

PRIORITY BRIEFING

The purpose of this briefing paper is to aid Stakeholders in prioritising topics to be taken further by PenCLAHRC as the basis for a specific evaluation or therapeutic research project.

QUESTION DETAILS

Question ID: 8

Question type: Intervention

Question: Will the integrated care pilot project into dementia care deliver improved services and outcomes for patients and their carers?

Population: Over 65's in Newquay (6,211 on GP lists) and in particular those with dementia.

Intervention: The intervention is an integrated pilot including: (1) GP training on the recognition, assessment, diagnosis and prescribing for dementia; (2) GP led memory clinics; (3) development and use of an integrated needs assessment and caseload weighting tool for dementia; (4) virtual teams of health and social care professionals anchored around GP practices to provide and directly commission care for all patients on a GP dementia register.

Control: Over 65's in the rest of Cornwall who will continue to receive the traditional secondary based older people's mental health services.

Outcome: Early detection and intervention in dementia. Improved management of and outcomes for patients with dementia including: increased life expectancy; delayed progression of dementia; maximise opportunities for independent and fulfilling living; earlier diagnosis and intervention with appropriate care and support; reduced acute care for dementia patients in crisis; improved patient and carer experience and raised awareness of dementia amongst health and social care professionals.

Note on the integrated care pilot:

This programme of interventions is already running but has not yet been evaluated. The DoH have funded a national evaluation and secured independent providers to carry it out.

Part 1: Research Background

Guidelines: NICE guidelines on Dementia: Supporting people with dementia and their carers in health and social care (2006) report that care managers and care coordinators should ensure the coordinated delivery of health and social care services for people with dementia. They also mention the importance of memory services for those with a possible dementia diagnosis and dementia care training for all staff working with older people in health, social care and voluntary sectors.

Research Summary:

One relevant systematic review was identified, conducted in 1998. This review was conducted to provide recommendations to aid primary health professionals in their management of people with all forms of dementia and their carers.⁵ The number of studies or patients covered by the review is unclear as are some of the selection criteria. However, the main conclusions of the review indicate that population screening for dementia in the over 65s cannot be recommended. Instead a case finding approach is suggested and that General Practitioners should consider the use of formal cognitive testing to enhance their clinical judgement.

There were no published trials looking at the implementation of an integrated care pilot for dementia involving the specific components described in this priority brief. However, some studies examined similar approaches. Several studies have developed and piloted their own dementia care systems (as the authors of this question plan to do) and reported their findings.^{1,2,3,8} These range from multi-agency, low cost, generic (and screening) services to enable early identification and intervention in dementia to multi-agency care management including aspects of care for the care-giver as well as the patient. Most studies reported benefits, such as increased numbers of dementia patients identified and treated appropriately, improved quality of life, improved quality of care, improved behavioural and psychological symptoms and in some cases evidence of cost effectiveness.⁸ However, the use of screening was considered an invalid/inaccurate tool to establish diagnosis of dementia.² A study conducted in 2004⁷ found that General Practitioners had difficulties in talking with patients about the diagnosis, responding to behaviour problems and coordinating support services in dementia. Support for general practitioners and others working with older people should concentrate on epidemiological knowledge, disclosure of the diagnosis and management of behaviour problems in dementia. This supports some components mentioned in the care pilot of this brief.

Ongoing Research:

One study sponsored by NHS R&D Regional Programme 'Can early psychosocial intervention offered to older people with dementia and their families through a Community Memory Clinic improve their quality of life?' by Dr Esme Moniz-Cook. This was registered in 2004 but results seem unavailable.

Another study sponsored by the University College London Hospitals NHS Foundation Trust 'Dementia early recognition and response project: Evidence-based interventions in dementia: a randomised controlled trial of an educational programme to improve early recognition and response in primary care' by Prof Steve Iliffe was due to begin June 2009 and complete in October 2012.

The Health Technology Assessment (HTA) Database has a record for The Netherlands Organisation for Health, Research and Development who are currently (2007-2010) running a study on the "Effectiveness and costs of post-diagnosis treatment in dementia coordinated by multidisciplinary memory clinics in comparison to treatment coordinated by GP's (project) (Project record)."

Part 2: Prioritisation Information

1. The health problem

Epidemiology:

The term 'dementia' is used to describe a syndrome in which there is progressive decline in multiple areas of function, including decline in memory, reasoning, communication skills and the ability to carry out daily activities. Alongside this decline, individuals may develop behavioural and psychological symptoms such as depression, psychosis, aggression and wandering, which may cause problems in themselves and can complicate care. These may occur at any stage of the illness. The causes of dementia are not well understood but there are structural and chemical changes in the brain leading to the death of brain tissue. Dementia is a terminal condition but people can live with it for 7–12 years after diagnosis. Family carers of people with dementia are often old and frail themselves, with high levels of depression and physical illness, and a diminished quality of life.

There are currently 700,000 people in the UK with dementia, of whom approximately 570,000 live in England. Dementia costs the UK economy £17 billion a year and, in the next 30 years, the number of people with dementia in the UK will double to 1.4 million, with the costs trebling to over £50 billion a year. While the numbers and the costs are daunting, the impact on those with the illness and on their families is also profound. It is estimated that 333 people in the over 65's living in Newquay have dementia but that only 41% are known to GP practices. In Devon the number of those thought to have dementia is approximately 12,000. The south west Peninsula has an increasing population of over 65's (a higher proportion than the national average for England) and it is predicted that those with dementia will double in number over the next 20 years.

2. Identification of the topic as a priority

National dementia strategy (2009) highlights the following areas as priorities for dementia care:

- Good-quality early diagnosis and intervention for all.
- Enabling easy access to care, support and advice following diagnosis.
- Improved intermediate care for people with dementia.
- An informed and effective workforce for people with dementia.

SW SHA Priorities framework 2008-11

- People diagnosed with dementia to have an initial agreed care plan within four weeks of diagnosis.
- Ensure all people with a long term condition have a personalised care plan that supports their self-management.

3. Local perspective

- Early diagnosis and treatment of dementia is a priority for Cornwall and the Isles of Scilly PCT.

Tractability:

- Feasibility depends on the extent to which this programme pilot has already been implemented.

- Possibility that an evaluation could be conducted (on top of the national evaluation) but more specific focus would be necessary and clarity about the content of the existing evaluation would be needed.
- This project has already been running for one year.

An overview of the local context

This project has been approved by the Department of Health as a pilot project for integrated care. There is a national evaluation planned which is to begin this year but it is limited to patient and staff satisfaction. There is limited funding available with the project for aspects of evaluation not directly related to service delivery.

References

(1) Banerjee, S., R. Willis, et al. (2007). "Improving the quality of care for mild to moderate dementia: an evaluation of the Croydon Memory Service Model." *International Journal of Geriatric Psychiatry* 22(8): 782-8.

BACKGROUND: The large majority of people with dementia receive nothing in the way of specialist assessment and care at any stage of their illness. There is a particular lack of services focussed on early identification and intervention in dementia where there is the possibility of long-term harm reduction for people with dementia and their family carers. We have developed a model of care that is complementary to local systems of health and social care (The Croydon Memory Service Model [CMSM]). This is a low-cost, high-throughput, generic service to enable early identification and intervention in dementia. It is a multi-agency approach with joint ownership by health services, social services and the voluntary sector with embedded specifically-tailored approaches to primary care and minority ethnic communities. **METHOD:** We completed a service evaluation of the introduction of the CMSM in a single borough in South London. Six predefined service goals were set: high acceptability; high appropriate referral rate; successful engagement with people from minority ethnic groups; successful engagement with people with young onset dementia; focus on engagement with mild cases to enable early intervention; and an increase in the overall number of new cases of dementia seen. Mixed qualitative and quantitative methodologies were used including a description and 6-month follow-up of a cohort of 290 consecutive referrals. **RESULTS:** All key predefined service goals were met: 95% acceptability; 94% appropriate referrals; successful engagement with minority ethnic groups (two-fold greater number compared with that expected from general population demographic data); 17% of referrals under 65 years of age; 68% referrals with mild or minimal dementia severity; and an estimated 63% increase in the number of new cases of dementia seen in Croydon. At 6-month follow up, those referred to the service had decreased behavioural disturbance and increased quality of life compared with baseline. **CONCLUSIONS:** Specific services for early dementia, which deliver diagnosis and care, can be established. These services can increase the numbers of people with early dementia identified and provided with care. Those receiving such services appear to improve in terms of quality of life and behavioural and psychological symptoms of dementia. Next steps should include the establishment of such services in other representative areas and evaluation of their effectiveness in comparison with other models of care.

(2) Boustani, M., C. M. Callahan, et al. (2005). "Implementing a screening and diagnosis program for dementia in primary care (Brief record)." *SO: Journal of General Internal Medicine*(7): 572-577.

(3) Callahan, C. M., M. A. Boustani, et al. (2006). "Effectiveness of collaborative care for older adults with Alzheimer disease in primary care: a randomized controlled trial." *SO: JAMA : the journal of the American Medical Association*(18): 2148-57.

CONTEXT: Most older adults with dementia will be cared for by primary care physicians, but the primary care practice environment presents important challenges to providing quality care. **OBJECTIVE:** To test the effectiveness of a collaborative care model to improve the quality of care for patients with Alzheimer disease. **DESIGN, SETTING, AND PATIENTS:** Controlled clinical trial of 153 older adults with Alzheimer disease and their caregivers who were randomized by physician to receive collaborative care management (n = 84) or augmented usual care (n = 69) at primary care practices within 2 US university-affiliated health care systems from January 2002 through August 2004. Eligible patients (identified via screening or medical record) met diagnostic criteria for

Alzheimer disease and had a self-identified caregiver. INTERVENTION: Intervention patients received 1 year of care management by an interdisciplinary team led by an advanced practice nurse working with the patient's family caregiver and integrated within primary care. The team used standard protocols to initiate treatment and identify, monitor, and treat behavioral and psychological symptoms of dementia, stressing nonpharmacological management. MAIN OUTCOME MEASURES: Neuropsychiatric Inventory (NPI) administered at baseline and at 6, 12, and 18 months. Secondary outcomes included the Cornell Scale for Depression in Dementia (CSDD), cognition, activities of daily living, resource use, and caregiver's depression severity. RESULTS: Initiated by caregivers' reports, 89% of intervention patients triggered at least 1 protocol for behavioral and psychological symptoms of dementia with a mean of 4 per patient from a total of 8 possible protocols. Intervention patients were more likely to receive cholinesterase inhibitors (79.8% vs 55.1%; $P = .002$) and antidepressants (45.2% vs 27.5%; $P = .03$). Intervention patients had significantly fewer behavioral and psychological symptoms of dementia as measured by the total NPI score at 12 months (mean difference, -5.6; $P = .01$) and at 18 months (mean difference, -5.4; $P = .01$). Intervention caregivers also reported significant improvements in distress as measured by the caregiver NPI at 12 months; at 18 months, caregivers showed improvement in depression as measured by the Patient Health Questionnaire-9. No group differences were found on the CSDD, cognition, activities of daily living, or on rates of hospitalization, nursing home placement, or death. CONCLUSIONS: Collaborative care for the treatment of Alzheimer disease resulted in significant improvement in the quality of care and in behavioral and psychological symptoms of dementia among primary care patients and their caregivers. These improvements were achieved without significantly increasing the use of antipsychotics or sedative-hypnotics. TRIAL REGISTRATION: clinicaltrials.gov Identifier: NCT00246896.

(4) Maeck, L., S. Haak, et al. (2007). "Early diagnosis of dementia in primary care: a representative eight-year follow-up study in Lower Saxony, Germany." *SO: International journal of geriatric psychiatry*(1): 23-31.
OBJECTIVE: To investigate whether primary care competency in early diagnosis of dementia might have changed during 1993 and 2001. METHOD: By means of a representative follow-up survey 122 out of 170 (71.8%) family physicians (FPs) in Lower Saxony, Germany, were randomly assigned to two written case samples presenting a patient with mild cognitive impairment (case 1a vs. 1b: female vs. male patient) and moderate dementia (case 2a vs 2b: vascular type (VD) vs Alzheimer's disease (DAT)), respectively. By means of a structured face-to-face interview, they were asked for their diagnostic considerations. RESULTS: In comparison to 1993, dementia was significantly more frequently considered. However, there was a striking tendency in overestimating vascular aetiology and under-diagnosing probable DAT (case 1a/1b: DAT: 11.0% in 1993 vs 26.2% in 2001; VD: 2.1% in 1993 vs 17.2% in 2001). As a possible contributor to a dementia syndrome, concomitant medication was considered only exceptionally (case 2a/2b: 4.4% in 1993 vs 2.5% in 2001). Physicians above 50 years of age showed a significantly lower early diagnostic awareness. At follow-up, the presumed interest in geriatric (psychiatric) topics dramatically faded from 66.9% to 35.2%. CONCLUSIONS: Our results demonstrate a persistent need of training efforts aiming at the early recognition of dementia, especially of DAT, in primary care.

(5) North of England Evidence Based Guideline Development, P. (1998). "The primary care management of dementia (Structured abstract)." *SO: University of Newcastle upon Tyne, Centre for Health Services Research*: 87.

(6) The Netherlands Organisation for Health, R. and Development (2006). "Effectiveness and costs of post-diagnosis treatment in dementia coordinated by multidisciplinary memory clinics in comparison to treatment coordinated by GP's (project) (Project record)." SO: The Netherlands Organisation for Health Research and Development (ZonMw).

(7) Turner, S., S. Iliffe, et al. (2004). "General practitioners' knowledge, confidence and attitudes in the diagnosis and management of dementia." SO: Age and ageing(5): 461-7. OBJECTIVE: To measure general practitioners' knowledge of, confidence with and attitudes to the diagnosis and management of dementia in primary care. SETTING: 20 general practices of varying size and prior research experience in Central Scotland, and 16 similarly varied practices in north London. Participants: 127 general practitioners who had volunteered to join a randomised controlled trial of educational interventions about dementia diagnosis and management. METHODS: Self-completion questionnaires covering knowledge, confidence and attitudes were retrieved from practitioners prior to the educational interventions. RESULTS: General practitioners' knowledge of dementia diagnosis and management is good, but poor awareness of its epidemiology leads to an over-estimate of caseload. Knowledge of local diagnostic and support services is less good, and one third of general practitioners expressed limited confidence in their diagnostic skills, whilst two-thirds lacked confidence in management of behaviour and other problems in dementia. The main difficulties identified by general practitioners were talking with patients about the diagnosis, responding to behaviour problems and coordinating support services. General practitioners perceived lack of time and lack of social services support as the major obstacles to good quality care more often than they identified their own unfamiliarity with current management or with local resources. Attitudes to the disclosure of the diagnosis, and to the potential for improving the quality of life of patients and carers varied, but a third of general practitioners believed that dementia care is within a specialist's domain, not that of general practice. More experienced and male general practitioners were more pessimistic about dementia care, as were general practitioners with lower knowledge about dementia. Those reporting greater difficulty with dementia diagnosis and management and those with lower knowledge scores were also less likely to express attitudes endorsing open communication with patient and carer. CONCLUSION: Educational support for general practitioners should concentrate on epidemiological knowledge, disclosure of the diagnosis and management of behaviour problems in dementia. The availability and profile of support services, particularly social care, need to be enhanced, if earlier diagnosis is to be pursued as a policy objective in primary care.

(8) Wolfs, C. A., C. D. Dirksen, et al. (2009). "Economic evaluation of an integrated diagnostic approach for psychogeriatric patients: results of a randomized controlled trial." SO: Archives of general psychiatry(3): 313-23.

CONTEXT: Because of the increasing number of elderly people with dementia, the costs of dementia and dementia care are expected to grow rapidly in the coming decades. Cost-effectiveness results are relevant for decision making about new strategies in dementia care. OBJECTIVE: To evaluate the cost-effectiveness of an integrated multidisciplinary diagnostic facility for diagnosing dementia in ambulatory psychogeriatric patients. DESIGN: Randomized controlled trial with an economic evaluation component. SETTING: The Maastricht Evaluation of a Diagnostic Intervention for Cognitively Impaired Elderly, Maastricht University Hospital, Maastricht, the Netherlands. PATIENTS: A total of 137 patients who received care in the multidisciplinary diagnostic

facility and 93 who received usual care. MAIN OUTCOME MEASURES: Quality-adjusted life-years (QALYs) as the main outcome measure and cognition and behavioral problems as secondary outcome measures. RESULTS: Compared with patients receiving usual care, patients who visited the diagnostic facility gained a mean 0.05 QALY at the extra cost of euro65. The incremental cost per QALY amounted to euro1267. This point estimate lies beneath commonly accepted thresholds and is within an acceptable range of uncertainty. With regard to the secondary analyses, cost-effectiveness results showed a substantial amount of uncertainty and were therefore indecisive. CONCLUSION: On the basis of the main cost-per-QALY analysis, the use of the integrated multidisciplinary diagnostic facility is cost-effective for the diagnosis and management of dementia in ambulatory patients.