

MSNAP 2nd National Report 2011-12





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Foreword

We have been fortunate to receive very strong support for the MSNAP quality improvement programme in 2012. This will greatly benefit people with dementia, carers and services as MSNAP goes from strength to strength. In March 2012 the Memory Services National Accreditation Programme was endorsed in the Prime Minister's Challenge on Dementia which aims to ensure that memory clinics are established in all parts of the country, and to drive up the proportion of memory services that are accredited by MSNAP. This enables organisation to benchmark and report their own performance to drive improvement. Moreover, in July 2012 the All Party Parliamentary Group on Dementia report Unlocking Diagnosis aimed to strengthen the role of MSNAP recommending that; accreditation for memory services should be mandatory, MSNAP collects additional key data on memory services, and, improves waiting times and community based work.

With 58 services now in MSNAP and our recent survey indicating there are around 130 memory services nationally this suggests that we now cover 40-45% of all services. The Royal College of Psychiatrists is currently conducting a national audit of all services which we expect to report on soon.

New standards include more detail about pharmacological treatment of dementia and use of antipsychotic drugs, and a new optional section on best practice in psychosocial interventions and support for people with dementia and carers. Following the PM's challenge we have included 2 new standards to promote access to research for all people with dementia and carers. Also introduced are 5 quality indicators into the Third Edition standards covering key areas such as waiting times which are useful to monitor a service's progress over time, and for services to benchmark themselves against others.

Across the UK MSNAP services are improving. Having previously been accredited and made improvements, services at their second review cycle: are better able to provide home visits; have improved access to multidisciplinary input, and are better at meeting waiting time targets.

The MSNAP process continues to be very well received and members report many benefits such as the opportunity to take a closer look at their own service to identify areas of improvement, and areas where they are doing well, the opportunity to visit other services as peer reviewers, share good practice and meet with other services. Many teams also attend the Annual Forum and use the email discussion group.

We hope you appreciate this excellent and thorough report of MSNAP's progress.

Martin Orrell

Chair of the Memory Services National Accreditation Programme (MSNAP)

James Warner

Chair of the Faculty of Old Age Psychiatry, Royal College of Psychiatrists

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Why are good quality memory services important?

If dementia is diagnosed early, more can be done to delay progression of the disease¹. Additionally, knowledge of the diagnosis can reduce the number and length of acute hospital admissions, delay the need for long-term residential care and allow families to plan future medical care and finances².

The National Audit Office² concluded that "early diagnosis and intervention in dementia is cost-effective, yet there is a significant diagnosis gap and only a third to a half of people ever receive a formal diagnosis... the average reported time to diagnose the disease in the UK is... up to twice as long as in some countries". Good quality memory services should be able to address some of this inequality.

In their recent reports, the National Audit Office³ and the Public Accounts Committee⁴ concluded that the Department of Health had so far failed to meet the commitments it had laid out in the National Dementia Strategy⁵, and therefore was jeopardising the quality of dementia care available for the people who need it. This included a lack of progress in increasing the likelihood that people will receive an early diagnosis of dementia. For this reason, the NAO and PAC urged the Department of Health to work with Primary Care Trusts "to commission sufficient memory services, which are based on best practice and accredited by the Memory Services National Accreditation Programme"³.

The Memory Services National Accreditation Programme works with services to assure and improve the quality of memory services for people with memory problems/dementia and their carers. This national report summarises the findings from the last two years of the programme.

¹ National Institute for Health and Clinical Excellence and Social Care Institute for Excellence (2006). Dementia: Supporting People with Dementia and their Carers. London: the British Psychological Society and Gaskell.

² National Audit Office (2007) Improving Services and Support for People with Dementia. London: National Audit Office.

³ National Audit Office (2010). Improving dementia services in England: An interim report. London: The Stationary Office.

⁴ Committee of Public Accounts (2010). Nineteenth report of session 2009-10: Improving dementia services in England: An interim report. London: The Stationary Office.

⁵ Department of Health (2009). Living well with dementia: A National Dementia Strategy. London: Department of Health.

Section 1: Introduction to MSNAP

The Memory Services National Accreditation Programme (MSNAP) was launched in 2009 by the Royal College of Psychiatrists' Centre for Quality Improvement. It helps memory services and memory clinics to improve the quality of their service and supports them to achieve accreditation. People with dementia and carers are involved in the programme alongside professionals and clinicians to ensure that the focus remains on high quality care for service users and those that care for them.

Teams are reviewed against a set of standards which are created from published documents, guidelines and expert opinion and are revised regularly. The MSNAP standards cover assessment, diagnosis, drug treatment and psychological and social therapies for people with dementia.

MSNAP is managed by the Royal College of Psychiatrists' Centre for Quality Improvement in partnership with the British Psychological Society, Royal College of Nursing, Alzheimer's Society and the College of Occupational Therapists.

Aims

The ultimate aim of the programme is to work with services to assure and improve the quality of assessment, diagnosis and care of people with dementia and their carers, ensuring that all receive a similarly high quality service and the information they need. It aims to engage staff and people with direct experience of using memory services in a comprehensive process of review, through which good practice and high quality care are recognised. MSNAP aims to support staff in identifying and addressing areas for improvement.

Section 2: The Accreditation Process

Accreditation involves assessing services against a set of evidence-based standards through the processes of self review and peer review.

Standards

The relative importance of standards are rated using the following system:

Type 1 standards are essential to safety, rights, dignity and the law.

Type 2 standards are those that an accredited service would be expected to meet.

Type 3 standards are those that an excellent service would be expected to meet or standards that are not the direct responsibility of the service.

Self review

Services undergo a self review period of three months in duration, which requires the service to gather data using a range of audit tools: case note audit; organisational checklist; staff questionnaires; referrer questionnaires; patient questionnaires and carer/next of kin questionnaires.

Peer review

Following self review, services receive a peer review; a one-day visit delivered by a multidisciplinary team of reviewers, including peers who work in other member services, a service user or carer and usually a member of the MSNAP team. The peer review team's role is to validate the self review findings, identify areas of achievement as well as areas for improvement, and suggest ideas for addressing the latter.

Accreditation decision

On the basis of the self review and peer review data, the MSNAP Accreditation Committee (AC) suggests an accreditation recommendation. These recommendations are then presented to the Royal College of Psychiatrists' Special Committee for Professional Practice and Ethics (SCPPE) for ratification. The SCPPE is the Royal College of Psychiatrists' awarding body.

There are four categories of accreditation status:

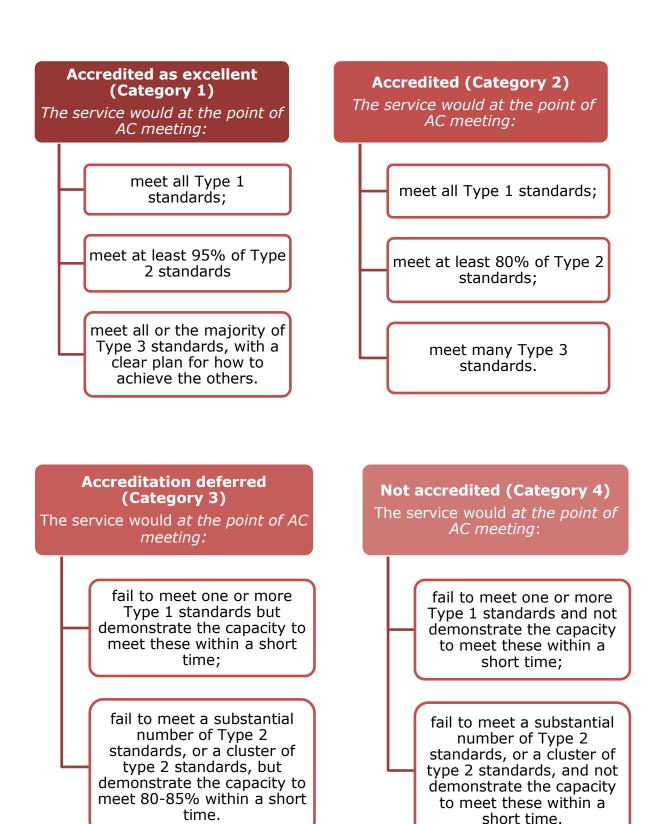


Figure 1. Categories of accreditation



Figure 2. MSNAP Accreditation Cycle

Ongoing quality improvement

The MSNAP process does not stop at the point of accreditation. Members are encouraged to continue thinking about how they can improve the quality of their service by submitting action plans shortly after being awarded accreditation. These action plans will incorporate the areas for improvement identified by the peer review team, and progress against the action plan will be taken into account as part of the brief interim review, which takes place at one year after initial accreditation. MSNAP Accreditation lasts for 2 years, after which time services undergo the full review cycle again. The areas for improvement from the last cycle are discussed at the service's next peer review visit.

Standards revision

To take into account new developments and publications, the MSNAP standards are revised regularly to ensure that they still represent current best practice for memory services. This is undertaken by the MSNAP Standards Development Group, a multidisciplinary panel consisting of clinicians from memory services participating in MSNAP, representatives from our partner organisations, people with dementia and carers. All MSNAP members have the opportunity during a consultation period to provide feedback and suggest standards for discussion.

Section 3: Opportunities for MSNAP members

Attending peer review visits

Staff from MSNAP member teams have the opportunity to attend peer review visits to other services, which is an excellent learning opportunity. Peer reviewers are able to observe how other teams function, talk to staff, share knowledge and good practice, and create useful contacts. Staff that want to become peer reviewers attend a one-day training event run by MSNAP which is free to attend for members. Trained peer reviewers are then asked to volunteer for visits, which happen around the UK throughout the year.

Since the last national report, 26 peer review visits have taken place across the country, which would not have been possible without trained MSNAP peer reviewer volunteers. The MSNAP team would like to thank all the professionals, service users and carers whose enthusiasm has made the peer review process possible.

MSNAP Forum

The MSNAP National Memory Services Forum is a conference held annually for staff that work in memory services, people with dementia and carers. Members are entitled to free or discounted places, while non-members pay a fee to attend. Each year there are keynote speakers as well as presentations and workshops by members on topical innovations and research.

The most recent MSNAP Forum held in Euston, London on 15 October 2012 welcomed Professor Mike Kopelman who spoke on the variety of memory disorders, Dr Chris Ball on supporting research in dementia services, and Dr Daniel Harwood about reducing the use of antipsychotics in his area. In addition to these keynote speakers, there were 10 sessions from MSNAP members on a variety of topics such as Life Story work, occupational therapy for dementia, anti-dementia drugs, CQUIN targets and much more.

Memory-Chat email discussion group

MSNAP members can join the email discussion group, which is a forum whereby memory service staff can receive advice from their peers in other memory services around the country. Queries are sent to a central address, and are then distributed to the group which currently has over 100 members. Members of the group can respond to these queries and replies are distributed to the group as a whole, so that others can benefit from the information.

Recent topics include memory service models, licensing of the MMSE, efficacy of Cognitive Stimulation Therapy, specialist interest groups for Occupational Therapists, dementia diagnosis by GPs, and more.

To join Memory-Chat, email 'JOIN' to Memory-Chat@cru.rcpsych.ac.uk

Section 4: What's new in MSNAP?

Endorsements of MSNAP

MSNAP has been mentioned in several reports in 2011-12, including the *Prime Minister's Challenge on Dementia (March 2012):*

"We will ensure that memory clinics are established in all parts of the country, and will work with the Royal College of Psychiatrists to drive up the proportion of memory services that are accredited, through publication of their national Memory Services Accreditation Programme, so that individual organisations can benchmark and report their own performance to drive improvement."

The All Party Parliamentary Group on Dementia report *Unlocking Diagnosis: The key to improving the lives of people with dementia (July 2012)* also makes strong reference to MSNAP:

"Recommendation 8: Strengthen the role of the Memory Services National Accreditation Programme (MSNAP) UK-wide

- Accreditation for memory services should be mandatory.
- MSNAP accreditation should include additional measures to ensure accurate recording of key data on memory services.
- MSNAP should strengthen strands of the programme that concern waiting times and community based work."

MSNAP welcomes the support of these bodies, and looks to engage further and work towards these recommendations in the coming year.

Affiliate membership

MSNAP now offers affiliate membership for services that would like to be part of the network but are not ready to undergo review and accreditation. It is a reduced cost membership subscription which lasts for two years, with the assumption that within that time the service will become ready to register for full membership. MSNAP provides support including access to self review tools, the email discussion group, peer reviewer training or observation of reviews, advice and reduced price places at the MSNAP Forum.

New standards

The MSNAP standards were revised and the Third Edition was published in June 2012. This publication covers a number of new areas:

- Pharmacological treatment of dementia appropriate prescription of antidementia and antipsychotic drugs
- Psychosocial interventions –provision of, and access to, therapies and support groups for people with dementia and carers
- Involvement in research ensuring all people with dementia and carers are offered the opportunity to be involved in a research study

At present the psychosocial interventions module is optional, and if completed it is accredited separately from the accreditation against the 'core' assessment and diagnosis standards. The results of these new standards will be presented in the next National Report.

Support from DeNDRoN

Key Commitment 14 in the Prime Minister's Challenge on Dementia was:

"Participation in high-quality research Offering people the opportunity to participate in research will be one of the conditions for accreditation of memory services."

As noted above, MSNAP has introduced standards surrounding involvement of people with dementia and carers in research, and DeNDRoN support this by providing information about research studies available in certain areas and a webpage to assist memory clinics in meeting research standards.:

http://www.dendron.nihr.ac.uk/research-in-memory-services/

Quality indicators

5 quality indicators were introduced into the Third Edition standards. These cover key areas that indicate the quality of a service, such as waiting times and rate of early diagnosis. These are phrased as a percentage, and at present are not used to inform the

accreditation decision but will be used to monitor a service's progress over time, as well as enabling services to benchmark themselves against others.

Memory Services Register

MSNAP was asked in 2012 to create a register of memory services in the UK by the Department of Health. Over 130 services registered themselves using an online survey and the results of this are now published on the MSNAP website.

Section 5: Status of MSNAP members

At the time of writing there are 59 members of MSNAP (see Figure 3 for locations of members). MSNAP serves England, Wales, Scotland, Northern Ireland and Republic of Ireland, however the programme currently only has members in England. Table 1 below shows the accreditation status of MSNAP members as of January 2013.

| Accreditation Status | Number of services |
|-------------------------|-----------------------|
| Accredited as excellent | 18 |
| Accredited | 15 |
| Deferred | 2 |
| Not accredited | 0 |
| In review stage | 15 |
| Affiliate members | 8 |

Table 1: Accreditation status overall of MSNAP members

15 MSNAP services underwent their second cycle of review in 2011-12. A comparison of their accreditation status between first and second cycles of review is displayed in Table 2 below.

| Accreditation Status | Number of services |
|---------------------------------------|--------------------|
| Remained accredited as excellent | 4 |
| Promoted from accredited to excellent | 3 |
| Remained accredited | 5 |
| Moved from excellent to accredited | 1 |
| Still under review in second cycle | 2 |

Table 2: Comparison of accreditation status in first and second cycle of review

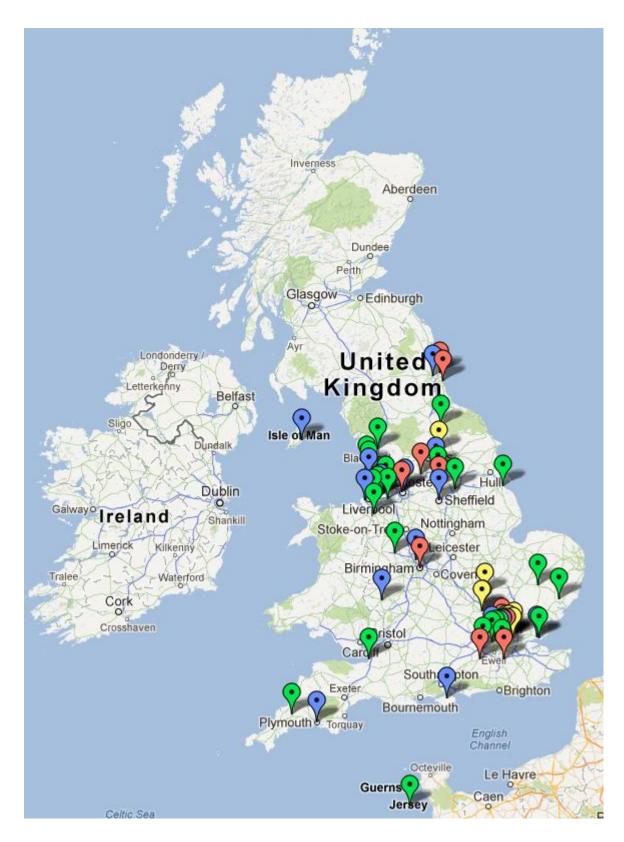
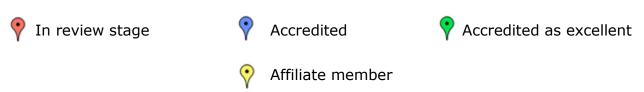


Figure 3: Map showing location of MSNAP members



Section 6: Contextual data

There is a large degree of variation between MSNAP memory services in terms of case load, number of staff, and time between referral and first appointment. There is an especially large difference between clinics in terms of their current caseload, which ranges from 110 to 3146 current service users (see Table 3). Overall, the previous year has seen a growth in the size and scope of the services provided. The mean caseload of services has increased to 671 services users (from 572 users in 09/10) and the mean number of new patients seen has grown from 33 to 43. MSNAP services have also made a significant improvement in the median waiting period between referral and first assessment, which has dropped to 28 days from 42 days during 2009-10.

| Question (number of responses) | Mean | Range | Median |
|--|-------------------|-----------------------------|-------------------|
| Current caseload (n = 37) | 663 service users | 110 - 3146 service users | 561 service users |
| Number of new service users in last 4 weeks (n = 39) | 43 service users | 12 - 141 service users | 36 service users |
| Average period between referral and first assessment (n = 39) | 38 days | 9 - 123 days | 28 days |
| Number of staff working for service (involved in assessment and diagnosis) (n = 37) | 15 people | 4 - 42 people | 13 people |

Table 3: Contextual data submitted by MSNAP members

Table 4 shows that the location of member services is fairly evenly split between community and hospital settings, with only slightly more services based predominantly in a hospital setting.

| Location of clinics (where | Community Setting | 18 services |
|----------------------------|-------------------|-------------|
| applicable) (n= 38) | Hospital Setting | 21 services |

Table 4: Location of Clinics

There is also a wide variation between services regarding the types of staff employed. Table 5 gives an overview of the most commonly employed types of staff and the average total number of sessions (half days) that each staff group works per week. All MSNAP respondents had at least one nurse in the team, while the majority employed an occupational therapist (74%) and/or a clinical psychologist (67%). However only a minority of MSNAP services provide access to support workers (28%), social workers (10%) or dementia advisors (8%).

| Staff Role | % of Clinics with at least one staff member | Mean number of sessions | Median number of sessions |
|---|---|-------------------------|---------------------------|
| Consultant Psychiatrist | 100% | 6 | 5 |
| Staff Grade and Associate Specialist | 64% | 5 | 2 |
| Clinical Psychologist | 67% | 4 | 2 |
| Occupational Therapist | 74% | 8 | 4 |
| Nurse | 100% | 29 | 26 |
| Support Worker | 28% | 4 | 0 |

Table 5: Staff composition of MSNAP member services

Section 7: Key themes of 2011-12 data

Waiting times

As noted in the previous section, median waiting times have decreased since 2009-10, however the aggregated case note audit data indicates that 9% of patients were not contacted within 2-3 weeks of referral to the memory service, and 21% did not begin their assessment process within 4-6 weeks of referral. The fact that some services still do not meet these standards may be due to an increase in referrals, staff cuts, or both.

Monitoring physical health

97% of the patients audited had had a basic dementia screen and blood tests. The referrer is usually expected to complete these and forward the results in the referral. 88% of people received a physical examination and other appropriate investigations, and 92% had had their vision, hearing and mobility checked. Assessing the physical health of people attending memory clinics is important, both because it is an opportunity to detect undiagnosed problems and also to exclude physical causes of confusion or forgetfulness which can mimic dementia. 100% of patients, however, had received an assessment for key psychiatric features such as depression and psychosis, which can also have similar symptoms to dementia.

Staff support

91% of staff surveyed reported receiving an annual appraisal, 93% personal development planning and 94% supervision.

89% of staff receive individual clinical and professional supervision and 74% receive management supervision. Of those who receive supervision, the vast majority rated its frequency and quality as either 'excellent' or 'sufficient'. 99% of staff were able to access additional advice and support if needed, so perhaps some 'supervision' takes place on a more informal, as-required basis. However, there does appear to be a significant minority who do not receive one or both forms of formal supervision.

Staff training

94% of staff said they felt their training, learning and development needs had been recognised and met. However 12% of staff had been refused training because of a lack of funding, and 7% had been refused due to a lack of staff cover. This is likely to become more of a problem with cuts to health services, which could lead to reduction of staff, training budgets being cut, and managers becoming less keen to release staff time for training.

Table 6 below shows percentages of staff who reported receiving training in different areas. Note: respondents who answered that training was 'Not available' were excluded from the counts.

| Training area | % of staff responded YES | % of staff responded NO | % of staff responded NOT APPLICABLE TO MY ROLE |
|--|--------------------------------|-------------------------------|--|
| Staff have completed training and development with their role with the service. This is | | portunities co | mmensurate |
| Dementia knowledge and awareness (n=448) | 81.9% | 5.4% | 12.7% |
| An introduction to local safeguarding vulnerable adults policy (n=451) | 89.1% | 4.4% | 6.4% |
| Applying the principles of person- centred care (n=434) | 73% | 12.5% | 14.5% |
| Communication skills relevant to the role (n=424) | 77.1% | 13% | 9.9% |
| Awareness of local demographic factors, including ethnic/cultural diversity and use of culturally appropriate measures (n=422) | 80.1% | 11.6% | 8.3% |
| The assessment and pharmacological treatment of dementia (n=447) | 62.6% | 7.7% | 29.7% |
| Non-pharmacological interventions (n=433) | 66% | 13.2% | 20.8% |
| The roles of the different health and social care professionals, staff and agencies involved in the delivery of care to people with dementia (n=423) | 74% | 13.9% | 12.1% |

| The Mental Capacity Act or the Adults with Incapacity (Scotland) Act (n=437) | 78.7% | 5.5% | 15.8% |
|--|-------|-------|-------|
| Undertaking nutritional screening using a validated nutritional risk assessment tool (n=424) | 25.2% | 29.5% | 45.3% |

Table 6: Percentage of staff that have received training in various areas

Generally, training is well completed. The figures here may be artificially low, since staff completing questionnaires during self review often do not realise on-the-job learning is acceptable so long as they are competent in the areas highlighted: this can be clarified at the peer review visit.

However the fact that only 81.9% of people working in member memory services had received training or learning about dementia knowledge and awareness is disappointing. 12.7% of staff felt that this was 'not applicable to my role'; arguably this is applicable to all staff working in a memory clinic. The MSNAP standards were updated in mid-2012 to include a standard stating that administrative workers should have dementia awareness training, because they had frequently not had any training in this area, although they are often the first point of contact for people with dementia.

Relationships with referrers and other professionals

100% of memory services have policies and protocols for referring into the service, however only 70% of referrers had been provided with this information. 77% of referrers had been provided with advice by the service, 22% had had training delivered by the service, and 41% had been provided with outreach (including joint visits). 94%, 83% and 81% of services reported providing advice, training and outreach respectively to referrers. 17% of referrers had been surveyed about their experiences by the memory service prior to the MSNAP questionnaire. Commonly it is reported that memory services do provide training and outreach, but this is not always taken up by GPs, and this may be a reason why the reports are low.

Service user involvement

92% of services involve people with dementia and carers in service planning, development and monitoring of the service via face-to-face involvement in a variety of settings. 94% of service users and 96% of carers felt that they had been involved in decision-making about their assessment and diagnosis. Service users and carers should feel equal partners with clinicians in the assessment and diagnosis process, and they should feel able to influence the development of a service they use if there are things they think could be improved.

Section 8: Update on 2009-10 data

The figures in Table 7 below are Type 1 Standards that were commonly unmet in the 2009-10 data. The 2011-12 data shows an improvement against all these standards. n= number of case notes audited.

| Standard | 2009-10 Case Note Audit Data | 2011-12 Case Note Audit Data | |
|--|---------------------------------|---------------------------------|--|
| The person who was assessed for the possibility of dementia was asked if they wanted to know their diagnosis | 52% met (n=459) | 80% met (n=781) | |
| The person who was assessed for the possibility of dementia was asked with whom the outcome of the assessment should be shared | 59% met (n=454) | 79% met (n=787) | |
| If the person drives, he or she was informed about the necessity of reporting the diagnosis to the DVLA | 66% met (n=455) | 86% met (n=774) | |
| The memory service ensures that a diagnosis of dementia is made only after a NICE-compliant comprehensive and holistic assessment of the person's needs by appropriate professionals, either within the service or elsewhere. This includes: | | | |
| A physical examination and other appropriate investigations | 85% met (n=461) | 88% met (n=791) | |
| An assessment of vision, hearing and mobility (NB: Changed to 'A check of vision, hearing and mobility' in October 2010) | 80% met (n=458) | 92% (n=792) | |

Table 7: Improvements against commonly unmet Type 1 standards

These data must be considered in light of the fact that they are taken from the self review of the services involved, before the peer review visit takes place. MSNAP provides services with a report containing their self review data in advance of the review visit, and many services are able make improvements in the intervening time.

In addition, 15 the services that responded in 2011-12 were completing their second cycle of review and it is assumed that as well as greater familiarity with the process, improvements to practice and recording made during their first cycle were carried through to the second cycle, showing better rates of compliance.

Section 9: Comparisons between Cycle 1 and 2

A comparison was made between data received in 2011-12 from teams undertaking their first cycle of accreditation, with those doing their second cycle.

Case note audit

In 74% of case notes audited by first-cycle members, the person was contacted within 2-3 weeks of referral, compared with 85% in the second-cycle members. This could be due to changes made to the process of contacting people during their first cycle, such as contacting by phone before sending a letter, more frequent allocation meetings or more dedicated administrative time to speed up the process.

Fewer people were asked if they would like a copy of the letter sent to the referrer in the second-cycle group compared to the first-cycle group (65% compared to 78% respectively), and fewer were asked if they would also like their carer to receive a copy in the second-cycle group (57% compared to 62% in the first-cycle group). However, more people were asked if they would like an informal, personalised non-medicalised letter in the second-cycle group (46%) compared to the first-cycle group (38%), suggesting perhaps a move to offer people personalised letters instead of the standard copies of letters to the referrer.

Staffing

Table 8 below shows different types of staff that memory services have dedicated time from, or access to, and compares the allocations for teams conducting their first cycle of review and those doing their second cycle.

A higher proportion of teams in the second-cycle group have dedicated time from a psychologist or neuropsychologist and occupational therapist compared to the first-cycle group. All teams in the second-cycle group have access to a speech and language therapist and dietician, compared with 88% and 94% in the first-cycle group respectively. This suggests that the MSNAP process is beneficial in supporting teams to access different professions over time.

The following professionals have dedicated sessional time to contribute to the processes of assessment and diagnosis of memory problems/dementia:

| Profession | First-cycle teams with dedicated time/access | Second-cycle teams with dedicated time/access |
|--|---|--|
| A medical practitioner and a multidisciplinary team consisting of at least two other professions | 94% | 100% |
| A mental health nurse | 100% | 100% |
| A clinical psychologist or neuropsychologist | 75% | 81% |
| An occupational therapist | 88% | 96% |
| The service has access to adequate administrative support | 81% | 89% |
| professionals for advice/support during diagnosing people with memory proble | - | assessing and |
| A speech and language therapist | 88% | 100% |
| A dietician | 94% | 100% |
| A physiotherapist | 100% | 100% |
| A social worker | | |
| A Social Worker | 100% | 100% |
| A geriatrician | 100% | 100% 96% |
| | | |
| A geriatrician | 100% | 96% |

Table 8: Comparison of professions available to first- and second-cycle teams

In contrast, fewer teams in the second-cycle group have access to an Admiral Nurse compared to the first-cycle group. It is not clear why fewer second-cycle teams have access to Admiral Nurses, but if Admiral Nursing services are under threat then this should be taken very seriously.

Links with referrers

A greater proportion of second-cycle teams offer training for referrers (85%) compared with teams undertaking their first cycle of review (75%), and this is reflected in the responses from the referrer questionnaires, with 24% of referrers in the second-cycle group agreeing that they had had training compared with 19% of those in the first-cycle group. As noted in Section 7, many teams offer training but this is not always taken up so that may explain the low responses from referrers. It also demonstrates that teams in the second-cycle group appear to have a greater focus on training for referrers, presumably driven by recommendations made in their first cycle. More second-cycle teams provide outreach than first-cycle teams (81% compared to 75%) but there were no large differences between second-cycle and first-cycle teams in the reports from referrers about receiving outreach, or about the provision or receipt of advice for referrers.

Home visits

88% of first-cycle teams provide home visits, compared with 100% of second-cycle teams. The remaining 12% of first-cycle teams presumably provide appointments at a clinic base only.

Post-diagnostic counselling

79% of second-cycle teams, compared to 69% of first-cycle teams, have access to a specialist post-diagnostic counselling service. This may also be related to the fact that a higher proportion of second-cycle teams have dedicated time from a psychologist, who often provide specialist counselling.

Overall, it appears that undergoing the full MSNAP process has benefitted the services and this is evident in conducting their second cycle of review. More teams at the point of their second cycle provide home visits; they are more likely to have access to diverse professions and post-diagnostic counselling services, provide training for referrers and meet waiting time targets. It is assumed that this is due to having completed one cycle

of review and made improvements from this; that they have utilised support and advice from the MSNAP team as well as encouragement to keep quality improvement on a rolling agenda; and that they have attended the Annual Forum, used the email discussion group, visited other teams as a peer reviewer, and other methods of sharing knowledge and best practice with peers.

Section 10: Patient and carer responses

As part of the MSNAP self-review process memory services are required to distribute questionnaires to service users and carers who have used their service. Between July 2010 and December 2012 MSNAP received 582 completed patient questionnaires and 657 completed carer questionnaires from 45 different memory services around the UK.

When interpreting the accumulated data from the questionnaires it is important to be aware that the data is from the self-review period of the MSNAP process and many services will have used the results from this data to improve their service already. Therefore, the results shown may have been improved since they were recorded.

Interactions with staff

At the MSNAP peer reviews memory service staff tend to receive overwhelmingly positive feedback during the patient and carer meetings. This is also supported by the data MSNAP received from the patient and carer questionnaires. 100% of service users and carers reported that memory service staff treat them with dignity and respect and are courteous at all times. 97% of both service users and carers also said that the staff had taken time to explain the assessment process to them.

"The staff were all very professional and made me feel at ease in which to me was a very daunting situation. Excellent."

Additionally, the results showed that 94% of service users are routinely asked whether they understand what they have been told. 95% of the carer responses also confirmed this. However, the fact that 22% of service users and 8% of carers have reported that they have felt pressurised into making a decision is slightly less positive.

Information Provision

Providing people with dementia and their carers with written information about their condition, their treatment and services/support that are available to them is an important way of making sure they have all of the information that they need and can refer to it as and when it is required. When people receive a diagnosis of dementia they will often have a lot to think about so it is important not to overload them whilst ensuring that they are aware that the information they need is available for when they do need it.

When asked if they felt they had been given enough information 84% of carers and 83% of service users answered yes.

"We have been given enough information for the present time, and I know that if I need more I only have to ask and we will get it"

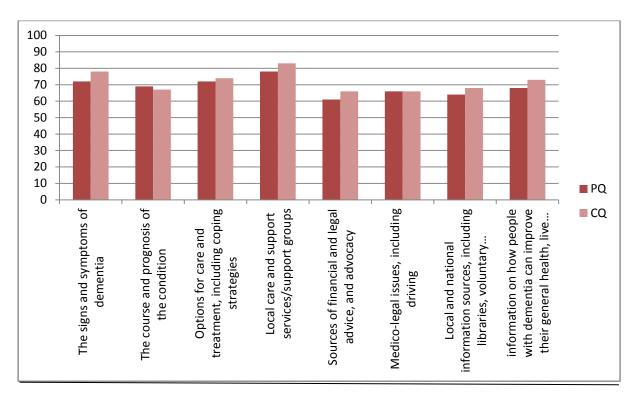


Figure 4: The percentage of written information that patients and carers have received about certain topics.

The results shown in figure 4 suggest that service users and carers are most likely to receive information about local care and support services/support groups (service users=79%; carers=83%) but less likely to receive written information about sources of financial/legal advice (service users=61%, carers=66%), medico-legal issues such as driving (service users=66%, carers=66%) and the course and prognosis of their condition (service users=69%, carers=76%). However, it may not be necessary to provide every person who is diagnosed with some of the above information, for example information about driving.

Figure 4 also shows that carers were more likely to report having received written information than service users. This may be because service users do not remember having been given the information, or perhaps carers have a greater interest in the literature received and are more likely to know what they have been given. These results are very similar to those presented in the previous MSNAP National Report and although there has been a slight increase in the amount of written information reported being received by service users and carers, there is still room for improvement.

Receiving a diagnosis

Receiving a diagnosis of dementia can be a very difficult time for a person and their family; therefore it is important that steps are taken to reduce stress and anxiety at this time. Encouragingly, 97% of service users and 96% of carers reported that they felt the dementia diagnosis had been delivered sensitively, and 93% of service users and 95% of carers confirmed that they had been given the diagnosis in a timely manner without any unnecessary delays. These results suggest that those involved in assessing and diagnosing dementia are trying very hard to make diagnosing dementia as pain-free as possible.

"The Doctor told my mother [the diagnosis] in a kind and sensitive manner, and when I became tearful, he showed the same to me. I feel they made sure we understood everything, and did not make us feel rushed at all".

In the previous MSNAP National Report which was published in 2010 it was reported that only 65.6% of service users were asked if they wanted to know their diagnosis before it was delivered, and 74.5% were asked who they would like the diagnosis to be shared with. Table 9 shows that this has now improved with 78% of service users being asked if they would like to be told their diagnosis and 80% of service users being asked who they would like their diagnosis to be shared with. In addition to this, 82% of service users were made aware that their personal information might be shared with people within the health care team.

| Source | Question | % |
|---------------------|---|-----|
| | | Yes |
| Patient | Were you asked whether or not you wanted to know | 78% |
| Questionnaire | your diagnosis? | |
| Patient | Were you asked who else you wanted to know your | 80% |
| Questionnaire | diagnosis? | |
| Patient | Were you made aware that your personal information | 82% |
| Questionnaire | might be shared within the healthcare team? | |
| | If yes, were you given the reasons why? | 84% |
| Carer Questionnaire | Was the person you care for made aware that his/her | 82% |
| | information might be shared within the healthcare | |
| | team? | 89% |
| | If yes, was he/she given the reasons why? | |

Table 9: Patient and carer responses about diagnosis and confidentiality

Obtaining Feedback

Obtaining feedback from service users and carers is a great way for memory services to improve the service that they provide. The results from the patient and carer questionnaires that were returned showed that only 56% of service users and 55% of carers had been made aware of how to make a complaint about any aspect of the service they had received. However, only 3% of the service users and 2% of the carers who responded to the survey had ever made a complaint. When asked if they provided information about how to make a complaint about any aspect of their service, 100% of

the memory services confirmed that they did. It is likely that the information is available for service users and carers if they need it but as the figures show, not many people have ever made a complaint so it is possible that they had never looked for the information.

"There may have been a poster [explaining how to make a complaint] in the waiting area but I was not looking for one as I was extremely happy with both the staff and facilities".

Even fewer people (30% service users; 27% carers) reported having been asked about their experiences of using the service. These figures are very low which is surprising because feedback from service users and carers would be very beneficial in helping services to improve. Feedback could be obtained by surveying service users and carers, focus groups, or having a comments/suggestions box in the waiting area.

Supporting Carers

Ensuring that carers feel supported is vitally important as it can sometimes be easy for the carer to focus solely on the person they are caring for and ignore their own needs. One of the findings in the previous MSNAP national report was that fewer than half of the carers surveyed (44.4%) had had an assessment of their own needs. Our recent findings show that this has increased slightly, but still only 51% of the carers who responded had had their own assessment. However, this figure could be low because people looking after a friend/relative with dementia do not consider themselves carers, or because they declined the offer of an assessment.

"Though I have answered no to having a full assessment of my needs, it has been made very clear to me that an assessment will be forthcoming as and when I need it".

Furthermore, over 2/3 of the service users and carers who responded to the survey reported having been told about support groups that they may want to attend (service users=73%; carers=78%). Support groups are an excellent way of enabling carers to access further information and they provide opportunities for people in similar situations to meet and discuss their experiences.

Despite this, only 49% of the carers who responded to the survey had been given information or advice about respite/short break services.

Overall, both carers and service users are happy with the service that they receive from their local memory service. It seems carers and service users are completely satisfied with the way that they are treated by memory service staff but there is still room for improvement where providing written information, ensuring that carers are supported and obtaining feedback are concerned.

Section 11: National Recommendations

Analysis of the aggregated data from teams taking part in self review in 2011-12 suggests that there are certain standards, or clusters of standards, that are commonly unmet. Below are some recommendations from MSNAP for memory services.

Recommendation 1: Ensure all patients receive a physical health check. The data showed that not all patients received a physical examination or a check or vision, hearing and mobility. A shared care protocol may help to ensure that GPs always complete physical examinations prior to referral, or services could create facilities to do this at the memory clinic. A check of vision, hearing and mobility could be added to assessment checklists to ensure all patients are asked about this.

Recommendation 2: Focus on improving education and support for referrers, especially GPs. The responses from the referrer questionnaire are shown in Section 9. Training, advice and outreach to referrers are not always offered, or taken up. People frequently report that their GP was a barrier to referral to the memory service and so education and availability of support from the memory service are crucial to engaging GPs in greater dementia awareness. With the advent of the Clinical Commissioning Groups, relationships with GPs are likely to become even more important to the memory services.

Recommendation 3: Formalise and prioritise staff supervision. Staff do not always receive clinical, professional and managerial supervision, either because this is not formally scheduled, because of a lack of supervisor or because workload is high and other tasks are prioritised. Staff should receive regular, individual, formal supervision to allow them to undertake their role in a safe and supported way.

Recommendation 4: Staff receive all appropriate training for their role. Ensure all staff are competent in basic dementia knowledge and awareness, including administrative and reception staff. Monitor mandatory training to make sure this is kept up-to-date.

Recommendation 5: Ensure service users and carers are given high-quality information on a range of topics to address their needs. Service users and carers do not always receive all the information required at the appropriate time. Information packs which can be personalized and added to over time can be a good idea to ensure that people have information to turn to when they need it, or make leaflets available in the waiting area of the clinic or at support groups. Ensure that carers are offered an assessment of their needs, regardless of the level of care required or their apparent ability to cope, and ensure they are given information about respite services at an appropriate time.

Section 12: MSNAP's goals for 2013

Goal 1: Improve our information management systems. MSNAP aims to set up a new information management system whereby self review data are aggregated in a central system and services can see for themselves what data has been collected using a members' portal. This should also speed up the process of producing service reports.

Goal 2: Greater service user involvement. MSNAP would like to recruit more people living with dementia to contribute to the programme – sitting on committees and attending peer reviews. MSNAP is in contact with the Dementia Engagement and Empowerment Project (DEEP) who it is hoped will be able to help link people with dementia up with the programme, and other avenues will be explored.

Goal 3: Produce data on psychosocial interventions. When enough members have completed the psychosocial interventions module, MSNAP will produce a report detailing the provision of psychological and social support for people with dementia and carers around the UK.

Appendix 1: Benchmarking – Services which have completed accreditation listed in order of compliance with type 2 standards and overall compliance

| Rank | Service | % Overall |
|------|---------|---------------|
| | Number | Standards Met |
| 1 | 36 | 100 |
| 2 | 41 | 98.6 |
| 2 | 43 | 98.6 |
| 2 | 5 | 98.6 |
| 2 | 24 | 98.6 |
| 6 | 40 | 98.5 |
| 7 | 32 | 97.9 |
| 8 | 29 | 97.2 |
| 8 | 13 | 97.2 |
| 10 | 1 | 96.5 |
| 11 | 34 | 95.9 |
| 12 | 44 | 95.8 |
| 12 | 14 | 95.8 |
| 14 | 45 | 95.1 |
| 15 | 18 | 94.5 |
| 15 | 6 | 94.5 |
| 15 | 35 | 94.5 |
| 15 | 39 | 94.5 |
| 19 | 28 | 93.9 |
| 20 | 46 | 93.8 |
| 20 | 2 | 93.8 |
| 20 | 31 | 93.8 |
| 23 | 9 | 93.7 |
| 24 | 37 | 92.4 |
| 25 | 10 | 92.2 |
| 26 | 27 | 92.0 |
| 27 | 11 | 91.0 |
| 28 | 7 | 90.4 |
| 29 | 47 | 89.7 |
| 30 | 33 | 88.5 |
| 31 | 30 | 83.7 |

| Rank | Service | % Type 2 |
|------|---------|---------------|
| | Number | Standards Met |
| 1 | 36 | 100 |
| 1 | 41 | 100 |
| 1 | 43 | 100 |
| 1 | 5 | 100 |
| 5 | 32 | 99.0 |
| 5 | 29 | 99.0 |
| 7 | 24 | 98.6 |
| 8 | 1 | 97.9 |
| 9 | 40 | 97.8 |
| 10 | 28 | 97.0 |
| 11 | 44 | 96.8 |
| 11 | 13 | 96.8 |
| 13 | 34 | 96.0 |
| 14 | 14 | 95.8 |
| 14 | 39 | 95.8 |
| 14 | 45 | 95.8 |
| 14 | 9 | 95.8 |
| 18 | 18 | 93.7 |
| 18 | 46 | 93.7 |
| 18 | 6 | 93.7 |
| 21 | 2 | 93.6 |
| 22 | 35 | 93.1 |
| 23 | 31 | 92.0 |
| 24 | 37 | 91.6 |
| 25 | 10 | 91.5 |
| 26 | 27 | 90.7 |
| 27 | 7 | 89.5 |
| 28 | 47 | 89.4 |
| 29 | 11 | 88.3 |
| 30 | 33 | 88.1 |
| 31 | 30 | 83.2 |

Appendix 2: Governance

Accreditation Committee

| Member | Professional Body / Role | Status |
|--------------------------|--|------------------------|
| Martin Orrell (Chair) | Royal College of Psychiatrists | Current |
| Sunita Sahu | Royal College of Psychiatrists | Current |
| Pradeep Arya | Royal College of Psychiatrists | Current |
| Emma Barton | College of Occupational Therapists | Current |
| Alice Moody | College of Occupational Therapists | Current |
| Kim Manley | Royal College of Nursing | Current |
| Emma Ouldred | Royal College of Nursing | Current |
| Reinhard Guss | British Psychological Society, Faculty for Old Age (PSIGE) | Current |
| Tamsin Fryer | British Psychological Society, Faculty for Old Age (PSIGE) | Current |
| Sophie Monaghan | British Psychological Society, Faculty for Old Age (PSIGE) | Current |
| Fiona Proffitt | Alzheimer's Society | Current |
| Peter Ashley | Service user advisor | Current |
| Felicity Freeman | Carer advisor | Current |
| Roger Le Duc- Barnett | Carer advisor | Current |
| Esme Moniz-Cook | British Psychological Society, Faculty for Old Age (PSIGE) | Former: left Sept 2012 |
| Nitin Purandare | Royal College of Psychiatrists | Former: left May 2012 |
| Jean Tottie | Carer advisor | Former: left Feb 2012 |
| Sue Watts | British Psychological Society, Faculty for Old Age (PSIGE) | Former: left Dec 2012 |
| Yve White-Smith | Alzheimer's Society | Former: left Jun 2010 |

Advisory Group

| Member | Profession / Role |
|----------------------|---|
| Chris Jagus | Consultant Old Age Psychiatrist |
| Paula Lonsdale | Nurse |
| Richard Clibbens | Nurse Consultant |
| Chris Maj | Memory Service Manager |
| Lynne Denton | Social Care Lead OPMHS/Team Manager |
| Peter Ashley | Service User Advisor |
| John Mulinga | Consultant Psychiatrist |
| Patricia Irogeme | Associate Specialist Psychiatrist |
| Erszebet Pek | Team Manager |
| Margaret Layfield | Nurse |
| Kumari Galboda | Psychiatrist |
| Sharon Stephenson | Team Lead |
| Antonia Garner | Memory Service Manager |
| Stephen Orleans-Foli | Consultant Psychiatrist |
| Karin Tancock | Professional Affairs Officer for Older People, College of Occupational Therapists |
| Donald Schofield | Carer Representative |
| Martin Orrell | Old Age Psychiatrist |
| Sue Watts | Psychologist |
| Nitin Purandare | Old Age Psychiatrist |
| Esme Moniz-Cook | Clinical Psychologist |
| Anne Hale | Alzheimer's Society |
| | |

Appendix 3: Publications and conference presentations

Publications

Doncaster, E., Hodge, S., Orrell, M. (eds) (2012). *Memory Services National Accreditation Programme - Standards for Memory Services (3rd Edition)*. London: Royal College of Psychiatrists.

Oral Presentations and Workshops

MSNAP Annual Forum, London, 29 November 2010 Update on MSNAP

West Midlands Memory Services meeting, Wolverhampton, 16 May 2011 Memory Services National Accreditation Programme

College of Occupational Therapists 35th Annual Conferences and Exhibition, Brighton, 28 June – 1 July 2011

Influencing at a national level: OT representation for the Memory Services National Accreditation Programme (MSNAP)

With Emma Barton

Delivering Quality Outcomes for People with Dementia, London, 30 June 2011 Memory Services National Accreditation Programme: A quality improvement initiative for memory services

Delivered by Dr Nitin Purandare

Alzheimer Europe Conference, Warsaw, 7 October 2011 Improving the quality of services that assess and diagnose dementia

MSNAP $2^{\rm nd}$ National Memory Services Forum, Manchester, 23 November 2011 $Update\ from\ MSNAP$

Royal College of Psychiatrists Old Age Faculty Meeting, Cardiff, 15 March 2012 Quality improvement for memory clinics: The Memory Services National Accreditation Programme (MSNAP)

Somerset Partnership NHS Foundation Trust Older Persons Conference, Taunton, 2 October 2012 Quality improvement for memory clinics: The Memory Services National Accreditation Programme (MSNAP)

MSNAP 3rd National Memory Services Forum, London, 15 October 2012 *MSNAP: An update*

Occupational Therapists Networking Day, London, 29 November 2012 Influencing at a national level: OT representation for Memory Services National Accreditation Programme (MSNAP) Delivered by Emma Barton

Poster Presentations

Doncaster, E. & Hodge, S. (2011, October). *Engaging memory services in quality improvement/ accreditation during times of financial constraint*. Poster presented at the 7th UK Dementia Congress, Brighton, 30 October – 1 November 2011

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http://www.rcpsych.ac.uk/memory-network MSNAP@cru.rcpsych.ac.uk

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