



All-Party  
Parliamentary Group  
on Dementia

# Unlocking diagnosis

The key to improving the lives  
of people with dementia

July 2012





House of Commons  
All-Party Parliamentary Group  
on Dementia

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# Foreword

I'm delighted to introduce this All-Party Parliamentary Group (APPG) on Dementia report into early diagnosis.

Evidence heard by the APPG highlights just how important early diagnosis is. A person has a right to know what is happening to them, and a diagnosis can answer many questions. It gives people greater control over their lives and allows them to plan for the future and manage their condition more effectively. It opens the door to treatments which can help people to recognise their loved ones or play with their grandchildren for longer.

There is also a financial imperative for diagnosis. The £20 billion question, the inquiry the All-Party Group ran last year, found that diagnosis is a key element in providing cost-effective dementia services. In a time of economic austerity, it is an imperative we cannot afford to ignore.

It is shocking therefore that today fewer than half of people with dementia have a formal diagnosis. This also varies significantly across the country. In Belfast 70% of people receive a diagnosis, but in parts of Wales this figure is less than 40%. Even in areas with the highest rates more than a quarter of people with dementia are living in the dark without a formal diagnosis. There is clearly a long way to go.

Rates of diagnosis do not need to be so low. The APPG wanted to explore the barriers that exist. We are extremely grateful to all the people who submitted evidence, particularly the 617 people with dementia, family members and friends who took the time to complete our questionnaire, and those who attended parliament as witnesses to the inquiry. I would also like to thank my colleagues on the APPG and at Alzheimer's Society for the secretariat support.

This report makes specific recommendations, for the UK government, for the NHS and others. I am confident that if the recommendations in this report are implemented there will be a significant increase in rates of diagnosis. This would mean more people with dementia being able to access the help and support that can help them, and their families, achieve the best possible quality of life.



Baroness Greengross  
Chair of the All-Party Parliamentary Group on Dementia  
July 2012



# 1 All-Party Parliamentary Group on Dementia

The All-Party Parliamentary Group (APPG) on Dementia was formed in 2007 to build support for dementia to become a publicly stated health and social care priority, and therefore meet one of the greatest challenges presented by our ageing population. Since the establishment of the group, dementia has been recognised by all political parties as a priority for government and policy makers. Today the challenge is to translate that commitment into actions that will positively impact on the lives of people with dementia and their carers.

## 1.1 Terms of reference for the inquiry

In December 2011 the APPG on Dementia announced that it would undertake an inquiry into improving the rates of diagnosis of dementia across the UK.

A key stimulus for this inquiry was the unacceptable variation between the number of people diagnosed with dementia compared to the dementia prevalence rates in each of the different countries within the UK, and in different geographical areas within those countries. The inquiry wanted to explore the following questions:

- Why is there a discrepancy in diagnosis rates across the UK?
- Are there examples of a cost benefit to services locally when dementia is diagnosed early?
- What are the barriers to diagnosis in the health system (including barriers in culture, attitudes, resources and structure of the NHS)?
- What is needed to overcome these barriers?
- What must happen beyond diagnosis to ensure people are supported?

The APPG was also interested to find current examples of good practice in diagnosis.

While the APPG represents people from across the UK at the Westminster parliament, health policy is devolved to the individual health authorities. This is taken into consideration in the recommendations.

## 1.2 Working group

Members of the inquiry working group, who heard a summary of written evidence received and oral evidence from organisations and individuals in the House of Commons on 13 March and House of Lords on 14 March 2012, are as follows:

Baroness Greengross

Hazel Blears MP

Tracey Crouch MP

Nick Boles MP

Julie Hilling MP

Lord Walton of Detchant

Baroness Browning

## 1.3 Acknowledgements

The group would like to thank Alzheimer's Society for its assistance in collating written evidence for the inquiry and organising the oral evidence sessions. We would like to thank Martina Kane, Policy Adviser at Alzheimer's Society, for writing the report and Nicola O'Brien, Public Affairs Adviser, for supporting and co-ordinating the inquiry.

We would also like to thank the witnesses who took part in the oral evidence sessions, as well as those individuals and organisations that submitted written evidence.

## 1.4 Enquiries

Please direct any comments or queries that you may have about this report or about the Group to the Secretariat at [appg@alzheimers.org.uk](mailto:appg@alzheimers.org.uk). Alternatively, contact the Chair, Baroness Greengross, at the House of Lords, London, SW1A 0PA.

# 2 Summary and recommendations

## 2.1 Summary

A diagnosis of dementia opens doors. It gives a person access to treatment and often support services. It allows them to plan for their future. It provides them with knowledge of what is happening to them. Yet it is still common for a person with dementia to live with the condition and never be given a formal diagnosis. The APPG wanted to explore why this was still the case, despite the political priority that has been given to early diagnosis.

The call for evidence ran between December 2011 and March 2012. The inquiry received more than 1,100 pieces of evidence from people with dementia, carers, family members, health professionals and other organisations and individuals with an interest in the subject. A questionnaire was available online and in paper format which asked about experiences of diagnosis, key barriers and possible solutions. Additional written evidence was also received.

The inquiry found there were barriers throughout the process of diagnosis, from people having poor understanding of dementia so not visiting a doctor, through issues faced by GPs and memory specialists, to problems with the quality of support offered immediately following diagnosis. In particular, the inquiry heard a large volume of evidence on problems in the following areas:

### **Public education**

The inquiry heard that people frequently did not present to their doctor with their symptoms of dementia. More than one-third of carers who responded to the inquiry reported that the person with dementia waited longer than a year to go to their GP. Nearly 10% never went to their GP at all. They reported that they thought problems with their memory were normal as they got older. Across the range of individuals and organisations responding, there was the overwhelming suggestion that greater public education was needed. There were also calls for more regular assessments for those at risk of dementia, and for dementia to play a greater role in public health.

### **Primary care**

Carers and people with dementia largely saw primary care, and particularly GPs, as barriers to a diagnosis rather than gatekeepers. It was felt that greater training on

dementia in general was needed, particularly on spotting the symptoms. Problems were highlighted with the Quality and Outcomes Framework (QOF) which is designed to incentivise good practice in all areas, but is regarded by some as a barrier to dementia diagnosis. GPs also highlighted problems with the assessment tools available to them. It was also felt that diagnosis needed to be more embedded in the community, with GPs taking ownership and working together with secondary services. The HEAT target in Scotland (see section 3.4.2) was seen as helpful in driving up rates of diagnosis by encouraging clinicians at this level to make changes in their practice.

### **Variability of memory services**

The inquiry heard evidence that there is great variability in memory services, with some pockets of good practice but also areas of the country where services are under-resourced. An example of this is the length of time people have to wait for an appointment, with some reporting just a few weeks, but others more than a year. The integration between primary and secondary care was also highlighted as an issue.

### **Post-diagnosis support**

The inquiry heard that people frequently received no information or support following diagnosis, leaving them isolated. While good practice does exist, this is not yet widespread and more could be done to improve the appropriate services and treatments available.

## **2.2 Recommendations**

The recommendations throughout the report apply to either the NHS or health systems in England, or to non-governmental bodies who have UK-wide jurisdiction. Suggestions that governments in devolved nations may like to consider are listed separately.

### **Recommendation 1: Invest in a sustained public dementia awareness campaign**

- The APPG supports the public awareness campaign for England committed to in the Prime Minister's challenge on dementia. We would like to see details of how this campaign will be sustained for the life of the challenge.
- The proposed campaign should have a strong focus on recognising the symptoms of dementia. It should also convey the message that it is possible to live well with dementia.

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**Recommendation 2: A quantified ambition that increases the percentage of people with dementia who have a formal diagnosis should be embedded in the NHS and used to lever change**

- The ‘quantified ambition’ in the Prime Minister’s challenge on dementia should be a standalone target based on the NHS Atlas of Variation Map 13. This would allow an immediate reporting of data.
- Indicators on dementia diagnosis should also be included as part of the Commissioning Outcomes Framework.

**Recommendation 3: Public health directors across the UK should make early dementia diagnosis a priority**

- Improving dementia diagnosis rates should be a key priority for local directors of public health.
- The Dementia Action Alliance action group on diagnosis should spearhead the creation of a clear and consistent message on the value of diagnosis, early in and throughout the course of the illness, for members to share and communicate.
- The champion group of the dementia friendly communities strand of the Prime Minister’s challenge on dementia should consider the role a high diagnosis rate plays in a dementia friendly community.

**Recommendation 4: Primary care workers and other health and social care professionals in contact with people in groups with an established risk of dementia should routinely ask questions to identify symptoms of dementia**

- The commitment in the Prime Minister’s challenge on dementia for regular checks for the over-65s should be widened to include regular checks for all groups at risk of developing dementia.

**Recommendation 5: UK-wide, all health and social care professionals working in a general capacity with people at risk of dementia should have pre- and post-registration training in identifying and understanding dementia**

- The APPG supports current proposals to extend mandatory GP training by at least one year and suggests that there should be a focus on dementia in the additional year.
- Healthcare assistants (HCAs) and healthcare support workers should have appropriate training for their role and be sufficiently regulated.

- Dementia should be a key focus for organisations co-ordinating the training of health professionals, including Health Education England and NHS Education for Scotland. Universities and deaneries who set the curriculum for health professionals should ensure that the detection of dementia is represented on healthcare courses.
- UK-wide Royal Colleges should act on the plans regarding member training in the Prime Minister's challenge for all members, not just those in England.
- The Royal College of GPs and members of the Dementia Action Alliance should compile and promote a list of available and effective training in dementia care for health and social care professionals.
- Service providers, including care homes, should commit dedicated time for training care workers in dementia care.

**Recommendation 6: Issues with the assessment tools used by UK GPs and other primary care professionals should be explored and addressed**

- The Dementia Action Alliance action group on diagnosis should explore the issues with assessment tools and suggest solutions to improve national practice.
- GP training on dementia diagnosis should contain information on known problems with assessment tools and encourage GPs to use their clinical judgement.

**Recommendation 7: Across the UK, commissioners should invest in appropriate memory service resources to cater to the needs of their population**

- All commissioners should prioritise investment in memory services so they are able to meet the needs of their population.
- Commissioners should be innovative in commissioning in order to meet the needs of their populations.

**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.

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### **Recommendation 9: Adequate information and one-to-one support should be provided to patients and their families immediately following diagnosis**

- There should be monitoring of the Prime Minister's challenge on dementia commitment to promote the information offer pioneered in the South West.
- There should be additional investment to develop the role of dementia advisers in England.

### **Suggestions for devolved health administrations**

While members of the APPG represent constituencies across the UK, health policy is devolved to the governments of the individual nations. Below are some suggestions based on the evidence received by this inquiry which the governments and relevant bodies in devolved nations may wish to consider.

#### **Scotland**

- The Scottish Government could explore options to raise public awareness and understanding of dementia.
- The Scottish Government could explore options to increase diagnosis in harder to reach groups. These could include care professionals routinely asking questions to identify symptoms of dementia in 'at risk' groups.

#### **Wales**

- The Welsh Government could commit ongoing funding to continue the information pack which is given to people following diagnosis. They could also make a commitment for people with dementia to have a named individual to provide co-ordinated support.
- The Health Minister could provide an update on the media campaign referenced in the dementia stakeholder groups action plan on information.
- The Health Minister could make a commitment on how data on diagnosis rates already available through the NHS Atlas of variation could be used in monitoring the progress of the Dementia Vision for Wales. Plans should be ambitious in order to drive good practice.

- The NHS in Wales could explore options to routinely ask questions to identify dementia through regular interventions with the over-65s and others at higher risk of dementia.

### Northern Ireland

- Improving Dementia Services in Northern Ireland: A Regional Strategy includes provision for an awareness raising campaign. Implementation of this element of the Strategy could be given a high priority.
- The Health Minister could make a commitment on how data on diagnosis rates already available through the NHS Atlas of variation could be used in monitoring the progress of the strategy. Plans should be ambitious in order to drive good practice.
- The Health and Social Care Board and the Public Health Agency could explore options to include questions to identify symptoms of dementia through regular interventions with the over-65s and others at higher risk of dementia.

# 3 Background

## 3.1 Background to dementia

Dementia is the name given to a collection of symptoms including memory loss, mood changes and problems with thinking and reasoning. It is caused by damage to the brain which may be the result of Alzheimer's disease or a number of other causes. While it predominately affects older people, it is not a normal part of ageing, and younger people can also be affected by it.

Dementia is a major and growing challenge to the UK. There are approximately 800,000 people with dementia, and this figure is set to rise to over a million by 2021 (Alzheimer's Society, 2012). Dementia costs the UK £23 billion each year (Alzheimer's Society, 2012).

## 3.2 Diagnosis

There is strong evidence to show the benefit of early diagnosis to individuals and families (Department of Health 2009b), and also to the taxpayer. As long ago as 2009, an economic metric was published by the Department of Health, which demonstrated the financial benefits of early diagnosis in delaying admission to hospital and to care homes (Department of Health, 2009a).

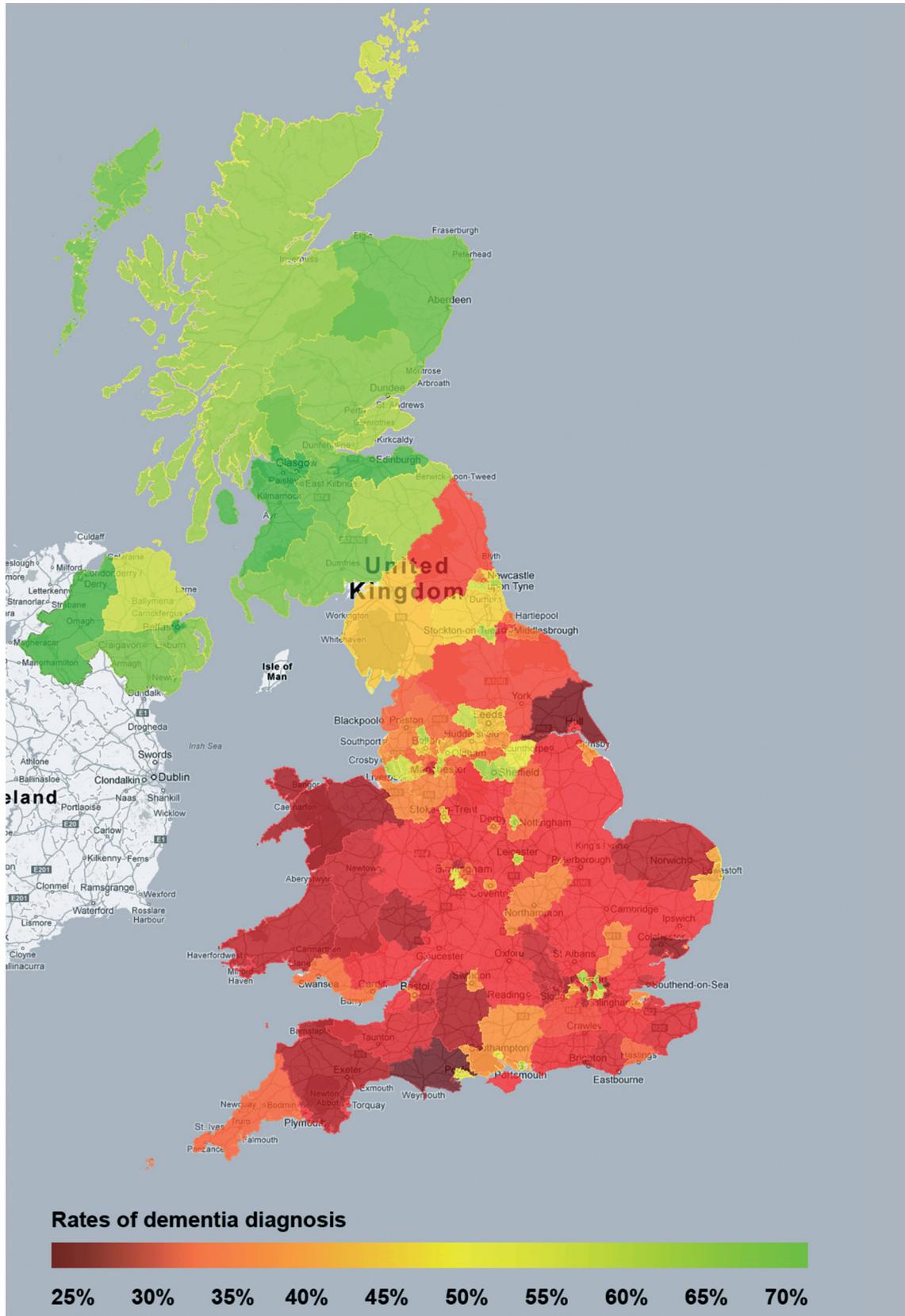
Yet despite the evidence, improvement in the number of people diagnosed is slow. In the UK only 43 % of people with dementia have had a formal diagnosis (Alzheimer's Society, 2011)<sup>1</sup>. Government and cross sector commitment in this area to drive swift improvement in the number of people with a diagnosis is therefore vital.

The figures also suggest there is considerable variation in diagnosis rates across the UK with 41 % of people with dementia in England receiving a diagnosis, 37.4 % in Wales, 64.5 % in Scotland and 61.5 % in Northern Ireland. As the following map, from Alzheimer's Society and Alzheimer Scotland shows, 70 % of people with dementia in Belfast have a diagnosis, whereas diagnostic rates are as low as 32 % in parts of Wales. The APPG sought to explore these differences and see if learning could be shared to drive improvements across all parts of the UK.

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<sup>1</sup> This is a proxy measure sourced from the best evidence available. It is based on a comparison between dementia prevalence rates and the number of people with dementia on GP registers (from the 2010 NHS QOF indicator number DEM1) used as a proxy measure of how many people have been formally identified as having dementia.

**Figure 1:** Map of rates of dementia diagnosis across the UK. Interactive version and data tables available at [alzheimers.org.uk/dementiamap](http://alzheimers.org.uk/dementiamap)



### **3.3 Existing evidence on why diagnosis rates are so low**

The existing evidence on diagnosis rates cites several common barriers which prevent people from getting a diagnosis. In this inquiry the APPG sought to explore these and other barriers to diagnosis.

#### **3.3.1 Public attitudes**

Despite improvements in awareness of dementia, there is still confusion amongst many about what the symptoms of dementia are. There is also still fear attached to dementia. Recent polling data has suggested that people over the age of 55 fear dementia more than any other condition.<sup>2</sup>

These factors combine to mean that people are often hesitant about going to a health professional with their concerns.

#### **3.3.2 GP attitudes**

The National Audit Office (NAO, 2007) found that in England GPs' attitudes and beliefs could prevent or delay early diagnosis. Common perceptions, such as that there is little support for people with dementia, can discourage GPs from referring people for a diagnosis. The more recent NAO report (NAO, 2010) suggested this situation may be beginning to change, with 77 % of GPs agreeing that it is beneficial to make an early diagnosis compared to 66 % reported in 2007.

#### **3.3.3 Provision of diagnostic services**

Limited provision of diagnostic services is also a barrier to timely diagnosis (NAO, 2010). There were also reports to Alzheimer's Society's services and helpline that waiting times for memory clinics could be very long, although data is not centrally collected by the government.

### **3.4 Policy context**

#### **3.4.1 Dementia strategies (England, Scotland, Wales and Northern Ireland) and NICE guidance (England)**

The 2009 National Dementia Strategy for England (Department of Health, 2009b) included a commitment to an early diagnosis and good quality intervention for all. This commitment was then reiterated by the coalition government. The National Dementia Vision for Wales (Welsh Government, 2011) included early diagnosis and timely intervention as a priority area. One of the two priorities in Scotland's National

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2 Alzheimer's Research Trust, You Gov Poll, May 2008; Alzheimer's Society survey, September 2008.

Dementia Strategy (Scottish Government, 2010) is support and information for people with dementia and their carers who receive a diagnosis. Improving Dementia Services in Northern Ireland, the Northern Ireland Dementia strategy (DHSSPS, 2011) also promotes access to earlier diagnosis and multidisciplinary assessment.

The NICE-SCIE guideline on dementia (NICE-SCIE, 2006) is clear that if health professionals detect potential symptoms of dementia, memory assessment services should be the single point of referral for diagnosis. The recent Dementia Quality Standard (NICE, 2010) also contains a quality statement that people with suspected dementia should be referred to a memory assessment service. Diagnosis therefore is considered to be a marker of quality for commissioners and providers.

### **3.4.2 HEAT targets (Scotland)**

HEAT targets are a set of Ministerial objectives, targets and measures for the NHS in Scotland.<sup>3</sup> Target 4 stated that ‘each NHS Board will achieve agreed improvements in the early diagnosis and management of patients with a dementia’. National reporting arrangements were established and local information systems were built so predicted rates of dementia could be estimated down to GP practice level. They then encouraged professionals to consider their practice and make changes to increase the diagnosis rate. Changes ranged from simple administrative changes, such as putting the diagnosis on the top of the referral letter, to exploring different service models that might suit the population better. The HEAT team began to work more directly with wards to enable them to meet the target. Three staff worked across three regions to provide local support. The Scottish Government estimate that they invested just under £1 million a year for the three year life of the target. The programme passed from being a programme into being a standard in 2011, and the number of people on the dementia register will continue to be collated and monitored in Scotland.

### **3.4.3 1000 Lives Plus (Wales)**

1000 Lives Plus is the national improvement programme supporting organisations and individuals to deliver the quality and safe healthcare in Wales (1000 Lives Plus, 2010). They have prioritised one of the Intelligent targets for dementia laid out in NHS Wales’ Annual Quality Framework to reduce time between onset of symptoms and diagnosis being communicated for people with dementia. They have also produced a ‘how to’ guide for health professionals to lead change in this area from the bottom up.

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3 The HEAT acronym stands for the four priorities which the targets are grouped around: Health Improvement for the people of Scotland; Efficiency and Governance Improvements; Access to Services; and Treatment Appropriate to Individuals. [www.scotland.gov.uk/About/scotPerforms/partnerstories/NHSScotlandperformance](http://www.scotland.gov.uk/About/scotPerforms/partnerstories/NHSScotlandperformance)

### **3.4.4 The Prime Minister's challenge on dementia and Commissioning for Quality and Innovation (CQUIN) (England)**

In March 2012 the Prime Minister launched The Prime Minister's challenge on dementia (Department of Health, 2012). This outlined 14 commitments on dementia to be delivered by 2015 in England. The Prime Minister has created 'champion groups' to report to him on the progress of the challenge through the Department of Health. The challenge also contains a 'List of actions' that will help to achieve these commitments.

The challenge commits to increasing diagnosis rates and was published during the period that the APPG inquiry was being conducted. In particular, it commits to a quantifiable ambition for diagnosis rates. The APPG sees this report as an opportunity to make recommendations that will support delivery of the Prime Minister's challenge.

Prior to the Prime Minister's challenge, the Department of Health had already announced plans for a national Commissioning for Quality and Innovation (CQUIN) objective on dementia (Department of Health, 2011). Part of hospital income will be dependent on meeting a target for every person over the age of 75 admitted to hospital being asked questions about their memory. This commenced in April 2012.

## **3.5 Methodology**

### **3.5.1 Questionnaires**

Short questionnaires were developed to encourage submissions from those who were not able to write formally to the inquiry. Specific questionnaires were available for people with dementia, carers, GPs, memory specialists, nurses, other professionals, organisations and other interested people. These were made available online and in paper form, and promoted through relevant organisations to reach the appropriate target audiences, including the Royal College of GPs, Royal College of Psychiatrists and Alzheimer's Society. The questionnaires for people with dementia and carers were also available in Welsh. Letters inviting written evidence were sent to relevant organisations.

It is important to note that respondents were self-selecting and this may have affected the type of responses received. For example, because the questionnaire for people with dementia was circulated through Alzheimer's Society's website, dementia support workers and membership magazine, the majority of people with dementia who responded were already in contact with Alzheimer's Society and therefore very likely to have had a diagnosis and some contact with dementia services.

We received 1,075 completed questionnaires. The table below shows the number of respondents who filled in each of the different types of questionnaire.

Responses were received from across the UK. As may be expected, there was a higher response rate from more densely populated areas.

**Figure 2:** Number of respondents to fill in each of the types of questionnaire

Type of questionnaire	Number of respondents
Person with dementia	51
Carer, family member or friend	566
GP	90
Psychiatrist/memory specialist	68
Nurse	23
Social worker	5
Other professional	100
Interested organisation	93
Other	79

### 3.5.2 Additional written evidence

The APPG received an additional 43 pieces of written evidence. A list of organisations that submitted written evidence or completed the questionnaire is given in Appendix 1.

The evidence that was collected has been used to inform the report and recommendations. Some examples are included throughout the report. The full written submissions and statistics from the questionnaire responses are available at [alzheimers.org.uk/appg](http://alzheimers.org.uk/appg)

### 3.5.3 Oral evidence

The APPG also heard from witnesses at oral evidence sessions on 13 and 14 March 2012. The witnesses who gave oral evidence are listed below in order of appearance.

- Dr Daphne Wallace, Former Old Age Psychiatrist, diagnosed with dementia in 2005
- Brigid Stubbs, carer for her husband with dementia

- Dr Imran Rafi, Medical Director of the Royal College of GPs Clinical Innovation and Research Unit (CIRC)
- Dr Simon J Hughes, Royal Victoria Hospital, Belfast
- Geoff Huggins, Deputy Director of Health and Social Care Integration, Head of Reshaping Care and Mental Health Division, Scottish Government
- Gayle Willis, Head of External Communications, Alzheimer's Society
- Prof. Sube Bannerjee, Professor of Mental Health and Ageing, Institute of Psychiatry, King's College London
- Dr Peter Connelly, Chair of the Faculty of Old Age Psychiatry, Royal College of Psychiatrists
- Martin Green, Chief Executive, English Community Care Association
- Mandy Kittlety, College of Social Work
- Lorraine Edmunds, Lead Nurse Older People, Aneurin Bevan Health Board, Wales.

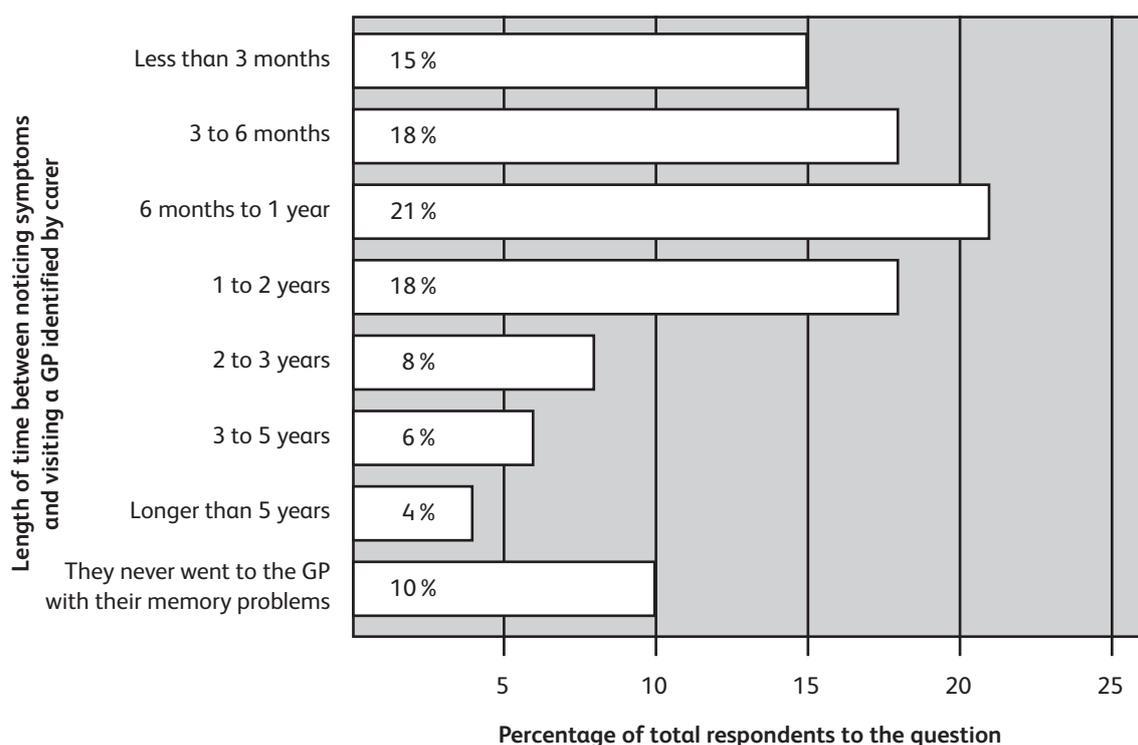
# 4 Recommendations and rationale

## Recommendation 1: Invest in a sustained public dementia awareness campaign

Poor public understanding of dementia was an overwhelming theme amongst the evidence received by the inquiry. A key barrier to early diagnosis identified by professionals, people with dementia and carers was the length of time between symptoms, such as memory problems, first arising and seeking professional advice, for example from a GP. Inquiry respondents identified that this was partly due to a lack of understanding of the symptoms of dementia and the benefits of an early diagnosis, which could be improved by a public campaign.

The graph below shows the length of time between noticing symptoms and going to the GP, as identified by carers, family or friends responding to the questionnaire.

**Figure 3:** Time identified by a carer, family member or friend between the person with dementia first having symptoms and going to their GP



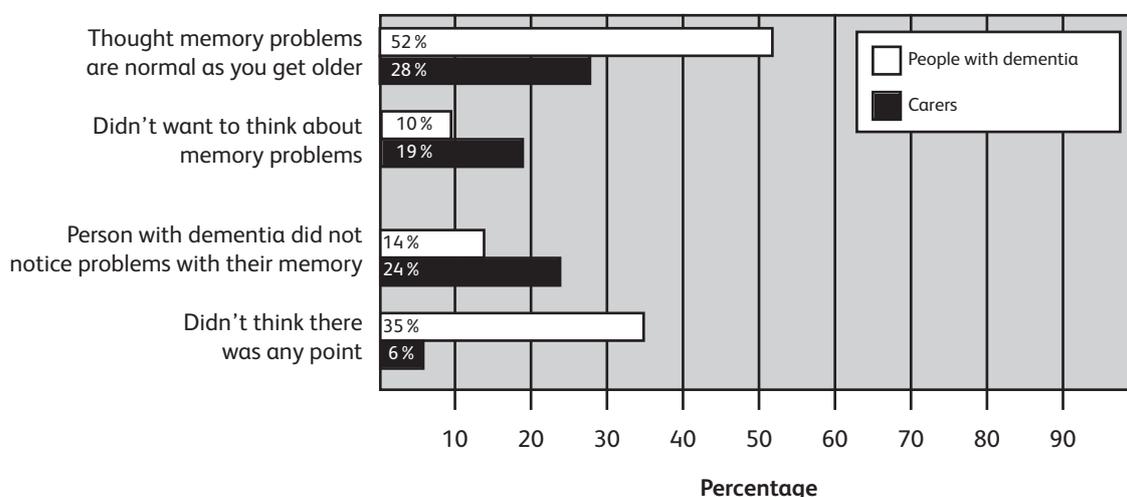
As the graph shows, fewer than 15 % of carers, family members or friends said they saw a GP within three months of noticing symptoms. Over a third (36 %) waited more than a year before going to the GP<sup>4</sup> and 10 % never went to the GP. Arc Research also submitted evidence based on interviews that they had done with more than 80 people with dementia and carers which found that it took an average of two and a half years between the person noticing problems with their memory and visiting a health professional.

Health professionals cited people not seeking professional help as the primary reason for under diagnosis. More than 76 % of GPs and 70 % of memory specialists who answered the questionnaire agreed that people do not come forward to professionals with problems with their memory. Additional evidence from the British Geriatrics Society suggested that the health professionals they represent also see this as a key barrier.

The questionnaire sought to explore some of the reasons behind this. The graph below shows some of the reasons identified by people with dementia and carers for not seeking help from a medical professional immediately. Over half (52 %) of people with dementia and over one-quarter (28 %) of carers, family members or friends who responded thought having memory problems was normal as you got older. In addition, 35 % of people with dementia who did not go to the GP straightaway said that this was because they didn't think that there was any point.

Organisations submitting evidence also reflected this concern. Bupa suggested that there was an 'ageist mythology' which portrayed memory loss as a normal part of ageing, and that stigma was a key part of under diagnosis.

**Figure 4:** Percentage of respondents agreeing with the statements



<sup>4</sup> 18% waited 1–2 years, 8% waited 2–3 years, 6% waited 3–5 years, 4% waited longer than 5 years.

This shows a clear need for public messaging both on the symptoms of dementia and when someone should feel concerned, and on the benefits of getting an early diagnosis. Many respondents to the questionnaire suggested measures to encourage greater public awareness of dementia, including formal investment in public awareness campaigns and greater understanding of dementia in the media. They were clear that this should not just be ‘awareness’, but should also have an emphasis on ‘understanding’, with clear messages on what the symptoms of dementia are and a positive message that it is possible to live well with dementia. This would help to reduce the stigma associated with the condition.

It is also possible that a large scale public awareness campaign could have a positive effect across the health system as well as on the general public. As Professor Sube Bannerjee from the Institute of Psychiatry expressed in the oral evidence sessions:

‘Public information campaigns will change people’s ideas about coming forward. Public information also, vitally, affects professionals, and it is that professional level of understanding that creates the likelihood in primary care that when someone who comes along either who shows that they might have a memory problem by forgetting something, saying something twice or whatever, or about whom there is a direct report from someone that there might be a memory problem or other things suggestive of dementia, that leads to a referral rather than a statement that we are all getting old and this is what happens to people.’

## England

**The APPG supports the public awareness campaign committed to in the Prime Minister’s challenge on dementia. We would like to see details of how this campaign will be sustained for the life of the challenge.**

The Prime Minister’s challenge on dementia made the commitment that ‘from autumn 2012, we will invest in a nationwide campaign to raise awareness of dementia, to be sustained to 2015’. Based on the evidence submitted to this inquiry, the campaign could make a real difference to dementia diagnosis rates. We would like to see details of this campaign, including how it will follow the good practice shown in successful and sustained public information campaigns.

**The proposed campaign should have a strong focus on recognising the symptoms of dementia. It should also convey the message that it is possible to live well with dementia.**

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It is important that messages in the campaign strike the right balance between highlighting the symptoms and seriousness of dementia, and the possibility of living well with dementia, as outlined above. It should include positive messages that highlight that it is possible to live well with dementia, to reduce the stigma associated with the illness. It is also important that the campaign is large scale, and has cross sector buy-in in order to reach people with dementia or carers who may be isolated. The APPG will share evidence that the inquiry received with the Prime Minister's challenge champion group.

## **Recommendation 2: A quantified ambition that increases the percentage of people with dementia who have a formal diagnosis should be embedded in the NHS and used to lever change**

During the oral evidence sessions the success of the HEAT programme in Scotland was discussed (see section 3.4.2). This scheme provided a framework against which progress could be measured, making each NHS Board in Scotland aware of the number of people who would be expected to have dementia compared to those formally identified on GP registers, and identified reasons for the discrepancy.

The evidence provided to the inquiry suggested that having a quantified target helped to ensure that diagnoses that had been made by specialists were recorded by the GP and formed part of medical records. It was also clear that the drive to reach a specific target also increases local awareness of what expected prevalence should be. It also challenges assumptions within the system about what is good practice, and what interventions needed to be put in place, providing a sense of urgency to improvement. As Geoff Huggins, Deputy Director of Health and Social Care Integration, Scottish Government, stated at the oral evidence sessions:

‘What we wanted to do was draw out what the expected diagnosis rates for different practices were within an area, so that we could then bring together groups of practice to have discussions as to why one practice might be closer to their prevalence rate than others, and to actually get clinicians talking to other clinicians about what it was that they were actually doing on the ground, and engaged in reflective practice to maybe understand why they might have different approaches, different reasons and different motivations, doing it within a context of an expectation of improvement and benefit.’

Alzheimer Scotland submitted evidence to the inquiry to highlight the progress which has been made in Scotland in recent years, attributing this success largely to the HEAT programme. The Royal College of Nursing also supported the programme, drawing attention to the workforce development which sat alongside this target.

The number of people registered by GPs as having dementia in Scotland increased from 29,761 in 2006/07 at the start of the target to 40,195 in 2010/11 at the end of the target, an increase of 35 %.<sup>5</sup> The APPG suggests that the success of a quantified ambition for diagnosis rates has been demonstrated, and could be used successfully elsewhere in the UK.

## England

**The ‘quantified ambition’ in the Prime Minister’s challenge on dementia should be a standalone target based on the NHS Atlas of Variation Map 13. This would allow an immediate reporting of data.**

The Prime Minister’s challenge on dementia states that from April 2013 there should be local quantified ambitions for diagnosis rates across the country. This is to be incentivised by including a new indicator in the NHS Outcomes Framework 2013/14.

Whilst the Group welcomes the quantified ambition and the plan to incentivise improved diagnosis rates, it suggests that placing this ambition in the Outcomes Framework alone has some disadvantages. In particular, the Outcomes Framework will not become operational until 2013/14, and data will not be available until later in 2014 at the earliest, which will not allow sufficient time within the life of the challenge to adapt if change does not seem to be occurring. In addition, having only one indicator that is based on diagnosis eliminates the possibility that the Outcomes Framework could be used to measure outcomes for the care that somebody receives beyond diagnosis, placing dementia on a significantly lesser footing than the other conditions named in the Framework.

The APPG suggests that a standalone target, based on the figures used in the NHS Atlas of Variation Map 13, should be introduced immediately. This would mean that maps from previous years could be used as an established baseline for improvement. The data is already collected, compiled and reported annually so it would not create an additional burden. This would also allow reports directly to the Prime Minister throughout the life span of the challenge, with time to hold people to account.

**Indicators on dementia diagnosis should also be included as part of the Commissioning Outcomes Framework.**

In addition to the standalone target, the Group suggests that indicators on dementia diagnosis should be included as part of the Commissioning Outcomes Framework, as well as in the NHS Outcomes Framework. This will provide a direct incentive to commissioners at a local level which clinical commissioning groups and health and wellbeing boards can address.

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5 [www.scotland.gov.uk/About/scotPerforms/partnerstories/NHSScotlandperformance/Dementia](http://www.scotland.gov.uk/About/scotPerforms/partnerstories/NHSScotlandperformance/Dementia)

### **Recommendation 3: Public health directors across the UK should make early dementia diagnosis a priority**

The inquiry received evidence about the benefits of early diagnosis, both to people living with dementia and to commissioners and providers of services and support. A diagnosis of dementia allows someone to understand their condition, and symptoms, and seek information to ensure that they live well with the condition. The Dementia Action Alliance consulted widely with their members on the inquiry and commented in their written response:

‘More could be done to sell the benefits of a diagnosis (and particularly an early diagnosis) to people with dementia, their carers and families. This also needs to happen to health and social care workers at all levels of the system. In the focus group with carers Uniting Carers [and] Dementia UK, the carers present said they had no idea of the potential benefits of a diagnosis prior to actually receiving one. The Association of Directors of Adult Social Services (ADASS) also has some interesting thoughts on the need for a national programme with local delivery, as a form of partnership between health and social care institutions and the voluntary sector.’

There were also comments that dementia needs to be a priority for the public more widely. The Royal College of General Practitioners (RCGP) called for better and more consistent public health messages. Other submissions also suggested that awareness campaigns that were tailored to local need were important. The Debenham Project, based in Suffolk, submitted information about their initiative which reaches out to carers of the undiagnosed, offering information to anyone who asks for it. They commented that an informal method of approach, rather than a formal medical process can seem less threatening.

Dr Simon Hughes, from the Royal Victoria Hospital, Belfast, gave oral evidence highlighting that a diagnosis can help reduce avoidable accidents, or the worsening of other health conditions the person may have, thereby creating savings for the system.

‘Before the diagnosis, there is uncertainty. If you have Lewy body dementia, for example, and you keep falling over, every time you fall, whether you have hurt or injured yourself or not, you go and see your GP. You are admitted; you have ECGs; you have a 24-hour tape to make sure it is not an arrhythmia. If you know that you have Lewy body dementia and you fall, and someone can say, “Are you okay, Dad?” you say, “I think I’m okay.” This is where you save the money, because a clear diagnosis, a clear education, says, “Yes, you have dementia. These are the things that may happen.” This is where the savings come.’

With the importance of public health being increasingly recognised, as the establishment of agencies such as Public Health England implies, the APPG believes that the public health importance of dementia diagnosis should be more strongly emphasised and early dementia diagnosis should be a public health priority.

## **UK-wide**

### **Improving dementia diagnosis rates should be a key priority for local directors of public health.**

Engagement from Public Health at a local government or health body level will allow health, social care and wider systems within an area to work together to meet the needs of their local populations in promoting early diagnosis. As well as improving diagnosis rates, this could help reduce costs elsewhere in social care and the health system.

### **The Dementia Action Alliance action group on diagnosis should spearhead the creation of a clear and consistent message on the value of diagnosis early in and throughout the course of the illness, for members to share and communicate.**

The Dementia Action Alliance (DAA) is the coming together of organisations from across the charity, public and private sectors to radically improve the lives of people with dementia. The APPG is a member of this alliance along with the Royal College of GPs, Royal College of Psychiatrists and numerous research institutions. They have action groups to explore particular issues.

The DAA currently has an action group looking at diagnosis. The APPG believes that it would be helpful for this group to define a clear and consistent message on the value of diagnosis early in, and throughout the course of the illness. Organisations should then communicate and get buy-in on this message from their staff, membership and networks, both in England and UK-wide where applicable. This would then drive an improvement in practice by the professionals who are members of, or employed by, these organisations.

### **The Champion group of the dementia friendly communities strand of the Prime Minister's challenge on dementia should consider the role a high diagnosis rate plays in a dementia friendly community**

The Prime Minister's challenge on dementia recognised that more could be done in communities to help people live well with dementia, and launched a strand committed to building dementia friendly communities across England. The champion group leading on this strand could helpfully consider the role that early diagnosis plays in this vision, and make suggestions about how it will link with the local quantifiable ambition on diagnosis rates mentioned elsewhere in the challenge.

#### **Recommendation 4: Primary care workers and other health and social care professionals in contact with people in groups with an established risk of dementia should routinely ask questions to identify symptoms of dementia**

In addition to the information on the gap between people with dementia noticing symptoms and seeking professional help (detailed under recommendation 1), the inquiry heard significant calls for systematically checking people who are at risk of developing dementia. While the APPG is not calling for population screening, the inquiry heard frequent examples of particular groups who would benefit from being routinely asked simple questions that would aid early detection.

The increasing prevalence of dementia as age increases is well proven. A substantial number of professionals suggested that questions to establish possible symptoms of dementia such as memory problems should be asked to older people who are in contact with primary care, either as part of either the routine health check in England, or when they receive their flu jab. Bupa suggested that people be placed on an 'at risk' register, to be checked annually and Guideposts Trust recommended regular checks for the over 70s.

Along with an increasing risk of developing dementia as age increases, the higher risk of dementia for certain groups is well established, including people with Down's syndrome, learning disabilities, Parkinson's disease or who have had a stroke. Parkinson's UK submitted evidence to highlight the established link between Parkinson's disease and Lewy body dementia. The Royal College of GPs suggested that there should be screening for people with Down's syndrome.

It was also suggested that even where diagnosis rates are higher, such as in the Belfast Health and Social Care Trust and in areas of Scotland, a lack of diagnosis might still exist amongst particular groups. In particular, those in care homes or receiving social care services who have not already received a diagnosis may often be overlooked because the path to diagnosis may be too difficult to navigate. As Martin Green from the English Community Care Association explained in his oral evidence:

'There is a real challenge for the connection which should exist between health and social care to get much better. It is my view that if somebody has an assessment for domiciliary care, or indeed a residential care placement, one of the first things that should happen is that they should have a medical diagnosis around why they are having to have those services.'

The pharmaceutical company Lundbeck also suggested that terminology should shift from 'early diagnosis' to 'timely diagnosis' in order to shift attention to identifying people who are already in the care system.

While the review of the evidence undertaken by NICE in 2006 (NICE-SCIE, 2006) did not suggest systematic population screening for dementia, evidence received by the inquiry suggests there is room for an increase in regular checks for groups at particular risk of dementia. Good practice in this area could be modelled on the CQUIN programme, which provides a financial incentive for hospital trusts to identify patients with dementia. This uses a ‘find, assess, refer’ model, with people over the age of 75 who are admitted to hospital. In the initial ‘find’ stage, members of staff will ask members of the family or friends of a person admitted to hospital if the patient has suffered any problems with their memory in the last 12 months. Patients are then assessed and referred to the appropriate place. A similar system could be usefully developed and implemented with all groups who are at risk of dementia.

## England

**The commitment in the Prime Minister’s challenge on dementia for regular checks for the over-65s should be widened to include regular checks for all groups at risk of developing dementia.**

The APPG welcomes the commitment to regular checks for the over-65s in the Prime Minister’s Challenge on dementia. We will share the evidence that the inquiry has received on good practice that already exists in this area with the champion group.

We also believe that the champion group should explore similar interventions for other at risk groups, including people with learning disabilities, Parkinson’s disease, Down’s syndrome, or those who have had a stroke. Professionals who are conducting social care assessments who suspect the person has undiagnosed dementia should routinely ask questions that will help detect this, and have avenues to check and refer to.

## **Recommendation 5: UK-wide, all health and social care professionals working in a general capacity with people at risk of dementia should have pre- and post-registration training in identifying and understanding dementia**

The group received evidence that all ‘generalist’ health professionals, such as GPs, geriatricians, wider primary care teams, ward nurses and care assistants, who are involved in the general care of people with dementia, needed more specific training on dementia and dementia diagnosis. An overwhelming number of responses to the questionnaire stated that GPs should have greater training in dementia. In addition, 40 % of GPs who responded to the questionnaire themselves said that they had ‘some but not enough’ or ‘none beyond basic training in medical school’ when asked about training in dementia diagnosis. Some GPs suggested that the training they had was ‘self guided’ or that the reason for having sought it out was a

reflection of their ‘own interest’. A similar proportion of nurses who responded to the survey indicated the same thing. The Royal College of Nursing also emphasised the importance of all staff working in a health and social care environment being aware of dementia, not only health and social care practitioners. There is also a role for social workers and care assistants in detecting possible signs of dementia and signposting. The Dementia Action Alliance submission expressed it like this:

‘The majority view of DAA members would appear to be that a major push is required to ensure that healthcare professionals understand the benefits of (early) diagnosis – not just GPs, but receptionists, practice nurses and other staff in primary care, and nurses, ambulance personnel, x-ray technicians and other specialists in secondary care.’

## Pre-registration

The Group emphasises that dementia training at the start of a professional’s career would help establish positive attitudes towards early diagnosis and an understanding of its importance right from the beginning. As mentioned above, the NAO report: (NAO, 2010) identified there is still some way to go with GP attitudes towards dementia diagnosis. Dr Simon Hughes from Royal Victoria Hospital stressed the importance of challenging attitudes:

‘We can change protocols and we can change procedures, but the most potent thing we can do is change the cultural view of dementia. [In Northern Ireland] We have taken the cultural view that this is a fatal disease and that it requires serious prioritisation. If you have a dementia and you die of nothing else, you will die of this disease. It is a very serious disease.’

He also commented:

‘I think there is a role for the Royal Colleges to say that you would not come out of medical education without a fundamental understanding of oncology and ischemic heart disease. Dementia needs to be in that group.’

This concern is key for all general health professionals who work with people with dementia. For example, one nurse who submitted evidence to the inquiry commented: ‘we didn’t have training as part of the student nurse curriculum. [It] should be mandatory for all nurses’. With the number of people with dementia in the UK predicted to increase to over 1 million by 2050, it will become increasingly important that coming generations of health and social care professionals in general roles are able to detect dementia and refer people for a diagnosis.

## **Already qualified practitioners**

As stated above, greater dementia training for GPs and other health and social care professionals is welcome, but additional training is also needed for already qualified practitioners. There is particular need for instant action on this as it is anticipated that the public awareness campaign which is to be rolled out in England in the autumn as part of the Prime Minister's challenge on dementia, will increase the number of people seeking help from their GP.

While additional training for GPs is particularly important, it is also needed for all health and social care professionals working with people at risk of dementia. Responses suggested that 10% of people never went to see their GP with their concerns; therefore GPs are not the sole source of information or referral. It is also likely that this is an underestimate, as carers, family members and friends who provided this response were largely accessed through Alzheimer's Society, and are therefore more likely to be those in touch with services. Therefore there is a need for training in detection and referral for all professionals working with people at risk of dementia. The need for training among hospital ward staff in England will become particularly pressing as the introduction of the CQUIN programme will increase pressure to have basic skills in detecting dementia.

In addition, care home staff may be in a particular position to identify people with dementia. It is estimated that as many as two-thirds of people in care homes have dementia, and many are undiagnosed (Alzheimer's Society, 2007). Training for care home staff on dementia, including on the value of diagnosis and the process they should follow if they suspect someone has dementia would equip them with greater skills to identify this population. The Dementia Care and Support Compact, which formed part of the Prime Minister's Challenge in England, contained commitments which if adhered to would drive up the quality of care, but this is only applicable in England, and not all organisations have pledged their support to this yet.

What was also clear from the evidence is that examples of effective training do exist. For example, the Royal College of Nursing highlighted a web-based resource they have developed to raise awareness of dementia amongst nursing staff. Over a period of five months, its resources have been accessed 58,260 times with 9,523 visitors spending time on the pages relating to understanding and supporting people with dementia.

## **UK-wide**

**The APPG supports current proposals to extend mandatory GP training by at least one year and suggests that there should be a focus on dementia in the additional year.**

The Royal College of GPs has recently won approval from the Medical Programme Board for its educational case for GP mandatory training to be extended from three years to four – an important step in the ongoing approval process. The APPG supports this bid as it moves forward to consideration by Medical Education England and, eventually, the Secretary of State for Health. We would like to see the additional time put towards diseases which will affect people in older age, in line with the proportion of a GP's workload. Time should particularly be devoted to training on detecting dementia.

**Healthcare assistants and healthcare support workers should have appropriate training for their role and be sufficiently regulated.**

Healthcare assistants (HCAs) provide day-to-day care on a hospital ward and are therefore very well placed to notice possible symptoms of dementia. The APPG supports the Royal College of Nursing in calling for mandatory training and regulation for HCAs. As a significant part of the workforce who come into contact with people with cognitive impairment, HCA training should include dementia as a component, in line with the Nursing and Midwifery Council's Standards for Pre-registration Nursing Education.

**Dementia should be a key focus for organisations co-ordinating the training of health professionals, including Health Education England and NHS Education for Scotland. Universities and deaneries who set the curriculum for health professionals should ensure that the detection of dementia is represented on healthcare courses**

It is essential that detection, referral and management of dementia is built into initial training for all health professionals. With the expected increase of dementia as the population ages, many more people will have dementia alongside other conditions, and only a properly trained workforce will be able to cope with the additional complications that this will add to their care.

**UK-wide Royal Colleges should act on the plans regarding member training in the Prime Minister's challenge for all members, not just those in England.**

The list of actions in the Prime Minister's challenge suggests that plans will be brought forward to ensure all Royal College members are capable and competent in dementia care, and this should be applied across all the nations in the UK. Many Royal Colleges are UK-wide, such as the Royal College of GPs. Others do not function across national boundaries, but the learning would be applicable to professions in England, Wales, Northern Ireland and Scotland. In these cases, the Prime Minister's Challenge team should make the same contact with the appropriate bodies in the devolved nations to share plans and work together.

**The Royal College of GPs and members of the Dementia Action Alliance should compile and promote a list of available and effective training in dementia for health and social care professionals.**

Existing dementia training that has shown to be effective should be utilised more extensively. Promotion of such training, including a centralised point where details of the training are available, would be helpful. This should include shorter courses, e-learning and more comprehensive training programmes, and highlight training that covers diagnosis and detection of dementia.

**Service providers, including care homes, should commit dedicated time for training workers in dementia care.**

It is important that all staff working with people with dementia should be properly trained in dementia care, including in detecting symptoms of dementia and being able to alert appropriate professionals. Service providers should allow dedicated time to this training, to show the level of priority it is given.

In particular, there is a clear need for dementia training for care home staff, particularly training which establishes the value of diagnosis. Care home managers should commit time for training and development of staff in dementia, which should be built into the existing systems for continuing professional development.

### **Recommendation 6: Issues with the assessment tools used by UK GPs and other primary care professionals should be explored and addressed**

The APPG received evidence from numerous sources that the cognitive assessment tools available to GPs are frequently inaccurate and can contribute to under-diagnosis. Alzheimer's Research UK commented in their written evidence:

‘Diagnosing dementia is a complex task:

- a There are many different causes of dementia. For example, it could be as a result of Alzheimer's disease, vascular dementia...
- b Determining the type of dementia is challenging.
- c The clinical features of dementia are widely variable and there is often overlap with other conditions, for example depression. This presents further challenges in making a clear diagnosis.
- d There is no such thing as a single accurate test at present. Currently GPs would use a process of exclusion and series of cognitive tests over time to reach a diagnosis.’

They called for greater research into tests which could diagnose dementia more accurately.

Many GPs explained the deficiencies of the tools available to them. Issues included that the cognitive tests were inaccurate in picking up a decline in function in articulate people, or people with a high IQ before the onset of dementia. The Faculty of Health Sciences at University of Southampton suggested that there were difficulties because the tools focus on cognition, and other symptoms of dementia are therefore missed. The Royal College of GPs also highlighted this problem. There were also specific problems reported with the mini-mental state exam including problems with the copyright.

Assessment tools are therefore a potential barrier to the process of diagnosis. There are numerous potential solutions, and there would be great benefit in exploring these further.

## **UK-wide**

**The Dementia Action Alliance action group on diagnosis should explore the issues with assessment tools and suggest solutions to improve national practice.**

The APPG believes the Dementia Action Alliance action group on diagnosis could helpfully explore issues with the cognitive assessment tools and could suggest potential solutions to members and ways to act on them. Care should be taken to work with organisations from all four UK nations to ensure that findings are applicable across the UK.

**GP training on dementia diagnosis should contain information on known problems with assessment tools and encourage GPs to use their clinical judgement.**

GPs should feel confident to use their clinical judgement in addition to assessment tools, particularly where there are known problems with the tools.

## **Recommendation 7: Across the UK, commissioners should invest in appropriate memory service resources to cater to the needs of their population**

Memory clinics, where dementia specialists perform assessments, are a key part of an effective diagnosis service. The inquiry heard evidence that high diagnosis rates in Northern Ireland could be a result of having adequately established and resourced secondary care services, such as memory clinics, which were able to deliver quality services tailored to the needs of the population. Dr Simon Hughes from Royal Victoria Hospital, Belfast, stated:

‘Quality has been key for the service. This is the quality of the referrals and the requests that we get, the quality of the scans themselves delivered on a

day-to-day basis and the scanning service, and the quality of the reporting as well. All of this has bred confidence in both the referrers and the patients in the services. We have also developed one of the things that I think has been absolutely crucial, which has been a regional Multi-disciplinary Team for dementia.'

It is clear that this is not the case across the UK. GPs and specialists responding to the inquiry reported waiting times for a memory service with a mean of several months and the longest of more than a year. Such a variation implies that there are many geographic areas where memory services either do not exist in sufficient number, or are overstretched. Evidence from numerous organisations supported this view. Alzheimer's Support quoted a client who said 'we keep hearing in the media that we should take action and get it seen to, but when we did it felt like we were being led down a blind alley. We didn't want to go private, but we felt we had no choice.'

In September 2011, the Department of Health announced an additional £10 million funding for memory services in England, although this amount was not ring-fenced. There is currently no evidence on whether the allocations from PCTs were then transferred to local authorities, and if they were spent on memory service provision. The APPG would like to hear whether this £10 million was spent on improving memory services.

The APPG heard evidence on the need for innovative commissioning, to ensure that different models of care could be delivered where this will meet the needs of their population better. Both Professor Sube Bannerjee from the Institute of Psychiatry and Dr Peter Connelly from the Royal College of Psychiatrists both described services that are working well. Dr Connelly described the Open Access service which he runs in Perth, Scotland:

'They do not need an appointment from their GP, they can simply come in and be assessed. In the first year of that, from a population of around 6,000 older people, we had 300 referrals... The diagnostic rates increased by 27% based on the HEAT targets, with a steady increase of 10% per annum; cholinesterase inhibitor [a type of drug used to treat Alzheimer's disease] prescription increased by 62%. Of the people who attended, only 11% had discussed their symptoms with their GP. The rest had not. None of those who had discussed their symptoms with their GP was referred after discussing their symptoms... The traditional methods that we have relied on up until now no longer work. If we really want to make a breakthrough in the way people are diagnosed, we need to change the systems and look at innovation, not simply at enhancing what is already there.'

A common concern expressed to the inquiry, including by the British Medical Association, was that with such a large number of people living with undiagnosed dementia memory services will be ‘overwhelmed’ if all who are currently undiagnosed are identified and referred at once. Initiatives to improve referral can be met with hesitance due to this fear. Dr Connelly compared the system to a watch:

‘Dementia service provision works best, I think, in the model of a watch with cogs. If you have your watch with all the cogs right, it works perfectly. If you double the size of one of the cogs in your watch, it does not work twice as well: it does not work at all.’

However, the APPG stresses that the solution is not to delay referral, but to prioritise investment in the parts of the system which require it, in this case secondary diagnostic services. As increasing numbers of people with dementia receive a diagnosis, this should be recognised by commissioners and increasing levels of services should be commissioned to meet the needs of this population. Without a diagnosis they remain hidden to the system as well as to health professionals individually.

## UK-wide

**All commissioners should prioritise investment in memory services so they are able to meet the needs of their population.**

There is a clear need for an increase in the capacity of memory clinics as shown by the long waiting times that people experience. Clear assessments of the level of need in each area are required. Commissioners then need to commission appropriate high quality services to meet the needs of the population.

**Commissioners should be innovative in commissioning in order to meet the needs of their population.**

Evidence to the inquiry suggested many different models of care which were proving successful in different parts of the country. These could be used more extensively.

## **Recommendation 8: Strengthen the role of the Memory Services National Accreditation Programme**

The inquiry also received evidence that there is a need for consistent quality within memory services. While the NHS Information Centre found there were memory services in 94 % of PCTs in England (NHS Information Centre, 2011), there is no indication of the appropriateness of these services. Without systematic regulation of quality, a memory service in an area with substantial need might only consist of a small infrequent service with few staff.

In addition, the NHS Information Centre also found that 19 PCTs, a small but significant number of those who responded, had no intention of joining the Memory Service National Accreditation Programme (MSNAP), so there was no mechanism to check the quality of provision. Professor Sube Bannerjee from the Institute of Psychiatry expressed his concerns about this:

‘I am very worried about the quality of the data that is saying that good things are happening in memory services all around the country. I know that there are islands of real excellence: places where people are doing a lot. But also, the clinical feeling is that in most places nothing much is happening and that the technique of the study that the Department used to be able to say positive things about the growth of memory services was really very weak indeed. The quality of the data means that the inferences made are strained at the very least. We do not know what is happening in terms of implementation. We need to know what is happening in terms of implementation.’

The evidence received by the inquiry suggested that existing memory services could strengthen what they offer by engaging more extensively with community services. For example, Harwick Health Commissioning Group felt that due to the way that dementia drugs had developed, there was too much concentration on traditional secondary care models in the process of diagnosis. A memory service that is involved in a community, visiting people at home, or running clinics in local primary care services for example, has the advantage of a good connection with primary care, creating better integration between the services. It also allows more extensive outreach to patients who are less able to travel. The evidence provided examples of good practice using this model. The British Medical Association suggested that this is working well in North West Wales. Gnosall Surgery in Staffordshire was cited repeatedly in the evidence as an example of good practice. They have embedded a memory service in primary care, and have managed to substantially increase the proportion of people who have a diagnosis, and reduce waiting times in the area from three years to four weeks.

It was also seen as important that memory services are able to be flexible. Lorraine Edmunds, Lead Nurse Older People, Aneurin Bevan Health Board, told the oral evidence session:

‘Memory clinics should not be seen as a building where people come to us, but as a core set of skills: we go out and do what is required in order to make safe diagnosis, and give support in the environment, wherever that might be, for a carer, a care home or for individuals or care staff. We should take that service to where it needs to be. That concept of a memory clinic on every corner probably went a long time ago in our heads. It is about going where you need to go.’

## UK-wide

### **Accreditation for memory services should be mandatory.**

The APPG welcomes the action detailed in the Prime Minister's challenge on dementia which commits to working with the Royal College of Psychiatrists to drive up the proportion of memory services which are accredited. The APPG would suggest going further and making the Memory Services National Accreditation Programme (MSNAP) mandatory for all memory services. We suggest there should be an aim that half of services are accredited by 2013 and all are accredited by 2015.

### **MSNAP accreditation should include additional measures to ensure accurate recording of key data on memory services.**

The APPG also welcomes the action in the Prime Minister's challenge to use MSNAP to drive up standards. To ensure that this is done effectively, it is essential that MSNAP is able to collect data on the quality of the services accredited through them, which should be published regularly. Additional resource should be provided to MSNAP to ensure that this can be centrally collected and used as part of the nationally available data on the quality of memory services.

### **MSNAP should strengthen strands of the programme that concern waiting times and community based work.**

Further to this, the APPG believes that MSNAP should strengthen the quality strands within their current programme on waiting times and the community based work of memory services. This should help drive up standards in these areas by highlighting them as factors which have an impact on the patient experience.

## **Recommendation 9: Adequate information and one-to-one support should be provided to patients and their families immediately following diagnosis**

Whilst diagnosis may be the starting point, opening the door to treatment and support, it is not enough on its own. Evidence to the inquiry reflected this. Many respondents were keen to emphasise that diagnosis was not a cure all, and that information, services and treatment also need to be provided. When asked what happened after a diagnosis had been given, a significant number of carers wrote 'nothing', suggesting that much greater attention on immediate support and information is needed. Many respondents to the inquiry commented that there was a lack of appropriate services and treatments generally. As may be expected, some suggested that the APPG should investigate improving care.

The focus of this inquiry was primarily on diagnosis, but it is clear that without follow up, many people with dementia and carers feel like they are abandoned after a

diagnosis has been made. There needs to be clear information, support and services provided to people immediately following a diagnosis.

## **England**

### **There should be monitoring of the Prime Minister's challenge on dementia commitment to promote the information offer pioneered in the South West.**

The Prime Minister's challenge included a commitment to promote the information offer pioneered in the South West. Here, the local NHS, local authorities and voluntary agencies have developed a web-based information service called Our Health. This uses the NICE quality standards and other evidence to provide information on the support people with dementia should expect to receive, and describes different services available and how they can be accessed. The APPG would like monitoring to assess whether the promotion of this tool ensures everyone in England receives sufficient information on dementia following their diagnosis.

### **There should be additional investment to develop the role of dementia advisers.**

The National Dementia Strategy (launched in 2009) created the role of dementia adviser, yet there are still an insufficient number of these roles to cater for the number of people with dementia in England. The APPG would like to see a formal guarantee for a named individual to provide co-ordinated support to each person with dementia immediately following diagnosis in England, similar to the commitment in Scotland.

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# Appendix 1: List of organisations that submitted written evidence

Age UK Cheshire

Age UK Shropshire, Telford & Wrekin

Alzheimer Europe

Alzheimer Scotland

Alzheimer Scotland Dementia Research Centre

Alzheimer's Disease International

Alzheimer's Research UK

Alzheimer's Society

Alzheimer's Support

ARC Research and Consultancy Ltd.

Association of British Neurologists

Association of Directors of Adult Social Services

Barchester Healthcare

British Geriatrics Society

British Medical Association

Bupa

Cambridge Cognition

Cardiff and Vale ULHB

Centre for Mental Health Services Development Wales

Creative Support

Dementia Action Alliance

Dementia Services Development Centre, Wales

Dementia UK

Department of Health, Social Services and Public Safety

Faculty of Health Sciences, University of Southampton

Friendship Services in the Highlands

GE Healthcare

General Medical Council

Gnosall Health Centre, Stafford and StayWell75+

Grand Home Care, Gibraltar

Guideposts Trust

Hampshire County Council

Hardwick Health Clinical Commissioning Group

Hywel DDA Health Board and Faculty of Old Age Psychiatry, RCPsych

Lundbeck

Manchester Care & Repair

Manchester Mental Health and Social Care Trust

Memory Services National Accreditation Programme

Mentaur Ltd

National Council for Palliative Care

National Institute for Health Research

NHS London

NHS Merseyside

Norfolk and Suffolk Dementia Alliance

Norfolk and Suffolk NHS Foundation Trust

RICE (The Research Institute for the Care of Older People) at Royal United Hospital, Bath

Royal College of General Practitioners

Royal College of Nursing

Royal College of Physicians

Royal College of Psychiatrists, Old Age Faculty

Social Care Institute for Excellence

South Essex Partnership University NHS Foundation Trust

Southern Health

South West Dementia Partnership

The Castle Medical Centre, Kenilworth

The Debenham Project

The Lewy Body Society and Parkinson's UK

The People Care Team

University of Plymouth

