

Inquiry of the All-Party Parliamentary Group on Dementia  
**How to improve dementia diagnosis rates in  
the UK**

**Minutes of the oral evidence session held in  
Commons Committee Room 17 on 13 March 2012**

**Before members:**

Hazel Blears MP (Chair)

Tracey Crouch MP

Nick Boles MP

Julie Hilling MP

Baroness Browning

**Witnesses:**

*Martina Kane, Policy Adviser, Alzheimer's Society*

*Daphne Wallace, Former Old Age Psychiatrist, diagnosed with dementia in 2005*

*Brigid Stubbs, Cares for her husband with dementia*

*Dr Imran Rafi, Medical Director of the Royal College of GPs' Clinical Innovation and Research Unit (CIRC)*

*Dr Simon J Hughes, Royal Victoria Hospital, Belfast*

*Geoff Huggins, Deputy Director of Health and Social Care Integration, Head of Reshaping Care and Mental Health Division, Scottish Government*

Time: 15.00 – 16.57

**Welcome and Introduction**

**Hazel Blears**

**Vice Chair of the All-Party Parliamentary Group on Dementia**

Good afternoon everybody. I propose that we make a start. Welcome to Tracey and to Angela, our parliamentarians with us today, to all our witnesses and to everybody who will hopefully join in the

discussion. My name is Hazel Blears, I am a Vice Chair of the All-Party Parliamentary Group. Our Chair, Sally Greengross – who is the most fantastic woman, as we all know – is currently in the House of Lords debating various amendments to the Health Bill. She has asked me to chair this afternoon. There is a running whip, so I have no doubt Angela may well be called away at various points, but it is very good to have her here.

We announced last year that we would do out next inquiry into early diagnosis; today is our first oral evidence session. Diagnosis has been highlighted as a very important issue, as only about 40% of people living with dementia in this country get a formal diagnosis. It is that diagnosis that then enables people to access services and take control of what is happening to themselves and their families. It is shown that if people have an early diagnosis you can sometimes avoid admission to hospital, which we all know can often then result in admission to residential and nursing care, which is bad for families but also costs the nation a huge amount of money. There are both financial imperatives to early diagnosis and human, emotional and carer issues around this agenda. We are delighted to have Daphne and Brigid with us as well, to hear your voices today.

We intend to hear evidence today and tomorrow from a whole range of expert witnesses and to have discussion and questions as well. We will be publishing our findings in the summer of this year. We are hoping to look at the current barriers to early diagnosis and why there is such variation in different parts of the country, which was something that really struck me. There is a diagnosis rate of only 26% in Dorset and a diagnosis rate of nearly 70% in Belfast. There is massive variation across the country; we want to explore the reasons for that. We also want to highlight some examples of good practice where people are getting it right, to try to translate that across the country more.

Just before Christmas we issued a call for written evidence, and I am told we now have more than 1,100 submissions – which is just amazing – from people with dementia themselves, from carers, GPs, nurses, psychiatrists, health and social care providers, and from a range of organisations involved in the field. To me, that says this work has struck a nerve: you do not often get 1,100 submissions to anything you call for. Martina is with us from the Alzheimer's Society; it is your unenviable task to try to summarise the points that were made in the 1,100 submissions you no doubt trawled through in the last few weeks.

### **Martina Kane**

I had to read them all last week, between the call for evidence closing and now.

### **Hazel Blears**

If you could take us through the summary of the key points that have emerged that would be really helpful.

### **Martina Kane**

First of all to say, I am Martina Kane, I am Policy Advisor at the Alzheimer's Society, and as the Alzheimer's Society provides the secretariat to this group I have the unenviable task of reading through all the evidence submitted. This presentation is a short summary of a lot of evidence; I cannot feasibly put it all in. I am going to talk for about 20 minutes, and I have space in my presentation for both Brigid and Daphne to give their real experience, not just the statistics.

**Hazel Blears**

Martina, just before you embark on that task, for the benefit of the people who have come to listen to us today, could Angela and Tracey introduce themselves and say what their experience and interest are?

**Baroness Browning**

I am Angela Browning, I am a member of the House of Lords and before that I was a constituency MP in Devon for 18 years. It was as a result of my constituency work that I took an interest in the All-Party Group here, not just from people with dementia but particularly carers. It was a very rural farming community, very difficult for people to meet together, share information and support each other, but they did form two separate carers' groups. Getting involved with those groups got me interested in what was going on in Parliament. I also sat on the Public Account Committee, where we received a report from the National Audit Office on dementia, which was instrumental in helping to move forward the agenda that we needed a lot of issues to be highlighted and to make progress.

**Tracey Crouch**

Tracey Crouch, the MP for Chatham and Aylesford and Vice Chair of the All-Party Group. Like Angela, I come to this from a constituency perspective, having met a gentleman whilst out canvassing whose wife had been quite badly treated in hospital. She had dementia and the care in the hospital was not suitable given her condition. It was from that that I got more and more interested in dementia as a wider issue. From that I spread out and have taken more of an interest in older people's issues in general. Dementia is the key issue I am interested in and how all the other services and requirements for older people fit in around that. That is my primary interest.

**Hazel Blears**

Thank you very much, Tracey, and we may well be joined by other parliamentarians throughout the course of the evidence. Please do not feel they are being discourteous; many of them will be in other meetings or have other requirements. I am the MP for Salford and Eccles and I got particularly interested in this area on a personal basis, because my mum has Alzheimer's and was diagnosed six years ago. My dad is a full-time carer, so we are very close to the issues personally. We also have one of the national demonstration projects under the National Dementia Strategy in my constituency, and we are trying to live up to the slogan of 'Living Well with Dementia'. We approach this with a positive frame of mind, whilst recognising the difficulties. Sorry about that Martina, I thought it was as well that people knew.

## **Overview of Submitted Written Evidence**

**Martina Kane**

**Policy Advisor, Alzheimer's Society**

### **I. Background to the Inquiry**

I will run through the evidence that existed about diagnosis beforehand to provide more context. This map might be familiar to some of you. As Hazel said, the current evidence suggests that a relatively low number of people with dementia have a diagnosis. The National Audit Office Report that has already been mentioned suggested that 40% of people had a diagnosis, and this map that was put together by the Alzheimer's Society and Alzheimer's Scotland suggests that only 43% of the people expected to have dementia across the UK are on GP registers as having dementia. That uses a traffic light colour coding system to reflect some of the variations across the UK. Areas in dark red have low diagnosis rates and the greener areas have higher diagnosis rates. Overall England is running at about 41% of people diagnosed, Wales at 37% of people, but Scotland have managed to get 64% of people diagnoses and Northern Ireland 61%. We have witnesses coming here later on from Northern Ireland and from the Scottish Government who will hopefully be able to talk through some of the things that are going on there that might be making some of that difference. However, as you have said, the evidence around this is quite lacking; we are not sure why these variations are happening. The inquiry was designed to explore some of the barriers there are to diagnosis.

### **II. Methodology**

#### **1. Evidence-gathering**

The evidence-gathering took place between December 2011 and the end of February this year. The launch received some great press attention, including coverage in *The Telegraph*. Beyond this we have done a number of things to encourage a large number of organisations and individuals to submit. In particular we produced a series of questionnaires tailored to different groups of people – they are listed on the slide – which were promoted through a number of channels and a range of relevant organisations. It is worth saying at this point that whilst the evidence was gathered through a questionnaire this was not academic research; people were not randomly sampled for this. For example, because the questionnaire for people with dementia was largely circulated through the Alzheimer's Society the people who responded have a bias because of that: they are the ones more likely to be diagnosed and accessing services, rather than it being a representative example.

#### **2. What Evidence was Received?**

As Hazel said, we received 1,123 responses to the questionnaire, and 39 responses through other means: letters from the public, formal submissions from organisations, that sort of thing. We think the high response rate was due to the questionnaire format, and the people who may not have had time to write formally were able to fill in the survey online in a shorter space of time. We made a map of where the questionnaire responses came from. As you can see, we got a good geographical spread. Although the majority of them did come from England we still received a good number of

responses from Scotland, Wales and Northern Ireland. As that shows, as you would expect, we got more responses from densely populated areas. That would reflect the populations being in those areas.

We received a good number of responses from people with dementia themselves. Carers, family members and friends also formed half of the number of responses received. The numbers from other different groups are listed on the slide. The evidence in general adds to a useful picture on the state of diagnosis within the different nations. Most of the carer responses and the people-with-dementia responses did report a struggle to get a diagnosis, although there were some good experiences coming through as well. This slide just shows that there are still long delays for people getting a diagnosis. The questionnaire asks the length of time between noticing the symptoms and the person with dementia getting a diagnosis. This chart shows the percentage of carers who chose each of the options. At the far left, in red, only 6% of carers reported waiting less than three months; more than half had to wait longer than a year; and 10% had to wait longer than five years in order to get a diagnosis.

I am now going to pass over to Brigid, who will talk a little bit about her own experience of trying to get a diagnosis for her husband Paul.

### **Hazel Blears**

Tell us a little bit about yourself, Brigid.

## **III. Experience from a Carer**

### **Brigid Stubbs**

I trained as a nurse when I was 19 in London, then I went to City University and did a degree. I met my husband; we moved out to Surrey, we have lived in Surrey ever since 1979. I have worked in Human Resources, I have done nursing. My last job was in medical insurance. We have two sons, both of whom are at university.

### **Hazel Blears**

One of whom is with us today.

### **Brigid Stubbs**

I do not know if you need to know anything else. My husband was given a formal diagnosis of Alzheimer's about 11 months ago, but I noticed changes in him from about 2005: he was losing interest in hobbies; he used to be very extrovert, he was becoming very introverted; he was quite happy to sit and watch television. He was made redundant in 2006 and I was not surprised. Other people were made redundant as well, but I was not surprised, but his demeanour changed completely when he was made redundant; he was like a fish out of water. He could not cope, he kept making mistakes. He even looked different to me. I was very concerned about him. I knew there was something wrong with him. He was trying to cope for a long time. He tried to train as a driving instructor but failed the theory test twice, so I said, 'Best leave that'. He tried other jobs. He could not seem to do anything successfully, which was obviously making him lose even more confidence.

Eventually, in June 2007, I persuaded him to see the GP, who did a small memory test on him and referred him on to see a psychiatrist. Because I had private medical insurance, and because we had waited 14 months from when I noticed there was something wrong to seeing the doctor I thought it was best to go privately, which we did. The psychiatrist thought it was depression and put him on antidepressants. Paul seemed to be in a holding pattern then; he was not getting any better, but he was not particularly getting any worse. That autumn, in 2007, he got a job at M&S in the warehouse, which then became permanent. He was fine for a couple of years, but then I noticed he was getting worse again. I was not happy with the diagnosis from the first consultant, who said it was pseudodementia caused by depression – dementia-like symptoms because he was depressed. I never thought my husband was particularly depressed, so we saw a different consultant, who unfortunately just referred us back to the original one as it was not his level of expertise, which I did not pursue at the time. I did not say, ‘What do you mean’, because I think I knew what he meant, but I was not ready to accept. All the time I had a gut feeling that my husband had Alzheimer’s, but I was happy to accept the original consultant saying it was depression, because that was obviously preferable.

Then in the autumn of 2009 my husband was making mistakes at work and got told off at work. He was more forgetful at home, and I thought it was only a matter of time before he was going to have big problems at work, which he did have. He had a disciplinary procedure brought against him at work for making mistakes. I knew that it was best to not work any more; I told him not to go back. By this time we went back to see the original consultant psychiatrist. By this time my husband was wandering around at night as well. I told the psychiatrist this, and I said, ‘What do you think is wrong with him?’ He said frontal-temporal dementia. Going from depression to frontal-temporal dementia is quite a jump from the same consultant. I thought, ‘Oh my goodness’.

After that my husband was off sick. The GP put dementia on the sick note, so I was able to get Paul dismissed on the grounds of incapacity from M&S, which was great, because he could then claim incapacity benefit, which he would not have been able to if he had resigned or was sacked through not being able to do the job. We also applied for disability living allowance. All this time we still had not had a formal diagnosis, and there was no treatment either. Unfortunately, because we had gone private, once we had this diagnosis the private insurance would not cover any more because dementia was a chronic long term illness. We tried to get a referral to the NHS. I do not know why, but our GP could not refer Paul to the local consultant in charge of dementia, so she could only refer Paul to a neurologist, who then referred Paul to a hospital in London – the National Neurological Hospital. He was kept in for seven nights and they did four tests on him: EEG, MRIs etc. Finally 11 months ago, he was diagnosed with Alzheimer’s.

For a long time we were in limbo, not really knowing what was going on. I had my suspicions, but it was very difficult really to accept it when we did not know what was going on. Since the diagnosis we have felt more comfortable with everything as a family, and we can plan, etc. It has been a lot better.

### **Hazel Blears**

That is quite a journey Brigid.

### **Brigid Stubbs**

It was a journey.

**Hazel Blears**

Six years.

**Brigid Stubbs**

Yes, it was six years.

**Hazel Blears**

What we will do, Martina, is when you have finished your presentation we will throw it open for questions and discussion. Thank you very much Brigid.

**IV. Evidence Gathered****Martina Kane**

I have approached the evidence received by the inquiry from the perspective of the patients. I am going to begin with the period of time before a person goes to the doctor and then run through primary and secondary care. I have summarised the evidence received, some of the reasons people gave for the problems they were experiencing, and some of the solutions suggested throughout.

**1. Time between experiencing symptoms and presenting to a professional**

As Brigid indicated, there is often a gap between a person with dementia experiencing symptoms and then seeking medical help. The questionnaire sought to explore this. The graph – similar to the previous one – showed the percentage of carers who stated a particular length of time between symptoms and the person with dementia then going on to present to their GP. On the far left in red, less than 15% of carers said it was less than three months between noticing symptoms and going to the doctor. More than a third waited longer than a year before presenting to a health professional – the teal, green, grey and black added together. The blue bar on the far right showed nearly 10% never went to the doctor at all. Additionally, people not presenting to medical professionals with the symptoms was the primary reason identified by health professionals for under-diagnosis. More than three quarters of GPs and 70% of memory specialists who answered the questionnaire said that people did not present with problems about their memory. Arc Research submitted evidence based on interviews with more than 80 people with dementia and carers. This found it took an average of two and a half years between the person noticing problems with their memory and seeking help from a professional.

*a. Suggested Reasons*

The respondents to the questionnaire who said the person with dementia did not go to a GP straight away were asked to think about why that was and tick as many of the separate statements as they agreed with. There are a range of reasons; most common was the belief that problems with your memory are normal as you get older. 28% of carers and 52% of people with dementia agreed with that. Carers and people with dementia also felt that to some extent the person with dementia did not want to think about problems with their memory or notice problems with their memory. Interestingly – and it is only a relatively low number – only 6% of carers agreed that they did not think there was any point. We often hear that lack of treatment is seen as a barrier, but this does not

seem to be the case for the people themselves when they are thinking about presenting; the lack of treatment is not one of the things they think of.

*b. Suggested Solutions*

Respondents also suggested solutions to some of these problems. Greater public awareness and understanding was seen as helpful, and it was the most common suggestion to the inquiry of what needed to be done to improve diagnosis rates. This could have been in the form of media stories, soap plotlines, as well as informal awareness campaigns. Some respondents also suggested that it is not just awareness that is needed but education and understanding, so an understanding of the difference between normal aging and the symptoms of dementia. Gayle Willis from the Alzheimer's Society will be coming tomorrow to talk more about public awareness campaigns they have done and other things they do to raise understanding and awareness.

Screening was also suggested by many people as a way of solving this problem. Whilst NICE does not recommend screening, GPs and others suggested that a question in the annual health check or a question for someone over the age of 65 getting their flu jab about memory problems would reach people who would not normally be presenting until much later. There is also a suggestion of screening for those who are at particularly high risk, such as people with Parkinson's and people with learning difficulties, who are of particular high risk of some types of dementia. Asking them and screening them early for symptoms of dementia was seen as a positive step by quite a few people.

## **2. Primary Care**

Moving on to primary care, many carers and people with dementia used the comments section of the questionnaire to detail some of the particular problems they had had in primary care. A common narrative with a person with dementia was that they were initially sent away misdiagnosed as having depression – again, this echoes what came across in Brigid's narrative. Misdiagnosis also ties with some of the comments from GPs. Many of them indicated problems they had encountered with the assessment tools available to them. The complaints included that the tests were inaccurate in picking up problems in well-educated people where there had been a decline in function. The Faculty of Health Sciences from the University of Southampton also wrote in to suggest that there were difficulties because the tools particularly focussed on cognition; any other symptoms of dementia therefore were missed. Other specific problems were reported with the mini mental-state exam, particularly around its copyright status.

Beyond this, one of the frequently reported barriers by GPs and others was the attitude of some that nothing could be done, as medical treatment for dementia are limited. BUPA referred to this as 'therapeutic nihilism', and there was a suggestion that GPs are unwilling to diagnose because they did not want to label people in this way. I have to say, the questionnaire evidence from the GPs gave a much less clear picture than this. Whilst 64% agreed that there was a lack of suitable treatments and this was a barrier to diagnosis, 63% of GPs who responded thought it was very important that someone got a diagnosis. A further 30% thought it was moderately important, so 93% of the GPs who responded to the inquiry said it was important in some way. This marks a similar shift to what was seen in the National Audit Office Report of 2010 as an attitude shift starting to happen to GPs, with more of them seeing early diagnosis as important. Equally, whilst some GPs used their comments section to discuss not wanting to label people, others talked about how diagnosis is helpful for understanding, providing solid reasons for missed appointments, and

something that can be described to members of the wider family. They also talked about it being a gateway to services, and about the patient's own right to know what is happening to them.

*a. Quality and Outcomes Framework (QOF)*

GPs were also asked about the QOF, insofar as it related to dementia. This scheme incentivised GPs for good practice. The QOF on dementia rewarded GPs who had a dementia register and carried out annual reviews with the people on it. GPs were asked if this was helpful in incentivising dementia diagnosis; 67% of them said no. When asked to make comments, many suggested it was a box-ticking exercise, and that the focus was not on diagnosis. If there was a focus on dementia it was on ongoing management. Some also suggested that it could be an active disincentive to diagnosis, as with more patients more reviews needed to be done in order to receive the same payment for the annual review. It is worth saying at this point that a number of the respondents raised issues with the use of the QOF registers to calculate statistics, as was used on the dementia map. In particular, the use of the QOF as a proxy for the number of people with diagnosis was questioned, as there are many reasons why people with the diagnosis might not be on the GP register. In particular, a number felt that this was an issue that could be resolved if the correct medical codes were put on people's medical notes. Professor Banerjee, who will speak later today, has been doing some work in London regarding this.

*b. GP education*

Throughout the submissions dementia education for professionals – particularly for GPs – was seen as important. As the statistics on the slide show, 50% of GPs who responded to the questionnaire felt they had some but not enough training on managing dementia and 35% felt they had some but not enough training on diagnosing dementia. In their submission, the Royal College of GPs suggested that they were considering plans to extend GP training from three years to four, in line with other specialisms, and that this extra time would allow more focus on illnesses occurring in older age, including dementia. In addition, other examples of good practice in GP training were submitted to the inquiry. It became clear that there are good models for training out there; they just need to be put into practice consistently and across all parts of the country.

Other suggestions to help solve some of the barriers to diagnosis in primary care grouped around GPs having a greater role in diagnosing, with community support from specialists. One respondent suggested that GPs lacked ownership of the process of diagnosis, and that if they had a greater role in designing it they would understand it, understand their place in it, and embrace it more fully. Others suggested that models where there was a community focus on diagnosis worked well. These included services where there was outreach from specialist services or community psychiatric nurses; when there were memory clinics based in primary care; or where GPs took a greater role in diagnosing themselves. The Gnosall Surgery in Staffordshire was cited as a good practice example by much of the evidence submitted, and Dr Ian Greaves, who is responsible for this practice, submitted evidence suggesting that this model has reduced waiting times from three years to four weeks, and increased diagnosis rates dramatically compared with the prevalence in their area. Again, the RCGP supported this, saying, 'We support GPs having an enhanced role to provide a coordinated and flexible assessment service to their local community. This could include local champions, primary care support services, local patient care pathways, named support staffs and in-reach services to care homes'.

### **3. Secondary Care**

#### *a. Memory clinics*

Progress further along the dementia pathway: evidence submitted to the inquiry also addressed memory clinics. One of the commonly cited complaints here was about waiting times. Within our survey professionals, GPs and psychiatrists were asked how long a patient would have to wait for an appointment in their area. The average waiting time reported was two to three months. However, there was a great range, particularly reported by GPs, with some reporting waits longer than a year. This points to the variability between memory clinic provision in different areas. One respondent also commented on the variability of neuro-imaging services available around the country. This is part of a wider issue regarding the integration between primary and secondary care touched on in previous slides. The Dementia Action Alliance has done some research into access to anti-dementia drug treatment, and suggested that many formularies have not yet caught up with the amendment to the NICE guidelines and almost a third of PCTs only stock drug treatments for either the early or the late stage of Alzheimer's, which is not consistent with the new guidance. The pharmaceutical company Lundbeck also submitted evidence, suggesting that not only were there formulary problems, but also that shared care protocols, which would allow GPs to manage a prescription initiated by a specialist, had not yet been established in all areas.

Many of the psychiatrists who responded to the questionnaire called for extra resources for specialist dementia services. The Royal College of Psychiatrists suggested that, where memory services were well resourced and coordinated, this can make a real difference, citing the service in Belfast as a key example. We have Dr Simon Hughes from that service in Belfast speaking shortly. The Royal College of Psychiatrists also suggest that secondary care should have a more leading role in coordinating services in the community, drawing the parallel with cancer, where you would not expect the management of this condition to pass back instantly into primary care for it just to be left there. There is also growing evidence about the quality of memory services. The memory services accreditation programme has been working to assess memory services against certain criteria. Professor Sube Banerjee, who is speaking shortly, has also had some involvement in this. This scheme is voluntary however, and not all services take part.

#### *b. Locations*

Memory specialists also suggested locating memory services outside of hospital and in community settings. This echoes what was said previously about strengthening the role of primary care in diagnosis. It was also thought that this would be helpful with the management of dementia by GPs, as they would be aware of the appropriate professionals to consult, and they would develop relationships within that community.

### **4. Other Pathways**

The inquiry focused on the standard dementia diagnosis pathway, highlighting barriers in the system and ways of overcoming these. However, it is clear that there are various points where an individual may fall out of the standard pathway for dementia or, if 10% of them present to primary care in the first place, they never join the standard dementia diagnosis pathway. People may not get a diagnosis until a time of crisis or a hospital admission. We have Lorraine Edmunds, a practising nurse and Lead from the Older People in Aneurin Bevan Health Board speaking tomorrow, who will be able to speak a bit more about the lack of diagnosis for people in general hospital. Within

England, the recent CQUIN initiative has also been designed to address this, but it has not yet been rolled out.

## **5. Under-diagnosis**

There is also a suggestion that there is under-diagnosis within care homes. In February, the Dementia Action Alliance hosted a roundtable event with care home organisations to talk about diagnosis. Those there suggested that there may be many who are assumed to have dementia who do not have a formal diagnosis. Also, people are often discharged from hospital into a care home, by which time, if they do not have a diagnosis by then, it is often too late. The rigidity of the system can also make a diagnosis a disadvantage within care homes. Some reported that patients may be better suited to a frail elderly placement, but would have to go into a dementia specialist placement because of the diagnosis. Martin Green, from the English Community Care Association, will be here tomorrow to talk about this a bit more.

## **V. Beyond Diagnosis**

Throughout the questionnaire, many of the respondents were keen to emphasise that diagnosis, in and of itself, was not a magic bullet, and that information, services and treatment were needed, and needed to be provided well. When asked what happened after the diagnosis had been given, a number of carers wrote 'nothing', and suggested that greater attention to immediate support and information is needed. The Centre for Mental Health Services Development in Wales mentions the information pack, which is part of the dementia vision for Wales, which would be provided to each person as they get diagnosed, as an instantly accessible form of information. As may be expected, some suggested that the APPG can investigate improving care; similarly, others suggested that services should be available to those who have a clear need but did not have a formal diagnosis. Many commented that there was a lack of appropriate services and treatments. For example, Alzheimer's Research UK submitted evidence to suggest that greater research into possible treatments was needed. Others suggested that, if everyone with dementia was able to get diagnosis, current services would be overwhelmed. What is clear from all of this is that the need for information and support is clearly there as well.

I am going to close by passing over to Dr Daphne Wallace, who worked in her professional career diagnosing dementia, before being diagnosed herself.

## **VI. Experience from a Psychiatrist Diagnosed with Dementia**

### **Dr Daphne Wallace**

Thank you. Not only did I work in this sphere but, in Leeds where I was a consultant, I was one of two posts that were created when I was appointed, where there had been no service for older people at all, in Leeds, before we were appointed. We were a bit like pioneers, going around trying to find suitable buildings to run our patient clinics in possible day hospitals and so on.

What happened was that I retired in 2000, and two things: one, I had a small private psychotherapy practice at that time, which I continued with, but there was a problem for some of the GPs who I worked with in my private practice, in that the consultant for the area that their PCT covered would not entertain using Aricept or any of the other medications. He diagnosed Alzheimer's disease, but he initially did not believe that they worked, then he said he did not have a budget and then he said

he did not have a memory clinic. I may say that, in Leeds, all of us were using them from day one. We did not have any special budget, but they were people many of whom would have presented anyway. Hopefully, because they presented earlier, we did a better job.

It never occurred to me; I do not have a family history of dementia, but I do have a family history of various forms of cardiovascular disease. I carried on, but I actually helped out these GPs, because what happened was the PCT allowed for me to see their patients to monitor them on the drugs. They were able to prescribe the medication, but I did the monitoring. It was a very strange situation, because this consultant's community nurse brought his patients to my clinic, so it was a rather bizarre situation, which had relevance to my own subsequent problem.

In the winter of 2004-05, I did a five-month locum back in Leeds, and not in the area of Leeds where I had worked, but farther away from my home. They had been able to cover much of the post that was vacant, but there were two things they could not cover: one was an outpatient clinic and the other was an acute ward. I could not face the thought of actually having to go on two different days, because it is quite a long way, so I gave myself quite a hard job with having to do that in two sessions but all on one day. However, it was work that was similar to what I had done before, before I retired.

As the time went on, by the time I stopped doing this five-month locum, I really was pretty stressed. I think that would be an understatement really; I was actually quite depressed. In my private practice, I shared premises with two non-medical colleagues, but they were very helpful. I eventually saw someone for some help with this depression, but it became evident to me that I was not able to cope with things in the same way I used to do. I do think that this is one of the important things that causes sometimes people to be diagnosed with depression. If you're someone like me, who has been used to being a very organised sort of person and very busy, and you have to have everything in control, as it were; if something happens so that you do not feel you are quite in control and things were not the same as they were, it is actually a very frightening experience. That was really what happened to me.

Eventually, once I was no longer obviously particularly depressed, it became clear to me that there were things that I just could not do in the same way that I used to be able to do. I talked to two friends who were quite senior consultants in this speciality, and they agreed with me that, if they had the symptoms I had, they would want to have some tests. Then I had the problem: whom should I go to see? In the meantime, I had just had my 65<sup>th</sup> birthday and so technically I should be referred to this consultant. Time moves on. That obviously was not practical. It was quite interesting, because we are told we have choice in the Health Service. Certainly in the PCT that I, at that time, lived in, the only reason for being referred to a different consultant in a particular speciality was if there was not that speciality available, but there was someone available.

My GP at the time was very good, and I helped a bit because I remembered that there was a neurologist at the local hospital who I had known when he was a senior trainee. I had seen patients for him and so on, so I suggested that they might ask if he would see me, although I technically should have been seen by a normal psychiatrist, which is what happened. He did not even see me; he had been told all the things that I had described in myself and he arranged for me to have a CT scan – MRI scans were not particularly available in that area at that time – and to see a neuropsychologist. It was quite evident from the scan that I actually had some vascular damage in my brain, which was what was causing the problems. This was confirmed by the neuropsychologist's tests. The neurologist then rather inconsiderately emigrated to Australia, so I was a bit left. Obviously, I did not particularly want to go to just – when I say 'just anybody', I do

not mean that, but technically a neurologist at my age would have been sending me to an old-age psychiatrist. I actually had no follow-up for three and a half years, which means that now I am very keen on making sure that people do have follow-up, even if they are diagnosed very early.

One of the difficulties, I think, is that when we did not have the medications we had, when we did not have the tests that we can use now to diagnose dementia early, perhaps it was not so surprising that people did not think of follow-up as being anything different than something for people with quite advanced dementia. That was irrelevant to me. I remember and you can see later that I was on the reference group for the dementia strategy. I remember I said something to Gordon Wilcox about the fact that I felt rather abandoned really. He said, 'You need to be a patient.' This was the important thing for me, because everyone somehow thought that, because I had been doing that job, I knew all about it; I did not need any support. I had experienced the same sorts of losses as anyone else. I did not have an ordinary straightforward rapid deterioration of my memory.

I have other things that I have lost. I cannot do mental arithmetic particularly. I cannot do anything particularly to do with numbers now, and yet maths was my best subject at school, and it is very strange to have difficulty converting recipes with quantities for four to quantities to two, and things like that. I actually have difficulties with that. Similarly, I never was very good at remembering names, so the fact that I am hopeless at it now is not such a strange thing, but I used to be able to remember faces. Twice particularly it happened to me, some years before, when I had seen someone I had not seen for well over 25 years, who I knew. I could not remember their name, but I knew where I had known them. We had been at school together and actually we are at opposite ends of the country, so I knew that I could remember faces. Now, people can come up to me, talk to me, know me obviously very well, and, as far as I am concerned, they are complete strangers. This is again something that is a big loss. Similarly, I get lost now. I do still drive – I do not get badly lost – but I need the satnav to prompt me that my turning is coming up and things like that.

They are all things that I previously was very good at, and one of the other difficulties is that I need to have people who I can talk to about these things, but also to keep an eye on whether I am safe to drive or whatever, but also to help me to understand that sometimes people, which I talk about when I talk about what it is like; that if people come and say, 'Oh, I have never been able to do that,' that is fine, but I could. Therefore, it is a loss. Memory is not a good understanding of it. My visual memory has changed, but not what you ordinarily think of as memory. I do not have that. It is quite difficult.

I do now do have follow-up after three and a half years. My GP and I hatched up a plot. This is a different GP. I have moved from where we were at the time, but it was agreed that they would write to one of the other consultants who is based in the same area but had a different catch. He actually comes to see me at home once every six months, but he is always there; if there are things that I want to talk to him about, I could get hold of him or his team. In fact, I have now done the process for donating my brain to the brain bank. Actually, Alistair Burns technically supervises that side of things as well, so I have actually seen his team as well. I am very fortunate, because the other thing that has happened to me is I am having more efficient treatment of my vascular disease. Although some things sometimes feel more difficult and I am more susceptible to getting tired and not being able to do things, basically, in neuropsychological tests, it has not been progressed anymore, but it is visible on the MRI scan that I have very early damage. It is easier for me than some people to actually campaign and try to teach people about why they need early diagnosis, and how there is life after dementia diagnosis.

## Questions and Answers

### **Hazel Blears**

Thank you very much, Daphne. That is amazing and a privilege for us to hear from you, as from Brigid as well. I think that is what makes our evidence session so special really. We have now been joined by two further parliamentarians. Do you just want to say a word for the benefit of the audience on why you have come to this and how you are involved? Julie?

### **Julie Hilling**

I am Julie Hilling; I am the MP for Bolton West, and I am just interested in the whole issue of dementia, aging and how we can make that much more positive for people. I am going to apologise as well; have to go in a minute, because I am on a Bill Committee. If it does not last very long, I will be coming back.

### **Nick Boles**

I am Nick Boles; I am the Member of Parliament for Grantham and Stamford. I have been involved with a local support group and found I have learned a lot about the whole condition and caring for it, with a particular focus on people who get it early, under 65 as it were, who find that the services are not particularly well designed for people who are in their 50s. They somehow assume that you are old if you have dementia.

### **Hazel Blears**

Thanks very much. Shall we pursue any issues with Martina, Brigid and Daphne, and then we will go on to the second set of evidence? Tracey.

### **Tracey Crouch**

Thank you for your presentations; I found them absolutely compelling. I am really interested in the fear-of-diagnosis issue. You had a slide up – I do not know if you can get it back – about one of the reasons about people perhaps not presenting themselves to doctors and trying to get diagnosis, which was because of their own personal fear and whether or not it was something to do with aging. I am very interested, because obviously both Brigid and Daphne have got previous healthcare experience, through nursing and obviously your professional background. Brigid, you referred to diagnosis as almost a positive experience, because it meant that you could claim the benefits and you knew exactly where you were then going. Daphne, I presume that there was some sort of ease of mind and comfort in that as well.

I have had a constituency case that was completely different, in terms of the fact that somebody had been diagnosed with dementia and that changed all of their things. For example, their travel insurance meant that they could not go on their Saga cruise and things like that. Actually, they found it was a complete hindrance because it was such an early diagnosis. Like yourself, Daphne, they were still driving, doing crosswords and living an incredibly normal life, but they actually found that the diagnosis had changed everything that they had already previously prepared for. Therefore, it turned out to be quite a negative experience. Martina, you referenced that in terms of

people who were in care homes and the care that they received there. I wonder – clearly there is a bit of a mixed experience of diagnosis. I just wanted your comments on that, and whether or not you thought that actually part of the problem was the fear of diagnosis for many people. Given the fact that both of you have a healthcare background made it more positive for yourselves. Actually, for people who do not have that background, maybe it is more of a negative experience.

### **Martina Kane**

I would just say that it seems to be a lot of the things like the travel insurance or, you were saying, like the private health experience, which seem to be based on an understanding of what dementia means, which may not be what that does mean for that person. That person may be able to go on for a very long time, and they need travel insurance, because the cruise is something that they want to do and is completely appropriate for them. It feels like not diagnosing is not the answer to that; there is something that needs to be more built into society more and built into understanding what a diagnosis of dementia will actually mean, particularly if it is coming earlier for more people. Whereas I think it may be a symptom of the problem that having a diagnosis would then mean, because diagnosis has historically been so late, what people understand this dementia being is therefore a much more incapacitated state.

### **Tracey Crouch**

We, in many respects, only ever hear about dementia in that incapacitated state. What we do not read about are the normal lifestyles that people are living when they are being diagnosed early. We are getting earlier diagnosis so, actually, we may still have very poor levels of diagnosis, but actually it is happening earlier. Therefore, perhaps we need to ensure that the awareness is improved around the varying stages of dementia.

### **Baroness Browning**

I just want to say thank you too, to Brigid and Daphne, for your accounts today. Thank you very much for telling us and sharing that with us. Can I just ask you – once a diagnosis is achieved – and I have some questions, Chairman, which perhaps would be more appropriate for later in the session. I will leave that; just park that. Once the diagnosis is there, what should be available? I know this is a rather idealistic question but, for example, memory clinics: do people have to fight to get a place at a memory clinic? Are they the sorts of things that people offer or are we still very poorly equipped with memory clinics? I am just using that as one example but, post the diagnosis, what is available, what can you ask for and, actually, what works? What is a help?

### **Brigid Stubbs**

As soon as we actually got the diagnosis, I was able to come to terms with it. You go through the whole grieving process, but then I thought I would tap into everything that is available for me and my husband – support for myself and for my husband. I am fairly young and computer savvy; I can research things and find out about a lot of things. Also, where I live in Woking there are probably quite good services. I think it varies around the country. There are things out there. There are carer support groups; my husband and I go to supper clubs and various groups around. We do things that are nothing to do with dementia; we go to a folk club every week. We go to a 50-plus club that is nothing to do with dementia. We do things together. I suppose because we are younger and we are both quite physically fit, we can do those things.

If you are able to search it out, there probably are a lot of things, but you have to do it all yourself and that is the hardest thing. You have to find out about everything yourself. There is some advice you could get, if you know where to look; the Alzheimer's Society has a lot of advice sheets and support. They run day centres, etc, but the initial thing comes from you. Nobody does it for you. Okay, you might be lucky enough to be regularly seen by a consultant, have memory tests and that sort of thing, but I found that, for everything else, you just have to do it yourself really. Nobody helps you to find out what works for you or what is out there. That is the problem.

### **Dr Daphne Wallace**

Yes, I would agree with that. In my case, some of the things that I needed were different, but then that is part of the problem; everybody's needs are different. I cannot imagine that there are many people, if any, who can manage to cope with the implications of the diagnosis, whatever the kind of dementia you have and whatever stage. Particularly if it is in the early stages at the moment, because so much of what is provided for support is designed for people who are either very elderly, which is difficult if you are younger and at working age, or people who are much further on in their dementia journey, because diagnosis is made late, the kind of support of just knowing there is somebody there who understands and whom, from my point of view – and that is because of my professional background as much as anything – I want someone who will be up to date. He will tell me if there are any new developments or something that might be good for me.

There needs to be a recognition that, occasionally, it is just good to chat to someone about what it feels like and to be able to express and deal with the bereavement. I did not have that for three and a half years. That is what it is; exactly the same adjustment is needed for somebody who's lost a leg. I think we are hampered by the fact that still, as Brigid has really said, the image of dementia – what people think of – because in the past the only ones you saw, you met, who you knew had a diagnosis of dementia were much more in the end stage of it, that is what people think of. They forget that some of us, for a variety of reasons, not just to do with the medications; it is to do with what is now recognised that, if you get good services, you can retain a much more normal sort of life. People are just not aware that is there, but you need support, just the same as someone who has a cancer that has been very life-threatening, but is having treatment that is keeping him well enough to carry on. The same thing applies to dementia, but people have not recognised it so much.

### **Hazel Blears**

There is also an issue, and certainly this was something that we experienced, that sometimes the memory clinics are part of a process for monitoring and prescribing, more than getting under the skin of what you need. For us, it was a very mechanical process and, in order to get your Aricept almost, you had to pass your tick-box memory clinic. The point you made, Martina, about shared care models not being across the country is very important. The consultants felt that they had to do the prescribing rather than trusting the GPs to do prescribing. In order to get your medicine from the consultant, you had to go to your memory clinic and tick all the boxes. I just think that there is still quite a process-driven issue around this, rather than looking at the people side.

### **Nick Boles**

It was the three and a half years that I was interested in, in the sense of what you should have had in those three and a half years, which you have well described. I guess the only other question would be that, aside from the support, understanding, coping and dealing with the diagnosis that you could

have had and would have welcomed in that period, would there have been anything...? You said you were now getting some treatment that had helped with the vascular – could that have started earlier, if you had had some follow-up in those three and a half years?

### **Dr Daphne Wallace**

No, that came from the diagnosis actually, and the GP was responsible for that. The neurologist told him; he made suggestions about certain things that I should be on, some of which, interestingly enough, I cannot be on. I am one of those funny people who cannot take the statins actually, which is what I should be having, but I use other methods, other things I have to buy that I can take that help. The actual treatment of my blood pressure and so in is more energetic, I think because it was not desperately manic before, but it obviously was bad enough to have caused this. What I have is small-vessel damage, so it is not like having big strokes. There is one little area that is like a mini-stroke, but the rest of it has just damaged the connections. Some of the funny experiences that I have, which I have written about in a training newsletter, actually are slightly odd things. It is obviously somehow in your brain some connection cross-wires.

### **Hazel Blears**

Thank you very much. We are really grateful. I think that was fantastic evidence and it will really inform our report, so thank you very much.

## **Introduction to the Second Panel**

### **Hazel Blears**

#### **Deputy Chair of the All-Party Parliamentary Group on Dementia**

In this second hour, we are now going to go on to hear from some healthcare professionals from Ireland, Scotland and all over the country. I think we are going to take Professor Sube Banerjee first.

### **Participant**

She is actually the only one who is not here.

### **Hazel Blears**

Well, we will not be taking her first then, will we? Shall we take Dr Rafi from the Royal College of General Practitioners? You can all come forward if you like.

We have with us Dr Rafi, who is the Medical Director of the Royal College of GPs' Clinical Innovation and Research Unit, so hopefully you will be somebody, as Daphne would say, who is up to date, knows what is going on and knows his treatments, so you might get tested here, Dr Rafi. We also have with us Dr Simon Hughes, who is from the Royal Victoria Hospital in Belfast. We

have heard already that Belfast has got quite a good rate of diagnosis, so we are very interested in your experience. Then we have Geoff Huggins with us, and we are really grateful that Dr Hughes and Geoff have come. Geoff is from Scotland, and is going to talk to us a little bit about the Scottish model. Geoff is the Deputy Director of Health and Social Care Integration, Head of Reshaping Care and Mental Health Division in Scotland. As a former Health Minister, I think that is a relatively short title. We look forward to hearing from you.

Perhaps, Dr Rafi, we could start with yourself. I am just asking people to keep their comments relatively brief. We are very interested in your evidence, but obviously members will also want to explore with some questions, and no doubt, perhaps, our other witnesses might want to do so as well. Thank you very much for coming.

## **Perspective from a GP**

**Dr Imran Rafi**

**Medical Director, Clinical Innovation and Research Unit, Royal College of GPs**

### **I. Background**

Thank you for inviting me and for the RCGP to be able to provide evidence to the Group. My job is I am a GP; I am Medical Director of the RCGP Clinical Innovation and Research Unit. The Clinical Innovation and Research Unit at the RCGP oversees the College's clinical priority areas, and dementia is a key College clinical priority area for 2012 to 2015. The summary feedback I will give you has been provided both by other College clinical providers, but also by our two national newly appointed Clinical Champions for dementia, who have both given their apologies for not being able to come to this meeting today.

### **II. Challenges**

#### **1. Consultation Times**

In considering barriers to improving dementia rates, we have heard a lot already from Martina about some of the challenges in primary care. The RCGP agrees about the need to raise professional and public awareness, particularly around the key features of dementia. One of the key challenges we have in primary care in general practice is the limited consultation times that we have. We would agree about the need for valid screening or diagnostics that could be used to aid rapid diagnosis.

#### **2. Co-morbidities**

Another challenge that we face is having to manage patients with multi-morbidities or co-morbidities – more than one important clinical problem. We also recognise that there are subgroups of patients, such as those with intellectual disabilities or individuals from ethnic minorities, where again diagnosis may be difficult to make or may be delayed.

### **3. Referral and Coding**

There is obviously a clear need for clear referral pathways and a need for good memory services. Again, there is quite a variation around the country. This would also include advocating the need for primary-care-based services that would help to aid early diagnosis. We have also heard about accurate information coding. This is particularly important when sharing information between primary and secondary care. Also, accurate coding in general practice is important, both in raising prevalence figures, but also being able to audit, for example, subsequent drug treatments in these patients.

## **III. Recommendations**

### **1. Public Health Messages**

In terms of addressing the barriers, public health messages around dementia are really important, both in terms of improving diagnostic rates, but we recognise that it is really important to complement this by the necessary social and financial infrastructures to support individuals and carers who have been affected by dementia.

### **2. Targeting**

As well as general awareness, it is also important to target people at risk. For example, the good management of vascular risk factors remains paramount throughout adult life. Professional awareness through GP education and GPs, and the access to information resources such as e-learning modules, remains important. The College has worked to develop educational tools for GPs. There may also be a need for more anticipatory care, so particularly through chronic disease clinics, which hopefully will help to avoid inefficiencies associated with episodic care, which you get with patients with more than one clinical condition – a multi-morbidity.

### **3. Memory Clinics**

The other really important thing is about standardisation of cost-effective specialist memory clinics. The Royal College of Psychiatrists' accreditation programme they run around the accreditation of memory services is very good. We would advocate the placing of memory clinics in primary care, which hopefully would give greater flexibility and allow better communication pathways between primary care and patients affected.

### **4. Community Support Services**

The other aspect is really about community support services and the influence that commissioning might make across health and social care, for patients affected with dementia. There is also the need, perhaps, to develop more liaison roles between primary and secondary care. We must not forget about the influence that QOF may make, that quality standards may make and that national CQUINs might make to the care of patients with dementia. Our Chair, Clare Gerada, is also keen that, as part of the Big Society, we should be looking at other avenues, for example linking schools or colleges with care homes. This is a matching process where perhaps we could create a culture where we can have people who would give up their time to help look after patients in the community.

## **5. GP Training and Workforce**

Specific challenges for general practice: we have heard about the need to extend GP training, and the college is working hard to cover that. We are also looking at the GP curriculum, which is a mandatory curriculum that newly qualified GPs go through. They have to go through the membership of the Royal College of General Practitioners. The GP curriculum covers the care of elderly people, including dementia. There is a need to increase the GP workforce, which will hopefully more time spend with patients with dementia, and the College also supports GPs having enhanced roles to coordinate services for local communities.

## **6. Diagnostic Tools**

Finally, I would just like to say that the College has been invited to take part in the national group. That has been organised by the DH to look at current electronic and paper diagnostic tools that could help with regard to consensus recommendations.

# **Questions and Answers**

## **Hazel Blears**

Thanks very much, Dr Rafi. I would perhaps just like to ask you one question, and that is about this integrated pathway between primary, secondary and community care, and the changes that are taking place in terms of shifts in clinical commissioning groups. Do you think that dementia will be a sufficient priority for the clinical commissioning groups? Do you think that they will have sufficient capacity to be able to commission what is sometimes quite a complicated care pathway, through the whole system, and be champions for their patients in this area?

## **Dr Imran Rafi**

I am actually a GP in Surrey as well, and the local commissioning group is already going through this process. There is a big meeting next week, when they are meeting with care organisations, GP leads and clinical leads, looking to see how the care of people with dementia could be improved. They have formulated a guidance for commissioners and, certainly at the local level, it is considered an important clinical priority. I imagine that is reflected across the country as well.

## **Hazel Blears**

Are you getting a push from national level that this really needs to be handled gently?

## **Dr Imran Rafi**

Yes, I think so. I think the National Dementia Strategy has had an impact and I think it is coming to ground. The factors that dictate this really depend on – which is, I guess, the whole point of the commissioning process – what is important for the local community. If the commissioning groups

are not responsive to this, then that would be sad, but I suspect that there will be plenty of people in local commissioning groups, in patient advocacy groups, who will help to push the agenda forward.

### **Baroness Browning**

You mentioned the work on co-morbidities. Can you tell us whether there is any work being done – for example, I was talking to Lord Rix, who of course is President of Mencap, today about this, and he said, because people with Down's Syndrome are now living longer, there is a prevalence for Down's Syndrome people in their 50s to be giving evidence that they have dementia as well. Is there any research being done on that particular group?

### **Dr Imran Rafi**

I am not sure about research, but I think there is good evidence and it is well known that people with Down's Syndrome to develop early Alzheimer's disease. The challenge really is to get the message out that these people need to be picked up early, not at the time they are 50, but to monitor vascular risk factors much earlier than that. Again, we have a clinical champion for learning disability – it is an important clinical priority area for the College – and one of the tools that we are looking to develop is commissioning guidance around intellectual disabilities. We hope to get the message out about the importance of recognising these people earlier.

### **Tracey Crouch**

Very quickly, you said that you thought it was important that that we improve liaison services. 'Such as?' is my follow-on question.

### **Dr Imran Rafi**

I guess the Staffordshire model is a good example of that. This is where primary care, the GP, worked with a health visitor, worked with an old-age psychogeriatrician. This liaison came up the community. Not only is this important from the point of view of communication and dialogue, but also picking up expertise and learning from the expertise from secondary care, translating it into primary care. If you can have good models like that, that would be a good way forward.

### **Hazel Blears**

We heard from the evidence that the QOF might actually be a disincentive to diagnosis. What is your experience of the incentives in the system? Are they sufficient and are they the right ones?

### **Dr Imran Rafi**

The feedback we had from the College's clinical advisors was that they thought it was very much process-driven. There are three aspects of QOF that relate to dementia. One is about having a register. I think that is a good thing; if you know who your patients are that is a first step. The second is about having a personalised care plan over the next 15 months. Again, I think that is a good thing, but it does not tell you; it does not actually stipulate what the care plan should be and what it should be aiming for, but it is a start. The third is about physical health checks on this group of patients, which again is important to do. I think the idealism behind the QOF indicators is very

good; it is a question of how well they are implemented and what actually occurs on the ground level.

### **Hazel Blears**

Thanks very much, Dr Rafi. Could we move on? There is no prejudice in my order; I just think that we get a bit from each bit of the system. Could I ask Dr Hughes perhaps to give us your presentation?

## **Perspective from Secondary Care**

**Dr Simon Hughes**

**Royal Victoria Hospital, Belfast**

### **I. Northern Ireland Service**

Thank you. I am delighted to be here. Really, I am here to talk about secondary and tertiary care today, which may be slightly different. We established an FDG PET service in Northern Ireland six years ago. We have gone from having 25 patients referred to 450 to 500 patients per year referred, out of a population of 1.6 million. I certainly see it as an imager, as a successful service. Really I am trying to look at why that might be. One of the things is I think this is a seed sown on fertile ground. Early dementia detection in Northern Ireland was promoted both politically and medically at that time, and the availability of licensed treatment throughout Northern Ireland was very important. Groups of clinicians were already established with research and clinical interest in dementia, and they were already cooperating. That is important. This has helped support this expansion of PET-CT in Northern Ireland.

### **II. Benefits**

#### **1. Business Case**

Really, we are trying to image brain failure, which is occurring in dementia. You can do CT scanning to exclude large things, like a heavy burden of vascular disease or a large tumour. You can also use MRI to look for changes in volume. One of the things we have seen in Northern Ireland is what I call a 'despair diagnosis', within neuroradiology, which is that you do not want to know; why would you want to know? This is still quite prevalent, both in Northern Ireland and throughout the UK. We established a business case early on, which looked at the costs of FDG PET-CT against other nuclear medicine tests established for the diagnosis, and showed that it was viable. We can show economic modelling. We can show that FDG PET-CT again is cost-effective, reducing the overall costs of care and delaying admission to nursing homes. If you look at the overall costs of care before and after diagnosis, it actually reduces after the diagnosis of dementia. These are the things that have helped us establish this service.

## **2. Appropriateness of Early Diagnosis**

All of these things have really helped us establish dementia services, within PET-CT, in an argument that it is difficult to suggest that the early diagnosis of lung cancer is appropriate for PET, but the early diagnosis of dementia is not appropriate for PET. This is a very powerful argument, I think.

## **3. Quality**

Quality has been key for the service. This is the quality of the referrals and the requests that we get, the quality of the scans themselves delivered on a day-to-day basis and the scanning service, and the quality of the reporting as well. All of this has bred confidence in both the referrers and the patients in the services. We have also developed one of the things that I think has been absolutely crucial, which has been a regional MDT for dementia. We have taken a similar model to the Calman Cancer Plan and applied it to this fatal disease, a disease that we take very seriously.

## **4. Multiple Assessments**

What we have done for the early diagnosis is taken triangulation of clinical assessment, detailed neuropsychological assessment and neuroimaging assessment. It is these three components that we use to make the diagnosis as accurately as we can. There is a Rush project in the US, which is showing us that the clinical definition of types of dementia is unreliable, and so we are heading towards an era where biomarkers are starting to define dementia. It may be in ICD-11 that these biomarkers might actually be a requirement for the definition of a diagnosis of dementia. These include PET, MRI and other things that we can assess. FDG PET-CT can be important in the assessment of all types of dementia, but some of those other biomarkers have really been established in Alzheimer's disease, but we have already seen that Alzheimer's disease is not the only dementia that we need to look at. PET can be important.

## **5. Other Methods**

I want to just quickly mention plaque imaging agents, because other people may not. These agents are really there for the diagnosis of beta amyloidosis of the brain, which is a significant risk factor for clinical dementia. Plaque imaging agents will be a component of the diagnosis of dementia, but are unlikely to replace FDG.

## **III. Conclusions**

We believe that there has been a cultural change in the perception of dementia over the last five to ten years, which has helped us to establish this service. With a committed dementia specialist, prioritisation of early dementia diagnosis, the development of the dementia MDT and the use of FDG as an important biomarker of dementia, we have a good story to tell of a high-quality service that could be replicated elsewhere in the UK.

## Questions and Answers

### **Hazel Blears**

Thank you very much, Dr Hughes. Could I just ask you, is there a sense that, in order to get the clinical purchase that you have talked about, if doctors feel that there is nothing they can do, then they are not very excited about getting involved? I am not saying that in a pejorative way, but they are not very excited about being involved if they feel there is nothing they can do. Therefore, your concentration on imaging, a clinical approach to it and the replication of the Calman stuff around cancer, has that given them more of an empowerment sense that there is something they can do? Just to follow up on that, when you do your diagnosis, is your team satisfied that the follow-up services are actually as good as what they are doing in terms of the harder end of it?

### **Dr Simon Hughes**

I think early diagnosis is important. Certainly our clinical experience and our audited experience is that the presentation of a patient with early dementia is a very poor predictor of whether the imaging tells them they have dementia or not. This is one of the things that has expanded our service. We have an NMSE of 28. I can see profound change; I can see no change at all. People feel this; this is the clinical purchase that I talk about. This is a test that reaches into the real clinical world and changes what clinicians think. This is what I mean by clinical purchase.

Certainly what we have tried to do, I think all of us in Northern Ireland, is go out to GPs and other groups and try to promote this cultural change. That is what I think it is. I am not experienced in changing the politics of medicine at all. We can change protocols and we can change procedures, but the most potent thing we can do is change the cultural view of dementia. We have taken the cultural view that this is a fatal disease and that it requires serious prioritisation. If you have a dementia and you die of nothing else, you will die of this disease. It is a very serious disease. Really, partly what we have achieved in Northern Ireland is this cultural shift that says 'no', and that is against some resistance. As I say, in neuroradiology, there is often this despair diagnosis that I talk about and try to resist. As far as whether that leads to an improvement in care, you will probably have to ask people who are far more involved in day-to-day care than me. I am really a secondary care specialist; I help the memory clinics to achieve the diagnosis they need.

### **Hazel Blears**

This integrated pathway is going to be more and more important, I think.

### **Nick Boles**

I am particularly interested by what you said about the economic case having been made on the basis that actually it was costing less to treat people after diagnosis than before. Can you just go into that in a bit more detail?

### **Dr Simon Hughes**

This is evidence from the Dementia Demonstration Project, which is a big project in America of about 8,500 patients, who they filled for a year prior to diagnosis and a year following diagnosis.

They found that the cost of care was less after diagnosis. I think this is because, before the diagnosis, there is uncertainty. If you have Lewy body dementia, for example, and you keep falling over, every time you fall, whether you have hurt or injured yourself or not, you go and see your GP. You are admitted; you have ECGs; you have a 24-hour tape to make sure it is not an arrhythmia. If you know that you have Lewy body dementia and you fall, and you say, 'Are you okay, dad?' he says, 'I think I'm okay.' He gets up and this is where you save the money, because a clear diagnosis, a clear education, says, 'Yes, you have dementia. These are the things that may happen.' This is where the savings come.

**Nick Boles**

Could I just ask if that chimes with your experience that, after diagnosis, you were dealing with things in a way that might mean less?

**Brigid Stubbs**

I was certainly dealing with Paul's behaviour much better once I recognised and fully accepted that he was ill. I was no longer irritated by my husband forgetting things, making mistakes and things like that. Certainly I was much better able to support him and think, 'Right, where do we go from here? Let us enjoy our lives while we can and make the best of the situation.' That is what we have done.

**Nick Boles**

Were you less likely to, as it were, call up and book an appointment with somebody because something has happened? Now you understand why it has happened.

**Brigid Stubbs**

Yes, exactly.

**Nick Boles**

That is very powerful.

**Dr Imran Rafi**

It goes back again to integrated care, does it not? With people who have diagnosis, if they are not being looked after at home, they do not need to be in a hospital in a key bed, but they could be in a step-up bed in a local college hospital or a local community hospital. Again, if you are looking from an economic perspective, this is another way of saving money.

**Hazel Blears**

Thank you very much, Dr Hughes. We are now going to move on to Geoff Huggins, who is going to give us a bit of information about the Scottish experience. Thank you very much for coming.

## **Perspective from Scotland**

**Geoff Huggins**

**Deputy Director, Health and Social Care Integration, Head of Reshaping Care and Mental Health Division, Scottish Government**

### **I. Background**

#### **1. Success**

Thank you. To begin with, the graph we put out at the beginning showed that we have been doing quite well in Scotland. Since this came out at the end of last week, I have had a few calls and am having to go and explain to my Permanent Secretary why it is that we seem to have done quite well.

**Hazel Blears**

It is better than the alternative

**Geoff Huggins**

It is better than the alternative, and I guess that says something for where we are.

#### **2. Target**

If we go back to when we began the work around the target in 2007 – the target began on 1 April 2008 – we would have looked very much like England and Wales, in that we were probably sitting at around 40% of diagnosis at that point in time. The change that we have produced is a change between 1 April 2008 and 31 March 2011 so, in three years, we have roughly added around 30% or 35% additional case funding in that time. When we look at the further figures within that, we then see for the period 2010/11, the year which is the most recent year, that eight out of the top ten most improved areas are within Scotland. I think almost all of our 14 health boards are somewhere around the top 20 across the UK. This is actually a bit disappointing for me, because I have been leaning very heavily on Borders, which is currently sitting at 22<sup>nd</sup> on the list. If they get hold of this, they will probably ease off, which I am not that pleased about.

#### **3. Phasing**

We have not done anything particularly magical to get there. In 2007, we began with a discussion about why we would have target, what the target might be, how we would set the target and how we would support it. We saw this as a necessary step to make changes that are perhaps more significant and bigger changes in a longer time. At the moment, we are now on the phase of work on creating our next target, which is our objective to set a commitment that everybody with a new diagnosis will get one year of post-diagnostic support, with an end in quarter four for 12 months. We will probably launch that later in the year, again with a commitment to be delivering that probably within two years, maybe three years. We are doing the nuts and bolts on that at the moment.

#### **4. Methodologies and Management**

That sort of discussion was quite important to the process of setting a target, in that we were trying to frame the target in the context that it would enable us to do things that would give better services for people with dementia and their carers. We agreed a methodology for counting these; the QOF has been very beneficial to us in that territory. We established national and local reporting arrangements, and we began to tie that into our performance management systems. I go out and I see every health board in Scotland twice a year, and sit down across the table with their chief executive. We talk about their performance on a range of mental health targets, between three and five over the last three years. The work on dementia largely mirrors the work that we have done on antidepressant prescribing, on suicide training and on readmissions to inpatient wards as well.

#### **5. Implementation**

We established the national reporting arrangements; we established the local arrangements; and then we began to work more directly with wards to enable them to meet the target. A lot of that work was focused around maybe three or four key components. We built local information systems so that we could take predicted rates of dementia down to GP practice level. That is quite interesting, because we had experience of the previous work we had done on antidepressant prescribing on work at that level of activity. Generally, our experience – and I am not a doctor myself, but I am a driver, and I believe I am a better-than-average driver, although I know that many –

#### **Nick Boles**

All men do.

#### **Hazel Blears**

Insurance companies do not necessarily agree.

#### **Geoff Huggins**

Many people hold these beliefs until something is shown to them to demonstrate that they are not quite doing what everybody else is doing. What we wanted to do was draw out what the expected diagnosis rates for different practices were within an area, so that we could then bring together groups of practice to have discussions as to why one practice might be closer to their prevalence rate than others, and to actually get clinicians talking to other clinicians about what it was that they were actually doing on the ground, and engaged in reflective practice to maybe understand why they might have different approaches, different reasons and different motivations, doing it within a context of an expectation of improvement and benefit. There is a degree to which, while having set a national target and then applied some performance management, we then took the delivery down to the local level within the context of an expectation of change.

## **II. Findings**

### **1. Best Practice**

We then also did some work at that level to learn, from both those practices that were doing better and those practices that were doing worse, to actually address issues within those areas. We identified particular issues around linkages between primary and secondary. We found that quite often the letters that came back from secondary care doctors were ambiguous; it may say something like 'has dementia-like symptoms'. Is that a diagnosis? Is it not a diagnosis? We went through the process of reworking and being a lot sharper and clearer around letters.

### **2. Research**

We also went through prescribing records to identify those people who were receiving Aricept who, for some reason, did not have a diagnosis of dementia. You might have expected the two to go together, but it was not always the case. We also went through the process of reconciling vascular and other registers. We began to try to dig into other forms of data.

### **3. Collaborative Approach**

We established a collaborative approach, which is broadly stealing ideas from England, largely, in terms of improvement technologies and methodologies that were somewhat in vogue here around 2002 to 2006. That was a period when you had quite a strong focus on these methodologies. We appointed three staff working nationally across three regions to actually provide local support, and that was the main investment we made. We estimate that to produce this scale of change we have probably invested just under £1 million a year for three years, which we think was quite good value. That is pretty much the only investment we made in additional dementia activity over that period, on the basis that we knew that we were getting significant additional work from social care and healthcare systems on the back of it.

### **4. Awareness and Knowledge**

We also worked quite hard on issues around awareness and knowledge. First of all, we made the connection with benefits and we increased availability of resources that would provide support. We increased access to post-diagnostic support as well, and we began to tap into what people with dementia, such as the Scottish Dementia Working Group and carers, were telling us that they were looking for. Broadly, what they were saying was that they were looking for different things at different times, depending both on their own personal experience and the support networks they had. They were not looking for a 'one size fits all'. Interestingly, they were also looking to provide support to other people with dementia, when they were at their earlier stages. They would be looking for support from people with dementia at the later stages, so they were looking to engage in peer-to-peer activity. This is quite interesting for us in terms of the broader mental health work that we are doing, in that it is suggesting that, while historically peer-to-peer work has looked at issues such as crisis and people with chronic mental illness, there is a place for peer-to-peer in this territory as well.

## **5. Benefits of Diagnosis**

We also did a lot of work around understanding the benefits of diagnosis. We did research in 2008 in Tayside; we sampled 500 people in Dundee and 500 people in Perth to assess their beliefs and understandings about the benefits of diagnosis. It told us that most people within those areas thought that, if they are having problems with their memory, they would go their GP. To be fair, Tayside doctors were up in arms about this; they were concerned that they were going to be stampeded with people going to GPs on the back of this campaign, which actually would have helped them get a slightly better result. You will see that Tayside are not exactly at the top of the table in terms of diagnosis.

## **6. Focus Groups**

We then did focus group work with people who had been surveyed. That was really quite interesting, because it told us that, in the abstract, they knew that the right answer was to go to your GP but, in most cases, many of them had a personally good reason why they themselves would not go, even though they thought other people should go. That again impressed upon us the need for us to work through the benefits of diagnosis programme, public awareness but also to be more visible in providing support, so that people could see that connections were being made.

## **III. Conclusions**

Broadly, I would say that we have done some very simple things. We have applied a bit of heat to the system. We have ensured that we are using data at each level of the system. We have provided support so that we highlight things that work and identify blockages. We have been quite careful to take out saboteurs, and we have also been quite clear about when we will and will not apply resources within the system. What we have said is that we will take the improvement approach as far as it will go, and that will tell us where additional resources might be needed, rather than by beginning by putting new money into the system. Our experience of that is people spend their time trying to spend money rather than actually focusing on change. Ultimately, we are about change.

## **Questions and Answers**

### **Hazel Blears**

Thank you very much. This is very impressive. The emphasis on a target, and then local delivery and collaboration, is a fairly tried and tested way of getting improvements, but it requires leadership to drive it. I think you have exhibited that kind of leadership this afternoon, so I am grateful for that.

### **Baroness Browning**

Could I just clarify with all three of our speakers this afternoon – when people present to the GP, do you expect the GP to diagnose or do you expect the GP to be the gatekeeper, with sufficient information and knowledge to make an appropriate referral?

**Geoff Huggins**

In terms of how we established the target, we said that we were happy for boards to organise themselves so that they were diagnosed within GP surgeries, or we were happy for them to diagnose within specialist services. Ultimately, we have a mix, with some boards allowing diagnosis in GP surgeries for particular groups of cases and not for other cases. We did not decide that that was an issue that we would have to resolve nationally, in that we decided that we would allow things to work themselves out, as boards themselves began to work through their processes. We do not think there are simple solutions like that and, to be fair, boards with different approaches have had similar outcomes.

**Baroness Browning**

Do others have the same view, Dr Hughes?

**Dr Simon Hughes**

I would say no; I think the trend for the idea that dementia is a clinical diagnosis should be abandoned. If you came with food sticking in your throat you would not expect your GP to say, 'You have oesophageal cancer. I am going to refer you to a cancer specialist.' That is what we are expecting clinicians to do. There is increasing evidence of clinical definitions; you need a clinician because they understand, once somebody has a diagnosis of dementia, what their clinical problems are, what their social context is, what their psychological context is and what their legal and financial context is. I would say that they are absolutely critical to the coordination of somebody's care, but I would argue that the diagnosis of dementia is leaving the realm of ICD-10, where you have a score. What that does is it says that you have 'dementia-like symptoms'. To define whether you have Alzheimer's, Lewy body, vascular disease or frontotemporal dementia will require these biomarker definitions in the future.

If I could advise anything to this group, it would be that this must be the clear direction of diagnosis in the future, which would place diagnosis clearly within the secondary care setting. We are going to need MR, PET, CSF markers or a combination of these biomarkers to define the disease. When you have a clear diagnosis, then you return to the primary care setting to say, 'This patient has a clear fatal disease.' You are honour-bound then; there is no ambiguity about that. That would be my view.

**Baroness Browning**

Thank you; that is very helpful.

**Tracey Crouch**

I wanted to ask Dr Rafi a follow-up question in that there is a massive difference, a 30% difference, between Surrey PCT and the best-performing area in Scotland, which I think is Greater Glasgow and Clyde.

**Geoff Huggins**

I actually have 2012 figures, which suggests that one of our boards is sitting at around 75%, based on these figures.

**Tracey Crouch**

I only have the 2011 figures. It would be unfair to suggest that Surrey is still at 40%. I just wondered, listening to Mr Huggins and Dr Hughes, whether or not you think that, from the Surrey perspective there is one learning – I appreciate there is more than just one of these things – that Surrey could take from what you have heard this afternoon. What would it be in particular?

**Dr Imran Rafi**

Around early diagnosis?

**Tracey Crouch**

Yes. There is clearly a big difference between what is happening in Surrey PCT and what is happening in Scotland and Northern Ireland. Therefore, from listening to the presentations from your colleagues, what could you take or what do you think Surrey PCT should be looking at?

**Dr Imran Rafi**

I guess first question to ask is what the estimated prevalence rates are likely to be for the two areas, because socioeconomic factors are going to have an influence, rates, carers, who is responsible for that person and whether they bringing those people forward for care. I guess if the prevalence rates express a prevalence that is likely to be similar, then clearly there is a need for looking at how local services are promoted. That includes the provision of memory services. We have heard that it is important to get an image – an important confirmation of diagnosis. Is it that we simply do not have access to those within Surrey PCT? That seems slightly unlikely compared to Scotland. I do not know, but I think access to imaging and memory services is going to be one of the key important issues that needs to be addressed, not only in Surrey PCT but UK wide.

**Tracey Crouch**

There has clearly been, both in Northern Ireland and Scotland, a direct message from the devolved responsible authorities to GPs to pay far more attention to this issue. Do you think that this is something that England should be learning from? Perhaps Mr Huggins, you can please tell me that the Department of Health has been in touch with you to come and give presentations about how to improve.

**Geoff Huggins**

It is an interesting perspective. While the Deputy First Minister Nicola Sturgeon has made this a personal commitment – and she came back, like you did, from the election trail last year having talked about her experience on the doorstep of dementia being one of the three main things that was raised with her in Govan in Glasgow. I am not convinced that GPs in Scotland particularly listen to the Cabinet Secretary. I am a lawyer; I am not a doctor. Again, when I go out and I speak to

doctors, I am not one of them. I think a lot of it does come down to local leadership. While we are very pleased with what has happened in Scotland, a lot of that is built on the basis of a shared and collective commitment, which has then manifested in a lot of local leadership, and occasionally us taking one or two key clinicians or managers around the bike sheds and giving them a bit of encouragement. The process has to be built locally.

### **Dr Imran Rafi**

Local issues, absolutely, and also collaboration between practices is fundamental. Federated groups of practices working together is the way forward. A lot of GPs are now used to sharing data between practices across a range of clinical themes, as we have heard around dementia. Also, do we have more care homes, for example, in Surrey compared to other parts of the country? We have already heard that there are many cases of undiagnosed patients in care homes, who are not being picked up. Is that a potential factor? Is it to do with the local population demographics that we just have not picked up on these patients? It is not just a professional issue; it is a population issue as well.

### **Geoff Huggins**

We went through something of these discussions as we were crunching through. At different times, different areas would suggest different reasons for why we were doing less well. My favourite was Fife, and they suggested they had lower diagnosis rates because people with dementia died more quickly in Fife than they did elsewhere in Scotland. I have to say it worried me that they were going to suggest that as a reason. It is actually not true; they were just doing less well at diagnosing. It does show how information and clinical reflection are really key to it, because a lot of that is about taking away these other theories people develop as to why their numbers would be different. Our objective with a lot of this is to remove those theories, because most of them do not hold water. Glasgow, which has the highest level in the figures that you have there, is one of the UK's most deprived areas.

Dementia is probably one of the only diseases in which they are under-represented in the statistics, in terms of life expectancy. Issues around social connectedness, exclusion and deprivation, which in many other areas reduce diagnostic rates, have had to be overcome within that context to get the figures that they have got. They have had to resolve these issues, but I think a lot of what we have done is to try to step beyond the theorising as to why our numbers might be right and lower to actually say, 'Let's move the numbers and make them higher.'

### **Hazel Blears**

Dr Hughes, you were passionate in your commitment to it being a secondary service for diagnosis. I went to see my local hospital the other day and they have made this a priority. They were looking at the CQUINs in the National Dementia Strategy, which is around screening. Some of that requires screening when people go into A&E for example – a short memory test as to whether or not people might have dementia. I could see, just from talking to the chief nurse and the other staff involved, that they were almost feeling quite overwhelmed of the prospect of everybody coming into hospital who is over 70, I think it was, being screened, whether they are coming in for day surgery, A&E or an actual elective procedure. Their worry was twofold. One was that, if they are screened, then you need diagnostic equipment in terms of scans and everything else. Is there going to be a huge rise in demand for that? Secondly, if it is a positive screening, then where is the

community support once somebody comes out of the hospital? It was the first time I had really appreciated the bottleneck that may well come through in a surge, rather than in a managed process. I just wondered if you had any comments on that.

### **Dr Simon Hughes**

Can I just say one thing before I try to answer that? I think that education of the medical profession is utterly key here. I have lectured over the last six to seven years on dementia, and people's perception of this disease is so bad; it is so poor, their understanding of the difference between Alzheimer's disease, Lewy body, frontotemporal, how they present, what their pathologies are, how this affects the clinical presentation of patients and how they are different – how vascular dementia is different from Alzheimer's disease. I think there is a role for the Royal Colleges to say that you would not come out of medical education without a fundamental understanding of oncology and ischemic heart disease. Dementia needs to be in that group. It needs to be so fundamentally bad that you do not have an understanding of the fundamental pathology of Alzheimer's disease, the complexity of its presentation and a variation of it.

What that does is – I am coming around in circles again – is it changes the cultural view of dementia. It says, 'This is not a normal process; it is absolutely not.' I have seen about 2,500 potential PET brains on patients, probably more than anyone else in the country. An 80-year-old brain does not have to have dementia. I have seen 80-year-old brains that are healthier than 50-year-old brains. Atrophy is not a normal process; it is an utterly abnormal process. It has consequences for people, real profound psychological consequences for people. I think that is the change. Somebody in A&E would not go, 'Oh, do you know, this person's got problems swallowing and I just cannot be bothered to refer them for an OGD to see if they have oesophageal cancer.' Why would they say, 'This person I think has memory problems; I cannot be bothered to assess their memory because they may have this fatal disease called Alzheimer's disease'? How can you have that? That is why there is this line, in my presentation, of how can early diagnosis of lung cancer be appropriate for PET when early diagnosis of this fatal disease called dementia is inappropriate for PET. You cannot have that argument. You must change the cultural view, both within the presentation and without the profession of this serious disease. That is about changing the way you perceive it.

Memory loss is not a normal thing. Some memory loss may be, but progressive memory loss is not a normal thing and that is the change you need. We have seen some political problems in Northern Ireland in the increasing diagnosis of dementia, which then puts an absolute pressure on social care services. Sometimes it is far easier not to have diagnosis; 'Oh, you've got a few memory problems.' Therefore, you do not have a diagnosis. Therefore, the local authority or the health service has no obligation to provide you with care. If we said that about oesophageal or lung cancer, it would be such a national disgrace that people would be fired. This is the change that we need to try to do.

### **Baroness Browning**

Could I just ask Mr Huggins – you clearly have given great emphasis to support services. You mentioned that you are looking at Link Workers being available for a year post diagnosis. You seem to have done that on a reasonably modest budget as well. How have you come to this conclusion? Is it that, once you provided some support services, people feel, if you like, a lot more comfortable about managing their condition at home? Is that what takes some of the pressure off, which is one of the things we have picked up from our other speakers today?

**Geoff Huggins**

There are probably a few things in that. First of all, in terms of Scotland's first dementia strategy, which –

**Baroness Browning**

I do apologise; I am afraid there is a Division in the Lords. I shall read what your answer was when I get the script. I do apologise.

**Geoff Huggins**

When we published our first dementia strategy, which was in 2009, as a three-year strategy, one of the two areas that we focused on as key change areas was post-diagnostic support and the experience of people with dementia in inpatient general medical environments. There has been some coverage of that more generally, both south and, indeed, we also have problems north of the border.

We also produced, as part of the methods they put forward, a publication called 'Standards of Care for Dementia in Scotland', which identified a series of areas in which we expected to see post-diagnostic support improved. We think we have seen some degree of that, but we have not seen the scale of change that we would have wanted to see around post-diagnostic support. At the moment, we are now revisiting that to identify the period of times, which would probably be 12 months, and the method of delivery, but also using that to connect people more effectively to existing community resources and new resources that will become available in the next couple of years. The Big Lottery has produced a dementia fund in Scotland as one of its key change areas. A lot of that will be on creating community and other resources.

At the moment, what we are running over the next three months, and it will be over that period of time, is some pilot work to assess the degree to which we can expect health boards and social care providers to meet the additional expectations around post-diagnostic support within existing budgets. At the moment, we know that there is activity going on, but we do not know the scale of that activity and we do not know what the additional cost would be for us to enhance that. We are doing something that is intended to be quite pragmatic to see whether we do or do not need to put our hands in our pockets to play fair with the system out there. One of our objectives is to play fair.

Our assessment of the total cost of delivering that for Scotland would probably be somewhere between £5 million and £7 million, if we had to fully fund the cost of a Link person per year, for each person with a new diagnosis. We do not think that is significant resource-wise, particularly if it does then connect people into a wider range of support services, most of which we do not pay for, many of which are provided voluntarily or on a peer-to-peer basis. Our objective with that is to raise the bar. We assess that we probably will need to find some funding, but we do not think it is going to be beyond possibility.

The economic case is quite interesting though, because in last year's visit to health boards, we were doing work to identify the number of people who were being coded in A&E as presenting with dementia who were over 60, and the number of people who were in general hospital settings, using SMR1 data. What that told us was that, in each of those settings, the number of people being coded was probably between 2% to 3%, whereas we know that, when we do research, the numbers that are actually going through those environments at that age group are between 30% and 60%. That

effectively means that people who are actually offering other forms of care in those environments are not doing it on the basis of knowledge of pre-existing conditions. That means you are going to get poorer quality care. Again, the diagnosis is also intended to feed that work and the work around antipsychotic prescribing.

### **Hazel Blears**

Are you going to do the screening, like the English dementia strategy, in A&E and in hospital in secondary care?

### **Geoff Huggins**

As we now have a higher rate of diagnosis, the issue now for us is about data linkage. It is less about screening. We are also significantly investing at the moment. All general adult hospital settings within Scotland are going through an inspection process to identify the degree to which they are offering quality dementia care services. Our view on that is people in care homes get good care and poor treatment; people in hospital get good treatment and poor care. We have a big piece of work going on, which is raising the quality of care in those environments. The key component of that is about knowledge of dementia, because the future of old-age care for people in Scotland is care for people's dementia.

### **Hazel Blears**

Dr Rafi, did you have a final comment to make, and then we are going to wrap up?

### **Dr Imran Rafi**

Just that there are clinician groups around the country that are looking at the use of virtual wards and community-based matrons, who can help to identify people at high risk and then possible admissions. That is quite a good link in terms of trying to identify people who have high needs, who are not being picked up by the standard support services. It may be another area to look at.

### **Hazel Blears**

Thank you very much. Can I say a genuine thank you to all of you for having travelled and come this afternoon? Your evidence has been really instructive for us, and hopefully will help us to produce a report that has a bit of clout behind it. It is good to see people so passionate. Brigid and Daphne, thank you so much for coming and giving us your personal stories, because that always reinforces what the professionals sometimes tell us. Sometimes it makes us think again, so thank you very much.

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