

The Newbury Memory

Clinic Project

Final Report

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Patrick Brooke

Marian Naidoo

Daphne Rice

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Summary

Aim

To develop a more accessible and holistic community based memory clinic through partnership involvement of users and carers and greater integration of voluntary, primary and secondary care.

Specifically:

Improved access to comprehensive multi disciplinary assessment and management of people with dementia.

Development of a model of care integrating primary, secondary, social and voluntary care, by providing them in one location within a ‘one stop’ chronic disease clinic format.

Improved communication between care providers, patients and carers.

Development of care pathway including the General Practitioner with Specialist Interest (GPwSI) role.

Develop care model encouraging emergence of a ‘Community of Practice’,

Method

An emergent process by collaborative inquiry using action research techniques. Action research requiring the participants in the study to ask the question “How can we improve what we do?”

We also monitored:

Referral to first assessment interval

Referral to treatment interval.

Quality of diagnosis by GPwSI

Patient and carer satisfaction questionnaires and interviews.

Results

Waiting times and time to treatment interval fell

Specialist review confirmed good quality assessment by GPwSI

Questionnaires showed satisfaction with multi-disciplinary style memory clinic.

Participants were equally happy to be seen by GPwSI or Consultant.

Individuals expressed satisfaction with clinic organised in this way, appreciating and supporting the move to primary care.

One carer summarised nicely our aims.

“This was the worst possible news – but given in the best possible way – and in the best possible place.”

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Introduction

This report describes the setting up of a holistic memory service within a primary care setting in Newbury, Berkshire. The clinic was established in December 2003 in order to create a more integrated service with a particular emphasis on improving collaboration and multi-professional working. This included the training and development of a General Practitioner with a special interest in Dementia.

The clinic began with a total of 6 people and included the following: -

Consultant in Old Age Psychiatry

Staff grade doctor

General Practitioner

Clinic Nurse

Support worker

Administrator

Throughout the period of this research from December 2003 until June 2005 the number of staff has increased to 11. This includes 1 neuro-psychologist, 1 member from the voluntary sector, 1 additional clinic nurse and 2 new doctors.

Rationale

Dementia is an important disorder, with Alzheimer's disease alone being the fourth most common cause of death in the Western world. The number of older people in our society is growing and the number of over 65 year old people is predicted to rise by 10% in the next 10 years. The greatest increase will be among those over 80 years of age. Of those over 65 years of age 6% have dementia and this proportion rises to 50% for those over 85 years of age. (Naidoo & Bullock, 2001).

Dementia affects roughly 1 in 120 people in the UK, thus ranking it in prevalence alongside conditions such as diabetes mellitus and stroke.

Dementia causes social isolation, disability and depression for both the patient and carers.

Only 25% of patients with dementia access specialist services in the UK.

Non-Cholinesterase intervention

Multiple evidence-based interventions exist for patients with dementia besides cholinesterase inhibitor medication. These interventions have been shown to reduce patient and carer stress, slow progression of the disease process and/or delay institutionalisation

- Carer support delays institutionalisation (*Brodaty et al.*)
- Modification of cardiovascular risk factors for Vascular Type Dementia
- Needs Assessment
- Benefits Assessment
- Access to information and education
- Access to respite care
- Review of compounding medical factors

Cholinesterase intervention

- Cholinesterase inhibitors have been shown repeatedly to improve cognition, function and behaviour in mild and moderate dementia. (NICE *Technology Appraisal Guidance No.19*)
- Cholinesterase inhibitors have been shown to work in Alzheimer's disease and Vascular Type dementia (*Pratt et al. 2002*) and case independent reports show benefit in Lewy body dementia also.
- International surveys have shown a delay of approximately 1 year from first referral to initiation of drugs.
- Considerable evidence supports rapid intervention to treat and manage dementia, in that delay in assessment and treatment by even a few months has a direct negative impact on patient outcomes. Clinical trials data confirms that those

patients treated initially with placebo never catch up with those on cholinesterase inhibitor *Doody et al. 2001*

- Even in environments with relatively open access to these drugs approximately only 10% of patients with dementia are on them.
- Cholinesterase inhibitors have substantial data to support their safety
- Cholinesterase inhibitors have been shown to reduce time to admission to nursing care by up to 2 years *McRae et al. 2001*
- Cholinesterase inhibitors have been shown to be at least cost neutral. *Bosanquet et al. 1998*

Models of Care

- The National service Framework recognised the need for greater integration of mental health services for the elderly.
- NSF targets.
“Older people who have mental health problems should have access to integrated mental health services, provided by the NHS and councils to ensure effective diagnosis, treatment and support for them and for their carers”.
- NICE does not recognise GP’s as able to initiate and prescribe cholinesterase inhibitors at present.
- Integrated Care
‘The Forget Me Not report’ noted that *the number of elderly people with mental health problems is growing rapidly, with the older patients requiring most help. They recognised the need for carers to get help and advice rapidly yet found that many GP’s are unable to provide appropriate advice, with specialist services for both users and carers being patchy and often uncoordinated. They stressed the need for health and social services to work closely together to be more flexible and responsive in meeting the needs of both users and carers.*

Problems

- Current models of care are often lacking integration, being based on multiple sites with rigid service provider boundaries, there is often no clear single point of access and subsequently they have poor communication.
- Patients find referral to secondary care stigmatising and access more difficult
- Current systems may delay and impede access for patients with dementia.
- NICE currently requires cholinesterase inhibitors to be initiated by specialists only.

Hypothesis

Joint multi professional / multi agency clinics including General Practitioner with Specialist Interest (GPwSI) as part of the team will increase access for patients and carers to a comprehensive model of dementia assessment and care without negatively affecting the quality of their care.

Proposal

To develop a more holistic approach to dementia care. To trial the development of a multidisciplinary chronic disease style clinic for patients affected by dementia that would diagnose, initiate and manage treatment of people with mild to moderate dementia within a community setting.

The clinic will aim to provide a comprehensive ‘one stop’ style service, using multidisciplinary concepts to organise joint working with voluntary sector (Alzheimer’s Society, Age Concern, Citizen’s Advice Bureau, St John’s Ambulance, Admiral Nursing etc.), practice and district nurses, psychology, social services, primary and secondary care.

Aims and Objectives

1. To improve access to comprehensive multi disciplinary, assessment and management for people with (or suspected of having) dementia.
2. Development of a model of care that seeks to integrate the services currently provided by primary, secondary, social and voluntary care organisations, by providing them in one location, so that they are available in a comprehensive chronic disease clinic format.
3. To improve communication between care providers, the patient and carers.
4. To develop a model of care that encourages the emergence of a ‘Community of Practice’, and to develop a care pathway to include the GP with Special Interest in Memory role.

Methodology

A collaborative inquiry using action research techniques. Action research requires the participants in the study to ask the question “How can we improve what we do?”

Although this is an emergent process it was anticipated that the project would include the following.

- Community based service.
- Collaborative approach between primary, secondary, social and voluntary sector care.
- GPwSI to be enabled to assess, diagnose, initiate treatment and follow up people with dementia.
- A holistic approach to dementia management and diagnosis (where services are not available on site the patient or carer will be ‘sign posted’ to the correct agency with subsequent clinic review monitoring that needs have been assessed and met).

- The study to focus on newly referred people with mild to moderate dementia. Existing patients would be excluded from the research.
- Quality of care would be monitored through review by involved secondary care specialists.

The Process

This research covers an 18 month period from December 2003 until June 2005. The research includes both quantitative and qualitative methods, combining the use of questionnaires, focus groups and in-depth interview with staff, patients and carers.

As this project is a collaborative inquiry it has been important for the team to be able to meet on a regular basis in order to discuss their progress, share their learning and to raise any issues or concerns that they have. This process of collaboration has been in place since the early plans for the development of the clinic were made but the process formally began on 2nd of December 2003. These reflective team meetings have been held throughout the period of this research firstly as regularly as was possible and when the clinic was well established at 3 monthly intervals. Most of the meetings were recorded using a combination of video and note taking. The data collected at each meeting was analysed, key themes identified and then fed back to the team at the next meeting. The purpose of this was to identify where progress was being made and in what way practice would need to change. (See Appendix 2).

At the same time patients and carers involved in the research were asked to complete a total of 2 questionnaires. The first questionnaire was given to both patients and carers at the first appointment. The second questionnaire was given to both patient and carer at the appointment where they were given a diagnosis. This information was analysed and fed-back to the team by the research lead at the team reflection meetings.

A series of in-depth interviews were also held with a total of 7 patients and their carers. These interviews were also filmed, the content analysed, key themes identified and then fed back to the team at their reflective meetings.

2 focus groups were also held with carers at their support meetings. These focus groups were also filmed, the data analysed, key themes identified and fed-back to the team at their reflective meetings. This continuous feed-back loop made sure that the team were able to respond to the needs of the patients and carers as part of the process of continuous improvement. (See Appendix 2).

Team meetings

The following team members attended a meeting which was recorded onto video the week before the clinic began.

Aaron Richards	– Administration support
Dr Daphne Rice	- Consultant in Old Age Psychiatry
Dr Patrick Brooke	- General Practitioner
Sharon Elson	- Clinic Nurse
Dr Sophie Lowrie	- Staff Grade Doctor
Carol	- Administration
Bernie	- Administration
Angus Mc Donald	- Psychologist (by telephone)

The aim of this meeting was to give the team an opportunity to talk to each other about what their expectations of the new clinic were what they hoped to achieve and also to express any concerns or worries about it.

When asked in what way the clinic would differ from the current service the following points were raised.

- It was on a different day
- Usually consists of just one doctor
- New clinic would be multi-professional and multi- agency.
- Would be seeing new patients

- Would be providing psychology assessment
- Can access voluntary sector
- Can access social services
- Can access elderly care worker
- Can access nursing for ECG's etc
- Improved communication
- Provide a more holistic approach
- Doctors not working in isolation
- Diversity from medical staff
- Direct access to clinical staff for volunteer sector
- Opportunity for team to talk to each other throughout the clinic

The team were asked how this clinic would be different for the patients.

- Patients will be seen quicker – should reduce waiting list time
- Will be able to see all members of a multi-disciplinary team
- Will have access to more information
- Will be able to meet other patients and carers
- Clinic should provide a less threatening and more friendly atmosphere
- Will be able to receive their care in the community
- Should reduce stigma
- Access to carers support packs
- More pleasant environment – tea and coffee and chat space available
- Easier and speedier access to service
- Will only have to go to one place
- Follow up appointments will be easier to access
- Service will be more responsive to their needs
- May be able to develop a drop-in facility
- Those not receiving drug treatment won't be lost from the system

- Better support for carers

The team were asked to identify any worries or concerns they have about the new clinic

- Change over of admin staff
- Staff grade leaving in a month – new doctor won't have a clue
- Team will need to be able to be open and honest throughout the project
- Team will need to be flexible and respond rapidly to change – this can be unsettling
- Increased workload on nursing
- Hope we don't fail
- Is there time for appropriate training and supervision for GPwSI
- Are we really comfortable with this amount of change and transparency
- Will we find the right patients for the GPwSI?
- Will we find time in the clinic for debriefing?
- Will we encounter problems re holiday leave and study leave?

These themes were presented to the team at their next formal meeting. The purpose of this was to assess their progress against specific aims. It will also give the team the opportunity to identify any additional themes and to raise any problems that the clinic may be facing.

Observing the Clinic Emerge

As part of the research process and the evolution of the clinic it has been important for the team to be able to meet on a regular basis as it was anticipated that change would emerge gradually as part of the process. It was important for the team to be able to discuss any issues as they emerged. This has sometimes been difficult to do within a busy clinic setting, but on the whole it has been possible for the team to find the time to come together in most weeks.

The clinic began on Tuesday 9th December 2003 with 4 new patients attending. As expected the first clinic was a little chaotic as staff were unfamiliar with their surroundings. A meeting room was established for patients to wait together and it is hoped that eventually this will become a resource room supported by the voluntary sector who will provide additional help and support for the patients and carers.

In this first session Dr Patrick Brooke, trainee GPwSI, observed the staff grade psychiatrist as part of his education for GPwSI role.

In the second clinic 3 new patients were seen and Dr Brooke observed Dr D. Rice, the consultant in old age psychiatry, as part of his education and development for the GPwSI role.

In the third week of the clinic Dr Brooke saw his first patient with Dr Rice observing. Over the next month Dr Brooke saw patients alone but went through a debriefing session after each patient with Dr Rice. The majority of patients seen by Dr Brooke were new patients and a significant percentage were from his own surgery.

On the 5th January 2004 the team were successful in involving the Alzheimer's society in the project. A member of the Alzheimer's society is now available, with resources, for both patients and carers. She is also fully involved with the research project and makes a contribution to the ongoing changes and developments. It is hoped that this facility will eventually be available to the local community on a drop-in basis.

It has been necessary to make some small adjustments to the clinic on a weekly basis. These changes have been mainly concerned with the layout of the clinic. Particular attention has been paid to maintaining a balance of patient confidentiality alongside a friendly meeting space.

Dr Brooke has just undergone an appraisal of his performance in the GPwSI role. This was undertaken by Dr Rice. This appraisal was satisfactory raising no major clinical

concerns. Areas of further work re cognitive screening, note keeping and on going education were discussed and will be followed up at the next appraisal.

Reflective Journals

As part of the action research process the team members have been keeping reflective journals. The purpose of the reflective journal is to enable team members to reflect on their learning and progress as part of the change process. The team were asked to make short summaries of their experience to date for both the interim report and the final report. These summaries are attached as Appendix 3.

Statistical Analysis

Measuring clinic efficacy in terms of timely assessment and diagnosis

Whilst much of the focus of the Memory Clinic Project has been centred on creating a more person-centred and holistic approach to the assessment and diagnosis of dementia, and addressing the more qualitative issues such as patient and carer perception of the clinic environment and the support and information made available to them at the clinic, there was also an underlying need for the secondary care service of Old Age Psychiatry to meet the growing demand being placed upon it by the referral volume being received from primary care.

Historically the prevailing sentiment has been that there was little that could be done for dementia in the form of available interventions, especially from a medical standpoint, and given the stigma and potential problems people have to face as the disease progresses it was often thought better to leave people to live in ignorance of a diagnosis of dementia (Slater 1996 p.87). As a consequence referral to secondary care tended to occur only where problems existed such as in behaviour management for instance, when primary care lacked the resources to deal with it. This viewpoint has changed somewhat with the advent of acetylcholinesterase (ACE) inhibitors for the treatment of Alzheimer's disease (AD), which along with recent developments in the psychological approach to the disease and interventions (see Clare et al 2003) has done much to change the approach taken to dementia assessment, diagnosis and treatment, and ongoing support and management of care. The number of both individuals presenting at their GP requesting referral for treatment, and referrals being received by our team from GPs would seem to be steadily increasing as information about the treatment and interventions available are becoming more widely known about.

The Memory Clinic started life as an ACE (treatment) Clinic when this medication was first licensed for (private) prescription back in 1998, With referral numbers increasing as the drugs became available on NHS prescription within this Trust in 2001. By June 2002

the ACE clinic had approximately 100 registered patients. With the need for ongoing monitoring of patients as well as assessment and diagnosis, the increasing patient numbers meant the existing four hour, one doctor, clinic session once a week required the addition of a further clinic session in October 2002 to keep pace with the number of referrals being received. At this time it was decided that the clinic sessions should be differentiated, with one to cover patient reviews and the other to undertake new patient assessment and diagnosis appointments.

By November 2003 with just over 150 registered patients and a waiting list approaching the 17 week patient charter limit the clinic needed to expand again. The Memory Clinic Project offered the ideal platform to further expand the service medically and develop a multi-disciplinary clinic team, as well as taking a more holistic approach to the services being offered to patients and their carers/supports in line with the emerging gold standard of clinical practice required for a Memory Clinic. The addition of a GPwSI to the team at this time provided us with the extra medical resource needed especially at the initial assessment and diagnostic stage which we would not have otherwise had. This has not only helped in forging the beginnings of a partnership between primary and secondary care services in relation to dementia care, but with over 300 registered patients as of May 2005 – the number having virtually doubled over the duration of the project – this addition to the team has proven vital in being able to both maintain and improve the high quality of service our patients receive and deserve.

The Memory Clinic itself serves eleven GP practices with approx. 14,500 registered patients who are aged 65 and over. With the widely accepted prevalence of dementia quoted at around 5% at age 65 and over and incidence increasing with age, then if such statistics are representative of dementia in our locality it is possible the clinic is barely serving half the people that could potentially benefit from its services. It is therefore not surprising that our patient numbers continue to swell at a rapid rate.

This increasing demand is reflected in the patient statistics kept during the study period and from those extrapolated from the period prior to the start of the study, although

unfortunately some of the data from these earlier periods is unavailable due to the lack of accurate prior records, and is thus missing from Table 1. What the table does show, is that despite some peaks and troughs, the number of referrals to the clinic has increased on a quarterly basis over time, and is now approx. double what it was two years ago.

Table 1 – Showing number of referrals received and patients seen by three month periods from June 2003 – May 2005.

Time period	No. of referrals rec'd	No. of new patients seen	Mean waiting time for 1 st Appt	Min. wait time for 1 st Appt	Max. wait time for 1 st Appt	Percentage of patients seen within 12 weeks
Dec 02–Feb 03	17	-	-	-	-	-
Mar-May 2003	15	-	-	-	-	-
Jun-Aug 2003	25	16	10	2	19	81%
Sept-Nov 2003	38	11	15	9	21	18%
Dec 03-Feb 04	32	28	12	3	23	61%
Mar-May 2004	43	15	12	5	17	73%
Jun-Aug 2004	30	30	15	5	28	32%
Sept-Nov 2004	30	29	10	1	25	65%
Dec-Feb 2005	33	19	7	2	15	89%
Mar-May 2005	37	16	4	1	9	100%

N.B. – Waiting time is no. of weeks from date referral accepted at weekly team meeting to date patient attends 1st appt.

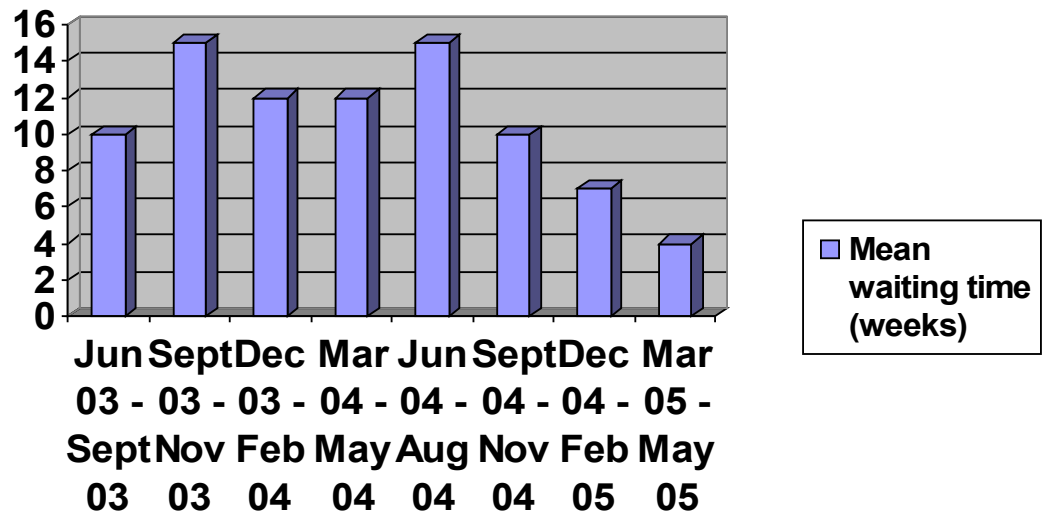
Max.waiting time is influenced by factors such as patient delay in attending due to illness and other reasons.

Min waiting time includes people who accept a last minute cancellation appt, which should help counterbalance against those who wait longer for whatever reason.

The aim in respect of medical cover from the start of the project in December 2003, was to try as far as possible to have three doctors available to take appointments each week.

This usually consisted of the GPwSI and any two from the Old Age Psychiatry Consultant, Staff Grade Doctor or Specialist Registrar. As a consequence the mean waiting time for a first appointment which was rising rapidly up to November 2003 and in danger of exceeding the 17 week Patient Charter limit has gradually fallen over time despite the increase in referrals, as illustrated in Figure 1 below.

Figure 1 – Showing mean waiting time in weeks for two quarters prior to the start of the project, and the six quarters of the project period



Given the wide range in minimum and maximum waiting times, a comparison figure of 12 weeks has been used in Table 1 to indicate the percentage of patients seen in a timely manner, since mean figures on their own do not always convey a complete picture. Our initial aim had been to see people for a 1st appointment within 2-3 months, since any delays in being assessed result in a longer wait to obtain a diagnosis and the instigation of any (drug) treatment plan. Clearly it is important that where a person may qualify for ACE medication, they are able to start taking it as soon as possible to derive the maximum benefit. Although Fig. 1 shows a mean waiting time of only 15 weeks in the quarter Sept-Nov 2003 just prior to the start of the project, in fact only 18% of people were seen within a 12 week waiting time, and thus waiting times would have been set to

increase further given the rise in the number of referrals being received by the Memory Clinic had additional medical cover not been forthcoming.

At the start of the Memory Clinic in December 2003, the waiting list came down rapidly with 73% being seen within 12 weeks. Despite our best intentions to have three doctors in all the clinic session this did not always work out, and in addition to the gaps left due to annual leave or sickness, we were without a Staff Grade Doctor or Specialist Registrar during the period February to May 2004. With the clinic working on a maximum of two doctors, and high volume of referrals in Mar-May 2004, this resulted in an increased waiting time for both 1st appointments and to some extent for follow up diagnosis appointments where these were required. This is reflected in the increased mean waiting time and the percentage seen inside twelve weeks for the June-Aug 2004 quarter noted in Table 1 and the corresponding peak seen in Fig. 1, being the time period when the effects of this were felt. Once medical cover was back in place the waiting times came back down again, and in the last quarter of the project (Mar-May 2005) 100% of people seen for a 1st appointment had waited less than 12 weeks for it i.e. were seen within our original target timeframe.

With the advent of the ACE medications, it is now crucial in assessing a person's memory difficulties to arrive at a more definitive diagnosis, as the medications are only licensed for use with people with an Alzheimer component to their diagnosis. Whilst it may be relatively easy to determine that a person's memory difficulties are due to a dementia, their clinical history and examination often does not always point conclusively to the type of dementia involved, and further testing is often needed to seek clarification on the possible neurological origins to their difficulties. In this clinic we may use CT scans, neuropsychological testing, or both for this purpose (in addition to the MMSE and/or Clock Drawing Test performed at the 1st appointment), however this results in a further wait for the patient whilst these tests are performed along with a need for a further appointment in the clinic to discuss the results of these. At this point a diagnosis should be the outcome (hence referred to as the diagnosis appointment), and ACE medication offered as appropriate.

Table 2 – Showing the requirement (or not) for further testing to achieve a diagnosis for patients seen for a 1st appointment during the three month periods Dec 2003 – May 2005 quoted.

Quarter when seen for 1 st appt	No. of patients seen for a 1 st appt	No. of patients given diagnosis at 1 st appt	No. of patients sent for neuropsych testing	No. of patients sent for CT scan	No. of patients sent for both neuropsych testing & CT scan	No. of patients seen at a diagnosis appt but no further testing done	No. of patients not seen for diagnosis
Jun-Aug 03	16	3 (19%)	6 (37%)	6 (37%)	-	-	1 (7%)
Sept-Nov 03	11	3 (27%)	4 (37%)	3 (27%)	1 (9%)	-	-
Total	27	6 (22%)	10 (37%)	9 (33%)	1 (4%)	-	1 (4%)

Dec-Feb 04	28	5 (18%)	12 (42%)	9 (32%)	1 (4%)	1 (4%)	-
Mar-May 04	15	6 (40%)	5 (34%)	2 (13%)	-	-	2 (13%)
Jun-Aug 04	31	14 (45%)	7 (23%)	6 (20%)	2 (6%)	-	2 (6%)
Sept-Nov 04	29	14 (49%)	2 (7%)	7 (24%)	4 (14%)	1 (3%)	1 (3%)
Dec-Feb 05	20	11 (55%)	1 (5%)	1 (5%)	1 (5%)	3 (15%)	3 (15%)
Mar-May 05	16	4 (25%)	6 (37%)	-	5 (31%)	-	1 (7%)
Total	139	54 (39%)	33 (24%)	25 (18%)	13 (9%)	5 (4%)	9 (6%)

N.B. Figure in brackets indicates the percentage of patients achieving diagnosis via this mechanism

In analysing the efficacy by which a diagnosis is achieved, it needs to be borne in mind that the causal origins of dementia can be complex. When assessing some people, the clinical picture may be fairly clear in terms of ruling in or out the involvement of an Alzheimer component to the dementia process. There is however, unlikely to be any regularity with which such people are referred to the clinic so it is not realistic to compare individual quarters, however looking at the average over the study period, 39% of people were able to be given a diagnosis at their 1st appointment (although in most quarterly periods the number is higher than this, and shows a rising trend except for Mar-May 2005). This figure is also nearly double that for the six month period prior to the start of the study, and there are perhaps two main reasons for this. Firstly there was no more psychology time available for neuropsychological testing despite the increased patient numbers, and therefore clinicians had to share a limited resource and perhaps reserve it

only for those cases when they were less sure of the diagnosis and felt it would prove more useful than a CT scan. Secondly, the rising trend observed in the data for more people to be given a diagnosis at 1st appointment also suggests the possibility that with increasing numbers of patients being seen, clinician experience and confidence in diagnosis improved allowing more patients to be diagnosed sooner.

Figure 2 – Showing distribution of further testing used by doctor type by quarterly periods Dec 2003- May 2005

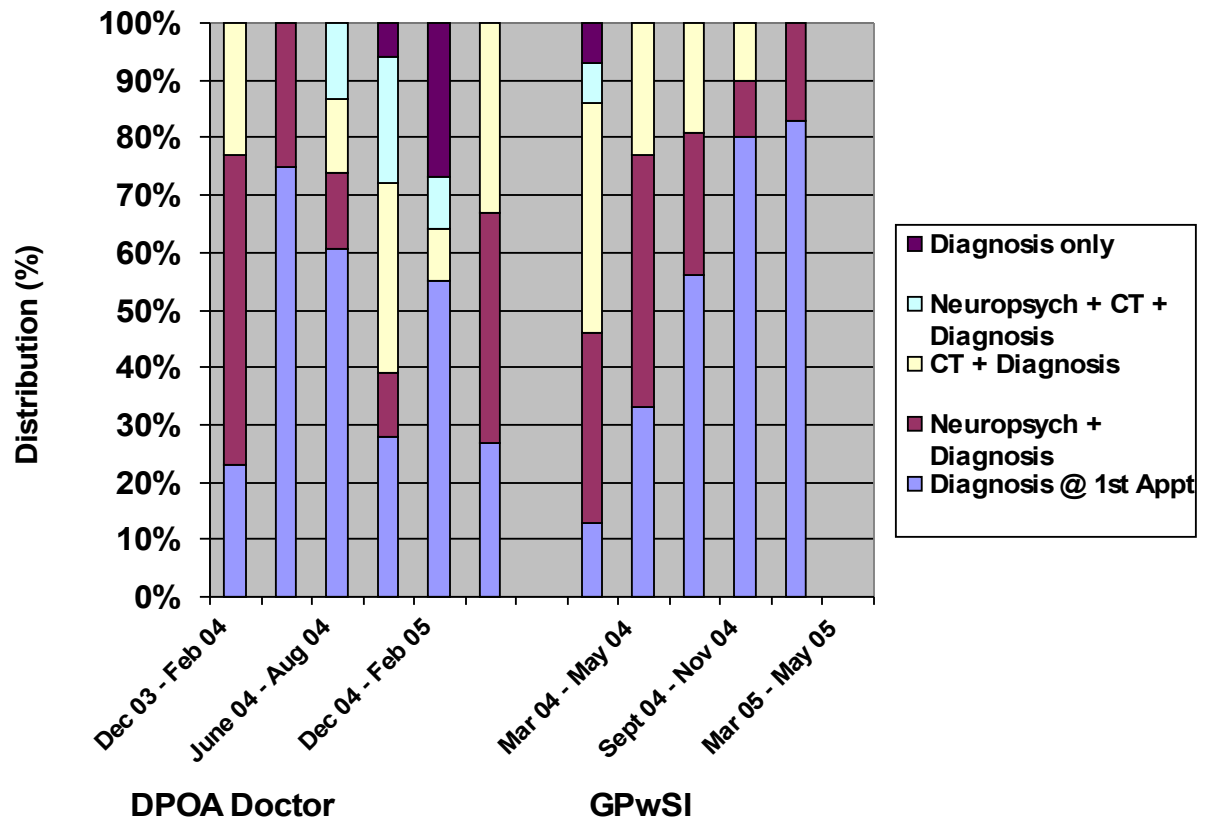


Figure 2 does suggest that over the period of the project the GPwSI showed an increased tendency towards diagnosis without the need for further testing. This pattern is not reflected among the data for the specialist psychiatry doctors (consultant, staff grade and specialist registrar), as although patients were not especially selected for the GPwSI, those which were noted from the GP referral letter to be more complex especially in terms of co-morbidity with other psychiatric conditions, were not allocated to him but to the psychiatry specialists. The added complexity of assessing such patients is likely to have an impact on making a diagnosis without further testing, and the randomly distributed appearance of such patients will naturally affect the observation of any patterns in the data.

Being able to make a diagnosis at the patient's 1st appointment not only allows them to know what the cause of their memory difficulties is sooner and obtain any relevant treatment, but also frees up more clinic time to see more people as the time that would have been taken for a follow-up diagnosis appointment is saved. In order to reduce waiting times as much as possible when a diagnosis appointment was required to interpret neuropsychological testing, an appointment with the psychologist was arranged to be followed straight after by the diagnosis appointment with the doctor so that feedback to the patient was immediate. Unfortunately for patients sent for CT scans, there was much less control on the waiting time which was dependent largely on how quickly the local Radiology Dept could see patients. We attempted to track when patients had a scan date allocated in order to then book a diagnosis appointment to coincide with when we could reasonably expect the results back, however in practice this was not always easy to achieve. Although a request was sent with the scan letter for radiology to let us know the scan date, we were often not advised and the Clinic Administrator was often left chasing this information which at times caused further delays for the patient especially on several occasions when the original scan requests appeared not to have been actioned. Where patients had both a CT scan and a neuropsychological assessment, they were booked in for a same day neuropsychology and diagnosis appointments when the scan date was known.

Table 3 – Showing number of people having a diagnosis appointment and the associated waiting times for this by three month periods Dec 2003 – May 2005.

Time period when seen for 1 st appt	No. of patients seen for a diagnosis appt in addition to their 1 st appt	Mean waiting time for diagnosis Appt with neuropsych testing	Mean waiting time for Diagnosis Appt after CT scan	Mean waiting time for Diagnosis appt after CT scan and neuropsych testing
Jun-Aug 2003	12	11	14	-
Sept-Nov 2003	6	12	12	32
Dec-Feb 2004	23	10	18	21
Mar-May 2004	7	8	20	-
Jun-Aug 2004	15	11	13	13
Sept-Nov 2004	14	11	19	18
Dec-Feb 2005	6	11	21	10
Mar-May 2005	2	10	-	-

N.B. – Mean waiting time is an average of the no. of weeks from date of 1st Appt to date of Diagnosis Appt.

For CT scans we are constrained by 6-8 week (or longer) waiting time at the local Radiology Dept.

In order to try and operate a more patient-centred appointment system, it was decided that the Memory Clinic Administrator and the Memory Clinic Support Worker would meet once month to allocate clinic appointments. Booking was done approximately 6-8weeks in advance only, to allow more flexibility in allocating people to appointments according to their needs, and in a systematic way. In order to ensure that people seeing the psychologist could be seen afterwards by the doctor it was necessary to book these first (done in order of priority), and patients were seen (as far as possible) by the same doctor who saw them for their 1st appointment to maintain continuity and consistency.

Psychology appointments are constrained to a maximum of two per week, although the average waiting time (see Table 3) has remained fairly constant both before and during the study period. New patients are not the only demand on psychology time however, as there are often people who are also requiring repeat neuropsychological assessments who have to be fitted in as well on a similar basis. This policy of seeing the doctor on the same day as the psychologist has meant that patients requiring both CT scans and neuropsychological assessment are mainly affected only by the wait imposed for the CT scan, as evidenced in Table 3 by the similarity in average waiting times between CT only

and CT+neuropsychology. Clearly though, patients are having to wait longer at times for a diagnosis if a CT scan is required, although this is out of our hands to some extent. What we do now do when allocating appointments is to leave some vacant slots where we know patients scans are imminent, so that they can be seen as soon as possible following receipt of their scan result. New patients requiring appointments are then slotted in around this based on order of referral, or sooner if their need is agreed as being more urgent by the team. In this way we try to balance the needs of all patients in the system to ensure they are all seen in as timely a manner as possible, and none slip through the net.

Table 4 – Showing average waiting time from referral to diagnosis in quarterly increments

Time period when seen for 1 st appt	No. of patients seen who receive a diagnosis at 1 st appt or thereafter	Mean wait (in weeks) from referral to diagnosis if received at 1 st appt	Mean wait (in weeks) from referral to diagnosis if received following neuropsych testing	Mean wait (in weeks) from referral to diagnosis if received following a CT scan	Mean wait (in weeks) from referral to diagnosis if received following a CT scan and neuropsych testing	Percentage of patients receiving a diagnosis within 24 weeks of referral
Jun-Aug 2003	15	13	19	25	-	67%
Sept-Nov 2003	9	15	25	26	45	55%
Dec-Feb 2004	28	12	22	29	33	50%
Mar-May 2004	13	12	19	29	-	69%
Jun-Aug 2004	27	14	26	29	24	70%
Sept-Nov 2004	28	12	22	28	20	79%
Dec-Feb 2005	17	7	17	25	17	94%
Mar-May 2005	6	4	10	-	-	100%

N.B. Not all people seen in Mar-May 2005 have yet been seen for a diagnosis appointment so these figures are incomplete for a true comparison to be made

Analysis of the data in Table 4 suggests that despite the increasing number of referrals being received, the expansion of the Memory Clinic has allowed the team to not only keep pace with the rate of referral but also improve the time frame within which patients can expect to receive a diagnosis (and thus treatment). Although the average waiting time when requiring CT scans is in excess of the 24 week target figure, hopefully as waiting times for a 1st appointment fall (as they are doing - see Table 1), so this group should also

fall within this time frame too. If we consider the waiting time from referral to diagnosis as a whole, then during the six months prior to the start of this study patients could expect to wait 21 weeks on average for this process to occur, whereas in the last six months of the study this average wait was down to just 10 weeks – a significant improvement.

As this study has taken place within a clinical (naturalistic) setting, the patient data used has not been changed or excluded where appointments have been delayed due to any problems on the patient’s part which might have prevented them attending sooner. Factors such as these will always be a factor in running any clinic, and it may not necessarily be possible to see patients in as timely a manner as hoped for due to these reasons rather than clinic efficiency. What we have tried to do however, is to keep a note of patients on the waiting list who are prepared/able to take a late cancellation appointment in order to be seen sooner, in order to keep wasted clinic time to a minimum. Of the 432 appointments offered to patients during the study period, there were only 32 DNA’s (did not attend) i.e. only 7% of clinic time lost to this. With advance warning of non-attendance, there were very few appointment slots that were not filled.

Let us now turn to the outcome of the diagnosis appointments held.

Table 5 – Showing the diagnoses given by doctor, and ACE medication uptake

Doctor	Alzheimer’s disease	Mixed Alzheimer’s/vascular dementia	Vascular dementia	DLB	MCI	Other dementia	No dementia found	Total no. of patients seen	Percentage of eligible patients electing to try ACE medication
Psychiatrist	22 (34%)	20 (31%)	13 (20%)	1 (2%)	6 (9%)	3 (4%)	2	67	98%
GPwSI	19 (38%)	16 (32%)	5 (10%)	1 (2%)	8 (16%)	1 (2%)	2	52	100%
Total	41	36	18	2	14	4	4	119	

N.B. Only one eligible person remains undecided about taking medication having only been seen recently.
 Percentages in brackets refer to the incidence of a particular type of memory problem being found.

The distribution in the form of dementia found among our patient group is fairly consistent with that usually cited. Slater (1996) quotes Alzheimer's disease at 50%, vascular dementia at 20%, co-existence of both of these forms at 20%, and other causes at 10%, although type (and prevalence) may show regional variations. In this study MCI (mild cognitive impairment) has also been included, as increased referral at an earlier stage of memory problems is giving rise to this diagnosis initially, and it is important to follow up this group so that should any of them convert to dementia, treatment and support can be made available for them to benefit from at the earliest opportunity. This will have changed the distribution figures slightly since all memory problems assessed at the clinic are being compared, and it would seem that some of the Alzheimer's disease only population is lost to the mixed AD/vascular group as a local variation. A key comparison here to note however, is that there is a fairly good concordance between the percentage forms of dementia diagnosed by the psychiatrists compared to the GPwSI. This suggests that with appropriate training and experience the GPwSI role within a Memory Clinic is able to offer an effective and appropriate service to the majority of the presenting patient group.

The data from the clinic would seem to show that demand for Memory Clinic services are on the increase, and that resources need to be found to keep up with it. In terms of medical cover, the role of the GPwSI offers good potential in helping to meet this demand, as with experience and training, they are able to provide effective assessment and diagnosis of dementia comparable to their psychiatric colleagues for the majority of patients who present. Equally they are in a position to promote the service amongst their GP colleagues, who, given the improved level of services now available to their patients needs may feel it more appropriate to refer them. Hopefully this will improve the links between primary and secondary care in the area of dementia. We have attempted to be as patient-centred as possible in our approach to assessment and diagnosis, not just from the medical point of view in being able to provide a diagnosis sooner but also in how we administer the appointment system. Whilst the clinic appointments did require more time to plan and organise – especially in the early days – this has all added to the clinic efficacy in managing patient care in as timely a manner as possible. The fact that the

average waiting time from referral to diagnosis has been halved during the 18 months of the study - and we are actively looking to reduce this further if possible - says much about the commitment of the whole team to improving the quality of the care that our patients receive.

Analysis of questionnaires

This report includes analysis of the 2 questionnaires. These questionnaires were developed collaboratively by the team and all stakeholders were able to contribute to this process. (Appendix 4).

A total of 57 patients were recruited to the research between December 2003 and December 2004. This was from a potential of 104 patients who attended for a 1st appointment during this period. During the study 7 people dropped out for the following reasons:-

1 person requested to be withdrawn

3 people withdrew by default when they declined to attend the memory service.

2 people passed away.

1 person was discharged from the memory service to a nursing home.

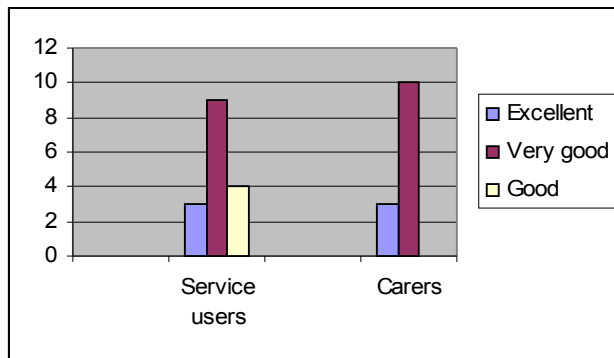
A total of 68 questionnaire 1 were distributed, 34 for patients and 34 for their carers. A total of 17 were returned from patients, one of these was returned blank. A total of 13 were returned from carers one was also returned blank. Some participants were asked not to complete questionnaire 1 – these included a few people for whom consent was only finally obtained at their diagnosis appointment or had not received a questionnaire by their diagnosis appointment. They were excluded because of the time delay and the impact on their memory of the appointment. Some participants were given a diagnosis at their 1st appointment and in this case questionnaire 2 was deemed to be more appropriate.

Questionnaire 1

The first part of questionnaire 1 is concerned with the experience of attending a memory clinic in a GP surgery, the overall quality of care provided by the memory clinic team and the preparation provided before the appointment.

Question 1.

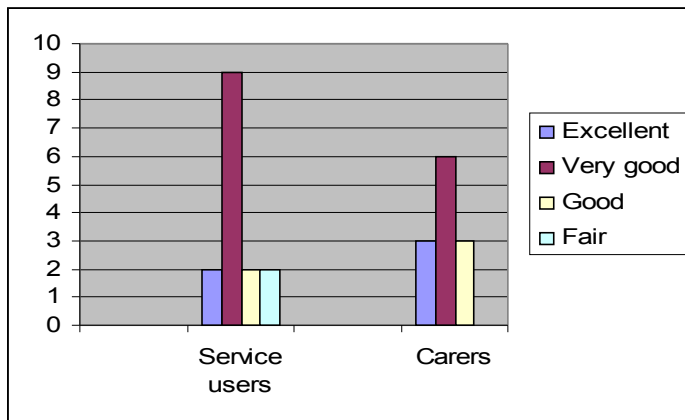
When asked what best describes the care given at their visit to the Newbury memory clinic, service users answered in the following way.



This response indicates that in a majority of instances both service users and carers were of the opinion that the care given at their 1st appointment was very good with 6 feeling that it was excellent and a further 4 service users expressing that the care was good.

Question 2

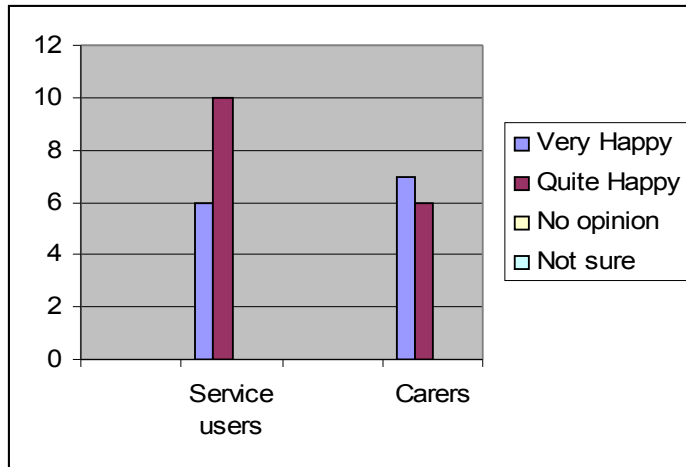
As part of the new process involved in the development of this service it is intended that all patients will be visited in their home by the memory clinic nurse prior to their appointment. The purpose of this visit is to introduce the patient and carer to a member of the memory clinic team and to provide an opportunity for questions or concerns to be addressed. Patients and carers were asked how useful this had been as a way of preparing them for their visit to the clinic.



This response indicates that overall this preparation visit by the clinic nurse was useful.

Question 3

As the memory clinic is now located in the Falkland surgery rather than in a hospital environment it was important to the team that patients and carers were given the opportunity to comment on the location. They were asked how happy they were with the clinic location.



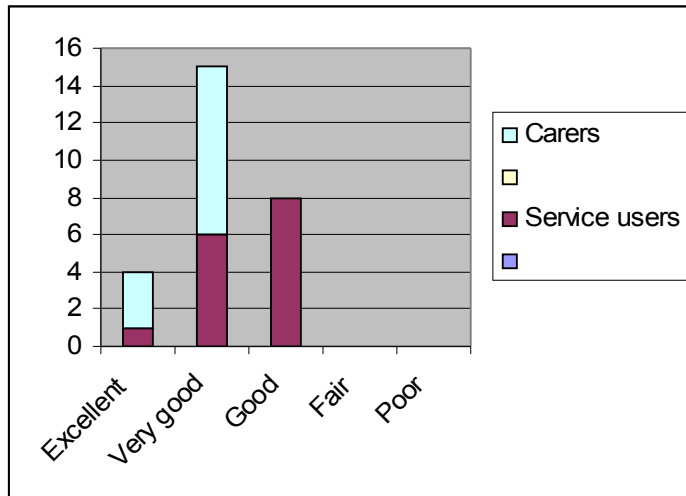
All responses to this question indicate that both patients and carers are either very happy or quite happy with the clinic being situated within a primary care setting. This response is a significant one as the location of memory clinics are traditionally in held in secondary care.

Question 4

Participants were asked if they would prefer to have had their first clinic appointment in a different venue. 1 Service user expressed a preference for the community hospital and one in their own GP surgery. I carer also expressed a preference for the community hospital.

Question 5

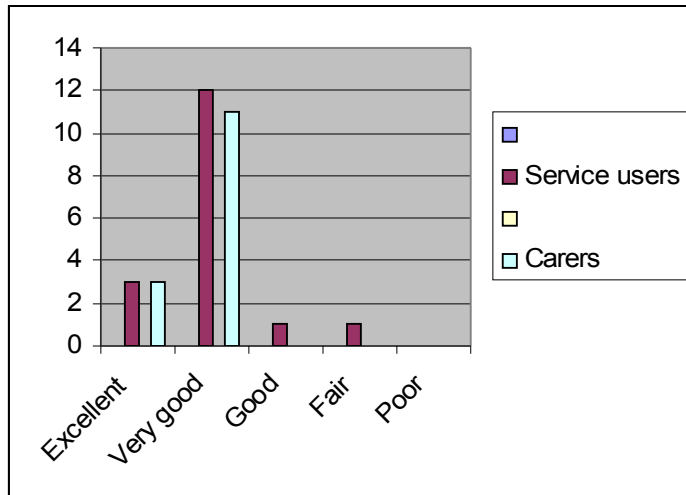
Participants were asked how well the doctor explained any tests they needed to have.



Again the responses to this question are very encouraging with both patients and carers feeling that any tests they needed to have were explained well to them.

Question 6

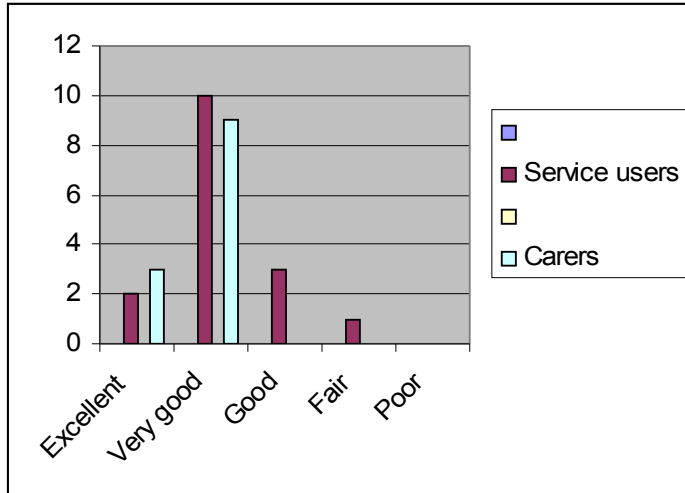
Participants were asked to rate the attention given to anything they wanted to ask the doctor.



The response to this question was again encouraging with 3 patients and carers feeling that the quality of the attention given to them was excellent, 12 patients and 11 carers that it was very good except in the 1 patient that it was good and 1 patient that it was fair.

Question 7

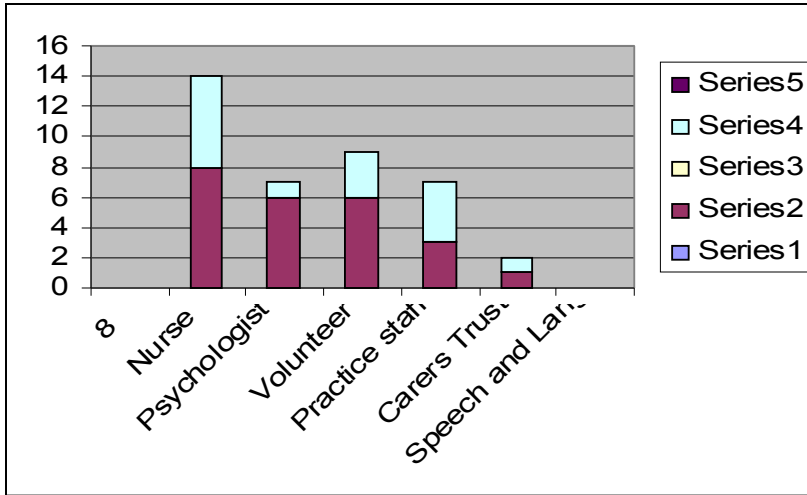
The participants were asked how well they felt that the doctor listened to them.



The response to this question is again very encouraging with 2 patients and 3 carers expressing that the quality of the doctors listening was excellent, 10 patients and 9 carers that it was very good, 3 patients felt that it was good and 1 patient fair.

Question 8

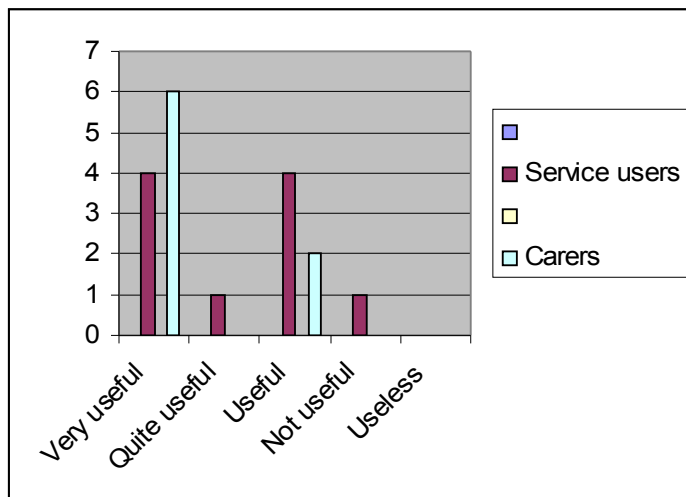
Participants were asked what other members of the clinic team they were able to spend time with.



This response indicates the effective use of the multi-professional make up of the memory clinic.

Question 9

Question 9 gave the participants the opportunity to comment on the usefulness of these additional contacts.



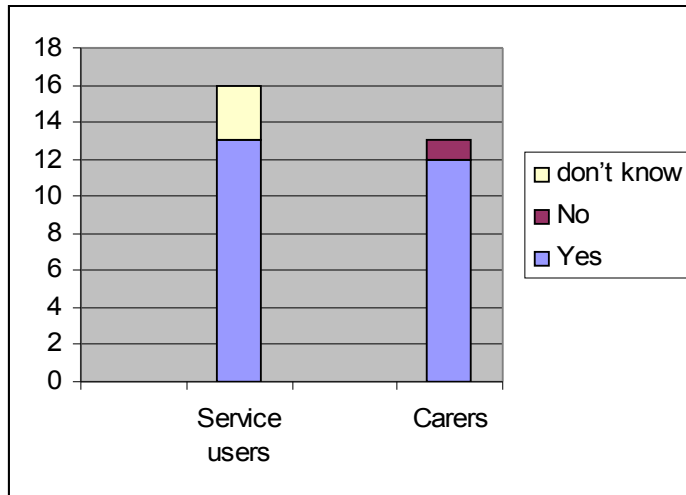
The response to this question is very important as it indicates that both patients and carers find the opportunity to access the wider team at their appointment to be useful except in 1 instance.

Question 10

Participants were given the opportunity to suggest other people who they thought may have been useful to see at this appointment. No suggestions were made.

Question 11

Participants were asked if they were given enough written information to take away with them.



This response indicates that in all but 1 case both patients and carers were happy with the amount of written information they were given at their 1st appointment to take away with them.

Conclusions

Overall the responses to this 1st questionnaire were very positive and reassuring for the team. The questionnaires have been analysed at 6 monthly intervals throughout the period of this study. The findings have then been fed back to the team at their reflective meetings for discussion, learning and action.

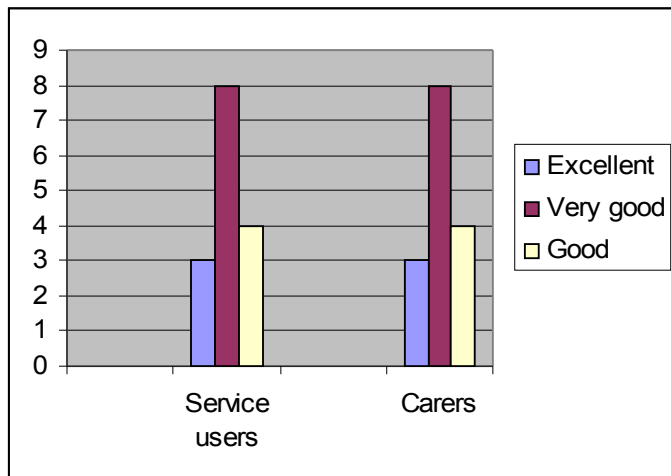
Questionnaire 2

The second questionnaire was distributed following the appointment were it was most likely that a diagnosis was given. A total of 72 questionnaires were distributed and a total of 46 were returned. Of the 23 questionnaires returned by service users 19 were completed and 4 were returned blank. Of the 23 questionnaires returned by carers 19 were completed and 4 were also returned incomplete. The main reason given for this was a problem with remembering the detail of the appointment.

The first part of questionnaire is again concerned with the experience of attending the memory clinic in a GP surgery, the overall quality of care provided by the memory clinic team and the preparation provided before the appointment.

Question 1.

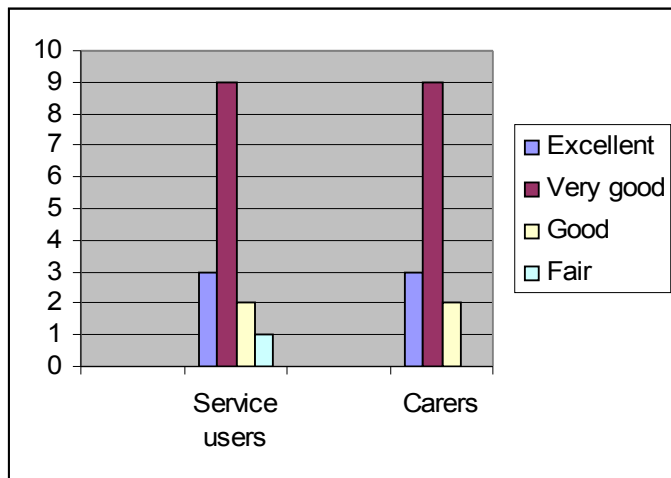
When asked what best describes the care given at their diagnosis visit to the Newbury memory clinic, service users answered in the following way.



The response to this question was very similar to the first questionnaire indicating a high level of satisfaction with the care given to them at the memory clinic. This is an important response as this reflects the quality of care given when they receive their diagnosis.

Question 2

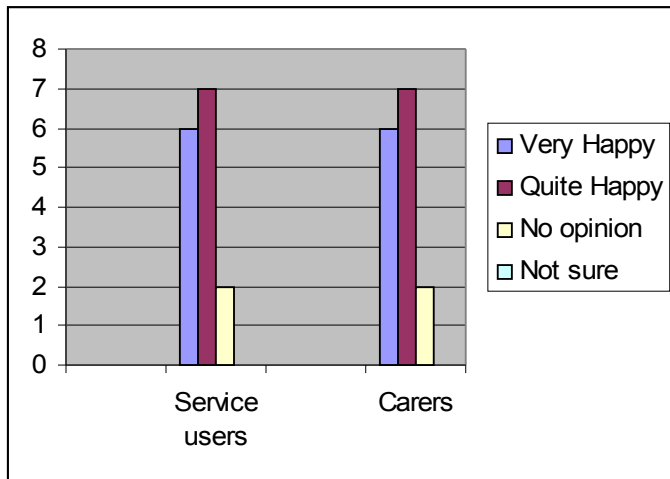
As part of the new process involved in the development of this service it is intended that all patients will be visited in their home by the memory clinic nurse prior to their appointment. The purpose of this visit is to introduce the patient and carer to a member of the memory clinic team and to provide an opportunity for questions or concerns to be addressed. Patients and carers were asked how useful this had been as a way of preparing them for their visit to the clinic.



This question again indicates high levels of satisfaction with the home visit. This is an important indicator of the way in which the team have managed to sustain this level of quality of contact throughout the period of their contact with patients and carers.

Question 3

As the memory clinic is now located in Falkland surgery rather than in a hospital environment it was important to the team that patients and carers were given the opportunity to comment on the location. They were asked how happy they were with the clinic location.



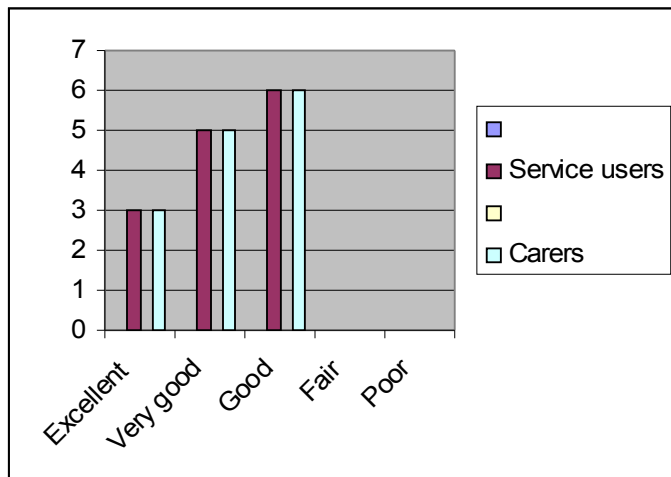
This is an important response from patients and carers because it indicates that they have no difficulty with their diagnosis appointment being held in a primary care setting rather than the more traditional secondary care setting.

Question 4

Participants were asked if they would prefer to have their clinic appointment in any other venue. 1 service user indicated that they would like to be able to be seen in their own GP's surgery.

Question 5

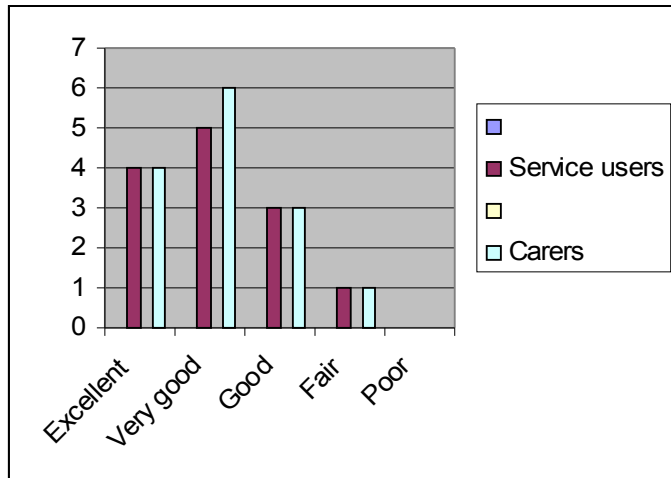
Participants were asked how well the doctor explained any treatment they needed to have following their diagnosis.



This again is an important question as it is concerned with the quality of communication following a diagnosis. The response to this from both patients and carers indicates a good level of satisfaction with the way in which their treatment was to be undertaken.

Question 6

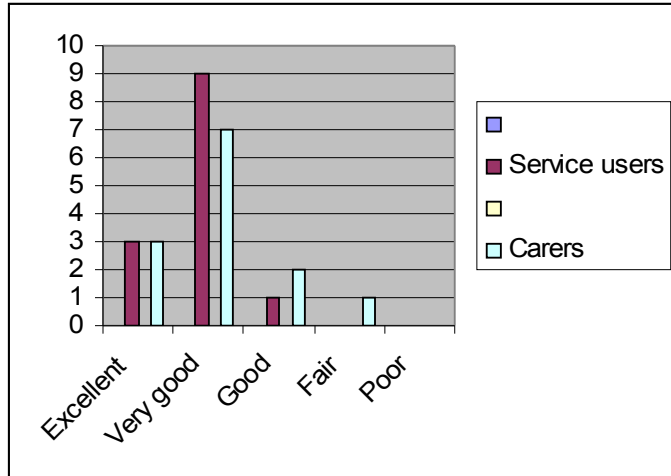
Participants were asked to rate the attention given to anything they wanted to ask the doctor following their diagnosis.



This is again a very important question for the memory clinic team as it is concerned with the way in which patients and carers perceived the attention given to them by the doctor following their diagnosis. Again there is a high level of satisfaction but in the case of 1 patient and 1 carer who felt that the level of attention given to them following their diagnosis was only fair.

Question 7

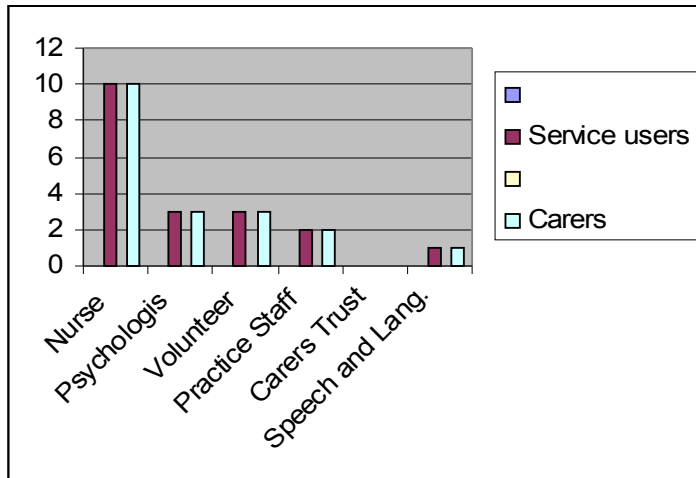
The participants were asked how well they felt that the doctor listened to them.



Although the overall response to this question again indicates a high level of satisfaction from both patients and carers in response to how well they felt that their doctor listened to their questions following the giving of their diagnosis – it is very important to note that 1 carer felt that the quality of listening was only fair.

Question 8

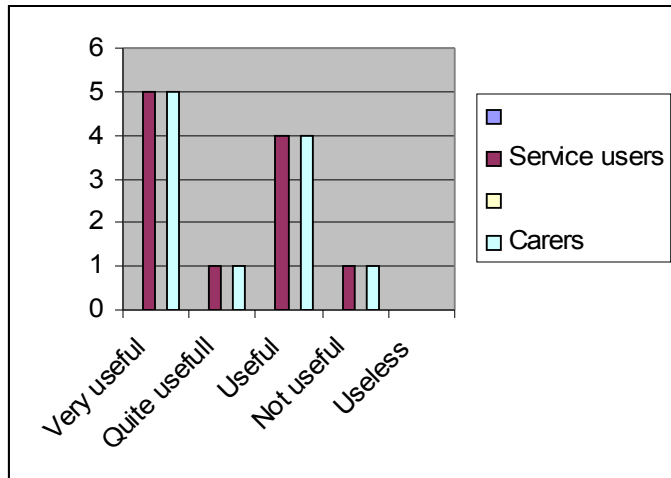
Participants were asked what other members of the clinic team they were able to spend time with.



The response to this question indicates that at the diagnosis appointment patients and carers are still accessing the wider members of the team.

Question 9

Question 9 gave the participants the opportunity to comment on the usefulness of these additional contacts.



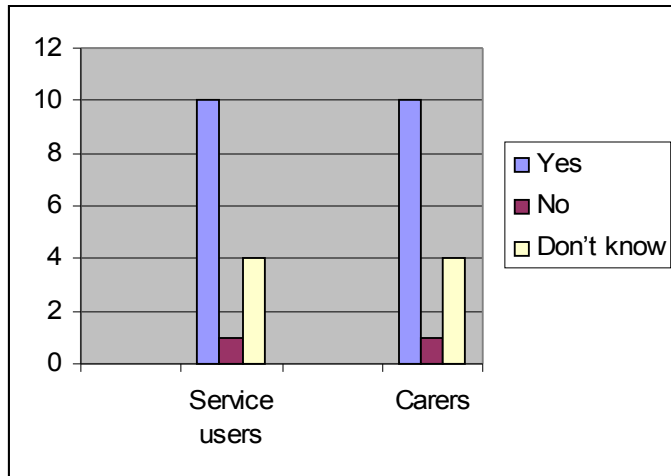
The response to this question indicates that in the majority of cases both patients and carers are still finding this contact with the wider multi-professional team useful. One patient and carer indicated that this was not useful.

Question 10

Participants were given the opportunity to suggest other people who they thought may have been useful to see at this appointment. No specific suggestions were made although 1 service user commented that it was difficult to know who was who and suggested that staff wore labels to help with this.

Question 11

Participants were asked if they were given enough written information to take away with them.



The response to this question indicates that 10 patient and 10 carers were happy with the amount of written information that was given to them following their diagnosis.

Although this again indicates a high level of satisfaction it is important to note that 1 patient and 1 carer wanted more information to take home with them but more significantly 4 patients and 4 carers expressed that they did not know how to judge whether they had received enough information or not.

Conclusion

The process of undertaking patient and carer questionnaires has been an important one for the development of the memory service. It has been a significant part of ensuring that patients and carers are directly involved in the development of the service. It has achieved this by acting as a feed-back loop in the development process. Following

intermittent analysis throughout the period of the study findings have been fed-back to the team at their regular reflective sessions. This has ensured that any issues raised by the answers to the questionnaire have been actioned very quickly. Additional feed-back has been gained through the use of patient and carer interview and focus groups.

Patient and Carer Interviews

Patient and carer involvement has been an important part of this project and in addition to the satisfaction surveys both focus groups and in-depth interview have been carried out.

A total of 7 interviews with patients and carers were undertaken as part of the research. These interviews were undertaken in their homes and in each case permission to film the interview for data collection and ongoing education and development purposes was obtained. The purpose of the in-depth interviews was firstly to ensure that there was direct involvement from patients and carers in both the development of the clinic and in the research. Secondly so that the experience of patients and carers was built into the development process by providing a feed-back loop for the team. Although the interviews with patients and carers was a very useful part of this process in the beginning a decision was made part way through the research process to cease these interviews. This decision was made following the feed-back from the interviewer that she was concerned that as patients were finding it increasingly difficult to remember the detail of their appointments that it may in fact cause them some distress. The decision was then made by the team to move this part of the process to focus groups held with the carers as part of their carers' course.

A total of 2 focus groups were held with carers at their carers' course. Carers were again given the opportunity to decline attending the focus group. Both focus groups were filmed and permission was granted by the participants for the content to be used for qualitative data analysis purposes and also for education and development purposes. The content of both the interviews and the focus groups is attached as appendix 7.

This process of interview and focus group has been a successful way of providing direct input for development from both patients and carers in a way that is sensitive to their needs. The team were able to make decisions and changes as a result of this input.

Conclusions

“This was the worst possible news given in the best possible way in the best possible place” (Carer)

The quote above is an apt summary of the progress that has been made in trialling a holistic, chronic disease type clinic in primary care. The Newbury Memory Service has been able to demonstrate the way in which this kind of clinic can be delivered in a truly multi-professional and multi-agency way.

The reflections from the team (Appendix 3) illustrates the way in which their practice has developed throughout the period of this study. These development include the following:-

- Broken down barriers between primary, secondary and voluntary care.
- Improved communication.
- Developed better relationships and trust.
- Taught the Doctors about joined up thinking.
- It has been an educational process for all rather than a performance management process.
- Blurred the boundaries around what people can do – much more holistic.
- Lost some concerns about GPwSI role.
- We’ve learnt to be on the same side – we do things differently because we have different backgrounds – but that’s OK.
- Fears and taboos have been broken down.
- Developed other things as a consequence:-

Research

Active Therapies

- Developed a culture of research and audit.
- Constantly looking for things we can do better.
- Engendered an enormous amount of enthusiasm to better everything for everybody.
- Reflective time is crucial to this process.
- Having GPwSI leaves consultant time to concentrate on more complex cases.
- The process has accelerated change.
- Enabled a focus on active partnership and therapeutic care activity as a complement to the medical model enabling people to stay well in the community.
- The focus has been on the quality of care and the quality of our relationships – not on waiting lists – these have improved anyway.
- Reduced waiting times.
- We all have equality within the team.
- The hierarchy has blurred.
- Reflective meetings have held the whole team together – its allowed us to reflect and to develop our services using the patient and carer feedback – we have all been able to make a contribution.
- Working smarter has increased our capacity.

The evidence from this study indicates that by using a methodology such as Action Research which places a greater emphasis on improving practitioner practice it is possible to involve the whole team, including patients and carers in a process of improvement. The team from the Newbury memory Service have been able to very quickly develop a culture of continuous quality improvement that uses an evidence base to aid their decision making process. The outcome of this is also demonstrated in high levels of staff retention and satisfaction. Those participating in this process have been able, because of their reflective team time, to respond to feedback by introducing change and then evaluating the impact of that change on satisfaction. The team have also been able to build this into their day-to-day practice which is also having an impact on other areas of their work

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