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A Multiple Method Evaluation of the Mid Essex Memory Assessment and Support Service

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EXECUTIVE SUMMARY

On 3rd February 2009, the Department of Health published "*Living well with dementia: A National Dementia Strategy*". This proposed a series of changes to the way services for people with dementia are organised and delivered, from raising awareness and understanding through to "living well" with dementia, whether in the community or in long-term care.

This report outlines the work undertaken by Bournemouth University in response to the "Specification for evaluation of newly created memory services in Mid Essex." (July 2009). It details the consultancy and research advisory/ assistance role in order to comprehensively evaluate the pilot memory service- which commenced in January 2009. The approach was essentially a pragmatic service evaluation utilising existing data, supplemented with additional reviews in order to allow comparison between the new service and previous provision. In addition it makes recommendations which can inform future provision and where necessary improvements. The model identified the component elements of the new service (patient pathway) as well as those previously offered through an initial scoping exercise. From these elements it was possible to obtain comparisons utilising quantitative and qualitative outcome measures. The report identifies a range of

positive benefits from the MASS provision and makes recommendations for the future.

Acknowledgements

The authors wish to thank those members of North Essex Partnership NHS Foundation Trust and staff of the Memory Assessment and Support Service for Mid Essex who supported this evaluation. In particular, Naushad Nojeeb, Michelle Thompson and Vickie Glass. All opinions expressed are those of the authors and do not necessarily represent the views of North Essex Partnership NHS Foundation Trust, nor Bournemouth University.

INTRODUCTION AND BACKGROUND TO THE PROJECT

Dementia is principally a disease of the elderly affecting 6% of people over the age of 65 years and 30% of people over the age of 90 years. With an increasingly large elderly population dementia rates are set to continue to rise. Further, Dementia affecting the under 65 years of age group is being increasingly recognised as an important medical and social problem (Alzheimer's Disease Society, 1996; Health Advisory Service, 1997). A recent study carried out by The Dementia Research Group, Imperial College School of Medicine identified 185 cases of young onset dementia, giving a prevalence of 67.2 cases per 100,000 at risk in the 30-64 years age group. Extrapolating these figures suggests that there may be 16,737 (95% CI: 13,975-19,879) people affected in the wider UK population. The prevalence rates for specific dementias included Alzheimer's disease (21.7/100,000 (15.6-29.3)), Vascular Dementia (10.9/100,000 (6.7-16.5)) and Frontotemporal dementia (9.3/100,000 (5.5-14.7)). It was notable that Alzheimer's disease accounted for less than half of the cases of dementia (Harvey et al., 1988).

The National Dementia Strategy (DoH 2009a) was published in February 2009 and set out a clear vision that people with dementia and their carers should be helped to live well with dementia. The vision was in three parts:-

- encourage help-seeking and help-offering (referral for diagnosis) by changing public and professional attitudes, understanding and behaviour;
- make early diagnosis and treatment the rule rather than the exception; and achieve this by locating the responsibility for the diagnosis of mild and moderate dementia in a specifically commissioned part of the system that can, first, make the diagnoses well, second, break those diagnoses sensitively and well to those affected, and third, provide individuals with immediate treatment, care and peer and professional support as needed;
- enable people with dementia and their carers to live well with dementia by the provision of good-quality care for all with dementia from diagnosis to the end of life, in the community, in hospitals and in care homes.

These aims were detailed in the following objectives:

Objective One:	IMPROVING PUBLIC AND PROFESSIONAL AWARENESS AND UNDERSTANDING OF DEMENTIA
Objective Two:	GOOD QUALITY EARLY DIAGNOSIS AND INTERVENTION FOR ALL
Objective Three:	GOOD QUALITY INFORMATION FOR THOSE WITH DIAGNOSED DEMENTIA AND THEIR CARERS
Objective Four:	ENABLING ACCESS TO CARE, SUPPORT AND ADVICE FOLLOWING DIAGNOSIS
Objective Five:	DEVELOPMENT OF STRUCTURED PEER SUPPORT AND LEARNING NETWORKS
Objective Six:	IMPROVED COMMUNITY PERSONAL SUPPORT SERVICES
Objective Seven:	IMPLEMENTING THE CARERS' STRATEGY FOR PEOPLE WITH DEMENTIA
Objective Eight:	IMPROVED QUALITY OF CARE FOR PEOPLE WITH DEMENTIA IN GENERAL HOSPITALS
Objective Nine:	IMPROVED INTERMEDIATE CARE FOR PEOPLE WITH DEMENTIA
Objective Ten:	CONSIDERING THE POTENTIAL FOR HOUSING SUPPORT, HOUSING RELATED SERVICES AND TELECARE TO SUPPORT PEOPLE WITH DEMENTIA AND THEIR CARERS
Objective Eleven:	LIVING WELL WITH DEMENTIA IN CARE HOMES
Objective Twelve:	IMPROVED END OF LIFE CARE FOR PEOPLE WITH DEMENTIA

The strategy was followed by a joint commissioning framework. The importance of PCT's delivering dementia services was then outlined in the Operating framework for the NHS in England 2009/2010 and some national funding was agreed to support the implementation of the strategy.

The scope of this specification relates to the work undertaken by North Essex Partnership NHS Foundation Trust (NEPFT) to introduce a memory service funded by NHS Mid Essex in line with the second part of the strategic vision.

THE SERVICE

A pilot Mid-Essex Memory and Support Service (MASS) compliant with the national model has been in place for the first time since January 2009. The stated Aim and Role of the Service is to offer a comprehensive assessment of the individual's current memory abilities and attempts to determine whether the individual has experienced a memory impairment which is greater than that to be expected, given their age. It aims to identify the cause of memory loss and if necessary discuss any possible treatments with the patient and their relative or friend. The service also offers support for carers of people with memory problems. MASS appointments can be in outpatient clinics or in the patient's home. This service has gone beyond the recommendation of the dementia strategy by being non-age specific.

The service is staffed by doctors, nurses (3 band 6 and one band 5 nurse and 3 support workers one of whom is from the Alzheimers Society), a band 3 whole time equivalent administrative support and psychology staff (recently recruited). It utilises existing medical staff to feed into the memory assessment on a sessional basis and one of the consultant psychiatrists has taken the clinical lead for the service. An occupational therapist is brought into the service as and when needed. The team leader at the local Redwoods day hospital also oversees the day to day management of the service. The base for the service is The Crystal Centre, Broomfield Hospital in Chelmsford and publicity has been carried out with local general practitioners/voluntary services to encourage referrals. The work of the team is to identify the cause of memory loss and to discuss possible treatments. Appointments may be carried out in a clinic setting and or people's own homes although of late the default position for first assessment is almost always

carried out in the patient own home with their carers and relatives. Physical examinations and blood tests are currently being undertaken in primary care settings and if a brain scan is required this is arranged at another time at the local acute hospital which is on the same site. Treatments may include memory enhancing medication, attendance at day centres and attendance at therapy groups. Support for carers is an integral part of the service. Figure 1 outlines the previous arrangements in terms of a patient pathway:-

[pic]

Figure 1: Service user experience pathway for first presentation and diagnosis of cognitive impairment prior to MASS

The new service aims to streamline these arrangements by offering the following:-

- A timely appointment in response to referral for any patient irrespective of age. Referrals are normally received from GPs as agreed within the pathway. This one hour appointment is available in the person's home or in a clinic. The first appointment is preferred to be carried out in the patient's own home, to get a holistic picture of the patient's situation in a familiar surrounding.
- The assessment visit is carried out by two members of the team, so that the family/carer is also seen/assessed. This begins a profile building of the patient and his/her carer's need.
- Being seen by a qualified practitioner to assess memory, medical history, psychiatric history and other information. A physical examination and blood tests will have been carried out by the GP. Memory tests will be carried out at the centre and a brain scan may also be requested.
- Feedback is given to the patient (the referrer) and family or friend in the form of a disclosure meeting with relevant staff who have been involved in the assessment process. The family is also seen immediately after this disclosure meeting by the support workers for further clarification, information giving and identified appropriate on-going support.
- If appropriate a range of services are offered to minimise the difficulties arising from poor memory e.g. memory enhancing medication, therapy groups and attendance at day centres.
- Follow up support to assess coping and offer specialist advice and support for the patient and carer including referral to other professionals. Figure 2 outlines the stages of the MASS service:-

[pic]

Figure 2: MASS service user experience pathway

ANTICIPATED BENEFITS OF THE MASS

- o **Single point of entry, seamless service** versus multiple points of entry (potential referrals went to one of 12 Consultant psychiatrist or 7 CMHTs with varying and chaotic journeys through the service).
- o Ageless versus previous poor access to service for younger adults with cognitive impairment.
- o Single uniform comprehensive assessment versus random possibly multiple assessments of varying quality and content.
- o Structured diagnosis disclosure appointment with support and aftercare versus random or possibly no formal diagnosis given.
- o Every carer offered carers assessment, support and sign posting versus random/inconsistent approach, possibly lack of carer assessment and support.
- o Access to Neuropsychological testing versus no access for complex cases requiring assistance for diagnosis.
- o Coordinated, comprehensive MDT discussion for every service users assessment and plan versus random and inconsistent approach
- o Avoids postcode lottery of prescribing of antedementia medications and subsequent monitoring ensuring consistency of service and fair access to treatment.
- o Supports the 3 key aims of the National Dementia strategy (Living well with Dementia) and 7 out of the 17 objectives for implementation of the strategy.

EVALUATION OF THE SERVICE

An evaluation was commissioned from Bournemouth University in response to the “Specification for evaluation of newly created memory services in Mid Essex.” (July 2009). It involved consultancy and research advisory/ assistance role in order to comprehensively evaluate the pilot memory service. The agreed approach was essentially a pragmatic service evaluation utilising existing data, supplemented with additional reviews in order to allow comparison between the new service and previous provision. In addition it sought to make recommendations to inform future provision and where necessary improvements. The model identified the component elements of the new service (patient pathway) as well as those previously offered through an initial scoping exercise. From these elements it was possible to obtain comparisons utilising quantitative and qualitative outcome measures. This necessarily allowed a focus on patient/ carer experiences as recipients of the service and as a means to transform services (DoH 2009b) Bournemouth University’s School of Health and Social Care has a strong record in this type of evaluation through its Centre for Practice Development and these approaches have been widely used in a wide range of health and social care settings. To maximise the range and scope of the evaluation within time, cost and geographical constraints the proposal recommended a project

management approach to facilitate co-ordination by the University of locally collected data following the scoping exercise and joint approaches to analysis, report-writing and dissemination. This required some resources to be provided by the Trust (as acknowledged in the specification) as well as provision of a consultative steering group to guide and monitor the process.

AIMS OF THE EVALUATION

The specific aims and objectives of the MASS pilot to be addressed in the pilot were:

- . Provision of a full diagnostic and assessment facility for adults experiencing cognitive impairment in line with the dementia care pathway and Dementia care strategy.
- . Promotion of awareness of dementia through distribution of information sheets and literature.
- . Improved support pre and post diagnosis.
- . Continuous support throughout the stages of the condition.
- . Early intervention to reduce crisis situations.
- . Provision of opportunities for social inclusion – social groups/lunches.
- . Reduce isolation through peer support at activities.
- . Sign – posting to other agencies in voluntary/statutory sector.
- . Support in accessing benefits and legal advice.
- . Improved access to local and national Alzheimer's Society helpline.
- . Access to individuals or group support.

The above aims are expected to be reflected in the achievement of the following outcomes:

- . Provision of a full diagnostic and assessment facility for adults experiencing cognitive impairment in line with the dementia care pathway and Dementia care strategy.
- . Promotion of awareness of dementia through distribution of information sheets and literature.
- . Improved support pre and post diagnosis.
- . Continuous support throughout the stages of the condition.
- . Early intervention to reduce crisis situations.
- . Provision of opportunities for social inclusion – social groups/lunches.
- . Reduce isolation through peer support at activities.
- . Sign – posting to other agencies in voluntary/statutory sector.
- . Support in accessing benefits and legal advice.
- . Improved access to local and national Alzheimer's Society helpline.
- . Access to individuals or group support.

METHOD

The project management comprised three phases (Figure 3) involving a variety of evaluation measurements:

PHASE I: SCOPING

Figure 3: Project management

PHASE I: SCOPING EXERCISE AND PROJECT DEVELOPMENT

AIMS

The aims of the initial meetings and site visits were to:

- . “map” the components of the memory service/ pathway in order to enable comparison with alternative provision (see Figures 1 and 2).
- . To benchmark the identified pathway against the National Dementia Strategy (2009).
- . To negotiate and agree with the steering group the data to be collected in order to achieve the specification aims.
- . To establish systems and processes and modes of communication in order to facilitate data collection and analysis.

DURATION

1 Month (commencing November 2009)

TEAM

The research involved discussions with members of the memory service team and nominated personnel within the Trust (identified in the specification) supported by Dr Jerry Warr and Dr Sarah Hean. As representatives of the university s/he will be responsible for:

- . A review of the existing literature and documents to determine the characteristics, content and impact of the memory services in the national context.
- . Identification of elements of the memory service using a pathway approach to enable data to be collected at set stages and enable comparison with pre-existing provision.
- . Determining the data to be collected to enable a comprehensive evaluation: quantitative outcomes, qualitative experiences and perceptions, indicators of costs to allow consideration of economic evaluation.

PHASE II: COLLECTION AND ANALYSIS OF AVAILABLE QUANTITATIVE DATA.

AIMS

The aim of this phase was:

. To collate and analyse available outcome measures to compare provision of care through the pilot memory service compared with previous provision. This included the following:-

- Assessment
- Diagnosis
- Referrals
- Medication rates
- Access
- Uptake
- Involvement of other services
- Treatment
- Admission to secondary care services
- Service location

DURATION

2 months

Phases I and II provided data to inform the interim review (January 2010) as well as outlining Phase III activity which were determined during this phase and data collection commenced.

PHASE III: COLLECTION AND EVALUATION OF ADDITIONAL DATA TO PROVIDE A COMPREHENSIVE SERVICE EVALUATION.

AIMS

Building on phase I and II additional data collection and analysis was undertaken:

. To evaluate the elements of the pathway model which pre-existing data do not cover: additional quantitative outcomes, qualitative experiences and economic data.

. To produce a final report and recommendations.

. To present and disseminate findings.

This phase involved the following additional methodological approaches:

- Feedback from patients and carers
- Feedback from stakeholders e.g. GPs and other services.
- Thematic analysis of qualitative data.
- Identification of known costs utilising the University of Kent's model of "Unit Costs of Health and Social Care" to allow some economic evaluation comparisons.
- Making recommendations.

As a general principle the qualitative data was collected by a nominated person within the trust using open questioning and anonymised surveys analysed by university staff.

DURATION

3 months

OUTCOMES AND DISSEMINATION.

Findings of phase I, II were disseminated through an interim review and presentation to the steering group.. Findings of phases I, II and III were collated into the final report and were presented to the steering group prior to wider dissemination with stakeholders and more widely e.g. as a publication for a health/ professional journal.

ETHICAL CONSIDERATIONS

This evaluation is based on principles of service evaluation rather than research and did not require formal approval through an NHS ethics committee. The study, however, fully complies with Bournemouth University's Research Governance framework and data protection requirements.

STAKEHOLDERS

In order to be successful, the study required the involvement and support of a wide variety of stakeholders, some of whom were represented on the Steering Group. Others contributed to the evaluation by consultation and/ or having the opportunity to provide qualitative data. The final report will also be made available as appropriate prior to finalisation.

STEERING GROUP

The Steering Group had overall control of the project and comprised representatives of the Trust and Memory Service, University Project Staff and stakeholders identified by the commissioners of the project. The steering group met in accordance with initial discussions but at least every two months for the duration of the 6 month project to oversee all phases of the project.

DETAILED PROJECT TIMETABLE

The detailed project phases and activities are outlined in the following timetable (Table 1)

Table 1: Evaluation timetable

ACTIVITY	Oct	
	2009	
No of Patients seen for Medication Monitoring within 3 months[1]	656	
No of patients seen for Medication Monitoring beyond 3 months	7	
No of Patients/Carers seen for Group Support	0	
No of Patients/Carers seen for Individual Support	333	
Percentage of Time/month Spent on Telephone Advice	15.25%	
No of Referrals for MRI	34	
No of Referrals for CT Scan	298	
No of Patients Referred on to Alzheimers Society Support Worker	187	

Figures from GP practices

The differences between the dementia registers held and maintained by each GP practice, before and after the onset of the service, were compared. There were 50 GP practices included in this sample. The register as of March 2008 and as of March 2009 was compared. There was an overall increase of 88 new patients on the register.

On average each practice had 27 dementia cases (M=26.6; n=50) on their register before the MASS pathway was introduced, and 28 (M=28.3; n=50) patients registered afterwards. Although there is not a significant difference between the numbers of patients registered (t=1.812; d.f.=49; p=0.076), a review of the individual data showed that whilst some practices showed a reduction in the number of cases (22 of the 50 practices) registered, a similar number (25; n=50) had showed an increase in patients cancelling out any overall changes observed. Three practices had showed no change. More exploration is required as to the reasons behind these different/opposing outcomes in each practice. Any reduction in register numbers in some GP practices could be attributed to patient moving away from a practice or dying.

QUALITATIVE FINDINGS

Feedback was gained from a total of 23 respondents: Service users, Family and Carers and Professional Staff.

Participants were positive about the service.

I have no negatives. Felt service was great. I do not know why Mum and I would be without it (carer)

Felt positive about the whole experience (service user).

They believe specifically that it provides personal care, that it is easily accessible by service users, that it covers the wide range of service user needs, that the service shows high levels of coordination and continuity, that it provided good medical treatment for users and imparted good coping strategies to carers and service. It also speeds up the rate at which care is delivered.

My 85 year old mother was diagnosed with dementia through the memory clinic in September 2009. Our family have found this service to be first class. The co-ordinated aspects are valued by my parents....F302 We have enjoyed seeing the same person throughout the treatment. My father (also 85 has benefited greatly from the referral to the Alzheimer's staff who are part of the unit. As a result my mother is receiving excellent medical treatment and, as a couple, my parents are managing to cope with the aid of practical aids and benefits. Congratulations on this initiative (family member)

I hope MASS continues as it helped me and my mum to overcome and treat mum *very quickly and her life has improved greatly and mine (carer)*

Respondents emphasise in particular the characteristics of the staff members at the memory clinic. Service users, professionals, family members and carers alike describe them as willing to help, friendly, open to discussion, knowledgeable and as treating service users with respect.

Staff have been very friendly and which has helped me to be relaxed (service user)

Promptness, friendliness, willing to help from staff (carer)

Feeling supported by the service

The service and nature of the staff made carers and service users feel supported and reassured. They felt the service had improved their quality of life and they write of the indispensability of the service in their lives.

Even after my mother was admitted to Manor Lodge – Anne continued to advise. My family and I are so very grateful for the support advice and reassurance provided by the service. It only leaves me to thank everyone involved – it would be wonderful if all were treated the same – unfortunately reading and listening to the media it seems not so. Anything else I could do to support the service – please let me know – my family and I are happy to do so (carer).

What would we do without it (carer)

The new building was seen as an asset to the service.

The first visits relating to the memory service were as hospital appointments. The home visits were very good and the only visit to the Crystal Centre was very interesting as much better surroundings. If only all appointments could be in such pleasant places with such helpful staff. We do hope your service continues (carer)

There are some criticisms of the service provided, however. In some instances a particular professional is named specifically, with language and means of communication with them being problematic. Time pressures on professionals during consultations, carers/service users not being sure whom to approach and delays in service provision are other challenges. Issues of equity are relevant with a respondent recognising that whilst this service was good others were not.

Found it difficult to get to the right people and get the answers needed (carer)

Wasn't impressed with the doctor. Found it difficult with communication (carer)

When you are retired and no longer in regular employment, times, dates are of less importance and in the grand scheme don't matter. I feel the questions are designed by much younger people

to whom every last minute must, these days be accounted for (carer)

Long delays in appointments to make progress and get help(carer)

Respondents recommended continuing with the service, increasing funding and recruiting more staff. They suggested further improving the coordination of the service specifically with the GP and other services including clinical psychologists. It was also suggested that carers be briefed prior to engagement with the service user.

When carer and patient arrive – for the carer to be separately interviewed regarding how a diagnosis should be given and the carer is more prepared when client is told diagnosis (carer)

Little comparison with previous services was made, but it was described as much better in the instances where this was mentioned.

Continuity and coordination

They believe specifically that it provides personal care, that it is easily accessible by service users, that it covers the wide range of service user needs, that the service shows high levels of coordination and continuity, that it provided the good medical treatment for users and imparts coping strategies to carers and service. It also speeds up the rate at which care is delivered.

Even after my mother was admitted to Manor Lodge – Anne continued to advise. My family and I are so very grateful for the support advice and reassurance provided by the service. It only leaves me to thank everyone involved – it would be wonderful if all were treated the same – unfortunately reading and listening to the media it seems not so. Anything else I could do to support the service – please let me know – my family and I are happy to do so. (carer)

My 85 year old mother was diagnosed with dementia through the memory clinic in September 2009. Our family have found this service to be first class. The co-ordinated aspects are valued by my parents (family member)

The ease of access, emphasis on personal care and the scope and speed of services provided by the MASS approach was highly valued.

We have enjoyed seeing the same person throughout the treatment. My father (also 85 has benefited greatly from the referral to the Alzheimer's staff who are part of the unit. As a result my mother is receiving excellent medical treatment and, as a couple, my parents are managing to cope with the aid of practical aids and benefits. Congratulations on this initiative (family member)

I hope MASS continues as it helped me and my mum to overcome and treat mum very quickly and her life has improved greatly and mine (carer)

Nature and attitudes of staff

Respondents emphasise the nature and attitudes of the staff members at the memory clinic. Service users, professionals, family members and carers alike describe the staff as willing to help, friendly, open to discussion, knowledgeable and as treating service users with respect.

Everyone was lovely and the building beautiful. Both my daughter and myself were treated well

(service user)

Staff have been very friendly and which has helped me to be relaxed (service user)

Friendly, knowledgeable, put me at ease. When we got the diagnosis it became more manageable dealing with the memory difficulties. (service user)

Understanding, sensitivity = absolutely brilliant! (carer)

Impact on carer and service user

The service was seen to be very beneficial in supporting both service user and carer, particularly as assessment and diagnosis were seen as very stressful events.

My view = it's nice to know that the memory service is here, supporting me through the process and putting me at ease (service user)

I hope MASS continues as it helped me and my mum to overcome and treat mum very quickly and her life has improved greatly and mine (carer)

Indispensable. What would we do without it (service user)

I have no negatives. Felt service was great. I do not know why Mum and I would be without it (carer)

Challenges and negative experiences

There are some criticisms of the service provided, however. In some instances a particular professional is named specifically, with language and means of communication with them being problematic. Time pressures on professionals and delays in service provision is also sometimes a challenge. Issues of equity are relevant with a respondent recognising that whilst this service was good others were not.

Wasn't impressed with the doctor. Found it difficult with communication (service user)

When with a psychiatrist felt the pressure of time (felt the need to take as little of the psychiatrist's time as possible) because of the amount of people wanting to be seen (service user)...

The strangeness of the situation and the unfamiliar language and questions caused some concerns, particularly for service users.

I found it difficult to get to the right people and get the answers needed. (service user)

Communication and language

The use of the word Alzheimer's. Also English spoken with a strong (side?) foreign accent and having to ask them to repeat the question several times before being able to understand them (service user)

I found the questions asked of patient rather strange (service user)

When you are retired and no longer in regular employment, times, dates are of less importance and in the grand scheme don't matter. I feel the questions are designed by much younger people to whom every last minute must, these days be accounted for (service user)

Recommendations suggested by respondents

Respondents recommended continuing with the service, increasing funding and recruiting more staff. There were recommendations to further improve coordination of the service specifically with the GP and other services including clinical psychologists. It was also suggested that carers be briefed prior to engagement with the service user.

When carer and patient arrive – for the carer to be separately interviewed regarding how a diagnosis should be given and the carer is more prepared when client is told diagnosis (carer)

The possibility of funding not being available to maintain the new service was raised by many. As was increasing staffing levels and reducing the number of patient appointments on each day.

We hope you are able to attract the funding necessary to continue the good work (carer)

(No negatives) except being able to be funded to employ more like (named staff member) (carer)

Additional funding and staff would aid (family)

Few other services were identified as being required although better communication with services outside of the MASS.

Access to professional services within the service needs reviewing i.e. clinical psychologist (carer)

Better co-ordination with GP (family)

One family member commented on the security deemed necessary for the unit.

Locking out/ Locking in/ what risks? (family)

Little comparison with the previous services was made, but it was described as much better in the instances where this was mentioned.

ADDITIONAL FEEDBACK FROM OTHER SOURCES

Each GP surgery is required to maintain an up to date Dementia Register and as an example, we have been able to obtain detail of the register for two surgeries in Mid Essex for example Sutherland lodge had 36 patients on their register in December 08 compare to 52 in December 09 and in Boreham Surgery they had 82 on their register in December 08 compare to 108 in

December 09. Comments from both of these surgeries is that GPs feel it is a good service and the pathway works well.

The following are comments from relatives, carer and others relating to outcomes:

"Extremely overwhelmed by all the support that has been provided since my wife's referral to MASS" (husband of patient)

"Very happy with the service as a whole and extremely impressed with MASS" (daughter of patient)

"I feel reassured and cannot believe how quickly everything has been processed and dealt with. I am extremely happy with the service" (son of patient).

We also got some feedback through the Alzheimer's Society from carers:

- Generally everyone feel positive about the service
- Quickness of the service
- Follow-up has been over and above what was expected
- Overwhelmed by the service provided by the team
- Families and individuals are aware of the service even though they do not need it now
- High impact on Alzheimer's society as people are made aware of the service, this comment is from the Society themselves.

Comments form the service is that the outcomes could even be better by providing:

- o A dedicated doctor....so that patients do not have to wait longer for disclosure.
- o More admin support because of the sheer volume of work and banding needs to be re-evaluated. The banding for this post is a 3 where the post is more like a medical secretary type role which is currently banded at 4
- o Better day care provision in Maldon, Witham and Braintree for Older Adults to support the pathway
- o CT scan, has been an issue that has held us back because it takes 6-10 weeks for a CT scan to be done.
- o There has been an increase in prescribing of antimentia medication

COST CONSIDERATIONS

It is beyond the scope of a small scale study undertaken in such a short period of time to undertake a meaningful comparative economic evaluation. Some elements, however, should be considered in relation to the development and continuation of the MASS. The previous service user pathway (as outlined in the previous figure) reflected a complex and diverse service response where cost was incorporated in the main within other service provision. Thus, it is difficult to extricate data to compare with the new service. The increased activity results in an

increased cost in paying for CT Scan/MRI and more patients being prescribed anti-dementia medication. Because there are better ways of monitoring, clinicians are able to take a greater chance in prescribing to high risk patient where in the past they would not have done so. The issue of sustainability given the level of activity and the swiftness of response has to be addressed. The service is supported by 3 community nurse practitioners (band 6) one nurse band 5 carrying out monitoring, one admin (band 3) and three support workers. There is not a single dedicated medical member of staff. Medical staff rotate on a sessional basis and might be considered problematic because of lack of consistency and is more time consuming due to the need to teach staff the new ways of operating. Another feature is that the MASS service is a bespoke service housed within a single centre. From a purely cost-minimisation viewpoint this would not be the approach of choice as it is inevitable that the new service would be considerably more costly. Similarly there are difficulties in making a comparison on cost-effectiveness grounds. This would require both pathways to provide the same outcomes i.e. meeting the aims and objectives of the National Dementia Strategy. The MASS approach was a direct response to recognised failings from previous provision. What can be considered are the effects on cost-utility and cost benefit. From a utility perspective, early diagnosis and treatment are likely to produce a marked improvement in a range of outcomes including improved functioning for a longer period with consequent reduction in costs of services for later diagnosis and management. This allows consideration of non-financial outcomes such as quality of life. If converted into a cost-benefit comparison these added advantages, which have been highlighted in the qualitative data in particular, could be quantified and expressed as both intervention and benefit costs. An example would be to include the cost-savings that improved support for carers produces expressed as a saving to services such as respite. These are possible measures for the future continuation of a service and could help to ensure that the benefits are sustained. This would represent a considerable challenge for direct comparisons of the previous and MASS pathways and would require a lengthened period of evaluation: probably up to five years to allow meaningful data to be collected. The final consideration would be to consider what would replace MASS if it is not deemed sustainable. Reversion to previous provision would not meet required outcomes without further integration and development necessitating increased investment. This hybrid development model is an option but poses the danger of losing the explicit advantages of the integrated MASS pathway.

LIMITATIONS OF THE STUDY

As previously stated this was a pragmatic evaluation of a service which was already operating. This means that assumption had to be made about previous provision due to the lack of baseline data. The short timescale (which was also affected by the change of role of the commissioning lead) precluded the use of some methods of data collection e.g. interviews and focus groups which would have enhanced the qualitative data. Similarly, the disaggregated quantitative data available was not designed specifically for this type of evaluation and limits the capacity to correlate the data and make more generalizable conclusions. That said we believe that the report identifies and highlights a good range of outcomes which should inform service development.

DISCUSSION

The MASS service was established with the following overarching principles and aims:

- People with memory problems/dementia have fair access to assessment; care and treatment on the basis of need, irrespective of age, gender, social or cultural background, and are not excluded from services because of their diagnosis, age or co-existing disabilities/medical problems.
- People with memory problems/dementia and their carers receive a service that is person-centred and takes into account their unique and changing personal, psychosocial and physical needs.
- All clients regardless of age have the same rights, value, worth and aspirations as any other person.
- All clients should be treated with courtesy and respect.
- All clients and their carers/relatives/advocates have the right to receive assessment, diagnosis and intervention as early as possible in their illness.
- Wherever possible clients should be empowered to make informed decisions about their own care and treatment.
- As far as possible support people with dementia in the community

This evaluation sought to explore these aspirations and evaluate the introduction of the MASS from a range of quantitative and qualitative perspectives. As the service was already operational there were constraints in terms of the amount of meaningful comparison possible. That said it has been possible to identify and compare the components of the new and pre-existing services and utilise audit data for both over a comparable twelve month period of operation. Cost issues are discussed but direct comparisons using agreed unit costs of health and social care would be misleading due to the diffused previous model and the establishment cost of the new service. What is apparent is the ability of the new arrangements to meet the National Dementia Strategy standards and the high levels of satisfaction with the service from the range of stakeholders. In considering both of these elements it would suggest that the current arrangements are an effective and efficient approach to the stated aims for the service. The data suggests that the following areas have improved as a direct consequence of the service introduction:

- . Provision of a full diagnostic and assessment facility for adults experiencing cognitive impairment in line with the dementia care pathway and Dementia care strategy.
- . Promotion of awareness of dementia through distribution of information sheets and literature.
- . Improved support pre and post diagnosis.
- . Continuous support throughout the stages of the condition.
- . Early intervention to reduce crisis situations.
- . Provision of opportunities for social inclusion – social groups/lunches.
- . Reduce isolation through peer support at activities.
- . Sign – posting to other agencies in voluntary/statutory sector.
- . Support in accessing benefits and legal advice.
- . Improved access to local and national Alzheimer's Society helpline.
- . Access to individuals or group support.

CONCLUSIONS

The MASS service has shown some distinct benefits over the previous pathway arrangements. Service activity has increased with a speedier response to referrals, assessment, diagnosis and

treatment. There has been a consequent increase in the number of people being diagnosed with dementia (at an earlier stage) and revealed in the numbers on the Dementia register. The integrated service, within a purpose-built unit has distinct advantages and this was emphasised by the positive comments from service-users, carers, family and staff. There are increased costs associated with the service, not least because of initiating and monitoring treatment, especially antidementia drugs to a larger population, based on earlier diagnosis. This might be seen as inevitable in meeting the requirements of the National Dementia Strategy and achieving the following previously stated service aims.

- People with memory problems/dementia have fair access to assessment; care and treatment on the basis of need, irrespective of age, gender, social or cultural background, and are not excluded from services because of their diagnosis, age or co-existing disabilities/medical problems.
- People with memory problems/dementia and their carers receive a service that is person-centred and takes into account their unique and changing personal, psychosocial and physical needs and particularly seek to address the carer's burden.
- All clients regardless of age have the same rights, value, worth and aspirations as any other person.
- All clients should be treated with courtesy and respect.
- All clients and their carers/relatives/advocates have the right to receive assessment, diagnosis and intervention as early as possible in their illness.
- Wherever possible clients should be empowered to make informed decisions about their own care and treatment.
- As far as possible support people with dementia in the community.

The MASS approach appears to meet its stated aims and has improved the service for people with dementia, their carers and families through its streamlined and integrated pathway.

RECOMMENDATIONS

It is difficult to make many specific recommendations on the basis of a relatively small and pragmatic evaluation. Some areas have been highlighted as potential points to consider:

- There is a need for ongoing and more detailed evaluation with a greater consideration of cost and activity data and effects over a prolonged period.
- The increased activity has put pressures on administration and increased staffing could be considered.
- Continuing audit against National Dementia Strategy objectives should be undertaken.
- A dedicated medical service rather than sessional input would improve consistency and continuity of care
- There is a need to ensure that the service is understood by all stakeholders
- Service user, carer and staff views should be regularly canvassed

REFERENCES

Alzheimer's Disease Society (1996) *Younger People with Dementia: a review and strategy*. London: Alzheimer's Disease Society.

Department of Health (2009a) *Living Well with Dementia: A National Dementia Strategy*. London: DoH

Department of Health (2009b) *Understanding what matters. A guide to using patient feedback to transform services*. London: DoH

Harvey RJ, Rossor MN, Skelton-Robinson M, et al. (1998) *Young onset dementia: epidemiology, clinical symptoms, family burden, support and outcome*. London: Dementia Research Group.

Health Advisory Service (1997) . *Heading for better care: commissioning and providing mental health services for people who have acquired brain injury, early onset dementia or Huntington's disease*. London: HMSO.

[1] This figure accounts for all patients receiving medication including those diagnosed in previous years before the introduction of the MASS pathway.

PHASE I

Scoping exercise and project development

PHASE II

Collection/analysis of available quantitative data

PHASE III

Collection/analysis of additional data. Report.

(for complex diagnosis)

testing with Psychologist

Neuropsychological

Carers assessment

support and on going input

Alzheimer's society worker session,

and advice

Signposting

MDT discussion

housebound clients

home visits,

–

CMHT

clinic

-

Out patients

monitoring

Meds

up

Follow

3 months

Medication

antidementia

Prescribing

Disclosure

Diagnosis with

assessment

CPA

Uniform

Internal

GP

Ageless, residing in any area in Mid Essex

Referral

that area

Denotes number of different Consultant psychiatrists working in

*

of referral through pathway

, route

live,,Consultant

which people

medication, depending on age, area

monitoring anti dementia

diagnosis, prescribing and

approaches, systems for

Random processes,

Back to Out patients for on going monitoring

Refer to OA Psychiatrist for prescribing/diagnosis

*

2

1

day hospital

Redwoods

Psychiatrist

Consultant

Older adult

Psychiatrist

Consultant

Older adult

Psychiatrist

Consultant

Older adult

*

9

8

7

6

5

4

3

2

1

Chelmsford

Witham

Maldon

Braintree

CMHT

Psychiatrist

Consultant

Adult

CMHT

Maldon

CMHT

Braintree

CMHT

Chelmsford

Over 65

Under 65

referral

GP