

A FUTURE STATE OF MIND

Facing up to the dementia challenge

Nida Broughton, Nigel Keohane and Ryan Shorthouse

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Answers That Matter.

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EXECUTIVE SUMMARY

There are an estimated 820,000 people with dementia in the UK (both diagnosed and undiagnosed), a figure that is set to rise dramatically over the coming years as the UK's population ages. One estimate puts the likely number of people with dementia at one million by 2021. As the number of people with dementia rises, so will costs. Estimates put the current cost of dementia to the UK at £23 billion a year – including the costs of social care, health care and unpaid carers. The Prime Minister, launching the Dementia Challenge this year, described this as “a national crisis”. Evidence suggests that diagnosis is important but the UK does not perform well compared to other countries.

In addressing this challenge, this report seeks to answer the following research questions:

1. Are there benefits to early diagnosis of dementia?
2. How does the UK's diagnosis performance compare internationally? And how does England perform compared to the devolved administrations in the UK?
3. What are the patient and professional barriers to early diagnosis?
4. What policies could improve the early diagnosis rate in England?

The most common form of dementia is Alzheimer's disease, a physical disease of the brain that causes confusion, memory lapses, mood swings and difficulty carrying out everyday activities. There is no cure for dementia or Alzheimer's disease, but it is possible to improve lives and save costs by diagnosing early. Patients can plan for the future with their family, receive support that improves their lives and access treatment that can relieve symptoms. Early support and treatment could also save public money in the long-term by reducing the need for care home places and unnecessary admissions to hospital.

But the performance of England and the UK on diagnosis is poor. Studies suggest that other European countries are better at diagnosing people with dementia early. There is also marked regional variation within the UK. Whilst Northern Ireland and Scotland have diagnosis rates of above 50%, in some areas of England and Wales, rates are as low as 27%.

The barriers to early diagnosis

This research includes an extensive literature review, in-depth qualitative research and quantitative analysis to unearth the reasons for low diagnosis rates. Semi-structured interviews were carried out with a mixture of patients diagnosed with Alzheimer's and their carers or relatives.

The barriers identified in the research stem from both the patient and professional side. Our interviews with patients and carers revealed the following common barriers on the patient side:

- a) Lack of knowledge about Alzheimer's, and the closeness of its symptoms to those associated with ageing.
- b) The gradual manifestation of Alzheimer's and the inability to treat problems as acute and serious.
- c) Fear of Alzheimer's, and the denial of the disease and its implications.
- d) The lack of trust in the health system with regard to medical practitioners.
- e) The lack of support, either from family or friends, or professional support.

Our analysis identifies four broad types of people with dementia: the 'unaware', 'fatalists', 'deniers' and the 'conscientious'. Each group displayed specific characteristics that affected the speed at which they sought medical advice after first detecting symptoms, with

the 'conscientious' more likely to be diagnosed early. Importantly, strong social networks are associated with early diagnosis. Relatives and friends who prompted patients to access medical advice improved the chances of early diagnosis.

Understanding the salient characteristics of those with dementia and their attitudes to seeking medical help are essential if policymakers are to resolve some of the patient-side barriers to early diagnosis.

However, our research demonstrated that barriers also emerge on the professional side. Early diagnosis is obstructed principally by problems in primary care associated with the capability of GPs, time constraints and physician perceptions of the benefits of diagnosis. Surveys suggest that many GPs feel that they lack the training, confidence and time to deal with dementia. At the same time, there remains a perception in some parts of the medical community that there is little that can be done for those with dementia, and that a diagnosis could cause more harm than good, though for most patients this seems unlikely to be the case.

Developing policy to promote early diagnosis

What then should policymakers do to improve diagnosis rates?

Some policy interventions are undertaken most effectively and efficiently at a national level, including regulation of the medical professions and national awareness campaigns.

However, the primary role of national policy makers and commissioners should be to create a framework within which local commissioners and GP practices are encouraged to innovate to develop the best interventions to increase diagnosis rates.



Some areas of the medical profession have introduced innovative ways of encouraging people with symptoms to come forward and make diagnosis happen earlier. This type of innovation needs to be encouraged and rewarded. There are financial incentives currently operating in the NHS – but none of them target diagnosis of dementia effectively. For example, there is a financial incentive for GPs to hold a register of dementia patients – but the reward payment encourages GPs to record any diagnoses they happen to make, rather than rewarding them for actually carrying out more diagnoses. The existing incentives are also too process-orientated rather than outcome-focused.

This report argues that local authority Directors of Public Health, Clinical Commissioning Groups and hospitals should all be financially rewarded for the same thing: increasing the number of diagnoses in their area, with a target adjusted for each locality according to the prevalence of dementia. This alignment of incentives should encourage joint-working between different agencies in a locality.

Sharpening the incentives that are currently in place is a fundamental lever that national policy makers can pull to increase the health system's focus on diagnosis. Over time, incentives should be shifted towards a focus on early diagnosis, rather than simply diagnosis rates.

Our analysis also suggests that there is a strong case for developing alternative commissioning approaches that attract external finance to boost early diagnosis, through 'Dementia Impact Bonds'. Social impact bonds for dementia could help local authorities, who fund social care, and clinical commissioning groups, to focus health providers on early diagnosis and save money in the long-term. External investors could help to finance

early intervention programmes, in return for a share of the measurable long-term savings that occur due to reduced care home placement and admissions to acute care in hospital.

Getting the financial incentives right at the local level would promote innovation, encouraging providers to focus on activities that they believe are likely to increase diagnosis in their area. These could include targeted screening, outreach work, investment in awareness campaigns, building support networks for those without close families or friends, and case-finding in primary and secondary care. Central government could encourage commissioners to adopt Dementia Impact Bonds through use of its £20m Social Outcomes Finance Fund. By reducing the risk to individual commissioners, this fund would encourage the joint commissioning that would be a prerequisite for such schemes.

The structure of the report

This report is structured in the following way:

- Chapter 1 describes the benefits of early diagnosis of dementia and how the UK performs on diagnosis.
- Chapter 2 introduces the research methodology.
- Chapter 3 presents the patient barriers to early diagnosis.
- Chapter 4 sets out the professional barriers to early diagnosis.
- Chapter 5 proposes policies to improve the early diagnosis rate.

CHAPTER 1: WHY DOES THE UK NEED TO PUSH FOR EARLIER DIAGNOSIS?

DEMENTIA: A GROWING PROBLEM

There are an estimated 820,000 people in the UK with dementia¹ (diagnosed and undiagnosed) – an umbrella term for a set of conditions that involve memory loss, mood changes and problems with communication and reasoning. The most common type of dementia, accounting for around two-thirds of people with dementia, is Alzheimer's disease.² Other forms of dementia include, among many more, vascular dementia, dementia with Lewy Bodies, Parkinson's dementia and fronto-temporal dementia. Alzheimer's disease is a physical disease of the brain, resulting in the death of brain cells. As the disease progresses, the brain becomes more damaged and symptoms become more severe.³

The risk of Alzheimer's disease and dementia increases with age: around one in 20 people over the age of 60 have dementia, rising to around one in five of people aged over 80.⁴ However, younger people can also develop the disease: around one in 1,400 40-64 year olds have dementia.⁵

Alzheimer's Research UK estimates that the cost of dementia to the UK economy is £23 billion per annum, more than the cost of cancer and heart disease combined.⁶ Chart 1.1 shows a breakdown of these costs.

1 Alzheimer's Research UK, "What is dementia?", <http://www.alzheimersresearchuk.org/what-is-dementia/?gclid=CKOQ08jM7rACFVMTfAodIXrOSA>. Based on estimates of prevalence.

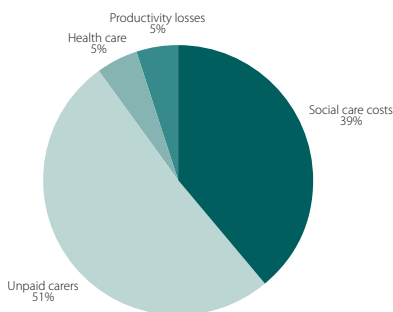
2 National Health Service Choices, "Alzheimer's in the news: fear and fascination", <http://www.nhs.uk/news/2011/08August/Documents/Alzheimer's%20in%20the%20press.pdf>.

3 Alzheimer's Society, "What is Alzheimer's disease?": http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=100.

4 Alzheimer's Research UK, "Prevention", <http://www.alzheimersresearchuk.org/prevention/>.

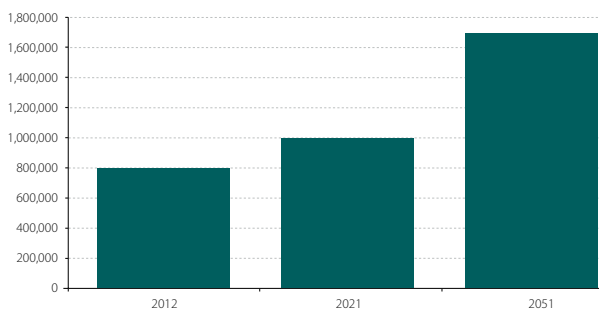
5 Alzheimer's Society, "Dementia 2012 infographic", <http://www.alzheimers.org.uk/infographic>.

6 Alzheimer's Research UK, "Dementia statistics", http://www.alzheimersresearchuk.org/siteFiles/resources/documents/ARUK_Dementia_statistics_2012.pdf.

Chart 1.1. The cost of dementia to the UK economy

Source: Alzheimer's Research UK, "Dementia statistics"

What is more, costs are set to rise over the next few decades, as the UK's ageing population brings an increased number of people with dementia. Some forecasts put the number of people in the UK with dementia at one million in 2021 and 1.7 million in 2051.⁷ Recognising the urgency of the situation, the Coalition Government launched a new challenge on dementia in 2012, and the Prime Minister commented: "We've got to treat this like the national crisis it is".⁸

Chart 1.2. Projected number of people with dementia in the UK, 2012 to 2051

Source: Alzheimer's Society, "Dementia 2012 infographic".

⁷ Alzheimer's Society, "Dementia 2012 infographic".

⁸ HM Government, *The Prime Minister's challenge on dementia* (HMSO: London, 2012), 2.



THE CASE FOR EARLY DIAGNOSIS

Although there is no cure for dementia and Alzheimer's disease, there is a strong case for diagnosing them. Diagnosis provides access to treatment and support, and allows patients and families to prepare for the future progress of their condition.

There are particularly strong benefits of early diagnosis. Early diagnosis can be described as securing a diagnosis soon after symptoms have emerged. There is emerging evidence which shows that changes to the brain can be detected 10 to 15 years before symptoms appear in patients who go on to have Alzheimer's.⁹ However, clinicians question the advisability and feasibility of diagnosis before the emergence of symptoms.¹⁰ This research focuses on the merits of, and barriers to, early diagnosis after the emergence of symptoms. Below is an overview of the merits of early diagnosis.

Early access to effective support and treatment

Diagnosis of dementia, and Alzheimer's in particular, can be a route to support and treatment. Early diagnosis gives both patients and carers time to access information and support services.¹¹ It also allows access to drugs which can alleviate symptoms.

Early diagnosis can help carers provide better support to patients. For example, when diagnosis is provided promptly, spouse carers are prepared to invest considerable effort in

9 Professor Dr Eric M Reiman, "Brain imaging and fluid biomarker analysis in young adults at genetic risk for autosomal dominant Alzheimer's disease in the presenilin 1 E280A kindred: a case-control study", *The Lancet Neurology*, 11:12 (2012), 1048-1056.

10 For instance, see evidence submitted to: APPG on Dementia, "2012 Inquiry – Improving dementia diagnosis rates in the UK – Summary of collated evidence", www.alzheimers.org.uk/site/scripts/download.php?fileID=1401.

11 Bob Woods and Rebekah Pratt, "Understanding awareness: ethical and legal issues in relation to people with Dementia", *Ageing and Mental Health*, 9: 5 (2005), 423-429.

maintaining self-esteem and agency of the person with dementia.¹² Carer support and counselling, such as regular support sessions and providing telephone counselling, can reduce care home placement by 28%.¹³ Peer support is also valuable to people with dementia and their carers.¹⁴

By their very nature, these types of interventions are likely to be more useful if they take place at an early stage, before the point at which it is not possible for patients to be cared for at home. Overall, support at an early stage appears to increase quality of life and reduce behavioural and psychological symptoms associated with dementia.¹⁵

Benefits accrue not only to the patient but also the carers: early provision of counselling and support improves carers' self-reported health and quality of life.¹⁶ This is particularly significant because of the adverse health effects associated with being a carer with studies showing that carers experience a higher rate of mental illness such as stress and depression compared to the general population.¹⁷

Planning for the future

Early diagnosis allows patients and carers the chance to make key decisions at a point where the patient can be fully involved.¹⁸

12 I. Hellström, M. Nolan, L. Nordenfelt and U. Lundh, "Ethical and methodological issues in interviewing persons with dementia", *Nursing Ethics*, 14: 5 (2007), 608-619.

13 MS. Mittelman, WE. Haley, OJ. Clay, DL. Roth, "Improving caregiver well-being delays nursing home placement of patients with Alzheimer disease", *Neurology* 67:9 (2006), 1592-99.

14 Department of Health, *Living well with dementia: a national dementia strategy* (London: HMSO, 2009).

15 S. Banerjee, R. Willis, D. Matthews, F. Contell, J. Chan, J. Murray, "Improving the quality of care for mild to moderate dementia: an evaluation of the Croydon Memory Service Model", *International journal of geriatric psychiatry*, 22: 8 (2007), 782-88.

16 MS. Mittelman, DL. Roth, OJ. Clay, WE. Haley, "Preserving health of Alzheimer's care givers: impact of a spouse caregiver intervention" 15:9 (2007), 780-89.

17 Aadil Jan Shah, Ovais Wadoo and Javed Latoo, "Psychological distress in carers of people with mental disorders", *British journal of medical practitioners*, 3:3 (2010), 327.

18 Allison Milne and Heather Wilkinson, "Working in partnership with users in primary care: sharing a diagnosis of dementia", *Journal of Integrated Care*, 10:5, (2002), 18-25.

In particular, legal and financial decisions can be made early: for example, wills can be written or 'lasting power of attorney' can be put in place, allowing the patient to appoint an attorney to manage his or her affairs in the event of incapacitation in the later stages of the disease.¹⁹ This includes both financial matters such as paying bills and managing property, as well as decisions on personal welfare such as living arrangements. The patient can also make advance decisions over whether they would like to refuse or accept treatment if they lose capacity in the future, for example, through living wills.²⁰

Emotional and psychological effects

Early diagnosis also provides patients and carers with time to come to terms with the illness while the patient is still able to understand its implications.²¹ Diagnosing dementia early gives patients and carers time to help people develop ways of coping with the condition and its effects on their lives. Studies show that those who adjust to having a diagnosis are more likely to seek out information and support.²²

There is little evidence that suggests that diagnosis causes undue emotional distress.²³ Over the long-term period after diagnosis, well-being studies demonstrate that people with an early diagnosis of dementia are as satisfied with life as the mainstream population: the key contributor to life satisfaction is

19 G. Ashton, P. Letts, L. Oates and M. Terrell, *Mental capacity: the new law* (London: Jordans, 2006).

20 D. Lush, "The legal framework in the British Isles for making decisions on behalf of mentally incapacitated people", in R. Jacoby, C. Oppenheimer, T. Denning and A. Thomas, (eds) *The Oxford Textbook of Old Age Psychiatry* (Oxford: Oxford University Press, 2008).

21 Alzheimer's Society, "Dementia: Out of the Shadows", http://www.alzheimers.org.uk/site/scripts/download_info.php?downloadID=133&fileID=453.

22 Ibid.

23 G. Pinner and W. P. Bouman, "What should we tell people about dementia?", *Advances in Psychiatric Treatment* 9 (2003) 335-341.

“family relationships.”²⁴ In fact, not disclosing a diagnosis to the patient can have a negative impact, leaving patients confused and less able to make sense of the symptoms and what is happening to them.²⁵

Financial costs

As set out earlier, the social and healthcare costs of dementia are set to rise over the coming years as prevalence increases.

The cost and benefit implications of early diagnosis are different for Government and for society as a whole. The costs to Government include the provision of early assessment and treatment, set against the potential savings from reduced spending on care homes and acute care required after accidents. But a substantial number of care home residents are privately funded – around a third in 2009.²⁶ So there are additional, private savings that can arise from early assessment and treatment. Other costs and benefits that may not have a direct impact on the Government’s finances include quality of life and the impacts on carers’ time.

Evidence suggests that early intervention can reduce institutionalisation: providing in-home support can reduce institutionalisation by 22%.²⁷ The Department of Health has estimated the savings that would arise from early intervention and

24 T. Katsumo, “Dementia from the Inside: how people with early stage dementia evaluate their quality of life”, *Ageing and Society*, 25, (2005), 197-214.

25 N. Aggarwal, A.Vass, H. A. Minardi, R. Ward, C. Garfield, and B. Cybyk, “People with dementia and their relatives: personal experiences of Alzheimer’s and of the provision of care”, *Journal of Psychiatric Mental Health Nursing*, 10 (2003), 187-197.

26 Department of Health, *Transforming the quality of dementia care: consultation on a National dementia strategy* (London: HMSO, 2008).

27 J.E. Gaugler, R.L. Kane, R.A. Kane and R. Newcomer, “Early community based service utilization and its effects on institutionalization in dementia caregiving”, *Gerontologist*, 45 (2005), 177-85.

treatment, based on its effect in reducing care home placements. It found that if early intervention and treatment reduced care home admissions by 10% (its lower end assumption for reduced admissions), this would result in savings of £120 million to the public purse, and £125 million to private individuals.²⁸ These estimates did not include impacts on quality of life and the cost of carers' time. Other studies have also shown that the costs of early assessment and treatment are outweighed by later cost savings.²⁹

THE UK'S TRACK-RECORD ON DIAGNOSIS

Research by the Alzheimer's Society suggests that around 59% of those living with dementia have not been diagnosed.³⁰ Of the 41% who are diagnosed, it is likely that many are diagnosed late. This diagnosis rate is a well-established estimate, used by the Government and others in the health and social care community, based on a study by academics from the LSE and King's College London in 2007. Box 1.1 details the methodology for working out this diagnosis rate.

28 Department of Health, *Transforming the quality of dementia care*. These numbers were compared to the costs of a specific early diagnosis and intervention service based on the Croydon Memory Clinic, which was estimated to cost £265m to roll out across the country. It concluded that such a service would be cost-effective even though there would be a net increase in public expenditure. If services reduced care home admissions by 20%, it found that the annual cost would be almost offset by the savings to public spending alone.

29 See, for example, D. Getsios, S. Blume, K.J. Ishak, G. MacLaine, L. Hernandez, "An economic evaluation of early assessment for Alzheimer's disease in the United Kingdom", *Alzheimer's and Dementia*, 8 (2012), 22-30.

30 Alzheimer's Society, "Increase in number of people diagnosed with dementia: over 400,000 remain undiagnosed, according to Alzheimer's Society", http://alzheimers.org.uk/site/scripts/news_article.php?newsID=1164. HM Government, *The Prime Minister's challenge on dementia*. Diagnosis rate calculations are based on comparing expected prevalence against actual numbers of diagnoses as recorded on GPs' registers. The Alzheimer's Society obtained expected prevalence rates by asking a selection of dementia experts to review available epidemiological studies. See Professor Martin Knapp and Professor Martin Prince, *Dementia UK* (London: Alzheimer's Society, 2007), http://alzheimers.org.uk/site/scripts/download_info.php?fileID=2, for more detail on how expected prevalence was estimated.

Box 1.1. Working out the diagnosis rate³¹

The diagnosis rate of 41% is derived from the Alzheimer's Society analysis of diagnoses recorded on GP registers and expected prevalence as calculated by the Personal Social Services Research Unit (PSSRU) at the London School of Economics and the Institute of Psychiatry at King's College London, for the Alzheimer's Society.

The most recent studies on the prevalence of dementia in the UK include six population-based studies from the 1980s and 1990s. The sample sizes of these studies varied from 365 to 13,009. In these studies, researchers used established techniques to discover whether those in the sample had any variant of dementia. The estimated prevalence of each age group in each of these studies sometimes varies significantly, implying that there is a wide range of estimates for the dementia prevalence rate. However, a systematic review of all the relevant studies was conducted by an expert panel and they synthesised the evidence into a single consensus estimate of likely prevalence. This process is called expert Delphi consensus. After arriving at the expected prevalence rate for each age cohort, the Alzheimer's Society compared the expected prevalence across the population with the number of people registered by GPs as having dementia nationally, giving the diagnosis rate.

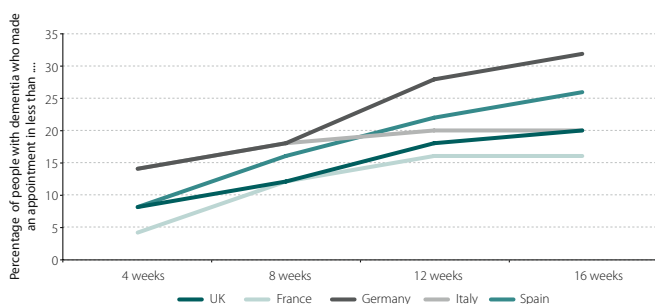
How does the UK compare to other countries?

Although sample sizes are often small, cross-country surveys paint a picture of the UK as performing less well on diagnosis relative to other countries. Delays in diagnosis occur both because patients leave it later to seek medical advice (patient barriers), and because of delays in the process of diagnosis itself (professional barriers), as will be explored in later chapters. International comparative analysis can help understand the challenges faced in England in both these instances.

31 Professor Martin Knapp and Professor Martin Prince, *Dementia UK* (London: Alzheimer's Society, 2007), http://alzheimers.org.uk/site/scripts/download_info.

A 2009 study of caregivers looking after individuals with Alzheimer's disease across the UK, France, Germany, Spain and Italy found that 16 weeks after noticing symptoms, only 20% of UK respondents had made an appointment with a doctor, compared with, for example, 32% in Germany.³²

Chart 1.3. Time between identifying symptoms and making an appointment, responses by carers of people with dementia (2009)



Source: Alzheimer's Disease International, "IMPACT Study database", www.alz.co.uk/impact-study (accessed November 2012)

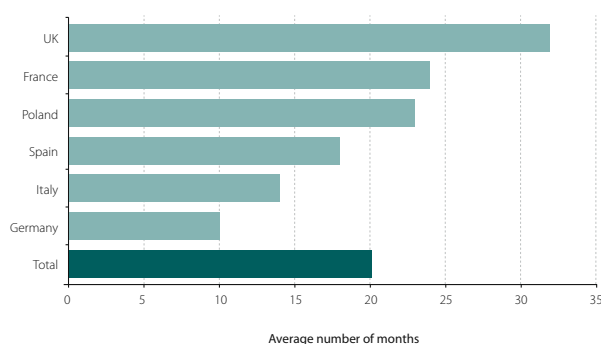
Across all five countries, a high number of patients waited longer than 17 weeks before making an appointment. But the UK stands out from the other countries in the relatively high percentage of patients who did not make an appointment at all: 14% compared to 0-2% in the other four countries. It is unclear from the survey how these 14% were diagnosed, but this high figure could corroborate concerns that a significant number of patients are only diagnosed after being admitted to hospital as a result of a crisis situation such as a fall, as will be shown in Chapter 3.³³

32 Alzheimer's Disease International, "IMPACT Study database", www.alz.co.uk/impact-study (accessed November 2012). The IMPACT (Important Perspectives on Alzheimer's Care and Treatment) study was fielded between April and May 2009 and was designed to assess current beliefs and behaviours surrounding Alzheimer's disease and dementia among key stakeholder groups from 5 European countries: France, Germany, Italy, Spain and the United Kingdom.

33 APPG on Dementia, "2012 Inquiry – Improving dementia diagnosis rates in the UK – Summary of collated evidence", submission by Bupa and submission by Guideposts Trust.

A survey from 2004 suggested that people in the UK with Alzheimer's waited an average of 32 months between noticing symptoms and obtaining a diagnosis – the highest among the six countries surveyed (the UK, France, Poland, Spain, Italy and Germany).³⁴ A more recent survey suggests that waiting times may still be long: around 60% of respondents waited longer than a year between noticing memory problems and obtaining a diagnosis.³⁵

Chart 1.4. Time between first noticing symptoms and receiving a diagnosis of Alzheimer's disease (2005)



Source: J. Bond, C.Stave, A. Sganga, O.Vincenzino, B. O'Connell, R.L. Stanley, "Inequalities in dementia care across Europe: key findings of the Facing Dementia Study", *International Journal of Clinical Practice*. Supplement, 8-14 (2005), 146. Note: Based on a survey of caregivers

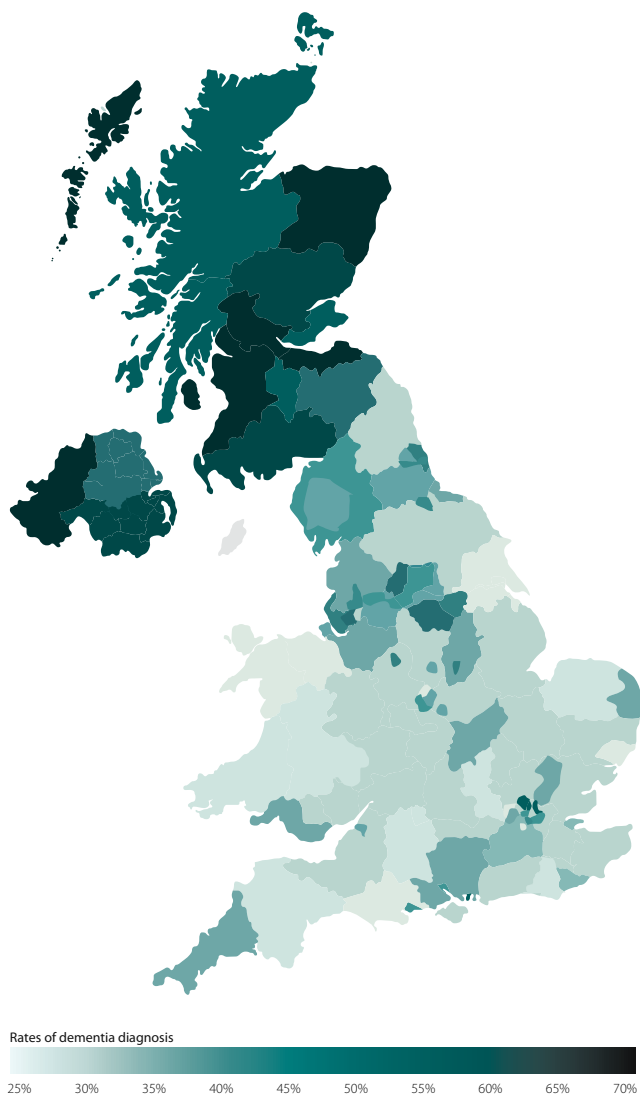
There is wide variability in diagnosis across the UK. Whilst Northern Ireland and Scotland have diagnosis rates of above 50%, in some areas of England and Wales, rates are as low as 27%.³⁶

34 J. Bond, C.Stave, A. Sganga, O.Vincenzino, B. O'Connell, R.L. Stanley, "Inequalities in dementia care across Europe: key findings of the Facing Dementia Study", *International Journal of Clinical Practice*. Supplement, 8-14 (2005), 146.

35 APPG on Dementia, "2012 Inquiry – Improving dementia diagnosis rates in the UK – Summary of collated evidence". Note the APPG survey did not ask respondents when they were diagnosed, so it is difficult to draw definitive conclusions on whether waiting times have improved or not.

36 Alzheimer's Society, "Dementia prevalence and diagnosis rates", <http://www.alzheimers.org.uk/dementiamap>.

Figure 1.1. Regional variations in diagnosis rates of dementia



Source: Alzheimer's Society, "Dementia prevalence and diagnosis rates", (2012). <http://www.alzheimers.org.uk/dementiamap>.

This marked contrast has been put down to a number of factors, including: the higher coverage of memory clinics in Northern Ireland; better integration of health and social care in Northern Ireland; and the use of national targets to promote the diagnosis and recording of dementia in Scotland.

The need for new analysis

This chapter has demonstrated that the UK has relatively poor diagnosis and early diagnosis rates. The rest of the paper seeks to explore the reasons for these findings and proposes policies to improve the early diagnosis rate.

There is a growing evidence base explaining why dementia is under-diagnosed. Much of this has focused on professional barriers, namely the views, perceptions and strategies of health professionals that may act as barriers to prompt diagnosis. As future chapters will show, the recent report of the All Party Parliamentary Group (APPG) on dementia provided valuable new evidence on this. It also provided important new quantitative evidence that illustrated some of the barriers from the patient perspective.³⁷

This research is designed to supplement the existing evidence with in-depth qualitative insights and experiences from patients with Alzheimer's and their carers. Specifically, we explored reasons for how and why patients and carers or relatives sought out diagnosis and any factors that prompted or delayed this. This new analysis is brought together with a review of existing evidence to assess the barriers to early diagnosis in England. The focus of our qualitative research is on Alzheimer's disease. However, the barriers that we discuss and the policy solutions we propose apply to dementia more widely.

37 APPG on Dementia, "2012 Inquiry – Improving dementia diagnosis rates in the UK – Summary of collated evidence", www.alzheimers.org.uk/site/scripts/download.php?fileID=1401.



CHAPTER 2: RESEARCH METHODOLOGY

Dementia typically manifests itself gradually over a long period of time. Patients experience an emotional journey in discovering they have dementia. Identifying the barriers for early diagnosis of dementia is therefore a sensitive and difficult task.

To identify the reasons for poor early diagnosis rates, both from a patient and professional viewpoint, this report took the following approach:

- Ten depth interviews with either a patient who had been diagnosed with Alzheimer's disease, or with their carer or relative who had consent to speak on their behalf.
- Follow-up interviews with carers were carried out in the three instances where initial interviews were with patients.
- The ten interviewees were asked to complete a 'My Story' diary about their experiences before and after an Alzheimer's diagnosis.
- Extensive literature review of the barriers to diagnosis.
- A regression analysis of different factors associated with differing diagnosis rates across the UK.
- An expert roundtable seminar to discuss the professional barriers to diagnosis.

The recruitment and fieldwork was carried out by TNS BMRB.

Fieldwork sampling

Although the focus of this report, especially the policy recommendations, is about the early diagnosis of dementia, it was decided that the focus of the interviews should be patients with Alzheimer's, a particular form of dementia. This was for two reasons:

- a) Alzheimer's Disease is the most common form of dementia, representing the majority of patients with dementia.
- b) Since the sample size was comparatively small, it was appropriate to focus on one particular condition in order to make fair comparisons.

Rather than attempting to recruit a representative sample, our qualitative sampling aimed to reflect the diversity within the group. Initially, the SMF sought interviews concerning a diagnosis which had happened in the past year whilst varying other characteristics. The initial sampling criteria are detailed in Annex 1. Due to difficulties recruiting interviewees, the lower level priority criteria were relaxed. The final characteristics of our participants are set out in full in Annex 1.

For those in the early stages of Alzheimer's disease, all of the interviews bar one were with the patient. In these three examples, there were follow up interviews with carers. For those in the mid and mid-late stages, all the interviews were with relatives who were either the carers or had power of attorney or consent to speak on behalf of their patient.

Recruitment and timing

Recruitment took place in August, September and October 2012. Recruitment was conducted face-to-face by professional recruiters using a screening questionnaire designed jointly by TNS BMRB and SMF. If a carer or relative was approached, they were asked to sign a form to prove they had power of attorney or consent to speak on behalf of the patient. All interviewees were offered a financial incentive to take part in the interviews. The interviews were carried out during September and October 2012.



Interviews

Each interview took place at the interviewee's home or over the telephone and lasted roughly an hour. Interviewees were also asked to complete a narrative about their life and the diagnosis of Alzheimer's in a task called 'My Story', which they returned to the interviewer or by post at a later day. The 'My Story' exercise was designed to ease the participant into the research, to give them the opportunity to talk about the diagnosis in their own words and in their own time and to provide background information for the depth interview.

Interviewers were provided with a specific brief detailing the information being sought from interviewees. This included:

- The journey and experience of patients before, during and after diagnosis, and their support and information needs at each stage;
- Cultural, social and practical barriers that may have prevented patients and their carers from seeking the medical advice that could lead to a diagnosis;
- The effects of earlier and later diagnosis on patients and their carers – in terms of the care they receive and the life they are able to lead; and
- Options for driving earlier diagnosis among more people – in terms of reforms to primary care, communications, information and support.

Research analysis

The data gathered in the interviews was analysed in the following ways: first, the SMF discussed findings and themes emerging from the primary research with the interviewers at TNS BMRB. Second, researchers from the SMF read the transcripts and My

Stories. From this, the research team at SMF sought to identify any emerging patterns, relationships and categories. This allowed us to develop typologies of patients, and identify common barriers to early diagnosis. Throughout the report, we draw on verbatim evidence from participants, as these comments represent the views of those who participated in the research, as well as case studies of specific patients.



CHAPTER 3: PATIENT BARRIERS TO EARLY DIAGNOSIS

This chapter seeks to uncover the patient-related reasons for the delay in seeking medical advice and subsequently obtaining a diagnosis. It also seeks to pinpoint the characteristics and attributes of those patients who experienced a shorter period of time between developing symptoms and seeking medical help.

It draws on evidence from our depth interviews with patients and carers to understand how the patient had received their diagnosis – alongside evidence from secondary literature – and any issues that may have explained why they received their diagnosis at the stage they did.

In assessing these factors, five principal reasons emerge explaining delay between developing symptoms and seeking medical advice:

- a) **Lack of knowledge about Alzheimer's** and the closeness of its symptoms to ageing.
- b) **The gradual manifestation of Alzheimer's** and the inability to treat problems as acute and serious.
- c) **Fear of Alzheimer's**, and the denial of the disease and its implications.
- d) **The lack of trust in the health system** with regards to medical practitioners.
- e) The **lack of support**, either from family or friends, or professional support.

Before proceeding, however, it is worth highlighting the advantages and disadvantages of diagnosis mentioned by patients and carers, to complement the evidence mentioned in Chapter 1. The consequences of diagnosis, both positive and negative, mentioned by patients are detailed in Box 3.1.

Box 3.1. The consequences of diagnosis mentioned by patients

Positives

One of the most striking benefits was the ability to access treatment to relieve symptoms.

It's been about 4 ½ months since he's been on the medication, and obviously it's still early days but I think he's not as muddled as he was before and he doesn't say to me as often 'my brain's not working today'.

Daughter of male patient, over 75, mid-late stages of Alzheimer's³⁸

Patients, particularly older ones, described how the diagnosis had led to them becoming closer to their friends and family.

[She said,] 'Dad I think it's about time you come down and be near us and I'll keep an eye on you and help you', which she does, does shopping for me...and she's a wonderful girl...It's a possibility that, without the diagnosis, I would still be in London.

Male patient, over 75, early stages of Alzheimer's

Some patients had been able to access more professional support as a result of the diagnosis – for example, more time from paid home carers and financial support.

She's looked after...all the money kind of goes through us so her care's taken care of.

Son of female patient, over 75, mid-late stages of Alzheimer's

Older people, and those who were cared for by their family or were in new accommodation and accessing new support, found themselves being able to engage in a wider range of social activities and hobbies. An elderly lady was driven to Church every Sunday and her whist club

38 Attributions for quotations are structured as follows: person speaking, age of patient, the stage of the patient's Alzheimer's.

every Tuesday by her son (her carer), for example. An elderly gentleman in Brighton, who lived in sheltered accommodation, was now able to do painting again.

Many patients talked of the emotional benefits of diagnosis: the reassurance that came from knowing their problems were a result of a recognisable condition.

I think it's a big weight off his shoulders.

Wife of male patient, under 60, mid stages of Alzheimer's

Some patients felt the diagnosis had positive social implications. Their behaviour could be explained and accepted, rather than hidden and feared.

I mean, I don't suppose I will ever get any better, but people accept for me what I am, and that makes a big difference.

Female patient, over 75, early stages of Alzheimer's

For one younger patient, the diagnosis led to an early retirement which was negotiated constructively with his employer.

Negatives

Some patients and carers mentioned that the diagnosis had led to members of their family and friends distancing themselves.

He's got two children, but they've not bothered with him since he got ill.

Wife of male patient, under 60, mid stages of Alzheimer's

For one of the younger patients, the diagnosis had led to being more isolated and introverted, and this was causing tension with his wife.

I have felt excluded and am only here to take verbal and mental abuse. As a result of this I've asked that we separate.

Wife of male patient, under 60, early stages of Alzheimer's

Lack of knowledge

Usually, patients – or their carers – have to identify problems in order to seek help and get a diagnosis. But misidentification is caused by a lack of knowledge about the disease and its symptoms. First, some interviewees had not even heard of Alzheimer's or dementia before being diagnosed. Second, participants had been unable to disentangle the symptoms associated with Alzheimer's – such as forgetfulness – with natural ageing.

I mean we knew that she'd got something going on and we just put it down to old age.

Granddaughter of female patient, over 75, early stages of Alzheimer's

Indeed, many respondents looked back and remembered symptoms. They regretted that they had not taken them seriously and dismissed them as a normal part of ageing.

I kick myself even to this day that I probably didn't take Mum as seriously as maybe I should have done.

Son of female patient, over 75, mid-late stages of Alzheimer's

Many respondents made light of the fact that they had memory loss, and expressed disbelief that anything could possibly be wrong with them.

I said, 'X, do you find you go from one room to another and forget what you've come in for?'. So she said, 'It happens all the time', and she's younger than me and it was a joke and I forgot about it.

Male patient, over 75, early stages of Alzheimer's

Lack of knowledge about the disease was particularly prominent among the two younger interviewees. The problem here was not a misperception that the symptoms were associated with ageing; rather,

that Alzheimer's disease was an old person's condition. Consequently, these individuals had not considered that they could have dementia in their forties and fifties. In these examples, patients and relatives felt that their problems were related to stress and the high-powered jobs they held at the time. Other events – such as bereavement in the family or heavy drinking – were blamed for memory problems.

I thought he was too young, he was 50 and I thought you can't get Alzheimer's at 50.

Wife of male patient, under 60, mid stages of Alzheimer's

Patients who are in the later stages of Alzheimer's disease may simply be unaware that they have the condition because of their cognitive state. Some carers mentioned the patient's lack of knowledge about having the disease and remembering they were diagnosed with Alzheimer's. Before family and carers intervened, this lack of knowledge could have prevented quicker diagnosis.

Secondary evidence supports the notion that there is a lack of knowledge about Alzheimer's disease generally, especially among those who have the condition in more developed stages. It is common to confuse the symptoms of Alzheimer's with the normal ageing process.³⁹ In a 2011-12 survey by the APPG on dementia, 14% of people with dementia did not notice problems with their memory and 52% of people with dementia thought memory problems were a normal part of getting older.⁴⁰ Among black and minority ethnic communities, lack of awareness is even more pronounced.⁴¹ Wider awareness of the symptoms of Alzheimer's and of who might be affected by it would mean people would be more likely to seek a check-up.

39 PA. Pollitt, "Dementia in old age: an anthropological perspective", *Psychological Medicine*, 26:5 (1996), 1061-74.

40 APPG on dementia, *Unlocking diagnosis: the key to improving the lives of people with dementia* (HMSO: London, 2012), 23.

41 Jo Moriarty, Nadira Sharif and Julie Robinson, "Black and minority ethnic people with dementia and their access to support and services", Social Care Institute of Excellence research briefing 35, <http://www.scie.org.uk/publications/briefings/files/briefing35.pdf>.

Gradual manifestation of Alzheimer's

Not only did respondents find it difficult to disentangle the symptoms of Alzheimer's from ageing and other related conditions, but the gradualness of the disease made it difficult for patients and relatives to accept something was wrong. It was common for patients to have good and bad days, meaning problems were not acute or immediate.

She started forgetting things, but not on a major scale, she was still functioning alright, but these were lapses.

Son of female patient, over 75, mid stages of Alzheimer's

Since Alzheimer's disease involves a gradual deterioration, respondents found it hard to take the symptoms sufficiently seriously to seek medical advice. Incidences of memory loss were often attributed to other causes, as shown in Case Study 3.1.

Case Study 3.1. Difficulty in identifying cause of symptoms

Y is a 52 year old man who has been diagnosed with mid-stage Alzheimer's disease. His wife is a full-time carer. He was a senior engineer and had a successful career. In 2006, his father died and he began drinking alcohol excessively. Over the next two years, he was moody and anxious, was sent home from work sometimes, upset friends in social situations and was jerky when driving. This behaviour was attributed to the death of his father and stress at work. Friends would say he was joking when he couldn't remember things. Medical advice was sought after his wife was in Newcastle visiting her daughter and he called asking what day of the week it was. They went to the GP who prescribed anti-depressants and also believed his symptoms were stress-related.

For the majority of interviewees, what triggered seeking medical advice was a crisis. The patient exhibited worryingly abnormal behaviour which, on top of the problems they had been

experiencing for a significant period of time, triggered the need to seek help. Seven clear examples of this are shown in Table 3.1.

His next door neighbour's son rang me one night at about 11.30 or something and said, 'You better go round to your mother's, she's standing on the doorstep with a suitcase saying you're going to come to collect her to take her on holiday'. So I said, 'Well we're going to have to get this investigated'.

Son of female patient, over 75, mid stages of Alzheimer's

Table 3.1. Trigger points for diagnosis

Interviewee	Trigger
Son of female patient, over 75, mid stages of Alzheimer's	One night in winter the son received a call from his mother's neighbour saying that she was standing outside at midnight with a suitcase thinking her son was going to collect her to go on holiday
Male patient, over 75, early stages of Alzheimer's	He discovered that he couldn't remember how to spell basic words and had to keep checking the dictionary
Male patient, under 60, early stages of Alzheimer's	He began forgetting simple things like people's names at a very young age
Female daughter of patient, over 75, mid-late stages of Alzheimer's	The patient and her husband went to a routine hospital appointment and he left her alone. She left unattended and wandered into town. A stranger found her and managed to contact worried family members
Son of female patient, over 75, mid-late stages of Alzheimer's	The patient walked into a patio door
Wife of male patient, under 60, mid stages of Alzheimer's	He called his wife one day when she was away visiting her daughter asking what day of the week it was
Nephew of female patient, over 75, mid-late stages of Alzheimer's	Police found patient wandering around at o'clock in the early morning just in her underwear

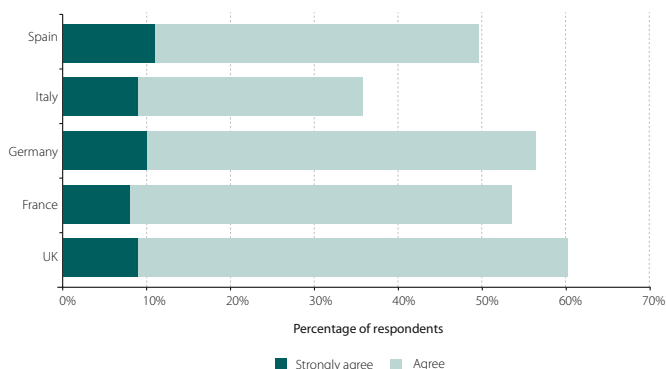
Fear of Alzheimer's

The secondary literature suggests that fear of the disease – as well as its social and practical implications – acts as a barrier to seeking medical advice and getting diagnosed. Polling indicates that people over the age of 55 fear dementia more than any other condition.⁴²

The fear of the disease is manifest in a survey which shows that although a majority of people would want to know what was wrong with them if they had cognitive impairment, a significantly lower proportion would want to know if it was Alzheimer's.⁴³

Fear of Alzheimer's disease appears to be particularly high in the UK: a 2009 survey of the general public found that over 60% of UK respondents thought that fear stops people from talking to their doctor.⁴⁴

Chart 3.1. Percentage agreeing that fear about Alzheimer's disease stops people from speaking to their doctor about it



Source: Alzheimer's Disease International, "IMPACT Study database", www.alz.co.uk/impact-study (accessed November 2012).

42 Alzheimer's Research Trust, YouGov poll, May 2008 cited in APPG on dementia, *Unlocking diagnosis*, 17.

43 Paul Elson, "The diagnosis of dementia: who wants to know?" *The Journal of Dementia Care* 14:5 (2006), 36-38.

44 Alzheimer's Disease International, "IMPACT Study database", www.alz.co.uk/impact-study (accessed November 2012).

There is also a cultural dimension to this: in certain black and minority ethnic communities, research suggests there is stigma associated with dementia.⁴⁵ Indeed, there is no word for dementia in most South Asian languages. Among those who believe in reincarnation, for example, dementia may be seen as punishment for behaviour in a past life.⁴⁶ Likewise, in cultures with arranged marriages, knowledge that a family includes a person with dementia jeopardises children's marriage prospects. Among black and Caribbean communities, dementia is commonly seen as a mental illness, rather than physiological changes in the brain.⁴⁷

None of our interviewees cited fear of the disease – or its social or practical implications – as reasons for delaying seeking medical advice. However, fear, denial, shame and stigma were all feelings that were mentioned by patients and their carers post-diagnosis. Other evidence shows that these feelings can be present before diagnosis and prevent people seeking medical advice.

Case Study 3.2. In denial

Z is a 42 year old-man with early Alzheimer's disease and lives with his wife and two young boys. He works full-time in financial services. He has been given a prognosis of 15-20 years but is hopeful that it will be 20 years and claims that death will be caused by related conditions, not the Alzheimer's disease. His children do not know he has the condition, nor do his friends. He describes it as 'a guarded secret' and believes it is a misunderstood disease and so is reluctant to tell others. He says he has lost his fear of dying and makes light-hearted jokes about the condition as 'a coping mechanism'. But, as Z recognises, this upsets his wife: in her

45 Moriarty, Sharif and Robinson, "Black and minority ethnic people with dementia and their access to support and services".

46 J.Mackenzie, D.Coates, F.Ashraf, T. Gallagher and L. Ismail, *Understanding and supporting South Asian and Eastern European family carers of people with dementia*, (Bradford: University of Bradford, 2003).

47 Moriarty, Sharif and Robinson, "Black and minority ethnic people with dementia and their access to support and services".

My Story, she describes being shut out of Z's thoughts and feelings. In his My Story, Z writes that he loves his wife and children very much and doesn't want them to be hurt by his illness, and says 'Life will never be the same again'.

Case Study 3.2 provides an example of a patient in denial. But friends and family could be in denial too. The husband of an elderly woman, for instance, was described by the daughter as stubbornly refusing to consider medical advice and denying that his wife had a serious problem.

Some practical problems of having Alzheimer's disease were highlighted which may also act to deter people or their families from seeking medical advice. In particular, patients felt that their ability to drive was threatened. The DVLA now asks particular categories of patients to apply for a driving license on a yearly basis. Indeed, a positive diagnosis requires patients to inform the DVLA and the insurance company. This has been cited elsewhere as a cause of delayed diagnosis.⁴⁸

The social implications of Alzheimer's disease – most notably, isolation – could be a significant barrier for people seeking medical advice for their problems. A common and poignant point from some interviews was the effect the disease was having on relationships with other family members. Sometimes, only one child was involved in the patient's life as their carer: other children either lived abroad or engaged little, or not at all, with their ill parent.

The secondary literature reveals that Alzheimer's disease patients sometimes try to hide their symptoms, often causing

48 K. Read and DJ Jolley, "Plus points". *Journal of Dementia Care*, Jan-Feb (2001).

stress and anxiety for themselves. Ten percent of people with dementia reported that they did not want to think about their memory problems.⁴⁹

Lack of trust in the health system

Polling by the APPG on dementia showed that 35% of people with memory problems did not seek medical advice because they did not think there was any point.⁵⁰ Though none of our interviewees mentioned this, the secondary literature suggests that some mistrust the health system, which could be preventing people from seeking medical advice.

The next chapter will illustrate in detail the professional barriers that exist in enabling patients to get a speedy diagnosis. The concerns our interviewees had with health practitioners, particularly GPs, actually emerged post-diagnosis.

Some patients and carers thought the health service was insensitive and inhuman. Diagnosis was often given via letter and delivered in a cold manner without signposting to any support.

The way we heard about the diagnosis was not great.

Male patient, under 60, early stages of Alzheimer's

People who ordinarily seek help for other health problems were more likely to seek medical advice if they had concerns about cognitive function. Indeed, an elderly man in our sample referred himself to the GP after deterioration in his spelling and suggested that he was one of those people who always sought medical advice when he thought something was wrong.

49 APPG on dementia, *Unlocking diagnosis*, 23.

50 Ibid., 23.

Don't forget there are certain people who go to the doctors more than others... If I'd coughed two or three times I used to take myself up to the doctor just in case... So immediately I had this forgetfulness, it was just part of what I get in my mind and go and see a doctor for.

Male patient, over 75, early stages of Alzheimer's

It was noticeable that some of those who were diagnosed at an earlier stage had a good relationship with their GP or were used to and comfortable with regularly visiting the GP surgery.

Lack of support

The literature reveals the importance of social networks to individual attitudes and behaviours.⁵¹ In fact, some evidence reveals that susceptibility to Alzheimer's is not just caused by the brain architecture and amounts of beta amyloid in the brain, but also the breadth of a person's social networks: if a person is more solitary and anxious, research suggests that they are more likely to develop the plaques and tangles that cause Alzheimer's.⁵²

Those who attained a diagnosis quicker tended to have a strong network of support, from friends and family. Friends and family often raised concerns with patients and prompted them to go to the doctors. Case Study 3.3 provides the instance of an elderly woman, who was quickly brought to the attention of the doctors by her sons.

51 David Brooks, *The Social animal: a story of how success happens* (New York: Random House, 2011).

52 Harry Boothby, "My memory is failing – will I get Alzheimer's?", *Standpoint* magazine, November 2012.

Case Study 3.3. A proactive family

An elderly woman with Alzheimer's lives with her husband, who is frail and has cancer. They live independently but have a professional care worker who visits twice a day to help with cleaning and washing. Their two sons also live nearby and visit regularly to support them, for example with cooking meals. The husband's physical and mental state has been deteriorating gradually for some years. The patient, on the other hand, experienced a sudden change in her condition: she was described as a very sociable person who entertained friends and family regularly. But one day she walked into the patio door. Following this, she struggled to speak and write, and was unbalanced on her legs. Her co-ordination and attention worsened dramatically. This frustrated her sons, and within a few weeks they took her to see the GP as they were very concerned about her condition. The GP did not diagnose anything initially. But the sons kept visiting and pushing for a referral to specialist opinion, which was eventually secured.

Often, relatives were quicker to identify symptoms and push for action when there was family history of Alzheimer's disease. Relatives were able to compare the symptoms of the patient with another member of the family who had Alzheimer's, and this forced him to confront the problem.

Critically, these networks can also influence in the other direction: family and friends could have a detrimental impact, when they dismissed the health service for example.

These support networks are not universal: a poll by MORI in 2010 found that 53% of people thought they did not know enough about dementia to help someone who has it. Fear and misconceptions also play a role: 32% in the MORI poll said "I

would find it difficult to spend much time with someone who has dementia”.⁵³ The Coalition Government has recognised the value of networks for helping diagnosis rates by setting up a Dementia Friends scheme, as explained in Chapter 5.⁵⁴ Though the carers and relatives interviewed in our sample were very supportive, they did complain that others in the family were not so supportive, and had in fact ceased any relationship with the patient.

Sometimes I think I am an only child as the help does not come from my siblings.

Daughter of female patient, over 75, mid-late stages of Alzheimer’s

Sometimes, diagnosis was picked up when the patient was visiting hospital for another condition, most commonly a stroke. So diagnosis was incidental to another problem, rather than sought out.

It got her into hospital into the system and otherwise the system wasn’t taking any notice of her.

Son of female patient, over 75, mid stages of Alzheimer’s

So far, this report has identified the barriers to seeking medical advice. In addition, certain characteristics of a person’s life have been identified as facilitating a quicker period between recognising symptoms and seeking medical advice. These are summarised below:

- **Strong family support.** Knowledgeable and proactive relatives often prompted patients to seek medical advice.

⁵³ Department of Health, “One in three admit to avoiding people with dementia”, http://webarchive.nationalarchives.gov.uk/+/www.dh.gov.uk/en/MediaCentre/Pressreleasesarchive/DH_113312.

⁵⁴ HM Government, *The Prime Minister’s challenge on dementia – delivering major improvements in dementia care and research by 2015: a report on progress* (London: HMSO, 2012), 9.

- **A crisis.** When something serious happens to a person – for example, putting themselves in danger or being injured – this acted as a trigger to seek medical advice.
- **Proactive attitude to health.** Patients who were regular visitors to the GP and proactive about looking after their health were more likely to seek medical advice for their symptoms.
- **In hospital.** Patients who were in the health system for other reasons – such as having a stroke – were more likely to be assessed by clinicians and picked up for dementia.

Patient characteristics that affect early diagnosis

This chapter has identified the key factors, and attributes of a patient's life, that affect the speed at which they seek medical advice after first developing problems. Based on these, the SMF has created a typology of different groups of people with Alzheimer's.

There are many unique reasons for delayed diagnosis. But common reasons do emerge. This section captures these broad themes in a typology to help policymakers identify the reasons for the UK's poor diagnosis rates, and focus policymaking on common barriers and groups of people.

Many patients will not fit neatly into one of the groups; they may have characteristics of more than one group. Likewise, there will be differences within the group, as will be demonstrated. Carers, relatives and friends may also fit into these groups, affecting where the patient sits in the typology.

This typology seeks to indicate the broad types of people with Alzheimer's disease who have not yet been diagnosed.

1. The unaware

These patients are unaware of their symptoms, because of their mental state, or are unaware of the severity of their symptoms, because of the fluctuating nature of their symptoms, and their belief their symptoms are a natural part of ageing. They lack knowledge and as such their motivation to seek medical advice is neither positive nor negative.

2. The fatalists

These patients know something is wrong but mistrust the health system. They believe nothing can be done so there is little point seeking medical advice. They have some knowledge about their condition but lack the motivation to seek medical advice.

3. The deniers

These people know something is wrong but refuse to do anything about it. They do this for two reasons. First, they tend not to accept that they have a disease or that they are any different from other elderly people. Second, they worry about the social and practical implications of the condition. They have some degree of knowledge about their condition but lack motivation to seek medical advice.

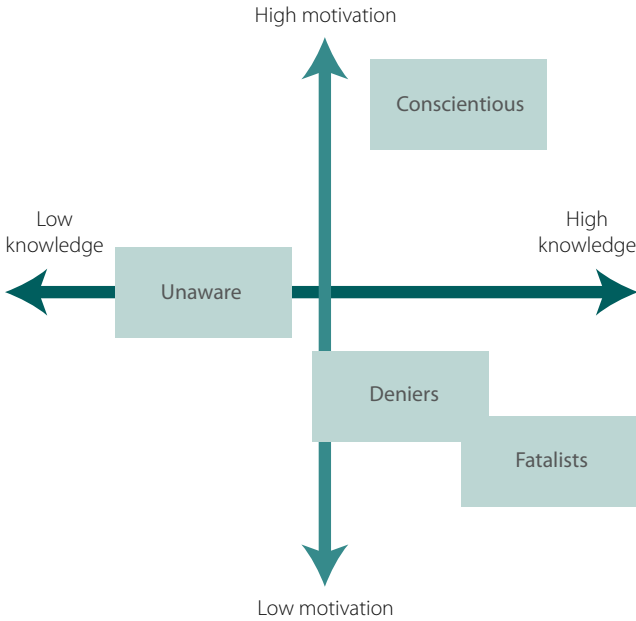
4. The conscientious

These patients have a good track record of engaging with health services and seek help once problems are detected. They trust GPs and would like as much information as possible about their physical and mental condition. They have a good degree of knowledge about their condition and are motivated to seek medical advice.

Figure 3.1 shows where the different groups exist on two axes: first, the amount of knowledge patients have about their

symptoms. Second, the amount of motivation patients have to seek medical advice. Having strong networks – namely, carers, family and friends – can push patients along these two axes: towards having more knowledge and more inclination to approach mainstream services. But, as mentioned previously, they can also pull in the other direction.

Figure 3.1. Different groups of people with Alzheimer's



CHAPTER 4: HEALTH PROFESSIONAL BARRIERS TO EARLY DIAGNOSIS

The previous chapter set out reasons why patients may not come forward with their symptoms and why, when they do, they often come forward late. This chapter analyses the barriers stemming from the practitioners – factors that prevent or obstruct clinicians and health professionals from making a diagnosis of dementia early. Even though our research was with people who had Alzheimer's, the clinician barriers identified relate to all types of dementia.

FACTORS DRIVING LOW DIAGNOSIS RATES

Diagnosis rates are highly variable within England – ranging from a diagnosis rate of 27% in Dorset to 67% in Islington (as a percentage of the expected population with dementia). There is little existing evidence on what is driving this variation. The SMF has undertaken regression analysis to understand whether there is a relationship between diagnosis rates and other factors that differ across England such as patients' experiences of obtaining medical advice from their GP, memory service spend and access, and demographic factors.⁵⁵

The analysis suggests that there is variation in these factors across England, but there is no clear single driver of diagnosis rates: a multitude of factors result in some areas performing well and other performing badly. Factors that are correlated with low diagnosis rates include:

⁵⁵ Specifically, we use data on diagnosis rates from the Alzheimer's Society "Dementia map", data from the GP Patient Survey (<http://www.gp-patient.co.uk/>), demographic data from the Office for National Statistics (ONS, "Population estimates by ethnic group", (ONS: London, 2011), Table EE1, and EE3), and data on memory services from GP Online (Stephen Robinson, "How the UK falls short on dementia", *GP Online*, March 7, 2012, <http://m.gponline.com/article/1120754/UK-falls-short-dementia>).

- **The time that a GP has to spend with patients,**⁵⁶ with lower patient ratings on 'GP giving you enough time' associated with lower diagnosis rates. Time constraints could affect the ability of GPs to fully investigate potential symptoms, and proactively identify those with dementia, as will be explored later in this chapter.
- **The percentage of a practice area's population that is over retirement age** is correlated with lower diagnosis rates.⁵⁷ It is unclear why this should be related to diagnosis rates.

Spending on memory services differs considerably across different areas of the UK, with expenditure in some areas exceeding those in other areas by a factor of ten or more.⁵⁸ Importantly, perhaps surprisingly, there does not appear to be a relationship between expenditure on memory services and diagnosis rates. This is potentially because of the importance of other factors. First, there are a variety of different types of services that promote diagnosis, not all of which will necessarily be defined by different local commissioners as 'memory services'. Second, it may also be explained by the fact that some areas with low diagnosis rates may be pushed to invest more in memory services, making it difficult to identify a causal relationship between the two from the data.

The regression analysis conducted by the SMF has some limitations. Availability of data limits the potential drivers that can be tested. For example, there is no data that breaks down differences in attitudes and awareness of the symptoms of dementia across regions. As is the case with Scotland, there is a possibility that some differences in diagnosis rates may simply reflect differences

56 More specifically, the rating patients give to "GP giving you enough time" on the GP Patient Survey. This survey asks patients questions about their experience of GP practices. The survey is not specific to Alzheimer's or dementia patients.

57 The data on demographics by primary care organisations was published by the ONS as experimental statistics and therefore this result should be interpreted with caution.

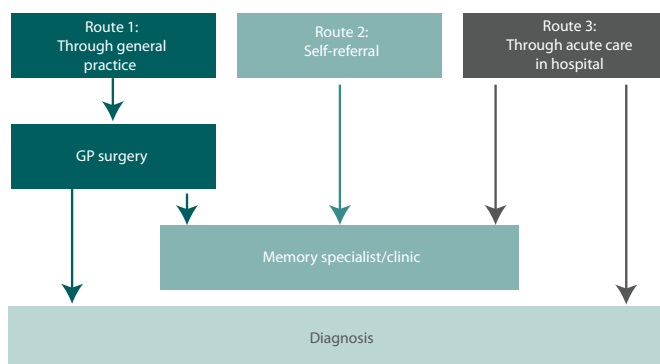
58 See Annex 2 for more details.

in the diligence with which practices record patients' diagnoses. And there is no data available on how early or late in the illness the different regions are diagnosing people. However, the analysis does underscore the multitude of potential drivers of diagnosis rates across regions, and the fact that focusing policy simply on one factor, such as investment in memory services, is unlikely to be the answer. A more in-depth analysis for poor diagnosis is now required. This is the focus of the next section of this chapter.

Diagnosis pathways

Patients with dementia may be diagnosed by their GP, by specialists at a memory service or clinic, or in hospital. These diagnoses are initiated either in primary care, through self-referral to memory services or in hospital.

Figure 4.1. Different routes to diagnosis



In the section below, we explore barriers to diagnosis first, in relation to the patient's first point of contact with the health system and, second, in terms of the assessment through memory specialists.

INITIAL CONTACT WITH HEALTH SYSTEM

1. General Practice and self-referral

The majority of diagnoses stem initially from contact with GPs. Because of their gatekeeping role, GPs play a crucial role in referral and diagnosis of dementia. GPs usually refer on before a diagnosis is made, but a recent survey suggests that around 10% of those diagnosed with dementia are diagnosed by their GP.⁵⁹ NICE recommends that diagnosis should be made by specialists rather than in primary care. This contrasts with Germany, where a GP can diagnose and treat dementia.⁶⁰

In some instances in our research, carers believed the failure of the GP and other medical practitioners to treat the patient's symptoms seriously resulted in delayed diagnosis. As a result, some blamed the GP for the deterioration in the patient's quality of life.

If she'd have been diagnosed soon and got the medication I feel it would've slowed down the progress of the disease without a doubt.

Son of female patient, over 75, mid stages of Alzheimer's

Drawing on insights from our primary research, existing secondary research and an expert roundtable with clinicians, the analysis below sets out five principal factors that explain why GPs may fail to diagnose or delay referral for diagnosis:

- The low importance that some GPs attach to the diagnosis of dementia.

59 All-Party Parliamentary Group on Dementia, "2012 Inquiry – Improving dementia diagnosis rates in the UK – Summary of collated evidence", Questionnaire summary, www.alzheimers.org.uk/site/scripts/download.php?fileID=1401.

60 International Longevity Centre, *The European dementia research agenda* (London: ILC-UK, 2011).

- Lack of time to make a proper diagnosis.
- The complexity of diagnosis of dementia and insufficient knowledge of the disease.
- A lack of clear accountability and responsibility for diagnosis across the healthcare system.
- Inadequate assessment tools.

Low importance attached to diagnosis of dementia

Clinical perspectives have a significant impact on the likelihood that patients will receive a prompt diagnosis. A survey in 2007 found that there is a widely-held perception among GPs that little can be achieved by diagnosis, resulting in a lack of urgency attached to diagnosing and addressing dementia. Only two-thirds of GPs thought that it was important to look actively for early symptoms.⁶¹ Nonetheless, there is some evidence that GP attitudes have since changed: in a more recent NAO report, 77% of GPs agreed that it is beneficial to make an early diagnosis compared to 66% in 2007, but nearly a quarter still think otherwise.⁶²

Box 4.1. Physician attitudes in the UK compared to European comparators

UK physicians are more sceptical about the benefits of early treatment of Alzheimer's disease than physicians in other countries. As shown in the graph below, physicians in some other countries appear to be more positive about the impact of early treatment on the progression of the disease.

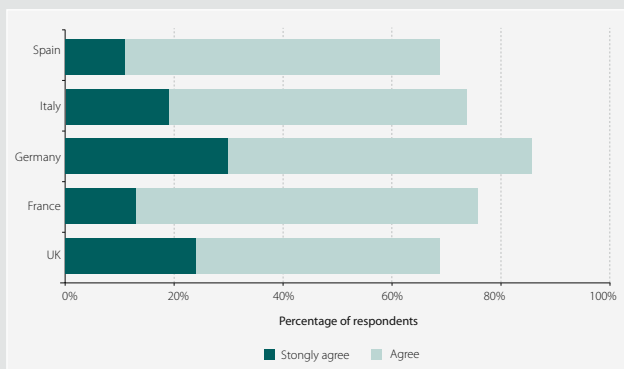
Scepticism about the benefits of early treatment may partly reflect attitudes of the wider general public. A more recent study found that physicians thought that it could be difficult to communicate Alzheimer's disease diagnoses to patients due to patient denial and

61 National Audit Office, *Improving services and support for people with dementia* (London: HMSO, 2007).

62 National Audit Office, *Improving dementia services in England* (London: HMSO, 2010).

social stigma; and physicians in the UK and France were more likely to report stigma than other countries.⁶³

Chart 4.1. Percentage of physicians who agree that early treatment can delay the progression of Alzheimer's (2009)



Source: Alzheimer's Disease International, "IMPACT Study database", www.alz.co.uk/impact-study (accessed November 2012)

In part this stems from 'therapeutic nihilism', namely a belief that treatment can do nothing to help the dementia patient.⁶⁴ Some GPs are reluctant pro-actively to identify those with dementia. Research from 2003 with a large number of practitioners noted that many viewed early diagnosis as a 'complex arena in which a 'best interests' approach' continued to dominate.⁶⁵ As such, GPs based their judgement as to whether to diagnose or disclose a

63 Lilly, "New international survey reveals multiple barriers to an accurate and timely Alzheimer's disease diagnosis", September 19, 2012, <https://investor.lilly.com/releasedetail.cfm?ReleaseID=707845>.

64 J.J. Barrett, W.E. Haley, R.E. Powers, "Alzheimer's disease patients and their caregivers: medical care issues for the primary care physician", *Southern Medical Journal*, 89:1 (1996), 1-9.

65 S. Iliffe, J. Manthorpe, A. Eden, "Sooner or later? Issues in the early diagnosis of dementia in general practice: a qualitative study", *Family Practice*, 20:4 (2003), 376-381.

diagnosis on a range of judgements which were not limited solely to the existence or otherwise of dementia. Other attitudinal causes of reluctance to diagnose include: belief in certain instances that the consequences of disclosure could be 'profoundly negative'; concern that diagnosis may 'distress the patient'; and the belief that diagnosis is 'simply not justified'.⁶⁶ Stigma and fear of mis-labelling a patient play a part for GPs: one study showed that when a label of 'cognitive impairment' was used, the sensitivity of diagnosis by GPs improved.⁶⁷

The importance of this factor lies not only in a refusal to diagnose, but also in the relative priority that a GP puts on dementia symptoms rather than the symptoms of other illnesses. As many dementia patients present with other health problems, which themselves require attention, this equivocation represents a significant factor in both under-diagnosis and in delayed diagnosis. At the very least, it means that GPs may not see dementia diagnosis as a priority.

Lack of time

This relates closely to a factor in under-diagnosis cited frequently by GPs, namely time constraints. GP appointments are typically only eight-ten minutes long.⁶⁸ Surveys suggest that lack of time is a problem: according to one survey, 70% of GPs felt that they had too little time to spend on people with dementia.⁶⁹ Much of their time is spent reacting to the complaint which prompted the visit to the GP. Time pressures have led to initiatives where specialist

66 A. Milne and J. Peet, *Challenges and resolutions to psycho-social well-being for people in receipt of a diagnosis of dementia: a literature review* (Alzheimer's Society, London, 2008), 43.

67 J.A. Eefsting, F. Boersema, W. Van den Brink, W. Van Tilburg, "Differences in prevalence of dementia based on community survey and general practitioner recognition", *Psychological Medicine*, 26:6 (1996), 1223-30.

68 NHS Choices, "GP appointments", <http://www.nhs.uk/choiceintheNHS/Yourchoices/GPchoice/Pages/GPappointments.aspx>.

69 National Audit Office, *Improving services and support for people with dementia*, (London: HMSO, 2007).

nurses are used to manage the caseload, which have helped to boost diagnosis in some practices (see Chapter 5 for more detail).

Complexity of diagnosis

Diagnosis of dementia is a complex task. There are many different causes of dementia, and it shares many symptoms with other illnesses such as depression. Evidence suggests that some GPs lack competence in dementia diagnosis.⁷⁰ The National Audit Office found that only 31% of GPs believe they received sufficient training to diagnose and manage dementia.⁷¹

Most patients and carers that we spoke to were satisfied with their GP, but some complained that the GP seemed to lack knowledge about Alzheimer's disease. In our interviews, some patients complained that the GPs were slow to diagnose and often attributed symptoms to other conditions such as stress. Some patients and carers mentioned that they kept going to the doctor and were disappointed with the doctor's lack of action, as the comment below illustrates.

*She was quite dismissive...She said, 'I think you're just stressed Y'.
And she signed him off work [for] stress...*

Wife of male patient, under 60, mid stages of Alzheimer's

Evidence suggests that doctors lack confidence and training in making a diagnosis. Forty percent of GP respondents to a recent survey felt that they had insufficient training in dementia diagnosis, which appears to be partly a reflection of the fact that in the past medical training on dementia has been relatively neglected.⁷²

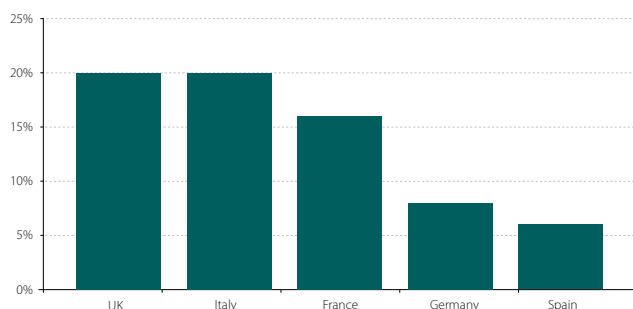
70 A. Milne and J. Peet, *Challenges and Resolutions to Psycho-social Well-being for People in Receipt of a Diagnosis of Dementia: A Literature Review* (Alzheimer's Society, London, 2008), 43.

71 National Audit Office, *Improving services and support for people with dementia*, (London: HMSO, 2007).

72 All-Party Parliamentary Group on Dementia, "2012 Inquiry – Improving dementia diagnosis rates in the UK – Summary of collated evidence", Questionnaire Summary www.alzheimers.org.uk/site/scripts/download.php?fileID=1401.

One study suggests that a significant minority of UK physicians initially mistake dementia for ageing, as shown in Chart 4.2. This could relate to a lack of knowledge about the condition.

Chart 4.2. Percentage of respondents whose physician initially said it was “just age” (2009)



Source: Alzheimer's Disease International, "IMPACT Study database", www.alz.co.uk/impact-study (accessed November 2012)

Diagnosis at the early stages of dementia is even more complicated. For example, mild cognitive impairment (MCI) describes a condition in which patients experience memory loss, but do not have other symptoms associated with dementia. In some patients, MCI is an indication of early stage dementia. In other patients, MCI may instead be caused by stress, depression or a physical illness.⁷³

Due to the complexity of diagnosing dementia, NICE currently recommends that patients with suspected dementia should be referred to specialist memory assessment services for diagnosis.⁷⁴ However, this does not entirely remove the problems associated with diagnosis complexity. For example, in making the decision

⁷³ Alzheimer's Society, "Mild cognitive impairment", http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=120.

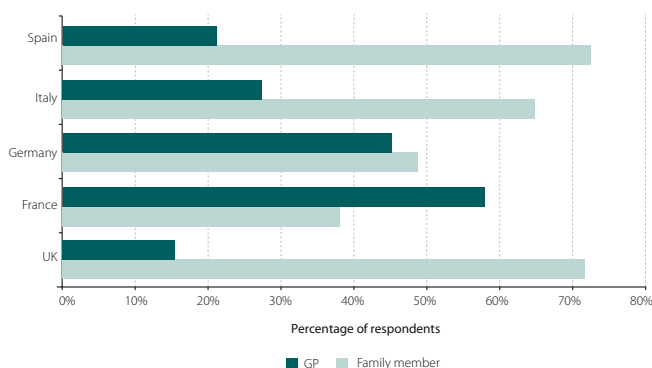
⁷⁴ National Institute for Health and Clinical Excellence, "Dementia diagnosis and assessment", <http://pathways.nice.org.uk/pathways/dementia/dementia-diagnosis-and-assessment>.

about whether to refer to a specialist, a GP will need to consider the possibility of other conditions such as depression.⁷⁵

Lack of clear accountability and responsibility

A recent study found that the general public in the UK were much less likely to expect GPs to recognise early symptoms of Alzheimer's disease – around 16% of UK respondents expected GPs to play this role, the lowest of the five countries surveyed. By contrast, 58% of French respondents expected GPs to play this role and 45% of German respondents.⁷⁶ This could indicate that in other countries GPs are expected to, and perhaps are more likely to, play a pro-active role in identifying potential patients who attend their practices.

Chart 4.3. Views on who is most likely to recognise early symptoms of Alzheimer's disease in potential patients (2009)



Source: Alzheimer's Disease International, "IMPACT Study database", www.alz.co.uk/impact-study.

More generally, clinicians at our expert roundtable identified a wider issue for the health service: namely, the lack of a dedicated health

⁷⁵ Bennett P. Leifer, "Early Diagnosis of Alzheimer's Disease: Clinical and Economic Benefits", *Journal of the American Geriatrics Society*, 51, 5:2 (2003), 281–288.

⁷⁶ Alzheimer's Disease International, "IMPACT Study database", www.alz.co.uk/impact-study.

professional taking responsibility for diagnosis, so practitioners often feel it is not their job.

Assessment tools

These factors would be ameliorated in part if there was an assessment tool that GPs could turn to with confidence. However, the accuracy of currently used assessment tools is also uncertain. The Mini Mental State Examinations (MMSE) is widely used in the UK. However, the MMSE has been criticised for being too long, its scores too difficult to interpret, its cultural and educational bias and its inability to pick up some forms of dementia.⁷⁷ A recent survey of 200 British doctors found that almost three quarters cited the lack of a definitive dementia test for their reluctance to diagnose.⁷⁸

Some of our interviewees believed the memory tests were too easy and unable to detect problems. Some complained that the patient had to take the test on several occasions before eventually being referred or diagnosed.

I'm sorry, the test is nonsense and that was said to me by a nurse at the practice where I used to go and she says ...'Intelligent people know the answers'.

Son of female patient, over 75, mid stages of Alzheimer's

It has been argued that other screening assessments would be more appropriate. These include the General Practitioner Assessment of Cognition (GPCOG), Memory Impairment Screen (MIS) and the Mini-Cognitive Assessment Instrument (Mini-Cog).⁷⁹

77 C. Parker and I. Philp, "Screening for cognitive impairment among older people in black and minority ethnic groups", *Age and Ageing*, 33:5 (2004), 447-52.

78 Stephen Adams, "Patients 'ignoring early dementia'", *Daily Telegraph*, September 20, 2012.

79 Alison Culverwell, Alisoun Milne, Reinhard Guss, Jackie Tuppen, "Screening for dementia in primary care: how is it measuring up?", *Quality in Ageing and Older Adults*, 9:3 (2008), 39-44.

Because of the problems with assessment tools, the recent APPG on dementia report recommended that GP training on dementia diagnosis should include information on known problems with various tools so that GPs can make informed decisions about how best to assess potential patients.⁸⁰

2. Diagnosis initiated in hospital

The section above explored barriers to early diagnosis at the primary care level. However, a significant proportion of patients – around a fifth⁸¹ – are diagnosed in hospital. Individuals with dementia may be admitted to hospital for reasons unrelated to their dementia, as shown in Chapter 3, or they may be there as a result of their condition. It has been estimated that, at any one time, around 6% of all people with dementia are likely to be in-patients in hospitals, but only half of these patients will have had a formal diagnosis of dementia.⁸²

Typically, one fifth of patients in a hospital at any given time have dementia, diagnosed or otherwise. Contact with hospital staff therefore offers the opportunity for diagnosis. One study of individuals aged over 70 with unplanned acute admission to a north London general hospital found that 48% aged over 80 years had dementia. Of these, only 21% had received a diagnosis of dementia prior to the research.⁸³

80 All-Party Parliamentary Group on Dementia, *Unlocking diagnosis: The key to improving the lives of people with dementia* (London: House of Commons, 2012).

81 All-Party Parliamentary Group on Dementia, "2012 Inquiry – Improving dementia diagnosis rates in the UK – Summary of collated evidence", Questionnaire Summary.

82 All-Party Parliamentary Group on Dementia, "2012 Inquiry – improving dementia diagnosis rates in the UK – Summary of collated evidence", submission by British Geriatrics Society.

83 Alzheimer's Society, "Counting the cost: caring for people with dementia on hospital wards", (London: Alzheimer's Society, 2009).

However, dementia is often not diagnosed effectively or necessary referrals are not made. Problems include:

- **A lack of training amongst hospital staff.** Only 12% of nurses said that they had received enough training in dementia.⁸⁴
- **A predominant focus on responding to acute conditions** crowding out attention to dementia. An audit of dementia care in hospitals found that although most hospitals had a policy that assessment for people with dementia should include mental state assessment, fewer than half of the caseload audited had received a standard mental state test.⁸⁵ An update of the study concluded that 'Hospitals have not yet taken seriously the need to routinely assess mental state as part of a comprehensive assessment of older people.'⁸⁶

To some extent, new financial incentives such as the CQUIN (Commissioning for Quality and Innovation) may focus hospital staff on spotting potential symptoms of dementia. The new CQUIN incentive, introduced in spring 2012, provides financial rewards for conducting dementia risk assessments for people over 75 who are admitted to hospital.

However, it should be noted that, for the majority of people in hospital, their dementia will not be in its early stages.

84 Alzheimer's Society, "Counting the cost: caring for people with dementia on hospital wards", (London: Alzheimer's Society, 2009). A recent AAPG survey suggests this is much less of a problem. However, the sample for the researched cited in the text above had a much higher response rate (657) than the APPG survey (23).

85 Royal College of Psychiatrists, "National audit of dementia (care in general hospitals)", <http://www.rcpsych.ac.uk/pdf/The%20Interim%20Report2.pdf>.

86 Royal College of Psychiatrists, "Report of the National Audit of Dementia Care in General Hospitals 2011" (London: Royal College of Psychiatrists, 2011), 70-71.

3. Memory services: memory clinics and consultants

Although our regression analysis did not identify expenditure on memory services as a significant factor in explaining variation in diagnosis rates across areas, other evidence has suggested that memory services have led to better diagnosis of dementia and that memory clinics have facilitated earlier diagnosis of dementia.⁸⁷ An evaluation of the Croydon memory clinic, for instance, found that there was a 63% increase in the number of new dementia cases seen in Croydon as a result of its installation.⁸⁸

In 2007 about 70% of GPs in England had access to a local memory service.⁸⁹ Additional funding was provided to PCTs in 2009-10 and 2010-11 to improve memory service: 94% of primary care trusts now have a dedicated memory service.⁹⁰ The number of people using memory services increased from an average of 605 per organisation in 2008-9 to 951 in 2010-11.⁹¹ However, there is evidence that access to memory services is variable across the country.

The most common form of memory service is the memory clinic, which generally provides early diagnosis, information dissemination, initiation and monitoring of treatment, and education and training. They were first established in the US and were introduced in the UK in the early 1980s, initially as a research function. Since 1997, as treatment of Alzheimer's disease and other dementias improved, they have become patient-centred, offering support, advice and care.⁹²

87 D. Jolley, S.M. Benbow and M. Grizzell, "Memory Clinics", *Postgrad Medical Journal*, (2005).

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

89 Michelle Roberts, "Memory clinics plan on dementia", BBC News, February 3, 2009, <http://news.bbc.co.uk/1/hi/health/7865494.stm>.

90 The NHS Information Centre, Community & Mental Health Team, "Establishment of memory services – results of a survey of Primary Care Trusts, final figures, 2011", 4. http://www.ic.nhs.uk/webfiles/publications/005_Mental_Health/Memory%20Services%202011%20FINAL/Establishment_of_Memory_Services_results_of_a_survey_of_PCTs_2011.pdf.

91 Ibid.

92 A.P. Passmore and D.A. Craig, "The future of memory clinics", *The Psychiatrist*, 28 (2004), 375-377.

Spending on memory services differs substantially across different areas of England. Whilst this might partly reflect the fact that some trusts have different models of memory service, there is evidence that the effectiveness of the service varies.⁹³ In addition, there are marked differences in waiting times. According to the APPG's survey of GPs, the average waiting time for an appointment at the memory service was three months. However, the longest waiting times were longer than one year and many were longer than six months. Almost a quarter of GPs cited long waiting times for memory clinics as obstacles to diagnosis.⁹⁴ The APPG also expressed concerns about whether the quality of memory services across England was consistent.⁹⁵

Conclusions

From the practitioner side, early diagnosis is obstructed principally by problems in primary care associated with the capability of GPs, time constraints and physician perceptions of the benefits of diagnosis. In secondary care, there is evidence that not all hospitals focus sufficient attention on diagnosing those with dementia. While memory services offer many advantages to effective diagnosis, access can be delayed and services are not universal.

93 See for instance: HMG, *The Prime Minister's Challenge on Dementia. Delivering major improvements in dementia care and research by 2015: a report on progress* (London: HMSO, 2012).

94 All-Party Parliamentary Group on Dementia, "2012 Inquiry – improving dementia diagnosis rates in the UK – Summary of collated evidence", Questionnaire summary.

95 All-Party Parliamentary Group on Dementia, *Unlocking diagnosis: The key to improving the lives of people with dementia* (London: House of Commons, 2012).

CHAPTER 5: HOW CAN WE INCREASE THE RATES OF EARLY DIAGNOSIS OF DEMENTIA?

Introduction

Improving rates of early diagnosis is a complex challenge. As the analysis in Chapters 3 and 4 suggests, policy action is required both to encourage the person with dementia to come forward more promptly and also to design an effective diagnosis pathway across primary and secondary care.

There are multiple barriers to overcome on the professional side. Within primary care, the obstacles may stem from a lack of awareness of the illness and its treatment, and a lack of time to diagnose a complex illness such as dementia. In secondary care, the problems may stem from poor coverage of memory clinics and a focus on acute care. In either case clinicians may simply be sceptical about the value of diagnosis.

But many people with dementia will not even reach this point – lack of awareness of the condition may prevent many from seeking medical advice. The typology in Chapter 3 indicated that there are multiple reasons why individuals may not come forward. Policy makers and commissioners must therefore open up appropriate pathways for these different people. They must also encourage those with dementia, and their families and friends, to play a pro-active role in identifying symptoms and presenting them, so that diagnosis can be co-produced.⁹⁶ At the end of Chapter 3, it was shown that when patients had strong networks of relatives and friends this helped to raise awareness and improve early diagnosis. In this context, the Government is wise to promote a new army of one million dementia friends who will be trained to spread knowledge about the condition, as well as pushing for the

96 For a discussion of co-production in health, see Paul Corrigan, "Why self-management is only a part of the co-production of health care value", May 9, 2012, <http://www.pauldcorrigan.com/Blog/creating-public-value/why-self-management-is-only-a-part-of-the-co-production-of-health-care-value/>.

realisation of more than 40 dementia-friendly communities across the UK by 2015. This could build stronger support networks for people with dementia, although it is unclear what resources are to be directed at this goal.

In addition, there are a number of policy interventions that can be undertaken most effectively and efficiently by national rather than local commissioners. These include more stringent regulation of clinicians, especially with regard to education levels. For instance, the APPG report proposed a requirement for all health and social care professionals working in a general capacity with people at risk of dementia to have pre- and post-registration training in identifying and understanding dementia.⁹⁷ The effectiveness of previous national awareness campaigns (such as HIV and seatbelts) suggests that social norms can be influenced from the centre. The Government's early diagnosis awareness advertising campaign therefore is to be welcomed.

Currently, investment in dementia research is about an eighth of that for cancer research.⁹⁸ The Government expects investment in dementia research to double before 2015. £9.6 million has been announced to enable researchers to develop and analyse the UK Biobank, so more information about why some people develop dementia and others don't can be extracted.⁹⁹ As this research develops and becomes more widely known, this will help practitioners and others to better detect the symptoms associated with dementia. So, in addition to the reforms we set out below, better research could also help improve early diagnosis.

97 All-Party Parliamentary Group on Dementia, *Unlocking diagnosis: The key to improving the lives of people with dementia* (London: House of Commons, 2012).

98 Robin McKie, "Scientists plead for urgent action to tackle the growing dementia crisis", *The Observer*, September 16, 2012, 18-19.

99 HM Government, *The Prime Minister's Challenge on Dementia*, 22-23.

DESIGNING A POLICY RESPONSE

Pathways to diagnosis: innovation and variation

Diagnosis and care pathways are far from uniform, and responsibility for case-finding, assessment and diagnosis is not clear-cut. In fact, the best approach to providing assessment and diagnosis services may well differ across regions, depending on likely prevalence and whether the area is rural or urban. Local commissioners and clinicians have a wide range of opportunities to promote early diagnosis and to stimulate demand for diagnosis. Box 5.1 sets out two initiatives developed in response to specific local circumstances.

Box 5.1. Case studies of innovative dementia diagnosis practice

Pathway 1: Diagnosis at Primary Care level: Gnosall Health Centre

Approach

The Gnosall Health Centre is a GP practice which does not generally refer patients on to secondary, hospital-based services for assessments. Instead, clinicians within the Practice pro-actively identify potential patients during routine contact or through their knowledge of risk factors.¹⁰⁰ Patients are then referred to a dementia support worker for an initial assessment. Patients are then seen by a consultant psychiatrist at monthly memory clinic sessions that take place within the Practice. For some patients, consultations can take place at home or within care homes.¹⁰¹

Performance

Indicators suggest that the Gnosall model performs well. It has a higher assessment rate of the at-risk population compared to secondary care

100 Gnosall Health Centre, *Gnosall Memory Clinic: A guide to the basics*; Ian Greaves and David Jolley, "National Dementia Strategy: well-intentioned – but how well founded and how well directed?", *British Journal of General Practice*, 60: 572 (2010), 193-8.

101 Nicola Greaves and Ian Greaves, "The Gnosall project: Setting new benchmarks for dementia care", *Journal of Care Services Management*, 5:1, (2011), 49-52.

clinics, and patients and carers have high satisfaction rates.¹⁰² It has the ability to provide faster diagnosis, and is less costly and more flexible than the model whereby GPs refer to secondary care for assessment. The model also arguably overcomes some of the patient barriers – through pro-active identification of symptoms by the Practice, and potential reduction in stigma.¹⁰³

Pathway 2: Open access assessment: Strathmore Dementia Service

Approach

The Strathmore Dementia Service is a Scottish Government National Demonstrator Site pilot for dementia care services, which includes an open access memory clinic. People who are worried about their memory can self-refer themselves to attend the clinic. The memory clinic assessment involves a three-stage process. Stage one involves basic questions on cognition and day-to-day function; Stage two is a more extensive nurse-based assessment; and Stage three is a consultant assessment.¹⁰⁴

Performance

The pilot has delivered good results in terms of early diagnosis. People who went through the clinics were seen on average 18 months earlier in their disease than people who were referred by their GP.¹⁰⁵ However, it is not yet clear whether this pathway is likely to be cost-effective. Of the 218 people who went to the Open Access Clinic, 6% received a positive diagnosis and 11% had mild cognitive impairment. Forty-eight percent had no indication of dementia.¹⁰⁶ Whilst a definitive confirmation of no signs of dementia can provide benefits, a model which involves a high level of non-diagnoses may not be very cost-effective. It is also concerning that 32% declined further assessment, suggesting that there may be some demand-side barriers that were not overcome.

102 Greaves and Jolley, "National Dementia Strategy: well-intentioned – but how well founded and how well directed?", 193-8.

103 Ibid.

104 All-Party Parliamentary Group on Dementia, "2012 Inquiry – improving dementia diagnosis rates in the UK – Summary of collated evidence", evidence submitted by Royal College of Psychiatrists.

105 NHS Tayside, *Interim evaluation of the Strathmore Dementia Service*, June 19, 2012.

106 Ibid.

Other innovative practices which have been implemented or suggested, include:

- Specialist nurses carrying out case-finding assessments and referrals onto memory clinics.¹⁰⁷
- GPs proactively looking for signs of dementia such as patients not taking prescribed drugs or patients failing to pick up prescriptions.
- Councils providing active support networks to increase the likelihood that the symptoms of dementia are detected amongst those who are living alone.¹⁰⁸
- Screening the population – either through GP practices, flu clinics or in retail settings.
- Presence of dementia liaison teams in acute hospitals to improve detection.
- A checklist of symptoms associated with dementia which elderly people can present to their GP.¹⁰⁹
- Routine cognitive screening of older adults with Down syndrome.¹¹⁰

Clearly, this is an exciting and developing field, with a range of techniques being employed to improve diagnosis rates. Encouraging and sharing innovative practices is therefore crucial. The Government has announced funding to reward innovative practices – including the Innovation Challenge which gives £1 million to the NHS to reward projects that demonstrate innovative ways of reducing the number of people with undiagnosed dementia. This should be welcomed. But more needs to be done. In

107 Paulina Szymczynska et al, Best practice review: *Diagnostic and post-diagnostic service provision to people with dementia and their carers with particular interest in remote and rural populations* (NHS Highland, 2010).

108 A model for this is Southwark Circle.

109 Social Innovation Lab for Kent, "Dementia pathway co-production project", http://issuu.com/silkteam/docs/dementia_insight_report/8.

110 For latter three see evidence to APPG from Alzheimer Scotland Dementia Research Centre.

the context of a complex service where any number of interventions could increase the levels of early diagnosis, the presumption should be in favour of enabling and encouraging commissioners to deploy resources to interventions and programme which they think are most suitable, alongside clear meaningful targets and incentives. This could be a route to overcome the wide variation in diagnosis rates through the dissemination and adoption of best practice. The newly created Strategic Clinical Network for Mental Health, Dementia and Neurological conditions through the NHS Commissioning Board Authority provides a platform for the dissemination of best practice. The policy environment should also encourage different services and actors to come together to improve early diagnosis rates.

The rest of this chapter proposes the following reforms:

1. **Reforming the national incentives structure** to encourage local commissioners to choose the most effective and innovative response to the challenge of early diagnosis.
2. **Proposing dementia social impact bonds** to be commissioned locally as a route to promoting the most innovative interventions to encourage early diagnosis.

1. REFORMING THE NATIONAL INCENTIVES STRUCTURE

Desirability of financial incentives in health

There are on-going debates about the desirability of financial incentives in healthcare. Studies have suggested that incentive schemes in health have delivered mixed results.¹¹¹ Some have raised concerns that inappropriate incentives might squeeze out other activity and undermine intrinsic motivation. If this were the

111 Paul P. Glasziou et al, "When financial incentives do more good than harm: a checklist", *British Medical Journal*, 345:e5047 (2012).

case, the costs may outweigh the gains.¹¹² However, the evidence shows that financial incentives can be strongly beneficial for some outcomes; indeed, the Quality and Outcomes (QoF) framework has incentivised general practices to have a more organised approach to chronic disease management, and has provided a strong incentive to engage in secondary prevention, particularly in the most deprived areas.¹¹³

The evidence on targets suggests that there remain compelling reasons to optimise the incentives framework for diagnosis of dementia. First, national targets have been shown to work in Scotland where the HEAT standard has been met with much higher diagnosis levels of dementia. Second, academics have drawn up criteria checks in a bid to limit the number of financial incentives used in the health service – but dementia diagnosis meets even these exacting criteria.¹¹⁴ Third, incentives are already in place and their design is sub-optimal: as with many aspects of payment by results in health services, the ‘results’ are not outcomes at all but processes; often, national decision-makers over-specify who should be the recipient of the reward payment thus limiting incentives directed at other health agencies to contribute to the outcome. This is the case in dementia services. The aim should be to reform the current incentives to enable better outcomes.

The following section explores four funding routes by which early diagnosis can be incentivised:

112 Tom Moberly, “QOF undermines motivation to provide good care, researchers warn”, GP online, August 16, 2012, <http://www.gponline.com/News/article/1145644/QOF-undermines-motivation-provide-good-care-researchers-warn/>.

113 Royal College of Nursing, “Paying for quality – commissioning for quality and innovation (CQUIN) in England”, Policy briefing 14/12, 3; Anna Dixon, Artak Khachatryan, Andrew Wallace, Stephen Peckham, Tammy Boyce and Stephen Gillam, “Impact of Quality and Outcomes Framework on health inequalities”, The King’s Fund April 2011 working paper, 1, <http://www.kingsfund.org.uk/sites/files/kf/Impact-Quality-Outcomes-Framework-health-inequalities-April-2011-Kings-Fund.pdf>.

114 Paul Glasziou et al, “When financial incentives do more good than harm: a checklist”.

- **Quality Outcomes Framework (QOF)** – this is decided by the NHS Commissioning Board and acts as a Payment by Results for clinicians to carry out specific processes. This reward payment sits alongside the core payment received through the General Medical Services Contract.
- **Commissioning for Quality and Innovation (CQUIN)** – this is decided by the NHS Commissioning Board and is received by secondary care providers, although a broad result is usually decided nationally with local commissioners (PCTs or CCGs) allowed to design the incentive to meet their specific local needs.
- **NHS Outcomes Framework** – this is a broad outcomes framework deployed by the NHS Commissioning Board to encourage Clinical Commissioning Groups to meet desired outcomes in their local areas.
- **Health Premium** – this is a reward payment that will be received by local authorities that meet public health outcomes set by Public Health England.

Re-designing the incentives framework

1. QOF

The current QOF incentive paid to GP practices for 2012-13 is that: 'The [GP] practice can produce a register of patients diagnosed with dementia'.¹¹⁵ This is ineffective as an incentive for dementia diagnosis, being poorly structured for the purpose and too easy to achieve. Rather than incentivising diagnosis it encourages GPs to record on the register any diagnoses that are made. Once a practice has recorded the first instance of diagnosis, there is no further incentive to act. This partly explains the fact that the target is so easy to hit. Figures show that 100% of practices now get the full five

¹¹⁵ BMA and NHS Employers, *Quality and Outcomes Framework for 2012/13* (London: NHS Employers, 2012), 15.

points out of five for this outcome.¹¹⁶ GPs themselves see the QOF as ineffective if process measurements are employed.¹¹⁷

These criticisms should inform a new QOF target framed around likely prevalence in an area; meeting an expected benchmark. There is existing data on expected prevalence that could be used to inform this, although it is important that local targets are calculated carefully to take into account local factors that may affect likely prevalence. These could include, for example, the cardio-vascular risk profile of the population and the number of people in nursing or residential care.

2. CQUIN

CQUINs incentivise quality improvements in secondary care, such as to the ambulance service, mental health services and acute hospital care. Over time, the amount that providers can earn for incremental quality increases above the standard contract will rise to 2.5%.¹¹⁸ Most CQUINs are locally determined, with local commissioners converting a broad national target into a CQUIN for a specific provider or set of providers locally. However, in exceptional cases, CQUINs are national. In these instances, not only the outcome but also the destination and detail of the incentive is designed by central commissioners. Two new national CQUIN goals have been introduced for use in 2012-13, including one 'to help identify patients with dementia and other causes of cognitive impairment, alongside their other medical conditions and to prompt appropriate referral and follow up after they leave hospital.'¹¹⁹

¹¹⁶ <https://indicators.ic.nhs.uk/webview/>.

¹¹⁷ All-Party Parliamentary Group on Dementia, "2012 Inquiry – improving dementia diagnosis rates in the UK – Summary of collated evidence", evidence submitted by GMB.

¹¹⁸ <http://www.dh.gov.uk/health/category/policy-areas/nhs/quality/qipp/>.

¹¹⁹ <http://www.dh.gov.uk/health/2012/05/guidance-on-new-national-cquin-goals/>.

Box 5.2. Aims of the new CQUIN according to the Department of Health

The CQUIN has three main aims:

- Identify people with dementia – members of staff will ask members of the family or friends of a person admitted to hospital if the patient has experienced any problems with their memory in the last 12 months.
- Assess people with dementia – if there is evidence to suggest a problem with their memory, that person will be given a dementia risk assessment.
- Refer on for advice – a referral would be made for further support either to a liaison team, a memory clinic or a GP.

Source: Department of Health, "Guidance on new national CQUIN goals", <http://www.dh.gov.uk/health/2012/05/guidance-on-new-national-cquin-goals/>

As identified in Chapter 4, there is undoubtedly a need to promote diagnosis of dementia in some hospitals. However, it is unclear that this new target will be the most effective method for raising diagnosis rates because it is a process-based target and limits potential innovation from local commissioners.¹²⁰

3. NHS Commissioning Outcomes Framework (COF)

Influencing the commissioning decisions of Clinical Commissioning Groups (CCGs) will be crucial if diagnosis rates are to improve. But, a recent assessment of COF has acknowledged that there is insufficient incentive to promote diagnosis and effective treatment of dementia.¹²¹ The Scottish HEAT target – which was introduced as a target in 2008 and became a 'Standard' in 2011 – was effective in markedly increasing the diagnosis of dementia. The target stated that 'each NHS Board will achieve agreed improvements in the early diagnosis and management of patients with dementia'. The approach included both national

¹²⁰ The assessment process through which hospitals will have to go is detailed here: <http://dementia.dh.gov.uk/files/2012/02/dementia-assessment.26.jpg>.

¹²¹ Department of Health, *Our NHS care objectives: A draft mandate to the NHS Commissioning Board* (London: HMSO, 2012).

reporting and locally-tailored practice-level prevalence rates. A modest investment was made in advisors who could help disseminate best practice.¹²² This indicates that a national target can operate as a tangible goal for practitioners and commissioners to aim for.

In the case of England, the Government has created space for two new incentives for dementia services in the refreshed NHS Outcomes Framework 2012-13, though the incentives have not been decided on yet.¹²³ In September 2012, the Government published a list of new outcomes to be included in the NHS Outcomes Framework, including: '2.6.i Estimated diagnosis rate for people with dementia.'¹²⁴

4. Public Health Outcomes Framework and the 'Health Premium'

The 'Health Premium' will be used by the government to drive improvement in achieving public health outcomes.¹²⁵ There is no detail yet on the specific targets nor on the level of reward on offer.¹²⁶ Directors of Public Health in local authorities will have significant funding and levers at their disposal to promote awareness of dementia and encourage people with the condition to engage with clinicians. Health Premiums will be an important method of promoting early diagnosis through stimulating demand for diagnosis among potential people with dementia.

122 All-Party Parliamentary Group on Dementia, *Unlocking diagnosis The key to improving the lives of people with dementia* (London: House of Commons, 2012).

123 Department of Health, *NHS Outcomes Framework* (London: HMSO, 2012).

124 National Health Service, "NHS outcomes framework indicators – September 2012 Release", <http://www.ic.nhs.uk/statistics-and-data-collections/audits-and-performance/nhs-outcomes-framework-indicators/nhs-outcomes-framework-indicators-september-2012-release>.

125 Department of Health, *Improving outcomes and supporting transparency – Part 1: A public health outcomes framework for England, 2013-2016* (London: HMSO, 2012).

126 Ibid.

Table 5.1. Summary of reforms needed to incentives framework

Incentive	Current problems	Options for reform	Desired impact of re-designed incentive
QOF	Process orientated Limited to the first diagnosis Takes no account of prevalence of dementia in local area No reward for prompt diagnosis	Broaden outcome to 'diagnosis of dementia' Link reward target to prevalence rate in locality.	Encourage GPs to invest in training and knowledge, to make sufficient time for diagnosis and to be pro-active in case-finding.
CQUIN	Process orientated	Re-design CQUIN as a broad national outcome that can be targeted by local commissioners at any local providers.	Provide local commissioners with sufficient freedom to direct the incentive at under-performing or particularly important providers in secondary care.
NHS Commissioning Outcomes Framework	N/A – not currently in operation	As QOF above.	Encourage CCGs to promote diagnosis.
Health premium	N/A – not currently in operation	Stipulate a simple outcome: number diagnosed as a proportion of the population with dementia in the local area.	Incentivise Directors of Public Health to develop social marketing campaigns, outreach work and other activities to promote awareness of dementia and encourage those with dementia to come forward for diagnosis.

As can be seen from Table 5.1, the aim should be to focus commissioners and GPs on a broad outcome measure of increasing the number of people diagnosed with dementia as a proportion of the population with dementia in their area.

There are clear routes for national government to incentivise local commissioners to promote early diagnosis. However, incentives must be aligned and left broad so that commissioners and clinicians can innovate in how they achieve the desired outcome. This would be a route to joint-commissioning between different relevant actors in the health system.

The incentives and the options for reform set out above refer to diagnosis rates. At the moment, diagnosis rates could be increased by diagnosing a larger number of those with dementia in the late stages of the disease. Whilst this may have some positive effects, in the future we need to move towards more effective incentivisation of **early diagnosis**. The first step would be to include financial incentives to record the stage of the disease at the time of diagnosis. Over time, targets could then be developed to incentivise diagnosis at early stages of the disease.

2. THE CASE FOR 'DEMENTIA IMPACT BONDS'

The above analysis demonstrated that there is a strong case to reform the incentives that national commissioners place on local commissioners. This section assesses how local commissioners can seek to design their own incentive frameworks to encourage providers to focus on early diagnosis as the most cost effective method of responding to the challenge of dementia.

Financial viability of early assessment

Many of the benefits of early diagnosis flow to the individual. However, there are also wider public benefits. These comprise:

indirect benefits, including reduction of the costs of informal care given and an increase in employment activity; and direct benefits, including the reduction of costs of institutional care.

The most recent evidence suggests that it is financially beneficial to the state to diagnose more cases earlier. The analysis by Denis Getsios and others indicates that early assessment and treatment would cost less than 'no early assessment and no treatment' (on average £3,600 less) and less than 'treatment without early assessment' (on average £2,135 less). The savings stem from reductions in cost of acute care and residential social care, with people treated earlier typically spending less time in each of these settings.¹²⁷ For instance, about a quarter of those occupying a hospital bed have dementia and it has been estimated that about 40% of these admissions are because of ambulatory conditions (such as urinary tract or respiratory infections), which can be managed in the community.¹²⁸ The National Audit Office concluded in 2010 that 'Joined-up working remains very patchy and as a result people with dementia are still being unnecessarily admitted to hospital, having longer length of stay and enter residential care prematurely. Whilst we found examples of good practice, these are not being adopted widely.'¹²⁹

Theoretically, therefore, there is a strong case for the state to invest in early diagnosis and make savings in acute care and residential care as a result.

127 D. Getsios, S. Blume, K.J. Ishak, G. MacLaine, and L. Hernandez, "An economic evaluation of early assessment for Alzheimer's disease in the United Kingdom", *Alzheimer's and Dementia*, 8 (2012), 22-30.

128 Department of Health, "Using the commissioning for Quality and Innovation payment framework: guidance on new national goals for 2012-13", http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_133859.pdf.

129 Professor George Tadros, *Can improving dementia care in acute hospitals save money? The RAID experience* (Stafford: Staffordshire University, 2012).

Box 5.3. The case for targeted screening for dementia

Screening can resolve many barriers on both the patient side (because the assessment is routine and less avoidable) and the practitioner side (because the assessment is taken out of normal primary care activity).

Screening of the general population has been dismissed as not cost effective. However, there is a stronger case for targeted screening. Specific risk factors are associated with undiagnosed dementia. These include: being older; having Down's Syndrome; having Mild Cognitive Impairment (30% to 40% of MCI patients go on to have dementia); having Parkinson's Disease; and being poorly or living alone.¹³⁰ Targeted screening with these groups would be more cost effective than whole population screening.

The Prime Minister's Dementia Strategy has proposed 'regular checks' for over-65s at primary care level. There will now be a requirement for all health-care practitioners to ask patients about their memory during a check-up.¹³¹ However, there has been no commitment to full screening.

Under the incentives frameworks set out above, local commissioners and providers would be incentivised to seek out the most effective route to early diagnosis, whether it be investment in GP training, outreach work, education and guidance, or investment in memory clinics. As such, over time, providers would be expected to explore the comparative benefits of different methods of assessment and screening. A Dementia Impact Bond would be a method to invest upfront in targeted

¹³⁰ Paulina Szymczynska et al, *Best practice review: Diagnostic and post-diagnostic service provision to people with dementia and their carers with particular interest in remote and rural populations* (NHS Highland, 2010).

¹³¹ HMG, *The Prime Minister's Challenge on Dementia. Delivering major improvements in dementia care and research by 2015: a report on progress* (London: HMSO, 2012).

screening to gain rewards through reductions in admissions to hospitals and residential care.

Designing a social impact bond for dementia

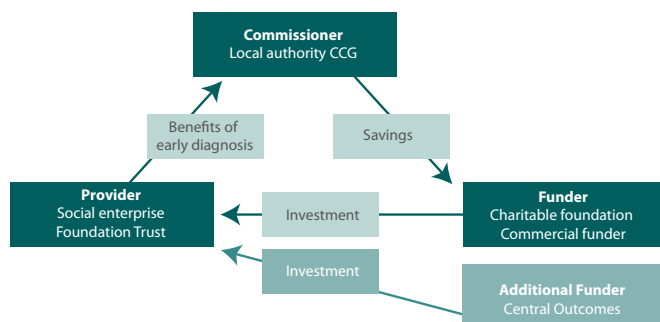
In the current fiscal context, with the NHS seeking £20 billion of efficiency savings, there is a strong case to seek to bring in external private investment to fund early interventions. There is increasing consideration being given to the role of Social Impact Bonds in funding interventions to reduce unnecessary admissions to hospitals or residential care homes.¹³² However, much less attention has focused on specific conditions such as dementia.

The savings from early diagnosis would accrue directly to a range of actors most especially the local authority (reduction in residential care costs) and the CCG (reduction in the time a patient spends requiring acute treatment). Given the high costs of NHS services, expecting a local authority on its own to invest in early assessment either directly or through a social impact bond (SIB) is unfeasible.¹³³ A Dementia SIB would, therefore, have to be commissioned collectively by the local authority and the CCG. Providers could then focus on any activity that increased diagnosis of dementia including targeted screening, outreach work, investment in awareness campaigns and case-finding in primary and secondary care.

132 Phil Hope, "Services for later life" (Age UK, 2012); The Young Foundation, "Social Impact Bonds in Health", http://youngfoundation.org/wp-content/uploads/2012/10/cial_Impact_Bonds_in_Health_-_Briefing_Paper.pdf.

133 Savings may also flow to the hospital as better diagnosis of dementia can reduce nursing costs by needing fewer specialists. All-Party Parliamentary Group on Dementia, "2012 Inquiry – improving dementia diagnosis rates in the UK – Summary of collated evidence", evidence submitted by Royal College of Physicians. This is a wider problem in health services, City of Westminster Council and LGIU, *Payment by results: The perfect storm of public sector finances* (London: LGIU, 2011).

Figure 5.1. Actors in a Dementia Social Impact Bond



Both the CCG and the local authority would have to be involved in commissioning the SIB. A central 'Outcomes Finance Fund' is being set up by the Cabinet Office to help promote the adoption of SIBs especially where the investment is being jointly commissioned.¹³⁴

Clinicians and commissioners who participated in the SMF's research roundtable noted that dementia diagnosis suffered from a lack of clarity about which clinicians and commissioners were ultimately responsible. The re-structuring of the NHS provides an opportunity to introduce clearer accountability. Despite the attempts to move towards the integration of health and social care, historically, there has been reluctance in many localities to pool budgets and commission collectively. Re-designed and sharper incentives, and new accountability structures locally, may make this more attractive. Local authorities and clinical commissioning groups (CCGs) will have an equal duty to prepare Joint Strategic Needs Assessments and Joint Health and Wellbeing Strategies, through the Health and Well-being Board.¹³⁵ In addition, they are being encouraged to commission jointly. Such approaches

¹³⁴ HMG, *Growing the Social Investment Market: Progress update* (London: HMSO, 2012).

¹³⁵ Department of Health, *Joint strategic needs assessments and joint health and wellbeing strategies – draft guidance proposals for consultation* (London: HMSO, 2012).

may encourage a more effective focus on early diagnosis and prevention.¹³⁶

Joint commissioning for a SIB could be further incentivised through the use of the Cabinet Office's Central Outcomes Finance Fund. This fund has been set up to co-invest in SIBs as a method of reducing the risk to commissioners and investors. The Fund could subsidise the cost of the SIB to the commissioners. Alternative funding arrangements for early targeted intervention could include drawing in investment from pharmaceutical companies through 'joint working agreements'. Under such an arrangement, a CCG would collaborate in a joint project with a pharmaceutical company to achieve clinical outcomes (such as identifying undiagnosed patients). However, commissioners would have to ensure that any such arrangements are in the best long-term interests of patients and that care pathways and priorities are not adversely affected.¹³⁷

Conclusions

Dementia is set to pose a major and growing challenge. The current cost of dementia in the UK is £23 billion a year – and is set to rise with the ageing population. Diagnosis, and in particular, early diagnosis can play a vital role in reducing long-term care costs and allowing access to treatment and support that improves patients' lives. But at the moment, incentives within the system are not set up to lead practitioners and commissioners to invest in improved diagnosis rates. This needs to change. Incentives for actors across the health care system should be directly linked to increased diagnosis rates. Practitioners and commissioners should be free to innovate, tailoring solutions to what works for patients and their local population.

136 For instance, see Islington Council, "Adult Joint Commissioning Strategy 2012-2017", <http://www.islington.nhs.uk/Downloads/CCG/JointCommissioningStrategy.pdf>.

137 Pulse, "Drug companies to work with CCGs on care pathways and case finding under DH-backed scheme", Pulse, May 28, 2012.

ANNEX 1: INTERVIEWS SAMPLE

Criteria for initial interview sample, in priority order

- a) **Interviewees.** All interviews to be with a patient, carer or close relative.
- b) **Recent diagnosis.** All patients to be diagnosed recently to ensure policy relevance.
- c) **Stage of disease.** A mixture of patients in the early, mid and late stages of Alzheimer's.
- d) **Gender.** A mix of male and female patients.
- e) **Geography.** A mix of patients from different regions in England due to varying diagnosis rates.
- f) **Accommodation.** A mix of patients who were living independently, in sheltered accommodation and living in a care home.
- g) **Support.** A mixture of patients who were self-supporting, cared for by a relative, received formal support only and received care from a relative and through formal support.

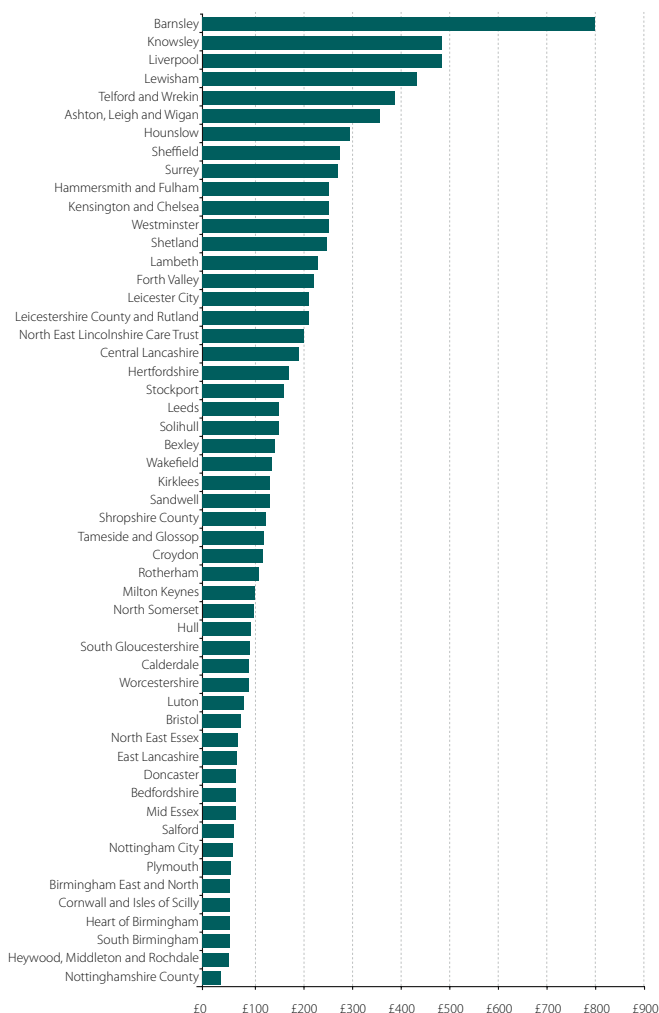
Final sample following relaxation of initial criteria

- Interviews with those who had experienced a diagnosis within the past 5 years
 - 3 x diagnosed in 2012
 - 6 x diagnosed in 2011
 - 1 diagnosed in 2009
- A mixture of patients in the early, mid and mid-late stages of Alzheimer's disease
 - 4 x early stages
 - 2 x mid stages
 - 4 x mid-late stages
- A mixture of patients, carers and relatives interviewed
 - 3 x patients
 - 6 x relatives/carers
 - 1 x relative

- A mixture of younger and older patients
 - 2 x under 60s
 - 8 x over 75s
- Different locations across England
 - 2 x Northern England
 - 2 x Midlands
 - 5 x Southern England
- A mixture of men and women with Alzheimer's
 - 6 x Female
 - 4 x Male

ANNEX 2: EXPENDITURE ON MEMORY SERVICES IN ENGLAND

Chart A.1. Spending on Memory Services by UK PCOs in 2011/12, per person with dementia in local population



Source: Stephen Robinson, "How the UK falls short on dementia", GP Online, 7 March 2012, <http://mgponline.com/article/1120754/UK-falls-short-dementia>.

ANNEX 3: EARLY DIAGNOSIS OF DEMENTIA – DOES IT MEET CHECKLIST FOR INCENTIVES IN HEALTHCARE?¹³⁸

Question	Incentive for early diagnosis of dementia
1. Does the desired clinical action improve patient outcomes?	Yes – see Chapter 1 above.
2. Will the undesirable clinical behaviour persist without intervention?	Yes – there have been improvements in diagnosis in some localities. However, the barriers are complex and multiple, see Chapter 3 and 4 above.
3. Are there valid and reliable measures of the desired clinical behaviour?	Yes – dementia prevalence rates are widely accepted.
4. Have barriers and enablers to improving clinical behaviour been assessed?	Yes – there has been significant academic research of clinical behaviour, including lack of capability at primary care level.
5. Will financial incentives work better than other interventions to change behaviour, and why?	Yes – many other actions have already been taken.
6. Will benefits clearly outweigh any unintended harmful effects, and at an acceptable cost?	Yes – there are no additional direct costs to the Exchequer if money paid for incentives is off-set by a reduction in the core payment. The most significant potential unintended consequence relates to diverting attention of GPs from other illnesses, but the level of undiagnosed dementia indicates that GPs attention should be focused.

138 Paul Glasziou et al, 'When financial incentives do more good than harm: a checklist', *BMJ*, 2012, 345, e5047.

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The number of people with dementia is set to rise over the coming years as the UK's population ages, bringing considerable emotional and financial implications. The Prime Minister has described it as "a national crisis". Increasing the number of people who are diagnosed early will reap significant benefits for individuals, families and government.

Currently however, the UK has a poor diagnosis rate, with only 41% of people with dementia estimated to be diagnosed. This report draws on in-depth interviews with people with Alzheimer's and their carers and a wealth of research to identify the barriers to early diagnosis, from a patient and professional perspective. New policies are proposed to better incentivise the health system to diagnose dementia earlier.

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