South West Dementia Partnership

Joint Review of Dementia Services in the South West - 2009

An Overview Report

Preface

This report provides a summary of the findings of a joint review of dementia services across the South West conducted in May – July 2009 involving NHS South West, local authorities, South West Alzheimer's Society, Department of Health South West and carer representatives. It provides the emerging priorities for local action to deliver the National Dementia Strategy and the basis for a regional action plan to support delivery.

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Foreword

The National Dementia Strategy was launched in February 2009 and is founded upon a strong evidence base, informed by the views of people with dementia and their carers. It describes how services should be delivered and provides us with a unique opportunity to improve services in the South West.

In order to implement the National Dementia Strategy, the major public agencies in the South West and the regional Alzheimer's Society began by undertaking a base-line peer review. This has enabled us to find out what services are currently commissioned, how they are provided and performing, and how prepared the fourteen health and social care communities are in taking forward implementation of the National Dementia Strategy.

I particularly valued the contribution made by people with dementia and their carers and I appreciate the efforts they made to attend the meetings with Innovations in Dementia. Taken together, their comments tell a powerful story about their experiences of services in the South West.

The review found many examples of good and innovative practice and many highly motivated staff doing their best to support people with dementia and their carers. However, the overriding finding was that services are not joined up and are therefore not delivering reliable support and care. It is clear that services need to be commissioned and delivered in more systematic, coherent way if care is to be consistent and effective. Ensuring good quality support and diagnosis at an early stage will be critical to success in the South West.

As result of the review we now have a strong platform to build on, both within individual communities and across the whole region. Although the review has identified many areas of shortfall this is to be expected. It is why we have a National Dementia Strategy with a five-year timescale for implementation, to ensure strategic service change happens in a sustainable way.

The review demonstrated that co-production, working across health and social care, provides both answers and opportunities. It has also shown that to deliver quality in the South West we need to embrace innovation, and to deliver on productivity we need to invest in prevention. Perhaps the most important finding of the review was to discover the level of commitment and enthusiasm of frontline staff and volunteers across public services and voluntary agencies.

We now need to harness this and realise the potential of pulling together in the same direction.

Lezli Boswell
South West Dementia Review Lead

Joint Review of Dementia Services in the South West

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Section 1

Introduction

This section introduces the Joint Review of Dementia Services in the South West and explains the content of the report.

1. Introduction

1.1 Living Well with Dementia: A National Dementia Strategy was published by the Department of Health in February 2009 and is a key step towards achieving the goal of building health and social services for patients with dementia which are fit for the 21st century.

1.2 Dementia is largely, though not exclusively, an age-related phenomenon. The South West has a higher proportion of older people compared with the rest of the UK. This means that in South West there will be a greater increase in the number of people with dementia in the future with a major impact on the demand for services.

1.3 In 2007 around 73,000 people in the South West were estimated to have dementia. This is set to rise to over 102,000 by 2021, an increase of 40%, with a number of communities facing increases in excess of 50%. In the South West only one in three people with dementia currently have a diagnosis. Appendix 1 sets out the detail for each Primary Care Trust.

1.4 People under 65 years of age can also develop dementia and their specific needs are often overlooked. Within the estimated 73,000 people there are currently around 1300 people with early onset dementia. This figure is likely to remain constant through to 2021.

1.5 The South West Dementia Partnership was formed in January 2009 following a regional summit held in November 2008. The purpose of the Strategy Group is to lead and support the development of dementia services across the South West. A key priority has been to conduct a peer review of dementia services in the 14 health and social care communities across the South West to assess their readiness for implementing the National Dementia Strategy. Twelve of these communities have a coterminous Local Authority and Primary Care Trust. Cornwall and Isles of Scilly community and Bournemouth and Poole community are each served by a single Primary Care Trust but each has two separate Local Authorities with distinctive features and accountabilities.

1.6 This joint review had the support of Department of Health South West, NHS South West, Directors of Adult Social Services and the Alzheimer's Society South West. It was based on a whole system and joint agency approach. The review team included representatives from each of these agencies and between them they had a wide range of professional and clinical backgrounds. It also included carer representatives.

1.7 The aim of the review was to:

- Gain an understanding of the current commissioning arrangements and provision of dementia services across the 14 health and social care communities, based on a common set of indicators and measures;

- Undertake an independent peer review baseline of the strengths and areas for development for dementia services in each community against each of the recommendations in Living Well with Dementia: A National Dementia Strategy;

- Give feedback and guidance to each health and social care community on areas to strengthen its own action plan to support its preparedness and prospects for the implementation of Living Well with Dementia: A National Dementia Strategy;

- Identify areas of innovation that could be shared via the South West Dementia Partnership website;

- Gain a regional overview of the state of readiness to take forward the National Dementia Strategy, identifying the common areas of service shortfall and barriers to change;

- Undertake an evaluation of both individual community and regional performance from the perspective of people with dementia and their carers.

1.8 The approach taken by the review team is outlined in Appendix 2.

1.9 The South West Joint Review has provided:

- A strong foundation upon which to build a successful regional approach to the implementation of the Living Well with Dementia: A National Dementia Strategy;

- An understanding of some of the capacity and capability requirements and the pace of change required to deliver improved services based on Living Well with Dementia: A National Dementia Strategy;

- Clarity about what next steps and actions need to be taken, and at what level;

- An understanding of the leadership requirements to achieve change to ensure improvement and efficiency in local systems;

- An understanding of clinical leadership and its importance in bringing about transformational change.

- Examples of innovative and exemplary practice.

1.10 Each community received a report following the review which included detailed findings and recommendations for local action.

1.11 The review process has confirmed the vital importance of:

- Engaging people living with dementia and their carers in determining priorities and the need to continue to listen to these individuals as well as staff;

- Delivering improvement in a coordinated way via strong partnership working across the NHS, Department of Health South West, Local Authorities and Association of Directors of Adult Social Services, Alzheimer's Society and other third sector organisations.

1.12 The findings of the South West Joint Review were reported back to the partner agencies at a regional conference on 20 October 2009. This provided an opportunity to discuss and confirm the priorities identified by the review in order that a regional action plan could be developed to underpin the work already being undertaken by local health and social care communities.

1.13 A second leadership summit is planned for early 2010 which will launch the regional implementation plan and confirm the ambitions for the South West in the delivery of the National Dementia Strategy for the next three years.

Report contents

1.14 This report provides:

- The overall findings from the reviews carried out in each of the 14 health and social care communities in the South West in section two;

- The specific findings by each of the objectives within Living Well with Dementia: A National Dementia Strategy. It also provides examples of current good practice in section three;

- Recommendations for the priorities which will form the basis of a South West implementation plan in section four;

- Relevant demographic information by Primary Care Trust, the methodology of the review process and a summary of the views of carers and people living with dementia in the South West contained within the appendices.

Section 2

General Findings

This section sets out the general findings of the joint review of dementia services in the South West that took place between May – July 2009.

2. General Findings

2.1 The review team found variation in the quality and way services are provided both across and within health and social care communities. There are pockets of innovation and exemplary practice however there is also shortfalls and inefficiencies in service delivery. This means some people with dementia are disadvantaged by virtue of where they live or which part of the dementia pathway they are on.

2.2 The overriding challenge facing the South West is to ensure that service delivery and service quality is consistent and universally available to all.

2.3 This variation had occurred because current systems have been built upon historical practice and resource allocation, rather than evidence based commissioning strategies. This has resulted in some services being duplicated or not being available and as a result presents many opportunities for improvement in quality, spread and improved productivity.

2.4 It was also clear that challenges posed to the health and social care systems by dementia are large and complex. Better integration and streamlining of health and social care systems will be essential in the future if we are to achieve improved outcomes and experience for people with dementia.

2.5 There will always be a number of individual components of service delivery which can be improved but the interconnection between them is critical. The joint commissioning of services to a defined pathway is therefore central to improving services.

2.6 The review team were regularly impressed with the high level of commitment and enthusiasm across all communities to develop good quality dementia care services. It will be important, in carrying forward the National Strategy, to harness this energy. There is enormous improvement potential to be realised if people can be enabled to work together across professional and organisational boundaries and to learn from and adopt best practice. It is also important that people are recognised for the work they are doing.

Delivery

2.7 In order to take forward the necessary improvement in dementia services the review team recommend to the South West Dementia Partnership that a South West Dementia Implementation Plan should be developed and implemented. This plan should include the adoption and spread of best practice that is already in place and was seen by the review team on their visits. There was evidence of solutions being found to address of common problems and this problem solving also needs to be available for all to benefit from.

2.8 A key principle of the South West approach should be to underpin and support the action plans which have been developed by local communities in response to the National Dementia Strategy and the findings of the review.

2.9 The value of a South West approach is that it:

- will bring a consistency of expectation and delivery for all;
- will ensure that learning and best practice are spread;
- address areas of common difficulty through regional initiatives;
- can facilitate effective engagement of other regional partners including the Care Quality Commission and NHS Ambulance services;
- can promote coordination in areas where NHS and social care boundaries are not coterminous;
- can strengthen the relationship between the local and regional implementation of other health and social care regional initiatives for example, Putting People First;
- will strengthen the alignment between local communities, national expectation and best practice knowledge.

2.10 The South West implementation plan should reflect the views and priorities expressed by people with dementia and carers and have clear and measurable outcomes.

2.11 The South West Dementia Partnership has convened a sub group to develop the detail and coordinate an implementation plan to deliver the initial priorities identified by the review process.

Longer Term planning for full implementation of the National Dementia Strategy

2.12 The initial priorities outlined in Table 1, in Section 4 of this report, were identified as the most appropriate starting point to support local implementation. In developing local action plans all communities will need to address all 14 strategic objectives within the National Dementia Strategy.

2.13 The progress in the delivery of the priorities within Table 1 will be reviewed and reported via the sub group to the South West Dementia Partnership. In time this will enable revised work streams to be incorporated into the plan to ensure strategic objectives are delivered in line with timeframes indicated in the implementation guidance which accompanies the National Dementia Strategy.

Key Themes

2.14 The key findings across the 14 communities can be summarised using the following themes:

- leadership;
- partnership working;
- mainstreaming improved dementia care;
- economic aspects of care;
- support for carers;
- benchmarking and data;
- the pace of change in delivering improved dementia services.

Leadership

2.15 The review team found that the review process provided an indication of the commitment of local leaders to improving dementia services. It demonstrated to the reviewers the vital importance of joint leadership approaches and agreements. In communities where this was evident the workforce felt empowered to deliver change and improve services.

2.16 In the majority of communities, the Chief Officers for Adult Social Services and Chief Executives of Primary Care Trusts and Mental Health Trusts attended, or provided senior representation. The initial meeting was designed to provide leadership perspectives and information. They also attended the feedback sessions.

2.17 In a minority of communities, the reviewers believe that the review meeting was the first time local leaders had met together to discuss dementia services and their local approach to Living Well with Dementia: A National Dementia Strategy. In a small minority of communities, it became evident to the reviewers that local leaders were not working within a whole system approach. This resulted in non-existent or poorly developed joint strategies and local action plans to the detriment of people with dementia.

2.18 Only a few senior managers from acute hospitals were present at the meetings, which could be indicative of the priority given to dementia within that sector of the NHS.

2.19 Clinical leadership varied considerably across communities. Primary care is clearly a particular challenge in the context of dementia services. The 2007 National Audit Office report confirmed that many General Practitioners feel they have neither the confidence nor knowledge to respond to memory problems. Some communities had begun to develop relationships with local General Practitioner. However, most places have further work to do to raise the level of General Practitioner engagement and practice. This is evidenced by the numbers of patients on General Practitioner dementia registers, as percentage of expected prevalence (referred to in Appendix 1).

2.20 There were good examples of leadership from the Old Age Psychiatry community, working with commissioners on service development, though this was not universal.

2.21 Clinical leadership within NHS Acute Trusts for dementia care is, with a few exceptions, not well developed and insufficiently pervasive across all parts of the acute hospital system. However, most NHS Trusts have a named lead and a few had a system of ward champions.

Partnership working

2.22 The review team found that dementia was understood as a whole systems agenda where the commissioned pathway should span health and social care and involve a variety of local partners. Local planning and leadership attempted to reflect this in the majority of communities.

2.23 In most areas, there was good evidence of data on prevalence within the Joint Strategic Needs Assessment.

2.24 However, capacity planning was less robust. In many areas it did not exist or was poorly developed. This meant that the difference between current and future demand for specific key services, based on assumptions about rising diagnosis rates, was not being highlighted. Examples of this include memory assessment services and specialist domiciliary care.

2.25 Estimating the gap between current service levels and potential demand for carer support was not well developed. This is particularly important for dementia services given the unmet need and direct financial benefit to statutory services of keeping people at home for longer, evidenced in the economic evaluation underpinning Living Well with Dementia: A National Dementia Strategy.

2.26 The majority of areas had established a group of stakeholders to lead change locally or were finalising revised arrangements, yet their impact was mixed. Only a small number had yet to develop an agreed joint strategy and most required further development and wider consultation. Therefore, local action plans were also variable.

2.27 The communities that had already identified a programme lead, or joint programme lead arrangements, have made the most progress in developing and implementing local plans. The majority of communities who were without dedicated project and/or programme lead time were strongly recommended to consider this as a fundamental building block in making appropriate progress in improving services.

2.28 Voluntary sector partnerships were strong in many places with partnership working evident in both identifying commissioning needs and provision of services. In some areas there was clearly a mature relationship between NHS and social care commissioners and the voluntary sector with clear thinking about how to fund third sector infrastructure costs whilst retaining the ability to tender services amongst a wider market. There were some occasions when voluntary sector services were heavily relied upon and not always formally commissioned, raising questions about local sustainability and equity.

Mainstreaming dementia care

2.29 The review team found a key challenge for most areas is the need to increase the capacity and competence of generic older people's teams in health and social care and improve links with specialist services. In effect, the role of generic and specialist services will need to change given the significant increase in numbers of people with dementia in the South West.

2.30 Generic services will need to have a wider remit and become more comfortable providing care which has a greater mental health component, whilst specialist services will need to consider their remit in terms of care thresholds and remit for education/advice. Some communities recognised this as a central task and were making good progress to develop, in parallel, an effective pathway between generic and specialist older people's teams supported by comprehensive dementia awareness training across sectors.

2.31 Most areas had some awareness training across all sectors but this training was very variable. It was not always carried out on a joint agency basis, across both statutory and non-statutory partners, or with full engagement of workforce development and training specialists. General Practitioners were often cited as needing to be better engaged and there were various strategies in place for doing this, such as the General Practitioner Academy in Cornwall. Some areas had not engaged with General Practitioners at all and this was identified as an area for development in several communities.

2.32 The need for good quality personal support at home is imperative for people with dementia and the availability of this was variable. Whilst some areas are beginning to combine this with the transformation and personalisation agenda work they are undertaking, very few areas had individual budgets set up for people with dementia.

Economic aspects

2.33 The requirement for enhanced and responsive services raises real challenges in an emerging era of low or no growth and requires a proactive work programme to prioritise investment.

2.34 The review team found some communities where dementia was clearly a commissioning priority with new investment in services and commissioning capacity in health and social care.

2.35 In other communities, however, there was a strong message that disinvestment in other services would be the only source of any development funding for dementia, other than invest to save cases with a rapid payback. This appeared to be more of a problem for the NHS than for social care commissioners.

2.36 However, there were also examples of capacity restrictions including waiting lists for day care and respite services and limited places in specialist domiciliary care contracts that compromised the experience of some people with dementia and their carers.

2.37 Although new money has been provided by the Department of Health in the form of £150m revenue over two years for Primary Care Trusts, very few Primary Care Trusts are protecting their share of £150m and some areas are only looking at invest to save business cases prior to decommissioning. This is a key issue. Without adequate investment to gain efficiency and productivity in the areas for development it will be difficult to deliver Living Well with Dementia: A National Dementia Strategy.

2.38 There is a need for greater emphasis on identifying costs, data for planning future services and recognition of the resources required for the management of commissioning dementia services.

2.39 Only a few communities had begun work to look at opportunities for disinvestment and reinvestment in dementia services through service improvement projects. The learning from these projects will need to be quickly shared for wider adoption, supported by robust demand and capacity evidence and clinically determined best practice.

2.40 Most health and social care communities were unable to identify their total spend on dementia services, with budgets often difficult to disentangle.

2.41 Therefore, a key challenge for commissioners will be linking capacity planning and service improvement to investment plans in health and social care funded services to match an anticipated rise in both prevalence of dementia and the proportion of people with dementia receiving a formal diagnosis.

Support for carers

2.42 The review team found that aspects of prevention and support to carers are areas that need investment in order to save.

2.43 The found review team that adequate support for carers and people with dementia was patchy. There were some examples of good services available, which were flexible and sought to give carers a choice about how and where support was delivered. However, in many cases commissioners lacked a sense of how comprehensive their coverage was for carers of people with dementia.

2.44 There were reports of carers not being offered assessments in some areas or, there were, capacity constraints in providing a support package with a lack of respite care and short breaks. There was concern in some areas that a carers strategy had not been launched locally or that it had not been supported. However, the review team is encouraged by the demonstrator site opportunities connected to the Carers' Strategy which are available in the South West. It will be important to ensure a dementia focus to these developments.

Benchmarking and data

2.45 A range of data was requested from each of the 14 communities, prior to the review, to provide some detailed baseline and background information for the review team members. It was envisaged that this information would then be collated and analysed to provide a set of benchmarking data for the South West to inform developments against Living Well with Dementia: A National Dementia Strategy.

2.46 The data requested, as set out in Appendix 3, was not fully returned by all communities. The gaps in data returned were followed up in the review visits, confirming that not all the data being requested was currently being collected. The reliability of data which had been returned was variable in terms of detail and definition.

2.47 However, within the South West Dementia Partnership, further work is taking place on metrics, which is contributing to a Department of Health consultation exercise on a dementia metrics framework. This should lead to the introduction of a common data set for dementia services.

2.48 The review found that, generally, there is only a limited amount of work which has been carried out locally on defining outcomes for commissioning, particularly for key NHS services such as memory assessment. This is another area identified for regional support.

2.49 Current frameworks available to commissioners, such as Quality and Innovation Payment and Quality Innovation Productivity and Prevention need to be utilised to incentivise improvement.

The pace of change in dementia services

2.50 Living Well with Dementia: A National Dementia Strategy sets out some clear aspirations for dementia services over a five year timeframe. However, there is no agreed or recognised milestones of achievement within that 5 years to show progress.

2.51 The individual outcomes within Living Well with Dementia: A National Dementia Strategy do not have quantifiable milestones or deadlines. As a result there is a danger of a lack of focus or priority relative to other service areas where local, regional and national ambitions are clear. The South West Dementia Partnership will ensure that there is clarity on the milestones for local communities over the five years of the programme.

The views of people with dementia and their carers in the South West

2.52 A compilation of the comments made by people with dementia and their carers during the course of the review has been included in Appendix 4.

2.53 When aggregated together the comments provide some powerful feedback about the current performance of services across the South West. In particular people with dementia and carers reported:

- Wide variation in the service provided by General Practitioners. Many were critical of the lack of expertise and understanding of their local GP;
- Long delays in achieving diagnosis;
- The sense of being abandoned after the diagnosis has been given;
- The unreliability of community teams particularly due to sickness absence and staff turnover;
- The importance and value to people’s lives of local groups often run by the voluntary sector;
- The need to have someone to talk to on a regular basis or at times of crisis;
- The strain on carers, the need for support and advice and the difficulties in obtaining breaks;
- Concern about hospital care including inappropriate provision of meals within hospitals;
- Concern about the lack of activity in care homes.

Section 3

Specific Findings by each Strategic Objective of the National Dementia Strategy

This section sets out the specific findings of the South West Review by each Strategic Objective of the National Dementia Strategy.

3. Specific Findings by each Strategic Objective of the National Dementia Strategy

Summary of findings by each of the National Dementia Strategy objectives

3.1 The review process focused on the first 14 of 17 objectives from the Living Well with Dementia: A National Dementia Strategy. The review team was keen to identify positive practice in the South West which resulted in good outcomes for people who use services and their carers and examples are included in this section. The following analysis has been produced by collating and analysing the findings across all of the South West communities.

Objective 1: Improving public and professional awareness and understanding of dementia

3.2 The requirement of Living Well with Dementia: A National Dementia Strategy is to ensure greater knowledge and understanding of dementia and reduce the stigma attached to it. There is a low level of awareness and understanding about dementia not only among the public but also among people who provide services. Many people do not realise that there are ways of supporting and treating people with dementia and that if there is timely diagnosis a lot can be done to help. There is also a lack of awareness of the benefits of support, and that promoting coping skills and social inclusion make it possible for people with dementia to have a good quality of life and independence.

3.3 Some communities have recognised the importance of sustained publicity and public information to promote early diagnosis and provide information and support to people with dementia and their carers. Running local campaigns is relatively easy and expertise can be drawn from other service areas and provides a tangible action for partnership working.

The review team found that:

3.4 There are few locally coordinated whole system strategies in place to raise awareness in the general public. This has not been seen as a priority. With the exception of Cornwall any strategies that exist are limited, underdeveloped and fragmented.

3.5 It was noted that some communities were uncertain about their role in public awareness raising in relation to the national campaign which is now due to begin in early 2010.

3.6 There were some examples of using other existing channels to provide information to the public, for example through community development or link workers in hard to reach projects.

3.7 Some communities have awareness raising programmes targeted at Primary Care Trust Non Executive Directors and council members.

3.8 In most communities there was low awareness of either dementia or the National Strategy amongst frontline staff in both health and social care. This was particularly significant in generic teams and was a serious concern in some reviews. In some areas there was a clear reluctance to release staff for dementia awareness training especially within the NHS. A small number of communities used dementia champions to spread the word.

3.9 The level of awareness amongst General Practitioners about dementia was generally very low. This was highlighted by feedback from people with dementia and carers who reported mixed responses from their General Practitioner as being inadequate and unhelpful.

Plans for the South West:

3.10 A pilot media awareness campaign, sponsored by the South West Dementia Partnership, has been undertaken and the results are currently being evaluated. Lessons learned about effective media management will be disseminated across the region along with supporting case examples which can be used as part of media releases.

3.11 Best practice projects on raising General Practitioner awareness will be shared across the region with the objective of recruiting more General Practitioner champions.

3.12 Information about the national media awareness campaign will be shared in advance across the region in order that local communities can capitalise on the national initiative.

Case example

“at every step of the way Mum and I were lucky enough to get the help we sought…but there is a vital need for more information on support services available – it seems that a carer needs to be assertive just when the energy levels are down at zero” (by letter to Innovations in Dementia)

Positive practice in the South West- the review team was impressed by:

Cornwall - A public awareness campaign is designed to be sustainable and has a target of one positive media release a month. A recent feature was the promotion of a vintage 1950s bus which visits local communities and encourages the public to take a trip down memory lane to launch the ‘Worried about your Memory?’ campaign.

There is also a General Practitioner Academy which is serving to engage and develop General Practitioner knowledge of and confidence in advising on dementia in a supportive and enabling way.

Dorset – The Partnerships for Older People Projects (POPPs) have an innovative and pioneering approach in 33 localities including evaluation – ten of which were dementia specific. Raising profile of transforming social care by leaflets and also personally delivered DVD.

Torbay - 7000 booklets on the dementia pathway have been distributed.

Wiltshire: quick win - messages about memory displayed on GP surgery screens.

Objective 2: Good-quality early diagnosis and intervention for all

3.13 The requirement of the Strategy is that all people with dementia will have access to care which gives:

- an early, high-quality specialist assessment;
- an accurate diagnosis which is explained in a sensitive way to the person with dementia and their carer;
- treatment, care and support as needed.

3.14 Local services must be able to promptly see new referrals of people who may have dementia. General Practitioner awareness, confidence and competence underpin this objective.

The review team found that:

3.15 Widespread evidence that communities are struggling to engage General Practitioners. The rates of diagnosis and registration by General Practitioners are generally low when compared nationally. Although the registration rate may have flaws, it is the best measure currently available.

3.16 A minority of Primary Care Trusts have agreed sessional arrangements for a General Practitioner to advise on service arrangements and raising awareness. Some Primary Care Trusts have a nominated General Practitioner lead for planning dementia services. Most had not included this in initial action plans, in which case the review team recommended that this should be reviewed.

3.17 All communities have a memory assessment service in place but the models vary in terms of the service offered, type of patient seen and capacity constraints including waiting times. Post diagnostic services were variable in terms of literature available, capacity and support groups. Services and priorities were generally provider led. Commissioning activity was weak in terms of specification, outcomes required, data collection and performance monitoring.

3.18 The result was that in a minority of communities service provision was ad hoc and fragmented leading to inequality, variable pathways and a lack of universal access.

3.19 Across the South West people with dementia and carers reported significant delays in obtaining timely memory assessments. The lack of dementia awareness amongst General Practitioners was universally highlighted as a serious impediment to achieving memory assessments, some General Practitioners were described as actively avoiding dementia diagnoses.

3.20 In two communities two different memory services operated causing significant confusion for referring agencies. In one area no memory assessment service had been commissioned.

3.21 The need for a single point of access for memory assessment services was a recurring theme.

3.22 Concern was voiced by one home care provider that people could have received preventative support if earlier diagnoses had been available.

3.23 Positive screening and identification of people with learning disabilities and dementia was identified in a number of communities.

3.24 In some communities demand was outstripping the capacity of existing provision, referral rates in some communities had doubled in the last year.

3.25 In some communities good post-diagnostic support was identified, including follow-up appointments a fortnight after diagnosis and referral or signposting to sources of support and training programmes. However a sense of abandonment was expressed by a number of people with dementia and carers following diagnosis.

Plans for the South West:

3.26 Effective memory assessment is seen as a high priority. A regional best practice pathway is being developed. It will focus on commissioning memory assessment services and will define clear expectations and specifications for good-quality memory assessment services.

3.27 Best practice in raising General Practitioners' awareness to be adopted and spread.

3.28 Links will be made with national initiatives to develop General Practitioners' dementia e-learning so that information about this can be disseminated.

Case example

- The General Practitioner said you can expect to lose your memory when you are 70. (Person with dementia, Innovations in Dementia consultation)
- I got the diagnosis by phone by somebody I had never met telling me 'your husband has Alzheimer's and vascular dementia'. (Carer-Innovations in Dementia consultation)
- Every time I approached the doctors they said 'well you can't have Alzheimer's as you are too young!' (Person with dementia, Innovations in Dementia consultation)

Positive practice in the South West- the review team was impressed by:

Swindon – the Forget–Me-Not Group is an innovative service for younger people with early onset dementia.

In Cornwall the use of World Class Commissioning outcomes to improve access to early diagnosis for dementia and strengthen care and support with a planned trajectory of people on General Practitioner registers.

In Torbay the Memory Café and assessment work has been developed over several years and a single assessment is in place.

In Cornwall the use of 'World Class Commissioning' outcomes improves access to early diagnosis for dementia and strengthens care and support with a planned trajectory of people on General Practitioner registers. General Practitioner practices receive comparative monthly information on registration rates. NHS Cornwall and Isles of Scilly has written and consulted upon a commissioned memory assessment service.

Bath and North East Somerset commissioners have a memory assessment specification.

In Devon, there are 107 GP Practices of which 40 are working as part of the DH Demonstrator Site programme to provide health and wellbeing checks for Carers, including carers of people with dementia.

Objective 3: Good-quality information for those with diagnosed dementia and their carers

3.29 The requirement of the Strategy is that people with dementia and their carers should be given good-quality information about dementia and services at diagnosis and during their care. The Department of Health has commissioned the Alzheimer’s Society to develop a specification about how this objective will be met which will be available in Spring 2010.

The review team found that:

3.30 There were numerous examples of information about dementia largely developed by providers or the Alzheimer’s Society. However there was no systematic, cross community approach to providing this to the public. There did not appear to be a systematic approach to audit to assess impact and penetration.

3.31 There was little good quality information for people with a diagnosis or their carers in plain English or easily accessible formats.

3.32 Areas of particular information deficit mentioned included information for younger people with dementia, Independent Mental Capacity Advocate services and carers’ assessments.

3.33 There has been some development of web based information. However it should be noted that many older people do not have access to the internet. It has been estimated that only 15% of elderly people have access to web-based resources.

3.34 There were some good examples of accessible information for people with learning disabilities including a DVD on growing old.

Plans for the South West:

3.35 The best practice specification which is being developed nationally will be disseminated.

3.36 As part of the dementia pathway development, the role of memory assessment in services in signposting people and providing advice will be highlighted.

Case example

“All I got was leaflets – nothing to help me make sense of it all or think about what we might want to do – that’s what we needed”
(Person with dementia, Innovations in Dementia consultation)

“Having got the diagnosis there should be some follow up with information on what you’ve got, how to cope with it, what to look for and what’s going to happen. (Person with dementia, Innovations in Dementia consultation)

Positive practice in the South West- the review team was impressed by:

South Gloucestershire – The FIND (First in Dementia) Project identifies and supports people with early stage dementia and provides web-based information.

Torbay has introduced a “yellow personal folder” for sharing information on assessment and care, support and other information with all involved which is held by the person using the service or their carer.

Bristol has already developed two dementia adviser posts from Practice Based Commissioning initiative and services to meet the needs of black and ethnic minority groups.

Objective 4: Enabling easy access to care, support and advice following diagnosis

3.37 The requirement of Living Well with Dementia: A National Dementia Strategy is that people with dementia and their carers should be able to see a dementia adviser to help them throughout their care and find the right information, care, support and advice. It is known that carers regard this relatively inexpensive service highly. Living Well with Dementia: A National Dementia Strategy gives a clear steer that the adviser does not need to be a highly experienced professional. The majority of communities had prepared information for a bid for Department of Health funding to be a demonstrator site. Two sites were selected, NHS Bristol and NHS Somerset. The initial challenge now is how plans will be taken forward by the remaining communities. The wider challenge is the development of comprehensive services that can be signposted by the advisers.

The review team found that:

3.38 Evidence of any activity across the region in relation to objective 4 was quite limited. There was also variability, some communities having no discrete or identified post diagnosis service;

3.39 Particular concern was noted about the lack of specific support for younger people with dementia.

Plans for the South West:

3.40 Early learning from the two South West dementia adviser pilots will be disseminated.

Case example

“the GP acted quickly, but then nothing happened – we weren’t offered any kind of support from anywhere” (Carer, Innovations in Dementia consultation)
2 carers mentioned the hiatus of a year caused by the absence of a memory nurse, during which time processes and services came to a halt.
(Innovations in Dementia consultation)

Positive practice in the South West- the review team was impressed by:

In Devon every Complex Care Team has a Voluntary Sector Representative to signpost and support people to access appropriate voluntary sector support, including dementia specific activities such as Memory Cafes and a range of carer support services.

North Somerset - The Coping with Forgetfulness course offers post diagnostic support for people with dementia at the Woodspring memory assessment service, which has been running for some years. This links with a long term monthly peer support group, supported by the Alzheimer’s Society.

Cornwall- Newquay Integrated Care pilot and the Whole System Demonstrator pilot.

Objective 5: Development of structured peer support and learning networks

3.41 Living Well with Dementia: A National Dementia Strategy requires that people with dementia and their carers should be able to get support from local people with experience of dementia. In addition they should be encouraged to take an active role in developing local services and thereby potentially continuing longer in their role. This is about providing a regular forum for people living with dementia and the carers, to exchange experiences and meet up with professional staff on an informal basis. In some places, this provides a strong focus for learning as well as support.

3.42 Feedback from people with dementia and carers in the South West highlighted the enormous value of peer support and community based activities, both in terms of practical advice and emotional support.

3.43 The South West has two peer support demonstrator sites, Cornwall and Torbay

The review team found that:

3.44 That a range of peer support networks are in place as the movement of Memory Cafes has developed but largely on a non-commissioned basis. These have been planned and delivered by the voluntary sector. There are, therefore, issues of consistent coverage, particularly in large rural areas, as the service has evolved piecemeal. In a few examples the service had been organised by NHS providers in association with the voluntary sector.

3.45 Duplication of services run by different voluntary organisations was noted in one community. There is additional potential competition between carers support organisations some of which are generic, others dementia specific.

3.46 In one community mental health team input into cafes run by volunteers was noted as a strength; this included weekly community psychiatric nurse input.

Plans for the South West:

3.47 Early learning from the national and regional peer support demonstrator sites will be disseminated.

Case example

“ If it had not been for the Alzheimer’s Society then perhaps I would have given up and sat in a chair and lost interest” (person with dementia, Alzheimer’s Society feedback)

The only person, the only direct contact I actually have with any help is a member of staff from the Alzheimer’s centre” (person with dementia)

Singing for the Brain” – (many café members also attend) a group organised by the Alzheimer’s Society was widely praised: “it’s a right laugh” “everyone gets involved”

The Caring with Confidence development for carers which provides education is very good although it seems to fix on the wrong things first. In the early stages you just want to know how to deal with this condition and are you doing the best you can? Yet the carer’s courses have all the generic bits first which seems wrong to me “(Carer)

Positive practice in South West- the review team was impressed by:

In North Somerset, the Coping with Forgetfulness course offers post diagnostic support for people with dementia at the Woodspring memory assessment service and also has a monthly peer support group, supported by the Alzheimer’s Society. The Forget-Me-Not project encourages self referral to Alzheimer’s Society from six General Practitioner practices.

South Gloucestershire has some excellent forums for people with dementia and carers and a dementia café.

“Forget – Me – Not” service in Swindon for Younger people with dementia.

Objective 6: Improved community personal support services

3.48 Living Well with Dementia: A National Dementia Strategy requires that there should be a range of flexible services to support people with dementia living at home, and their carers, and that services should consider the needs and wishes of people with dementia and their carers.

3.49 Local Authorities, via Adult Social Care, are the main commissioners for these services which focus around a range of day care and domiciliary care services, or alternatives, arranged through individualised budgets. The NHS provides continuing health care for people living at home.

3.50 The transformation of social care is a key priority for local authorities with a focus on personalisation and individual budgets. People living with dementia are still largely marginal in these developments. In April 2009, the Adult Social Care Reform Grant was allocated to Councils to enable delivery of the Putting People First vision. LAC 1, Department of Health 2009 lays out the changes that were expected to be delivered using the Grant including integrated working with the NHS and commissioning strategies which maximise choice and control whilst balancing investment in prevention and early intervention.

3.51 The Department of Health has agreed with the Association of Directors of Adult Social Services and the Local Government Association that there are five key priorities during this first phase of transformation by April 2011. These are that:

- the transformation of adult social care has been developed in partnership with existing service users (both public and private), their carers and other citizens who are interested in these services;
- a process is in place to ensure that all those eligible for council funded adult social care support will receive a personal budget via a suitable assessment process;
- partners are investing in cost effective preventative interventions, which reduce the demand for social care and health services;
- citizens have access to information and advice regarding how to identify and access options available in their communities to meet their care and support needs;
- service users are experiencing a greater choice and improvement in quality of care and support service supply. This greater choice is built upon involvement of key stakeholders, (Councils, Primary Care Trusts, service users, providers, third sector organisations) that can meet the aspirations of all local people, whether council or self-funded, wanting to procure social care services.

3.52 Some providers feel threatened or are worrying about the potential impact of individual budgets and they need more help to understand the new model of service delivery and develop their contribution.

The review team found that:

3.53 The thresholds applied for access to community services preclude a significant number of people with mild or moderate dementia from accessing services and minimises preventative approaches unless organised via a non-mainstream funding route;

3.54 There is a variety of approach in commissioning domiciliary care for people with dementia. Some innovation was noted, for example using more flexible forms of contracting based on outcomes rather than time slots. In some areas specialist domiciliary care for dementia is being promoted although there was a comment that it can be expensive. Some areas offer extended 24 hour homecare services, some include only twilight services (6-10pm). Particular mention was made of the use of floating support workers across Bournemouth, Poole and Dorset to provide low-level enablement to people with dementia. This enabled people to remain living in their own home for relatively low unit costs;

3.55 Although many services are being commissioned through the third sector, particularly with Age Concern and the Alzheimer's Society, the commissioning of preventative services with the third sector was generally undeveloped. The lack of coverage and capacity by voluntary organisations across larger, rural areas presents a challenge for commissioning authorities. In addition many voluntary organisations do not have the infrastructure or skills base to enter into or deliver on contracts. Sustainability, accountability and demonstrating outcomes are key challenges. Some councils are responding by proactively building third sector capacity, for example developing commissioning through consortia arrangements or providing support with infrastructure costs;

3.56 In some rural areas long journey times is prompting the need to consider alternatives to traditional day care;

3.57 There were a number of references to difficulties in the interface between generic adult social care teams and specialist mental health teams. In some areas mental health teams had long waiting lists and high caseloads raising the necessary debate about how dementia case management can be sustained for people with more advanced and complex needs. The problem with capacity within these teams was exacerbated as professionals felt unable to discharge cases as there was nothing in place to refer people on to. The region has two integrated care pilot sites which offer the region a positive opportunity to learn from new integrated models of care management, although scaling up such projects was seen as a potential challenge;

3.58 Many people with dementia and carers reported that they had been let down by statutory services, particularly as a result of staff sickness and turnover, cases being closed without their knowledge and promises not being kept.

3.59 Younger people with dementia said their particular needs were not recognised and that any support available was often targeted towards older people and not appropriate. There were some exceptions to this, although because of low numbers of young people, these services had high unit costs.

3.60 Some councils for example Bath and North East Somerset, had made significant progress with the use of individual budgets and their experience will be invaluable to others. In other communities the use of individual budgets and direct payments was clearly underdeveloped. Incompatibility of IT systems was identified as one barrier to developing personal budgets.

3.61 Variable attention has been given to capacity planning and the market management of services which can be purchased directly by people living with dementia or their carers.

Plans for the South West:

3.62 Close links will be maintained with existing parallel regional work on transformation, Putting People First and individual budgets in order that the specific needs of people with dementia and their carers are considered.

3.63 There will be a particular South West work stream examining the interrelationship between generic and specialist team working.

3.64 There will be a particular South West work stream examining the cost benefit analysis of dementia specific domiciliary care. A national work stream is also being considered and the work in the South West may form part of this initiative.

3.65 Learning from the two integrated care management sites in Newquay and Bournemouth and Poole will be disseminated across the region and provide potential models for streamlining service delivery.

Case examples

What we need is localised services and a good choice of interesting activities to suit all tastes for both carers and the person with dementia and joint activities are often very enjoyable (Carer, Innovations in Dementia consultation)

“We need more continuity in our services – turnover of staff seems much too high” (person with dementia, Innovations in Dementia consultation)

Positive practice in the South West- the review team was impressed by:

Plymouth - specialist dementia domiciliary care and specialist training with an opportunity to co- locate with the Community Mental Health Teams.

South Gloucestershire, The Limes - ASSET service for younger people provides activity based support through a mentoring service in lieu of day care.

Bournemouth and Poole have an Integrated Pilot with the intention to develop a wider range of locally based, low-level interventions and links with General Practitioner practices.

The Melcombe Day Hospital in Dorset makes creative use of resources and provides a very enabling environment and the POPPS scheme offers a countywide approach to community engagement and thereby supporting people who may not be in contact with adult social care services.

In Devon, people with dementia are included in work on Individual Budgets.

A range of good quality community based services are in place across Torbay.

The Limes day resource for younger people with dementia commissioned by South Gloucestershire and provided by the Alzheimer's Society. Reviewers commended the service for being highly person centred and for its innovative practice.

Objective 7: Implementing the Carers’ Strategy

3.66 Living Well with Dementia: A National Dementia Strategy highlights the imperative that carers’ needs are included as part of implementation, with prompt assessments and personalised breaks. Supporting carers to care for people with dementia as long as possible at home, underpins the Department of Health economic assessment which in turn underpins Living Well with Dementia: A National Strategy.

The review team found that:

3.67 The support options for carers and coverage varied considerably. Support for carers was found to be not always fully reflected in local priorities. In some communities local carers' strategies had not yet been launched and service planning is often undermined by the lack of specific dementia carer data.

3.68 There were good examples of commissioned services for carers including:

- short break services, in a variety of settings;
- direct payments being used to promote choice and control on the part of carers;
- Carers' Emergency Schemes, offering the reassurance of guaranteed 48 hours of immediate care in a crisis situation;
- intention to appoint dementia specific carer support workers.

3.69 Bottlenecks in access to daytime breaks and respite care are a significant problem everywhere leading to very prolonged local waits. Carers said that access to breaks is often impossible and they also reported that agencies often failed to work together, causing unnecessary frustration and delay.

3.70 Carers commonly reported long delays in obtaining diagnosis for the person with dementia and that this had serious consequences for them as they struggled to cope without an understanding of the problems they were trying to manage. A further concern was that support tended to be offered very late in the day.

3.71 A particular feature was the poor data available on the number of carers' assessments carried out. Where assessments were occurring it was acknowledged that these were not always accurately recorded and that not all interactions with carers were recorded in the same way. As a result, most communities could not identify what proportion of carers of people with dementia had been assessed recently or were receiving services. Some of the paperwork associated with carers' assessments was found to be onerous and off-putting.

3.72 Arrangements for seeking the views of carers varied between communities. The best practice seen by the review team included a clear system for independent evaluation of the experience of carers of older people with mental health problems.

3.73 Carers' peer support and education arrangements are variable.

3.74 Low cost sitting services were available in some communities and were highly valued but not commissioned in a sustainable way.

3.75 Transport difficulties compounded problems for some carers, restricting access to services, support groups and adding to the difficulty of getting the person with dementia to daytime respite.

Plans for the South West:

3.76 Supporting carers is seen as a priority work stream in the South West. There is a significant parallel piece of work in relation to implementing the National Carers' Strategy. A baseline audit of the region's performance in relation to carers is currently being prepared by Carers UK and will be available in December 2009. This will result in a report to each community and recommendations for strengthening action plans. A development worker has been appointed to provide short-term support to some communities. There is also a professional awareness training audit and opportunities to bid for additional support to enhance professional awareness. Carers UK will also provide an overview report on the performance of the region in respect of implementing the Carers' Strategy. A conference on 25 January 2010 will present the findings which will assist in identifying regional activity to strengthen implementation.

3.77 The South West has the benefit of five carers' pilot demonstration sites, three in relation to carers' breaks, one in relation to NHS support to carers and one in relation to health checks for carers. Carers for people with dementia are likely to figure significantly within this activity. Early learning from these demonstrator sites will be disseminated.

Case example

- “just someone to sit with my husband so I can go shopping” (Carer, Innovations in Dementia consultation)
- “A day off a week would be fantastic” (Carer, Innovations in Dementia consultation)
- “I need practical help not scented candles” (Carer, Innovations in Dementia consultation)

Positive practice in the South West- the review team was impressed by:

In North Somerset, a group of mental health service users trained in the evaluation of local services, funded by NHS North Somerset, undertook a survey of carers of older people with mental health problems. Although some findings were critical, the report has been included by the Primary Care Trust as an appendix to the strategic document Improving Mental Health and Mental Health Services for Older People in North Somerset, and there is a commitment to undertake a follow up review.

Wiltshire has a range of innovative measures for carers. These include a Carers Emergency Card scheme offering a guarantee of 48 hours service in a crisis to 400 carers; a community safe haven scheme, offering a temporary place of safety such as a shop or library; and a carers’ strategy which is shaped by the voluntary and statutory sector, with feedback regularly sought via a carers’ audit and interactive carers’ website.

Objective 8: Improved quality of care for people with dementia in general hospitals

3.78 Living Well with Dementia: A National Dementia Strategy aims to ensure people with dementia will get better care in hospital by identifying leadership, defining the care pathway in hospitals and the commissioning of specialist older people’s mental health teams to work in general hospitals.

The review team found that:

3.79 The review team found that dementia care was not seen as a corporate priority or core business in some hospital settings. The ambition within the South West to have a full range of liaison services for people in hospital receiving care for physical conditions by 31 March 2010 is positive, but the scale of change requires greater commitment.

3.80 Whilst positive initiatives to improve hospital care were widely reported to be in place, for example ward based dementia champions, care practice varied from inspirational to examples of unsatisfactory person centred care. Carers reported that dementia was not understood or catered for in hospitals and described care experiences as poor. Particular mention was made of lack of support at mealtimes, for example food being served in unrecognisable or inaccessible forms and then taken away because it had not been eaten. In some hospitals dementia was seen exclusively as an elderly care issue with the result that there was a lack of appropriate care on other wards.

3.81 Many hospital wards have poor environments, unsuitable for the care and support of people with dementia.

3.82 Delays in discharges of people with dementia were reported to be occurring in a number of hospitals. Reasons included delays in CHC screening, lack of prompt physiotherapy, time taken to set up home care packages and delays in achieving mental health assessments.

3.83 Reducing inappropriate transfers is a key issue. The role of the dementia adviser could be instrumental here in providing a link between the person, the hospital staff and the carer.

Plans for the South West:

3.84 Hospital care has been identified as the priority and a specific programme to address shortfalls in hospital care and delays in discharge is to be developed.

3.85 Consideration is to be given to developing a hospital person centred passport scheme similar to that introduced in some areas for people with learning disability.

3.86 Best practice initiatives resulting in improved patients will be disseminated.

3.87 Avoiding hospital admission is also seen as a priority. In addition to the development of intermediate care, specific links are to be developed with NHS Ambulance services to clarify how they can contribute to improved outcomes for people with dementia.

Case example

- There was a person with Pick's disease discharged home at 5.00am with no warning (Innovations in Dementia consultation)
- There were problems with pulling out catheter tubes, and the nursing staff seeming not to understand that this might be a problem or what to do about it "they just didn't understand about dementia" (Innovations in Dementia consultation)
- My mother was moved to seven different wards during her stay in hospital – making her extremely confused. (Carer, Innovations in Dementia consultation)

Positive practice in the South West- the review team was impressed by:

- Royal United Hospital Bath NHS Trust has audited areas of good practice and areas for improvement in the hospital dementia pathway; results showed very good practice in discharge planning and end of life discussions with family and carers, but lack of consistency in the identification and management of patients with dementia, with an action plan now in place to meet a range of service improvement aspects and a new dementia pathway in place. Royal United Hospital Bath NHS Trust's project on improving dementia care.
- Torbay Hospital –privacy and dignity initiatives in wards/departments.
- Gloucestershire Hospitals NHS Foundation Trust and 2Gether NHS Foundation Trust –The Governors of the Trusts have worked together on identifying initiatives to improve dementia care.
- In Bournemouth and Poole, Merrick Ward Assessment Unit - Staff training was comprehensive, learning outcomes were assessed. Simple, innovative ideas were evident such as the clothing identification system, which promotes and maintains patient dignity. These ideas could be rolled out extensively.
- Swindon Victoria Centre and Great Western Hospitals NHS Foundation Trust examples include: life story work led by the drama therapist; the physiotherapist in the Victoria Centre extending knowledge and experience of dementia through the inclusion of the Centre in the rotation of physiotherapists within the general hospital; mental health liaison nurse training; the work of the Kings Court Research Centre.
- NHS Bristol has a mental health liaison team that works in wards where there is a high proportion of people with dementia. Ward teams, hospital social workers and other staff are trained to better identify and manage dementia, making it easier to treat primary medical conditions.

Objective 9: Improved intermediate care for people with dementia

3.88 Living Well with Dementia emphasises intermediate care should provide a service which will enable more care for people who want help to stay at home.

3.89 This was a difficult area to assess. Although many communities had a policy confirming that a patient with cognitive impairment should not be excluded from rehabilitation services, there is relatively little data on case-mix and co-morbidity for community services in health and social care to demonstrate compliance. In talking to staff in several communities, however, the review team noted there were differences of opinion locally about the extent to which this principle was upheld, with suggestions that ‘no rehabilitation potential’ was a label that could easily be applied to someone with dementia.

3.90 Guidance, July 2009, on intermediate care services from the Department of Health, emphasises the core message that all teams need to have competency in mental health and dementia care and ready access to specialists. It highlights there are a range of models of care involving, for example:

- recruitment of mental health professionals as core members of a generic intermediate care service, to enable members of the team to accept people with dementia or mental health needs with confidence;
- close links with a community mental health team;
- provision of a specialist service for assessment and care.

3.91 The guidance further emphasises that specialist members of generic teams should not be expected to take on all the dementia or mental health cases themselves. But rather they should provide support and training to colleagues and that all members of intermediate care teams should receive some training in mental health and dementia care. The importance of access to community psychiatrists and to liaison teams working in acute hospitals is also mentioned.

The review team found that:

3.92 Some communities had developed specific services to meet the rehabilitation needs of older people with dementia and others had made efforts to include specific mental health expertise in their intermediate teams by including mental health nurses. Community teams with a physical health focus stated that they would benefit from greater training in caring for people with dementia and would like to develop closer links with local community mental health teams. Some people commented that current, generic models of intermediate care do not provide a good service to people with dementia. Data from one review suggested that 25% of intermediate care patients have dementia.

3.93 There were common reports that access to intermediate care for people with dementia was either poor or limited and that there was a lack of specialist mental health support to intermediate care teams. There was strong support in the consultation exercise carried out by Innovations in Dementia for specialist intermediate care to be provided for people with dementia. A number of carers said that people with dementia were often excluded from intermediate care and assumed to be unable to improve or regain skills.

3.94 There was significant potential in some communities to reduce the number of people with dementia being admitted to hospital or discharged from acute care to residential homes.

Plans for the South West:

3.95 Intermediate care will be primarily addressed through the commissioning and dementia care pathway work streams having the potential to avoid unnecessary hospital admission or placement in long-term institutional care.

Case example

> "So often if you have a label of dementia you don't get what other people get "(Carer Innovations in Dementia consultation)

- The notion of improvements to the provision of intermediate care was strongly supported, not least by the participant whose husband's loss of mobility she links to lack of rehabilitation (Innovations in Dementia consultation)
- Another participant reported very poor input from physiotherapy while her husband was in acute care – with no physiotherapy for three weeks during Christmas and new year period during which he lost mobility altogether. As a result he moved directly into a care home. 'I am sure he would have been able to return home if he had not lost mobility' (Innovations in Dementia consultation)

Positive practice in the South West- the review team was impressed by:

- Gloucestershire offers community based intermediate care which addresses the requirements of the National Dementia Strategy.

- In Torbay the new intermediate care service at St Edmund's was very impressive with nine specialist beds for people with dementia rehabilitation and plans over the next 18 months to set up a re-ablement team, separate from St. Edmund's.

- In Bristol, in addition to community-based intermediate care teams, residential re-ablement support for patients with dementia, predominantly post-discharge from hospital, who can benefit from rehabilitation for up to 8 weeks, is run at Saffron House. Based at an independent sector nursing home with specialist staff from Avon and Wiltshire Mental Health Partnership Trust, this offers a fixed period of residential re-ablement support. This has reduced both placements to residential care and the intensity of ongoing support required for individuals.

Objective 10: Considering the potential for housing support, housing-related services and telecare to support people with dementia and their carers

3.96 Living Well with Dementia: A National Dementia Strategy requires that people with dementia and their carers should be included in the development of housing options, including assistive technology and telecare. Commissioners should use emerging evidence to promote options to prolong independent living.

3.97 The review team was impressed by the localities that have or are developing new facilities as a result of close working with strategic planning and housing providers. Those local authorities that retained in-house residential accommodation over the last 10-15 years have had more opportunity to redesign services. Despite assistive technology developments and pilots over the last ten years the evidence of large scale impact on people living with dementia is still emerging.

The review team found that:

3.98 Provision of housing for people with dementia was very patchy across the South West with few examples of imaginative use of telecare and extra care housing. This is an area which has huge potential to enable people be better supported to stay at home longer. Some areas have started to consider this as a planned approach to shifting resources away from residential care and providing real alternative choices for people with dementia to retain their independence and remain in their own homes or move to supported living. The reviews did not provide any clear analysis as to the breakdown between generic and dementia specific schemes and whether any differentiation in approach is desirable.

3.99 In many communities the development of telecare and telehealth solutions was quite limited. In one area this was due to scepticism about the evidence base for the use of this technology.

Plans for the South West:

3.100 Priority will be given to dissemination of the evidence-based benefits of telecare and telehealth. The best practice emerging in some communities and from the Cornwall Whole System Demonstrator site will be shared across the region.

Case example

- “an emergency alarm would be great – I’m really worried what would happen if I fell and couldn’t raise the alarm” (Carer, Innovations in Dementia consultation)
- “I could have cared for him myself - but now he’s in a care home” (Innovations in Dementia consultation)
- “They told me to telephone the police if he attacks me again – but what if I can’t get to a telephone? Surely there must be an alarm system or something?” (Carer, Innovations in Dementia consultation)

Positive practice in the South West- the review team was impressed by:

- Wiltshire has an accommodation and support strategy and a modelling tool which predicts demographic increases and has been used to plan extra housing for the future as an alternative to care homes.
- Dorset has positive opportunities for the development of telecare with an open access referral across the county.
- In Bristol, housing and housing support is a priority with a network of sheltered housing schemes.
- Plymouth has given Extra Care Housing high priority and has made progress with many having dementia facilities
- North Somerset has a housing strategy with dementia dimensions.
- Wiltshire also has developed a very comprehensive telecare service which enables people to use assistive technology to remain at home.

Objective 11: Living well with dementia in care homes

3.101 Living Well with Dementia: A National Dementia Strategy requires services to work together to ensure better care for people with dementia living in care homes. This includes identifying a staff member with a clear responsibility for dementia, having a clear description of how people will be cared for, visits from specialist mental health teams and better checking of care homes. This is a key objective given one third of people with dementia live in care homes and at least two thirds of all people living in care homes have a form of dementia.

3.102 The rating given to care homes by the Care Quality Commission (CQC) is one significant indicator of quality. The proportions of poor/adequate/good and excellent homes vary around the region, yet overall there are 40 homes rated poor and 250 as adequate.

The review team found that:

3.103 All communities were targeting their homes rated ‘poor’ with support. There were some good examples of efforts to raise standards, but this was often reacting to crises rather than a proactive approach. In tackling homes rated ‘poor’ there was a strong emphasis on training and awareness raising amongst staff.

3.104 Several communities are working on new contracts with care homes, increasing their contract monitoring. The systems for regular review visits for local authority funded clients vary across authorities.

3.105 The amount of training generally provided varied considerably as did NHS in-reach and support services, covering nutrition, continence, depression and medications.

3.106 There was good evidence of training in other key areas such as safeguarding and the Mental Capacity Act for care homes and evidence that in some communities Primary Care Trusts had targeted care homes as a priority for relevant training from NHS community staff. Take up of training amongst lower rated care homes was not always high.

3.107 In many areas, the rating of specialist dementia care homes was good and typically there were strong links between Primary Care Trust continuing healthcare team nurses and these homes, offering regular informal review and feedback on individual clients.

3.108 The review teams found a constructive partnership approach to continuing healthcare decision-making across the majority, but not all, health and social care communities in the South West. The investment in NHS Continuing Healthcare has increased substantially in all areas since the introduction of a national assessment framework.

3.109 Some care homes were visited by the review teams and were clearly of a high standard. However, there were also reports, during the consultation carried out by Innovations in Dementia, of poor services and environmental conditions with lack of staff training. A key theme was that care homes can pass minimum standards required by the Care Quality Commission but are not seen as acceptable by people with dementia or their carers. There were reports of poor quality environments in terms of décor and smell, clothing being lost, concern over the use of anti-psychotic medication, high staff turnover and language difficulties. There was a need identified for much more stimulation and more activity and for smaller, more homely units.

3.110 One Authority (North Somerset) offers a quality premium linked to care homes Care Quality Commission rating.

Plans for the South West:

3.111 Improving care provided in care homes is a priority. A focused piece of work has already been undertaken outside of the main review to understand the barriers to improving care home experiences and identify a plan to promote improved and person centred care in care homes. This included an analysis of the characteristics of poor and excellent services, and a focus group including Care Quality Commission inspectors, providers, commissioners and carers of people with dementia. A separate report is available via the South West Dementia Partnership website.

3.112 It is the intention to ensure that all care homes have dementia link workers in place and to improve the quality of training across the sector. It will also include promoting awareness of the invaluable material now available from the Social Care Institute for Excellence, www.scie.org.uk/publications/dementia/index.asp.

3.113 Best practice care service commissioning will be disseminated across the region.

Case example

“you see the certificates on the wall but no-one can tell you what this means for their knowledge about people with dementia” (Carer, Innovations in Dementia consultation)

“There is so much opportunity for improving levels of meaningful activity and stimulation for people with dementia” (Innovations in Dementia consultation)

“I was frightened to complain in case it affected my husband’s care” (Carer, Innovations in Dementia consultation)

One participant reported significant improvement in her husband’s cognition and memory whilst in care “they should be paid better for the work they do” (Carer, Innovations in Dementia consultation)

“why can’t people stay in one home for longer? They are so quick to move people on as their needs increase – they never get the chance to make a home for themselves” (Innovations in Dementia consultation)

Positive practice in the South West- the review team was impressed by:

Bristol - Residential Futures project to modernise in-house provision of dementia care homes and develop a more flexible bed-base and links to supporting services, like STAR, via four new Resource Centres. This has included taking advice to inform the redesign of the dementia environment.

Somerset - Specialised Residential Care (SRC) scheme and the work of Care Focus. There also appears to be firm control of the NHS Continuing Healthcare assessment process and spend.

In Bournemouth and Poole, dialogue with care home providers about the need to re-shape their services in line with social care transformation and the impact of an ageing population, has resulted in 23 residential homes in Bournemouth expressing interest in securing registration as homes for people with dementia, and contract monitoring in Bournemouth is encouraging a more person centred approach from care home providers.

Gloucestershire has carried a successful programme of medication reviews in some care homes with an economic evaluation by UWE (University of West of England) which suggest that if the medication review work was replicated across all care homes in Gloucestershire there were potential savings of £2.5m.

Gloucestershire has been particularly active and successful in promoting and developing dementia link workers within care homes. There has also been successful use of NHS in-reach support and the use of the local provider association to provide advice to homes which are struggling.

Objective 12: Improved end of life care for people with dementia

3.114 Living Well with Dementia: A National Dementia Strategy requires that people with dementia and their carers should be involved in planning end of life care, based on the principles outlined in the End of Life Strategy published in July 2008. One in three people aged over 65 years will have dementia in the last year of their life. To be effective, developments must closely link both of these strategies.

3.115 *Out of the Shadows* published in February 2009 includes the first national survey of the palliative and end of life care needs of people with dementia and carers. The analysis shows the importance of good quality physical care, education and training of nurses in care homes and hospital settings, information support and the importance of an overall framework of support to enable choice to be made. North Somerset is one of seven Marie Curie's pilot sites for palliative care.

3.116 There are aspects such as end of life care at home whereby the district nurse needs to have knowledge and skills in caring for people with dementia and the impact of dementia on normal medical symptoms such as constipation. Access to specialist dementia nursing advice is also required for carers and to care home staff on the specialist input to care for people with dementia at end of life.

The review team found that:

3.117 End of life care provision for people with dementia is variable in the South West. In most communities there was no evidence of any clear, consistent end of life pathways for people with dementia. In some communities generic end of life pathways were well established with the roll out of the Gold Standards Framework and Liverpool pathways. In others end of life care for people with dementia is underdeveloped.

Plans for the South West:

3.118 This is an area of general weakness in the South West and although there are initiatives in relation to the Liverpool Pathway and Gold Standard Framework to draw upon, there appears to be little evidence of best practice dementia-specific end of life care. It is understood to be an area of specialism. The plan is to establish connections through the National Dementia Strategy national implementation team with other parts of the country to create opportunities for the South West to benefit. This will be coordinated by the South West Dementia Strategy implementation sub group.

Case example

The local palliative care team did not feel that they would be able to offer any care as Mildred had a primary diagnosis of dementia. The hospice also declined admission for the same reason. She was admitted back to the general hospital where she died within eight hours of admission (End of Life Strategy Case study)

Positive practice in the South West- the review team was impressed by:

In Bath and North East Somerset, the End of Life work involving a training package in conjunction with the hospice for seven - eight care staff and ten managers (overall) from the five domiciliary care strategic partners along with people from the community. This has been developed in the wider context of a domiciliary care strategic partnership between a group of nominated providers and the Council.

Somerset End of Life Care model established within the care home visited.

South Gloucestershire - Laurels Ward, Callington Hospital – commendable environmental features, including the End of Life care room and utilisation of the Liverpool Care Pathway, links with St Peter’s Hospice and the Southmead End of Life Team.

Objective 13: An informed and effective workforce for people with dementia

3.119 Living Well with Dementia: A National Dementia Strategy identifies that all health and social care staff who work with people with dementia should have the right skills to give the best care, get the right training, and get support to keep learning more about dementia.

The review team found that:

3.120 Workforce strategic planning and development in respect of dementia care was generally weak. In most areas there was no effective, co-ordinated workforce development strategy in respect of dementia. Data collection on training was also often lacking. Even where dementia training was being provided it was described as piecemeal and patchy. Some areas had made good progress in developing links with local workforce development specialists, building links across agencies including provider services and were devising a joint training strategy. Most NHS commissioners had not yet begun to consider how Non-Medical Education and Training (NMET) funding for workforce development could be influenced through commissioning activity. In social care there was more evidence that workforce grant funding was being used to target dementia care.

3.121 The experience of those communities who had made progress in planning a training and workforce development strategy was that a sustained effort over several years was required to develop a range of training and support interventions, to develop interest amongst practitioners and secure support from the range of provider organisations to release staff and encourage uptake.

3.122 It was hard to differentiate between general “awareness training” which was quite prevalent with more in depth skills based training designed to develop competencies. Generic older people and neighbourhood teams in particular appear to lack skills in responding to dementia.

3.123 There is development of e-learning in some parts of the region. The effectiveness of this will need to be evaluated.

Plans for the South West:

3.124 The South West needs an integrated workforce development plan. It also needs to be aligned with developments by Skills for Care both in establishing the new qualifications framework and the development of dementia specific training modules.

3.125 This review noted that the plan needs to incorporate a wide range of staff including personal assistants and staff operating in the expanding range of housing with care facilities.

Case study

- “Awareness needs to be improved, as many people assume that my husband won’t be able to communicate with them” (Carer, Innovations in Dementia consultation)
- “They assume that people with dementia are incapable of anything” (person with dementia, Alzheimer’s Society)
- Training for care home workers cited as important by many participants (Innovations in Dementia consultation)
- “They need to improve respect for the person with dementia” (person with dementia, Alzheimer’s Society)

Positive practice in the South West- the review team was impressed by:

Gloucestershire County Council has been working collaboratively to lead the development and implementation of a county-wide dementia training and education strategy, to improve services for people with dementia and their carers. There is an agreed approach across agencies with the development of a stepped programme to acquire skills and knowledge by county dementia passport which is externally accredited and mapped against the Skills for Care dementia knowledge sets. Priority has been given to care home and domiciliary care staff. The development of dementia link workers in care homes trained to NVQ level III has been extremely positive. A bespoke e-learning package was a good example of making individual training available to busy frontline staff. This has a Gloucestershire flavour and links to local resources and policies.
Paid sessional General Practitioner dementia champion has been particularly affected in promoting interest in dementia care.

Wiltshire has a dedicated workstream developing a training and awareness plan for staff in generic teams across the NHS, Adult Community Services and the independent sector which is high profile, flexible and comprehensive. There is a multi-agency Workforce Development Group, chaired by a workforce development lead to plan joint workforce development across the statutory and independent sector for dementia, beginning with the mapping of occupations and roles.

Objective 14: A joint commissioning strategy for dementia

3.126 Living Well with Dementia: A National Dementia Strategy requires local commissioning and planning mechanisms to be established to determine the services needed by people with dementia and their carers and how best to meet these needs. The commissioning plans should be informed by World Class Commissioning guidance for dementia services and the Joint Commissioning Framework for Dementia published by the Department of Health in 2009.

3.127 Most areas have a joint commissioning strategy in place across health and social care. In the majority of cases this was still in draft format and had not been fully consulted upon or formally approved. In some review visits the team found front line staff were not aware of a strategy for their community.

3.128 More than half of the 14 communities had identified a lead officer for dementia commissioning. The majority of these commissioners had responsibility for either older people's commissioning or older people's mental health. Strong joint leadership is identified as critical to reshaping services and in many communities joint commissioning boards have been established to drive forward changes. In some communities commissioning was not joined up across health and social care.

3.129 A number of voluntary organisations in the South West are in the process of reorganisation and reconsidering their role in the community. Coverage by voluntary organisations across the South West is uneven which means that people in more dispersed rural communities are less likely to have access to services. There would appear to be benefit in understanding the role, capacity and challenges of both regional players like Age Concern, the Alzheimer's Society and Princess Trust for Carers as well as more groups.

The review team found that:

3.130 Few examples of joint NHS /Local Authority arrangements, where the capacity and capability of commissioners had directly influenced substantial progress in the development of plans. There was little evidence of significant disinvestment and reinvestment in order to increase capacity.

3.131 Service development and provision appears to have been opportunistic or based on historic patterns of service provision. Many third sector services have not been commissioned and have evolved through historical funding arrangements. NHS trusts providing specialist services have often led on service design and change.

3.132 Recurring themes included:

- Lack of any anticipation of the increased prevalence in years to come or the impact of increased levels of formal diagnosis;
- Lack of gap analysis between required and existing service provision, for example in relation to carer services;
- Lack of financial modelling;
- Failure to commission to pathway or across a whole system;
- Lack of definition of outcomes or quality standards;

- Lack of project planning to achieve implementation, for example with timescales and milestones.

Common challenges identified were:

- Working with diverse range of providers particularly in the independent care home sector;
- Commissioning sustainable services from the third sector;
- Estimating current spend on dementia related services;
- Lack of dementia specific data in relation to current service provision. There were also challenges in data analysis because of different IT systems operating across teams;
- Differences in approach and perspective between different NHS providers of mental health services.

Plan for the South West:

3.133 Effective commissioning was identified by the review team as the critical and overarching activity which establishes a joined up framework of service provision as well as promoting good outcomes. Commissioning impacts on all of the other 13 objectives considered by the review.

3.134 The plan for the South West needs to be integrated with regional commissioning workstreams and the national joint commissioning workstream. The starting point is therefore to ensure coordination with these other areas of activity. Commissioning models will need to take account of predicted prevalence and cost benefit models.

3.135 Central to the plan and the South West is to develop a commissioning framework which is aligned to the pathway specification which is being developed in the region.

Case example

- “all I got were leaflets – nothing to help me make sense of it all or think about what we might want to do – that’s what we needed” (Carer, Innovations in Dementia)

- “so we waited for a crisis, and rang, but there was a new social worker so we had to go through it all from scratch with her – there was no continuity” (Carer, Innovations in Dementia)

Positive practice in South West- the review team was impressed by:

NHS Gloucestershire has been working with Gloucestershire County Council, 2gether NHS Foundation Trust, the independent sector and voluntary organisations to develop a strategic work programme to drive local implementation of the National Dementia Strategy.

Cornwall - Commissioning intervention/treatment and support from a range of providers through a pathway approach – e.g. Developing and consulting on a service specification for a memory assessment service.

Bournemouth and Poole have redesigned commissioning arrangements between the Primary Care Trust and the two local Boroughs to create one team to include a dementia programme manager.

Wiltshire - There is a transparent approach to providing appropriate support for the voluntary sector from health and social care commissioners, via two funding streams

Section 4

Joint South West Dementia Implementation Plan: Purpose, Process and Regional Priorities

This section sets out the proposed priorities for an Implementation Plan to support local delivery and next steps which will ensure that the findings of the review influence future practice.

4. Joint South West Dementia Implementation Plan: Purpose, Process and Regional Priorities

Implementation Plan Purpose

4.1 The proposed objectives for the South West Dementia Implementation Plan are to:

- ensure all local communities are able to achieve significant progress in implementing the National Dementia Strategy and that variation within and between communities is minimised;
- deliver regional projects on identified areas of challenge which will assist in the implementation of the National Dementia Strategy across the region;
- provide information and opportunities for communities to learn from best practice both regionally, nationally and internationally;
- ensure local communities have access to wider information about developments and learning relating to the National Dementia Strategy;
- ensure that there is synergy and coordination with other related regional programmes;
- ensure that there is a reliable and effective infrastructure in place to support implementation the strategy, including information dissemination (e.g. website and newsletters) and events (e.g. conferences);
- ensure that the views of people with dementia and their carers remain central to the implementation of the National Dementia Strategy;
- support the development of tools to demonstrate the impact of the National Dementia Strategy and evaluate implementation within the region.

4.2 These objectives reflect the expectations set out for regional support teams by the Department of Health in the Implementation Plan published in July 2009 to accompany the National Dementia Strategy.

4.3 In delivery of these objectives the importance of local engagement and co-production are assumed.

Implementation Plan Process

4.4 Following a detailed feedback report from the review team, each community was required to provide an action plan detailing the response to the priorities recommended for change. They were also asked to identify any support requirements.

4.5 The implementation sub group, established by the South West Dementia Partnership, will identify a link person from the sub group for each community. The link person will be responsible for providing advice and support to the local community in carrying forward their action plan and will help the community establish contact with others who have achieved or are developing solutions. The link person will also be able to provide references to national developments, best practice and research findings.

Implementation at a regional level

4.6 The South West Dementia Partnership:

- will promote a series of regional priorities for common challenges and where is benefit to be derived by looking at experiences together. The work streams associated with these priorities will be led by a member of the implementation sub group supported by people within the region who have expressed an interest. The priorities are set out in Table 1 below;

- recognises the potential and value of information sharing in an area of service delivery which is evolving and developing at a fast pace. The importance of disseminating regional and national messages and best practice is recognised. The primary method for this will be the regional website supplemented by newsletters; www.southwestdementiapartnership.org.uk.

- will use this opportunity to develop networks, build and assist coalitions regionally and nationally. These connections will be important in developing links with regional bodies and related regional work streams. This will strengthen the implementation in the South West and ensure that activity is coordinated.

- will develop tools and metrics to assist in the evaluation of implementation of the strategy for use at both a local and regional level. This will enable reporting of progress to the Department of Health.

Regional priorities

4.7 Following the national consultation, seven priority objectives were identified that are likely to require focused attention to achieve urgent changes in the experiences of people with dementia and their carers. These are:

- early intervention and diagnosis for all;
- improved community personal support services;
- implementing the New Deal for Carers;
- improved quality of care for people with dementia in general hospitals;
- living well with dementia in care homes;
- an informed and effective workforce for people with dementia;
- a joint commissioning strategy for dementia.

4.8 These objectives were confirmed as being the initial priorities for the South West following the dementia review.

4.9 In addition the review team took account of the economic modelling underpinning the National Dementia Strategy. This indicates priorities which should include extending the network of memory clinics, larger community mental health teams funded by the NHS and enhanced social services for older people with memory problems.

4.10 The South West review team also considered that improving services to reduce the delays and inappropriate discharges within acute and community hospitals would make a positive impact on costs in the short and medium term.

4.11 The following table 1 identifies key priorities arising from the review and proposed activity to carry implementation forward.

Table 1: Priorities for South West Dementia Implementation Plan

Theme	Review findings	Action
Ensure good quality early diagnosis and intervention Objective 2	The review team found that most communities have not commissioned memory assessment services with defined and agreed outcomes. Carers and people with dementia reported long delays in obtaining diagnoses and noted the critical role played by General Practitioners many of whom seemed under confident or not knowledgeable in respect of dementia. Review found evidence of some GPs avoiding diagnoses of dementia. Pathway in some communities confused by having different memory services operated by different parts of NHS.	Ensure memory assessment services are universally commissioned meeting certain minimum standards. Ensure pathway clarifies role and competence of GPs in respect of undertaking assessments and thresholds for referral to more specialised assessment services.
Improved community support services Objective 6	People with dementia and carers reported high level of activity at time of diagnosis and then an experience of abandonment. Instability and sickness absence amongst community teams was regularly reported creating unreliability and a failure to deliver expected plans. Variable team working arrangements exist in the region. In some areas there is a lack of coordination /disjuncture between local adult social care teams and community mental health teams. Range of arrangements for home care commissioning and specialisation evident. People with dementia and carers consistently reported high satisfaction with support from local voluntary organisations e.g. dementia cafes, Singing for the Brain. Use of individual budgets by people with dementia is very limited	Ensure effective integrated community personal support service models that are personalised, reliable and offer choice. Develop models for effective working between adult social care and community mental health teams. Develop best practice models for the commissioning and provision of home care to people with dementia. Development with key regional third sector providers to consider how regional coverage might be improved. Establish link to Putting People First to understand how individual budgets for people with dementia might be promoted.

Theme	Review findings	Action
Implementing the carers' strategy Objective 7	The review found that carers had difficulty in gaining access to assessments, support or breaks. Carers really appreciated emergency cards where schemes were in place. Data collection in respect of carers was generally weak. **The DH economic assessment reinforces the need for early support for carers**	Ensure that the implementation of the Carers' Strategy has a fully embedded dementia focus. There is a parallel work stream being undertaken on implementing the Carers' Strategy beginning with a benchmarking exercise being undertaken by Carers UK due to report December 2009.
Improved quality of care in general hospitals Objective 8	The review team found that improved dementia services did not pervade all relevant settings. Transformation of care is required in all relevant services within general and community hospitals for people with dementia and carers, with agreed quality standards around assessment and discharge. This should include development of metrics and performance monitoring arrangements.	Support commissioners and providers to develop patient safety and quality of care standards. Promote participation in core audit of dementia care received by people in general hospitals provision developed by Royal College of Psychiatrists with agreed action plans
Improved quality of care in care homes – Objective 11	The review team identified good practice in care homes but ample scope for extending the depth and spread. Many services remain very traditional and have not adopted a personalised approach.	Coordinated and targeted activity across CQC and commissioning teams to improve the quality of care being provided by services in SW. Spread of best practice commissioning, CQC and provider lead initiatives to promote personalised care using evidence based interventions. Spread of best practice in NHS/local authority in reach support to all care homes and targeted support to homes not reaching required standards. Supporting the transformation of intermediate care to ensure equality of access for people with dementia. Scope the roll out of medication reviews, based on best practice in Gloucestershire.

Theme	Review findings	Action
Ensure workforce planning and development addresses the needs of the Living Well With Dementia: A National Dementia Strategy Objective 13	The review team found that workforce planning and development is very mixed both across social care and health. There is a need for regional coordination to support improved planning and action.	Ensure a South West Strategy for developing a dementia workforce to reflect requirements of new service models.
Ensure effective joint commissioning linked to national strategy Objective 14	The review identified wide variation in service approaches which, if not addressed, will perpetuate inconsistency in implementation of any agreed priorities across the South West. With few exceptions current joint commissioning strategies are very underdeveloped. **Note:** Joint commissioning is a fundamental activity which shapes services. It should establish a reliable continuum of provision to support people at different stages on the dementia care pathway Substantial progress will not be achieved unless there is sufficient joint commissioning capacity in each health and social care community along with required commissioning capability.	A regionally led work stream to develop financial and service planning models and tools to ensure better understanding and application of economic modelling for use in 14 communities. Development of modelling to inform revised strategies incorporating local detail of disinvestment and re-investment timetable; this will be assisted by a care pathway, new service models and specifications. It needs also to include spreading best practice in joint contracting arrangements and uses of pooled budgets e.g. care home placements.

Existing work streams

4.12 In addition to the South West review of dementia services two other work streams had already been established by the South West Dementia Partnership to support the implementation of the National Dementia Strategy.

- <u>Development of a Dementia Care Pathway</u>. This work is being led by Dr Denise Cope, Chair of the Clinical Pathway Group for Mental Health and Wellbeing. It will provide a core pathway to inform local development and is planned to be available in April 2010. This will specifically address both the needs of younger people with dementia and the needs of people with learning disabilities.

- Awareness Raising Study. A South West media campaign was commissioned by the South West Dementia Partnership with Northcliffe Media Group, to raise awareness of dementia and receive feedback about services. The campaign has included editorial spreads in daily papers and print coverage in all weekly newspapers. It incorporated a questionnaire for the public which is currently being analysed. The outcome of this exercise will be available in January 2010. A communications sub group has been established by the South West Dementia Partnership to include NHS, Local Authority and Alzheimer's Society representatives to ensure a regionally coordinated approach.

Appendices

Appendix 1

Demographic Table

This appendix sets out demographic information by Primary Care Trust and rates of registration by General Practitioners against estimated prevalence levels.

1. Demographic Table

1.1 Currently there are approximately 700,000 people with dementia in the United Kingdom and this is estimated to rise to 1.4 million by 2038, at a cost of £17 billion in 2008, and over £50 billion in 2038.

1.2 Dementia is predominantly a disorder of later life, but there are at least 15,000 people under the age of 65 in the United Kingdom who have the illness.

1.3 In the South West, where there is a higher than average population of older people, and, consequently, more likelihood of people developing dementia, it is estimated there are currently 72,000 people with dementia.

1.4 Of the nine English regions, the South West has the highest percentage of people of retirement age and above at 21.8%, compared to an English average of 18.6%. Dorset and Torbay both have more than a quarter of their population of retirement age and above as stated in the 2005 Mid Year Population Estimates. The population of the South West is expected to grow by almost half a million people between 2003 and 2018, and by another 325,000 by 2028, according to Office of National Statistics 2003 based sub-national population projections.

1.5 Of the nine English regions, the South West has the highest life expectancy for women; 82.7 years compared to an English average of 81.6 years. For men, it is the joint highest, along with the south east, of the nine English regions; 78.5 years compared to an English average of 77.3 years.

1.6 The expected increase in population aged over 80 in 2025, compared to 2009 is expected to be 55.1% in the South West, compared to 51.9% in England as a whole.

Figure 1: Table showing numbers of people with dementia by Primary Care Trust, projected increase in 2021, the numbers of people registered with dementia by a General Practitioner, Ranking - position of PCT area compared to other PCTs where 1st is the PCT with the highest proportion of people on a register and 152nd is the lowest

Primary Care Organisation	**Estimated number of people with dementia in 2007**	**Estimated number of people with dementia in 2021**	**Projected percentage increase in number of people with dementia by 2021**	**Numbers of people with dementia on a GP register April 2007 - March 2008**	**Percentage of the numbers of people with dementia on the GP register**	**Ranking**
NHS Bath	2219	2833	**27.7%**	746	**33.6%**	125th
NHS Bournemouth and Poole	5344	6315	**18.2%**	2332	**43.6%**	38th
NHS Bristol	4125	4364	**5.8%**	1540	**37.3%**	90th
NHS Cornwall and Isles of Scilly	7964	11699	**46.9%**	2654	**33.3%**	127th
NHS Devon	12177	17518	**43.9%**	3527	**29.0%**	149th
NHS Dorset	6673	9624	**44.2%**	1952	**29.3%**	147th
NHS Gloucestershire	7386	10390	**40.7%**	2825	**38.2%**	84th
NHS North Somerset	3510	5090	**45.0%**	1095	**31.2%**	135th
NHS Plymouth	3162	4222	**33.5%**	1063	**33.6%**	124th
NHS Somerset	7640	11495	**50.5%**	2425	**31.7%**	134th
NHS South Gloucestershire	2629	4006	**52.4%**	855	**32.5%**	129th
NHS Swindon	1687	2373	**40.7%**	829	**49.0%**	11th
Torbay Care Trust	2775	3726	**34.3%**	845	**30.5%**	141st
NHS Wiltshire	5520	8367	**51.6%**	1716	**31.1%**	136th
	72811	102022		24404		

Source: Alzheimer's Society

1.7 Figure 1 shows that:

- NHS Devon will have the highest projected number of people in the South West living with dementia in 2021, with NHS Bath and North East Somerset with the lowest number;

- the lowest projected increase of people with dementia is projected for NHS Bristol, at 5.8%, and the highest projected increase in South Gloucestershire, at 52.4%;

- NHS Swindon has the highest percentage of people with dementia on a General Practitioner register with 49%, and NHS Devon the lowest at 29%;

- NHS Swindon and NHS Bournemouth and Poole are the only Primary Care Trusts in the South West to be in the top 25% for General Practitioner registration of people with dementia.

1.8 The generally low numbers of people on General Practitioner registers in the South West is a cause for concern; especially as early diagnosis and support from General Practitioners is highlighted as extremely important in Living Well With Dementia: A National Dementia Strategy.

Appendix 2

Methodology and Review Process

This appendix sets out the methodology and process followed by the South West review of dementia services.

2. Methodology and review process

2.1 The method for the Joint Review of Dementia Services in the South West was based on a whole system, partnership approach, using a range of clinicians, managers, carers and Alzheimer's Society representatives from each of the local areas to undertake a peer group review. This was the first time such a process has been used in the United Kingdom to identify strengths and areas for development in dementia services against the National Dementia Strategy. The process is now being replicated by NHS Yorkshire and Humberside and we have shared our approach with them.

2.2 The review process began with the collection of a set of core data set. This included quantitative and qualitative information based on priority themes and benchmarks set out by the South West Dementia Services Strategy Group and provided by each of the local health and social care commissioning leads. In addition local action plans and strategies were also submitted. It was fair to say that many areas found this challenging and often information was either not collected locally or there were different definitions or interpretations e.g. memory assessment clinics are provided in many different ways.

2.3 The review visit was carried out over a period of two days to enable the review team to meet with managers, practitioners, clinicians, service users, carers and lead commissioners, including an opportunity for some services to be visited. The programme was organised locally to provide evidence and additional information to the baseline information already produced.

2.4 Members of the review team were identified and drawn from organisations within and outside the South West, including NHS bodies, adult social care departments, and the voluntary sector and carers representatives. There were a number of different review teams established in order to undertake the review in each of the 14 health and social care communities within the planned timescales. The key requirement to successfully complete this project was sufficient experienced volunteers for the review teams, nominated by their organisations.

2.5 The forty review team members were identified by chief officers to ensure a cross- agency, multidisciplinary approach from a range of mental health, social care and other backgrounds including:

- geriatricians and old age psychiatrists;
- nurses;
- care managers;
- mental health commissioners;

- Alzheimer’s Society staff and carers’ representatives;
- primary care staff;
- allied health professionals;
- psychologists;
- service and senior managers.

South West Dementia Strategy Review Sub Group

2.6 The review process was led by Lezli Boswell, Chief Executive, Cornwall Partnership NHS Trust and has been one of the main work streams overseen by the South West Regional Dementia Strategy Group. The review sub group was made up of the project lead, officers of each partner organisation, NHS South West Programme manager and independent project managers who were appointed on a temporary basis for the review process.

2.7 The group undertook the detailed planning of the review, directed the project managers to ensure the quality assurance function for the project and offered strategic and technical advice to ensure that the Joint Review of Dementia Services in the South West was achieved and met its specified outcomes.

2.8 A detailed Project Plan which outlined the stages, key milestones, timescales and person responsible was developed and was invaluable in terms of identifying dependencies, timescales and efficient co-ordination and communication of all people involved.

2.9 The review team visits followed the following format:

- introduction and explanation session;
- meeting with the Primary Care Trust and Adult Social Care commissioners to explore current commissioning patterns and development plans;
- meetings with staff providing services across the care pathway – to include voluntary sector services, primary care, specialist services and independent sector home and long term care;
- meetings with carers and people with dementia;
- opportunities to visit local services;
- team discussion of outcomes;
- initial feedback of findings.

2.10 At the end of the visit, the review team produced a written report for each community, indicating where existing action plans need to be revised, and with suggestions of further work and support.

Key aspects

2.11 It was emphasised at all stages that this was a peer review and **not** an inspection. The review team's role was that of a critical friend, rather than inspector, encouraging health and social care communities to consider their development priorities for dementia services in the context of the National Dementia Strategy;

2.12 This was a whole systems review across health and social care and included independent sector service provision;

2.13 As part of the review, Innovations in Dementia, an Exeter based specialist dementia Community Interest Company, was commissioned to meet with representatives of carers and people with dementia in each community and share headline findings with the review team in a report in advance of our visit. This forms Appendix 1 of the review visit report.

Review tools

2.14 As part of the process, the review team received a folder with background information, baseline data from review sites and a set of review tools including assessment framework, record and summary sheets. A briefing event was held to provide some initial training on how the review should be carried out and an opportunity for review team members to influence some of the documentation and process.

Appendix 3

3. Data Request Form

This appendix sets out the data requested from each health and social care community to inform the South West review of dementia services.

Appendix 3

Metric	Data Item
Numbers of patients registered with GPs as having dementia, and as a % of expected local +65 population with dementia	Number of people with dementia
Numbers of patients registered with GPs as having dementia, and as a % of expected local +65 population with dementia	Population 65 years of age and over
Numbers of patients registered with GPs as having dementia, and as a % of expected local +65 population with dementia	Percentage of population over 65% with dementia
Does a system/policy exist for social care staff (social workers and home care staff) to refer on to other agencies if they suspect dementia?	Yes/No/Other
Memory clinics/service: new patients seen	New patients seen (2008/09 pro-rata)
Memory clinics/service: current wait time for new referrals	Wait in weeks (including range of weeks if submitted)
Memory clinics/service: current wait time for new referrals	Maximum waiting time in weeks
Is there a single system for referrals to memory clinics from primary care?	Yes/No/Other
Are there plans to implement a core set of assessment tools?	Yes/No/Other
Are there clear systems/pathways from memory clinics to follow up/voluntary sector services?	Yes/No/Other
Wait time for CT/MRI brain scans in weeks for clarification of dementia diagnosis	Wait in weeks (including range of weeks if submitted)
Wait time for CT/MRI brain scans in weeks for clarification of dementia diagnosis	Maximum waiting time in weeks
Do you offer a counselling service for new dementia diagnoses, and how are these functions assured?	Yes/No/Other
Number of new and existing attendees (people with dementia <u>and</u> carers) at peer-support networks e.g. dementia cafes and carer's support groups	New Attendees in 2008/09 (pro rata)
Number of new and existing attendees (people with dementia and carers) at peer-support networks e.g. dementia cafes and carer's support groups	Existing attendees in 2008/09 (pro rata)
Number of new and existing attendees (people with dementia and carers) at peer-support networks e.g. dementia cafes and carer's support groups	Total attendees in 2008/09 (pro rata)
Annual hours of specialist dementia domiciliary care support offered	Annual hours for 2008/09 (pro rata for 2008?09)
WTE staff in community mental health teams or dealing with dementia health needs in the community, plus CPNs in intermediate care teams	Total number of WTE
Number of dementia-specific NHS assessment and treatment beds run by any NHS organisation.	Number of beds
Do effective links exist between home care and community nursing services to seek specialist clinical support/advice where appropriate?	Yes/No/Other
Do you offer a single access point to dementia services?	Yes/No/Other
Do you have a resource allocation system to cover older people with dementia, or when do you plan to introduce this?	Yes/No/Other

Appendix 3

Metric	Data Item
Number of people with dementia with an individual budget	Number of people
Provision of carers: number of carers' assessments for dementia carers	Number of assessments
Provision of carers: number of dementia carers benefitting from short breaks	Number of carers
Specialist older peoples' mental health liaison service in acute trust: WTE and approx bed numbers in Trust	Total WTE staff
Specialist older peoples' mental health liaison service in acute trust: WTE and approx bed numbers in Trust	Number of beds
How many people with dementia are supported to live at home, including in extra care of sheltered accommodation (funded privately or by local authority)	Total number with dementia
Number of people with dementia supported at home with a telecare device	Total number of people supported
Are local intermediate care & re-enablement services inclusive of people with dementia and other mental health disorders?	Yes/No/Other
What % of registered beds in residential and nursing care in your community are for dementia?	Percentage of beds for dementia
What % of care homes either registered or not registered for people with dementia in your community are 4/3/2/1 star rated by CSCI?	Percentage with 1 star
What % of care homes either registered or not registered for people with dementia in your community are 4/3/2/1 star rated by CSCI?	Percentage with 2 star
What % of care homes either registered or not registered for people with dementia in your community are 4/3/2/1 star rated by CSCI?	Percentage with 3 star
What % of care homes either registered or not registered for people with dementia in your community are 4/3/2/1 star rated by CSCI?	Percentage with 4 star
Do you have policies regarding: contracts to incentivise quality care	Yes/No/Other
Do you have policies regarding: how contracts are monitored	Yes/No/Other
Do you have policies regarding: continuing to use homes with lowest quality rating	Yes/No/Other
Does a link or liaison service exist between community services and residential/nursing homes, or what plans exist to implement these links locally?	Yes/No/Other
Does End of Life training include the needs of people with dementia and their carers?	Yes/No/Other
Does your local palliative care strategy and services include people with dementia?	Yes/No/Other
Over 65 population: now and in 2025	Population over 65 in 2009
Over 65 population: now and in 2025	Population over 65 in 2025
Over 80 population: now and in 2025	Population over 80 in 2009

Metric	Data Item
Over 80 population: now and in 2025	Population over 80 in 2025
Population of people with learning disability (all ages)	Number of people with learning disabilities
Ethnicity data for over 65	White
Ethnicity data for over 65	Mixed
Ethnicity data for over 65	Asian or Asian British
Ethnicity data for over 65	Black or Black British
Ethnicity data for over 65	Chinese or Other Ethnic Group
Ethnicity data for over 65	Population over 65
Numbers of referrals for +65s through Adult Safeguarding processes in 2008/09	Number of referrals
Can this be broken down further into people with dementia from NHS/other sources?	Yes/No/Other

Appendix 4

4. Comments by People with Dementia and their Carers

This appendix sets out comments made by people with dementia and their carers which was collated to inform the South West review of dementia services.

Comments by people with dementia and their carers

These are verbatim comments made during discussions between Innovations in Dementia and people with dementia and carers during the review. In addition to the comments, summaries of the discussions which took place were made available to individual communities:

Early diagnosis and intervention

Lots of comments about General Practitioners not knowing about dementia, poor explanations and long waits for diagnosis.

- “I had to fight for four years to get a diagnosis”
- “As we were walking out he said to my son – not to me ‘I think she has dementia’ – he was looking at my son – not at me”
- “If they had an Alzheimer’s nurse that you could talk to at the GP – no, not a nurse – no- not in a uniform – someone who knows about dementia like the staff the forget-me-not centre.”
- “After we saw the consultant and got the diagnosis – there was just no follow up – so I had to make it my business to gather as much information as I could – it was 12 months before we got any contact from social services - felt like I was having to fight the GP for information – at a time when I didn’t know where I was.”
- “the GP didn’t want to do anything himself but referred us to the psychiatric team, but they told us we had been sent to the wrong people – but they tested (my husband) anyway ……we were then referred on to Bodmin, and then to Truro. The GP didn’t seem to understand the right person to refer to which made it a lot worse …..we didn’t think of that – we were very stressed and we just trusted that we would be sent to the right people – we weren’t.”
- “my GP made me feel a lot better”
- “he didn’t tell you what could happen”
- “he didn’t tell me what I could do about anything”
- “at the time no-one came to talk to us about what to expect – we were just left – once the adult social care team got involved it just got worse”
- “I asked the GP what was wrong with Mum and he said “oh, dementia” but there were no tests or anything to base that on – he referred us to the CPN who was very good – did the MMSE, then the brain scan was done within 6 weeks – then the consultant just turned up with results – didn’t involve me even though I was down as contact.”

- “ the GP was very good – he did the test (mmse) and then referred my wife to the elderly mental health place – we had so much more there – the dementia got worse – she was hallucinating badly so she went in for six weeks on a voluntary basis while they got the balance of drugs right – it worked well - very good”
- “my GP was out of his depth – I paid for private consultant – which made a huge difference. It was done quickly and they were very caring”
- “they just sent me home – you’ve got memory loss they said – you are too young there is nothing we can do”
- “I needed “ someone to go with me – things might not have been so mixed up”
- “GPs don’t know about memory problems”
- “After the diagnosis there was nothing – I heard nothing from anyone”.
- “Immediately after the diagnosis the house was full of people- so many people I had no idea who they all were – and then nothing – silence.”
- “I filled in the forms like they asked – sent them off – and nothing has happened”
- “Things were fine ‘till the CPN went off sick – no-one replaced her or told us what was happening – so everything just stopped.”
- “The left hand doesn’t know what the right hand is doing”
- “They said they would come but no-one ever did”
- “It was almost as if they were saying “what do you expect us to do about it?” It was hard for us because it was all new – we didn’t know what the options were so it was hard to answer her question – it must have looked like we wanted no help – someone should have been able to explain what our options might be”

Improved community personal support services

Lots of comments about staff going off sick, cases being closed, people being abandoned. Strong agreement that continuity of both support and staff is crucial. A lot of appreciation for dementia cafes and local groups. Strong support for Dementia Advisor proposals.

- “What I would really like is to be able to socialise more with other people in the early stages of memory problems – I really would like to talk about things and hear other people’s perspective” (participant with dementia).

- “the CPN visited and said she’d get the OT to come which she did but when she came she didn’t do anything apart from saying she’d look into what was available but then she went off sick and haven’t heard from her since – the psychiatrist last saw (my husband) 18 months ago”

- “They came to my house to help me but I didn’t want to do it then (housework) I have my own days to do it – I told them – she walked out in the end – I didn’t want to do it when she was there – I don’t like it”

- “he’s brilliant – but I need someone outside of the home I can talk to – someone who won’t judge me and who understands about dementia – I get that here”

- “My son tells me that I was told there was nothing for me as I was too young –“

- “I haven’t got any tablets – I did a trial but – how bad do they want me to get – I have seen myself going downhill on a monthly basis -I feel as if I am in a torture chamber I really do – I’m sick of it”

- “They (staff and other users at the centre) give me confidence they encourage me ….so it’s a bad day today but I know with them I can say anything to them”

- “they said they would help me do golf (person with dementia) ……………well that was what the OT said, but then she went sick – when I rang, the woman in her office read me from her notes left on the desk and all it said was “the leisure centre do swimming or you can do golf” just a list of things - no plan – anyway she went sick and that was the end of that”

- “I have been lucky recently – social care arranged for someone to come in and keep him company on a Wednesday afternoon – gardening or out for a walk. This 1-1 support is brilliant and I can’t fault it – if only it was available more……….”

- “It’s not as if the need has gone away – if anything we need more help” (participant who’s had been reduced from 1 day a week to 2 hours.”

- “There are lots of isolated carers out there - you lose a lot of your social network when dementia happens – and the social side of things is so important – both for carers and for the person with dementia – more could be done to help people keep this side of life running – get that side of life right and people can cope with things much easier you know.”

- “We all know that dementia is progressive and that your need for support increases not diminishes so how can they close the file and wait for you to have a crisis? People are under strain enough – there is no ongoing contact and monitoring – some people are lucky, but mum and dad have just been dumped”

- “Now we see psychiatrist at least every 6 months and have been given dementia support worker, they are very good and social care very good – the psychiatrist communicates well with the GP”

- “I could have cared for him myself – but now he’s in a care home”: participant whose husband’s loss of mobility she links to lack of rehabilitation”

- “the back-up has been very good since the diagnosis”.. “this group is excellent” “the memory café is brilliant”

- “Singing for the Brain ..it’s a right laugh” “everyone gets involved”

- “they told me to call if there was a problem – but you don’t really like to – by the time there’s a problem – there’s really a problem and sometimes it seems too late as the damage is done”

- “— a bad day – I’m sick of it – if I weren’t needed now I would just finish it – there’s nothing – they don’t even give me an aspro – I just need help and its not there – and I cant do this in front of my husband – I shouldn’t do this as I know it affects everybody here but I just want to throw myself under a bus – but I cant because I’m needed here and that’s the only thing – I only have them.”

- “They can try talking better to people - we want smaller units like this, where people can get to know you and understand what you are feeling and experiencing – you don’t call them staff you call them friends – you need people with the time to be sensitive to your needs”

- “I need continuity – I get that here people who will listen – my husband is brilliant but I need someone on the outside I can talk to”

- “Regular visits would be good – someone just to check that things are OK – so you know you are in contact and connected – that you are not alone.”

- "the only thing we have been offered is in a residential home – which is all older people with much more advanced dementia – I couldn't do that to him"

Implementing the Carers' strategy

Strong support for Carers in Crisis scheme:

- "Peace of mind – here's mine look" (shows card).
- "My part-time job is very important to me – I don't need help right now but it would be great if I knew that when and if I need it – I can get help to carry on working."
- "I don't mean to seem ungrateful – but please stop sending me on relaxation courses – I can organise that for myself – what I need is practical help and advice – I need to know how to lift – how to do an injection - not scented candles"
- "I think there should be more support for carers whose loved-one goes into a home or dies – it feels like as a carer you become an ex-person"
- "You know – I really want to do the best for my Mum – I have been caring for her for many years – but without the help to do that – things like respite especially – I cannot see how I can do what I need to do – what I want to do – what everyone else seems to want me to do – I just need a little help and increasingly it isn't there for me."
- "I really need a holiday – but it's impossible to make an advance booking of more than three weeks, which makes it very hard to book a holiday"
- *I need* "someone to make contact just once a week – to see how things are going – to make you feel connected"

Improved quality of care for people with dementia in general hospitals

- "I went onto hospital and I told them I had dementia and they put me in a wheelchair – then I told them I mustn't have morphine – which they gave me and I almost died – when I told them I had dementia it changed the way they talked to me – everything changed – they treated me like I had a screw loose"
- "My mother was moved to seven different wards during her stay in hospital – making her extremely confused."

- One participant reported having to make a 40 mile round-trip three times a day to feed her husband – “the food was just left next to him and I couldn’t get across to the nursing staff that he couldn’t feed himself – if he didn’t eat it they would just take it away”
- “they wouldn’t take the lid off the food for him – and he didn’t know it was food”.
- “they would ask him if he had finished and of course he would just reply “yes” – or they’d say ’don’t you want it?’ and he’d say ‘no’ “

Living well with dementia in care homes

- “Why can’t people stay in one home for longer? They are so quick to move people on as their needs increase – they never get the chance to make a home for themselves”
- “Inspectors don’t seem to be checking the things that matter – I don’t care if the rooms aren’t regulation size – I need to know that my husband is cared for by people that really care”.
- “you see the certificates on the wall but no-one can tell you what this means for their knowledge about people with dementia.”
- “They need more smaller units – more homely”
- “there seems to be a real lack of activity which is meaningful for him – not everyone wants to watch the television all day do they?”
- “There needs to be much more stimulation – more activity”
- on respite care – “I knew my husband would not be happy in the care home – I cried for a week and visited him every day as he was so unhappy– I might as well not have bothered – it was totally inappropriate”

Appendix 5

5. Living Well with Dementia: A National Dementia Strategy – Implementation Plan Timetable

This appendix sets out the implementation plan timetable to accompany the National Dementia Strategy.

Figure 1: Implementing the Strategy: 2009 – 2014