Pathways to Dementia Diagnosis: A review of services in the south-west of England

Dr Edana Minghella, Independent Consultant

November 2013
Foreword

I am most grateful to Dr Edana Minghella for undertaking this independent review of Pathways to Dementia Diagnosis in the South West of England. My thanks go also to commissioners, service providers, GPs and most importantly people with dementia and their carers for willingly giving their time to provide honest, detailed information about the Pathways and their related experiences of them.

The NHS is currently faced with a major challenge: on the one hand we have forecasts of rising numbers of people with dementia, an existing gap between those with a diagnosis and those still waiting for one, and in some areas unacceptably long waiting times from referral to diagnosis; and on the other hand the need to commission excellent, reliable and acceptable dementia diagnosis services within existing financial resources. Many commissioning organisations in the South West have responded to this challenge by exploring new pathways to diagnosis and a variety of models are now emerging.

This report seeks to make an early comparison of these pathways, and what happens after diagnosis, to identify what makes a good pathway. I believe that the information herein will be useful to both commissioners and service providers in developing existing models to suit the needs of their local populations whilst maintaining or improving standards.

This review also raises the profile of a cohort of people emerging from diagnostic services with not dementia but the even less certain diagnosis of Mild Cognitive Impairment. Whilst this suggests that the public and GPs are getting the message about the value of earlier diagnosis, commissioners now also need to answer questions about how best to follow these people up in the future, and what support or prevention strategies to offer them in the meantime. If we can influence their risk of progression to dementia this may prove to be the most important intervention this decade.

Dr Nick Cartmell
GP and Associate Clinical Director, South West Strategic Clinical Network
Contents

Part One: Introduction ......................................................................................................................... 5
Dementia .............................................................................................................................................. 5
The diagnosis pathway – what we already know ............................................................................... 5
Problems in the diagnosis pathway ................................................................................................. 6
The project .......................................................................................................................................... 7
Aims and objectives of this project .................................................................................................... 7
Methods ............................................................................................................................................ 7

Part two: Findings ............................................................................................................................... 9
Hopes and ambitions for Memory Assessment services in the South West ........................................ 9
In-depth reviews of services ............................................................................................................... 11
The selected services ......................................................................................................................... 11
Primary care ....................................................................................................................................... 13
Identifying a problem ......................................................................................................................... 13
Primary care testing and referring ................................................................................................... 14
Diagnosing in primary care .............................................................................................................. 14
Characteristics of referrals ................................................................................................................ 16
Age, gender and ethnicity .................................................................................................................. 16
Health circumstances ....................................................................................................................... 17
Waiting for an assessment .................................................................................................................. 18
Assessment and Diagnoses ................................................................................................................ 21
First experiences ............................................................................................................................... 21
Assessment and testing ..................................................................................................................... 21
Dementia and other diagnoses .......................................................................................................... 23
Giving and receiving a diagnosis ....................................................................................................... 24
Post diagnosis support and next steps ............................................................................................. 26
Discussion and points of learning ..................................................................................................... 29
More people diagnosed with dementia ........................................................................................... 29
Shorter waiting times ......................................................................................................................... 29
Dementia and MCI .............................................................................................................................. 30
Services are valued ............................................................................................................................ 31
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Part One: Introduction
This paper reports on a project investigating the pathway from primary care to diagnosis for people living with dementia in the South West of England. It is intended to support commissioners and service designers wishing to refine and improve the diagnostic pathway. It was commissioned by NHS South of England Strategic Health Authority and has been completed on behalf of the South West Strategic Clinical Network for Mental Health, Dementia and Neurological Conditions

Dementia
Dementia is a term used to describe a range of progressive, terminal organic brain diseases, the most common of which is Alzheimer’s Disease (AD) which accounts for more than 62% of dementia in England.¹

There are increasing numbers of people with dementia in the UK. A report for the Alzheimer’s Society recently suggested that by 2020 there will be 750,000 people with dementia living in England.² Risk increases with age, but there is a significant group of people with dementia under the age of 65. The National Dementia Strategy quotes a figure of at least 15,000 people under the age of 65 with the condition in the UK but this is highly likely to be a gross underestimate (Department of Health, 2009).

The Alzheimer’s Society have pointed out the importance of differentiating between the dementias because their presentation can be quite different and needs can differ significantly³. For example:

- People with vascular dementia, which is the second most common form of dementia, may not initially show memory problems.
- Dementia with Lewy Bodies shares symptoms with Parkinson’s Disease.
- People with fronto-temporal dementia are often under 65 and may more obviously show aggression and disinhibited behaviour.

Moreover, people may experience more than one kind of dementia and may have additional long-term conditions. Thus it is clear that there will be differences in where people show up in the care pathway, why they might present, and what is needed at each point.

The diagnosis pathway – what we already know
For the individual and families living with dementia*, a diagnosis is a critical stage in the dementia journey. It opens up choices about next steps, potentially provides access to medication, treatment, support and a range of other services, and offers an opportunity for planning for the future⁴.

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*Please note, the term ‘living with dementia’ is used in this paper to refer to the person with the condition and their family/carers
For health and social care commissioners and providers, it is essential to have a clear understanding of the numbers of local people with dementia, in order to be able to plan and deliver services effectively and efficiently. The Department of Health’s Commissioning Framework for Dementia set out person-centred outcomes that commissioners should expect to achieve for people living with dementia, including at the very early stages. These person-centred outcomes, linked to NICE quality standards, included:

- People are confident that primary care practitioners take their concerns seriously
- People are confident that primary care practitioners understand the nature and cause of memory problems
- People are confident that primary care practitioners could arrange for a timely, appropriate assessment.

Service options that could deliver the required outcomes were also identified.

Objective Two in the Living Well with Dementia, the national dementia strategy, is the objective to provide good quality early diagnosis and intervention for all. The strategy expects all those with dementia to have access to a rapid, competent assessment and a sensitively communicated accurate diagnosis, followed by treatment, care and support. The strategy also notes that the local care system needs to have the capacity to see all new cases of dementia locally – a critical issue for commissioners and providers if they are to deliver outcomes successfully.

The publication of the Dementia Strategy sparked a range of initiatives and commissioning guidance. In particular, funding was allocated to develop memory services to facilitate timely diagnosis, with a further wave of funding allocated at the end of 2011. Timely diagnosis continues to be a priority for government, which has recently advocated dementia case-finding in primary care.

Despite the plethora of initiatives and funding, however, the NHS Atlas of Variation in Healthcare has found a huge variation in the proportion of people diagnosed with dementia. The Atlas reported that numbers of people with dementia on GP registers in PCTs ranged from 26.8% to 58.8% of expected prevalence; hence even in the best areas, more than 40% of people did not have a diagnosis. A recent All-Party Parliamentary Group on Dementia also found poorer than expected diagnosis rates, as well as unwarranted variation. Even more recently, an Alzheimer’s Society report found that only 44% of people with dementia in England, Wales and Northern Ireland have a diagnosis, and that this figure is only 3% higher than the year before despite efforts and intentions to increase diagnosis rates.

Problems in the diagnosis pathway

Problems can exist in each step of the diagnosis pathway, even before consulting the GP.

1. Seeking help

Stigma, fear and lack of knowledge are likely to contribute to some people not seeking help from the GPs. More than a third of carers responding to the All-Party Parliamentary enquiry waited more than a year to see their GP and almost 10% did not attend at all. This implies that work to improve the dementia diagnosis pathway must begin before GP consultation.

2. Experiences in primary care
People living with dementia have reported experiencing issues such as feeling dismissed by GPs. Lack of knowledge and skills in primary care may be contributing to these problems. It has also been suggested that the problems are exacerbated by a lack of ownership of dementia issues, as the role of diagnosis and treatment has hitherto been located within memory services and secondary care.

NICE have this month issued proposals for new QOF indicators for dementia, that are likely to help improve this sense of ownership. The new dementia targets, based on quality standards, would see GPs paid to hold contact details for a carer on the records of people with dementia, keep a register of dementia carers who are patients of the practice, and assess their health annually. They would also earn extra for patients with a new diagnosis of dementia who have attended a memory service up to 12 months before diagnosis.

3. **What happens next: diagnosis and beyond**

Even if the experience along the dementia diagnosis pathway has gone well and there is a timely referral to a specialist services, problems may ensue. The All-Party Parliamentary Group mentioned earlier noted variable standards and experiences with memory services, with some having long waiting times of up to a year. They also found poor integration between primary and secondary care and poor post-diagnosis support.

Some practitioners may be reluctant to give a diagnosis and some suggest professionals compare it to giving the diagnosis of cancer. Poorly informed attitudes and a rigid medical model of dementia may be contributing factors.

Post-diagnosis information, care and support is also often lacking. While more and more people with an early diagnosis of dementia are being prescribed anti-dementia medication, there may be very little help with managing the diagnosis, lack of clarity about next steps, or information about available future support.

**The project**

**Aims and objectives of this project**

The aims of this project were to:

1. Undertake a survey of current dementia diagnosis pathways in the South West
2. Critique selected dementia diagnosis pathways against agreed standards and criteria
3. Identify experiences and potential outcomes for people experiencing selected diagnosis pathways
4. Produce a report based on the project’s findings and relevant policy and other literature, to help commissioners interpret different models for dementia diagnosis services for people living with dementia.

**Methods**

The following methodologies were used to achieve the objectives of the project:

- **Survey** using brief electronic questionnaire to commissioners to identify current dementia diagnosis pathways
- **Workshop** with stakeholders to identify agreed quality standards

And in five selected areas:

- **Audit methodology** providing empirical quantitative and qualitative data to understand actual patient pathways in the selected areas. Data was collected using an audit tool developed by the author from previous work. The audit was carried out on the pathways of ten consecutive referrals in each area, at least six months before the project started in order to be able to see the ongoing pathway.

- **Interviews with clinicians** and practitioners in the selected areas, using a semi structured interview schedule.

- **Focus groups or individual interviews with people living with dementia** in the selected areas to learn about their lived experience of specific pathways.

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1 One site started later than 6 months before the project started, so for this site the audited pathways started slightly later.
Part two: Findings

Hopes and ambitions for Memory Assessment services in the South West

Diagnosis rates in the South West have been among the lowest in the country with some adjusted rates as low as 37% of expected prevalence\(^{15}\). Local ambitions to improve these rates are high, at between 47% and 56% in 2013/2014 and up to 75% in 2014/2015, as shown in Figure 1. These ambitions are indicative of a strong commitment on the part of commissioners, very evident in the survey carried out for this project, to improve dementia services locally.

Figure 1: Local dementia diagnosis rates and ambitions for improvement

Many commissioners have set improved dementia diagnosis rates as key outcome measures for services, along with reduced waiting times. For example, several CCGs have set 4 weeks as the waiting time from referral to assessment.

Most commissioners have worked together with statutory and voluntary sector provider colleagues to identify care pathways for memory services. Some specify primary care involvement in the diagnostic process with a LES or DES providing financial incentives to GPs for increased diagnosis rates.
Case finding in primary care and in other parts of the healthcare economy also features in some commissioning ambitions. For example, one CCG’s community health provider is asking people over 75 as part of their assessment process if they have significant memory problems. If so, a Mini-Cog test is carried out and, if positive, a referral made.

Some have also included care pathways specifically for people with learning disabilities who may be referred for memory assessment. Care pathways vary but Figure 2 shows a general overview of what pathways look like across the region.

Figure 2: The Diagnosis Care Pathway

Primary care involvement, the initial appointment and the diagnosis are the key elements. How referrals are managed, how tests are processed and what happens after diagnosis are elements that vary considerably. The next section describes how these pathways actually work in practice, based on the indepth review of five selected areas, including the perspective of people using services. However, it is worth noting here that variations to how the pathways are actually commissioned can be found within each of the steps in all areas. Some CCG areas have separate primary care pathways, for example. Some also have separate pathways for people with complex conditions. Key areas of commissioning differences include:

- The nature and involvement of primary care in diagnosis and treatment. Some pathways are focused on primary care diagnosis and treatment for people with non-complex dementias; some have primary care dementia workers (although one commissioner noted that GPs were not referring to this service despite it being in place for some time)
• Whether GPs may refer to a mental health service rather than to the MAS. This can cause confusion and is noted by commissioners as a source of some people being passed between services.
• Whether GPs may refer to MAS or other services (for example, to neurology)
• The range and nature of services commissioned alongside the MAS service – including post diagnostic services
• The nature of performance indicators (for example, whether or not there are indicators around carers).

Costs were difficult to ascertain and compare, primarily because so many Memory Assessment Services are provided through a block contract. However, some financial issues of importance were raised by commissioners, especially in relation to provision of Enhanced Services (LES, DES etc).

In-depth reviews of services

The selected services

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<th>Table 1 – the five Memory Assessment Services</th>
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Services were selected for in-depth review by the Strategic Clinical Network in negotiation with the services themselves. Selection was based on providing some variation in service design and/or particular aspects of services known to be of special interest. One service declined to take part in the in-depth review due to already being the subject of an ongoing extensive evaluation. In all, five services from across the South West took part. In order to help preserve some confidentiality – especially of people using the service – the services are not fully identified here. Instead they will be known by colour. A full description of each service is not possible here but Table 1 shows notable features.

How each of these selected services works in practice is now described in more detail, from the perspectives of people using the service, practitioners and managers, combined with data from the Pathways Audit.
Primary care

Identifying a problem

This project found wide variation on how memory problems or other early signs of dementia were identified in primary care. Sadly, many people living with dementia in all five areas reported poor experiences in relation to their first contact with a professional (usually a GP) about memory or other relevant problems. They found their concerns were not always taken seriously or treated appropriately, despite persisting.

“Our concerns were batted away by the GP. I gave my husband a cutting about Aricept to take to the next visit. The GP threw it in the bin.” Wife of person with dementia.

“We were getting nowhere fast.” Carer.

“The GP said nothing was wrong. I went back when the GP retired. The new GP did a brain scan and referred us.” Carer.

“We went numerous times to the GP, 5 or 6 visits. The first diagnosis was anxiety. But mum was getting stressed. He gave her antidepressants. But mum’s friends and I were concerned. The antidepressants weren’t working. She was still forgetting and losing stuff.” Daughter of person with dementia.

Some people had positive experiences, although it has to be said these were in the minority of people interviewed for this project.

“The GP was helpful and supportive.” Carer.

“The GP was very good, picked up on memory problems and referred.” Carer.

“Went to the GP, who was very sympathetic.” Person with dementia

Most practices are signed up to the national Dementia Enhanced Service (DES) specification which aims to encourage GPs to identify people at risk of dementia, provide assessment and referral where necessary, and to support carers. Examples of actions some GPs in this project were taking included practice nurses asking people over 75 with long term conditions about possible memory problems and district nurses being trained in the use of cognitive testing tools.

One interviewee noted, however, that merely signing up to the DES earns GPs additional monies; they don’t have to take any further steps and it is unclear how widespread case-finding actions are. Another GP expressed resistance to the idea, taking the view that this should not take place without further training and support:

“No training? No case-finding.” GP.

Some dementia-friendly elements in GP practices were found, with a clear aim of encouraging people to come forward. This was particularly noted in the Green service area where service development is primary care led. Here, there are local ‘roadshows’ using positive images of people
with dementia, dementia leads in each practice and receptionist training, with some reported positive results. For example, forgotten appointments may be picked up by the receptionist as a possible sign of memory problems.

**Primary care testing and referring**

Interviewees stated that GPs were referring more people to services as awareness increases and the services themselves adapt and become streamlined. As a result some services that had offered self-referral were reporting fewer self-referrals and fewer people accessing a pre-referral memory group (to the extent that this group was not currently running). The Pathways Audit data, though not complete in this area, found that GPs rarely waited before referring if they suspected a memory problem. Where data was available, 90% of referrals were made on the day of first presentation.

Increased confidence in MAS services was notable amongst GPs. All GPs interviewed for this project were impressed with services and highly valued them:

“I get good feedback from [the service] when I refer.” GP

“The service is well embedded in my work and in the community so it works well.” GP

“The service is more responsive. Because the memory nurses are freed up they can respond really quickly if we contact them, so patients are not in limbo.” GP

The Map of Medicine dementia pathway has been designed for use starting in primary care, enabling GPs to make decisions about testing and next steps when someone presents with memory problems. Most GPs interviewed for this project said they used the Map of Medicine pathway, yet the Pathways Audit data showed that many people were referred without having undergone the steps set out in the Map of Medicine.

Of the 50 people referred, fewer than half (24, 48%) had a formal memory test (MMSE, GP-COG or CIT-6) on referral; five of these people had also been sent for a brain scan. Blood tests were required by the Purple service and this was the only service where blood tests were formally recorded as having been received by the service as part of the referral (in 6 out of 10 referrals). The MAS service where referrals were most likely to be accompanied by a formal memory test result was the Green service which has a primary-care led component, and where it is clearly expected that GPs should follow the Map of Medicine protocol.

Interestingly, services did not routinely ask for further tests in primary care before seeing the patient. In one notable, anomalous instance, the Purple service did request blood tests leading to extended waiting times for the patient (details below). Some experts consulted for this project expressed the view that tests in primary care might actually be unnecessary and will mean needless duplication for the patient. However, this does then raise the question as to whether GPs should be following the Map of Medicine pathway or not, and if not, what should they do be doing in advance of the referral.

**Diagnosing in primary care**

Diagnosis in primary care was a strong official part of the pathway in only one of the five sites examined in depth for this study. In the Green service, GPs are signed up to diagnosing where possible and starting treatment. Only more complicated presentations or people under 65 are
routinely referred to the MAS service. If the GP is unsure, he or she can speak to the MAS service and there is a strong relationship between them. This has led to a reported increase in local diagnostic rates from 37% to 53% of expected prevalence in one year.

Other sites reported some diagnosing among GPs, notably of older, frailer people, where some said they did not consider it necessary, or even fair, to have the patient go through the process of MAS referral, further testing and so on. The experience of primary care diagnosing was mostly positive:

“Even with the old memory clinic model we were doing bloods and MMSE anyway, and were following up. So technically not really more time consuming.” (GP)

“Amazed at how positive GPs have been.” (GP)

“I felt deskilld under the old system.” (GP)

However, there was some scepticism from GPs and others across all sites:

“In my experience, most GPs aren’t interested. They don’t want to diagnose, they don’t want skills, they don’t have the time.” (Psychiatrist)

“Commissioners didn’t want a primary care model” (Psychiatrist)

“Don’t want greater role without resources. We are stretched beyond breaking point”. (GP)

“GPs can diagnose but I’m not sure how many actually are.” (GP)

“Giving a diagnosis is a process and might take time. I worry that in primary care it’s seen as a one-off. “ (MAS doctor)

“I worry about GPs diagnosing because there are too few new cases of dementia for each practice, so they can’t develop the skills.” (MAS doctor)
Characteristics of referrals
The Pathways Audit gathered data on socio-demographic characteristics of the 10 consecutive referrals in each service.

Age, gender and ethnicity
The age range of all 50 referrals was 44 to 91, with a median age of 79 years. All sites reported younger referrals coming through over time although three of the five sites had median ages of 80+ which suggests this impression is not wholly accurate. The Red service had the lowest median age of 73 years with 6 of the 10 referrals being under 75, perhaps surprisingly as this service is situated in a fairly rural area which has a relatively older population. Differences in ages of referrals is shown in Figure 3.

Figure 3: Age range of Pathways Audit Sample

More men (56%) than women were referred, with little difference between most sites, apart from the Blue service where only 3 referrals were men. In the total of 50 referrals, only one person was non-white with English as a second language. Whilst the south-west does not generally have a high non-white population, people from minority ethnic communities do appear to be underrepresented in this sample. This is an area that needs further investigation to ensure that services are meeting the needs of all their communities equally.

A large majority of people (n=36, 72%) in this sample were living with others – spouse, partner or other family members. This may reflect the way people seek help, rather than need. GPs and others pointed out that it is difficult to identify memory needs of people living alone, especially if they do
not come in to the surgery themselves. Even when practices are actively involved in case-finding, this group might still be missed if they are under 75 or do not have another long-term condition that means they are likely to come to the surgery for other reasons.

Further, GPs said they are often alerted to memory problems by a person’s partner or offspring. Services were also aware of not getting referrals of people living alone:

“The person living alone, with no active family involved, little insight into what’s happening and think they’re managing perfectly well? Not sure we’re engaging with them.”
(psychiatrist)

Only 8 people in the whole sample lived alone completely, with a further two people living in sheltered accommodation. People living with dementia themselves recognised the huge value of being part of a family that cared or in a couple. Many spoke of it.

“If I was living alone it would be a nightmare.” Person with dementia

“I’d be in a lot more trouble if it wasn’t for my family. I’d go mad, I’d be worried about getting worse.” Person with dementia.

Health circumstances
A majority of people (n=36, 72%) in the sample were recorded as having a co-existing medical condition, most commonly cardiovascular disease, hypertension and diabetes. However, very few (18%) were in contact with any other service on referral. Two were in touch with mental health services and a further 7 in touch with a variety of other services such as district nurses, stroke service and home care. This is important because when discharged from MAS, in most cases no other service was recorded as being involved with the person other than the GP which does confer a lot of responsibility on to primary care.

Most people were referred solely because of memory problems, with only a few referrals adding other kinds of cognitive, behavioural, speech or mood issue as reasons for referral. This could have implications for spotting early signs of dementia in people where memory issues may not be the first reason for presentation.
Waiting for an assessment

Dates of referral and first appointment were collected in the Pathways Audit. It is worth noting that some services talked of contacting people by phone between referral and their first appointment (assessment), and most also sent out information, such as a leaflet, during this time.

The data showed a wide range of waiting times for an assessment. Because the data was skewed with some outliers, median waiting time gives the best picture of averages. For the whole sample, the range was from 3 days to 184 days, with a median of 30 days’ wait – approximately a month. This demonstrates that services have generally reduced waiting times in line with, or close to, commissioners’ expectations. Sites themselves were very aware of waiting times, which were a stronger driver for changes in practice and processes:

“We were consistently failing.” (MAS practitioner)

“People are no longer in limbo.” (MAS practitioner)

The variation shown in this small sample of data is very wide, as shown in Figure 4. The shortest median waiting times were found in the Red and Green services. In the Red service, nobody had to wait longer than 38 days to be seen and the median wait was 22 days. This is a nurse-led service in a semi-rural community. Nine out of ten patients were seen by the lead nurse, either in the central clinic or the primary care based outlying clinic. The Green service average wait was only a little longer at 24 days. This service has been redesigned to focus on primary care diagnosis and a faster response, when necessary, from the Memory Assessment Service. Seven out of ten patients were seen at home by either the lead nurse or doctor. Before the service was redesigned waiting times were unacceptably long, according to the service itself and service users.

The long wait of 184 days in the Purple service was anomalous, as demonstrated by the service’s median wait of a reasonable 31 days. However, it is worth noting the reasons for the long wait as it shows how problems can occur if GPs do not provide required test results with a referral and if the service will not see a patient without those tests. When this man was referred, the service requested further blood tests from the GP, which this service routinely asks for. No tests results came through, so the service re-requested the blood tests. There was then a further delay before the results finally came through. So the long wait was due to a) the referral not being accompanied by usual blood tests b) by the service not seeing the patient without the blood tests c) a further delay in the GP ordering the tests required and submitting the results and d) this delay being allowed to continue by both the referring GP and the service. It may also be relevant that the Purple service is run as a charity and therefore may not have the same financial flexibility as statutory services to, for example, order its own blood tests.

The site with the longest median waiting time, of 59 days, was the Blue service. This service provides a very comprehensive service but where the team themselves recognises waiting times are a weakness.
The reasons for differences in waiting times are not always clear cut. In the Green service, GPs are signed up to diagnosing dementia themselves where possible. They can consult the MAS team by phone to discuss where they are unclear. So, fewer people are referred to the MAS team and their waiting times have reduced radically.

In contrast, there is much less primary care input into diagnosis and shared care in the Blue service, so the team has to work with all, or most, memory problems:

“We offer support to GPs in non complex cases to help them make a diagnosis. But they don’t take it up much as they are not confident.” MAS Practitioner

Interestingly the service is commissioned to be ‘aligned’ with primary care – seen as a strength by the commissioner – but it would seem that this relationship needs further development.

The team itself mentioned having a large number of referrals and this was borne out by the audit data: for the Blue team, 8 out of the 10 referrals were made on the same day, whereas no other team had more than 3 referrals made on the same day.

Other differences between the services that have shorter and longest waiting times are more difficult to disentangle.
For some, referral triage may be causing unnecessary delay. For example, in the Blue team, a formal triage of all referrals take place and can take up to a week – yet only a very small minority (about 1-2% according to one interviewee) of referrals are triaged out or signposted to other services. For the Yellow team a primary care referral management service reviews referrals, liaises with the MAS and CMHT and then allocates referrals to appropriate service. This may account for this team’s longer median waiting time.

Some of the cause may lie further along the pathway, in how the service works once the referral is accepted. Keeping people on the caseload for ‘review’ every 6 months may contribute, especially as many (including patients and families) were unsure about the value of these reviews:

“I feel medication reviews are wasteful. I don’t want people lost in the ether but more and more people are involved, and I’m not sure just monitoring is any good. It’s neither medically useful nor a dementia review.” MAS practitioner

The Green service found that radically reducing their ongoing caseload of frequent reviews freed up practitioners to spend more time on assessment.

Lengthy and repetitive processes may also take resource away from the initial assessment. In the Blue team, there appears to be duplication of assessment (with often the nurse’s assessment followed by a psychologist’s and an OT’s), a multi-disciplinary meeting in which all referrals are discussed, and a post-diagnostic appointment usually with the same person who carried out the initial assessment. This approach is of very high quality but the team itself is questioning whether such a comprehensive service is needed for everybody or whether the service could be streamlined so that it is tailored to be briefer where need is not so great, and thereby reduce waiting times. However, it is worth noting that the Blue team pathway audit showed a higher number of people actually diagnosed with dementia (see below), so some of the complexity within the pathway may be a necessary response to higher need.
Assessment and Diagnoses

First experiences
The first contact people had with services was often an appointment letter and/or an information leaflet. In two sites, the information leaflet did not mention dementia, and for some people this was confusing:

“*I didn’t know what I was coming here for. I was worried they were going to lock me up.*”  
*Person with dementia.*

Services themselves recognised this and have changed the leaflets.

Some services telephoned people before their first appointment, partly as a way to compensate for waiting times but nonetheless welcomed by people being referred.

Initial assessments – first impressions – were very important for people living with dementia consulted for this project. Most were very impressed with services and relieved finally to be in touch with them and despite any fears or apprehension were reassured by the first visit.

“*I can’t praise them enough.*” *Person with dementia.*

“*I didn’t come away feeling intimidated.*” *Carer*

Many people valued flexibility in services, and where people were seen at home they appreciated it.

“*They were very flexible. We couldn’t come to [the clinic] so they came round to us.*” *Carer*

Some practitioners and services were happy to see people at home, and indeed said they would have liked more information from GPs about referred patients’ mobility, so that they could make a decision about where best to see the person. The audit found that three out of the five services saw some people at home or in a primary care based clinic – the Blue service, for example, saw 7 out of the 10 people in their own homes -- whilst two of the services (Yellow and Purple) only saw people in the central clinic.

Where clinic attendance was unavoidable, practical issues such as parking were important to people being referred, as well as the environment itself.

“*Only real complaint is the building is not appropriate and poor car parking.*” *Carer*

“*My first appointment was at the clinic on the old mental hospital site. I was early and there was no-one about. I felt desolate.*” *Person with dementia*

Assessment and testing
In four out of five services, the audit data showed that initial assessment was carried out by one team member, usually a nurse or psychologist. In nearly all cases, a family member or carer was present – something that people with dementia and also carers themselves generally valued:

“*As a partner, you’re in shock. I felt like someone was actually listening. They fully explained everything.*”
Testing at assessment consisted primarily of cognitive and memory testing (most commonly ACE-III), though one service – Red - notably also used the Cambridge Behavioural Inventory which is completed by a family member or carer without having to discuss it in front of the patient (consent is gained from the patient). This may be useful for some as one or two carers did point out they could find it difficult to talk about the person with memory problems in their presence:

“I felt uncomfortable giving history in front of my husband. I kept saying, I’m sorry Jim. I’d have liked to do it separately without him there.” Wife of person with dementia

After the initial testing, services (not Yellow) frequently ordered further tests, including scans, which would then require the person to return for test results at a later date, and possibly for diagnosis (although some people had more than one return visit). On the one hand this created further waiting time for patients. People in the sample waited up to 199 days from referral to a diagnosis of dementia, with a median of 113 days (numbers with dementia are too small for comparisons). Where people had had to wait a long time for a diagnosis they found it very hard:

“We had to wait two years for a diagnosis.” Carer.

“I think the earlier the diagnosis, the better.” Carer

On the other hand, some practitioners said they particularly valued the gap between first assessment and subsequent appointments, as it allowed them to assess whether the person’s condition had changed in the interim. Some people referred to the service also valued the opportunity to come back later:

“You can’t ask everything you want to ask at the initial consultation.” Person with dementia

This presents a challenging contrast to the idea of the one-stop shop Memory Assessment Service, such as the Yellow service. Here the assessment consisted of a two-to-three hour stay at the clinic where assessment with nurse, doctor and psychologist and (usually) diagnosis took place in one appointment. This clearly resulted in a much shorter waiting time from referral to diagnosis than the average, with a median wait for diagnosis of only 48 days. Whilst the Yellow service had developed their one-stop shop at least partly in response to feedback from people living with dementia, they were concerned that patients might feel pushed through the process too quickly, without being able to pause for breath and take in what was happening. Indeed, this was borne out by one patient who said she was frightened she was going to be told she was dying because everything happened so quickly.

A related issue resulting from the fast turnover of people coming through the Yellow service was a fear of burnout amongst staff, with a sense that the work could become repetitive, unrewarding, especially for more junior staff.

“It is designed to be a ‘factory’, an assessment service that people go through. We don’t stop.” MAS Practitioner

“How do we make this burn out proof as, for example, a Band 5 assistant psychologist doing test after test.” MAS Practitioner
Dementia and other diagnoses
Reducing waiting times was a key driver for all teams, as well for commissioners, when reconsidering their service design. Another important driver was increasing dementia diagnosis rates. All sites reported increased rates in line with, or beyond, commissioner expectations.

Fewer than half of the people (19, 38%) referred to services were diagnosed with dementia by the MAS assessment in this pathways audit. For a further 4 people there was remaining uncertainty about the diagnosis. The proportions of people with different diagnoses are shown in Figure 5. As already stated, the Blue team had the highest proportion of people eventually diagnosed with dementia, while the Green team had the lowest number (2). The Green team is generally seeing people not easily diagnosed in primary care, so it is interesting that most of the people they do see – if this audit is in any way indicative – don’t actually have dementia, although this team also had the highest proportion of people whose diagnosis remained uncertain.

A large proportion (16, 32%) of the sample were diagnosed by the MAS as having a Mild Cognitive Impairment (MCI), most frequently in the Green and Purple teams. Services, and even practitioners within services, had different responses to this phenomenon.

“We are not a Memory Service. We are a dementia-finding service. We have a lot of people with MCI but we’re not set up for that.” (Psychiatrist)

“Some GPs worry about slightest thing and refer, so we see a lot of people with MCI.” (Practitioner)

Some felt they were seeing too many people with MCI, regarding their role as to find and diagnose dementia. Indeed, services are mostly set up for this; in other words, the processes and services offered are geared towards people with dementia, not MCI. One service carried out its own audit over a 6 year period, and found that of 109 people with MCI, only 20 converted to dementia. However, one service said it is hoping to provide a specialist service for people with MCI, on the basis that it may prevent further problems in future. One service already offers an 8 week Cognitive Stimulation course for this group.

A small number of people (5, 10%) were given other diagnoses. Three people were diagnosed with depression and two with alcohol-related memory problems. The remainder (10, 20%) had no diagnosis or there was still some uncertainty as to the diagnosis.
Giving and receiving a diagnosis

Practitioners reported that the nature of diagnosis was changing. Where GPs were offering diagnosis (as in the Green service’s area in particular), there was a concern that GPs might miss the complexity of diagnosis for some people. The Green service described seeing many more unusual and complicated presentations, which they attributed to primary care colleagues diagnosing more straightforward presentations without referring on.

“We are more able to see more difficult diagnoses in a timely way and our waiting list is down. But the sacrifice is loss of complexity of the diagnosis.” MAS doctor

However, other sites also reported more complex presentations.

MAS practitioners and GPs mostly regarded the diagnosis as important but some had ambivalent views. The biggest question was whether or not giving the diagnosis was always the right thing for every patient, especially if the patient themselves had not sought help, for example if referred via the general hospital. There was also a sense for some people that the principle of increasing diagnosis rates was inappropriately taking precedence over the particular needs of each individual.

“If we have person-centred care it should be about the person, not diagnosis rates” MAS Practitioner

“Diagnosis needs to be something that improves the quality of the person’s life – if not, why are we doing it?” MAS Practitioner

“Is giving a 90 year old with depression a diagnosis of dementia the right thing to do, or does it just frighten her?” Practitioner
“Not everyone wants or needs a diagnosis but they might still need to access a service”. MAS Practitioner

A further dimension to this was the question of the importance of diagnosis rates in performance and contract management. Services expressed concern that they were being ‘judged’ by the change in numbers of people on the GPs’ QOF Dementia Register, whilst having no control over the Register.

“GPs vary with knowledge and interest. But WE are measured on QOF registers even though we have no control over it. We know [the registers] are inadequate. We had 600 people on our database. When we compared with GPs we discovered only 30-40% correlation. They hadn’t put people we’d diagnosed on the QOF.” MAS doctor

“Clearly not everyone with dementia is on the [QOF]register. We compared our GP register with the Memory Clinic list and we’re pretty good but it added 10% to our list.” GP

The Pathways Audit asked whether people diagnosed with dementia had been placed on the GP register within (in most cases) six months from referral. Of the 19 people diagnosed with dementia, only 2 were known to be on the QOF register. For the rest, the people completing the audit ticked ‘unknown’ for this item.

While initial assessments were almost always carried out by a nurse or psychologist, diagnoses were almost always given by a doctor. One service said that it aimed for nurses to be able to give the diagnosis and in house training had taken place to enable this to happen.

For people living with dementia, having a choice about whether they received a diagnosis was important:

“How that initial diagnosis is given is important. He did give us the choice. I said yes. I’d sooner know than not know.” Person living with dementia

The majority of patients in the audit (28, 56%) were recorded as having had a choice about whether they would like a diagnosis. However, one doctor disagreed with this principle:

“Why should we ask if you want a diagnosis? I find that difficult.” MAS Practitioner

In that particular service, there was no recorded evidence of patients being able to choose whether they received a diagnosis. Having noted people’s wish for a choice, most people interviewed for this project said they wanted to know the diagnosis, especially as more often than not, people had been speculating about it for a while. Critical to this was the manner in which the person was told:

“ Probably took about a year before we got the diagnosis. But when we did, the doctor explained everything so carefully. Brilliant.” Carer.

“We didn’t like [getting the diagnosis] but we’d been discussing it for some time. The doctor was very good, very professional.” Carer.

One person though, did not accept the diagnosis at all:

“I’m going along with it. I’m not saying they’re wrong, but..” Person with dementia.
Post diagnosis support and next steps
People living with dementia – including carers - had mixed experiences regarding post diagnostic support. Where they had it, they welcomed it. Those who had ongoing contact with the MAS services were extremely positive about the experience:

“They’re brilliant here. Alway helpful, always happy and chatty.” Person with dementia

But many hoped for more than they were receiving. The well-documented gap between diagnosis and the beginning of receiving support does seem to continue to be in place for many. Further, while services have streamlined and responded to new commissioning imperatives, some people appear to have been left behind:

“We’ve had a diagnosis, we have medication, but other than that no one knows we exist. Everyone in our group is in the same situation. New people might be getting a better deal but what about us already in the system, lost, and doing reasonably ok at the moment? What will happen to us?” Wife of person with dementia

“The carers’ course was vital, opening up other avenues. I met another partner who advised me to get on to the system as a registered carer.” Carer

“Once we got on the course it all began to fall into place. But it came a long time after the diagnosis.” Carer

“They gave us a number to call if we needed help.” Person with dementia

“We’ve now got to go back to GP for prescription and things. I’m worried - does the GP have the knowledge? I’m not confident.” Person with dementia.

Services varied extremely widely in terms of the support they provided post diagnosis (including post diagnosis of MCI). Support ranged from information at a one-off appointment through to referral to carers’ groups and provision of cognitive stimulation and other groups for people with dementia. Information was highly valued by people living with dementia:

“I’m a great one for lots of information. I had interactions with people from the clinic talking about stuff I’d picked up on the internet. They didn’t make me feel silly. They had a professional, empathetic approach.” Carer

However, it was recognised by people living with dementia and by services themselves that the timing of receiving this information, or other support, may not always be right; now that diagnosis is taking place earlier, people are not always aware of immediate or future information or support needs.

Variation of post-diagnostic provision was partly a commissioning issue. At least two services said they were not commissioned to provide anything other than an assessment and diagnosis service:

“It wasn’t considered in the service design that people might want a follow up or to come back at some point. Just not considered.” MAS practitioner
For these services the audit showed a brief offer of information and then discharge to ‘routine’ GP care. Some commissioners surveyed had detailed requirements for post-diagnostic support. Some required information only, while some commissioned the post-diagnostic information, support and care separately but had specified indicators for the MAS service to refer people, including carers, on. The Pathways Audit data, however, showed very few people were referred on to any service unless the service was closely linked already to the MAS; for example, a Carers’ service spent time at the Purple service clinic and nearly all those referred to this clinic were also referred on to the Carers’ service.

Again as well documented in the past, younger people with dementia and younger carers (such as offspring) were not well catered for, even when post-diagnostic services were available. In one service, a woman whose husband was diagnosed at 50, had started a support group herself, with the support of the service. But at the same service, a younger carer said:

“I’m suppose I’m not really a carer. I have to go to work full time. It means mum has appointments but I can’t go with her as I’m not the official carer and I can’t take time off. I feel outside.” Daughter of person with dementia.

Some commissioners have commissioned a network of services for people diagnosed with dementia, drawing on the strengths of the voluntary sector as well as statutory sector to provide a range of different types of support. Where services worked in partnership with others or were part of a wider service, ongoing support seemed to be more readily available. For example, the Blue team is embedded in the mental health trust’s dementia service with its specialist nurses, and also closely linked into Dementia Advisers. The Red team is also part of the local dementia service. Even so, relationships were not always clear-cut and there was a sense of separateness of services:

“We’re sat inside the complex dementia team & they do pick up cases but sometimes it’s a bit of a struggle” MAS practitioner

“The services are not joining up. To get a dementia nurse you have to be discharged from the Memory Assessment Service.” MAS practitioner

Where services felt isolated (and some did), it was unclear how and when people diagnosed with dementia would get support, despite a range of services being commissioned.

“The link with onward services is poor. Why can’t someone contact us from the onward service?” Carer

“It’s confusing. There are so many different agencies. The GP, the district nurses, the memory clinic. Who do I go to? Do I go to the GP or do I phone them here?” Carer

The Purple service, run as a charity, has very strong links with research organisations and receives some of its funding through this route. Uniquely, therefore, many people referred to this service had continuing contact with the service by default since they were often participating in an ongoing research project. Another service – Red – also had strong research elements which meant, for example, that people using services were given additional options such as the opportunity to discuss Advance Care Planning. Research was clearly valued by the people involved:
“Being in the [research] trial is very important because it keeps you in touch.” Person with dementia.

Another issue raised by services was that at the time of diagnosis, the kind of help they could offer was not always needed at that stage. Services who did offer post-diagnosis support were discovering that the earlier diagnosis meant a different approach to provision.

“The system is efficient. The OT sees people for follow up and gives all the information, signposting etc, but the problem is that people are not usually at the point where they want help yet. It’s too early in the process.” MAS practitioner

“We are seeing people a lot earlier in their dementia journey so the network of support we refer people on to no longer right for them. Two years later they come back, then what?” MAS practitioner.
Discussion and points of learning

The pathway to dementia diagnosis in the South West of England is primarily via Memory Assessment Services designed to provide a responsive assessment and diagnosis service following a referral from primary care. These services have evolved from Memory Clinic models, driven to a large degree by an imperative to improve dementia diagnosis rates and to reduce waiting times.

The Memory Assessment Services are run and delivered by strikingly passionate and skilled people, who clearly want to do the best they can for this classically under-served group. Most teams work well together and there is very little staff turnover – an indicator that teams are working well. People using services clearly experienced this compassion and were immensely positive about the services, as were colleagues in primary care.

Pathways appear to be quite similar on paper. However, how services are commissioned, the role of primary care and the services themselves all function in subtly different ways with different strengths, challenges and opportunities for learning.

More people diagnosed with dementia

Most commissioners sought higher diagnosis rates following continuing national and local concerns about large gaps between the expected numbers of people with dementia and the numbers of people actually diagnosed.

The services reviewed for this project had increased dementia diagnosis rates (one, for example, had moved to 56% which is toward the higher end of national rates and matches the commissioning ambition for the area). Skilled, comprehensive assessments were provided by these services to mostly increased numbers of referrals, partly due to improved processes, increased awareness in primary care, and seeing people much earlier in the dementia pathway.

However, there were concerns that services’ performance would be measured by QOF figures which most services had very little control over. Moreover, where services’ patient databases were compared with local QOF registers, large discrepancies were found. One service suggested that including Read Codes on GP letters may help increase the number of local people recorded as having a diagnosis of dementia.

Shorter waiting times

Where people living with dementia had to wait for assessment and diagnosis, this caused them great distress. A quick response, on the other hand, nearly always came as a relief. Many commissioners also expected to see shorter waiting times, most commonly 28 days from referral to assessment.

All five services reviewed for this project reported having changed practice and processes to address waiting times. The median waiting time recorded through the Pathways Audit was 30 days which is pretty close to meeting that objective, especially given that this figure refers to actual number of days from date of referral to date of assessment, rather than working days. Services with the shortest waiting times were distinguished by having more primary care involvement in diagnosis and treatment and smoother and simpler pathways to diagnosis and beyond.

Two critical lessons emerged here:
• The first is that the whole diagnosis pathway, including what happens after initial assessment, may need to be refined and streamlined to continue to improve waiting times.
• The second is that a model which encourages and enables diagnosis and ongoing management in primary care results in shorter waits and frees up MAS staff to be more responsive and to diagnose where there are more complicated presentations. Moreover there are added benefits for people with dementia in that such practices appear to be more likely to have dementia-friendly features, such as displaying positive images of dementia.

Dementia and MCI
Fewer than 40% (n= 19, 38%) of the people in this Pathways Audit were given a diagnosis of dementia, meaning that most people (n=31, 62% of this sample) referred to these MAS services did not have dementia. Looking more closely at the 31 people, 16 of them (32% of the total sample) had a mild cognitive impairment (MCI) while 10 people (20% of the sample) were discharged with no or uncertain diagnosis and 5 (10% of the sample) were given an alternative diagnosis such as depression.

This is a finding with important implications:
• If services are designed to find dementia, they are designed in a particular way. The design could be cumbersome for the majority of people who don’t have dementia, while causing delays in assessment and treatment for those who do, by diverting resources away from them.
• It may be that a diagnosis of MCI or no diagnosis at all is an important and valuable outcome for people referred to the MAS. On the other hand, we don’t know from this project (and there appears to be little research evidence available elsewhere) whether the experience of the full diagnostic pathway could, for example, cause unnecessary anxiety and inconvenience for these people.
• There is a lack of consistency in both commissioning and providing. Currently services may or may not provide support for people with MCI. Most in this audit provided nothing after MCI diagnosis, some offered cognitive stimulation therapy and at least one was seeking funding to provide a specialist MCI group.
• But while people with MCI represent a significant proportion of MAS referrals, the question of what kind of service response is actually needed – whether in primary care, MAS or elsewhere – remains. Are people with mild memory problems being referred to MAS too readily? Is this an area where more and better liaison with GPs could be of benefit? Are people with MCI at significantly greater risk of developing dementia? One of the sites carried out its own audit and found that few people converted from MCI to dementia. A recent systematic review found widely varying rates from as low as 3% to as high as 17%, increasing to between 11% and 33% two years after diagnosis\(^{16}\). What factors increase the risk? What help and support could be provided to people with MCI to minimise the risks, who is best placed to provide that help and when?
• This issue may be a consequence of designing services around function (ie. detecting – or eliminating – dementia to increase diagnosis rates) rather than around the person.
• A shortcoming of this project is that there was no consultation with anybody with MCI or who had experienced the pathway but had no diagnosis. Similarly, where service user involvement has taken place in MAS service design, it has involved people living with
dementia not with MCI. It may be important for future service development to include such people in co-designing services. Co-producing services with people who have or might need to use the service requires a rethink of user involvement; not just asking for patient feedback or consulting user groups, but working together with end-users over time to harness their personal stories, special knowledge and experience.17

Services are valued

People using services found them friendly, helpful and supportive. They wanted contact with them and were generally relieved to have a diagnosis and find that there was support available to deal with it. GPs were also very positive about services.

People living with an early diagnosis of dementia particularly valued:

- Friendly, non-intimidating people and environments
- Service flexibility – for example, home visits if necessary
- Knowing that support is available in the form of emotional and practical support, and information.
- Peer support

GPs valued:

- Responsive, reliable services
- Being able to phone for advice
- A relationship with the service
- Prompt feedback following a referral

Where people did not have access to services, they were understandably angry and frustrated. Some people interviewed for this project had been referred for memory assessment before services had been redesigned, had experienced long waits for assessment and diagnosis and felt now that they were left out in the cold. It would seem that there is a large gap here: people who had an early diagnosis in recent years who have not had the benefit of the current, newly refined services, appear to have very little support if they don’t (yet) have more complex needs.

Post diagnostic services

Services varied considerably in the post diagnostic support they provided and commissioners had a range of expectations and specifications. What is clear is that people living with an early diagnosis of dementia highly valued information and ongoing support. If they did not have it, they felt very alone, confused about who to call when they needed help, and frequently unconvinced that their own GPs (to whose care most people in the audit were discharged) would be able to help them.

Where services were closely aligned to other services – especially if there was a physical co-presence – it was more likely that people would be referred for ongoing help, such as carers’ groups. Good relationships with voluntary sector services, such as Dementia Advisors, were also extremely helpful. The relationships with specialist mental health dementia services were however, not always clear cut, and there was some fragmentation evident and some confusion over each others’ roles.

Teams recognised that, as they were now seeing people much earlier, their needs for information, help and support might not be immediately obvious but would surface in due course. People living
with a very early diagnosis of dementia were aware of this too. But it was unclear to services as well as to people living with dementia, what support would be available when needed, and how to get it. Indeed, services were starting to get re-referrals of people who they had diagnosed early through Memory Clinic, and whose needs had now changed. The MAS was not set up to work with this group but there appeared to be little else available for many.

**MAS teams – valuable staff**
The MAS teams are staffed with highly skilled, dedicated and loyal practitioners with a keen desire to improve the lives of people living with dementia. The established services, and those providing at least some post-diagnostic support, had very long-serving staff with a wealth of experience, and low turnover. Creating services primarily geared to deliver quick, efficient processes without the satisfaction of delivering a better experience and outcome for people with dementia, could backfire. There is a real risk of burnout, that was raised especially by the Yellow team providing the one-stop shop service.

**A note on equality and diversity**
The Pathways Audit sample was a relatively homogenous group of people: almost all white, with English as a first language, living with a spouse, and with a median age of 79. There is work to be done to ensure equality of provision to people from minority ethnic communities (recognising that, for example, people with memory problems from these groups might be at risk of forgetting their English language skills which has many implications including the need for interpreters), people from LGBT communities, people living alone and younger people.

**Summary**
In summary, this project found a range of models for Memory Assessment Services with a variety of strengths. Waiting times are reducing, more people are being given a comprehensive memory assessment and more people are being diagnosed with dementia. Commissioners expect clear diagnostic pathways and these appear to be setting in. Staff are highly skilled, dedicated and very much valued by people using services.

The Memory Assessment process does risk being highly standardised rather than tailored to individuals, and, as such, processes can be cumbersome, repetitive and resource-intensive for everyone. Key risks here include long waiting times for diagnosis and MAS resources diverted away from people with dementia to deal with the majority who don’t have it.

Strong involvement of primary care in diagnosis, treatment and (by implication) ongoing management of people with dementia was a critical factor in providing smoother, more flexible pathways and shorter waits, enabling the MAS to be more responsive and focus on more complex presentations.
Acknowledgements

The author is extremely grateful to all who contributed to this project, especially the five MAS services, GPs, and most importantly, the people living with dementia who generously shared their time and experiences. She would also like to thank Jean Alger-Green for her tireless administrative support.

Dr Edana Minghella, Independent Consultant

November 2013

edana@minghella.com
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