



Enhanced Service for people with dementia in Primary Care

Alistair Burns and Laurence Buckman

September 2013

Summary

The Enhanced Service for dementia, introduced in April 2013, is based in Primary Care and provides for the identification of people with dementia by incentivising case finding in people known to be at risk. As part of a wider debate and consultation on a variety of interlinked issues around the timely diagnosis of dementia, a multi-disciplinary group met to consider how the Enhanced Service might be optimally used to increase the numbers of people receiving a diagnosis and accessing post diagnostic support. Suggestions for amendments to the existing system included introducing a question similar to that used in the Hospital based CQUIN and providing protected time in Primary Care for a care planning meeting. This short paper summarises the discussion held.

Background

Dementia is a national priority for Health and Social Care and NHS England have articulated the ambition that two thirds of the estimated number of people with dementia should receive a formal diagnosis, with the support that this attracts, by 2015. There are a variety of views surrounding this apparently straightforward aspiration including debate about how this may be best achieved, the need for post diagnostic support and the concern that this is a form of screening being introduced without people's consent or due consideration of the potential harms.

The Enhanced Service for Dementia (known affectionately as the DES where D is for Directed, as it has to be offered by every part of the English NHS) has suggested that GPs could be incentivised by asking people in certain at risk groups about their memory. Initial proposals included all people over 75 then subsequently, in the light of feedback, the final Enhanced Service was for people known to be at risk of dementia in three groups – those with cardiovascular risk factors, people with long term neurological conditions and people with learning disability (<http://www.england.nhs.uk/wp-content/uploads/2013/03/ess-dementia.pdf>).

In June 2013, a multi professional meeting was held with the aim of trying to achieve a consensus on the next steps (*Timely diagnosis of dementia: Integrating Perspectives, Achieving Consensus*, copy will be attached to the final report). Five complementary themes emerged with the suggestion that a group should be tasked with taking each forward: consideration of the

Enhanced Service for dementia; a national reference group to support Clinical Commissioning Groups on their local plans for dementia; consideration of an information prescription; review and scoping of the evidence base in dementia diagnosis and; prospects for prevention in vascular dementia.

On 11 July 2013, a meeting was held (attendees listed in Appendix 1) to discuss the Enhanced Service for Dementia and this short report summarises the discussion and conclusions.

Objective of the Meeting

The purpose of the meeting was to review the Enhanced Services specification for dementia and consider how it might be developed further to enhance the care package offered to patients, their families and carers. It also gave the opportunity to consider, specifically, views as to how it could be used to best effect in supporting the national ambition of diagnosing dementia in two thirds of the estimated number of people with the condition and providing the best high quality post diagnostic support.

The output of the meeting was planned to be an agreed set of conclusions outlining some of the clinical issues involved and the opportunities the Enhanced Service may provide. It was emphasised that the group had no mandate or influence on the confidential discussions between the BMA General Practitioners Committee and NHS Employers (acting on behalf of NHS England). However, it was agreed that the observations may be of some interest to the negotiators.

Any change to the Enhanced Service would need agreement of NHS England (and if necessary the Department of Health) following negotiations between NHS Employers and the BMA General Practitioners Committee.

Discussion

There were diverse views expressed in the meeting about the current Enhanced Service, specifically around case finding. The current summary and conclusions attempt to highlight those areas where there was broad agreement (and where there was not) on what an ideal service for people with dementia and their carers would look like, while at the same time recognising the reality that, in practice, supporting and adapting rather than extirpating the current Enhanced Service would be a positive outcome. In other words, the feeling of the group was that it is still better to have something which shone a light on dementia, albeit still work in progress, rather than having nothing at all.

The main points of the discussion were:

- There was a debate on case finding with support for the current Enhanced service, a recognition that it was likely to be included in the next iteration but views expressed that it was not the correct way to proceed.
- It was the view of the group that patients and carers would benefit most from a dedicated consultation with their GP (or appropriate member of the primary care team) at least once a year, and in particular, shortly after diagnosis.
- This consultation would give the opportunity to provide the opportunity to clarify concerns, to review current and future care including the carer's health needs. Where it was deemed appropriate, a separate consultation could then be arranged for the carer.
- The memory question recommended in the existing dementia enhanced service could be replaced with a question more in line with that in the hospital CQUIN ie a question a clinician would ask of themselves (eg "Do you think the person may have a memory problem?").
- There was a consensus that the enhanced service should focus as much on the care of people post diagnosis rather than solely focusing on diagnosis of new patients. This view built upon the output from the Timely Diagnosis of Dementia meeting which gave a strong message that post diagnostic support was crucial.
- There is a need to encourage integration of care and stronger ties between the different care organisations involved in a dementia patients care package.
- Where possible family members need to be involved in every stage of care and often felt excluded from the process of diagnosis and needed to be included in consultations with the GP and other health care professionals.
- It is recognised that patient confidentiality has to be acknowledged and respected, and the involvement of others has to be with the patient's consent. However, patients should be encouraged to involve family members.
- More discussion was needed and the role of Advanced Care Planning was emphasised. Carers often felt they were excluded from access to information that would have informed them that their family member had dementia. If this

information had been made available it would have allowed family members to support the patient and understand changes in behaviour.

- It was suggested that some current policies and guidance inhibited GPs and other practitioners from disclosing information even when it would be in the patient's best interests.
- Advanced care planning for people with dementia would be beneficial and should be standard procedure for people with dementia.
- In addition an information pack which outlines the services and support available to patients and their families would be a great support and should be made available to patients as soon as is practical post diagnosis.
- Appropriate respite care is seen as essential for carers and helps everyone.
- Healthcare professionals, patients and carers need to be more aware of the services and support offered by charities and other third sector organisations.
- Residents of care homes (most of whom have dementia) need the same standard of care as other patients.
- There was recognition that the funding envelope for any change in the service would have to be assessed as part of the negotiation.

Main Conclusions

The two principle conclusions offer an opportunity to provide **diagnosis** and **support** following diagnosis to people with dementia and their carers to improve quality of care, and also to align with NHS England's ambition.

Diagnosis: case finding

Views on this were on a spectrum. First, that case finding was a positive notion and a suitable and desirable inclusion in the Enhanced Service. Second, that some form of case finding was highly likely to remain in the Enhanced Service and it was therefore prudent to try to exert influence on its form. Third, that case finding was too aligned to screening to be considered an appropriate activity. The meeting had the advantage of not having to come to a conclusion so reflecting and respecting the views is the purpose of this summary.

To maintain the primacy of clinical impression, it was suggested that the question be amended to reflect this and to become in line with the Hospital Dementia CQUIN (eg "Has the person been more forgetful in the last 12 months to the extent that it has significantly affected their daily life"). This has the disadvantage of concentrating on memory but has been widely accepted elsewhere and is a question a clinician addresses to themselves, therefore

taking into consideration information they have on record and can encourage a conversation with family and carers.

A broader question might be: “Is there anything to suggest that there may be symptoms related to dementia that potentially would benefit from further assessment and that assessment would be wanted by, and acceptable to, the patient and family?” This would raise awareness in Primary Care and allow creativity in the approach to diagnosing dementia and providing post diagnostic support. Only if the answer is positive, and further assessments took place (such as a cognitive test like the GP Cog or Mini Cog) would the incentive system be triggered.

Support: care planning

It was clear that having specific time (say half an hour a year) with patients (and their families and carers where appropriate) would be very advantageous and would provide much needed post diagnostic support.

The Practice could offer a specific appointment each year to every patient on the dementia register (the exact format and content to be agreed with the patient and family). This may consist of a general review, the development (and monitoring) of a care package, including a discussion of Advanced Care Planning (ACP). Patients and families should be encouraged to make a recording of their wishes and lifestyle choices and to make plans for the future. It is recognised that discussion of ACP is a sensitive topic that many practitioner’s are wary of raising and that some patients may not be ready to discuss. The focus of the consultation would be led by the patient and carer concerns. For some patients the consultation may focus on short to medium-term lifestyle changes that may be beneficial, others will want to formalise this into an Advance Care Plan.

Where desirable, a separate appointment would be made for the carer to address their personal health needs. (It is accepted that the carer of the person with dementia may not be a patient of the same GP.) Perhaps a GP with an extended role in each practice could do this or it could be undertaken by a Specialist Practice Nurse who has undergone preparation in the competencies identified in Primary Care Dementia Liaison Skills.

An alternative which was discussed was that the Practice might consider, in collaboration with the Alzheimer's Society, providing an open ended group to disseminate information to patients who may be worried about their memory. This could explore some of the issues involved in going forwards for further investigation – such as what this might mean in terms of driving or concerns about the consequences of a diagnosis of dementia.

Other considerations

The QOF: The three Dementia aspects of the current QOF are summarised in Appendix 2. To facilitate the harmonisation of the approach to dementia and provide focus, it was suggested that the Review aspect should be drawn out of QOF and incorporated into the DES. This would avoid the issue of duplicate payment.

The QOF measures the number of people with a diagnosis and is more a process rather than outcome measure. At one level, it simply represents a list generated by a Practice when searching specific Read Codes (outlined in Appendix 3). There have been several examples where simplifying the Read codes can result in a significant increase in those identified who are known to have dementia but simply not coded (for example, people in care homes being prescribed anti dementia drugs). Keeping that, and the third measure of blood tests, in QOF seems appropriate.

Screening: the UK Screening Committee are still carrying out their review of screening in Dementia and one of the other groups to come out of the Dementia Consensus meeting was examining vascular dementia, including the prospect for screening for vascular risk factors (planned for 20 September 2013). A report of a recent study (1) showed no evidence in favour of benefit or evidence of harm from population screening for dementia (or Alzheimer's disease).

Involving Family and Carers: A major concern expressed (at this and the Timely Diagnosis meeting) was the involvement of family members, particularly at an early stage of dementia where they may express more concerns than the patient. It was suggested that guidance from the GMC on how to address this issue might be helpful.

The Enhanced Service: The focus of the original enhanced service for dementia is “Facilitating timely diagnosis for people with dementia”. The current ideas represent an extension of that. The argument in favour of this is that there has emerged an appreciation, from the *Timely Diagnosis meeting* that post diagnostic support is key and providing that, in tandem with the diagnosis, will improve quality of life for people with dementia and their carers.

Next steps

This report will be made available to the teams negotiating the GP Contract between the NHS Employers (on behalf of NHS England) and the BMA.

This Group does not need to meet again and the outputs will be made available to the Timely Diagnosis

1. Systematic review finds no benefits to population screening for dementia *BMJ 2013; 347 doi: <http://dx.doi.org/10.1136/bmj.f4638> (Published 19 July 2013) Cite this as: BMJ 2013;347:f4638*

Appendix 1 : Attendees

Name	Email Address
Alistair Burns	alistair.burns@manchester.ac.uk
Laurence Buckman	l.buckman@ntlworld.com
Beth Britton	beth@bethbritton.com
Martin Brunet	martin@binscombe.net
Mark Brodigan	markbrodigan@nhs.net
Dean Marshall	wdeanmarshall@btinternet.com
Jill Rasmussen	Jill.Rasmussen@virgin.net
James Warner	j.warner@imperial.ac.uk
Barbara Woodward Carlton	barbaracarlton@hotmail.co.uk
Tom Denning	Tom.Dening@nottingham.ac.uk
Michelle Place	michelle.place1@nhs.net
Amanda Howe	Amanda.howe@nhs.net
Alison Cook	alison.cook@alzheimers.org.uk

Appendix 2: Current dementia components of the QOF

DEM001	The contractor establishes and maintains a register of patients diagnosed with dementia	5	-
DEM002	The percentage of patients diagnosed with dementia whose care has been reviewed in a face-to-face review in the preceding 12 months	15	35-70%
DEM003	The percentage of patients with a new diagnosis of dementia recorded in the preceding 1 April to 31 March with a record of FBC, calcium, glucose, renal and liver function, thyroid function tests, serum vitamin B12 and folate levels recorded between 6 months before or after entering on to the register	6	45-80%

Appendix 3: Primary Care Dementia Registers – Four Read codes

ICD 10		Read Code
F00	Dementia in Alzheimer’s disease	Eu00
F00.2	Dementia in Alzheimer’s disease, atypical or mixed type (“Mixed Dementia”)	Eu002
F01	Vascular dementia	Eu01
F03	Unspecified dementia	Eu02z

(From Paul Russell and Sube Banerjee, originally NHS London)