

# **Timely diagnosis of dementia: Integrating Perspectives, Achieving Consensus**

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**(on behalf of the Timely Diagnosis of Dementia Consensus Group)**

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## Summary

The benefits of a timely, high quality diagnosis of dementia for patients, their families and carers, where appropriate, are compelling. Diagnosis is not an end in itself, but a gateway to making informed personal life choices. It should provide access to a full range of treatment options (medical and psycho-social), and, importantly, appropriate post diagnostic support and services. While there are many examples of excellent practice, there is regional variation across England and people with dementia, their families and carers, wherever they live, have the right to information that supports a timely diagnosis, enabling them to receive the best possible treatment, support and care.

In June 2013, a meeting brought together people living with dementia, clinicians and policy makers to debate the key issues around the diagnosis and support for people with dementia. The key outcome was a broad consensus that post diagnostic support was essential and probably the most important component of all aspects of their care. 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. It is planned to reconvene the Group to review progress in six months.

## Introduction

The importance of dementia is widely accepted. The personal effect of dementia on people with the diagnosis and their families and carers combines with the numbers affected (800,000 in the UK), the projected increase (doubling in a generation) and the economic effects, to make it one of the greatest challenges to health and social care in the world.

In England, the National Dementia Strategy was published in 2009 with the Prime Minister's Challenge on Dementia, launched three years later in March 2012, highlighting a number of areas of importance including: the diagnosis of dementia (less than 50% receive a formal diagnosis) ; the need for post diagnostic support for people with dementia, their families and carers; the need to have dementia friendly communities; research; dementia in care homes, (80% of whose residents have significant cognitive impairment or dementia); hospital care (25% of NHS beds are occupied by a people with dementia); and the appropriate prescription of antipsychotic medication.

The issues around the diagnosis of dementia have been centre stage and the number of people who have had a formal diagnosis (using General Practice based Quality and Outcomes Framework [QOF] figures as the numerator with the estimated prevalence from national reports as the denominator) is around 46%, although the rate has edged up a few percentage points in recent years. There is a significant variation in diagnostic rates

between Clinical Commissioning Groups (CCGs, 38 % to 69%). The figures in Scotland and Northern Ireland are higher.

Successive reports from the Alzheimer's Society, Alzheimer's disease International and the All Party Parliamentary Group on dementia strongly suggest that an accurate high quality diagnosis is what people with dementia and their carers want and that delays in diagnosis are frustrating. Beliefs that dementia is part of normal ageing and that nothing can be done are believed to all contribute to the low diagnosis rate. The response of the Department of Health, supported by a broad consensus, has been to raise awareness and to encourage people to come forward for investigation and treatment. In an attempt to counter stigma and to increase awareness of dementia and its early symptoms, three awareness campaigns have been launched over the last three years. These have been justified by the presumed benefits of a diagnosis which include empowerment of people, facilitating autonomy, allowing planning plus acting as a catalyst for discussions about Power of Attorney, maintaining health, driving vehicles and advanced care planning.

In addition, incentives have been placed in the system. The Dementia CQUIN (Commissioning for Quality and Innovation) allows for the assessment and onward referral for people over the age of 75 admitted to a general hospital who stay longer than three days, the NHS Health Check raises awareness of dementia and the Enhanced Service for Dementia (known 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 difficulties.

It has been suggested that these approaches could be seen as a form of screening, masquerading under a banner of case finding. However, it is clear that the issue of screening for dementia (and Alzheimer's disease) has been considered carefully by the UK National Screening Committee (2010) who have concluded that there is no justification, at present, for such an approach. The evidence base for early diagnosis and the potential harms of the diagnosis, (such as over diagnosis, misdiagnosis, issues of mental capacity, consent, availability of services and diversion of resources) have to be balanced with the harms of not making a diagnosis and need to be addressed.

Over the last few months, there has been debate and discussion about many of the issues surrounding the diagnosis of dementia in the British Medical Journal, and print and social media. The suggestion has been raised that defining a predetermined rate of diagnosis is a politically driven target and the assumption made that this might be "hitting the target but missing the point". The terminology of "timely" as opposed to "early" diagnosis (as described in the Nuffield Bioethics report) has also been discussed. Also, concerns have been expressed about the probity and practicality of asking about memory problems when a person is coming for something completely unrelated. The hospital CQUIN does include a question about memory loss affecting the person's life but is part of an assessment of delirium and is about identifying where there are concerns about memory which impinges on a person's life.

## The Meeting

It was decided to convene a meeting to debate the issues, the three objectives of which were to:

- **air perspectives** on the major clinical, pragmatic, academic and ethical issues around timely diagnosis, also touching on contractual issues;
- bring these together, reconcile differences and **work towards consensus** on the major issues;
- agree on a **plan** for the **next steps**.

### Objective 1: airing perspectives

The agenda is reproduced in Appendix 1 and the slides of the presenters are on the NHS England website. Briefly, Alistair Burns and Laurence Buckman introduced the day noting the crucial importance of dementia, the current strains on primary care, the need for post diagnostic support and that current initiatives were about case finding and not population screening

Martin Brunet questioned the value of early or timely diagnosis in the absence of people or their families asking for help and said that finite resources should be directed toward post diagnostic support.

Jill Rasmussen cautioned about the dangers of not diagnosing people and that a holistic assessment of the patient was essential, and wished to explode the myth that nothing can be done.

Nick Cartmell detailed the term timely diagnosis as one which emphasised that benefit would accrue from the diagnosis.

Sube Banerjee (stepping in at the last minute for James Warner) advocated diagnosis earlier in the illness than often happened which could be too late to avoid a crisis admission to hospital or a care home and denied people and the families the opportunity to plan ahead. He pointed out that transforming toxic uncertainty into empowered understanding was a goal.

Tom Dening emphasised that, in line with the WHO checklist for acceptability of screening, there was no justification for population screening in either dementia or Alzheimer's disease

Chris Dyer spoke about his experience of the hospital CQUIN, noting that it had been successful in identifying a number of people with dementia, and cited a case study where the family were particularly grateful that an admission to hospital had given the opportunity to make a diagnosis of dementia and put in place a package of care and support.

There followed two powerful presentations from Barbara Woodward Carlton and Peter Dunlop. Barbara spoke of the clarity which her mother's diagnosis had afforded her in terms of understanding her behaviour, facilitating access to help and allowing greater

understanding amongst family and friends. Peter described his own experience saying that the diagnosis was a relief to him and his wife who were able to manage the situation much better.

Other carers, Beth Britton, Sally Ann Marciano and Ming Ho contributed their experience emphasising that support is essential and that good outcomes for the whole family, in addition to those of the person with dementia, should be taken into consideration.

## **Objective 2: working towards consensus**

### **General Discussion**

Rather than trying to reflect the richness of the discussion in a narrative, the following brief statements attempt to capture the main comments made, on which there was general consensus.

#### **There is a need to raise the awareness of dementia:**

- Awareness raising is important and can help reduce stigma
- The benefits of a diagnosis need to be more clearly articulated – for individuals and clinicians
- More can be done to raise awareness and support informed decision-making
- That nothing can be done for dementia is a myth
- We should turn toxic uncertainty into empowered understanding

#### **Terminology and practice around dementia diagnosis is important**

- Timely (rather than early) diagnosis is the best way of describing the diagnostic process
- We need to say exactly what we mean by timely diagnosis and differentiate it from screening
- Diagnosis is not necessarily in and solely of itself a benefit
- A quick diagnosis following the onset of symptoms is important
- The decision to embark on the diagnostic process should be an informed choice
- The potential harms to those without dementia of any strategy to enhance diagnosis (such as misdiagnosis) should be considered
- The harms of not diagnosing need to be considered
- There is a need to improve diagnostic practices in dementia
- People who are worried about their memory should be offered a diagnostic assessment
- If patient presents with a problem, diagnosis is a good thing
- The advantages of a timely diagnosis of dementia should be articulated
- Barriers to a diagnosis should be removed
- The diagnosis of the cause of dementia is equally as important as the detection and diagnosis of dementia *per se* – the analogy drawn between recognising (or diagnosing) that someone is in pain and diagnosing the cause of the pain
- There is a need to improve primary key support for people with dementia

#### **Support to People with dementia, their families and carers is essential**

- Support for patients and their carers post diagnosis is key
- It is not just about diagnosis – there is a need for post diagnostic support, as soon as possible on diagnosis

- Carers and families need to be involved in the assessment process
- Outcomes are better for everyone when diagnosis and support are in place

### **Person centred care is essential**

- There is a need to individualise diagnosis
- Patient Centred Care is key to high quality care
- Physical co-morbidity is common – “dementia rarely travels alone”
- Access to physical treatment for people with dementia is essential

### **There needs to be a whole system, holistic, integrated care service that is fit for purpose:**

- The whole system has its part to play in improving diagnosis and support
- Carers and wider networks of those with dementia have a pivotal role: good dementia care is more than about the person with dementia
- Integration of health and social care could be an important driver in improving dementia care
- Dementia care can be fragmented and would be better if health and social care were more integrated

### **There is variation in diagnosis and services**

- There is significant variation across the country in the availability of diagnostic processes, treatment, care and support
- Support is not currently there in all areas – in some, it is less good than others
- People should be confident when approaching their GP that services will be available

### **More community based, accessible memory services**

- People should feel confident in approaching their GP and that services will be available
- Barriers between primary and secondary care should be challenged with much more support based in primary care, and integrated within it
- When people seek diagnosis then access to memory service and diagnosis should be prompt
- Development of services for diagnosis, post diagnosis support and care is a good thing
- Memory services within GP practices would help to break down stigma and help enable people to access diagnosis and support

### **Ethical issues should be considered**

- Confidentiality needs to be approached flexibly and individually
- The impact of the diagnosis on the family has to be taken into account

### **Innovative models of care should be supported**

- Examples of good practice and research nationally and internationally should be available
- The Gnosall model of innovative links between primary and secondary care should be disseminated
- The Rapid Access Interface and Discharge (RAID) model for liaison psychiatry in general hospitals should be disseminated

### **Evidence is important**

- The evidence base for, and examples of good practice in, dementia diagnosis needs to be widened and made easily available

- High quality evidence of care such as in the EVIDEM programme (see appendix 3) should be made available
- International research such as that in ALCOVE (see appendix 3) should be disseminated
- Prevention of dementia is important in particular in relation to vascular dementia

### **Education and training is a priority**

- Education is a key part of improving the system
- Education is vital for increasing quality of diagnostic ability and post diagnostic support
- The most powerful thing is listening to patient and carer experience
- It is important to share good practice and not reinvent the wheel
- Learn from areas of best practice and efficient use of services – Scotland

### **Population Screening should not be undertaken**

- There is no evidence that population screening for dementia or Alzheimer’s disease should be undertaken

Additionally, several points were made which prompted discussion rather than achieving immediate consensus

- The question in the current Dementia Enhanced Service Part of the Directed Enhanced Service, the DES) is not ideal and risks excluding the family
- GPs have a responsibility to look after the two groups of patients – those with a memory problem and those who think they have one
- The time a GP has with a patient is very limited and a discussion of memory risked eroding that further
- The DES is a way of introducing something which is not evidence based, where, at least, the QOF has to be evidence based
- The process of increasing diagnosis rates should be driven entirely by providing post diagnostic support
- There are differing agendas between primary care, policy makers, the voluntary sector and politicians.
- There needs to be more joined up thinking and working together in best interests of patients and carers – not GP bashing
- Concerns around at what point the person with dementia loses their autonomy
- The DES – even if we think it’s a good thing - can be improved
- Not enough people are getting a diagnosis
- GPs are under huge pressure

**Summing up** all the comments in three words: **“more than diagnosis”**

## **Objective 3: planning next steps**

### **Specific Actions**



It is proposed that there are five parallel and complementary groups who could be tasked with taking forward specific actions. These are (in no particular order):

### **Enhanced Service for dementia**

**Proposal:** In view of the concerns expressed by some people about the current make up of the Enhanced Service for dementia, it is proposed that a group is convened, jointly by the General Practitioners Committee of the BMA and NHS England to discuss the clinical aspects of the Enhanced Service and how it might be used to support the dual aims of increasing the diagnosis rate but, crucially, help GPs to support people with dementia, their families and carers. This would be a clinically focussed discussion group and would neither pre-empt nor influence the confidential negotiations that take place between NHS England and the BMA. However, the output of the meeting would be available to the negotiating teams if they wished.

**Action:** To convene a small group, co chaired by Laurence Buckman and Alistair Burns to consider this.

**By whom:** Laurence Buckman and Alistair Burns.

**By when:** aim to meet before the end of July 2013, to produce a draft report to be circulated to members of the group, reporting back to the main group in six months.

### **Dementia Information Prescription**

**Proposal:** The importance of enhancing the role of information in post diagnosis support and providing high quality information was emphasised again and again. It is proposed that the existing work being undertaken by the Dementia Action Alliance to provide information be supported by NHS Improving Quality (NHS IQ) to carry out further work to assess what opportunities exist to harmonise information which is available. This may include scoping what is available already and exploring the opportunities to spread good practice where it is available. NHS Choices, the new NHS digital platform, the information offer available in the South West and experience such as that offered by the Guideposts Trust are examples of where experience could be drawn upon. NHS IQ will coordinate a brief recording the powerful presentations of Peter Dunlop and Barbara Woodward Carlton which will be made widely available.

**Action:** To assemble key individuals to consider the most appropriate next steps.

**By whom:** The DAA (Paul Springer/Simon Kitchen) and the Guideposts Trust (Rachel Niblock) in collaboration with NHS IQ (Beverly Mathews/Anne Wilkinson) and Public Health England.

**By when:** aim to meet by the end of September, reporting back to the main meeting in six months.

## **Dementia Diagnosis National Reference Group**

**Proposal:** Key to the success of NHS England's ambition of two thirds diagnosis and support by 2015, will be accurate information about progress across CCGs. To help support CCGs in their individual plans, the Group might receive and review information about diagnosis rates and the availability of post diagnostic support. The group may consider coordinating requests from CCGs who ask for advice and dissemination of good practice.

**Action:** to canvas for members of such a group.

**By Whom:** Alistair Burns, colleagues from NHS England, NHS IQ, Strategic Clinical Networks, Area Teams and NHS Clinical Commissioners.

**By When:** aim to meet by the end of October, reporting back to the main meeting in six months.

## **Dementia Diagnosis: widening the Evidence base**

**Proposal:** There was a discussion at the meeting about the clinical evidence and research base concerning the proposals, specifically around the case finding schemes, and the issues of research into potential harms and benefits which could include ethical and economic considerations. There was a definite feeling that there needed to be proper consideration of the evidence which may include suggestions for further evaluation and research. It would bring together work by groups such as the Cochrane Group, ALOIS programme, Nuffield Bioethics and international studies.

**Action:** To put together a Task and Finish Group which will consider the evidence, assimilate it in a form which could be disseminated and put forward suggestions for future work

**By whom:** Tom Dening has agreed to host a group.

**By when:** aim to meet before the end of 2013 and report back to the main group in six months

## **Dementia and cerebrovascular disease: prevention and treatment**

A key area to consider is the prevention of dementia and specifically the opportunities that management of vascular risk factors may provide. The NHS Health Check has raised awareness of the potential for prevention in the setting of the presence of cerebrovascular disease. The objectives for such a meeting would be: to broaden out the appreciation of **dementia in** stroke clinics and awareness of vascular risk in **memory clinics**; prospects for **prevention** of dementia by managing vascular risk factors and a discussion about the practicalities of **case finding** for dementia in people with cardiovascular risk factors.

**Action:** Convene a group to consider what further evidence may be needed.

**By whom:** NHS England and Public Health England to co host a meeting (jointly chaired by Charles Alessi, Alistair Burns and Anthony Rudd [National Clinical Director for Stroke]), in collaboration with colleagues from The National Screening Committee.

**By when:** aim to meet before the end of September, report back to the main group in six months.

There would be strong patient and carer input to all the groups and Alistair Burns would take the lead in co-ordinating actions between them.

## **Further work**

A record of this meeting should be produced and made widely available. The suggestion would be to meet again in six months to review progress of the groups and plan the sustainability of the individual pieces of work.

## Appendices

### *Appendix 1: Agenda for the Meeting*

#### **Timely Diagnosis of Dementia: Integrating Perspectives, Achieving Consensus**

**Wednesday, 5 June 2013, 12:00 – 17:30, Maynard Theatre,  
The Kings Fund, No.11 Cavendish Square, London W1G 0AN**

#### **Programme**

**12:00 – 12:30**

Light lunch available

**12:30 – 12:50**

Introduction and scene setting: Alistair Burns, Laurence Buckman

**12:50 – 14:30**

Five x ten minute presentations, each with ten minutes discussion

- Primary Care: Martin Brunet
- Primary Care: Nick Cartmell/Jill Rasmussen
- The evidence base: Tom Denning
- Memory clinics: James Warner
- The Hospital Dementia CQUIN: Chris Dyer

**14:30 – 14:45**

Perspective of the person with dementia: Peter Dunlop

**14:45 – 15:00**

Perspective of a carer: Barbara Woodward Carlton

**15:00 – 16:00**

Tea and break into groups: Glen Monks

**16:00: 17:00**

Group Feedback, Discussion, Moving Forward (5 – 7 minutes each group)

**17:00 – 17:15**

Concluding remarks and next steps

## *Appendix 2: Delegate List*

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### *Appendix 3: Further Reading*

<http://dementiachallenge.dh.gov.uk/>

Summary of all the work being done on dementia with current news

<http://www.alzheimers.org.uk/appg>

The All Party Parliamentary Group report on Diagnosis of dementia

<https://www.gov.uk/government/publications/living-well-with-dementia-a-national-dementia-strategy>

The 2009 dementia strategy

<http://www.england.nhs.uk/2013/05/15/dementia/>

Work by NHS England on dementia

<http://www.rcgp.org.uk/clinical-and-research/clinical-resources/dementia.aspx>

Royal College of General Practitioners on dementia

[www.alzheimers.org.uk/cognitiveassessment](http://www.alzheimers.org.uk/cognitiveassessment)

Advice on what cognitive tests to use

[www.dementiapartnerships.org.uk/diagnosis](http://www.dementiapartnerships.org.uk/diagnosis)

Resources to support the dementia prevalence calculator

<http://www.alcove-project.eu/>

The European ALCOVE project

<http://www.evidem.org.uk/>

The Primary Care EVIDEM project

<http://www.alz.co.uk/>

Alzheimer's disease International

<http://www.nuffieldbioethics.org/dementia>

Nuffield Bioethics and dementia

<http://www.screening.nhs.uk/alzheimers>

Public Health Screening Report on Dementia