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DERBYSHIRE County Council
Improving life for local people

NHS
Erewash; Hardwick; North Derbyshire;
Southern Derbyshire; Tameside & Glossop
Clinical Commissioning Groups

Derbyshire Joint Dementia Strategy: Living Well with Dementia

Full Version 2014

Derbyshire Joint Dementia Strategy reviewed and updated 2014 for the period 2014 - 2019

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Introduction

Dementia presents one of the biggest health and social care challenges. People affected by dementia and their families and carers often face difficulties in trying to live well with the dementia. There are currently 800,000 people with dementia in the UK and it is predicted that there will be over a million people with dementia by 2021 (Alzheimer's Society. In Derbyshire this equates to over 10,000.

Around 50% of people do not have a formal diagnosis. This can mean being unable to access treatments and support. The prevalence of dementia is predicted to double in the next 30 years and this strategy will encompass actions to reduce the incidence of dementia by supporting possible lifestyle changes alongside new and revised intentions for health and care services.

To deal with this challenge this strategy will set out evidence based actions aimed at preventing the incidence of dementia within the population, slowing the rate of its progression once diagnosed and supporting individuals their friends and families to minimise the impact of dementia on independence and wellbeing.

It has never been more important to prioritise services that are cost effective, valued by people and avoid higher alternative expenditure. Spending on the NHS in the UK as a share of national income has more than doubled since its introduction in 1948, rising by an average of 4.8% in real terms1. This period of rapid growth has now come to a halt but funding pressures on the NHS continue to rise. The NHS is targeting efficiency savings of £20bn (known as the Nicholson challenge) by 2014/15 to meet this challenge. Looking further ahead, in July 2013 NHS England published the "Call to Action", which projected that the NHS may have to make a further £30bn of efficiency savings by 2020/21 to meet demand. Derbyshire's share of the £30 billion could be approximately £500m across providers and commissioners. Derbyshire County Council corporately has to make savings of £157 million over a 5 year period.

A Joint dementia commissioning group has been established to bring together Derbyshire County Council Adult Care (DCC), Clinical Commissioning Groups (CCG's), and Public Health to review and refresh an existing Derbyshire strategy which began implementation in 2010. The aim of the review is to keep the local strategy relevant to local views; local needs; best practice and national guidance on dementia care

We would like to take this opportunity to thank all the people with dementia and their carers who have already and continue to volunteer their time to give their views about this strategy and its implementation.

Tameside and Glossop CCG and Derby City have separate dementia strategies but collaborative working will ensure consistency of approach and an exchange of ideas.

What is dementia?

Dementia is an umbrella term for a range of conditions that affect the brain:

Alzheimer's disease: is the most common form of dementia where the chemistry and structure of the brain changes. Dementia typically leads to memory loss, inability to do everyday things, difficulty in communication, confusion, frustration, as well as personality and behaviour changes. People with dementia may also develop behavioural and psychological symptoms such as depression, aggression and wandering.

Vascular dementia: is caused by reduced blood flow to the brain because there is a problem with the blood vessels which affects the supply of oxygen to the brain. Early signs of vascular dementia symptoms are slowness of thought, difficulty with planning, memory loss, trouble with language, and mood or behavioural changes. It may be prevented from progressing further if identified early.

Lower incidence dementias: dementia with lewy bodies (spherical structures develop inside nerve cells); fronto-temporal dementia (damage focused in the front part of the brain; behaviour initially more affected than memory); Korsakoff's syndrome (associated with heavy drinking over a long period); Creutzfeldt-Jakob disease (prions attack the central nervous system and invade the brain). HIV and AIDS (sometimes people develop cognitive impairment.

Mild cognitive impairment: is a recent term describing people who have some memory problems but do not have dementia.

Testing: There is no single test for dementia, but a range of blood tests and brain scans can help rule out reversible causes. Diagnosis is made by an assessment of symptoms and the use of brief questionnaires testing ability to remember facts, or draw simple diagrams.

Most dementias progress slowly. People may live with the condition for ten years or more, requiring increasing levels of support as they become less independent. By carefully planning the person's environment and giving structure to their day with supportive activities it may be possible to reduce the impact of the symptoms.

Prevention and Cure: There is no certain way to prevent all types of dementia. However reducing the risk of cardio vascular disease can reduce the risk of a stroke and so vascular dementia.
To reduce the risk of developing dementia and other serious conditions it is recommended that individuals:
Eat a healthy diet
Maintain a healthy weight
Exercise regularly
Do not drink too much alcohol

Do not smoke
Keep blood pressure at a healthy level
Healthy lifestyle programmes available across the County aim to motivate and support people to reduce unhealthy behaviours.

The Alzheimer's Society website offers useful further detail about 'what is dementia?' www.alzheimers.org.uk

Many documents about dementia refer to a 'dementia journey'. The fundamental aim of this strategy is for people to live well with dementia so there is a timely response to changing needs along the journey in accordance with National Institute for Clinical Excellence (NICE) guidance, described below. The Derbyshire Dementia Pathway is provided at **Appendix A.**

What is shaping this strategy?

In 2009 'Living Well with Dementia: A National Dementia Strategy' was published by the Department of Health for dementia services in England and Wales. It included nine statements to capture what people with dementia should expect in terms of their health and social care. These are included in the implementation plan derived from this report.

The national strategy picked out four priority areas:

- Good quality diagnosis and intervention
- Improved quality of care in general hospitals
- Living well with dementia in care homes
- Reduced use of antipsychotic medication

The 2010 joint Derbyshire Dementia Strategy set out local actions consistent with the national strategy. This document refreshes the original Derbyshire strategy in the light of recent developments:

- Views of local People: A range of events involving people with dementia and their carers identified priorities which informed the 2010 strategy. A significant public engagement exercise was arranged in mid. 2013. Adding to feedback from existing dementia services. The details of this are provided at **Appendix B**

- Population Predictions: Local Authorities undertake and update a joint strategic needs analysis (JSNA). The JSNA estimates future population numbers and composition together with anticipated levels of health issues. The JSNA helps to understand anticipated service demand and to offer baselines to measure the success of outcomes of services. In short the number of people with dementia is predicted to double in the next 30 years. See also **Appendix C**

- All Parliamentary Party Group Report (July 2011): four main conclusions included developing 'whole systems' to improve cost-effectiveness; hospital environmental changes to improve experiences of hospital stays and greater efforts to prevent inappropriate hospital admissions; better community services; care homes need to provide a good quality of life for people with dementia, as most residents will have some form of dementia. The report estimated the annual cost of dementia to the UK to be £20 billion in 2010 which is expected to grow to over £27 billion by 2018.

- Prime Minister's Challenge on Dementia (March 2012) This aims to deliver further improvements in dementia care and research by 201 through:
  - Increased diagnosis rates through regular checks for over 65s
  - Incentives for hospitals offering quality dementia care.
  - Innovation
  - Promoting local information on dementia services
  - Dementia friendly communities across the country*
  - A high-profile public awareness campaign.
  - A dementia care and support compact signed by leading care home and home care providers
  - Better research (with funding increased from £26.6 million in 2009/10 to an estimated £66.3million in 2014/15)**.

- Government Mandate (November 2012): The Department of Health published its first Mandate between the Government and the NHS Commissioning Board, setting out the ambitions for the health service for the next two years. Key objectives of the Mandate include better diagnosis, treatment and care for people with dementia.

- Everyone Counts (December 2012): The NHS Commissioning Board published planning guidance for Clinical Commissioning Groups (CCGs) for 2013/14. The planning guidance 'Everyone Counts: Planning for Patients 2014/15 re-iterates that CCGs must set local trajectories for Dementia.

*The aim of dementia friendly communities is to create communities in which people will understand more about dementia and people with dementia feel included and free from stigma. Practical steps to achieve this include Dementia Action Alliances being set up by the Department of Health and hosted by the Alzheimer's Society. A Derbyshire branch of the Alliance has started and is bringing together a range of organisations, many of which do not work directly with people with dementia but can play a role in assisting people to live well. There is also a programme to educate 1 million people to become 'dementia friends'.

**Research findings support the diagnosing of dementia early and offering information, support and advice to both the person with dementia and their relatives as early in the dementia trajectory as possible.
Research also shows that early diagnosis offers a chance for people to come to terms with dementia; to understand its prognosis when they are able to do so; make use of information about their condition as well as treatment options and to make decisions for the future.

- Clinical Commissioning Groups (April 2013): The creation from the 1st April 2013 of CCG's as autonomous statutory organisations (replacing Primary Care Trusts). CCGs are made up of groups of GP practices, are chaired by a local GP and now have responsibility for setting commissioning intentions.

- Care Quality Commission's (CQC) review of dementia care (current 2013): CQC, the independent regulator of health and social care in England is inspecting hospitals and care homes in 22 local authority areas as well as consulting nationally and will publish a report in 2014 about people's experience of care across the different services they use and make recommendations.

- NICE Guidance QS 30 Supporting People to Live Well with Dementia (April 2013) and QS 1 both list 10 quality standards which commissioners of dementia care should aim to ensure are being provided within their services. These will be applied as the strategy is implemented and are listed at **Appendix D**

- G8 summit (December 2013): A world dementia envoy was appointed to raise funds for research towards a cure. The UK committed a £90 million package to improve dementia diagnosis (a target of two thirds of people diagnosed by March 2015). Additionally leading British businesses also signed up to the cause with over 190,000 staff at M&S, Argos, Homebase, Lloyds Bank and Lloyds Pharmacy to learn to support customers who have dementia as 'dementia friends'.
- Named GP's (from April 2014): Every person over 75 will have a named GP and the most vulnerable two per cent in each practice will receive an enhanced service.. People diagnosed with dementia and their carers will also be able to sign up to a new service on the NHS Choices website to get essential help and advice in the early stages of their condition.

- NICE dementia care pathway (2011 updated 2014): This is supported by a set of quality standards for services for people with dementia and are described in this strategy

- Legislation (major changes May 2014): Further legislation has been passed since the Derbyshire dementia strategy started. The latest is the Care Act (2014). This represents a major reform of the law relating to care and support for adults and the law relating to support for carers. It strengthens the direction of integration of health and social care and includes a duty to promote physical and emotional wellbeing and personal dignity. It also highlights the duty of Local Authorities to promote preventative services.

- Better Care Fund (from April 2015): Councils and the NHS are receiving funding via the Better Care Fund to work with each other and the voluntary sector. In Derbyshire this has resulted in DCC and the CCG's covering Derbyshire to agree spending plans linked to 7 objectives (building asset based communities; supporting people to remain independent/ in control; community support; reduced need for hospitalisation or admission to long term care; improved service outcomes/quality; reduce inequalities; develop infrastructure to achieve objectives. A set of metrics have to be in place as a framework for evidence of performance compared with objectives. The objectives give strong backing to the direction of this dementia strategy. Derbyshire has opted to include a local measure regarding the number of people diagnosed and the prevalence of dementia.

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What has been achieved since 2010?

What we said we would do	What we have done
Commission a direct access memory assessment service (MAS)	The number of clinics has increased. CCGs are commissioning dementia diagnosis with a mixed model of MAS centres (e.g. Staveley and Oakland Community Care Centres) and GP practice based sessions as they continue to raise the diagnosis rate. Further work referenced in implementation plan N2 below.
After diagnosis the person with dementia and their carer will be offered the Living Well Programme for information and education.	Community Mental health teams from Derbyshire Healthcare Foundation Trust and the Alzheimer's Society Dementia Support Service and Derbyshire Community Health Services are involved in offering sessions. The Programme has had very positive feedback when taken up and used and the aim is to increase take up. It has been found important that carers have a choice as to when they access the information they need. Many do not feel able to take in the information available at diagnosis as they may be too shocked or upset. Further work referenced in implementation plan N3 below.

What we said we would do	What we have done
Every person with dementia and their carer knows where to access information and support from / develop a dementia support service	A County service commissioned via Alzheimer's Society offers advice, information; home visits; dementia cafes; carers' information groups. Dementia Support workers increasingly link in with memory assessment clinics. Further work referenced in implementation plan N2/3/4below. Carers benefit from peer support and learning from each other. Some groups include younger carers and the timing allows attendance after work. This age group is often under particular stress as they struggle to care for parents as well as looking after their children. Ratings for the dementia support service are 91% satisfied or extremely so. Ratings about staff approachability, understanding and respect are higher.
Offer to provider organisations an E learning package for basic dementia training to be piloted with the private and independent sector	E Learning has been introduced as a training option. We will review the extent to which it is used. Further work referenced in implementation plan N13 below.
Develop training quality standards to be used as part of commissioning and contracting process	Social Care staff at the new centres; specialist staff and care homes staff across the Council and independent sector have participated in advanced dementia training. This continues. The Commissioning for Quality and Innovation (CQUIN) payment framework enables commissioners to reward excellence at local level and this is starting to make an impact on contracting by stipulating requirements for health service staff to have either dementia awareness training or more specialist training.
Provide dementia education and information programmes to carers of people with dementia in an accessible format	Community Mental Health Teams and the Dementia Support Service are both involved in offering sessions. Carer training is a key part of the Living Well Programme. Further work referenced in implementation plan N2/3/4 below.

What we said we would do	What we have done
Develop and promote the Dementia Information Prescription	A Dementia Information Prescription has been done but is not accessible at present because of website reorganisation. The availability of information now developed through the MAS and dementia support services will prompt a review of where to place the focus for making information available.
Develop a specific dementia section on the Derbyshire County Council website/ information portal.	This has been created and will be updated on a regular basis.
Offer dementia training for carers. 6 programmes to be offered, one in each locality.	Community Mental health teams and the Dementia Support Service are both involved in offering sessions.
Develop Community Care Centre in Staveley to provide residential care; short breaks; intermediate care; information and resources; day services; memory assessment services	The Staveley Centre was opened in 2011 and provides all services planned plus increasing health care and community use of the centre. A group of carers who originally undertook dementia training together continue to meet at Staveley as the 'STAG' group. They are self-supporting and have accessed funding for pamper days. They also use Crossroads to look after the cared for while they meet. They value Staveley Centre and the facilities there and continue to recruit members.
Exploration of the S. Derbyshire Specialist Dementia Home Care Service as a model for roll out for the rest of the County.	A two year pilot commenced in 2012 in Chesterfield testing out a specialist home service for people with dementia – run in partnership with the mental health team. It is being researched and compared with the S Derbyshire service. It is planned to be expanded in a pilot into the integrated care arrangements of primary care.

What we said we would do	What we have done
Develop Carer specific breaks that support Carers who meet the criteria for substantial support	A range of things are being offered e.g. short breaks; carers support via Derbyshire Carers Association including home visits, carers support groups, carers emergency grant; newsletter. Many Dementia carers have accessed the carer grant and also receive support from Derbyshire Carers Association. The need for a break is paramount and many ask for this from the grant scheme. Many also want a break with their loved one but with support from a family member for example. Further work referenced in implementation plan N7/11 below.
Develop a joint specification for intermediate care services to ensure patients with dementia are included	Specifications for intermediate care have been negotiated for Staveley and Oakland Community Care Centres and people with dementia are benefiting from intermediate care. A County strategy is being devised as part of integrated health and social care services.
Development of a further Community Care Centre in Swadlincote	Oakland Community Care Centre, Swadlincote, opened in 2013. The Centre is integrated on site with 88 extra care apartments. Take up of facilities including open community use has been excellent.
Development of six further Community Care Centres across the County (Adult Care Accommodation Care and Support Strategy)	The strategy is under review by DCC Elected Members. Plans are underway for the construction of further Community Care Centres at Heanor and Darley Dale. There will also be increasing availability of extra care apartments e.g. Chesterfield (2014); Alfreton (2014); Clay Cross including day services (2015).
Undertake audit to determine whether prescribing of anti-psychotic drugs for behavioural problems in dementia is in line with current guidelines	An Audit has been undertaken. Prescribing rates for anti-psychotic medication have fallen. Further training work on managing behaviour without recourse to drugs is underway.
Develop a culture at Staveley where staff are enabled to provide support to individuals without resorting to anti-psychotic medication	Staveley services are based on a social model of dementia care and have eliminated the use of anti- psychotic drugs where appropriate. A medicines management audit has been carried out with some of the primary care results to be reviewed.
Completion of dementia health equity audit	A Dementia Health Equity Audit was done and will be kept under review. Further work referenced in implementation plan N4 below.

Other Developments

Singing for the Brain	Found to be popular. Music therapist works across the County doing sessions and training some residential care staff. This service has been commissioned through the Alzheimer's Society
Older Peoples Mental Health Liaison Service	The service was commissioned for acute settings including Chesterfield and Derby Royal hospitals and has achieved good outcomes. It has now been superseded in Derby Royal with investment in RAID (a rapid assessment process). RAID for Chesterfield is due to be implemented in late 2013.
Housing Related Support:	Much of this fits with the Accommodation strategy where 24 hour support is being made available to enable people to stay in their own accommodation rather than a care home.
Social Model of Dementia Care	Services being commissioned using this model which relies on behavioural approaches and less reliance on medication, advanced training underpins this.
Derbyshire Dignity Campaign	Joint DCC/NHS campaign since 2010 to improve the experience of people using health and social care services. Bronze and silver awards can be applied for. Applications at both levels are steadily increasing.

Analysis and Next steps

Testing the themes: The themes emerging from national initiatives (described in this report); the priorities of Derbyshire people (Appendix B) and demographics (Appendix C) have been collated. They were tested and gained support at a NHS Listening Event in October 2013.

Endorsement of themes: The themes were then taken to the 14 November 2013 meeting of the Adult Care Board (ACB). The ACB has a mix of Elected Members (the Chair is the Cabinet Adult Care lead) and senior managers from the health and social care sector as well as other public services.

The ACB endorsed a proposed 'direction of travel' for the next stage of the joint dementia strategy with a recommendation that the joint Derbyshire Dementia Commissioning co-ordination group will develop and deliver precise plans and costed out priorities.

The themes within the direction of travel agreed by the ACB have been developed and have led to the formation of the implementation plan (see following section).



Looking at the Evidence: Many excellent local initiatives are already underway across the County. The joint commissioning group will ensure that the published evidence base of what type of interventions should be provided is prioritised for delivery and then local good practice which is in line with the evidence base is then also delivered.

In the course of researching the strategy initiatives which work well have been seen. As the strategy is delivered Commissioners will prioritise services which show evidence of good service results, value for money and invest to save outcomes e.g. The SHINE project has demonstrated benefits from investing in the training of nursing staff in Care Homes A project in 2011-12 funded by the Health Foundation (Shine awards) developed the role and basic awareness training in a small group of Homes in and around the City of Derby. Residents have been found to an improved experience (e.g. diet change) and to avoid costly interventions associated with aspiration pneumonia (e.g. GP call out, prescribed medication, acute hospital admission). Benefits are

achieved by earlier implementation of a dysphagia care plan, timely management of symptoms, delayed involvement of dysphagia specialist, and better end of life planning.

An initial exercise for the Dementia Action Alliance will to scope the existing provision, identify gaps and prevent duplication thus ensuring the most effective use of limited resources.

Delivery of the Strategy

Implementation Plan: The Implementation Plan below sets out the intentions of this strategy

Making the Strategy Happen: The AC/ NHS joint commissioning group referred to in the introduction will ensure that the strategy is delivered. Hardwick CCG has a County lead role on the commissioning co-ordination group and each CCG has a structure for local development of dementia commissioning plans.

Governance: Arrangements for governance for delivery of this strategy are shown in the diagram at **appendix E**

Reporting: The joint commissioning group will devise a dashboard for quarterly reporting on milestones in the Implementation plan (this will be a component of the dementia dash board referred to in item 32 of the Implementation Plan)

Taking forward Engagement: It was proposed and agreed by the ACB that a framework for on-going public engagement will continue through existing engagement structures such as the over 50's forums, patient participation groups and Healthwatch Derbyshire so that co-design can be a feature of service design as the strategy is turned to action.

The assistance of the Adult Care Engagement team will be sought to take this process forward. The team has expertise in connecting with local groups which can contribute. The Engagement team has a regular format setting up plans for working out the power/ interest of particular groups which guides appropriate levels of engagement. This may vary from active involvement in service design to simply communicating information.

Implementation Plan for Derbyshire Dementia Strategy 2014 'Living Well with Dementia'

NB The Joint Dementia Commissioning Group will ensure that systems are in place to ensure evidence of outcomes for each action named in this implementation plan. Reporting Milestones should offer clear make clear how outcomes have been evidenced, either completing the action or making progress clear so far.
This plan will be reviewed half yearly by the Joint Commissioning Group and will remain a working, changing document.

County Theme	What do we want to achieve? Coded to national objectives	Outcomes we aim to achieve	Reporting Milestone	Organisation Lead
Prevention	**N 1a. Improving awareness and understanding: prevention** **(KEY ACTION)**	1. Commission by 2015 the NHS health checks in GP practices which include dementia awareness and signposting in accordance with the national statutory NHS health check programme	May 2015	**DCC Public Health (1) and Local Clinical Commissioning Groups (2)**
		2. Primary care clinicians conducting NHS health checks are aware of and participate in the dementia awareness e-learning training resource.	May 2015	**As in (2)**
		3. Continued support and investment in public health lifestyle and behaviour change programmes are preventing or reducing the impact of dementia e.g. reducing cardio vascular disease	Dec 2015	**As in (1)**
		4. Annual primary care reviews of people with existing cardio vascular disease or diabetes includes a dementia awareness and signposting element (backed by dementia awareness training).	May 2015	**As in (2)**

County Theme	What do we want to achieve? Coded to national objectives	Outcomes we aim to achieve	Reporting Milestone	Organisation Lead
		5. People not meeting FACS eligibility criteria are given information about universal services with the transition to potential reduced availability being managed. 6. Support systems are in place where people have medication only needs for support	Dec 2014 May 2015	**DCC Adult Care (AC) (Prevention) (3) & Fieldwork (4)** **As in (2) & AC (Direct Care) (5)**
Person Centred Services	**N 1b. Improving awareness and understanding: good quality environments for people with dementia** **Alternatives to traditional. 'service' solutions**	7 Initiatives are developed via the Derbyshire Dementia Action alliance to promote dementia friendly communities. This includes: 7.1 Building on community strengths and expertise from carers/volunteers as an asset 7.2 Public awareness further raised to challenge stigma 7.3 Practical measures taken to challenge isolation	Apr 2016	**As in (2) (3) & AC Commission/g (6)** **Capital Invest Team (7)**

County Theme	What do we want to achieve? Coded to national objectives	Outcomes we aim to achieve	Reporting Milestone	Organisation Lead
Improved Joint Working	**Transport**	8. Link made with operation of new Corporate transport policy to mitigate impact of loss of licence by people with dementia.	Dec 2014	**As in (6)**

County Theme	What do we want to achieve? Coded to national objectives	Outcomes we aim to achieve	Reporting Milestone	Organisation Lead
	N 2. Good quality early diagnosis and intervention for all			
Improved Joint working	**Timely diagnosis**	9. Increased diagnosis rate with timeliness evidenced by increased access to treatment and support (qs1,2)	May 2015	**As in (2)**
		10. Diagnosis is proportionate, by the right person and efficient (qs1,2)	May 2015	**As in (2)**
Improved Joint Working	**Learning disability**	11. Services are better adapted to better recognise, screen and diagnose people with a learning disability	Dec 2015	**Hardwick & N Derbyshire CCG Contract Teams**
Improved Communication	**N 3. Promoting local information about dementia services**	12. An Information plan shows improved information access to people and carers including provision of Well Being zones.	Dec 2015	**As in (2) & (3)** & **Contracted Dementia Support Service**
	N 4. Provide support following diagnosis			
Person centred services	**Access**	13. The dementia support service is re-commissioned and accessible at an increased number of Health outlets	May 2015	**As in (2) & (6)**
		14. A named contact person is available to assist a person at each point on a clear support pathway without	May 2015	**As in (2) & (4)**

County Theme	What do we want to achieve? Coded to national objectives	Outcomes we aim to achieve	Reporting Milestone	Organisation Lead
		the need to keep repeating personal information (cross ref 43). 15. The Health equity audit is renewed and relevant follow up actions put in place	 Apr 2015	 **As in (1)**
Improved Joint Working **Improved communication/ Prevention**	**N 5. peer support & learning and volunteer engagement** **Improve dementia care at home** **Engagement**	16. Integrated treatment/ support e.g. referral to dementia support service and living well programmes help more people to live well at home (ref also 26; 29-31; 42). 17. People's experience of dementia is used to assist their communities through e.g. buddying; training 18. Engagement with local people continues when working out details of strategy.(further described on pp13 &14)	Oct 2015 Dec 2015 May 2015	**As in (2) (6)** **As in (2) (4) Acute Hospitals (8)** **As in (2) via Patient Participation (9) & AC (Engagement) (10)**
Person Centred services	**N 6. Good Quality care for people with dementia (KEY ACTION)** **Improve Dementia Care at**	19. Coverage of the specialist dementia home care service extended, with learning captured and contributing to service improvement (see also Research) 20. Prompt appropriate provision of assistive	Dec 2014 Oct 2014	**As in (6) & Hardwick CCG (11)** **AC (Accomm. & Support) (12)**

County Theme	What do we want to achieve? Coded to national objectives	Outcomes we aim to achieve	Reporting Milestone	Organisation Lead
	Home	technology facilitated to people FACS eligible or not. e.g. Use of low and high-tech interventions e.g. E. payment swipe cards for carers, medicine dispensers (further description at P42)		
	Living well with dementia:	21. The Joint Commissioning group defines and responds to key points arising from public engagement: i. e. stimulation; better advocacy; Dementia friendly health services; better continence management.	Oct 2015	**Joint Commiss/g Group (13)**
	Dignity	22. The Derbyshire dignity campaign increased numbers of silver award holders and launches the gold	Apr 2015	**As in (6)**
		23. The use of 'This is Me' profiles is extended and used to promote person centred care in all dementia care services	Dec 2014	**As in (2) (6)**
		24. All developments based on a social model of dementia care.	May 2015	**As in (2) (6)**
	Young Onset	25. Service gaps for people with young onset dementia are identified and addressed	Dec 2015	**As in (2) (6)**
	Promoting Independence and Re-ablement	26. Integrated working is achieving positive results in promotion/ maintenance/recovery of independence e.g. care homes with access to physiotherapists & mental health nurses	May 2015	**As in (2) Director for Care Home Quality (15)**
	Cultural Appropriateness	27.Excellent examples of culturally personalised services are available and shared to highlight what can	May 2015	**As in (2) (6)**

County Theme	What do we want to achieve? Coded to national objectives	Outcomes we aim to achieve	Reporting Milestone	Organisation Lead
		be achieved		
Improved communication	**N 7. Supporting Carers**	28.The Carers strategy addresses dementia and expressed wishes of carers of people with dementia (further detail P42)	Dec 2014	**As in (6)**
Person centred services	**N 8. N 6. Hospital Admission and avoidance (KEY ACTION)**	29. Reduced unplanned admissions of people with dementia ore to avoid the need to admit to hospital (acute/ dementia wards) 30. Investment in community services through an exchange of hospital beds where not needed for replacement elsewhere where needed. 31 Development of Community support teams and care coordinators to identify those people at highest risk of health deterioration to prevent hospital admission 32. A dementia dashboard is created demonstrating outcomes for people with dementia. 33. Identify any instances where capacity to support people with behaviour that challenges may be insufficient and make recommendations. 34. Improve in-patient experiences e.g. Butterfly scheme and mental health liaison teams in acute settings	Dec 2015	**As in (8)** **As in (2)** **As in (2)** **As in (2)** **As in (2) (6)** **As in (8)**
	N 11. N 6. Quality care in care homes			

County Theme	What do we want to achieve? Coded to national objectives	Outcomes we aim to achieve	Reporting Milestone	Organisation Lead
Person centred services	**Residential care minimise admissions**	35. The need to admit people to long term residential care reduced to bring Derbyshire admissions in line with comparator Local Authorities.	May 2015	**As in (2) (4) (6)**
		36. A Rapid Access Interface Discharge (RAID) programme reduces unnecessary delays to hospital discharge.	May 2015	**As in (8)**
	Maximise experience	37. Care homes and hospitals supported to develop more dementia friendly physical and social environments as part of a policy of joint commissioning of best care.	Dec 2014	**As in (2) (6) (7) (8) AC (Contracts team) (15)**
	Anti – Psychotic Medication	38. Enable more care homes to support people without relying on anti-psychotic medication e.g. use of activity and improved communication skills	May 2015	**As in (2) (5) (6) (8) (14) (15)**
Training and development	**N 13.** **Learning Networks for professionals**	39. Networks are set up to ensure successful local initiatives are known, shared and adopted (qs5,6)	Dec 2015	**As in (2) (5) & via Memory Assessment Service**
	Mental Capacity Act	40. The training plan to ensure more staff have an understanding of the Mental Capacity Act.	Dec 2015	**AC DOLS team**
	Staff training	41. The training plan for Derbyshire Professionals and Carers ensures staff are appropriately dementia trained.	Dec 2015	**As in (2) & NHS Workforce**
	N14. Joint Commissioning Strategy			

County Theme	What do we want to achieve? Coded to national objectives	Outcomes we aim to achieve	Reporting Milestone	Organisation Lead
Improved Joint Working	**Integrated working and cross service developments (KEY ACTION)**	42. Increase integration of health and social care services at local level through joint structures and finance to address dementia as a long term condition.	Dec 2015	**As in (2-7)**
	Integrated working and cross service development	43. Dementia support pathways are publicised starting with GP's giving choices as dementia develops.	May 2015	**As in (2-7)**
Research	**N16. Research (DH responsibility)**	44. Continued involvement of Derbyshire residents in research (qs7,9)	May 2015	**As in (9) (10)**
		45. Commissioning intentions are evidence based (qs3,40) e.g. the specialist home care service; utilisation of Derbyshire Healthwatch.	Oct 2015	**As in (2) (6)**

National Objectives dementia strategy 2009 (Some paraphrasing)

N 1 **Improving awareness and understanding:**

N 2 **Good quality early diagnosis and intervention for all**

N 3 **Promoting local information about dementia services**

N 4 **Provide support following diagnosis**

N 5 **Peer support and engagement and**

N 6 **Good Quality care for people with dementia**

N 7 **Supporting Carers**

N 8 **Care of people living with dementia in general hospitals is improved**

N 9 **Improved Intermediate care**

N10 **Housing and Housing related support**

N11 **Quality care in care homes**

N12 **Good quality End of Life Care for people with dementia**

N13 **Informed and effective workforce**

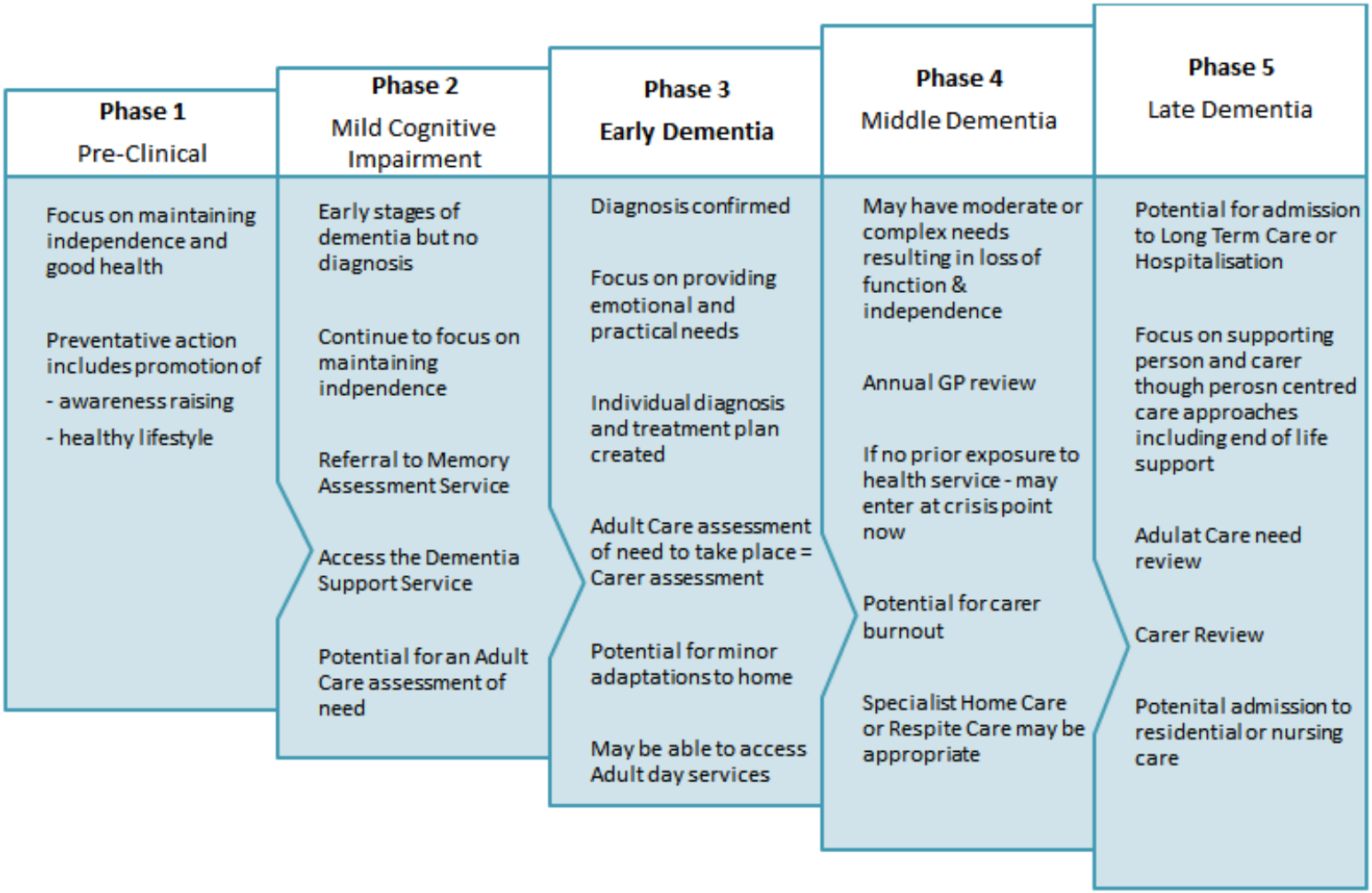
N14 **Joint Commissioning Strategy for dementia**

N15 **Improved assessment and regulation**

N16 **Research**

N17 **National and regional support**

APPENDIX A: The Derbyshire Dementia Pathway



APPENDIX B: Engagement

Perspectives 67

Stakeholder Engagement Team Nov 2013

Dementia Strategy Refresh 2013/14

Dementia presents one of the biggest health and social care challenges. Around 50% of people (428,000) in England, Wales and N Ireland living with dementia do not have a formal diagnosis. This can mean being unable to access treatments and support. The incidence of dementia is set to rise significantly. In December 2010 an All Parliamentary Group (APPG) on Dementia began an inquiry into how to improve outcomes for people with dementia and their carers. A stimulus for the inquiry was pressure on health and social care budgets and an urgent need to improve cost-effectiveness. Dementia was estimated to cost the UK £20 billion in 2010 which is expected to grow to over £27 billion by 2018.

Over the last 3 months, Derbyshire County Council (DCC) and Clinical Commissioning Groups (CCG's) in Derbyshire have joined together to review and refresh an existing Derbyshire strategy which began implementation in 2010. The aim of the review was to ensure that the local strategy was still relevant to local views; local needs; best practice and national guidance on dementia care.

Perspectives 67 provides a summary of the views and comments captured at a range of engagement workshops and events, questionnaires, face to face interviews and telephone interviews. Over 250 people took part including people with dementia, family carers, 50+ forums, people attending dementia cafes, people living in rural communities, health and social care staff, mixed stakeholder groups, BME communities including gypsy and travellers, and LGB and T groups in Derbyshire are included.

Top Priorities

- ✓ Being supported to stay in your own home for as long as possible;
- ✓ Training - staff need greater cultural awareness and need to fully adopt a person centred approach;
- ✓ Early diagnosis and timely help to avoid crisis;
- ✓ One point of contact;
- ✓ Communication - Listening and understanding carers concerns;
- ✓ Support:
  - signposting for people not meeting eligibility criteria;
  - support for people experiencing early onset dementia;
  - support to help carers feel able to cope with dementia;
  - support/help to relieve 24/7 caring role;
  - better listening to and understanding of carers concerns;
  - good quality support to enable social interaction.

BACKGROUND

Aim: To involve a wide range of stakeholders to refresh and confirm the priorities in the Derbyshire Dementia Strategy. To add to and develop further a Derbyshire dementia network of people with dementia, carers, relatives and people working in the field of dementia prevention and dementia support.

1.2 OVERVIEW OF THE CONSULTATION METHODOLOGY

A mixed approach was used to engage including workshops, information and engagement events, attending existing events and forums as well as interviewing people living, caring and supporting people with dementia.

Specific events included attending farmers markets, Patient Participation Groups, dementia cafes, Black Minority Ethnic forums, Community Care Centre dementia events at Oaklands. The Stakeholder Engagement team linked with the Alzheimer society, Mind CVS, Derbyshire Rural Action and NDVA along with Derbyshire Clinical Commissioning Groups.

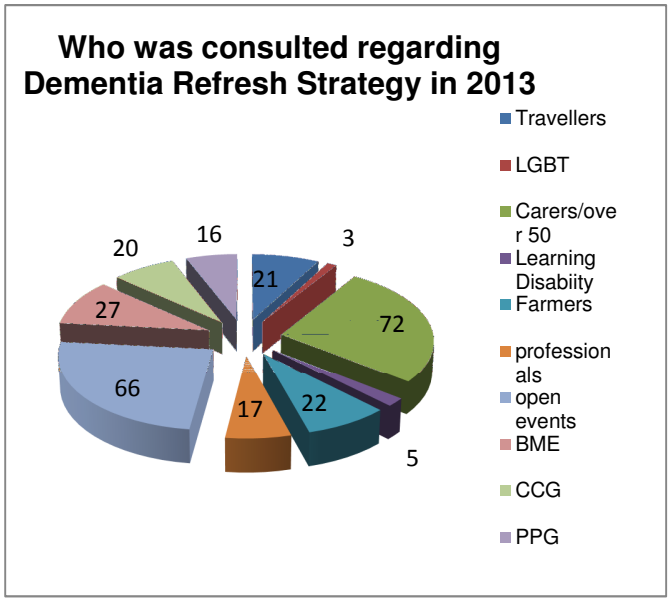
The Stakeholder Engagement Team used a range of trained, paid peer reviewers to carry out interviews with clients living in residential and nursing care homes who have dementia, their carers and relatives and with staff working in this sector.

In addition the Team commissioned help from specialist, local practitioners including a farmer liaison worker, gypsy and traveller liaison worker and representatives from Derbyshire's Black Minority Ethnic community and Lesbian Gay Bisexual and Transsexual groups.

People with early onset dementia were invited to give their views. Derbyshire fieldwork assessors and Direct Care staff, Community Mental Health Teams and GP surgeries were also asked for their assistance.

The locally established 50+ forums were involved through DOPAG - (Derbyshire Older Peoples Advisory Group) which has older people representatives from across Derbyshire. Other existing forums were also approached and invited to take part in the consultation.

The project was managed by the Stakeholder Engagement Team, based in Adult Care at Derbyshire County Council. The Healthwatch Derbyshire team assisted with the engagement, working collaboratively to share and build a network of dementia stakeholders to be involved in the refresh of the dementia strategy and also remain engaged ahead as details of existing and new services are worked out.



1.3 DEMOGRAPHICS

Over a period of 4 months the Stakeholder Engagement Team developed and identified the network in which it gauged views on the current dementia services and what stakeholders would envisage to be pivotal to providing an excellent service for future developments.

During the consultation the Team were supported by various specialists liaison workers from the groups identified which enabled engagement directly with groups and individuals.

The Stakeholder Engagement Team successfully interviewed over 21 people with an interest in dementia from the farming community. 27 representatives attended a group forum from the Black Minority Ethnic Community. Over 22 1 to 1 interviews were carried out via the traveller liaison worker.

A group of 66 people with dementia and their carers were interviewed at the various Alzheimer cafes which are held around Derbyshire and their views captured. Stakeholder Views were sought via the liaison worker at Derbyshire Friend together with a generic email to all Derbyshire County Council employees who are networked via the employee support group for LGBT.

1 to 1 interviews were carried out with carers of people with downs syndrome together with professionals working within the Learning Disability community. Voluntary sector providers and campaign groups were also invited to submit their views.

Two events were held; one in the north and one in the south of the county. This was via an open invite and over 66 people attended over the two events.

Professional views were also sought from GP's and staff working with people with dementia in both health and social care settings. Views were also sought from the Patient participation Groups in the Hardwick PPG and Erewash PPG.

We also used other recent research in our consultation which included:

- Stonewall Report (LGBT in later life) 2010
- 'What am I afraid of' – a film that highlights the concerns relating to dementia for the LGBT community. This is a collaborative film between several agencies i.e. Senior Human Right Derbyshire, Derbyshire Friend, Age UK and Comic Relief.
- Younger People with Dementia Report 2013 (Sue Whetton Derbyshire County Council Service Manager)
- The Evaluation of the Specialist Homecare Service 2013 (Sophie Heffernan DCC)
- National Voices Campaign
- 'Tell us more' report by South Derbyshire CCG and Derby City

1.4 QUESTIONS ASKED

To encourage participation the Team asked 4 very open questions to determine people's views. The questions were:

- **What do you or would you value most?**
- **What is most difficult?**
- **Where are the gaps?**
- **What are the top 3 priorities?**

During the consultation with the PPG's the questions were varied slightly to include

- **Thinking about your surgery/community what can we do to make it more dementia friendly?**

- **If you had an experience of being referred to hospital what could the hospital have done differently?**

1.5 FINDINGS

Over 250 stakeholders took part in the engagement sessions. Below is a summary of the comments and provides some analysis of the common themes emerging from the discussions.

What do you or would you value most?

All stakeholder groups stated that:

Being supported to stay in their own home for as long as possible was paramount - however this support needed to be flexible enough to enable people to carry on with their life style i.e. timings of home care calls.

The following are some of the views/experiences that were captured

'We need to look at alternatives to acute hospital settings. Look at facilities for acute hospital treatment to be provided at home e.g. Infections being treated with IV antibiotics.'

'coping to care for someone with incontinence is difficult and extra help is needed – perhaps allowing more pads and considering a charge for these.'

Transport is an issue and very often the dementia sufferer loses their driving licence and further reduces their independence early on.

The gypsy community told us that often they felt professionals feel intimidated by some of their behaviour but the issue is lack of cultural awareness. To quote one participant 'in the gypsy community we have a huge respect for our elders and they will still be the head of their family even if they are suffering from dementia – so it is a very difficult thing for us to have to start making decisions for them especially if they are distressed or angered by the choices made…….it makes it so difficult to pass the care of your loved one on to outsiders who only have time to see to their basic daily needs.'

Good quality support for social interaction. There was much praise for the work of the Alzheimer's Society and the support groups that they run such as the dementia cafes and singing for the brain. However there is a need to promote these opportunities further.

The following are some of the views/experiences that were captured…

'Should encourage activities that stimulate someone with dementia with specific services for young sufferers and their carers e.g. signing for the brain.'

'Emotional support is an important as practical support'

'I really value time to allow me to go out and not worry about the person I care for – this helps relieve the stress of caring.'

'Singing for the brain was a wonderful distraction which everyone attending seems to like. More of these would help.'

The PPG (Patient Participation Group) raised issues about the ability to be able to complain without the fear of repercussion or it affecting the standard of support or care their loved one received.

What do you find most difficult?

Lack of cultural awareness The following are some of the views/ experiences that were captured:

'The fear that you would have to hide your relationship and that for the remainder of your life in residential care would 'mean having to go back in the closet' - LGBT community

The Romany gypsy community feared losing their cultural identity as they felt residential care accommodation would not cater for this need.

24/7 caring role This comment was reiterated by stating that the caring role is hard work, frustrating, tiring and isolating.

Change of relationship – People interviewed commented that it was difficult to cope with a loved one that you do not recognise any longer and they do not recognise you.

Listening and understanding carers concerns – here carers voiced many negative experiences and said they felt that their concerns and observations needed to have an equal waiting during the diagnostic part of their pathway.

Lack of joined up working – the PPG highlighted the need and importance of all the agencies having a joined up approach.

Consistency of Care – again the PPG highlighted the need for consistency of the care and support which was being provided. They suggested that the larger GP practices should adopt the precedent of once a GP has been allocated to try (wherever possible) to ensure that it was the same GP that sees the dementia patient. They also felt that the approach to consistency needed to be managed.

Gaps

Training and cultural awareness – This has already been commented on when people interviewed were asked what people found most difficult when receiving services for dementia. Although this was largely identified by the hard to reach communities we interviewed – it was also evident that overall people receiving services for dementia and their carers felt more time could be spent in identifying cultural needs and that this would be helped if a person centred approach was adopted.

One point of contact – This was a problem for many participants feeling that there were far too many agencies to deal with at a difficult time.

Support for people and carers not meeting eligibility criteria – again a concern across all communities was that if you do not meet any ones criteria you do

not receive any support. To quote one carer:

> 'Care in the community is ok – but if you cope you are left to cope.'

A drive to increase the numbers of volunteers which are needed to help with care and stimulation of patients.

To ensure that the 'this is me' document was well known and used throughout agencies supporting and caring for the dementia patient

Support for early onset dementia clients was identified as an area requiring particular attention that was person centred, holistic and age appropriate.

Priorities

Training – participants reported a great need for training around cultural awareness to ensure a person centred approach.

Early, timely diagnosis to help avoid crisis – With all sections of the communities which were interviewed early diagnosis was an issue. To a large extent this was linked to the carers concerns – that their voice had little standing in any consultations. It was felt that the delay in getting diagnosis often lead to crisis moments. The following are some of the views/experiences that were captured …

> 'took over 8 months to get a diagnosis'

> 'It took two years to get medication'

> The appropriateness of the memory test carried out – doing the alphabet backwards … sometimes the fact that memory tests are not culturally appropriate can often lead to indications of a problem being missed' The BME forum offered to work with professionals on this issue to ensure that the test is fit for purpose.

> 'Being recognised as a carer by your GP 'I appreciate the fact that my GP respected my mother, when she wrote raising concerns about my father. Dad had a lack of insight to his changing behaviour and mental health and was unlikely to go to the doctors of his own volition. The GP was able to broach the issues sensitively and supportively and a 'memory clinic' appointment was set'

> 'once labelled as having a learning disability this becomes predominant – overriding factor information passed to GP's by professionals working with people with LD should be taken on board by GP for referral and utilised for diagnosis' LD health professionals

> 'At the point of diagnosis a person with a learning difficulty should be referred to the LD Health team.'

> LD professionals highlighted the 'need for screening and they recommended this from the age of 30.'

Carers 'appreciated appointments being kept on time with the GP as this avoided the person with dementia becoming agitated and adding to stress of caring.'

'Having access to an interpreter during an appointment.' BME community.

Clean well maintained accommodation – as we have already mentioned this was a particular concern for the Romany Gypsy community – however this was also echoed across all groups.

Access to services for all

PPG's supported "Easy access to relevant services and education about these services and their availability"

Other Helpful suggestions and developments

Identifying Dementia patients
Participants advocated for a system in place that 'flags' dementia patients in A&E on admission to make a smoother journey for their patient and to adopt the butterfly scheme – a small blue butterfly that identifies people who have dementia and is particularly helpful when people go into hospital – this is currently operational in over 100 Trusts.

"Hospitals have no concept of someone's usual patterns of behaviour but don't want to listen to the people that know them best".

Developing Dementia Friendly Communities
1 village in Derbyshire has a 'winter meeting (community association) to identify any vulnerable members of the community.

Importance of evening Support
People with dementia often experience what is called 'sun downing i.e. they become more anxious/agitated in the evening. This can be very isolating and challenging for family carers and has a huge impact on their emotional well-being. Services should be more accessible to include support in an evening – this may also enable people to stay at home for longer.

Joint Working
People advocated the advantages of joint working.

'At our present stage we have been most encouraged by the care received from the NHS Memory Clinic and the Assessment follow up at Lee Hurst, Walton Hospital together with unrequested help and Adult Care who have anticipated our needs and provided physical aids.'

Drop in sessions at GP surgeries
Was suggested would help support carers and encourage people to come forward and find out more about the illness. It was suggested that this did not have to be run by the GP themselves but could be run by specialist shared workers who visit the surgery every third Tuesday In the month.

Assessment and memory tests should **tie in with the Annual Health Assessment.**

It was suggested by a GP that it would be **feasible to ask for a CT scan at the same time as the blood test** to try and cut down waiting times.

Publicity on Dementia
It was suggested that a TV campaign similar to the stoke FAST campaign would raise awareness of dementia – however the BME community had reservations that further publicity would also need to be done as not all their community watch English TV.

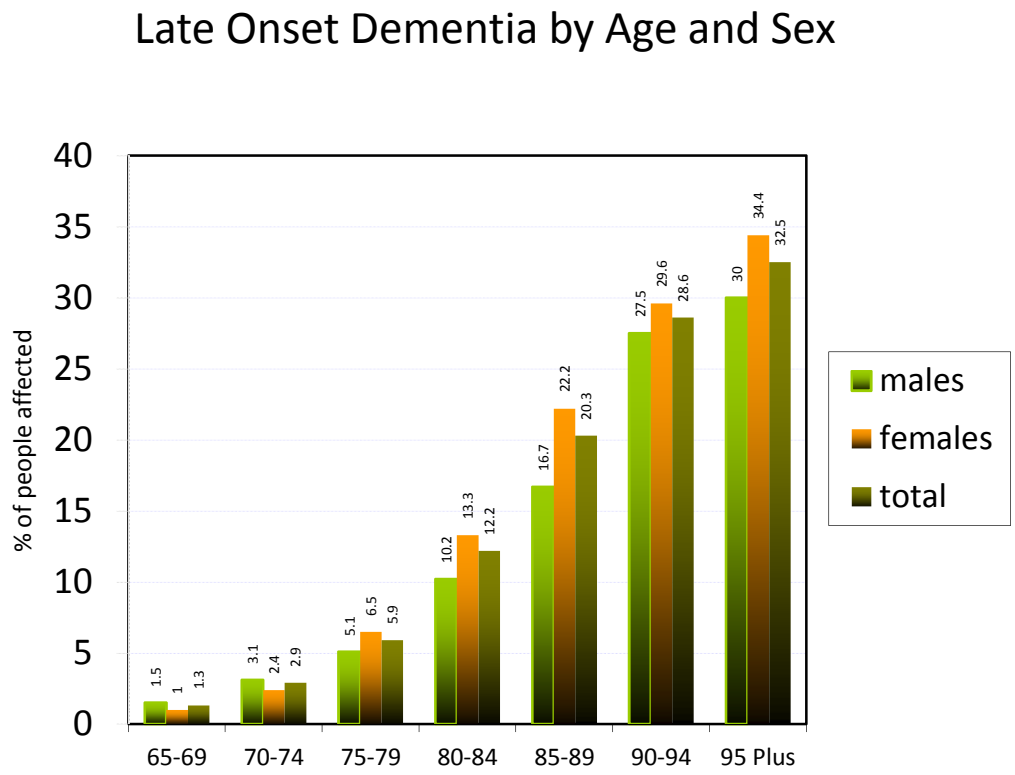
The PPG suggested to use free door to door magazines to raise awareness of dementia but also to provide information on benefits and services in the area.

WHAT HAPPENS NEXT

Information from this consultation was shared with the Derbyshire Adult Care Board in November 2013 who supported the overall recommendations presented to them. A Joint Adult Care/ NHS Commissioning group will work to deliver the strategy including how to both feedback progress to members of the public and also when to engage people further regarding detailed planning.

APPENDIX C: Prevalence and Demographics in Derbyshire 2014

Figure 1



- *Dementia UK* Consensus estimates[1]
- The incidence of dementia is positively correlated with age i.e. as age increases the percentage of people affected by dementia increases. Between the ages of 65 & 69 only 1.3% of people are affected but between 85 & 89 the proportion increases to 20%
- Between 65 and 74, the incidence rate is higher for males than for females
- The incidence rates for late onset dementia are reversed with females after age 74 having a greater pre-disposition to dementia than males.
- Recent research[2] suggests that there may be a lower prevalence in UK than previously predicted; nevertheless the number of people with dementia will rise greatly over the next 2 decades.

[1] 2006, Produced by King's College London & LSE
[2] The Lancet, Tuesday 16th July, 2013

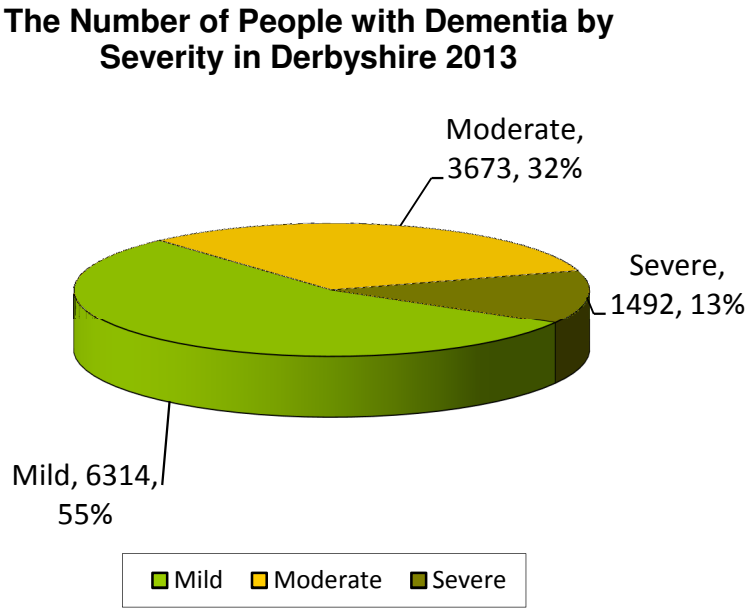
Table 1: Derbyshire Older Population Increases 2013 - 2028[3]

					Percentage change from 2006 to:			
Aged:	2013	2018	2023	2028	2013	2018	2023	2028
65-69	51,300	47,700	48,100	54,800	33%	24%	25%	42%
70-74	35,900	47,900	44,900	45,300	11%	49%	39%	41%
75-79	28,300	32,100	43,000	40,400	8%	22%	63%	54%
80-84	20,700	23,200	26,700	36,000	5%	18%	36%	83%
85 plus	20,000	22,700	26,900	32,200	13%	28%	52%	82%
All 65 plus	**156,200**	**173,600**	**189,600**	**204,700**	**16%**	**29%**	**41%**	**55%**

- Significant growth in Derbyshire's older people's population
- An increase of 55% of people aged over 65 between 2013 and 2028
- An increase of 82% of people aged 85 or over between 2006 and 2028
- Given that dementia is a disease that is strongly associated with increasing age, we can expect to see large increases in prevalence, as the Derbyshire population ages and lives longer
- Increasing numbers of people with dementia from the oldest age-groups in the population have multiple physical impairments; hospitalisation for treatment of their physical impairments can serve to exacerbate distress due to dementia and the effects of disorientation, confusion, anxiety and depression
- Research[4] reliably demonstrates that people with dementia who are admitted to hospital receive poorer quality care than people without a dementia.

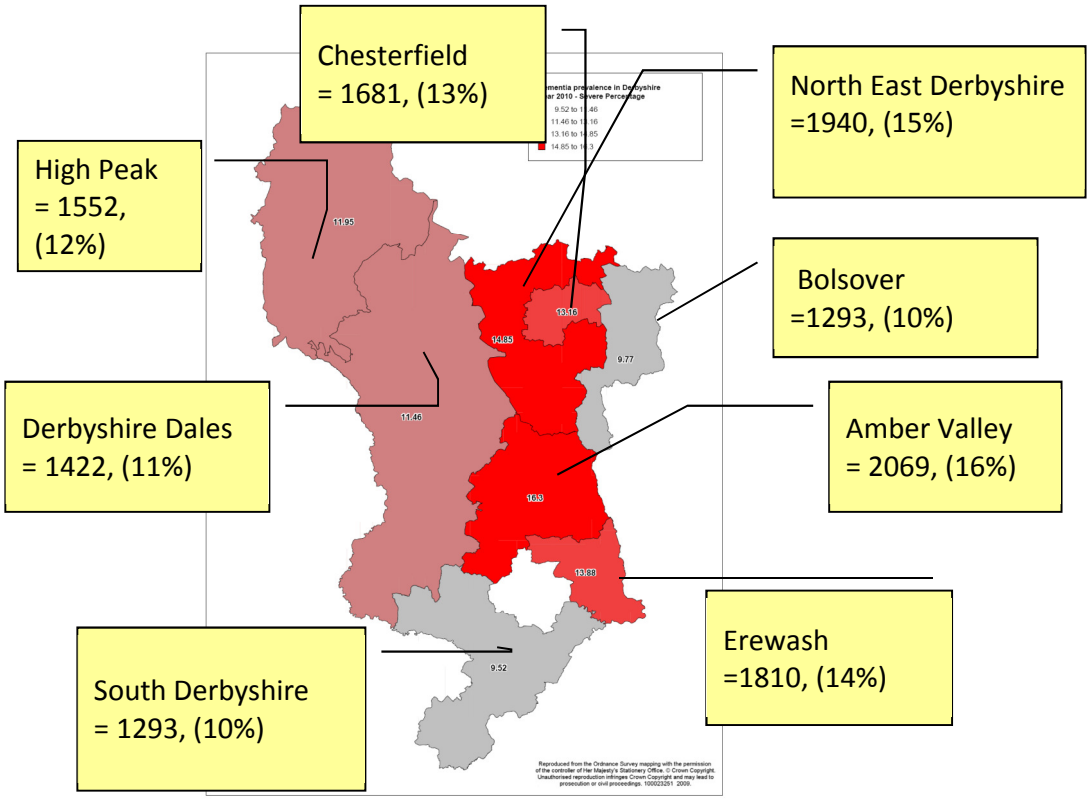
[3] 2010-based, sub-national population projections, ONC, © Crown Copyright
[4] Published July 2013, National Audit of Dementia, Royal College of Psychiatrists

Figure 2



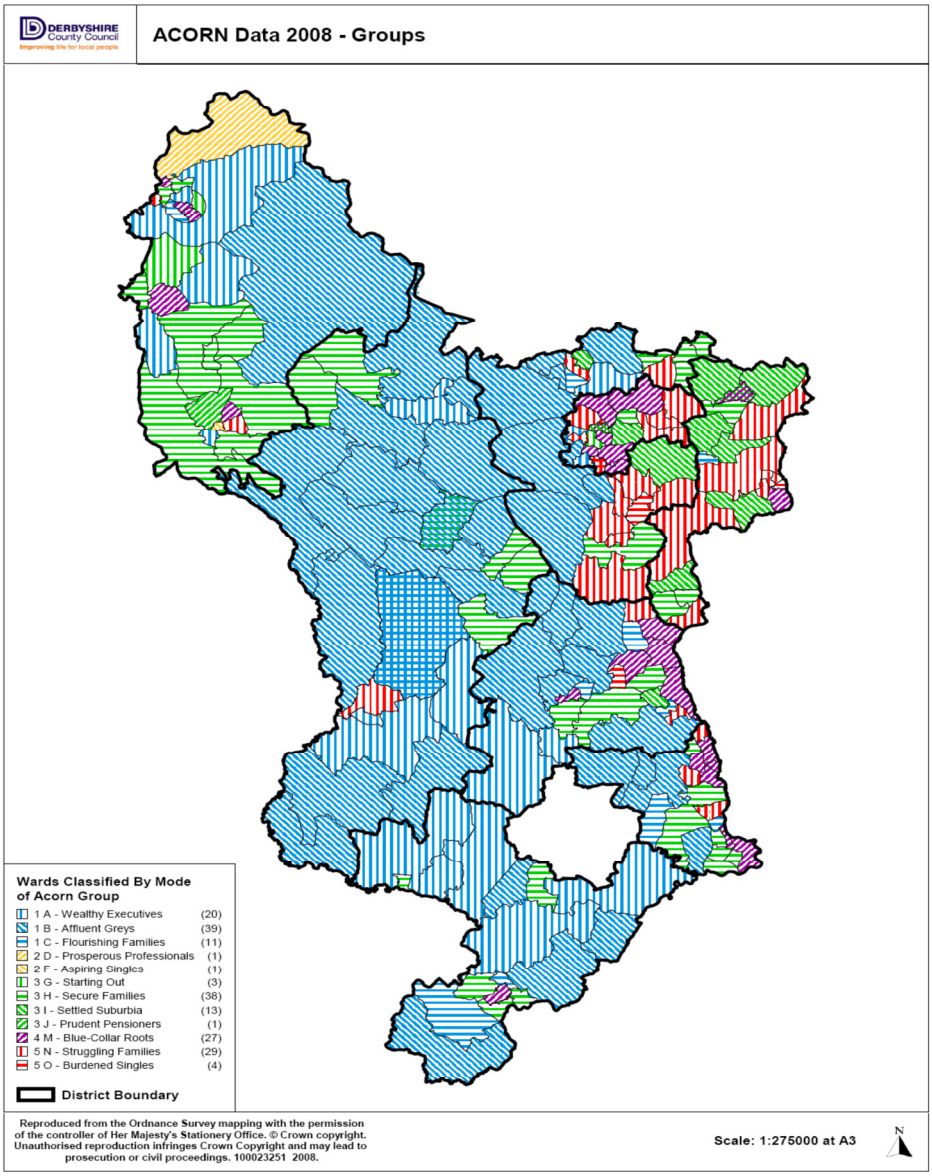
- It is estimated that there are just under 11,500 people affected by a dementia in 2013 living in Derbyshire
- At any one time, the majority of people (55%) have a mild condition.
- A smaller number of people are moderately affected (32%).
- Just under 1500 people in Derbyshire in 2013 have a severe dementia (13%)

Figure 3: **Late Onset Dementia by District 2018**



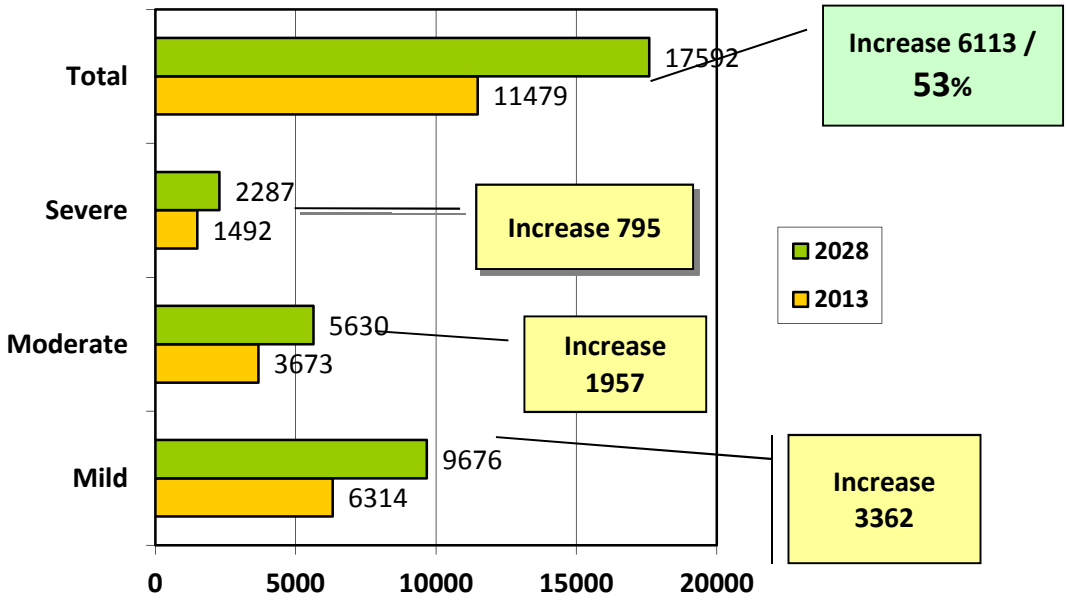
- Dementia UK Study divides severity into Mild (55%), Moderate (32%) and Severe (13%). If we apply these figures to Derbyshire it means that there will be 7,100 people affected by *Mild Dementia, 4*,150 by *Moderate Dementia*, and 1700 by *Severe Dementia* by 2018.
- This gives a total of just over 12,900 people affected by dementia in Derbyshire in 2018.
- If we break the figures down further by district, we obtain the distribution of dementia as shown in Figure 2 above.
- Though not the largest in terms of absolute numbers, 2 areas of particular concern are Derbyshire Dales due to its very rural nature, and Bolsover, due to its tendency of not accessing community resources effectively combined with high social deprivation.
- Anecdotal evidence suggests there are more than the estimated number of people affected with dementia in Bolsover due to a higher incidence of vascular dementia, caused by its heavy industrial past specifically in relation to coal mining.
- Together in those 2 districts, there will be over 2000 people affected by dementia.
- The numbers will grow to 17,800 in Derbyshire by 2028.

Figure 4



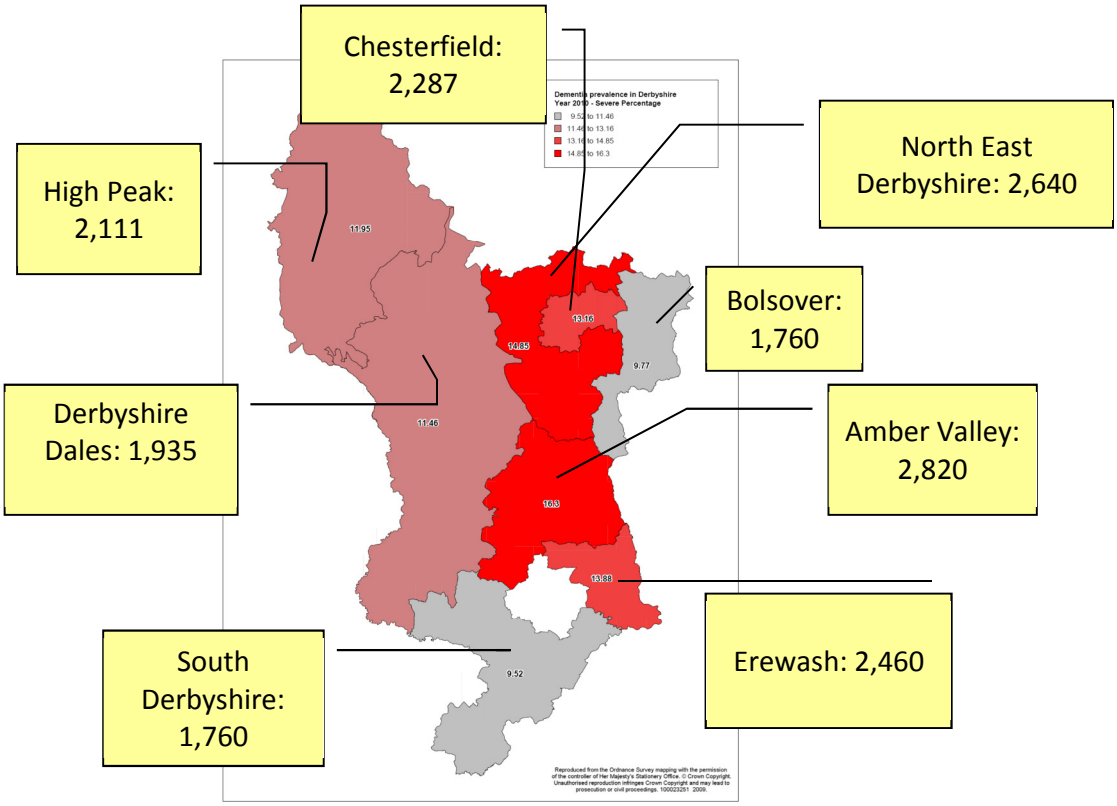
- Figure 4 shows Derbyshire's Residential Neighbourhood Classification (ACORN).
- ACORN classifies areas according to a range of marketing and other socio-economic data.
- The Predominant group in Derbyshire Dales is "Affluent Greys" in contrast to Bolsover which is "Struggling Families".
- We know that Dementia is not associated with social class.
- There are marked differences in life expectancies between the west and east side of the county ie males in Bolsover can expect to live 15.2 years at age 65 compared with 17.1 years in Derbyshire Dales.
- Despite the contrasting socio-economic fabric of the two districts, both are disproportionately affected by dementia: Derbyshire Dales because of its ageing population living in predominantly rural isolated situations and Bolsover because of its coal-mining legacy (and increased levels of vascular dementia) and high social deprivation.

Figure 5: Late Onset Dementia Projections to 2028



- Because of the ageing of the population in Derbyshire, Dementia will rise quite dramatically between now and 2028.
- The estimates give a rise of about 6100 people.
- By 2028, it is estimated that almost 18,000 will be affected by dementia, a rise of 53%.
- Mild Dementia will rise by just over 3,300 people, Moderate by just over 1957 and severe by just under 800.

Figure 6: **Total Dementia by District 2028**



- The map illustrates the estimated number of people affected by dementia in 2028 based on population projections.
- The number in Derbyshire Dales will rise to just over 1900.
- There will be just under 1800 people affected in Bolsover.
- All areas will have significant numbers of people affected by dementia
- The total number of people affected by 2028 will be close to 17,800

Early Onset Dementia

Table 2: **Early Onset Dementia Prevalence in Derbyshire**

Age	18 - 24	25 - 49	50 - 64	Total (18-64)
2013	0	30	180	220
2018	0	30	200	230
2023	0	30	210	240
2028	0	30	210	240

Source: Planning4care

Prevalence estimates suggest that there are only 220 adults in Derbyshire with early onset dementia (before 65th years of age). Whilst small in number, the onset and progression of the condition can be devastating to the lives of working age adults and their families, whilst age appropriate provision is still being developed.

One subgroup of people who have a disproportionate likelihood of developing early onset dementia is people with Down's syndrome. It is estimated that 330 Derbyshire 18 – 64 year olds have Down's syndrome, of who 40 have early onset dementia[5]. The projected number of 18 – 64 year olds with Down's syndrome (and with Down's syndrome and dementia) are projected to remain stable between 2013 and 2028.

[5] Planning4care, (with prevalence of dementia among people with Down's syndrome based on Coppus et al (2006) [Dementia and mortality in persons with Down's syndrome, Journal of Intellectual Disability Research, vol 52, pp 141-155]).

Commissioning discussions for social care should focus on:

8 The number of people aged 65 plus affected by dementia will grow substantially over the next 2 decades.
9 The number of older people caring for a spouse or family member affected by dementia will grow significantly too. The number of people providing informal care to a family member increased between 2001 and 2011 by over 6,000 in Derbyshire
10 People with dementia do not respond as well to hospitalisation as people without the condition. They tend to become more confused and their overall condition worsens.
11 Carers need much more support to enable them to continue to care and not to "burnout". They need training in how to cope with dementia. They need more respite opportunities and more domiciliary support in times of crises (cf Specialist Home Care Service).
12 With better support, and a more personalised service, the negative impact of dementia can be ameliorated and early admission rates to residential or nursing care can be reduced
13 We must work to achieve "dementia-friendly communities"; there are some very simple, low-tech as well as high-tech interventions that can be deployed. Electronic payment swipe cards for carers of people with dementia would most likely increase the numbers taking up a *Personal Budget* option, medicine dispensers that obviate the need for supervised medication dispensing, and door systems that can "remind" people that it's not time to go out.
14 There need to be more "dementia friends" who will voluntarily provide befriending services.
15 Fundamentally, at present there is a national mis-match between growing need and support levels. As a consequence too many people are being left to care without help.
16 There needs to be far more publicity about dementia and its impact on an individual put into the public's awareness. Only then can communities start to become "dementia friendly".
17 Whilst the number of Derbyshire people with early onset dementia is relatively small (220), it will be important to ensure that provision and support are relevant to their needs. Given that some of these people will have jobs or run a business, have families of their own, and be younger, the necessary support will not simply be just replicating the support needed by older people with dementia.
18 For those under or over 65 years with dementia, there may well be a need for welfare rights support to successfully claim some of the benefits they and their carers may have entitlement to.

APPENDIX D: List of NICE Guidance

NICE Quality Standards – Dementia (QS1)

Statement 1. People with dementia receive care from staff appropriately trained in dementia care.

Statement 2. People with suspected dementia are referred to a memory assessment service specialising in the diagnosis and initial management of dementia.

Statement 3. People newly diagnosed with dementia and/or their carers receive written and verbal information about their condition, treatment and the support options in their local area.

Statement 4. People with dementia have an assessment and an ongoing personalised care plan, agreed across health and social care, that identifies a named care coordinator and addresses their individual needs.

Statement 5. People with dementia, while they have capacity, have the opportunity to discuss and make decisions, together with their carer/s, about the use of :

- advance statements
- advance decisions to refuse treatment
- Lasting Power of Attorney
- Preferred Priorities of Care.

Statement 6. Carers of people with dementia are offered an assessment of emotional, psychological and social needs and, if accepted, receive tailored interventions identified by a care plan to address those needs.

Statement 7. People with dementia who develop non-cognitive symptoms that cause them significant distress, or who develop behaviour that challenges, are offered an assessment at an early opportunity to establish generating and aggravating factors. Interventions to improve such behaviour or distress should be recorded in their care plan.

Statement 8. People with suspected or known dementia using acute and general hospital inpatient services or emergency departments have access to a liaison service that specialises in the diagnosis and management of dementia and older people's mental health.

Statement 9. People in the later stages of dementia are assessed by primary care teams to identify and plan their palliative care needs.

Statement 10. Carers of people with dementia have access to a comprehensive range of respite/short-break services that meet the needs of both the carer and the person with dementia

NICE Quality standard for supporting people to live well with dementia – QS30

Statement 1. People worried about possible dementia in themselves or someone they know can discuss their concerns, and the options of seeking a diagnosis, with someone with knowledge and expertise.

Statement 2. People with dementia, with the involvement of their carers, have choice and control in decisions affecting their care and support.

Statement 3. People with dementia participate, with the involvement of their carers, in a review of their needs and preferences when their circumstances change

Statement 4. People with dementia are enabled, with the involvement of their carers, to take part in leisure activities during their day based on individual interest and choice.

Statement 5. People with dementia are enabled, with the involvement of their carers, to maintain and develop relationships.

Statement 6. People with dementia are enabled, with the involvement of their carers, to access services that help maintain their physical and mental health and wellbeing.

Statement 7. People with dementia live in housing that meets their specific needs.

Statement 8. People with dementia have opportunities, with the involvement of their carers, to participate in and influence the design, planning, evaluation and delivery of services.

Statement 9. People with dementia are enabled, with the involvement of their carers, to access independent advocacy services.

Statement 10. People with dementia are enabled, with the involvement of their carers, to maintain and develop their involvement in and contribution to their community.

APPENDIX E: Governance for Delivery of the Strategy