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Memory Matters:
A report exploring issues around the delivery of anti-dementia medication

January 2005

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Executive Summary

The arrival of cholinesterase inhibitors and guidance from the National Institute for Clinical Excellence (NICE) about use of these drugs has led to a rapid growth in memory clinics and other services designed to deliver them. However, little work has been done on the essential attributes of such services. This report takes an in depth look at two contrasting services in an attempt to elucidate some of the key issues. The research on which it is based involved a detailed comparison of the two services from a variety of viewpoints:

- Service users, those who care for them and local Alzheimer's Society branches
- General Practitioners referring to the services
- Clinical service providers
- Those responsible for steering and developing services.

It also explored the financial costs of the two service models and their ability to deliver compliance with the NICE guidance.

The project examined the Wakefield Memory Clinic (MC) and the Huddersfield Memory Monitoring Service (MMS), two distinct services for people with dementia within South West Yorkshire Mental Health NHS Trust. The research objectives were as follows:

1. To evaluate service user, carer, referrer and staff satisfaction with the two services.
2. To examine compliance with the National Institute of Clinical Excellence guidelines in the two services.
3. To examine the process for patients who were not selected for treatment or for whom treatment was discontinued.
4. To compare the direct costs of the two models.

In order to ground our evaluation in the experience of service users and carers we began the study with detailed interviews with users and carers from both services. We also conducted interviews with local Alzheimer's Society staff and conducted focus groups with staff. Based on a qualitative analysis of these interviews and groups, we constructed a questionnaire that was sent to larger numbers of patients, carers and referrers. To examine compliance with NICE guidance we conducted an audit of notes from both services. The cost data was based on the audit data and our analysis of the two service

models. Because of recruitment problems, we were unable to examine the experience of patients who were not selected for treatment.

Satisfaction with the effectiveness of drug treatments was high in both services. Though users, carers and referrers were generally well satisfied with both services, higher levels of satisfaction with the service were recorded amongst users of the MMS. This related to a number of issues:

- People preferred being seen in their own homes
- They enjoyed having a single worker (nurse) to whom they mostly related
- They experienced better links between the service and the local Alzheimer's Society branch, leading to better availability of information
- They did not like the within-clinic waits at the Wakefield clinic.

In both services, users and carers were reasonably well satisfied with general waiting times though providers were concerned that demand could outstrip supply, leading to increased waiting times. Service users and carers thought both services could have provided more information and links to other services. Staff were often concerned about the same issues as service users and carers.

Compliance with NICE guidance on the use of cholinesterase inhibitors was high in both services. The MC used a more comprehensive battery of cognitive, behavioural and other instruments, providing more robust diagnostic and monitoring data. The MMS utilised a smaller range of testing, reflecting the service's priority in monitoring drug treatments amongst patients solely with Alzheimer's disease. Compliance with local standards was high.

Financial analysis showed substantially lower costs for the Huddersfield (MMS) model.

Both services were providing high quality and valued services to patients and their carers. The more personalised and community focused MMS was generally preferred and less costly. However, it did not provide such a robust and wide range of monitoring data. Both services could have been improved by the provision of more information and by better links into other aspects of social and psychological support services.

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Introduction and Literature Review

1.1 Introduction

Dementia is a devastating disease that affects a significant proportion of people, mostly over the age of 65 years. Services for old people with dementia have developed in the UK and around the world over the last twenty to thirty years or so, usually as part of specialist old age psychiatry services (Wattis, Wattis and Arie 1981). Services for the smaller number of younger people with dementia have developed more recently. In the last five to ten years services have been revolutionised by the launch of drugs for the treatment of Alzheimer's disease, the commonest form of dementia. In the UK, this has resulted in a proliferation of Memory Clinics and similar services to facilitate early diagnosis and treatment of Alzheimer's disease. The production of guidance from the National Institute for Clinical Excellence (NICE) has encouraged and shaped these developments. This report details a study comparing two services, one a "conventional" Memory Clinic and the other a nurse-led community-based service. The study involved interviews with patients, carers and staff, a questionnaire survey of a wider group of patients, carers and general practitioners, an audit of compliance with NICE guidance and an analysis of the direct costs of the two services. This chapter gives the background to the study and subsequent chapters deal with methodology, the different phases of the study and the conclusions to be drawn.

1.2 Dementia and Alzheimer's disease

Dementia is a chronic, progressive organic mental disorder characterised by impairment of memory, thinking, orientation, comprehension, calculation, learning, language and judgment. Alzheimer's disease is the commonest cause of dementia involving a subtle onset and slow deterioration, leading to difficulties in recognition and diagnosis (Askham, 1995).

The Mini Mental State Examination (MMSE) (Folstein, Folstein & McHugh 1975) helps identify dementia and has been used to grade the severity of Alzheimer's in accordance with the score achieved by the patient as detailed in table 1.1

Table 1.1 Stages of Alzheimer's Disease

STAGE OF ALZHEIMER'S	MMSE SCORE	DESCRIPTION
Mild	21-30	The patient has temporary memory loss; they forget how to do familiar tasks and may be unable to remember familiar names or words.
Moderate	11-20	The patient is more disorientated and may also become paranoid/delusional. Significant life episodes may be forgotten and there may be increased difficulty in recognising close relatives. Help is needed with personal hygiene and care.
Severe	0-10	The patient has great difficulty in using appropriate verbal communication; they may have trouble feeding due to difficulties with swallowing. Twenty-four hour care is needed and increasingly there will be periods of bed confinement. The patient is also more open to secondary illnesses.

1.3 Epidemiology

In 1996, an estimated 750,000 people within the United Kingdom had some form of dementia. This was forecast to rise to 840,000 by 2010 (Alzheimer's Society 2003). Dementia of Alzheimer Type (DAT) accounts for approximately 55% of all cases of dementia (Alzheimer's Society 2004). In the UK in 1996, approximately 413,000 people had Alzheimer's disease. This is set to rise to around 462,000 by 2010. Dementia was estimated by to cost the United Kingdom £6.1bn a year (at 1998-9 prices), with £3.3bn of this as direct spending by health and social services (O'Brien & Ballard 2001).

1.4 Impact of cholinesterase inhibitors

Acetylcholine is a neuronal transmitter, important in memory function and reduced in Alzheimer's disease. It is broken down by cholinesterase enzymes. Cholinesterase inhibiting drugs, including donepezil, rivastigmine and galantamine are used for mild to moderate Alzheimer's disease. They effectively amplify the action of the acetylcholine produced and released in the brains of people with Alzheimer's disease, thereby reducing symptoms (Cameron *et al* 2000, NICE 2001, Lindesay *et al* 2002).

The advent of cholinesterase inhibiting drugs has added impetus to the development of memory clinics and other services, specifically designed to facilitate early diagnosis of Alzheimer's disease and delivery of theses drugs.

1.5 National Institute of Clinical Excellence (NICE) guidance

NICE provides the public and practitioners with authoritative, robust and reliable guidance on current best practice. In January 2001 NICE published guidance on the use of donepezil, rivastigmine and galantamine for the treatment of mild to moderate Alzheimer's disease. Guidance incorporated the following recommendations:

- A diagnosis of Alzheimer's disease must be made in a specialist clinic, which also investigates cognitive, global and behavioural functioning, activities of daily living and probable patient treatment concordance.
- Specialists should initially prescribe treatment but general practitioners using a shared care protocol can continue treatment.
- Prior to treatment commencing, and throughout the course of treatment, the carer's views of the patient's condition should be sought.
- Once the patient's maintenance dose has been determined, they should then be assessed 2 to 4 months later. Treatment should be continued if the patient's MMSE score remains the same or improves and if the patient shows improvement on other measures, for instance on behavioural and functional assessments.
- The patient should then have an assessment every six months with drug treatment continued only if their MMSE score remains higher than 12 and if the patient shows improvement or stability on other measures, for instance, on behavioural and functional assessments.

1.6 Memory clinics

The introduction of National Institute for Clinical Excellence (NICE) guidance has influenced the development of memory clinics in the UK, with fifty-eight active clinics operating at the last recorded count (Lindesay *et al* 2002). Van Hout et al (2001) identified the main objectives of memory clinics as to: *'provide an ambulatory diagnostic, treatment and advice service for people with memory impairment and to act as a focus of research into dementia.'* However, the scope and functions of memory clinics vary widely, from those mainly concerned with research to those established more recently focusing on early diagnosis and treatment. Clinics are often multidisciplinary with teams including psychiatrists, psychologists, geriatricians, occupational therapists and mental health nurses (Wright & Lindesay 1995, Lindesay *et al* 2002). While there are a variety of service models including community based care (Psychologists' Special Interest Group in Elderly People 1998), most clinics are based upon institutional modes of care (Downs 2000). This represents a shift away from traditional community oriented old age psychiatric services (Wattis *et al* 1999). The memory clinic was listed in the recent National Service Framework for Older People (DoH 2001) as an essential component of services but as yet there is no general model within the NHS for the structure, function and clinical remit of a memory clinic. (Wright & Lindesay 1995, Lindesay *et al* 2002).

An audit of 93 patients over a three-month period in routine clinical practice found that 47% of patients showed an improvement when treated with donepezil, but that treatment guidelines were not well followed (Cameron *et al*, 2000). The report argued for specialist services to improve compliance with guidelines. Memory clinics also probably help in early detection with patients being seen at earlier stages of the dementing process. (Luce *et al*, 2001). Moniz-Cook & Woods (1997) recognised psychosocial support for both patients and carers as a function of memory clinics and Lindesay *et al* (2002) showed that over half of the clinics they sampled provided some psychosocial support as well as delivering and monitoring medication.

Recently, work has been conducted on the role and impact of memory clinics in supporting carers, reflecting wider recent concerns about the health and wellbeing of carers (Moniz-Cook & Woods 1997, Murray & Livingston 1998, Logiudice *et al* 1999, Van Hout *et al* 2001, Vernooij-Dassen *et al* 2003). One study in the Netherlands demonstrated that memory clinics were more likely to communicate information on diagnosis to patients *and* carers when compared to traditional old age psychiatric services. Outside memory clinics diagnoses were more commonly withheld from patients, largely rendering them voiceless in the doctor-patient-carer triad. (Haug 1994) Van Hout *et al* (2001) also demonstrated that patients and carers rated clinics positively in terms of the information provided to them on diagnosis and treatment. A randomized clinical trial (Logiudice *et al,* 1999), showed memory clinics to have a positive impact on the quality of life of carers, particularly in the area of providing carers with support networks. Vernooij-Dassen *et al* (2003) recognized the need to consider the psychosocial impact of the diagnosis on patients.

1.7 Alternative service models

While memory clinics are becoming increasingly common, varieties of other services exist and contribute to management and care of people with dementia. In the UK, Psychiatric Services for Older People, traditionally community-focused, have always considered dementia in this age group within their remit (Wattis, Wattis and Arie, 1981). Keady & Adams (2001) in their examination of the roles of Community Mental Health Nurses (CMHN's) found a paucity of evaluative work on nursing in dementia care. They found that Community Mental Health Nurses *did not* routinely differentiate subtypes of dementia though earlier work had demonstrated that nurses *could* effectively diagnose different types of early dementia using structured methods (Seymour *et al* 1994). Community oriented approaches to the treatment of dementia have been shown to provide particular benefit to patients and carers with respect to psychosocial support (Keady & Adams 2001, Woods *et al* 2003).

1.8 The current study

This study was a detailed comparative evaluation of two service models:
   1) The nurse led and community focused Memory Monitoring Service (MMS), and
   2) The hospital-based memory clinic (MC).

Service models are shown in Fig 1.1. We aimed to compare the two models in respect of the following variables:

- Stakeholder satisfaction,
- Compliance with NICE guidance and
- Other benefits and costs.

The methods used combine qualitative and quantitative measures of satisfaction with an audit of compliance with NICE guidance and of costs. The study aimed to give patients

and carers a voice in how services should develop and, by highlighting what works best, to facilitate innovation and the development of humane, effective and efficient services.

Wakefield Memory Clinic

Huddersfield Memory Monitoring Service

1st Visit Home Memory Clinic Nurse Prelim history & tests.	**1st Visit** Home Memory monitoring nurse Prelim history & tests.
2nd Visit Clinic Baseline Diagnostic visit Full baseline assessment (more prolonged and rigorous than the MMS)	**2nd Visit** Out patient Department Baseline Diagnostic Visit Full baseline assessment And home visit shortly afterwards
3rd Visit Contact by phone or visit 1 month after commencing treatment, with further 6 weekly dose titration	**3rd Visit** Telephone call 1 month after baseline. Side effects check. Dose titration
4th Visit Clinic 3 month monitoring visit SMMSE, B-ADL etc.	**4th Visit** Home 4 months after baseline MMSE, BADL etc.
5th Visit Subsequent clinic visits at 6 monthly intervals Efficacy assessment	**5th Visit** Subsequent home visits at 6 monthly intervals Efficacy assessment

Fig 1.1 Outline of Memory clinic/Memory Monitoring Service models.

These models are approximations. The Wakefield Memory Clinic introduced a preliminary nurse visit part way through the study and the Huddersfield MMS included a baseline assessment visit after the short diagnostic attendance at clinic. Neither service achieved complete 'fidelity' to their model. The MMS protocol allowed for the nurses to report six-month assessments to the Consultant. Sometimes this was done face to face, sometimes by written message. Patients were not routinely reviewed in clinic like the Memory clinic service. If they required complex care packages, these were arranged in the usual way, by or through the Community Mental Health Teams and/or the Social Services department. The memory clinic was not any different in this respect. Both services were complimentary to existing services rather than aiming to be 'one stop shops' for all the needs of people with dementia and their carers.

2
Research Methods

We used different methods for each part of the study. These are outlined below. The study was conducted in accordance with the Declaration of Helsinki. The protocol was peer reviewed and approved by the ethics committee of the School of Human & Health Sciences at the University of Huddersfield. The Research Approval group of the South West Yorkshire Mental Health NHS Trust and the Wakefield Local Research Ethics Committee (LREC) also approved the study. Necessary variations in the protocol were approved by the LREC. Further details of how we managed ethical considerations around interviews, focus groups, potential distress, and withdrawal from the study and confidentiality are available on the web version. All data was anonymous at the point of collection and stored and disposed of appropriately, in accordance with the Data Protection Act (1998).

2.1 Objective 1: Satisfaction with the service

This was split into two phases. In the first we used qualitative interviews to explore user, carer and staff views. In the second we developed questionnaires based on the qualitative data and used them in a wider sample to enable a more robust comparison of the services. We tried to include patients, carers, referrers (GP and Consultant) and staff from both services in the first phase and patients, carers and GPs in the second.

2.1.1 Phase 1

Patients and carers
For each service we identified a link nurse to help recruit possible participants and prevent selection bias by the researchers. A variation in the protocol allowed representatives of the Wakefield and Huddersfield branches of Alzheimer's Society to help with recruitment. Eligible service users (patients and carers) were identified, given an information sheet and personally invited to participate.

We asked those who were willing to participate to send confirmation in writing to the research office. One of the researchers telephoned potential participants and reminded them that involvement was voluntary and that they could withdraw at any stage. The researcher went through details of the study again, answered any questions and set a mutually convenient date, time and place for interview. A written information sheet was provided.

Before the interview, the researcher provided any further information required. All consent forms were signed in the presence of a researcher or a member of NHS staff. We assessed competence to consent on the basis of the participant being able to understand the outline of the study and their potential role in it. They needed to be able to remember the information for long enough to weigh it in the balance and come to a decision. Subjects were asked to agree to their main carer also being approached.   We obtained informed consent from carers according to the same principles.   30 patients in Huddersfield and 30 patients in Wakefield were given information and invited to participate. Five patients and their carers from each service agreed to participate.

We conducted interviews at the homes of the patients. Two members of the research team conducted the interviews. Interview schedules were structured to explore the following issues:

- Satisfaction or lack of satisfaction with the services.
- Timeliness.
- Preferences for being seen at home or in clinic.
- Satisfaction with information provided.
- Communication.
- Any other aspects raised by participants.

With permission, we recorded interviews. Each lasted approximately one hour. We give a full qualitative analysis of these interviews in chapter 3.

Referring GPs and Consultants

We approached referring GP's and consultants and asked them to take part in an interview. The lead consultants of the two services signed invitations for interview in the hope this would improve recruitment. Unfortunately, none of the referring GP's and Consultants (other than the two consultants involved in the research) agreed to be interviewed, in some cases citing lack of time as a reason for refusal. We managed to collect GP data later, through the questionnaire (see below).

Memory service staff

We asked the link nurses to list the staff and others involved in steering and providing their services. We then wrote to these people inviting them to a focus group. We included an information sheet and consent form with the invitation. Before each focus group, the researcher explained the participant's rights and the ethics of the study, and obtained written consent from participants.

We asked 10 people from Wakefield and 10 from Huddersfield to participate. Six from Wakefield and four from Huddersfield agreed. Two members of the research team conducted focus groups with the staff/steering groups of each service. We explored the perceived advantages, disadvantages, strengths and weaknesses of the services and examined satisfaction with service models.

We seated participants in a circle to facilitate interaction. We standardised group introduction including a description of the study, its purpose, data handling and dissemination. We requested permission to tape record the discussion and to take notes. The focus groups each lasted approximately one hour. We include a full analysis of these interviews in chapter 5.

Alzheimer's society representatives
We conducted two further interviews with representatives of the Alzheimer's Society recruited through their involvement in the research steering group. We explored themes pertinent to services in their locality that had arisen during the patient and carer interviews. Before each interview, the researcher explained the participant's rights and the ethics of the study and obtained informed written consent. We interviewed one representative from Wakefield Alzheimer's Society and one from Huddersfield Alzheimer's Society at the branch offices. We questioned representatives regarding their involvement with the Memory Monitoring Service/Memory Clinic, and with patients using these services and their carers.

2.1.2 Phase 2

On the basis of analysis of these interviews and groups, we constructed brief patient, carer and doctor questionnaires. We piloted these on five patients and their carers from each service, and then sent them to a sample of patients and carers from each service, their referring consultants and general practitioners. The questionnaires explored satisfaction with different aspects of the services.

Patient and carers
Link professionals provided the researchers with the names and addresses of patients believed to be actively receiving treatment within the service. We sent all patients and their carers study information, a questionnaire and audit consent form. A total of 415 questionnaire packs were sent to patients using the services, 225 in Huddersfield and 190 in Wakefield. Each contained information sheets a patient and carer questionnaire and pre paid envelopes to encourage response. We sent a covering letter with the questionnaires, highlighting the anonymity and confidentiality of names, addresses and data and making it clear that participation was voluntary. We invited patients to contact the research office in the event of them requiring assistance to complete the questionnaire. We also alerted the link professionals and the representatives of the Alzheimer's Society prior to questionnaires being sent out, to enable them to deal with any queries that came their way. We received 46 patient and carer questionnaires from the MMS and 15 patient and carer questionnaires from the MC.

We standardised questionnaires between the Huddersfield and Wakefield services and between patients and their carers to enable cross comparison but tailored the wording of questions to reflect each service. We also included a consent form requesting individual patients to consent to taking part in an audit of patients' medical records for phase 3 of this research project.

Referring GPs

We sent questionnaires to referring GP's. We recruited GPs for Huddersfield from a list provided by the MMS. The MC could not provide a list of referring GPs in Wakefield and to gain an appropriately sized sample, we sent questionnaires to all GP practices within the MC catchment area. We sent 82 questionnaire packs to Huddersfield practitioners and 114 to Wakefield practices. Each contained a questionnaire, an information sheet detailing the study, and pre paid envelopes. We sent a covering letter, detailing the project and its objectives. Huddersfield GPs returned 17 (21%) questionnaires and Wakefield GPs. 21 (18%). The GP questionnaire was brief to encourage response. It also requested descriptive information from GP's, allowing for some qualitative evaluation of responses. Questionnaires were designed with the assistance of medical and academic professionals with relevant expertise.

2.2 Objective 2: Compliance with NICE guidance

We explored compliance by conducting an audit of case notes from each service. We sought informed consent to examine the medical records of service users during the questionnaire stage. Most respondents gave consent. Case notes were audited on hospital premises by or in the presence of professional staff. The poor response rates meant that numbers were small. Because of this, at the analysis stage, we augmented the data with anonymous data from clinical audit. A total of 67 patient case notes were audited from the MC and a total of 78 case notes were audited from the MMS.

2.3 Objective 3: Satisfaction of those not receiving treatment

Originally, we planned to approach five patients from each service who had not been able to start treatment or for whom treatment had been discontinued. We wanted to interview them and their main carers to gain their views and experiences about not receiving treatment. We identified patients with the assistance of the link professionals. Unfortunately, nobody consented to take part in an interview. Link professionals attributed the lack of volunteers to: a) a relatively small population for whom treatment was not started or discontinued; and b) severity of dementia, other illness or death in this group. Another possible reason was disaffection with a service that had either refused or terminated treatment but we were not able to explore this. Consequently, we had to abandon this stage of the research.

2.4 Objective 4: Cost analysis

We drew up a schedule summarising the frequency of and types of contacts in the two services. We used the clinical audit to determine routes of entry into the service, and to record the range and frequencies of diagnostic tests conducted. We used this information to determine the financial costs of the services. We collated other direct costs of the different models of service, for example transport. The schedule was applied to all patients from each service to enable a comparison of costs-per-case on a like-for-like basis. As a cross check we used financial information collected from link professionals as part of a preliminary report written in May 2003.

Costing model

We developed a costing model to analyse costs per case of each service. All costs were entered into this model and subjected to a sensitivity analysis applying different scenarios identified in the audit phase of the study.

Total number of patients per year	X	Intervention cost per patient	=	Total intervention cost

No. patients fluctuating/increasing	X	Annual intervention cost	=	Service Implications
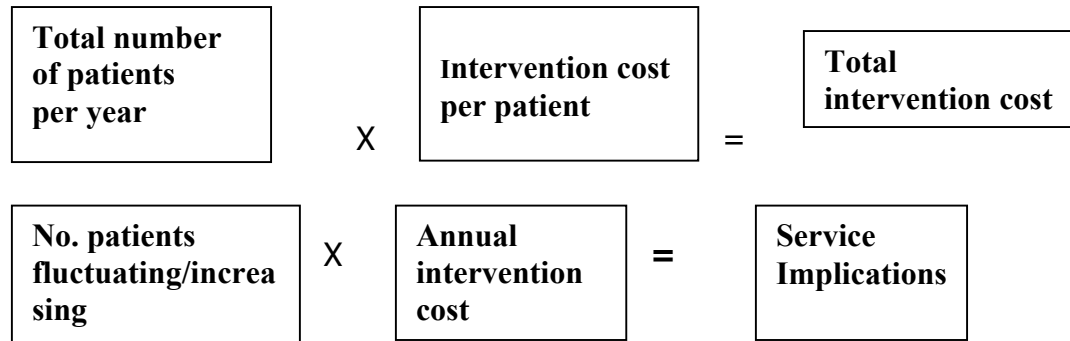
Fig 2.1 Annual cost model for memory service resource implication

Data analysis

Identification codes were used to protect anonymity and all tapes were destroyed in compliance with the 1998 Data Protection Act. We analysed quantitative data using SPSS (the Statistical Programme for Social Sciences) version 11. We transcribed all qualitative data verbatim and subjected it to template analysis (Crabtree and Miller, 1992).

In template analysis, the researcher develops a number of codes (a template), highlighting themes and constructs found within the text. The template is modified as the researcher repeatedly reads, codes, and provides interpretation to relevant text Template analysis is similar to 'content analysis' (Weber 1985) and 'grounded theory' (Glaser and Strauss, 1967). However, in content analysis, all codes are made prior to analysis of the text, which is carried out statistically. In grounded theory there are no preconceived ideas about the codes to be used. Template analysis lies somewhere between these approaches and is more flexible (King 1998).

One researcher developed a template for patient and carer transcripts, starting by reviewing the text from a pair of transcripts, adding annotation and simple, descriptive, coding using the interview schedule to predefine categories. The researcher then returned to the text and provided more interpretation by clustering codes together and ascribing meaning to each group. This began a process of hierarchical coding, with more general codes leading to more defined and specific ones. All the other transcripts were then coded, using the initial templates which were revised as a result of observing the other transcripts. Existing classifications were adjusted, further dimensions were added to codes, areas were deleted, and new constructs were developed.

A second template was developed for the analysis of the Alzheimer's Society representative interviews, initially using the text of one transcript and subsequently developing and revising the template as detailed above. A third template was developed

in a similar way for the focus group data. The final templates were indexed and provide a tight and clear organisation of the data and a well-ordered means for analysis.

2.5 Establishing research trustworthiness/ reliability and validity

The structure and findings of the study are reported (with more detail available on the web version). The theoretical background, the general methodological framework and method of analysis involving peer review are specified and appropriate to the research subject. Quantitative data were analysed using standard methods with appropriate corrections. Qualitative data were evaluated by comparing the responses of all participants. As all participants mentioned similar issues, there was confidence in the credibility of themes. A second researcher provided a check on the plausibility of all categories and the consistency of subsequent coding for each template. There was usually consensus on common themes emerging from the data but some disparity as to the best way to capture these within categories. Through discussion of the rationale underpinning each category and re-examination of the data, agreement was reached. Outstanding discrepancies in themes were resolved by modifying the boundaries of themes or creating new themes. The study structure is not limited to the environment and sample used; the same procedures could be used to investigate other phenomena. The steps taken in carrying out the study are clear, systematic, efficiently documented and include safeguards against bias.

2.6 Study organisational structure

We established a research steering group to support and monitor the project. This included representatives from Alzheimer's society and university based researchers with expertise in qualitative and quantitative methods and research into old age psychiatry.

3
Objective 1: Patient and Carer Interview Findings

3.1 Introduction

Ten dementia patients and their carers were interviewed where possible separately. Of the ten carers interviewed, four were married to the patient and two were long-term partners. Four of the patients within the MMS sample were male. Four of the MC patients were female. MMSE scores for MMS patients ranged from 22-30 and for MC patients from 12-26. Five main themes and a range of related themes were identified (Table 3.1).

Table 3.1 Summarised patient and carer interview coding template.

FIRST LEVEL THEME	LOWER LEVEL THEMES
1. Perceptions of dementia	1.1 Causal attributions of dementia
	1.2 Events leading to diagnosis
2. Treatment location	2.1 The community based model
	2.2 The hospital based model
	2.3 Preference for treatment location
3. Timeliness	3.1 Satisfaction with waiting times to access the service
	3.2 Clinic waiting times
4. Satisfaction with the service	4.1 Drug treatment
	4.2 Assessment and diagnosis
	4.3 Personal qualities of staff
	4.4 Individualised service
5. Information provision	5.1 Range of information provided
	5.2 Satisfaction with information provided
	5.3 Communication style
	5.4 Satisfaction with external information sources.

3.2 Perceptions of dementia

The perceptions participants held of dementia shaped their behaviour and reasoning. Two main sub-themes were identified: *causal attributions of dementia* and *events leading to diagnosis*.

Causal attributions of dementia
Each participant discussed their own perceptions about the origins of dementia. Most thought dementia to be a natural part of the ageing process. Dementia was initially understood as a heightened sense of 'absent mindedness', rather than as a clinical condition. Despite being given information about the disease, some participants still had their own ideas about possible causes, actively searching for evidence to support these

ideas. Dementia was seen as due to old age together with other factors, including level of intelligence, previous career, and in one case, having been anaesthetised:

> **'My wife had an operation and ever since then, her memory has not been so good … I believe it is the anaesthetic… I said to the nurse…'would you mind asking the consultant if it can be the anaesthetic what causes it' and she said 'well to be honest with you… it has already been put to the consultant and he says if the weakness is there it will bring it out' …so do not ever have an anaesthetic if you can help it' (MMS carer).**

Events leading to diagnosis
Most dementia patients, with their carers, made incremental adjustments in their daily lives to cope with dementia as it progressed, often scaling down their expectations of quality of life. Patients and carers were aware of difficulties arising from memory loss, but fear and embarrassment discouraged a visit to the GP until a 'crisis point' where struggling with the difficulties led them to feel that medical advice or intervention was needed, for example:

> **'I realised it… four and a half years ago. My husband could not remember eating his Christmas dinner. There were a few incidents before that… But it would be about six o clock in the evening when he asked me what day it was, and of course it was Christmas day'** (MMS carer).

And,

> **'Mainly it was the forgetfulness. I mean I had a good brain before, I mean I were in the [] service for twenty-five years… and suddenly I started forgetting things. I had to ask the wife time and time again for all sort of things… I got very frustrated to start with; I could not come to terms with it'** (MMS patient).

Memory impairment was difficult to accept and adjust to for both patients and carers and some ignored the signs in the hope that they would improve or at least not get worse.

3.3 Treatment location

The major difference between the two services evaluated was that one was community based and the other hospital based. Participants made interesting comments with regard to this. These are summarised and addressed in three main themes; *the community based model, the hospital based model* and *preference for treatment location.*

The community based model
The community basis of the MMS was highly regarded by patients and carers. This was commonly viewed as the main advantage of the MMS. Participants highlighted the fact that they did not need to use public or other means of transport to regularly travel to a

clinic for appointments. While several participants retained mobility, several noted that since the onset of dementia, their mobility had been restricted. Several participants also noted a desire to avoid using public transport where possible. Being seen at home eased the burden felt by the carer, and avoided the anxiety and distress felt by patients in considering the practicalities of attending hospital.

Whilst most MMS participants appreciated the need for an element of the service to be clinic based, for instance for medical scans to be conducted, all participants expressed a preference for the design of the MMS: '**It has been damn handy and they have been damn good, well they have been good for me …You're more comfortable in your own home than you are going waiting in a corridor**' (MMS Carer). Participants from each service said that hospital visits could cause increased anxiety for patients, exacerbating memory difficulties. No one noted lessened contact with consultants as being a particular criticism of the service.

Increased anxiety felt by patients within clinic settings was attributed to a variety of causes; including the length of time waiting within clinics, difficulties in traveling to clinic, the physical environment of the clinic and general perceptions of hospital environments. One MMS patient mentioned the anxiety associated with exposure to others with more severe dementia. This could cause distress to patients and carers by showing what might be expected as the disease progressed. Several carers, perhaps projecting their own feelings, attributed this distress to the patient. Receiving help at homes removed the risk of this exposure: **'I think if you went into the hospital you would be sat in a waiting room, you are going to see people far worse… that can be very distressing in itself'** (MMS carer). MMS carers particularly felt that being assessed at home allowed for a more accurate depiction of the patient's cognitive decline:

> '**I think it is more friendly if its in your own home…and especially for my husband because he is in his own environment, and he will be more relaxed, whereas I think if you go to a clinic, you can all be very tensed up, and wondering what is happening with the people coming in white coats' (MMS carer).**

MMS participants felt that receiving treatment at home enabled them to communicate more openly. They felt more able to "be themselves" within the home environment:

> **'If you are in the hospital you are in a different place altogether, you are sitting on your own settee, with your own carpet and your own furniture all around you, you can be yourself… But in hospital, some change comes over you, and you simply are not the same, you are not as relaxed, tense, wondering what they are going to say next, what is going to happen next and so on'** (MC carer).

Several carers noted that they did not feel as free to discuss pertinent issues within hospital environments, where their interpretations and previous experiences of hospital

settings constrained their ability to communicate freely and in a relaxed manner with the medical professionals.

The hospital based model
While most participants thought that treatment had benefited patients, two MC carers questioned whether the level of benefit achieved was worthwhile, given the perceived effort required in gaining the treatment: **'I mean the treatment is limited, as you know, so it makes you wonder sometimes if you are going through a lot of hoops for no reason at all, if you understand my logic'** (MC Carer).

One major cause of variation in levels of satisfaction with the MC was the particular pathway patients took within the clinic. Two distinct pathways were identified. In one, patients were seen in a single appointment conducted by a nurse consultant. Within these appointments, tests were conducted prior to a consultation and diagnosis with the same professional. Because the nurse consultant could provide a diagnostic opinion, a second appointment with a psychiatrist was not required. Carers and patients on this pathway expressed high levels of satisfaction: **'I like that man; (…) He makes me feel comfortable'** (MC Patient). These feelings of comfort were helped as patients in this pathway remained in regular contact with one member of the clinic staff. The alternative pathway involved two distinct appointments within the same visit; an initial appointment with a nurse where assessments were conducted, combined with an appointment with either a staff grade or consultant psychiatrist, in which diagnoses were made and treatment initiated. Several participants expressed dissatisfaction with this system, largely based on the wait between appointments. Appointments also regularly fell short of their allotted time-slot, further increasing the waiting time between the nurse and psychiatrist appointment.

Another problem in the MC, raised by MC carers, was the need to travel to the nearby Pinderfields Hospital pharmacy to collect prescriptions. This was a particular problem for frail patients using the clinic, and was an inconvenience for carers, as it placed an extra task upon them. One MC carer suggested that drugs could be distributed within the clinic itself, streamlining the system: **'Well you would not want to push somebody in a wheelchair would you… why they cannot be distributed in the clinic I do not know'** (MC carer). However, since the data collection phase of this study the MC service has developed and carers no longer have to collect all prescriptions from the hospital pharmacy, as GP's take over all prescribing after the initial dose titration. For MC participants, the issue of traveling to the clinic was also a concern. Several lived a good distance from the clinic, resulting in patients having to endure long journeys. While several relatively young carers stated that it was not a problem for them personally, they recognised that traveling to the clinic might cause problems for patients less mobile or without transport:

> **'I am fortunate in being younger; having a car and being able to travel… a lot of people struggle to get into Wakefield. If I went on the bus I would have to change four times from here… or wait for an ambulance… so it can be a problem'** (MC carer).

Amongst patients and carers who were not able to drive themselves to clinic, most stated that they relied on friends and family for transport. Several said they had been offered ambulance transport, but usually made other arrangements. While the ambulance was thought to be a necessary service for many individuals using the clinic, for most of the participants interviewed it was seen as a last resort.

Preference for treatment location

All participants were questioned regarding their preference for a clinic or community based model. All participants had received community-based assistance at some point and thus felt able to give some opinion, in all cases stating a preference for a community-based service. The preference for a community service was most commonly based upon the issues of comfort and familiarity with the home environment. One MC carer stated that the patient felt anxious about visiting the memory clinic and described how the patient's lack of familiarity with the clinic environment and staff, increased feelings of discomfort and anxiety:

> **'They go through the initial anxiety each time… which is not helpful… I have found with (patient)… if she is anxious… she will almost become like a headless chicken… the more anxious they get, the less able to deal with a situation they are. That is my experience anyway… other people might find it different'.** (MC carer).

The feelings of anxiety resulting from attending a clinic were thought to impact upon the patient's cognitive and functional abilities, maybe adversely affecting any assessment. Several carers noted that prior to clinic visits patients became nervous. Several MC patients stated that they thought they would be able to perform at a level more reflective of their true abilities if the tests were conducted at home.

A community nurse who occupied a relatively new post in the MC had visited one patient and carer. The duties of this post included preliminary home visits to patients, when diagnostic testing was conducted, and where patients and carers were given information about the clinic. Both were highly satisfied with the visit, and the assistance provided. They appreciated advice provided to them on how to adapt to memory problems:

> **'Carer: What happened was, we got a letter back from them, and they said that if we were willing, (memory clinic community nurse) would come, and he would give us an assessment here. He came, and he was very good. He asked us to…**
> **Patient: Told me to get something like this (points to tear off calendar) tell me what day it was, something like that'** (MC patient and carer).

The MC community nurse post was also judged effective in preparing individuals for clinic visits and in reducing apprehension experienced prior to clinic appointments. The community-based element that has been added to the clinic-based service model has increased levels of stakeholder satisfaction. All MMS participants reported satisfaction with the service they received and would like the service to remain community based.

Patient and carer preference for care at home appeared to be influenced personal memories and local history. For one MMS carer in particular, a general dislike of St Luke's hospital in Huddersfield, where clinical appointments took place was a major reason for preferring a community-based service. This dislike was based on personal memories of the hospital where both the carer's parents had died and on the history of the hospital site. It had been a workhouse and a mental hospital where patients were taken prior to transfer to Storthes Hall, a local asylum closed years ago:

> **'I hate the place. I absolutely hate Saint Luke's, I dread it, I dread going because my mother died there and my father died there… and you see in my days it was the workhouse. It was the local workhouse. It was a stigma to be sent to Saint Luke's'** (MMS carer).

Other participants shared this dislike but did not feel it so strongly. The community-based design was felt by several carers to reduce the perceived stigma of dementia and mental illness by lessening exposure to sites associated with bad memories.

3.4 Timeliness

We asked questions about satisfaction with waiting times. Responses identified two main themes, *waiting times to access services* and *waiting times within clinic*.

Waiting times to access services
Few participants expressed any problems with an acknowledged waiting time of approximately 2-3 months between the GP/consultant referral and the contact with MMS/MC personnel. Most patients and carers had a generally favourable reaction:

> **'Carer: And he actually, you know we got a day and a time to go and see a nurse and a doctor, and so we did not seem to be waiting long at all…
> Patient: I know they have had complaints… I was sort of really surprised…
> Carer: They were really good'** (MC patient and carer).

The experience of the waiting time for access to dementia treatments was judged in comparison with experiences of other NHS services:

> **'The one thing we do not agree with is, like he is waiting for a replacement knee… they said there was a long waiting list for that obviously… but you see he has got to wait between six and nine months before they can even consider him for a knee replacement… so we have no arguments at all with this memory service'** (MMS carer).

The level of satisfaction was also related to the level of cognitive decline found in patients. Most showed minor impairment, and were still able to perform many activities of daily living. Because of this, carers did not generally feel a high level of urgency. Two carers were concerned about waiting times. For one MMS carer, this was based on

the stress experienced in caring for her husband and anxiety about progression of the illness. One MC carer was also concerned about illness progression. The patient had started treatment a number of years previously when waiting times were longer. All were satisfied with the regular six monthly nurse follow up. Some would have preferred more frequent visits.

Waiting times within clinic

As part of the MMS model, patients attended a single diagnostic clinic assessment. Due to preferences amongst consultants operating in conjunction with the MMS, some patients also had clinic appointments as well as the regular visits from MMS nurses. Several were dissatisfied with the waiting time in clinic for their consultation. One carer described waiting for two hours for a consultant appointment.

For memory clinic participants, this anxiety was sometimes exacerbated by the length of time they had to wait to see a doctor and nurse separately: **'So even after half an hour you have got half an hours wait if everything, if you have got an appointment that follows straight on. But more often than not they do not follow on; you might follow on another hour after that'** (MC carer). Carers felt that this increased the amount of inconvenience they suffered. These problems were attributed to the organisation and management of appointments, rather than individual clinic staff.

For patients allocated to the MC's single appointment pathway, participants were highly satisfied with waiting times within clinic. All patients acknowledged that a certain amount of waiting was expected and the waiting times within clinic were never unacceptable. One carer congratulated the MC on promptness and flexibility:

> **'I do not think it was the last one, but maybe the one before, we were there early, we were in early and out… so, the other times, quarter of an hour to half an hour after the appointed time. But that is not something I would worry about, with the hospitals as they are… and I certainly would not moan about being seen after time when we have been seen before time'** (MC carer).

Most carers were flexible regarding waiting for clinic appointments, and forgave minor increases in waiting times. While patients and carers may and do complain amongst themselves, they appeared unlikely to make any formal complaints. One carer attributed this to having an innate respect for medical professionals.

3.5 Satisfaction with the service

All participants were satisfied with the service they received. This was most commonly based on benefit experienced from the anti-dementia medication. Four major themes were identified; the *Drug treatment, assessment & diagnosis, the personal qualities of the staff* and the perceived *individualisation of treatment.*

Drug treatment

All patients were receiving anti-dementia medication. Patients and carers were highly satisfied with the benefits of drug treatment. MC carers were generally more aware of the limited benefit that treatment might have, and realised that major improvements in cognitive ability were unlikely. Where benefits did occur, carers felt that the drugs had usually performed as well as could be expected based upon the knowledge given to them by staff in the memory clinic. Treatment, at the very least, stabilised overt memory loss:

> **'She seemed to me to get a lot worse very quickly, and I do not think she has got any worse. I think, like he said, its going to hold it a bit, hold it a while... I would not say she was any better no... certainly over the last few months, while she has been on them, she has not deteriorated to my mind as quickly as she did before'** (MC carer).

A few carers reported treatment had helped to stabilise the increasingly erratic behaviour exhibited by patients in the moderate stages of the disease.

Carers of patients with milder levels of impairment noted improvements to memory recall, and to the patients' general attitude. All carers stated that patients Mini Mental State Examination (MMSE) scores had stabilised or improved. In one MMS participant, an overall improvement of six points was seen: **'When we started with this, they gave him a test out of thirty... the first test he did he was 23 out of 30. The second test was 27, then it went up to 29 which they were thrilled with'** (MMS carer). Several carers thought the drug had lifted apparent depression / disinterest in the patient:

> **'My husband had stopped being interested in the garden for a start, the garden got on top of him and he lost all interest in it...well in this past twelve month his interest has picked up, he has redone the garden he has restyled the back rockery and he has started on the front rockery... periodically, flowers and that, he would forget to put the bulbs in and what-have-you, well now he remembers'** (MMS carer).

Patients described how they felt medication had improved memory, general ability to cope with disease-related changes and well-being:

> **'In some respects my memory, it has improved...if I talk I can confuse myself a little bit, but when I am out... with all my friends, on a walk, we have a chat and I can remember more now...I mean I would like to store a little bit more but I mean...I am accepting it yes, It has not been, how can I put it, as devastating as I thought it would be because these drugs are helping me'** (MMS patient).

Assessment and diagnosis

Most participants accepted that memory tests and other measures were needed to help diagnosis and assess progress. However, two MC carers raised issues about how they were separated from patients whilst assessments were performed. They assumed that this

was to enable staff to measure memory without carer assistance but were concerned about the patients' possible distress as a result of this separation.

Amongst MC participants, the use of memory tests and other rating instruments were understood to be part of a formal and hierarchical system, based around the requirements of the service to provide a rapid service to many patients. They thought the main role of nursing staff was to administer memory tests. Patients and carers felt that clinic appointments were solely based upon testing, diagnosis and treatment. Patients saw the MMSE as a formal test that they were required to pass. Several participants noted that they had asked memory clinic staff whether they had "passed" the test: '**I do not know if I was that good at it. I asked them if I passed…She did not actually say…**' (MC carer). Carers were concerned about whether a patient might become distressed during the test as a result of answering incorrectly, or of being unable to give an answer.

One MC carer said that some rating instruments given to *carers* were hard to understand. This carer also challenged the numerical basis of many of the assessments, noting difficulties in comparing current answers with those given during previous assessments:

> '**It can be counterproductive because if you fill them in every three months you have forgotten the level you put last time so you are having a complete stab at it, you have forgotten. You have not got a baseline to work from. So your points can be all over the place. You know. Have things got worse; well what did I put last time. 1, 3, 4, 7, 12, whatever. Well I have put six, and last time I put 7, because you have not got a baseline to work from'** (MC carer).

Personal qualities of staff
The relationship between patients, caregivers and memory service personnel influenced the degree to which participants valued the service they received. All MMS participants were highly satisfied with the MMS nurses, highlighting their friendliness and informality. The same nurse routinely visited each patient and carer. Participants valued this continuity, especially in the earlier stages of the process.   They felt more able to 'get to know' the nurse visiting them, and more able to build trusting relationships with them.

The relationships developed between MMS carers and nurses enabled carers to feel more confident in discussing difficult and sensitive issues. Participants felt that visits by the MMS nurses were informal, relaxed affairs in which patients and their carers were able to feel comfortable: '**There is no officialdom or anything about them, they come in, they will sit and they will have a coffee and they will chat you know. Which is what we like.   And they make you feel comfortable'** (MMS Carer). Several participants highlighted that the nurses offered them support as if they were friends, rather than medical professionals. Some carers described the nurses as like family members: **'The nurses that come, they are wonderful… they come in and they are more or less one of the family'.** (MMS, carer). Carers did not identify any specific methods that the nurses used to monitor their physical and mental health but all felt that the nurses showed concern for their needs, and either provided or directed carers to sources of support and

assistance. MC participants developed less formal relations with the nurses and more formal relations with the doctors at the clinic. They felt more at ease with the nurses.

Individualised service
MMS carers felt that the service was individualised to meet the needs of patients and carers. Carers reported different levels of support and information provision, but overall more MMS than MC participants thought the service they used gave sufficient support.

Participants stressed the ease of use of the MMS. They suffered little or no inconvenience from the nurse's visits: **'Everything that has had to be done has been done. I cannot criticise them and with regard to the manner in which I have been treated I could not ask for better. No I could not really'** (MMS patient). Participants did not think that the friendly approach had resulted in any loss of medical rigour. This approach to service delivery was contrasted with participants' previous experiences of other NHS services.

3.6 Information provision

Most interviews included discussions about information. Participants expressed a desire for more knowledge regarding the condition and help that might be available. We identified four main themes; *range of information provided, satisfaction with information provided, communication style* and *satisfaction with external information sources.*

Range of information provided
Several interesting contrasts were apparent. Most participants said that the MMS nurses gave little general information to participants. Most information from the service appeared to be given verbally during appointments, with a paucity of written information. Several participants valued information given by consultants at diagnosis but some acknowledged that the stresses experienced at diagnosis meant much of this information was not fully understood or was forgotten. Written information provided seemed to be little more than contact telephone numbers for use in the case of an emergency.

MC participants stated that information was provided on their diagnosis, and the range of drug treatments that were available to them within the clinic. In all cases, information regarding the possible side effects of anti-dementia treatments was also provided, combined with methods of coping with these side effects, and contact details should side effects become too serious for the patient or carer to cope with. MC participants felt well-informed regarding side effects, and knew what to expect about the likelihood and severity of any problems. MC participants were predominantly satisfied with the information they had been provided, although some participants thought that more written information should be provided at diagnosis, which could be referred to later.

However, most participants (irrespective of service) identified other information needs. Carers needed information on how to cope with emotional and behavioural changes in patients. Participants highlighted a lack of information on the range of financial support available to them. They felt that gaining access to financial assistance from social

services and local authorities was a long, complex and difficult process, which might often result in more isolated elderly patients or carers not making a claim:

> **'I am fairly mobile and vocal when it comes to things like that. But the little old lady on the top floor of a tower block of flats without a phone may be struggling… It can sort of be a lonely situation to be in, and you start thrashing about for information on how to deal with problems or where to get help. Or Benefits, I mean that is a minefield'** (MC carer).

MC participants felt they received little or no assistance in access to these services. Further gaps in information included other support services available such as day and respite care.

Satisfaction with information provided

While relatively little information was provided by the MMS, what information was provided was useful and relevant. High levels of satisfaction were also expressed with the information given to them through the informal referral process existing between the MMS and the Huddersfield branch of the Alzheimer's Society. Several participants had received assistance from the MMS nurses in completing assessment forms for the range of financial and other benefits available. This was particularly valued by participants because of the complexities involved in the process of submitting claims for benefits. One carer, *satisfied with the treatment and verbal support gained from the MMS*, was dissatisfied with information available on treatments for Alzheimer's disease *prior to referral* to the MMS. She only became aware of treatment for Alzheimer's, from a TV programme, after her husband had suffered from the disease for four years:

> **'I see the GP quite regularly and he had not told me anything about tablets, Aricept or any tablet, any medication at all for Alzheimer's disease. I did not know there was such a thing, until I saw it on the television. Seems a bit hard, to find out through the telly but… it seemed so wrong to me that there could be help there and we had not the knowledge to get it'** (MMS carer).

Satisfaction with the type of information provided by the memory clinic was generally low, with participants unhappy with the lack of information on the availability of external support and services. Participants were satisfied with information on diagnosis and treatment options, although in one case criticisms were made regarding the way in which the diagnosis was communicated and the overwhelming amount of information given.

Several carers noted a lack of information on how to adapt to changes in the behaviour of their partners, particularly how to cope with challenging behaviour. Carers who complained about this said the knowledge they had gained was a result of trial and error:

> **'I have learnt the hard way… If you deal with something incorrectly, it can have a detrimental effect to her. It has a tremendous knock on effect to her. And nobody explained this to me at the outset. So you go through tremendous ups and downs, you know where you get things wrong, and it affects the patient tremendously, more than it would in normal times'** (MC carer).

Several participants thought that the memory clinic would provide a perfect opportunity for information on this area to be shared.

While many MC carers stated that the clinic should provide some support for carers, a small minority of carers were less certain as to whether this provision fell under the remit of the clinic, given its primary function in providing diagnosis and treatment for the patient. When questioned on this issue, several MC carers initially were unsure as to whether the clinic should provide clinical or information based assistance to carers:

> **'I do not think anybody has actually said 'how are you coping?' They have just been interested in how (wife) is and is she better or worse… I am not sure whether I would expect them to ask me that… should the clinic care whether the carer is coping? I do not know whether they should really… they certainly have not taken an interest in me, and until you have just mentioned it I had not thought it was odd'** (MC Carer).

While carers acknowledged their own health problems, and in several cases attributed them to the burden of caring, few felt that the memory clinic should be involved in them. Carers were more likely to contact their own health practitioners, rather than approach clinic staff. This may result in an increased burden upon carers and other health practitioners who do not possess specialist knowledge in the area of dementia care.

The lack of information provided by both services placed the onus in gaining access to information upon the carer. Younger carers felt that many their elderly counterparts might lack the knowledge and drive to access relevant information sources:

> **'I am young, I have got a car, I can afford petrol to get somewhere, but some little old lady… is going to struggle with this system. It must be a hell of a struggle for them, even finding out how to get benefits and who to ask to fill the form in'** (MC carer).

Generally, younger carers of patients with early onset dementia were more critical of the information provided. Older carers were more accepting of the limited information given. This was attributed to a variety of factors including the lack of knowledge about particular information sources, a lack of skills needed to access the Internet, and a deferential wish not to inconvenience staff. In this respect, the memory clinic was seen to be an important regular contact point for participants, where there was potential for other needs to be more rigorously assessed, and assistance offered where necessary.

Communication style

Most participants were satisfied with communication with clinical staff and valued the empathy they experienced. When probed, some participants preferred the informal and individualised approaches that nurses adopted. All emphasised the friendliness of the MMS nurses. One carer emphasised the humorous banter that occurred between her husband and the MMS nurse. According to this carer, this showed not only her husband's improved cognition, but also his feelings of ease and comfort with the nurse:

> **'The nurse is excellent and she could not be better at the job because she is casual, she is not formal, she is completely informal, and she has a good laugh with you, and makes a joke of it as much as (husband) does. You could not ask for anything better than that in my opinion'** (MMS carer).

Many felt that the nurses valued and treated them as individuals, rather than simply as patients. Several MMS carers expressed that nurse visits were events to look forward to, much in the same way that carers would express anticipating a visit from social contacts:

> **'In fact I look forward to it, and I try to make the best of my appearance, because she is always so attractively dressed and she makes the best of herself, as we all should. And I was sorry, I felt I have lost another friend, and that is how I feel about losing (MMS nurse) and that is how I feel, both in her work, and as a person, I feel I have lost a friend'** (MMS carer).

This carer was apprehensive regarding the reduction in frequency of visits by the MMS nurse due to the success of treatment. Many patients and carers felt socially isolated. Within this context of social isolation, visits from the MMS nurses provided patients and particularly their carers with an important opportunity for social contact.

Most MC participants were satisfied with the level and range of communication with staff within the clinic. Clinic staff were viewed as friendly and helpful. Patients highlighted this when discussing the nurses: '**They were very good; we were there about two hours. But they were very good with the interview and everything'.** (MC patient). Although each nurse was complimented, some carers felt unable to build a relationship with staff, owing to the distribution of patients to different nurses. This was particularly important at the earlier stages, where patients and their carers might be making frequent visits to the memory clinic for assessment and monitoring of side effects. This contrasted with patients and carers who visited the single nurse consultant and usually highlighted his friendliness and the continuity of care. This opinion may have been strengthened by the fact that carers had more contact with the nurse consultant than with other nurses or doctors. Many MC carers had a hierarchical understanding of the clinic, its operations and the positions of staff working within the clinic. This shaped how they viewed the roles of different professional staff, and how they communicated with professionals within the clinic. Many MC carers felt that they had little formal communication with nursing staff, as nurses usually tested patients in the absence of

carers. Several carers felt that psychiatrists were too important to 'waste their time' providing information to patients and carers. Instead, it was thought that a nurse or someone could provide this information. Clearly, this unwillingness to approach senior staff, combined with small amounts of contact with nurses might have influenced the opportunity that carers had to communicate all their concerns to staff.

One MC carer was strongly dissatisfied with how the diagnosis of dementia was communicated to the patient. The diagnosis was given to the patient without the carer. The carer said this caused emotional distress for the patient and felt this method of communicating the diagnosis was cruel to the patient. He felt that he should have been present while the diagnosis was discussed to provide emotional assistance and support.

Satisfaction with external information sources
Of the ten patient and carer pairs seen, eight were in regular contact with Alzheimer's Society. Once the Society had been contacted, it became the main source of support and information about the disease. Participants enthusiastically expressed their satisfaction with the information provided. There appeared to be good integration between the MMS and the Society, where the MMS provided diagnostic information, then put participants in touch with Alzheimer's Society:

> **'The nurse does not give me any written information… I get all my information through the Alzheimer's society. I get the national newsletter, which comes out about every three months and when my husband was first diagnosed, the Alzheimer's society gave me a booklet with everything in it so I am kept up to date with what is going on by the Alzheimer's society rather than the memory service' (**MMS carer).

While most carers were in contact with the Society, 'referral pathways' into the Society from the MC were erratic. Participants had made contact independently of the memory clinic and other health services, discovering the society through friends or family, or through their own research. Within the MC, some staff appeared to inform all patients about the Society while others did not. Some staff appeared to be mistaken regarding who could be referred to the Society. Some participants claimed that they had been told that only patients with *Alzheimer's* disease could be referred. Only one carer had been encouraged to make contact with the Alzheimer's Society by MC staff.

Several patients attended an early stage support group organised within the local branch of the Society. They had increased contact with MMS nurses through their presence at support groups and other meetings the Society held. This provided a further important opportunity for carers and patients to build less formal relationships with the nurses. Little direct integration appeared to exist between the MC and the Alzheimer's Society.

3.7 Summary

Patients and carers understood dementia to be a consequence of old age possibly augmented by the stress of life events. They coped with behavioural changes prior to diagnosis by trying to "normalize" them and deny difficulties. Often some crisis caused the carer to approach the GP leading to referral to the memory services.

Community contact was valued. In the service designs studied, the community service (MMS) also tended to provide more continuity of care. When this continuity was provided in the clinic setting (MC) it was also appreciated. The community service minimised potential stressors associated with having to travel to a hospital setting, especially if the hospital had bad historical associations. At home, service users could be more relaxed and able to complete assessments and talk more freely about their day to day life experiences and any worries. Waiting times for access to the services were generally acceptable and compared favourably with other NHS services but excessive waiting within clinic caused frustration in both services, though it appeared to be more frequent in one pathway through the MC that involved separate appointments with doctor and nurse. Participants were generally well satisfied with the benefits of drug treatment and appreciated the need for formal assessments. They appreciated the personal qualities of staff and valued being seen by the same person repeatedly, especially in the early stages of engagement with the services. They enjoyed the individualized friendly service characteristic of the MMS and of the pathway through the MC where they saw the consultant nurse. They generally found it easier to relate to nurses than doctors. Neither service was particularly good on information provision. Overall, the MC appeared to provide more detailed medical information and, through links with Alzheimer's Society, the MMS dealt better with information on practical approaches to behaviour problems, benefits and other services.

These findings were tested in a larger sample through the questionnaire phase of the study.

4
Objective 1: Alzheimer's Society Representative Interview Findings

4.1 Introduction

We interviewed two representatives of the Alzheimer's society at their places of work (the Huddersfield branch and the Wakefield branch). Semi-structured interviews facilitated freedom of discussion. Interviews lasted from thirty to forty five minutes. We identified four main themes and a range of related themes (Table 4.1).

Table 4.1 Summarised Alzheimer's society representatives' coding template

FIRST LEVEL THEME	LOWER LEVEL THEMES
1. Perceived memory service staff views of the society	1.3 Lack of shared understanding of the populations served by the society and the aims of the service
	1.4 Integration issues
2. Treatment location	2.1 The community based model
	2.2 The hospital based model
3. Satisfaction with the service	3.1 Support
	3.2 Individualised service
4. Information provision	4.1 Range of information provided
	4.2 Satisfaction with information provided
	4.3 Communication style

4.2 Perceived memory service staff views of the society

The Alzheimer's Society representatives expressed their perceptions of how they thought the memory service staff viewed the work of the Society. We identified two main sub-themes; *a lack of shared understanding of the populations served by the society and the aims of the service* and *integration issues.*

Lack of shared understanding of the populations served by the society and its aims
Interviewees reported that many patients and carers using the Wakefield service had been ill advised as to who could access the Society. The Wakefield representative reported instances of people contacting the branch for advice about what other organisations they could access because their diagnosis of dementia was not Alzheimer's disease:

> **'On a number of occasions I have had people telling me that they did not think they could access our service because they do not have Alzheimer's disease. I think the problem is that many of the doctors these people are seeing also think that the Alzheimer's Society is just for people with Alzheimer's Disease'** (Wakefield representative).

Both thought that it was mainly doctors who promoted this misunderstanding. They suggested that the memory services and the Society could collaborate to increase awareness of the Society as a resource for all patients with dementia and their carers.

Integration issues

Both representatives discussed integration issues. The community model adopted by the Huddersfield service had maintained an efficient referral process. The MMS staff informed all their patients of the Alzheimer's Society. In many cases they made links with the society on behalf of patients and carers: **'The memory monitoring unit send us I think more or less everybody that goes through… they mostly get sent to us'** (Huddersfield representative). Many patients and carers were being reached by the Society via the MMS. Indeed, the Huddersfield representative was more concerned for individuals who had not accessed the MMS and how the Society was to reach them.

The Wakefield representative believed there could be better integration between the Wakefield branch and the memory clinic. She argued that if the memory clinic were a community service, the referral process to the Alzheimer's Society would be more efficient because the visiting nurse could introduce the society and provide contact details. The presence of a representative from the Alzheimer's Society within the memory clinic would be a costly but positive move for the Wakefield Memory Service:

> **'In an ideal world with lots of funding… if the clinic remained hospital based it would be ideal if we had a presence in clinic to follow patients and be there for their information and support needs at each stage… if it developed into a community service well then I think our referral system would work better, because if we were informed of everyone we could keep in contact'** (Wakefield representative).

4.3 Treatment location

We questioned representatives regarding the service operating within their area. They each had views about the appropriateness of each service model for patients and carers.

The community based model

Both representatives had a preference for a community based memory service model. They reported that many families had difficulties persuading the patient to attend clinic because the patient does not feel that there is anything wrong with them. Patients and their families were put at ease if a professional came out and saw them in their own homes: **'Families really struggle to get them to hospital… so being able to say that someone is coming out to you I think is a really good thing'** (Huddersfield

representative). Many patients and their carers felt isolated after a diagnosis and uncomfortable about entering a clinical situation. The burden of being diagnosed with a mental illness was lessened if both patient and carer were able to strike up a friendly relationship with a memory nurse: **'I think having the same psychiatric nurse coming regularly helps them… I feel really sorry for those who are not receiving the service'** (Huddersfield representative). Those individuals who were not involved with the MMS had more fears and worries when they accessed the Alzheimer's Society. Regular home attendance from a memory nurse gave individuals the support they needed to be able to adjust to a diagnosis of dementia and associated behavioural changes. It also helped meet their information requirements either directly or through referral to the Society.

The hospital-based model

Families were said to find it difficult to persuade patients that they needed to attend clinic. The age of the patient population and the local history surrounding the hospital site added to their anxiety: **'We have struggled to get through to some people, I mean one, they are not ready to admit that they need to go to a mental health hospital and there is nothing wrong with them…'** (Huddersfield representative). Historically, the mental health hospitals in the area were workhouses and mental asylums. Patients and carers found it difficult to come to terms with attending these stigmatised environments.

There were also reported complaints about delays occurring for patients and carers *within* the Wakefield clinic. The representative reported to have received numerous letters from people complaining about distress caused by having to wait in clinic for a number of hours: **'several carers have said that their partners have been distressed by the amount of time they have had to wait in clinic as well'** (Wakefield representative). Though delays are sometimes unavoidable, there was a fear that carers would begin to question the benefits of treatment in relation to the stress incurred in clinic attendance.

4.4 Satisfaction with the service

Both representatives expressed satisfaction and dissatisfaction with different aspects of the local services. We identified two main themes: *Support* and *individualised service.*

Support

The Wakefield representative thought that insufficient time was spent with patients and especially carers in clinic. Some complaints had been received by the Society about carers being separated from patients and feeling as if their experience was not valued:

> **'In general what carers feel is that they do not have the time to talk to anyone about what is happening at home. They would ideally like to talk to someone about the things that have been happening at home in the last month and how things have changed but they do not get the chance to do that'** (Wakefield representative).

Ideally, the representative argued, more time should be given to carers in consultations. However, she realised that time and financial constraints made this difficult to achieve:

'I think things are moving in the right directions, purely because the staff realise the gaps in their provision… they know they should be looking at the full picture but currently don't have the resources to do that… at present it does appear that they only have the time and resources to sort out the right drug treatment' (Wakefield representative).

The Huddersfield representative said that patients and carers appreciated the high level of support they received from the MMS. They saw the nurses as companions to whom they could voice their concerns. Both representatives reported that staff facilitated support groups at the Society branches.

Individualised service
The MMS seemed to offer a more individualised service. Frequent home contact by the same professional promoted trust and limited anxiety for both patients and carers:

'They remember their name, which is something a lot of carers cannot remember, the names of the psychiatric nurses. They probably see them infrequently. Whereas because they see more of them, you know they've got more contact they remember their names' (Huddersfield representative).

The clinic-based service had a more narrow medical focus with little time available to concentrate on the wider issues that might influence treatment adherence and care.

4.5 Information provision

Issues surrounding information frequently recurred over the duration of each interview. We identified two main themes: *Range of information provided* and *communication style.*

Range of information provided
The Society had a lot of information on dementia, ranging from physiological information to information about the social effects of dementia and help available:

'They get an information pack about local services… and they get a book as well… and then we have fact sheets about all aspects of elderly life, with Age Concern… and then we have all the Alzheimer's Society fact sheets… so we're a resource really, we've got a library, a video… so anything they want, from the simplest of information to the more in depth we have got' (Huddersfield representative).

If all patients and carers were referred to the Society, it could provide information for many of their needs. If specific information about drug treatments was needed the representatives would refer to the memory services. Although the Society held texts on drugs for dementia, representatives did not want to provide out of date information:

> **'The one thing we do not do is dabble in the drugs side of it… if there were any questions on drugs or problems with drugs I would turn to the memory monitoring unit for that… and I have never not been satisfied with what they have provided… and I have not heard of complaints'** (Huddersfield representative).

The representatives thought they were viewed by the memory services, at least by those who understood the purpose and aims of the Society, as an information resource for patients and carers. The representative in Wakefield feared that many people were not put in touch with the Society to receive the information they needed:

> **'I do not know if it is down to the time limitations within clinic or what but it is quite frustrating how many people have not received anything… we are well known to the staff but we have found that people get mixed messages'** (Wakefield representative).

The MC and the Society are developing a pack of information to distribute at clinic:

> **'Information is improving… when people are sent to us we pick out the information they need… because of this experience we are working with the clinic to put together an information pack that can be given out at clinic'** (Wakefield representative).

Communication style
Both representatives noted that patients came from a generation with unconditional respect for medical staff. Once referred to the Society, patients and carers would tend to use it as the first point of contact for any query, so as not to disturb the nurse or doctor:

> **'I think sometimes people might find it difficult picking up the phone and phoning such as the nurse, because she is a nurse, but I think that is the way of the world. We are probably seen as less intimidating. But the fact that the link is there we can ring for them… sometimes they think they are pestering, you know, they don't think they have the right… it's a generation that doesn't ask'** (Wakefield representative).

This was more often the scenario in Wakefield. Perhaps this reflected the more formal relationships there as opposed to the more informal relationships in the MMS.

4.6 Summary

In summary, a good relationship was reported between the MMS and the Huddersfield branch of the Alzheimer's Society. The Society appeared to possess the defined role of information provider and all patients and carers using the MMS were referred to the Society for this purpose. No complaints had been received by the Society with regard to the MMS service design. The informal nature of the service model strengthened the

success of the service and helped patients and carers to dissociate dementia from the historical stigma of the local mental hospitals and workhouse buildings.

The MC service design did not enable sufficient time to be spent on carer needs. Carers disliked being separated from patients within clinic and felt that their experience was not valued. Waiting times within clinic were also a problem for patients and carers. Referral to the society in Wakefield needed improving, in that not all MC staff referred to the society or understood its purpose. Due to the identified difficulties, however, work was in progress to develop an information pack with the Society to distribute at clinic.

5
Objective 1: Professional Focus Group Findings

5.1 Introduction

A total of 10 professionals participated in two focus groups conducted at their place of work. The length of the discussions ranged from forty to ninety minutes. Of the professionals interviewed, three were doctors, three were clerical staff and four were nurses.

Participants identified positive aspects of recent service developments as well as a range of problems and gaps associated with the current organisation and delivery of care, in line with the views of patients, carers and the Alzheimer's society representatives. Themes were identified as detailed in Table 5.1.

Table 5.1 Summarised professional focus groups' coding template

FIRST LEVEL THEME	LOWER LEVEL THEMES
1. Service focus	2.3 Drug treatment
	2.4 Future needs
2. Strengths	4.3 Service model
	4.4 Integration with other services to meet patient needs
3. Weaknesses	3.1 Awareness
	3.2 Information provision and meeting carer needs
	3.3 Waiting times and staffing

5.2 Service focus

Participants of both focus groups discussed the focus of their service. Two distinct themes pertained to this area of discussion: *Drug treatment* and *Future needs.*

Drug treatment
The MC was seen as, a service focused on dementia assessment and the provision of anti-dementia drugs and an integral part of wider older people's services. Similarly, the MMS primary focus was seen as the prescribing and monitoring of anti-dementia medication:

> **'Our main job is to assess the patient, provide the medication and monitor it… but that doesn't mean we ignore other things that may be affecting the patient or their carer, but yes our role is to provide and monitor the medication really'** (MMS participant).

However, it was realised that the patients and professionals from other services might think the service had a wider focus. Time and financial restrictions limited the degree of care that could be provided by each service. Despite frustrations, participants of both focus groups thought their services were operating well and adhering to the service plan.

Future needs

Despite the narrow focus of each service around drug treatment staff acknowledged that wider care issues were often addressed. Referrals to other services were important and attention was given to the coping and adjustment difficulties of both patient and carer:

> **'We do not have an awfully long time to spend with these patients and carers on things other than obtaining the information through conducting the different tests… but what I can say is that through talking through for example the MMSE with the patient and even just having a short discussion with the carer, we can pick up on other issues and, if we feel it necessary, we can then refer them on to other professionals or services… obviously we do not see the full picture as you would through a home visit'** (MC Participant).

Future service development should concentrate on a memory service providing a more complete package of care. Ideally, this would involve the provision of psychosocial interventions for patients and carers, the provision of more detailed information and other professionals feeding into the community service or having presence within the clinic to enable more detailed assessments and to provide a coherent multidisciplinary service.

5.3 Strengths

All participants were eager to emphasise the strengths of their services. We identified two main themes: *Service model* and *Integration with other services to meet patient needs.*

Service model

Staff within the MC had received a positive response from all stakeholders with regard to the structured diagnostic process and the community nursing aspect of the service:

> **'Through the development and continued success of the memory clinic we have had a lot of feedback from other clinicians and staff, the structured diagnosis process is viewed very positively and the more recently evolved community nursing element of our service has been welcomed'** (MC Participant).

Staff thought that the service was viewed as already 'comprehensive', friendly and accessible amongst fellow NHS personnel.

MMS staff were more focused upon the strengths of the service with regard to patient and carer needs. There was consensus that the service was succeeding because of its flexibility. The community focus meant that patients were seen in their own homes at times most suitable for them. A home based service provided staff with a more accurate clinical picture, as patient and carer could be seen in the context of their everyday lives:

> **'I think we benefit from the service being a community service as well as the patients and carers… we are flexible as to when we can visit, if patients want us to visit in the evening or even at weekends we do and they are happy with that… and I think because we do go out and we go out and see them in their own homes we can really make a more realistic assessment… for example we see how they are coping, how they are living, if they can make a cup of tea when they say they can you know'** (MMS Participant).

Integration with other services to meet patient needs
Both focus groups agreed that the level of integration they have with other services could be improved. Ideally, each service would be more holistic in focus, drawing on the expertise of varied professionals. The risk of loss of continuity of care was not emphasised. Participants of the MMS focus group claimed that they had forged good links with the local branch of the Alzheimer's Society. All participants agreed that they viewed the Society as a referral point for information. This could be a two way process in that the Society would also inform unknowledgeable individuals about the MMS:

> **'We have quite a good working relationship with the Alzheimer's Society… everyone we see we mention the support that they could get from them and either put them in contact with the society or with permission pass on the patient details ourselves to the society… and the process works both ways really… if they get enquiries about our service or they think someone may benefit from our service then they contact us'** (MMS Participant).

Participants of the MC focus group were aware of the work of the Alzheimer's Society and referred to support work staff members facilitated with the Society:

> **'We do run support groups at the Alzheimer's Society… it is something additional to our work here because we recognise the benefit these patients and carers can receive from participating in a support group… ideally we would have more time in clinic to provide psychosocial interventions'** (MC Participant).

They acknowledged that improved integration was needed. Current time, financial and space restrictions prevented the presence of an Alzheimer's representative in the clinic.

5.4 Weaknesses

Despite the strengths of each service being highlighted, all participants were aware of weaknesses in their service structure and delivery. Three themes were highlighted: *Awareness, information provision and meeting carer needs, waiting times and staffing.*

Awareness
Participants of the MMS focus group argued that despite many GPs in the area now being aware of the MMS they did not all understand that they could refer directly to the service: **'It is surprising that still not all GPs realise that they can refer directly to the service'** (MMS Participant). Staff recognized the need to promote direct referral but thought that higher staffing levels would be required to achieve this. Similarly, MC participants sometimes experienced misunderstandings regarding referrals. Despite efforts to promote the aims and purposes of the memory clinic and the general support amongst NHS staff for the service, inappropriate referrals were still received.

Information provision and meeting carer needs
Neither service provided any formal therapeutic input for carers. MMS participants argued that on an informal level they made sure that carers were coping with their situation and provided verbal information. They referred all patients and carers to the Alzheimer's society for further information and support. At the MC, carers were asked to fill in caregiver burden questionnaires but participants acknowledged that insufficient time was available to discuss lengthy carer issues. In defense of this situation, staff repeated that the main focus of the clinic was to provide drug treatment to the patient. The understanding was that other services were in place to attend to the wider needs of both patient and carer: **'We do pick up some of the other problems that the patient or carer may experience but really it is the remit of other agencies to identify and attend to these' (**MC Participant). Understanding the current situation however, participants suggested that the way forward would be to provide more integrated services.

Waiting times and staffing
Participants of the MC focus group discussed the difficulty of waiting times within clinic combined with the further difficulty of transport waiting times. There were also difficulties matching up nursing and medical appointments. Despite these weaknesses of the current MC design participants argued that the clinic basis of the service enabled them to achieve the balance between the needs of patients, carers, staff, health and safety and cost effectiveness:

> **'We do incur problems in relation to waiting times in clinic... if transport is delayed and our first patient is late well that can knock us out for the rest of the day... we also have two systems working, one whereby the patient will just see the nurse consultant and the other whereby they will see both a nurse and psychiatrist and so for these patients they may have a longer wait because they have two appointments... I can imagine in comparison a community service would avoid such but it maybe would not be as cost effective, as safe or practical in consideration of psychiatrist case loads and equipment costs and safety issues for example'** (MC Participant).

Indeed due to the success of the service and increase in patient numbers, efforts had been made to reduce waiting times by increasing staff numbers.

MMS participants were concerned about staffing. They argued that, despite the success of the MMS and the rapidly increasing number of patients within the service the staffing remained limited. If staff numbers were not significantly increased, waiting times that are currently acceptable would rapidly increase:

> **'So far the service has been very successful and our patient numbers are forever increasing, if we are not careful we risk our success by not being able to cope with the patient increase because the staff numbers are staying the same' (MMS Participant).**

Indeed, the main theme and concern that ran through the discussion of both focus groups was their future staffing capacity and ability to meet the future needs of patients, especially in view of the possible future licensing of drugs for advanced dementia.

5.5 Summary

Participants from both services argued that their main purpose was to provide and monitor anti-dementia drug treatments. They were not ignorant of the patient or carers wider needs. If needs were identified, they were not hesitant to refer to other services. However, participants from both services claimed that a more multi-disciplinary approach to memory care could only serve to improve and strengthen current service designs. Current strengths to each design were identified, including good diagnosis, assessment and patient monitoring processes, and in the case of the MMS their level of working integration with the Alzheimer's Society. Reported weaknesses pertained to insufficient time, space and funding. Ideally, there would be more time and funding for staff to promote the services, and professionals and interventions in place to improve information provision and support for both patients and carers. Furthermore, waiting times in clinic were a problem and staffing in both services an issue if patient numbers were to continue to increase.

6
Objective 1 : Questionnaire Findings

6.1 Introduction

This section provides a summary of the results of a statistical analysis of questionnaires distributed to patients, carers and GP's using the MC or the MMS. Questions were designed to address themes arising from a preliminary analysis of qualitative data collected during patient and carer interviews. Nominal and ordinal methods of ranking data were generally chosen to promote ease of understanding and response for patients and their carers, while also retaining a level of differentiation between responses (Diamantopoulos & Schlegelmilch 1997).

Sixteen questions were developed based upon the five main objectives of this stage of the study. Patients and their carers were also given the opportunity to express in writing any concerns relating to the service they received. We conducted a qualitative analysis of these comments. Statistical analysis was conducted on the raw data but, because of the different response rates, results in tables are given as percentages for easy comparison. Implications of differences in response rates are discussed fully within the discussion section of this report. Results were recorded and analysed using the Statistical Package for Social Sciences (SPSS) Version 11. Questionnaires were analysed by frequency count, the Chi Square statistic, and the Mann Whitney U test. Where appropriate degrees of freedom are also provided. Where differences in the number of degrees of freedom occur, this is a result of differences in either the number of responses available for an individual question, or because of no participants using either service entering a response for a particular variable. In some cases tables of results have been condensed for brevity. Full statistical results are available in the web version of this report.

6.2 Patients' and carers' questionnaires

Response rates

One hundred and twenty two responses were received from patients and carers, 30 (25%) from the MC and 92 (75%) from the MMS. Response rates were 30/190 (16%) for the MC and 92/225 (41%) for the MMS. Differences between response rates and the generally low overall response rate mean the results should be viewed with caution.

6.2.1 Satisfaction with the service

General Satisfaction with service

Participants using the two services were asked to give their general levels of satisfaction with the service they received. Answers are summarized in table 6.1

Table 6.1 Satisfaction with memory service. (n = 122)

	Memory Clinic (%)	MMS (%)
Very Happy	26.7	34.8
Happy	43.3	51.1
Neither happy nor unhappy	10.0	10.9
Unhappy	20.0	1.1
Very unhappy	0.0	2.2

High proportions of participants were either happy or very happy with the two services; with significantly fewer participants expressing unhappiness with the MMS Differences in determining levels of satisfaction amongst users of the two services did not reach statistical significance. (Mann Whitney U = 1121.5, p<0.094).

Satisfaction statements

Eight statements were used to evaluate the level of participant satisfaction with particular aspects of the service. A five point Likert scale was used; with responses ranging from strongly agree to strongly disagree. The results are shown in table 6.2:

Table 6.2 Percentage of participants agreeing/strongly agreeing with satisfaction statements.

Statement	Memory Clinic (%)	MMS (%)	P value
a. The patient gets a benefit from being seen by the service (n = 122)	73.3	80.4	0.411
b. The carer gets a benefit from being seen by the service (n = 120)	80.0	76.1	0.494
c. I am happy with the amount of time spent with us on appointments (n = 121)	73.4	83.7	0.714
d. I am satisfied that staff can help with the patients memory problems (n = 122)	63.3	76.0	0.203
e. The service asks about the health and wellbeing of the carer (n = 118)	46.7	57.7	0.145
f. I am happy with how we receive the drugs given to us by the service (n = 122)	76.7	91.3	0.01*
g. The length of time we had to wait before being seen by the service caused us problems (n = 122)	13.3	14.1	0.696
h. The purpose of the tests was explained to me. (n = 121)	76.6	81.5	0.374

* P value significant at 5% level or higher

Responses to these statements were generally positive, with most participants either agreeing or strongly agreeing with the above statements. Most participants using both

services either disagreed or strongly disagreed that waiting times were a problem. Statistically significant differences were found in only one case, with higher levels of satisfaction with the MMS service occurring in respect of processes for supplying medication (Mann Whitney U = 988.5 p <0.01).

6.2.2 Timeliness

Perceived length of waiting times

Table 6.3 Perceived waiting times prior to first appointment with memory services. (n = 115)

	Memory Clinic (%)	MMS (%)
Less than 1 month	10.0	16.3
1-2 months	36.7	44.6
2-3 months	16.7	22.8
Over 3 months	33.3	9.8
missing	3.3	6.5

The highest proportion of patients in both services reported waiting between one and two months. Waiting times appeared to be significantly higher amongst individuals using the memory clinic (Mann Whitney U = 933.5, p<0.05) While 33 % of Memory Clinic service participants stated that they had to wait over 3 months for treatment, only 10% of MMS participants reported waiting this long. Perceived waiting times were falling within both services, with recently referred patients more likely to have been seen quickly. Since this is not a systematic sample of patients not much significance can be attached to this finding but both services were making efforts to reduce waiting times prior to this study (Hassan 2002, SWYT 2002).

Frequency of check up appointments

Participants were asked how frequently they would like repeat assessments within each memory service (see table 6.4).

Table 6.4 Desired frequencies of repeat assessments. (n = 122)

	Memory Clinic (%)	MMS (%)
Every 1-2 months	26.7	4.3
Every 2-3 months	10.0	19.6
Every 3-4 months	23.3	21.7
Every 4-5 months	6.7	2.2
Every 5-6 months	20.0	40.2
Less than every 6 months	10.0	7.6

While differences were found between the two services, these did not reach statistical significance (Mann Whitney U = 993.5, p = 0.64). Little uniformity in the distribution of individual opinions regarding repeat assessments was found in those using both services. Within the MMS, 40% of participants appeared to be satisfied with the current six monthly post efficacy assessment appointments, compared to only 20% of MC

participants. In contrast, 26.7% of MC participants desired regular monthly checks, compared to just 4.3% of MMS participants.

Table 6.5 Percentage of participants agreeing/strongly agreeing with timeliness statements (n = 122)

Statement	Memory Clinic (%)	MMS (%)	P value
a. I am happy with the length of time we had to wait until out first appointment	66.7	71.7	0.389
b. I am happy with the length of time we had to wait between appointments.	53.3	70.6	0.006*
c. Appointments with staff take up too much of our time.	23.0	2.2	0.044*

* P value significant at 5% level or higher.

Participants in both services appeared to be satisfied with the length of time between repeat assessments. However, satisfaction with the period between repeat assessments was higher amongst MMS users and their carers, with 70.6% of MMS participants giving positive responses regarding the length of time between appointments, compared to 53.3% of MC participants. Differences were also found to be statistically significant (Mann Whitney U = 953.0, p<0.01).

Relating to length of appointments within each memory service, statistically significant differences were found in favour of participants using the MMS (Mann Whitney U = 1073.5, p<0.05). This may be partly due to traveling time, and waiting time as well as time spent face to face with staff.

6.2.3 Treatment Location

Satisfaction with location of treatment

Participants were asked a range of questions relating to their satisfaction with the location in which treatment was received, reflecting the differing clinic and community focus of the two services.

Table 6.6 Satisfaction with treatment location. (n = 122)

	Memory Clinic (%)	MMS (%)
Very happy	20.0	51.1
Happy	43.3	38.0
No opinion	20.0	5.4
Unhappy	16.7	3.3
Very unhappy	0.0	0.0

Participants were generally satisfied with the location used by their service. Higher levels of satisfaction were found amongst participants using the MMS. The proportion of MMS participants who were either happy or very happy with receiving treatment at home was

significantly higher than the proportion of participants expressing similar levels of satisfaction with the clinic (Mann Whitney U = 771.0, p<0.01).

Satisfaction with treatment location statements

Five Likert scale statements were designed to gain information on different aspects of satisfaction with treatment location. These are summarised in table 6.7.

Table 6.7 Percentage of participants' agreeing/strongly agreeing with treatment location statements.

Statement	Memory Clinic (%)	MMS (%)	P value
a. Traveling to clinic causes/would cause problems for us. (n = 121)	10.0	57.6	0.0001*
b. Seeing staff at home/in clinic makes the patient anxious. (n = 122)	30.0	3.3	0.006*
c. Staff spend enough time with us during appointments (n = 122)	80.0	82.6	0.983
d. I would prefer to be seen by staff at home. (n = 121)	40.0	80.5	0.0001*
e. I would prefer to be seen by staff in clinic (n = 121)	56.7	1.1	0.0001*

* P value significant at 5% level or higher

Differences in attitudes regarding traveling to clinic were found to exist within this sample. MMS participants commonly felt that difficulties in traveling to clinic would cause significant problems for them. However, MC participants who regularly attended clinic as part of their treatment did not commonly express this concern. These results were highly significant (Mann Whitney U = 689.5, p<0.01).

Statistically significant differences were detected relating to levels of anxiety felt by participants; with fewer MMS participants reported feeling anxious about appointments when compared to memory clinic users. (Mann Whitney U = 980.5 p<0.01).

Participants from both services were generally happy with the amount of contact they had with staff. Few expressed any dissatisfaction with the length of appointments, or the level of contact with staff. No statistically significant differences were found to exist between participants using the two services.

Statistically significant differences were detected relating to preferences for treatment location amongst participants using the two memory services (d; Mann Whitney U = 659.0, p<0.01. e; Mann Whitney U = 607.0, p<0.01). Generally participants appeared to specify a preference for the service they currently received, with 80.5% of MMS participants preferred to be seen at home, compared to 40% of memory clinic participants. In contrast, 56.7% of MC participants preferred the clinic-based service they currently receive, compared to just 1.1% of MMS participants. While participants generally appeared to state a preference for the familiar, differences in levels of preference can be seen. Nearly all MMS participants preferred a community-based service, whilst opinions of MC users were more varied.

6.2.4 Information Provision

Information provided by the service

Participants were invited to complete six questions about the range and amount of information provided by the memory service they used and by other services. These questions also covered their satisfaction with information received and satisfaction with the methods by which information was communicated. Questions about information were a major part of the questionnaire, with 6/15 questions relating to this issue.

Information sources for service users

Six sources of information were identified from interviews. Participants were asked to indicate whether they had received any information or support from each of the sources.

Table 6.8 Information sources used by participants.

Sources	Memory Clinic (%)		MMS (%)		
	Yes	No	Yes	No	P value
a. Memory Clinic/Service (n = 121)	50.0	50.0	88.0	10.9	0.001*
b. CPN's/CMHT's (n = 121)	36.7	63.3	46.7	52.2	0.312
c. G.P.s (n = 120)	23.3	76.7	50.0	47.8	0.008*
d. Alzheimer's Society (n = 120)	46.7	53.3	50.0	47.8	0.673
e. Other charities for older people (n = 120)	3.3	96.7	10.9	87.0	0.201
f. Other (n = 119)	13.3	86.7	9.8	87.0	0.625

* P value significant at 5% level or higher

MMS participants appeared to be more commonly in receipt of information from health services and other organizations. Differences were statistically significant in favour of the MMS in respect of two sources; the memory service (Mann Whitney U = 832.5, p<0.01), and GP's (Mann Whitney U = 975.0, p<0.01). Amongst participants using both services, approximately half were in contact with the local Alzheimer's society.

Information provided by memory services

These issues were developed into nine statements, divided into two distinct groupings:

Group 1: Diagnostic and treatment information needs.   *Statements 12a-d*
Group 2. Support & Psychosocial information needs.   *Statements 12e-i*

Group 1 statements related to information about how the service operated, the diagnosis given, and the range and effects of drug treatments available. Group 2 statements related to formal and informal support that might be required by patients or carers, information regarding financial benefits, and information on how to cope with changes that the onset of dementia brings. Participants were asked to identify whether they had been provided with any information in each of these areas by the memory service they used.

Table 6.9 Range of information received from memory services. (n = 120)

Statement	Memory Clinic		MMS		P Value
	Yes (%)	No (%)	Yes (%)	No (%)	
a. How the memory clinic/service operates	53.3	43.3	71.7	20.7	0.02*
b. Diagnosis of memory problems given to the patient	40.0	46.7	57.6	30.4	0.08*
c. Treatments available	60.0	36.7	70.7	16.3	0.038*
d. Possible side effects of treatment	53.3	43.3	75.0	15.2	0.002*
e. Financial help available to patient/carer	16.7	73.3	42.4	41.3	0.004*
f. Help with care available to patient	10.0	80.0	33.7	53.3	0.008*
g. Help with care available to carer	10.0	83.3	33.7	50.0	0.004*
h. How to cope with changes in life due to memory problems	3.3	93.3	26.1	57.6	0.003*
i. Changes to expect in future	20.0	66.7	21.7	50.0	0.488

* P value significant at 5% level or higher

Group 1 Needs: statements a-d. Differences in favour of the MMS were statistically significant in all four areas: information on how the service operated (chi square =5.409, d.f. = 1, p<0.05), Diagnosis of memory problems provided to the patient (chi square = 4.311, d.f. = 1 p<0.05) treatment options (chi square = 6.780, d.f. = 1, p<0.05), side effects of treatment (chi square =9.183, d.f. = 1, p<0.05)

Group 2 Needs: statements e-i. Information provided about practical and psychosocial support was relatively low in both services but statistically significant differences were found in favour of the MMS in four out of five statements; information on financial benefits (chi square = 8.455, d.f. = 1, p<0.05); help with care available to patients, (chi square 7.113, d.f. = 1, p<0.01); help with care available to carers (chi square =8.186 d.f. = 1, p<0.01) and information on how to cope with changes in behaviour found in patients (chi square =8.982, d.f. = 1, p<0.05).

A question was also included regarding how easy information provided by the memory service was to understand. We included an option to select 'no information received'.

Table 6.10 Was information provided by memory services easy to understand? (n = 85)

	Yes (%)	No (%)
Memory Clinic	36.7	16.7
MMS	72.8	2.2

Where participants received information, significant differences were recorded regarding ease of understanding of this information. (chi square = 13.815, d.f. = 1, p≤0.01).

Respondents were questioned regarding whether the services provided written contact details should carers need to contact staff in an emergency.

Table 6.11 Percentage given any written contact details for the memory service? (n = 112)

	Yes	No
Memory Clinic	46.7	33.3
MMS	83.7	12.0

Written contact details were more regularly provided to patients and their carers by the MMS. This difference was statistically significant (chi square = 10.530, d.f. = 1, p≤0.01).

Satisfaction with information provided by the memory service

Respondents were asked to answer six Likert scale statements relating to their satisfaction with the range and level of information provided by the two memory services, and with the nature of communication they had with the service.

Table 6.12 Percentage of participants agreeing/strongly agreeing with information/communication statements. (n = 122)

Statement	Memory Clinic (%)	MMS (%)	P
a. Memory clinic/service provides information on the patient's memory problems	63.3	51.0	0.118
b. Staff are friendly and informal when talking to me.	100.0	88.0	0.685
c. I feel comfortable talking to the staff I see	96.6	90.2	0.412
d. Staff show concern for the health and wellbeing of the carer.	66.7	55.4	0.245
e. Staff listen to and answer my questions	93.4	73.9	0.152
h. Staff tell me about other places and groups where I can get help.	10.0	29.4	0.091

As shown in table 16, participants were generally satisfied with both the information they were provided with by the two memory services, and with the range and type of communication they had with memory service staff. In particular the communicative abilities of memory service staff were highlighted. In most cases higher levels of satisfaction were recorded amongst participants in contact with the memory clinic. However these were not statistically significant. Both services appeared to perform poorly in respect of providing information on other services, with only 10% of MC participants and 29.4% of MMS participants either agreeing or strongly agreeing that the services provided information on other services.

6.2.5 Participants' comments

At the end of the questionnaire participants were given the opportunity to make comments. Comments were received from 25 participants, predominantly from carers. 18 commenting on the MMS, 7 on the MC. Comments varied from single sentences to short letters. Comments also varied in content, but were generally congruent with findings from the qualitative survey and questionnaire. In some cases comments appeared to be unrelated to the services, but served to illustrate general concerns amongst people with dementia and carers about health and social assistance.

MC comments

Comments on the MC were mainly negative. Several carers noted that they received little support from the service. Two comments compared unfavourably the support provided to people with dementia and carers to support provided for cancer sufferers.

> **'People I have spoken to feel very much on their own. Compared with say the support that cancer sufferers and carers receive'.** (Carer, MC).

> **'When you compare the service provided with say the service provided to someone who has cancer (terminal or not) it is not very good. There is no overall plan and it is not patient orientated'.** (Carer, MC).

Two individuals noted the performance of professional staff within the clinic. Both praised members of the nursing staff for the assistance they provided. However one was highly critical of some of the doctors previously active within the memory clinic. This carer's experience of some staff within the clinic resulted in a dislike of attending:

> **Some of the large number of doctors have been very good, many have been appalling … Nursing staff at the clinic were brilliant. I almost made an official complaint about one of the doctors as his attitude and behaviour was so dismissive of (patient). To be fair one or two of the doctors were good but you know you would not see them again and I used to get so worked up and full of dread going wondering what to anticipate that the really bad ones just dominated.** (Carer, MC).

In this case the largely negative experience of the clinic was also expressed as part of a more general negative experience of overall care and assistance provided to people with dementia and their carers. While individuals and organisations such as the Alzheimer's society were highlighted for praise, institutional systems of support were heavily criticised as being bureaucratic and insensitive to the needs of patients:

> **'With the worst there has been no sensitivity to (patient) at all. Nursing staff have been superb. After the distress some put her through I would have chosen not to go to the clinic but it is a necessary hoop to jump through, to access the support. The Alzheimer's Society have provided more support, helpful intervention, insight and decent common sense than anyone…we have managed to get round the many blocks put in our way by a system apparently designed to confuse, depress and destroy.** (Carer, MC).

MMS comments

In the case of the MMS, comments made by participants were generally positive. Most participants who made comments were complementary about the staff visiting them as part of the service they received.

> **'I very much appreciate the care and concern shown by members of the memory monitoring service who have visited me'.** (Patient, MMS).

One carer highlighted that the home visits enabled him to carry on working, as absences for clinic appointments were not required:

> **'As things are my wife can care for herself to some degree. She can see the MMS nurse on her own whilst I am at work. If we had to go to a clinic I would have to take time off work to go with my wife and this would cause difficulties for me at work'.** (Carer, MMS).

However several comments were either critical of the service or questioned the effectiveness of the treatment they received. Where participants were critical of the service, this was often as a result of a paucity of information provided:

> **'I was pleased to have a diagnosis and an opportunity for my mother to be prescribed medication but the six monthly monitoring appointments with the nurse have been of no real benefit to me or my mother apart from allowing the service to determine the suitability of continuing the medication'.** (Carer, MMS)

> **'A little more information needed on progress'.** (Carer, MMS).

> **'I do not think I have enough information from the service though their visits are appreciated and the staff very friendly'.** (Carer, MMS).

One participant criticised the service about a lack of communication and reported that they were not informed regarding visits by staff, treatments given and other issues.

> **'My mother was simply put onto Aricept by the MMS after the GP suggested she might be suitable. The MMS just visit her at intervals at home. Neither me nor my sister are advised of when they are going (sometimes this includes Sundays!!), nor are we advised of the results. (…) I consider the lack of communication from the MMS to be very bad and it seriously concerns me.** (Carer, MMS).

This comment was against the general trend of comments and while it cannot be discounted, may represent an idiosyncratic experience.

6.2.6 Summary

The questionnaire results identify a number of interesting issues.

Responses rates were higher amongst MMS participants, with a response ratio of approximately 3:1 compared to the MC. This may have reflected more accurate recent contact lists provided by the MMS or a generally greater degree of engagement with the MMS. It means that results have to be interpreted with caution.

Patients and carers participating in this questionnaire were generally satisfied with both services. While general trends showed higher levels of satisfaction amongst individuals using the MMS, these did not reach statistical significance.

Perceived waiting times for both services were approximately 1-2 months, with longer waiting times reported by MC participants. Fewer MMS participants reported waiting times of 3 months or more. Waiting times appeared to be falling within both services. Participants appeared to be satisfied with the length of time they had to wait prior to contact with the service, with no significant differences between services. Patients and carers were satisfied with the length of appointments, with higher rates of satisfaction occurring amongst participants using the MMS.

Participants were generally satisfied with the location in which they received treatment. Higher levels of satisfaction were recorded amongst individuals using the MMS. Patients and carers commonly preferred the type of service they received, and disliked possible alternatives. This finding was stronger amongst MMS participants who gave higher levels of satisfaction with aspects of the MMS service when compared to participants using the MC.

The memory services were the most common source of information for participants. More information appeared to be provided by MMS staff. Where information was provided by the services, this was focused on the design and operation of the service, diagnosis of dementia and treatment options available. Fewer participants reported that information relating to their everyday practical and psychosocial needs was provided. When provided by services, the MMS appeared to provide significantly more information in these areas.

Written comments showed that participants were often positive regarding the care they receive from health care professionals, especially nurses. In both the MC and the MMS this was seen as a positive aspect of the service. However within the MC and to a lesser extent within the MMS, concerns were raised regarding the amount of information provided. Criticisms were also made regarding general care services provided for people with dementia, which were seen by some individuals as more of a hindrance than a help.

6.3 General practitioner questionnaire findings

6.3.1 Introduction

This section provides a summary of the results from the questionnaire distributed to general practitioners who referred patients to the memory services involved in this study.

Issues of interest were identified using the same methods used for patient and carer questionnaires. Questionnaires were developed using qualitative analysis of interviews conducted with patients, carers and staff, and as a result of a preliminary analysis of questionnaires to patients and carers. Piloting took place prior to the distribution of the questionnaire. Initially, in order to recruit referring GPs, carers completing the patient/carer questionnaire were asked to provide details of their referring GP and/or consultant. Because of problems with differences in sample sizes for the two services, alternative sampling methods were used. In the case of the MMS, a list of referring GPs was provided by nursing staff within the service. This resulted in a total sample of 82 referring GPs within the MMS catchment area. Of these 82 GPs, 17 responded, giving a response rate of 20.7%. In the case of the GPs referring to the memory clinic, questionnaires were sent to the practice managers of surgeries within the MC catchment area. A total of 140 questionnaires were sent to these practices. Of these GPs, 25 responded, giving a response rate of 17.9%. Of these responses, 4 stated that they had not referred any patients to the MC, and thus were removed from the analysis. Problems arising from these sampling methods will be further considered in the discussion chapter.

A total of six questions related to the five main objectives of the study. Each used a five point Likert scale, with responses ranging from very satisfied to very dissatisfied. Written comments were invited at the end of the questionnaire.

Results were analysed as for the patient and carer sample by comparing satisfaction scores, and through the use of Mann Whitney U test to test for and compare significant differences.

Satisfaction with the memory service

Participants were asked to rate satisfaction with the overall quality of the service.

Table 6.13 GP satisfaction with memory services. (n = 37)

	Memory Clinic (%)	MMS (%)
Very satisfied	9.5	11.8
Satisfied	71.4	76.5
Neither Satisfied or dissatisfied	14.3	11.8
Dissatisfied	0.0	0.0
Very Dissatisfied	4.8	0.0

Satisfaction was high for both services with no statistically significant differences. (Mann Whitney U 162.5 p = 0.543)

Satisfaction with waiting periods for the two services

Participants were asked to give a level of satisfaction with the waiting period between referral and first appointment for the service they used.

Table 6.14 GP satisfaction with waiting times. (n = 36)

	Memory Clinic (%)	MMS (%)
Very satisfied	0.0	0.0
Satisfied	19.0	47.1
Neither Satisfied or dissatisfied	47.6	41.2
Dissatisfied	19.0	11.8
Very Dissatisfied	14.3	0.0

Many GPs were ambivalent about the waiting times for the services. Significant differences were detected in the spread of answers given by GP's, highlighting higher levels of satisfaction amongst GP's using the MMS (Mann Whitney U = 100.0, p>0.05). Five GPs commented that waiting times were a problem in the MC:

> **'The wait between the first appointment and second appointment is too long, hence delaying the commencement of treatment'.** (GP, MC)
> **'Long Waiting List. Low use of Aricept'.** (GP, MC)
> **'Usual problem is how long patients have to wait both for initial assessments by the nurse and then the wait for the clinic appointments'.** (GP, MC)

Only one GP using the MMS commented that waiting times were a problem.

Satisfaction with treatment location

Participants were asked to give their level of satisfaction with the location of the service.

Table 6.15 GP satisfaction with treatment location (n = 38)

	Memory Clinic (%)	MMS (%)
Very satisfied	9.5	11.8
Satisfied	57.1	76.5
Neither Satisfied or dissatisfied	23.8	11.8
Dissatisfied	9.5	0.0
Very Dissatisfied	0.0	0.0

Levels of satisfaction were high. There were no statistically significant differences (Mann Whitney U = 139.0, p = 0.168). Only one GP commented on service location, acknowledging that patients might face difficulties in getting to the clinic:

> **'Can be difficult to get the elderly to the clinic particularly early morning in Wakefield but do get assessed at home as well'.** (GP, MC).

Satisfaction with information provided to patients and carers

GPs were asked to give their levels of satisfaction with the amount of information that the service provided to patients and their carers.

Table 6.16 GP satisfaction with information provided to patients (n = 37)

	Memory Clinic (%)	MMS (%)
Very satisfied	17.6	14.3
Satisfied	64.7	47.6
Neither Satisfied or dissatisfied	17.6	38.1
Dissatisfied	0.0	0.0
Very Dissatisfied	0.0	0.0

GPs were generally satisfied with the levels of information that both services provided to patients and their carers. Differences were not statistically significant (Mann Whitney U = 142.0, p = 0.338).

Satisfaction with information provided to GPs

GPs using the two services were asked seven Likert scale questions relating to the range and type of information they were given by staff in the two memory services. Generally little dissatisfaction was recorded amongst GPs using both services.

Table 6.17 Percentage of GP's satisfied/very satisfied with information provided by service. (n = 38)

Statement	Memory Clinic (%)	MMS (%)	P value
a. How the Memory Clinic/ Service operates	23.8	70.5	0.019*
b. Referral methods to the service	42.9	76.5	0.031*
c. Range of treatments available to patients with dementia	23.8	58.9	0.018*
d. Effectiveness of treatments available to patients with dementia	19.0	23.5	0064
e. Possible side effects of drugs given to the patient	19.0	35.3	0.084
f. Range of interventions available for caregivers of dementia patients	14.3	53.0	0.003*
g. Range of external support services available to patients and their carers.	9.6	64.7	0.004*

* P values significant at 5% level or higher

Significant differences regarding the level of information provided to GPs were found in favour of the MMS for five items: how the service operated (Mann Whitney U = 96.5, p<0.05), referral methods to the service (Mann Whitney U = 110.0 p<0.05), range of treatments available to people with dementia (Mann Whitney U = 100.5, p<0.05), range of interventions available for caregivers of dementia patients (Mann Whitney U = 83.5, p<0.01) and the range of external support services available to patients and their carers (Mann Whitney U = 85.5, p<0.01). In all cases statistically higher rates of satisfaction were found amongst GP's referring patients to the MMS.

When GPs commented about the level of information provided to them by the memory services several noted that communication with the MC could be improved.

> **'Not enough info on what is available'.** (GP, MC)
> **'Provides a very good service but communication between them and us could be improved'.** (GP, MC)

Similarly, three GPs felt uncertain about how the clinic operated the position and role of GPs with respect to the clinic, and the prescribing of medication by the memory clinic.

> **'Often uncertainty whether they will prescribe anti-dementia drugs as patients and carers come to us for them after memory clinic initiates'.** (GP, MC)
> **'Not quite sure about follow-up arrangements sometimes when patients are on medication'.** (GP, MC)
> **'I am unclear as to the range of options available'.** (GP, MC)

Satisfaction with shared care protocol arrangements

Finally, GPs were asked to give their levels of satisfaction with the arrangements for shared care between the memory services and primary care trusts.

Table 6.18 GP satisfaction with shared care protocol arrangements. (n = 38)

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	Memory Clinic (%)	MMS (%)
Very satisfied	0.0	11.8
Satisfied	38.1	47.1
Neither Satisfied or dissatisfied	47.6	29.4
Dissatisfied	9.5	5.9
Very Dissatisfied	4.8	5.9

Few GPs appeared to be dissatisfied with existing arrangements. Trends in favour of the MMS did not reach not statistical significance (Mann Whitney U = 136.5, p = 0.185)

6.3.2 Summary

GPs were generally satisfied with both services. While satisfaction was slightly higher with GPs using the memory monitoring service, this difference was not significant. GPs appeared to be neither satisfied nor dissatisfied with the length of waiting times found within both memory services. Higher levels of satisfaction with waiting times were recorded amongst GPs using the MMS, though these did not reach statistical significance. Several GPs expressed written concerns relating to the length of waiting times within the MC. GPs using each service were satisfied with the location in which the particular service they referred patients to was based. GPs were satisfied with the level of information that the memory services provided to patients and carers. With respect to information provided to GP's, significant differences were detected in favour of the MMS in two areas: information on how the service operated, and information provided to people with dementia and carers on the range of external support services and agencies.

7
Objective 3: The Clinical Audit

7.1 Introduction

The main objective of this section was to check compliance with NICE guidance with respect to assessment, inclusion criteria, monitoring, review and withdrawal of treatment. Routine clinical records in each service were examined against a schedule of NICE guidance.

Consent for permission to examine the medical records of service users was sought as part of the questionnaire distributed to patients and their carers. Records were selected according to the following inclusion criteria:

- Presence of probable dementia of Alzheimer's type
- Currently receiving anticholinesterase drug treatments.

Patients who had been removed from treatment, or who were presenting with vascular or other forms of dementia were excluded. Patients presenting with both dementia of Alzheimer's type and vascular dementia who were receiving treatment with anticholinesterase drugs were included.

Checklists identifying the criteria for diagnosis and the prescribing, monitoring and discontinuation of anticholinesterase drugs were developed from NICE guidance and used in anonymous audit of records from the two services. The case notes of consenting individuals were then examined according to these criteria. To increase numbers, data were combined with anonymous data from clinical audits using the same criteria in both services. Data were analysed using SPSS Version 11.

7.2 Audit Results

The records of 78 MMS patients and 67 MC patients were identified and audited. The mean age of patients using the Memory Clinic was 78.07 (range 60-92, sd 6.79), while the mean age of patients using the MMS was 79.13 (range 59-97, sd 8.68, NS).

All three anticholinesterase drugs currently licensed were available within both services.

Compliance with NICE guidance

The findings are given in table 7.1.

Table 7.1 Clinical audit of compliance of memory services with NICE guidance. (NICE 2001).

NICE Guidance Standards	Compliance with NICE Guidance							
	Yes (%)		No (%)		Don't Know (%)		N/A (%)	
	MMS	MC	MMS	MC	MMS	MC	MMS	MC
Diagnosis made in a specialist clinic	100	100	0	0	0	0	0	0
Standard baseline assessments before treatment	100	98.5	0	1.5	0	0	0	0
Assessment conducted in specialist clinic	100	100	0	0	0	0	0	0
Likelihood of compliance with treatment assessed	100	100	0	0	0	0	0	0
Presence of carer/careworker to ensure compliance guaranteed.	100	100	0	0	0	0	0	0
Treatment initiated by specialist	100	91.0	0	0	0	0	0	9.0
Carer opinions (CGI) included in consultant assessment	98.7	85.1	1.3	6.0	0	0	0	9.0
3-4 month efficacy assessment taken place	96.2	71.6	0	1.5	2.6	1.5	1.3	25.4
Repeat assessments conducted at 6 month intervals	96.2	71.6	0	1.5	2.6	1.5	1.3	25.4
*Prescribing passed over to shared care protocol	93.6	0	2.6	0	2.6	0	1.3	100

* Memory clinic retains control over prescribing drug treatments. Treatment not transferred under shared care protocol

7.3 NICE Guidance Criteria

Diagnosis of Alzheimer's disease made in a specialist clinic according to standard diagnostic criteria

Specialist assessment and diagnosis of Alzheimer's disease was made in all cases in both services. In the MC, the diagnosis and decision on suitability for treatment took place during baseline assessments. In the MMS, diagnosis and decision on suitability for treatment took place in a regular local outpatient's clinic external to the service.

All diagnoses were based on standard diagnostic criteria. As the two services used different detailed assessments, these were audited for compliance with local standards.

Assessment in a specialist clinic, including tests of cognitive, global and behavioural functioning and of activities of daily living

Compliance with guidance to determine cognitive, global and behavioural functioning was high, with assessments taking place in all cases for both services. While both services used assessments that complied with guidance, each used a different range of assessments. Both used a variant of the Mini Mental State Examination and a standard scale to measure activities of daily living. However the memory clinic used a greater range of cognitive and other measures during assessments.

Clinicians exercise judgement about the likelihood of compliance with treatment

During assessments the likelihood of compliance with treatment was assessed in all cases. Clinicians were shown to ascertain and assess the presence of a care-worker or informal carer able to ensure compliance with treatment in all recorded cases.

Only specialists should initiate treatment

A specialist initiated treatment in all cases. Observations from carers were considered in most baseline assessments; with 98.7% of MMS cases and 85.1% of MC cases showing evidence that carer opinion were included in assessments. Where carer opinions were not included, this was indicated as being due to the absence of a carer during assessments. Where carers were not present arrangements were noted in patient's records for carers to be consulted at a later date either by telephone or during further assessments.

2-4 month efficacy assessment conducted

An efficacy assessment at 2-4 months was conducted in 96.2% of cases within the MMS, and 71.6% of cases within the MC. Where efficacy assessments had not been conducted, this was usually because patients had only recently been placed upon treatment, and had not yet reached the first efficacy assessment. This accounted for 25.4% of audited cases within the memory clinic. Three measures were identified within NICE guidance to be used to ascertain efficacy at 2-4 months;
- improvement/stability in MMSE score, plus
- improvement in activities of daily living and/or
- observed improvement in abilities by carer.

Compliance was high within both services. No cases were recorded where patients who were non compliant with all three measures at the first efficacy assessment were continued on treatment.

Table 7.2 Compliance with 2-4 month efficacy assessment.

NICE Guidance Statements: 2-4 Month Efficacy Assessment	Compliance with NICE Guidance					
	Yes (%)		No (%)		Don't Know (%)	
	MMS	MC	MMS	MC	MMS	MC
MMSE Stabilised/Improved	94.8	88.0	2.6	10.0	2.6	2.0
Improvement in activities of daily living	67.5	70.0	28.6	20.0	3.9	10.0
Observed improvement in ability from carer	85.7	74.0	3.9	20.0	10.4	6.0

Different measures of activities of daily living were used by the two services so that despite similar percentages, results may not be directly comparable. Observed improvements by carers were recorded as taking place in 85.7% of cases within the MMS, compared to 74.0% of MC cases. Cases within the Memory Clinic where compliance was not achieved were from newer patients who had not yet reached the first efficacy assessment. These cases were recorded as N/A. This accounted for 25.4% of cases within the Memory Clinic. Results marked as N/A have been removed to reflect frequencies of audited cases reaching the first efficacy assessment.

Transfer of prescribing under shared care protocol

Prescribing was passed over to GPs under shared care protocol arrangements within the MMS in 93.6% of cases. As the MC retained control over the prescribing of anti dementia medication, no cases occurred where prescribing was transferred to GPs. Since the study Wakefield has adopted a shared care protocol based on that used in Huddersfield.

Repeat assessments at 6 month intervals with treatment only continued if MMSE >12

Compliance was high in both services with well over 90% MMS and about three quarters of MC patients having repeat assessments. Those not receiving repeat assessments in the MC were at an earlier stage of the process. Only 2% MC and 2.6% of MMS participants scored less than 12. Both service protocols allowed for patients with MMSE scores below 12 to be given treatment if a trial withdrawal caused deterioration. In these cases efficacy was assessed using an alternative measure.

7.4 Audit of services for compliance with local standards

Use of standard diagnostic criteria

Table 7.3 Use of standard diagnostic criteria.

	Compliance with Standards							
Local Standards	Yes (%)		No (%)		Don't Know (%)		N/A (%)	
	MMS	MC	MMS	MC	MMS	MC	MMS	MC
Standard baseline assessments before treatment	100	98.5	0	1.5	0	0	0	0
Psychiatric History	98.7	97.0	0	3.0	1.3	0	0	0
Physical examination	0 *	83.6	0	16.4	0	0	100	0
Height/Weight	0	4.5	0	95.5	0	0	100	0
Urinalysis	0	34.3	0	65.7	0	0	100	0
Blood tests	87.2	77.6	5.1	22.4	7.7	0	0	0
CT Scan	26.9	65.7	69.2	34.3	2.6	0	1.3	0
ECG	82.1	6.0	14.1	94.0	3.8	0	0	0
Nursing assessment	98.7	97.0	0	1.5	1.3	1.5	0	0
Carer opinions gained at baseline assessment	98.7	91.0	0	7.5	1.3	1.5	0	0

* Shared care protocol made this a GP responsibility

Both services used a range of standardised assessments in diagnosing patients. The MC performed a wider range of assessments, conducting physical examinations and urinalysis more commonly than the MMS. As part of the shared care protocol arranged between primary care and old age services within Huddersfield, physical examinations and other assessments were conducted by general practitioners prior to referral to the MMS. Psychiatric assessments, nursing assessments and consultation with carers during assessments occurred in most cases. All three assessments occurred in 98.7% of cases within the MMS. Psychiatric assessments and nursing assessments took place in 97% of cases within the MC, while consultation with carers took place in 91% of cases.

Blood tests, Electro-cardiograms (ECG's) and Computerised Tomography (CT) scans were not used in all cases in either service. Significant differences were found.

Blood tests were conducted in most cases, with significantly more tests conducted on patients using the MMS (MMS 87 % vs. MC 78%, chi square = 13.746, d.f. = 2, $p \leq 0.001$). Greater variations in the frequency of CT scans were found between the two services, with the MC much more likely to conduct a CT scan (MMS 27%, MC 66%, chi square = 22.916, d.f. = 3, $p \leq 0.0001$). Consultants assessing patients within the MMS referral pathway were much more likely to have ECG's (MMS 82.1% vs. MC 6.0%, chi square = 92.178, d.f. = 2, $p \leq 0.0001$). Variations in usage of blood tests, ECG's and CT scans reflect differences in service design and practice between the MMS and the MC. ECGs are mostly performed to reduce risk from possible cardiac side effects of

cholinesterase inhibitors. CT scans are mostly performed for diagnostic reasons. A long waiting time in Huddersfield at the time of the study discouraged their use.

Assessment in a specialist clinic, including tests of cognitive, global and behavioural functioning and of activities of daily living

Table 7.4 Cognitive, functional and behavioural assessment measures used within the memory services.

	Compliance with Standards							
Local Standards	Yes (%)		No (%)		Don't Know (%)		N/A (%)	
	MMS	MC	MMS	MC	MMS	MC	MMS	MC
Assessment conducted in specialist clinic	100	100	0	0	0	0	0	0
Cognition (MMSE/SMMSE)	98.7	95.5	0	1.5	1.3	0	0	3.0
Depression. (Geriatric Depression Scale)	0	92.5	0	4.5	0	0	100	3.0
Activities of daily living	98.7	95.5	0	1.5	1.3	0	0	3.0
Behaviour (BEHAVE-AD)	0	92.5	0	4.5	0	0	100	3.0
Stage of dementia (Global Deterioration Scale)	0	16.4	0	80.6	0	0	100	3.0
Carer Stress (Screen for Caregiver Burden)	0	89.5	0	7.5	0	0	100	3.0
Critical Flicker Fusion & Reaction time	0	71.6	0	25.4	0	0	100	3.0

The MC used a more comprehensive battery of cognitive, functional and other measures than the MMS, reflecting its stronger research orientation. The clinic routinely used six instruments to assess patients and carers at baseline: the Standardised Mini Mental State Examination (SMMSE) (Molloy et al 1991), Geriatric Depression Scale (GDS) (Yesavage et al 1983), Bayer Activities of Daily Living (B-ADL) (Hindmarch et al 1998), Behavior Pathology in Alzheimer's Disease (BEHAVE-AD) (Reisburg et al 1987), Screen for Caregiver Burden (SCB) (Vitaliano et al 1991) and Critical Flicker Fusion & Reaction Time (Curran & Wattis 2000). These tests were used in the majority of cases, with SMMSE, GDS, B-ADL, and BEHAVE-AD being used in over 90% of cases. Critical Flicker Fusion was used in 71.6% of cases. In addition, the Global Deterioration Scale was used in 16.4% of cases. The range of tests generally complies with the original memory clinic service model.

In comparison the MMS used a less rigorous regime of assessments, with only two instruments conducted at baseline; the Mini Mental State Examination (MMSE) (Folstein et al 1975) and Bristol Activities of Daily Living (BADL) (Bucks et al 1996). These measures comply with the original service protocol for the MMS (SWYT 2002). These tests are also routinely used during each repeat assessment along with an opportunity for the chief relative or caregiver to give a global impression of change.

Side Effects Check and Dose Titration

Table 7.5 Frequency of side effects checks within both memory services

	Compliance with Standards							
Local Standards	Yes (%)		No (%)		Don't Know (%)		N/A (%)	
	MMS	MC	MMS	MC	MMS	MC	MMS	MC
1 month side effects check conducted	97.4	64.2	0	10.4	2.6	6.0	0	19.4
Nurse/clinic visit to make side effects check & dose titration	32.1	64.2	62.8	9.0	5.1	1.5	0	25.4
telephone call to make side effects check & dose titration	62.8	0	32.1	0	5.1	0	0	100

Assessment of any side effects resulting from treatment was conducted in most cases for users of both memory services. Side effect checks were conducted in 97.4% of cases within the MMS, and 64.2% of cases within the MC. While a large difference between the two services appears to have been recorded, 19.4% of audited cases within the MC had not yet reached this stage of treatment, and thus were recorded as Not Applicable (N/A). Side effects assessments were not conducted in 10.4% of cases within the MC. This figure is significantly higher than recorded in the MMS, where no cases were recorded where side effect checks were not conducted. Amongst patients using the MMS, side effects checks were made by telephone in 62.8% of cases, with home visits in a further 32.1% of cases. Side effects checks within the MC when conducted were almost universally clinic based.

7.5 Audit Summary

Both services operated at high rates of compliance with NICE guidance. While the two services were based upon different modes of treatment provision, both were highly compliant with NICE guidance.

As noted previously, variations occurred in the use of baseline diagnostic assessments between the services. The MC used CT scans more often, while the MMS in contrast used ECGs far more often. The MC also conducted a wider range of cognitive and other assessments, reflecting its research orientation. Both services conducted assessments of side effects relating to drug treatments. However, in 10% of cases within the Memory Clinic side effects checks did not formally occur until the first efficacy assessment. Side effects checks within the memory clinic were usually more comprehensive, taking place within a full clinic assessment, whereas in the MMS, side effects checks were commonly conducted via a telephone call.

Both the MC and the MMS were fully compliant with measures used to ascertain efficacy of treatment. All patients complied with the NICE guidance regarding continuance of treatment at the first efficacy assessment held at 2-4 months.

8
Objective 4: Cost Analysis

8.1 Assessing intervention costs

We estimated the costs of staff time and diagnostic tests from hospital costing data and by consulting hospital finance staff and the managers of the services concerned.
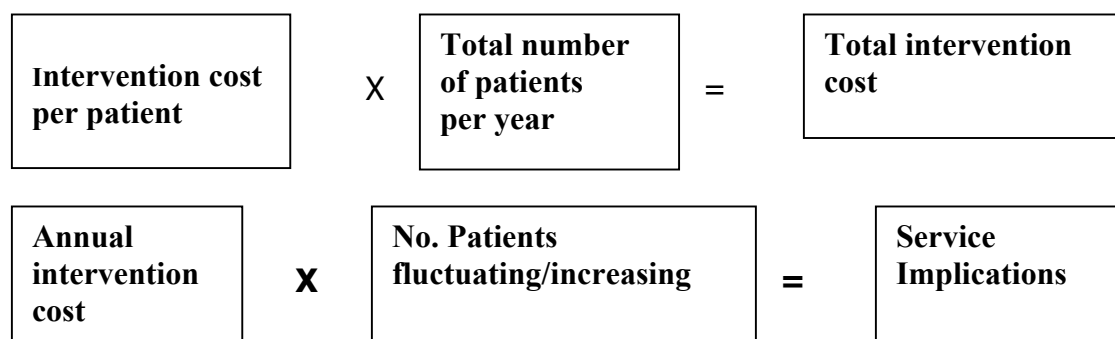
Table 8.1 Costing categories.

Costing categories:
*Staff time
consultations
transactions
*Diagnostic tests
Radiology
Haemopathology
Chemical pathology
Electrocardiography

In the total cost estimate, we included only categories of resource use for which costs were highlighted as differing between the two services. Hence drug treatment and referral costs were not considered. We excluded common fixed costs, such as overhead costs as the two services under study belonged to the same NHS trust. We included an element for clinic space. Data on capital and intervention costs were obtained from clinical records and savings were calculated for differences identified through the audit. Throughout the study service developed so costings are assumed and calculated at the close of the study.

Costing model

We used the costing model shown in figure 8.1 for calculating the resource implications of the interventions under real life conditions. In this section, we describe the annual intervention costs and service implications.

| Intervention cost per patient | X | Total number of patients per year | = | Total intervention cost |

| Annual intervention cost | X | No. Patients fluctuating/increasing | = | Service Implications |

Fig 8.1 Annual cost model for memory service resource implication.

Calculation of total annual intervention costs

Patient number assumptions

Calculations were based on information provided by each service about total patient numbers. These were estimated at 294 for the MMS and 500 for the MC.

Intervention cost per patient

The annual intervention costs for the MMS and MC Service models were calculated assuming fully operational services employing doctors on a sessional basis and nurses on an annual basis.

Table 8.2 Annual costs of implementing the MMS service model, investigation costs not considered.

		MMS
Overall service costs:	Salary costs:	
	0.8 WTE G grade nurse	£19204
	Full time F grade nurse	£20450
	Half time E grade nurse	£10328
	Consultant clinic appointment costs	£2338.73
	Transport allowance for nurses	£4232
	Clinic transport costs	£17640
	(@£60 per patient visit = 294 visits, assuming ambulance transport required for each patient)	
	Total annual service cost	£74192.73

The unit cost per patient was therefore calculated as £252.36 for the MMS model.

Table 8.3 Annual costs of implementing the MC service model, investigation costs not considered.

		MC
Overall service costs:	Salary costs not incurred by the memory clinic budget: Receptionist	
	Secretary	£2315.56
		£13927
	Costs incurred by the memory clinic budget: Full time F grade community nurse	
	0.8 WTE F grade community nurse	£20450
		£16360
	0.2 WTE G grade nurse	£4801
	Nurse Consultant services	£7599.80
	Consultant clinic appointment costs	£7299.76
	Staff grade Psychiatrist appointment costs	£6768.84
	Preparations for clinic	£1157.52
	3 consulting rooms, resource room and treatment room	£4755.92
	Transport allowance for nurses	£2576
	Clinic transport costs @ £60 per patient visit = 3 x 500 visits, assuming ambulance transport required for each patient)	£90000
	Total annual service cost	£161768.84

The unit cost per patient was therefore calculated as £323.54 for the MC model.

The annual intervention costs of both services need to be considered against the impact that costs associated with patient numbers, investigations, ambulance costs and staff changes would have on each intervention. These are discussed in the next section.

Service cost implications and sensitivity analysis

Many assumptions were included in costing intervention costs and marginal costs, and in order to test the robustness of the model, sensitivity analysis was carried out. The areas most likely to be subject to variation were evaluated.

Patient numbers

The intervention costs per patient were based on the assumption that each patient was routinely adhering to each service model care pathway. There may however, be some patients who do not follow the standard protocol. For example, patients may miss appointments or attend more clinic appointments than suggested by each service model. Patient numbers may change, as the public becomes more aware of the memory services and GPs more aware that they can refer direct to these services. Service implications of the audit results were considered. Patient costs were calculated identifying a fluctuation

or increase in patient numbers by 10%, and investigation rates reported with 95% confidence intervals (Drummond & Jefferson 1996).

Table 32 below shows the comparison between the two service models when the patient volume is raised or lowered by a 10% margin.

Table 8.4 Service model costs

SERVICE MODEL	Patient numbers	Unit cost per case
MC	550	£294.12
	450	£359
MMS	323	£229.70
	265	£279.97

The MC costs per case are larger than MMS costs when patient numbers increase and they are subject to a lesser degree of fluctuation when patient numbers increase.

Investigation costs

Many assumptions were made in calculating costs. Through the audit phase we explored the costs of each care pathway individually and in aggregate to identify the variation in costing. Some of the categories of investigation comprised only small numbers of events. Confidence intervals of proportions were calculated to identify cost implications and to enable readers to calculate costs given different populations.

Table 8.5 Confidence interval calculations for the MC

1.CT SCANS

65.7% patients received scan

= 328.5 cases

p = 328.5/500 = 0.657, 1-p = 0.3433, n= 500

0.657 +-1.96 x $\sqrt{0.001024}$ = 0.657+-1.96x0.03200 = 0.657+-0.0627

= 0.5943 to 0.7197 = <u>297 to 360</u>

2. BLOOD TESTS

77.6% patients received tests

= 388 cases

p = 388/500 = 0.776, 1-p = 0.224, n= 500

0.776 +-1.96 x $\sqrt{0.000790}$ = 0.776+-1.96x0.028108 = 0.776+-0.05509

= 0.72091 to 0.831 = <u>364.5 to 415.5</u>

3. URINALYSIS

34.3% patients received tests

= 171.5 cases

p = 171.5/500 = 0.343, 1-p = 0.657, n= 500

0.343 +-1.96 x $\sqrt{0.00102432}$ = 0.343+-1.96x0.032005= 0.657+-0.0627

= 0.281 to 0.405 = <u>140.5 to 202.5</u>

4. ECG

6% patients received test

= 30 cases

p = 30/500 = 0.06, 1-p = 0.94, n= 500

0.06 +-1.96 x $\sqrt{0.0002563}$ = 0.06+-1.96x0.016011 = 0.06+-0.0313822

= 0.028618 to 0.091382 = <u>14 to 46</u>

Table 8.6 MC investigation costs

	MC investigation costs					
			Cost (£)			
Cost category	No of potential episodes		**Total**		**Per case**	
	Assumed	CI	Assumed	CI	Assumed	CI
CT scan	328.5	297-360	4993.2	4514.4-5472	15.20	15.20
Urinalysis	171.5	140.5-202.5	154.35	126.45-182.25	0.90	0.90
Blood tests	388	364.5-415.5	271.6	255.15-290.85	0.70	0.70
ECG	30	14-46	9	4.2-13.8	0.30	0.30
Transactions	500	500	3050	3050	6.10	6.10
Total investigation costs: £8478.15						
Total cost at the upper 95% confidence limit: £7950.2						
Total cost at the lower 95% confidence limit: £9008.9						

Table 8.7 Confidence interval calculations for the MMS.

1.CT SCANS
29.9% patients received scan
= 87.9 cases
p = 87.9/294 = 0.299, 1-p = 0.701, n= 294
0.299 +-1.96 x √0.001047995 = 0.299+-1.96x0.032372 = 0.299+- 0.06344912
= 0.235 to 0.362 = <u>69 to 106</u>
2. BLOOD TESTS
87.2% patients received tests
= 256.4 cases
p = 256.4/294 = 0.872, 1-p = 0.128, n= 294
0.872+-1.96 x √0.00055808 = 0.872+-1.96x0.0236237 = 0.872+- 0.046302452
= 0.82569 to 0.91830 = <u>243 to 270</u>
3. URINALYSIS
0% patients received tests
4. ECG
82.1% patients received test
= 241.4 cases
p = 241.4/294 = 0.821, 1-p = 0.179, n= 294
0.821 +-1.96 x √0.000734 = 0.821+-1.96x0.0271071 = 0.821+- 0.053129916
= 0.767870084 to 0.874129916 = <u>226 to 257</u>

Table 8.8 MMS investigation costs

MMS investigation costs						
Cost category	No of potential episodes		Cost (£) **Total**		**Per case**	
	Assumed	CI	Assumed	CI	Assumed	CI
CT scan	88	69-106	1337.6	1048-1611.2	15.20	15.20
Urinalysis	0	0	0	0	0.90	0.90
Blood tests	256	243-270	179.2	170.1-189	0.70	0.70
ECG	241	226-257	72.3	67.8-77.1	0.30	0.30
Transactions	294	294	1793.4	1793.4	6.10	6.10
Total investigation costs: £3382.5						
Total cost at the upper 95% confidence limit:£3079.3						
Total cost at the lower 95% confidence limit:£3670.7						

More investigation costs were incurred by the Memory Clinic. The audit data suggests that patients referred to the MMS service more frequently had already had investigations conducted by their GP. Hence, costs to the MMS service were reduced. In consideration that not all patients have had all the tests conducted, the unit total investigation cost per patient identified through this analysis was calculated as £16.96 for implementing the MC model and £11.50 for the MMS. The total unit cost at the upper 95% confidence limit was calculated as £18.02 for the MC and £12.48 for the MMS and the total cost at the lower 95% confidence limit was £15.90 for the MC and £10.47 for the MMS.

Ambulance costs

Ambulances were costed between £40 and £80 pounds a visit. Therefore, the mid point of this range at £60 was the assumed cost in calculating the total service costs. Therefore, we estimated the costs of the two services adopting the highest and lowest ambulance costs given the current patient numbers and staffing configurations.

Table 8.9 Potential service costs implementing varied ambulance transport costs per visit

	MMS			MC		
Cost per ambulance visit	40	60	80	40	60	80
Total cost of service	£68312.73	£74192.73	£80072.73	£131768.84	£161768.84	£191768.84
Total cost per patient	£232.36	£252.36	£272.36	£263.54	£323.54	£383.54

Staffing

In consideration of the current staffing of the services and the need for development to cater for the expected increase in patient numbers, we estimated the costs of providing the same services using different configurations of staffing.

Table 8.10 Potential annual costs of implementing the MMS service model, investigation costs not considered

	MMS	
Overall service costs:	1. Salary costs:	
	Full time G grade	£24005
	2x Full time F grade nurse	£40900
	1x Full time E grade nurse	£18240
	Consultant clinic appointment costs	£4677.46
	Transport allowance for nurses	£6992
	Clinic transport costs (@£60 per patient visit = 588 visits)	£35280
	Total annual service cost	£130094.46

In significantly increasing the staffing capacity of the MMS and effectively allowing the patient case load to be doubled, the annual cost would be £31674.38 less than the current cost of operating the MC (£161768.84) with 500 patients. The unit cost would be slightly less than the current MMS service model at £221.24 per patient.

Table 8.11 Potential annual costs of implementing the MC service model, investigation costs not considered

		MC
Overall service costs:	Salary costs not incurred by the memory clinic budget: Receptionist	
	2 x Secretary	£2315.56
		£27854
	Costs incurred by the memory clinic budget: 2x Full time F grade community nurse	
		£40900
	0.8 WTE F grade community nurse	£16360
	2x 0.2 WTE G grade nurse	£9602
	Nurse Consultant services	£7599.80
	Consultant clinic appointment costs	£7299.76
	Staff grade Psychiatrist appointment costs	£2707.36
	Preparations for clinic for two days	£2315.04
	3 consulting rooms, resource room and treatment room for two days	£9511.84
	Transport allowance for nurses	£3434.66
	Clinic transport costs @ £60 per patient visit = (3 x 1000 visits) Clinic transport costs	£180000
	Total annual service cost	£279,730.46

Again we have significantly increased the staffing capacity, with a slightly different but workable staffing configuration that would allow the clinic to run over two days and serve double the amount of patients at clinic and within the community. This service cost if halved would be £139,865.23. This would make an annual net saving of £21,903.46 as compared to the current staffing configuration to run the service for one-day (£161,768.64). In this case, the unit cost per patient would be reduced to £279.73 (from £323.54).

Through these tabulations we can identify the workable staffing ratios to meet future patient volumes adopting the MC and MMS service designs.

Implications of the analysis

Decision-makers should appraise the net costs of the services based on point estimates, bearing in mind that values toward the centre of a confidence interval are known to be likely, and that lower limits of confidence rarely play a practical part in decision-making (Briggs & Fenn 1998).

9
Discussion

We discuss the results of the research in relation to the issues identified, the study objectives and previous research in the field. We also discuss the methodological limitations of the study and implications for practice and service development.

9.1 Stakeholder satisfaction with the two memory services

General issues

All stakeholders were generally satisfied with the performance of both services. The majority of participants were enthusiastic about the effectiveness of the drug treatments. Levels of benefit amongst participants varied, from minor benefits in some cases (stability/+1 MMSE score) to major improvements (highest recorded a +5 improvement in MMSE). Satisfaction with the service was also affected by these drug benefits and treatment waiting times. Waiting times prior to the commencement to this study were high but during the course of this study they fell. This was probably a result of streamlining the services (e.g. MMS referral practices, appointment of a MC community nurse). However, the ability of the services to further improve waiting times may be limited given the increasing volume of referrals; at the completion of this study the MMS had 94 more referrals and the MC had 270 more referrals than at the start of the study. By stimulating increased demand, these services may become victims of their own success.

9.1.1 The MMS

Patients, carers and professionals involved with or using the MMS recorded high rates of satisfaction. The key issues are summarised in the box below:

MMS Key Findings
- The MMS is designed to minimise inconvenience to patients and carers. - The MMS nursing staff understands that providing care in the home gives them the opportunity to assess dementia patients within their everyday settings. Thus receive a more realistic picture of the patient's condition and needs. - The community focus of the service causes patients and their carers to differentiate the MMS from traditional surgery/clinic/hospital based services. This removes stigma associated with hospital sites previously associated with mental illness. - The MMS possessed a high level of integration with the Alzheimer's Society, which assumed the role of information provider, as well as acting as an intermediary between patients and health care services. Carers regularly highlighted this integration as one of the major benefits of the service. - Information provided was often given verbally during consultations. - GP's noted generally high levels of satisfaction with information provided. - Patients and carers reported that issues could be openly discussed with the memory nurses. This helped to reduce levels of anxiety experienced by patients and their carers relating to the treatment process.

9.1.2 The MC

The MC provided a greater range of diagnostic testing in the form of baseline assessments and instruments to determine cognitive and behavioural changes than the MMS. The key issues are summarised below:

MC Key Findings
- The more rigorous testing at the MC was not a major concern amongst patients and their carers, who were often ignorant of the role of individual testing. - Some carers highlighted concerns regarding the number of tests conducted, and also with the system used in the clinic where carers were not present during cognitive testing, which contributed to feelings of anxiety in patients. - Carers expected some clinic attendance but some felt that a clinic setting was not the best place for assessment to take place. - Some carers thought that testing the patient in their home environment would provide a more accurate picture of their level of dementia. - Both the qualitative and quantitative data highlighted more erratic provision of information in the MC. Some individuals felt under-supported in their needs for information on dementia and support available. - Patients and carers felt that little time was available within the MC to allow carers the opportunity to discuss issues. - The MC was a good potential place for psychosocial support and information to be provided to carers, either through an information pack, or through a suitably trained individual who could assist during clinic visits. - Issues were also apparent relating to communication with and information transfer to other agencies. Lower levels of satisfaction with information provided by the service were found amongst GP's referring patients to the MC. There were also lower levels of satisfaction in Wakefield in relation to shared care protocol arrangements.

9.2 Clinical audit of patient records for compliance with NICE guidance

The analysis of patient records showed that both services exhibited high levels of compliance, both with NICE guidance and with local standards based upon the original service designs for both the MC and the MMS.

While both services exhibited high levels of compliance with NICE guidance, extensive differences were recorded in the range of tests used. As noted, generally the MC conducts a more extensive range of cognitive and other tests, reflecting a service design less dependent on GPs making preliminary assessments. The MC was research active to a higher degree than the MMS, with several projects and trials being conducted in conjunction with the clinic (resulting in useful outcomes!), and with a more extensive system of computer records used for research and audit purposes.

In contrast the MMS did the minimum assessments needed to comply with NICE guidance, reflecting the sole focus of the MMS on delivering treatment in accordance with this guidance. The MC performed more CT scans than the MMS and the MMS performed more ECGs than the MC. This probably reflected easier access to CT scans in Wakefield and higher concerns about cardiac side effects in Huddersfield.

9.3 The process whereby patients are not selected for treatment or treatment discontinued

This phase was abandoned due to recruitment difficulties as detailed earlier in the report.

9.4 Cost analysis

Many assumptions were made in calculating the costs of the two services. However, the transparency of the analysis identifies cost implications for both services and given different populations. The MMS costs were significantly lower than the MC costs. These findings need to be weighed in the balance in combination with all other factors reported by this study. Although the MC may have higher costs, more comprehensive assessment procedures were conducted by the service and it served as a resource for research as well as service delivery.

10
Conclusion

10.1 Comparisons with previous research

Communication and information

The relationship between patient, carers and memory services staff influenced the degree to which the service they received was valued. Patients and carers appreciated having close relationships with the nurses, rather than distant and professional ones. Indeed, it was felt by MMS participants that the patient, carer, nurse relationships provided informal therapy. Communication with patients has been recognised previously as one of the most important aspects of nursing older people (Armstrong-Esther et al 1989, Van Cott 1993). Indeed, research has shown that psychosocial intervention, even at an informal level can have significant benefit for patients and carers. A randomized controlled trial has shown that psychosocial intervention for spouse care givers can improve social support and reduce depression among the care givers, helping prevent or postpone a residential/nursing home placement of their spouses with Alzheimer's (Mittelman 2003). Our findings strengthen the case for memory nurses to develop good, consistent, person-centred relationships to support patients and caregivers.

Patients and carers identified the need for explanations and opportunities to ask questions and clarify treatment not only at diagnosis but also throughout the disease process as the condition or treatment changed. There has also been a growing debate on whether patients with dementia should be informed of their diagnosis. Until recently, little was known about patients themselves. Pinner & Bouman (2003) showed that patients wish to be fully informed. Patients and carers wanted to be prepared for what might come next, to help them to understand more fully the future challenges and problems they might encounter. They also wanted the opportunity to be able to discuss concerns and observations. The importance of listening to the 'voice' of patients and carers in order to appreciate the diversity of their experience has been noted (Laws & Radford, 1998).

All carers felt that they should be provided at the earliest opportunity with more information about the range of health and social care provision. There was agreement that information given by professionals within both the memory services was often limited and / or provided too late. Carers wanted professionals to anticipate their needs and instigate early referral to appropriate care agencies or professionals to prevent crisis.

Other research has shown that patients and carers tend to rate services positively in terms of the information provided to them (Van Hout et al 2001).

The professional participants recognised the importance of providing timely accurate information. The services, in accordance with the National Service Framework for Older People (Department of Health 2001) provided ample information on the diagnosis of dementia, treatments available, side effects of treatment and other health related issues. However, they provided little information on coping with dementia, or about other services providing financial and other forms of assistance. Given the nature of dementia, with a long term, progressive deterioration in cognitive and emotional states within patients, many carers felt that by not providing information and support in this area, a vital part of the overall treatment process was being overlooked. The psychosocial impacts of the diagnosis on patients must be considered, with appropriate support as a central function of memory care services (Vernooij Dassen et al, 2003)

Social support

Most of the patients and carers interviewed viewed the symptoms of dementia as a natural part of the ageing process. This, in some cases seemed to delay patients and their carers seeking help. The immediate response of denial has previously been shown to cause delay in seeking care, although it is eventually recognised that medical intervention is needed (Morse 2000). Thus, a focus upon receiving assistance at the early stages of the disease process would be beneficial in preparing patients and carers for the future. The introduction of drug treatment has brought new hope for patients and their carers. Their fears of living with dementia may have developed historically from seeing how persons with the condition were stigmatised and institutionalised.

An earlier study of carers of people with Alzheimer's disease found them to be at greater risk for adverse health related outcomes than caregivers of older people with other health problems (Ory et al 1999). The dominant paradigm used by social and behavioural scientists in family care-giving research is based on the stress and coping model (Lazarus 1966), developed most creatively in the work of Pearlin and colleagues (Pearlin & Schooler 1978, Pearlin et al 1990). In elaborating on the stress process underlying family care for relatives with dementia, Pearlin and colleagues (1990) presented a conceptual model linking the background and context of stress, the immediate sources of stress, mediators of stress (coping and social support), and the outcomes or manifestations of stress. In our study, it appeared that participants, regardless of whether they were patients or carers, were able to cope better with the condition when they were given diagnosis and treatment related information and social support. For these participants, the Alzheimer's society was a highly valued source of information and the memory nurses of psychological or social support.

The term 'social support' is generally used to refer to the perceived comfort, caring or help one individual receives from others and includes esteem support, information support, social companionship and instrumental (or practical) support (Ogden 2000). The inter-dependent nature of the components of social support is evident in the accounts

given by the carers, memory service staff and the Alzheimer's society representatives. For example, carers gain considerable esteem and companionship support from other carers of patients with dementing conditions. Carers struggle where inadequate information given to them about support groups and when referral is delayed. Carers also receive considerable support from professionals with whom they develop trusting relationships. Community oriented approaches to the treatment of dementia have previously been shown to provide benefits to patients and carers in the realm of psychosocial support (Keady & Adams 2001, Woods et al 2003). When insufficient instrumental (or practical) support is provided by statutory and voluntary agencies (such as respite care) this impacts upon coping.

Whilst the importance of support for carers was identified by professionals, many of the concerns professionals rose about service delivery and organisation illustrated the inadequate levels of social support currently provided. The accounts provided by professionals are reflected in those given by carers who feel socially isolated and perceive themselves to be not fully supported by statutory services. In their accounts patients and carers described individual styles of coping including denial, long-term positive outlook or on day-to-day well being. However, they found maintaining emotional equilibrium difficult and at times reported periods of crisis and emotional turmoil. Service planners need to acknowledge the potential psychological consequences of dementia for patient and carer and provide appropriate support services. In this study, professionals recognised and identified many of the stressors and factors affecting coping and adjustment including the need for support during periods of deterioration, the wider needs of the carers, inadequate respite and the financial implications for families.

Adjustment

This study demonstrated that adjustment to a diagnosis of dementia is more than just a discrete event for both patient and carer. It involved patients and carers going through a period of denial and life reorganisation to a period of adjustment and hope. Researchers have previously attempted to approach the adjustment phenomenon as if it is 'linear' and 'static'. There is a lack of thorough understanding of the processes through which older people make their day-to-day adjustments before and after a diagnosis of dementia. The onset of dementia places major demands on coping resources, and the development of adaptive coping strategies, and so the development of adaptive coping strategies is crucial in optimising well being and minimising excess disability (Clare 2002).

Understanding how people with early stage dementia differently and naturally attempt to adjust and cope is an important starting point in developing interventions that can enhance self-efficacy and adaptive coping. It is apparent that a community service is easier for patients and carers to adjust to. A major finding in the current study was patients and carers dislike for the locality of the hospital appointments, in relation to the history of the site and the inconvenience and anxiety associated with attendance. User satisfaction is not a simple measure based upon service practices and clinical measures of efficacy. The ethnographies of inclusion and exclusion can shape perceptions of health and social care services (Parr 2000). In sensitive and stigmatised areas such as mental

health, issues relating to the reduction of this stigma as felt by patients and carers should be an important element of service design. Recognising how patients and carers cope with the diagnosis of Alzheimer's disease and respond to memory monitoring and treatment can only enhance current and future specialised memory services that incorporate into their service model facets of care to meet both patient and carer need.

10.2 Methodological limitations

Interpretation of the findings of the study must take account of the limitations of key elements of the research design including the sampling design, characteristics of study participants and the general assessment of current service provision and needs.

The characteristics of patient and carer participants included in the final sample reflected the limitations associated with the sampling design. The sample was wholly Caucasian and does not reflect the ethnic diversity of the population studied. The population under study includes a relatively high ethnic minority population and so the results of the study cannot necessarily be generalised to patients and their families, from ethnic minority communities. For the qualitative phases of the research, both patients and carers were identified and invited to participate by a link professional for each study centre. They acted as gatekeepers to recruitment of participants to prevent any intrusion on the part of the researchers and to comply with the Data Protection Act (1998). An important limitation resulted from this approach. Where the link professional considered a patient invitation to participate inappropriate (for example, due to main language spoken or concerns about the potential for distress) then no invitation was made.

Furthermore, the relationships among variables cannot be considered causal because the study was cross-sectional. For example, the affective responses reported by patients and carers may not have resulted from lack of support but may instead have reflected a pre-existing condition which influenced self-reports. The cross-sectional design also restricted the application of the results, which cannot be used to assess the effects of service changes over time.

A number of limitations were evident in the questionnaire phase of the research. One was the relatively small sample sizes achieved, in combination with differing response rates between patients and carers within the two services. This discrepancy in response rates might have been attributable to a variety of factors, and might also serve to contribute to the findings of the questionnaire relating to levels of satisfaction experienced by service users and their carers. Questionnaires were sent to all users currently active within each service, based upon data provided by staff within the two memory services. A variety of issues arose from the use of this data. Many patients who received questionnaires were unable to complete them due to their level of cognitive impairment. Questionnaires were also sent to patients, rather than to their main carers. This was unavoidable, as carer details are not routinely collected by the services. This may have resulted in difficulties where carers were not present. Carers played important roles as gatekeepers which may have impacted upon the final response rate for patient questionnaires. For example, some carers contacted the researchers and clinical staff concerning the distress caused through

receiving questionnaires. This distress was often based upon a perception that treatment might be removed depending on the results of the questionnaire. Although attempts were made to reassure carers regarding the issues of confidentiality and anonymity, in many cases this was unsuccessful, resulting in a reduced response rate.

In the case of the MC, one problem that may have influenced response rates, related to the accuracy of records kept in the clinic as some questionnaires were sent to patients who were deceased. This understandably caused a great deal of distress to relatives who received these questionnaires, and clearly would have impacted upon the response rate. The research would have benefited from a suitable checking process, such as permission to contact the GP prior to attempting contact with an older person who has not recently been seen at clinic.

Difficulties in the analysis of questionnaire data were seen as a result of discrepancies between the response gained from patients using the MC and MMS. Comparison of results using frequency counts became difficult. As a result all data was expressed as percentages to enable intuitive comparisons between the two services. Raw numbers were, of course still used for statistical purposes. However, because of the small sample size, results may not truly be representative of opinions amongst memory clinic users and their carers.

Relating to the questionnaire distributed to GP's within the Huddersfield and Wakefield areas, limitations arose relating to the different sampling techniques. Originally, contact details were to be collected from patient and carer questionnaires. However as a result of poor response rates amongst MC service users, alternative methods of recruitment had to be used. As the MMS had provided a list of referring GP's, a census of all GP's that were currently referring patients was conducted. However because a similar list could not be gained from the MC, alternative sampling methods had to be used. In the case of the MC, questionnaires were sent to the practice managers of all GP practices that were identified as being within the MC catchment area. These different sampling techniques may have affected the data that was collected.

In relation to the cost analysis, the limitations of hospital costing information should be considered. Although financial estimates have been refined in recent years, there are still large disparities between hospitals in their cost estimates for the same procedure. Until costing conventions and hospital accounting practice are universal, the generalisability of such costing data will be limited. This study, though, identifies models that could be used to assess other schemes using locally based costs.

Despite these limitations some research and practice implications may be drawn from the research findings. These are discussed within the following sections.

10.3 Implications for practice and service development

Research implications

The findings carry implications for research on dementia. Participating in the study, for some individuals, conveyed a sense of being 'useful' and of having something special to offer. A similar observation is reported by Sabat (2001), who engaged a number of people with dementia in a collaborative research endeavor aimed at understanding the experience of the disease. The philosophy underlying qualitative methodologies such as Interpretative Phenomenological Analysis (IPA) often leads to a view of research participants as collaborators in the research enterprise (Yardley 2000), and participant feedback and comments may be incorporated into the process of data analysis. The observation that participating in research could provide a source of self-esteem means it would be valuable to explore the further possibility of conducting genuinely collaborative research with people who have early stage Alzheimer's disease and their families. The subjective experience of dementia, once neglected by researchers (Cottrell & Schulz 1993) is now clearly on the agenda.

More memory service evaluation research is required especially because there are no current guidelines with regard to how such a service should work. Furthermore, as recognised by Keady and Adams (2001), there is a paucity of evaluative work on nursing in dementia care.

Practice implications

Although further research is indicated, the findings nevertheless provide a comprehensive overview of the two memory services and provide a valuable foundation for developing memory services.

The research findings illustrate the inter-dependant nature of relationships, service provision, social support and coping. The findings highlight the importance of:
- Professional inter-personal skills
- Professional communication skills
- The provision of information to patients and carers
- A need to respect patient and carer views

And
- To adopt a holistic patient and carer centered approach to service delivery.

Alongside the increasing emphasis on early detection of Alzheimer's disease, there is a growing emphasis on the development of early psychosocial interventions [for example, counselling at the time of diagnosis (Husband 1999, 2000), support groups (Yale 1999), cognitive rehabilitation (Clare et al 2000, Camp, Bird & Cherry 2000), and the provision of advice and support to patients and families (Moniz-Cook et al 1998)]. Such interventions need to be underpinned by an understanding of the coping strategies and processes that are naturally used by people with dementia.

Service development

The accounts presented here suggest that memory services should be developed to incorporate a range of elements that could be selected and adapted according to individual needs, including the following:

- A community focus where practicable to reduce anxiety and stigma.
- A service structure that allows contact with one consistent member of staff and avoids professional "distance".
- Enhancing social support, and reducing isolation.
- Providing opportunities to talk about the experience and emotional impact of dementia.
- Helping people identify and engage in activities they still enjoy.
- Identifying ways of patients being useful and making a contribution
- Enabling people with dementia and their carers to access information that is appropriate to their needs

Specifically, local service planning and development needs to consider:

- The support needs of dementia patients and their carers
- The role of the wider multi-disciplinary team in the direct support of patients and carers or indirect support through education and information support.

Final remarks

One important finding from the current study is the preference most stakeholders held for patients being seen in their own homes. This does not deny the highly commendable work of clinic based services but may be consideration for future memory services. Memory clinics are evolving and existing clinics constantly changing and as the ageing population increases and public knowledge of anti-dementia therapies become more widespread the demand for memory services will increase (Ellis 2004). In this knowledge, it may be impractical in the future to reach the patient population via a mainly clinic based service. In developing a memory service to meet the future patient increase and preference a more 'virtual' community clinic could be designed gathering results centrally for research purposes and requiring clinic attendance only if essential for diagnosis. The ability of specialist nurses to support GPs in making the diagnosis and monitoring treatment could lead to future services being community based with input from secondary services to train and enable and to deal with diagnostic and management problems.

11
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