Access to Alzheimer’s disease drug treatments and memory services

By Yvonne Kay and Simon Kitchen
Executive Summary

This report summarises research into access to drug treatments and memory services within England, Wales and Northern Ireland. The results are based on an online survey of Alzheimer's Society staff working with people with dementia.

The online survey was completed by 143 respondents. 46% of respondents were Dementia Support Workers, 24% of Dementia Support Managers and 15% Dementia Advisers.

Findings:

Despite changes in NICE guidelines people with Alzheimer’s continue to have problems accessing these drug treatments and memory services, with lack of GP understanding being the most common barrier for both.

Key results:

Survey - Drug Treatments:
- 39% of responses stated that respondents were yet to see any changes in prescription levels for people with dementia in their areas
- Those that are receiving treatment are experiencing positive improvements in their quality of life, including improved ability to perform daily activities (21% of responses) and slowing progression of the condition (22% of responses)
- GPs are stated as the biggest barriers to treatment (mentioned in 37% of responses)

Survey - Memory Services:
- The majority of respondents stated that people with dementia access memory services at local hospitals (56%) and local community settings (14%)
- 49% of respondents had witnessed people with dementia having difficulty in accessing memory services in their area
- Again, a lack of GP awareness is the most common barrier for access to memory services, being mentioned in 53% of responses
Introduction

Purpose of study:
The aim of this research is to measure the impact of changes to NICE guidelines made in March 2011 which extended access to drug treatments for Alzheimer’s disease. It also aims to review accessibility to memory treatments.

Background:
The National Institute for Health and Clinical Excellence (NICE) is an independent organisation responsible for providing national guidance on good health practice, setting guidelines in protocol and access to drug treatments and memory services.

Drug treatments
NICE guidance 217, issued in March 2011, recommended that for the mild to moderate stages of dementia, Aricept (donepezil), Reminyl (galantamine) or Exelon (rivastigmine), should be options on all Primary Care Trust (PCT) and Mental Health Trust (MHT) formularies. The guidance also recommended that Ebixa (memantine) should be prescribed as part of NHS care for patients with severe Alzheimer’s disease, or for those with moderate disease who cannot take the cholinesterase inhibitor drugs.

These recommendations differed from the 2006 NICE guidance TA111 which stated that the cholinesterase inhibitor drugs should only be prescribed to people in the moderate stages of the disease. Ebixa was previously not part of NHS care, but was to undergo further studies and research.

From March 2011 there was an obligation for PCTs to follow NICE guidance and provide funding for the drug treatments. PCTs were given until June 2011 to implement the change.

Memory services
According to NICE guidance, memory assessment services should be the single point of referral for all people with a possible diagnosis of dementia. These services may be provided by a memory assessment clinic or by community mental health teams. These services will provide an assessment for those with mild cognitive impairment and will be given a Mini Mental State Examination (MMSE), followed by support and treatment if diagnosed.
Methodology
To assess the accessibility and impact of drug treatments and memory services, the study team used one source of evidence: an online survey of frontline Alzheimer’s Society staff.

The survey was circulated to all Alzheimer’s Society members of staff working with people with dementia in November 2011. A total of 143 members of staff completed the survey over 21 days. A full copy of the survey questions can be found in Annex 1.

Dementia Support Workers were the largest group of respondents, with 46% of responses, followed by Dementia Support Managers at 24% and Dementia Advisers at 15%. The full breakdown is shown in Chart 1 below:

Chart 1: Who completed the survey

The survey collected both qualitative and quantitative data. Responses to qualitative questions have also been categorised to provide frequency counts to themes of responses.
Drug Treatments

Access to Drug Treatments

PCTs and MHT’s were given until June 2011 to implement new NICE guidance on drug treatments for people with Alzheimer’s. The survey provided a six month review of the impact of these changes.

To assess whether people with Alzheimer’s were accessing these drug treatments respondents we asked:

“Since June 2011, have you seen any changes in the prescribing of the following treatments for Alzheimer’s disease amongst people with dementia in your area?”

61% have witnessed changes in the prescribing of drug treatments for people with Alzheimer’s disease in their area, of this (48%) of respondents stated there had been significant changes in the prescribing of Aricept and to a lesser extent Ebixa (24%), Reminyl (18%), and Exelon (16%, 12% patches, 4% capsules). However, 39% of respondents stated that they had seen no change despite changes to guidance.

The full results can be found in the Chart 2 below:

Chart 2: Changes in prescription of drug treatments

<table>
<thead>
<tr>
<th>Treatment</th>
<th>Proportion</th>
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<tbody>
<tr>
<td>No change</td>
<td>39%</td>
</tr>
<tr>
<td>Exelon Capsules</td>
<td>4%</td>
</tr>
<tr>
<td>Exelon Patches</td>
<td>12%</td>
</tr>
<tr>
<td>Reminyl</td>
<td>18%</td>
</tr>
<tr>
<td>Ebixa</td>
<td>24%</td>
</tr>
<tr>
<td>Aricept</td>
<td>48%</td>
</tr>
</tbody>
</table>
Impact of Access

Up to 61% of respondents have seen a change in the prescribing of drug treatments. To assess how these changes had impacted on the lives of people with dementia, we asked:

“Have any of the recipients of these treatments seen improvements in their quality of life? If so, could you please give a brief, anonymous, description of the person and their improvement below.”

The results indicate the largest improvement in the quality of life (22% of the responses) was a slow down in the progression of the disease and stabilisation of the symptoms:

“According to the family of one lady, she has improved since being on Aricept.”

“Reduced anxiety appeared to stabilise the symptoms of Alzheimer’s Disease (Aricept). Have heard of a number of cases where the Exelon patch has been more readily given allowing access to this drug.”

“Improvement in general living function and maintaining mental health possibly a longer time than not having the drug treatment.”

“Yes - improvement has been seen. The process of disease has been halted or slowed down and the mini mental test has remained the same score for some time.”

“Have been told that clients medications have changed, heard about a lady who could not easily take medication orally, she was therefore prescribed Exelon Patches. I can’t specify one particular person, but carers generally think medication does help.”

“Man with dementia taken off Aricept as score too low but behaviour rapidly deteriorated. Put back on Aricept after visit from CPN, much improved.”

“The clients say that their Memory Problems seem more stable and they don’t feel as if their memory has got any worse.”

“Stabilisation of symptoms”

“Yes, their dementia has shown signs of stabilising”

“Our memory assessment service started to issue Aricept to people with a mixed Alzheimer’s dementia, where possible. This obviously impacts positively for people with mixed Alzheimer’s diagnosis and provides a wider audience for people eligible for medication.”

“Yes, a client of mine was prescribed Aricept approx 3 years ago and has found it to be very beneficial. Although not related directly with work; a close relative of mine has recently been prescribed Metamine and I have noticed a difference.”
“Yes – people with dementia I spoke to told me that he felt that the drug really worked for him, and his wife agreed. Their quality of life had improved.”

This was closely followed by the claim that people were able to resume participation in daily activities, often described as ‘having their relative back’; this made up 21% of the results:

“One of the recipients I see went from sleeping all day and having no energy to being able to help with the housework and gardening again.”

“A lady who’s memory was very impaired has seen great improvements since starting on Aricept...she is now able to prepare food, select clothing, make herself a drink, use the telephone whereas previously she was losing the skill to do this.”

“Yes, carers I have been in contact with have reported greater motivation and sociability.”

“Yes this gentleman has seen an improvement in the life of his wife, her mind he said is so much clearer and she has more confidence to go out now and whilst they both know the medication is not a cure it has none the less made "such a difference" this lady is under 65 years old.”

“At least two people have told me that Aricept has made a big difference to them and they have found it beneficial.”

“People have told us that they have seen significant improvements after taking the drugs - and that they feel it helps them to live as they used to.”

“A client's sister has said that she has seen a marked improvement in my client, who is now able to live without any home care.”

“Have been notified that 1 possible client has been able to leave a care home after taking this drug.”

A further 16% of responses suggest that the general behaviour of people with dementia had improved, with a decrease in frustration and agitation:

“I have heard several reports from people who have noticed a remarkable difference in behaviour and general well being of the person they care for when these dementia drugs are prescribed.”

“One client who is YPWD was recently prescribed Ebixa and the improvement was quite obvious. His wife has also noted some improvement in his behaviour and abilities.”

“Some have seen improvements. More moments of clarity and perkier moods.”

“Some people show signs of better mental clarity/less agitation/more cooperation and a better understanding of their condition.”

“Some evidence of improvements in mood and behaviour.”
“I have heard both families and staff share many anecdotal stories that carers report changes. In particular reduced agitation in the person living with dementia.”

“This gentleman was living in what I call torturous torment. He was seeing and hearing things that were not there had sundowners and pleaded with me for help. The hospital had tried him on several drugs which either did help or didn’t suit him. Then the CPN prescribed Ebixa for him 1 to be taken at night but he was still having difficulties during the day so his wife asked if she could give it to him in the morning. The CPN told her to give it to him morning and night. This gentleman’s quality of life has improved tremendously he is happy, smiling, joking with people, knows his wife and able to contribute to some conversations. He still has times where he is really confused but at the moment the good far out weigh the bad.”

“Yes lady with stroke & vascular dementia was prescribed Ebixa for episodes of restlessness and agitation, since taking this these episodes are less frequent.”

“Benefits - less aggressive behaviour towards spouse. someone with a vascular dementia has been prescribed medication (mixed).”

“Several clients have definitely improved with Aricept - usually becoming ‘more themselves’ again.”

People with Alzheimer’s disease also felt supported from receiving the drug treatments (3% of responses) and 11% claim the drug treatment reduces the ‘foggy moments’.

“Being prescribed this medication makes people feel they are being supported instead of being told there is nothing we can do. Lots of people say they see a change in the highs and lows of Dementia. It is very difficult to measure improvement in a person’s dementia but quality of life is improved by the feeling of support people receive by taking medication.”

“Aricept would be a particularly common drug prescribed by the local consultant. One client has seen a significant improvement to the quality of his life as a result and describes a ‘fog’ being lift and he can think more clearly which allows him more freedom and independence.”

“I have heard from 2 service users, whist working as a Dementia Support Worker who felt strongly that their Alzheimer’s had improved since taking Aricept. Both felt they could recall things more easily, felt less foggy and had more confidence as a result.”

“Early stage dementia clients, living alone, with insight into their condition feel positive benefits in terms of confidence to manage their condition.”

“Yes many of the people whom I work with have been on Aricept and they see massive improvements in their condition many describe a mist being lifted, they can think clearer, they can function much better.”

“Yes one of my clients is on Aricept the feel now that there life has a meaning now and they feel in control of there life.”

“Clients have reported that the ‘mist has cleared’.”
“Overall the response has been positive, the people I have spoken to say their head feels less foggy and they are able to do more, as a consequence they feel better able to cope with the changes.”

“Some people have described more clarity and less “fuzziness” some are finding that understanding money is clearer.”

Despite over four fifths of responses describing positive changes in the lives of people with dementia receiving drug treatments, just under a fifth of responses experienced no improvement or mixed results:

“Most service users have been unsure of its effects and there have been a couple who have had negative side effects such as a change in eating habits and displaying challenging behaviour.”

“Some people have while others comment that they do not feel any different. Ebixa in particular seems to have good results in those people it agrees with but sometimes in others it can have a detrimental effect.”

“Varies from person to person.”

“The memory assessment service I am linked to, is proactive in its prescription of medication, but I have noted that changes in consultants can bring differing views the memory assessment service has prescribed Aricept to people with a mixed diagnosis, including Alzheimer’s.”

Chart 3 below presents the breakdown in the types of changes experienced by people with Alzheimer’s disease:

**Chart 3: Changes in quality of life from taking drug treatments**

<table>
<thead>
<tr>
<th>Change Description</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Slows down dementia / stabilises symptoms</td>
<td>22%</td>
</tr>
<tr>
<td>Increased energy / able to participate in daily activities again</td>
<td>13%</td>
</tr>
<tr>
<td>Improved behaviour / less frustrated or agitated</td>
<td>11%</td>
</tr>
<tr>
<td>More alert / improved concentration</td>
<td>8%</td>
</tr>
<tr>
<td>Less fog / mist</td>
<td>3%</td>
</tr>
<tr>
<td>Feel more supported and have increased access to the drug treatments</td>
<td>2%</td>
</tr>
<tr>
<td>Mixed results</td>
<td>2%</td>
</tr>
<tr>
<td>No improvement or not applicable</td>
<td>16%</td>
</tr>
<tr>
<td>Negative side effects</td>
<td>23%</td>
</tr>
</tbody>
</table>
Barriers to treatment

Six months after the changes in NICE guidance, the survey team wanted to identify what continued to be barriers to treatment. Respondents were asked:

“Are you aware of any of the people with dementia, in your area, having experienced problems accessing the following drug treatments for Alzheimer's disease in the last three months?”

67% have not encountered barriers in accessing drug treatments. Nevertheless, 33% of respondents have witnessed problems in access to at least one drug. 22% of respondents have witnessed problems with accessing Aricept, and 20% Ebixa. A small number of people with dementia have had trouble accessing Exelon capsules and patches (both 6% of respondents), and 7% have had difficulty in accessing Reminyl.

Chart 4 below presents the percentage of respondents witnessing problems broken down by recommended drug treatments.

Chart 4: Experience of problems accessing the following drug treatments

Delving more deeply into the reasons for these problems, respondents were asked:

“What have been the main problems accessing these drug treatments in the last three months? E.g. lack of GP awareness?”

Over 50% of the barriers stated by respondents related to a lack of awareness amongst GPs and the reluctance on the part of medical professionals to prescribe the treatments.

Over a third of respondents stated a lack of GP awareness to dementia symptoms, services and treatments generally (37%).
"I have spoken to many people who when going to their GP with memory loss are sent away and told 'to see how things are in 6 months'.'"

"The Memory Services in the East Kent area are very good. It is fair to say they were prescribing the drug treatments mentioned above to those even in the early stages before NICE changed the criteria. Access to the whole range of medications appears to be very good. Occasional GP ignorance remains the hindrance to people being able to access secondary care health services and Psychiatrists."

"As a befriender I am not often in conversations about medication, but over the years I have gathered that there is a lack of GP awareness."

"Still finding that some GP are telling people that it is 'old age' we often do the MMSE and then sent to GP asking him/her to refer on for further investigations if they have found no reason after doing the bloods/urine test etc."

"Late diagnosis - possibly lack of awareness from GP especially when people are 75 years plus - GP’s express that memory loss is just part of aging. On the other scale younger people with dementia i.e. 45 years plus take a lot longer to diagnose - and may well miss the window of opportunity to have drug treatment."

"Concern that person had not been referred by G.P. to memory clinic and told it was depression."

"Lack of GP awareness and lack of diagnosis."

"Lack of GP awareness / willingness to prescribe. Difficulties in communication due to admin procedures at GP's surgeries"

"GP awareness."

"Family had spent thousands of pounds accessing Aricept privately since diagnosis in 2007. Having briefed the family in March 2011 re the changes to the NICE guidelines, and suggesting that they challenge their situation, they now receive the prescription free of charge. The family were not made aware of the changes by their GP. It was only when they challenged their GP that changes were made."

"Lack of GP awareness and consistency with Memory Services appointments."

"GPs not referring to specialist services, just saying the person has dementia and leaving it at that, until difficulties arise with the person with dementia."

"Confirmation of diagnosis from consultant to GP resulting in a delay of medication being prescribed. GP’s unaware that other medications are available to people with dementia."

"Once through to the memory service, these drugs seem to be readily available - main problem is if a GP will not refer them on to memory services."
A further 16% of responses stated specifically the unwillingness of GPs or Consultants to prescribe the drugs for a variety of reasons.

“Consultant unwilling to prescribe Ebixa, consultant describing negative side affects first and putting people off. GP unwilling to take over prescribing so person has to keep travelling to hospital. Person and family not sure how to clearly describe positive changes they have noticed therefore being taken off them as consultant presumes none.”

“I’m not aware of any one taking Ebixa at present. The main reason that I am aware of is the Consultant in this area will not prescribe as the Community Mental Health Team is responsible for monitoring their patients currently on anticholinesterase inhibitors. They do not have extra capacity to monitor another drug, and have requested extra staffing to help with monitoring patients.”

“Prescribing Aricept by GP’s is poor and most tell patients they can’t give them the medication, we are fortunate that in our area our Memory Clinic prescribes the medication. Ebixa was not readily prescribed due to NICE guidelines, however since June 1st 2011 people seem to be given it on the NHS.”

“GP's reluctance to prescribe/inform about choice.”

“One particular GP is constantly telling people how much it costs them to prescribe Aricept.”

Long waiting lists or delay in referrals were the third largest barriers with 9% of responses relating to this:

“Long delays awaiting appointments at Memory Clinic.”

“Main barrier to medication rests with the fact that many people in Calderdale are still being diagnosed a long way along the journey where it is felt that medication will not benefit the individual.”

“This is caused mostly by delays in getting a diagnosis from the Memory Services and also waiting lists for CT Scans.”

Furthermore, 9% of responses claimed that their PCT doesn’t provide the drug treatments because they are either unavailable or cost too much, and (as 7% claim) there was a lack of resources to provide them:

“None that I am aware. The main issues that have been given in the past is cost of the drugs.”

“Consultants have told some patients that Aricept will be available early 2012.”

“Our PCT will not give sanction for its use.”

“We have a new Memory Assessment Service, so numbers have increased but they are still not seeing everyone who falls within the NICE guidelines due to funding restrictions. Ebixa is still only available here privately.”

“Access denied due to funding issues.”
“Lots of people referred but not enough funding or resources to deal with the numbers. Seems to be inconsistency about who gets referred and who doesn’t.”

“CMHT under stress due to major changes. Dedicated Staff are off sick, maternity leave, seconded to other jobs or have left to take up a new position resulting in a waiting list for the CMHN to start patients on the drugs.”

Nevertheless 7% of responses have seen an increase in the prescription of drug treatments for people with Alzheimer’s, combined with the 13% who have experienced no problems. This means 20% of responses referenced that they had seen no people experiencing barriers to accessing drug treatments.

“There were patients who were referred but were not able to access the medication due to lack of funding.”

“GP’s only refer people who visit them because of suspected dementia to consultants. They can’t prescribe all the above drugs. Solely up to psychiatrists.”

“Quite difficult to answer. I have become more aware of dementia drugs being prescribed locally recently because of support workers being more involved at the memory clinics. So I am not sure if this is because the prescribing has actually increased because of the changed guidelines or not.”

“No knowledge of problems, in most areas increased access due to MATS.”

“Not aware of access problems to medication. Memory assessment service has regular medication titration clinics for prescribed clients.”

“Whilst not able to comment on individual cases, we have noticed that a change in memory assessment service consultant can impact on local medication prescription policy.”
Chart 5 below provides a break down of the categories of problems.

Chart 5: What have been the main problems accessing drug treatments?

The results show that 33% of the respondents claim to have witnessed difficulty in obtaining access to at least one of the drug treatments. This question has found that there are still a number of barriers, in particular the lack of GP understanding.
Memory services

Access to memory services:
NICE guidance also states that memory assessment services should be the single point of referral for all people with a possible diagnosis of dementia.¹

Without a referral to a memory service, people with dementia are unable to gain a formal diagnosis and therefore access the support and treatment that should be available to them.

To identify the location of the memory services people were accessing, respondents were asked:

“Where do people in your area go to get a memory assessment?”

The results indicate that the majority of people with dementia have memory assessments in their local hospital with 56% of the responses. Only 14% of respondents stated that people with dementia in their area attended memory services in their local health or community centre.

Chart 6 below provides a break down of where people access memory services

Chart 6: What difficulties are there in accessing memory services?

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**Barriers to accessing memory services:**

To identify barriers to access, we asked:

"Have any people with dementia, in your area, had problems accessing these memory services?"

49% of respondents had witnessed people with dementia having difficulty in accessing memory services in their area, and over a quarter of respondents had not had any problems in accessing memory services (28%). A further 23% were not sure whether people with dementia had experienced these difficulties.

**Chart 7: Experienced people having problems accessing memory services**

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<table>
<thead>
<tr>
<th></th>
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</thead>
<tbody>
<tr>
<td>Yes</td>
<td>49%</td>
</tr>
<tr>
<td>No</td>
<td>28%</td>
</tr>
<tr>
<td>Don't Know</td>
<td>23%</td>
</tr>
</tbody>
</table>

To expand on these issues, we asked:

"If so, what problems have people had accessing these services?"

Again a lack of GP awareness dominates the responses with 53% of the answers.

"Doctors saying that there isn’t a problem it’s just their age."

"Lack of GP awareness to refer."

"Getting through the GP."

"Some of the GPs in the area do not seem to refer people on to specialist services. They either diagnose themselves, or tell people there is nothing available for their condition, or that it is just age related."

"GPs are the main problem. People still report GP's as not pursuing a diagnosis for their relatives because they deem it to be a normal part of
aging and “what do they expect?” These GPs are in the minority but not as rare as people presume.”

“GP response is the biggest issue, once referred appointment to the clinics are quite fast.”

“GPs not referring on again telling people that it is old age.”

“Lack of referral via GP. Waiting time to be seen by consultant to long.”

“Occasionally people fall through the net and are not picked up quickly enough i.e. they are not referred to the relevant consultant.”

“Historically Bradford Memory Assessment centre (funded by companies) have taken referrals but not always prescribed. They have not cross referred and people have been left in limbo. Some anecdotal evidence that people from South Asian Communities are not always being referred on for diagnosis from GP in Keighley.”

“Not being referred by GPs in the first instant is a problem. Long waiting times to be seen at memory assessment services once referred, although these have been reduced. The long assessment process itself causes great stress.”

“Some GP’s are slow to refer patients to the Psychiatrist from the elderly.”

“When GP’s don’t feel able to diagnose or refer onto memory clinic.”

“They don’t know they can have this service. GP doesn’t refer on quickly enough.”

“Maybe if GP’s do not refer to service and refer to CMHT instead.”

“GPs not aware of referral procedures.”

“Getting referred by GP.”

“Takes GP’s too long to recognise the problem and refer to CMHT.”

“Some GPs in Sunderland don’t refer people to memory clinic.”

“Some GPs are reluctant to refer into clinics. Medicine reviews and re-assessments are taking far too long.”

“I can only think of one and that was because the GP didn’t think the person had a problem.”

“Difficulty in getting GP to refer to Memory Assessment services.”

“The central Lancashire dementia adviser service has supported people to get a referral to memory assessment services from GP.”

“Lack of information and general problems getting GP ref to Memory Services.”

“Some GPs are slow to refer but once referred people seem to get a good service in this area.”

“Lack of awareness about diagnosis, and lack of specialist referral.”
“Some people do not get a GP referral.”

“Lack of GP awareness.”

The second highest response type was long waiting lists and delays in referrals, reference in 28% of the answers.

“Some people have reported a delay in the GP referral to the memory clinic and reluctance from GPs to make these referrals quickly.”

“Sometimes they haven’t been put on the system, and also waiting lists are extremely long.”

“Long waiting times for appointments and difficulty getting GP to refer them in first place.”

“Some not aware of them. Long wait for an appointment.”

“Main problem is the duration and frequency of clinics i.e. waiting list.”

“Delays due to waiting lists to be seen by a medic and then referred to Ct scans.”

“They are not made aware at time of diagnosis and because of the length of time before a diagnosis is made may not meet the eligibility criteria to attend memory clinic.”

“There is a wait for appointments at Mountnessing court, which covers a vast area, Basildon, Vange, Pitsea, Laindon, Wickford, Billericay, (Essex).”

“A couple of referrals appear to have been lost in system leading to delays. Waiting list is so long. Certain GPs not keen to refer people on to memory clinic.”

A further 9% of responses stated people with dementia in the respondent’s area had difficulty in attending memory clinics due to the distance they needed to travel and poor transport:

“GP’s tell patients that it is easier to be seen by the GP about their Dementia as they will not have to travel to the Memory Clinic (which is a fair distance from most of the area it covers). So patients decide not to use Memory Clinic Services therefore missing out on specialist information advice and guidance. Some GP’s have also been reported as suggesting that the Memory Problems are down to old age.”
“Some carers find it is difficult as there is no memory clinic available therefore they see the consultant at the same time their loved one is in. They are not given the opportunity to speak to consultants. They also receive the diagnosis and are not given the opportunity to access vital information and support at this time.”

“GP has not referred. Transport.”

**Chart 8: Difficulties are there in accessing memory services**

Similar to access to drug treatments, lack of GP awareness remains the biggest barrier keeping people with dementia from memory services. This is usually a result of GP reluctance or ignorance about the services that the memory clinics provide. Once referred, people with dementia have also encountered long waiting times for appointments, delaying further important treatment and support.
Conclusion

This research was undertaken to measure access to drug treatments and memory services for people with Alzheimer’s disease and dementia.

The research was conducted 6 months after changes to NICE guidance in March 2011. The new guidance extended access of cholinesterase inhibitor drug treatments to people in early stages of Alzheimer’s disease. The guidance also stated that people in the later stages should be able to access Ebixa.

PCTs had until June 2011 to implement the changes and meet their legal obligations. By the time of this research, all PCTs should have been providing access to these drug treatments for at least three months. Memory services should have been available for over two years.

On the whole, research describes an improving situation. The survey found that the majority of people do have access to the drug treatments and memory services. As a result perceptions of prescription levels are changing, which is having a positive impact on lives of people with Alzheimer’s disease.

There is room for further progress. People with Alzheimer’s disease continue to experience barriers in accessing drug treatments. 33% of survey respondents have witnessed people with Alzheimer’s disease experiencing problems in accessing at least one drug, with lack of awareness amongst GPs and the reluctance on the part of medical professionals to prescribe the treatments, being described as the most common barrier.

There have also been challenges in accessing memory services. Evidence suggests that these are predominately located in local hospital. 49% of respondents have though witnessed people with dementia experiencing difficulties in attending these services, with lack of GP awareness on the condition and referral options and transport being the most common barriers.

In summary, while progress has been made in expanding access to drug treatments for people in both the early and later stages of Alzheimer’s disease, a number of PCTs are still failing to meet their legal obligation to stock them. What’s more, many people with Alzheimer’s disease and dementia continue to fail to receive a diagnosis and prescription because of a lack of GP awareness.
Recommendations

In responding to these findings the study recommends:

- People living with Alzheimer’s disease continue to struggle to gain access to drug treatments. All Primary Care Trusts and Mental Health Trust must meet their obligation to fund NICE recommended drug treatments for people with living Alzheimer’s disease.
- GPs remain a barrier for accessing both drug treatments and memory services. It is therefore recommended that Dementia Action Alliance members build on this momentum to redouble their effects to boost GP understanding of dementia, referral options and treatments. This could be through promoting the use of Shared Care Protocols.
Annex 1: Online survey

Access to drug treatments and memory services

1. Introduction

Earlier this year the National Institute for Health and Clinical Excellence changed its guidance on Alzheimer's drugs. The new guidance says that people in the early stages of Alzheimer's disease should be able to access treatment. The guidance also says that people in the later stages should be able to access Ebixa.

Alzheimer's Society wants to assess whether in reality people are getting access to drugs and memory services, so we can highlight any issues. This survey is for staff working with people with dementia and will take 5-10 minutes to complete. The deadline for completion is Friday 18th November.

I appreciate that this is a particularly busy time of year so thank you in advance for your support. If you have any questions about the research, please email Simon Kitchen on simon.kitchen@alzheimers.org.uk.

2. Drug treatments

Since June 2011, have you seen any changes in the prescribing of the following treatments for Alzheimer's disease amongst people with dementia in your area?

Please tick the box next to the treatments you have seen changes in: *

- Aricept
- Ebixa
- Exelon Capsules
- Exelon Patch
- Reminyl
3. Have any of the recipient of these treatments seen improvements in their quality of life? If so, could you please give a brief, anonymous, description of the person and their improvement below:

4. If you would like the survey team to develop a more in depth case study with the person with dementia, that could be used in publicity, please provide their details below:

3. **Barriers to treatment**

5. Are you aware of any of the people with dementia, in your area, having experienced problems accessing the following drug treatments for Alzheimer's disease in the last three months?

Please tick the box next to the treatments you have seen people have problems accessing:

- □ Aricept
- □ Ebixa
- □ Exelon Capsules
- □ Exelon Patches
- □ Reminyl
6. What have been the main problems accessing these drug treatments in the last three months? E.g. lack of GP awareness

4. Barriers to accessing memory services

7. Where do people in your area go to get a memory assessment? E.g. Salisbury hospital

8. Have any people with dementia, in your area, had problems accessing these memory services?
   - Yes
   - No
   - Don't know

9. If so, what problems have people had accessing these services?

5. Profile

10. What is your job title?
11. Which PCT area are you based in?

12. If you don't know your PCT, please provide your work post code below:

6. Thank you

13. Thank you for taking the time to complete this survey.

The survey will be used to identify areas for further research, develop case studies to demonstrate the positive impact of the changes, identify gaps in services and access to treatment and provide a straw poll which can publicise the issue at the first Annual Event of the Dementia Alliance Action on the 29th November.

If you would like to receive a short briefing summarising the results, please provide your email below: