of memory clinics which involve people with dementia and carers in the appointment of new staff

Figure 6: Percentage of memory clinics which involve people with dementia and carers in delivering feedback on service quality

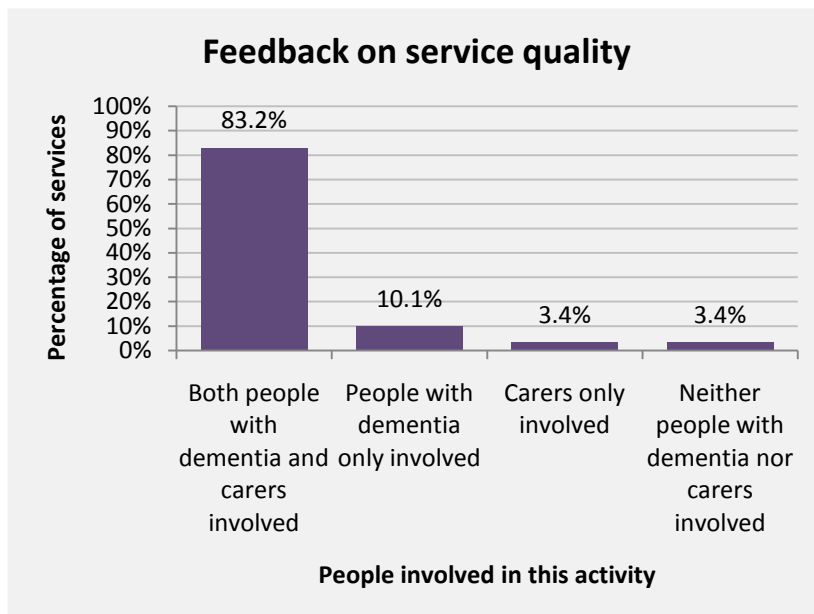


Figure 7: Percentage of memory clinics which involve people with dementia and carers in planning changes to service organisation and delivery

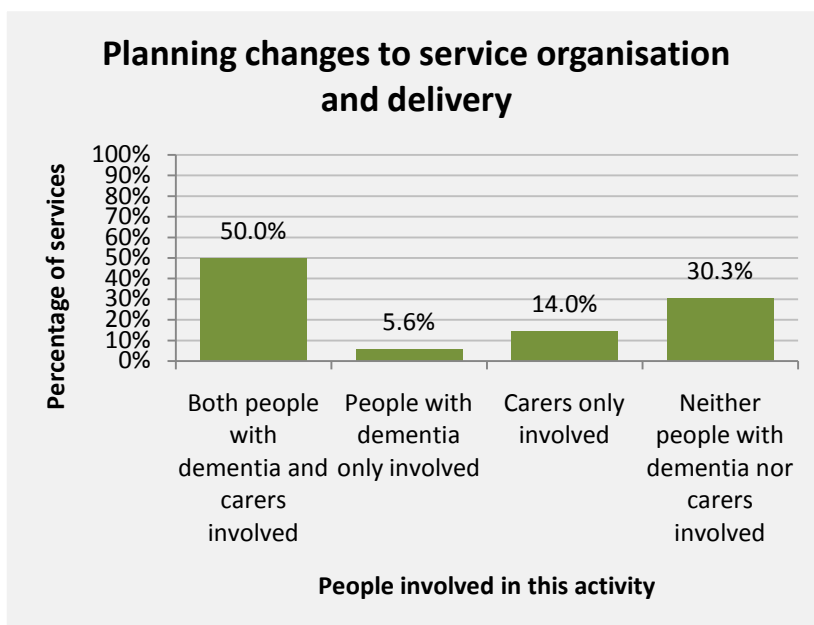


Figure 8: Percentage of memory clinics which involve people with dementia and carers in staff training



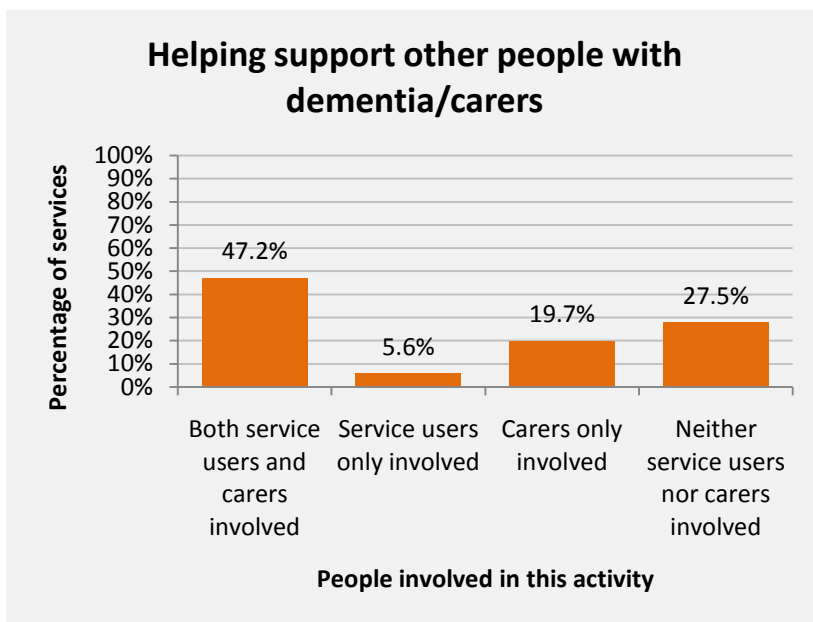


Figure 9: Percentage of memory clinics which involve people with dementia and carers in helping support other people with dementia and carers

With the exception of service feedback and helping support others with dementia/carers, the other graphs suggest that services tend to involve both people with dementia and carers, or neither group. Few services involved only one of the groups.

It is also interesting to note that people with dementia alone were more likely to be involved in service feedback, however carers were more likely to be involved in appointment of new staff, changes to service organisation and delivery, staff training and helping support other people with dementia or carers.

Research

Table 14: Number of memory clinics which ask people with dementia to register their interest in participating in research studies

Ask people with dementia to register interest	130 (73.0%)
Do not ask people with dementia to register interest	48 (27.0%)

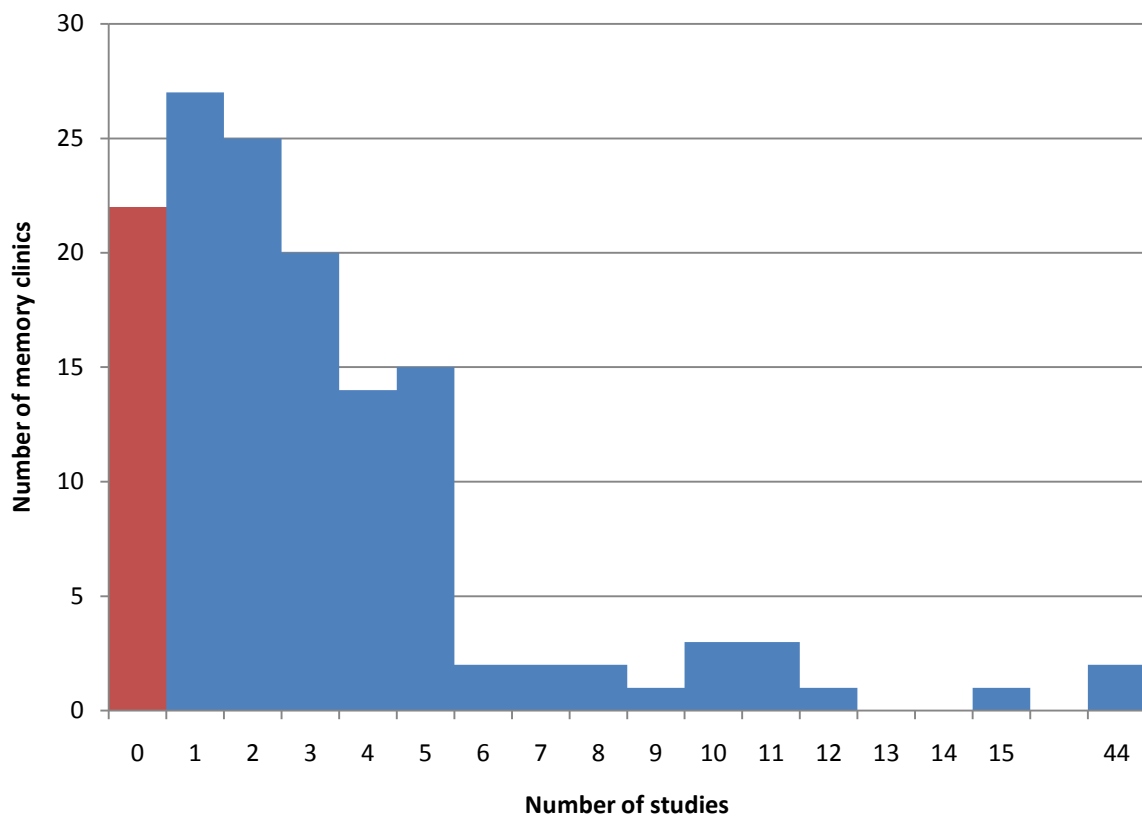
Memory clinic involvement in research was included as a key commitment in the Prime Minister's Challenge on Dementia, in order to increase the possibilities for research into dementia. It is expected that memory services will offer all people with dementia the opportunity to be involved in a research project, or to be added to a register for future researchers to access.

Table 15: Number of research studies each memory clinic recruited patients to in the past 12 months

Average	3.55
Memory clinics that recruited people to at least one study	118 (84.3%)
Range	0-44
Median	2
Mode	1
Non-response	38

22 memory clinics did not recruit to any research studies, while 2 memory clinics recruited to 44 research studies each. Memory clinics' involvement in research is one of the key commitments of the Prime Minister's Challenge on Dementia and it is encouraging to see the proportion of clinics which do ask people to register their interest; however there is still over a quarter of clinics who do not raise this issue with patients. It may be that additional support and education is needed to help memory clinic staff approach this subject with patients.

Figure 10: Number of different research studies which recruited patients through memory clinics in the last 12 months



Membership of the Memory Services National Accreditation Programme



Details of membership of MSNAP were taken from the membership list on the [MSNAP website](#) and it was noted which of the responders were members of the programme, and their accreditation status.

MSNAP is a quality improvement programme which reviews memory clinics against a set of evidence-based standards, and supports clinics to achieve accreditation.

Table 16: Percentage of memory clinics which are members of the Memory Services National Accreditation Programme

Members	60 (33.7%)
Non-members	118 (66.3%)
Breakdown of memory clinics by accreditation status	
Accredited as excellent	15 (8.4%)
Accredited	12 (6.7%)
In review stage (not yet accredited)	27 (15.2%)
Affiliate member (part of network but not reviewed)	6 (3.4%)

Increased membership of, and accreditation by, MSNAP is also a recommendation in the Prime Minister's Challenge on Dementia, although currently two thirds of clinics in England are not members of the programme. The NHS Information Centre report in 2011 noted that of those which were not members of the programme, 15 of 119 Trusts were working towards or considering joining the programme, and 24 of 119 were not seeking accreditation. The most common reason for not joining the programme was financial considerations (14 of 119 Trusts), as the programme does incur a small annual subscription fee. The fee has not changed since 2011, and so it is likely that this reason for non-membership continues to be significant.

The 2011 report also noted that 27 Trusts had all their memory clinics accredited by MSNAP and 8 Trusts had some but not all of their clinics accredited. With an average of 3 clinics per Trust, a modest estimate based on 3 clinics in each of 27 Trusts and 1 in each of the 8 Trusts, gives 89 accredited members. However, membership of MSNAP as of 20 September 2013 (according to the membership list on the MSNAP website) stands at 74 clinics and of these, 27 are accredited. This has risen substantially since 2011, therefore it may be that the question posed in the 2011 audit was misinterpreted.

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