

2014-2017

Appendix 2

Dementia Strategy

for County Durham
and Darlington



Final Draft



Prepared by the Dementia Strategy Task Group for County Durham and Darlington:



North Durham Clinical Commissioning Group
Durham Dales, Easington and Sedgefield Clinical Commissioning Group
Darlington Clinical Commissioning Group
County Durham and Darlington NHS Foundation Trust
Tees, Esk and Wear Valleys NHS Foundation Trust
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Executive Summary

Introduction

In County Durham and Darlington, the Clinical Commissioning Groups (covering Durham Dales, Easington and Sedgefield; North Durham and Darlington) have teamed up with Durham County Council and Darlington Borough Council, as well as the providers of dementia services, Healthwatch County Durham and Healthwatch Darlington to develop a new strategy for dementia.

The future needs of people with dementia and their carers need to be planned. A dementia strategy task group was set up to plan the future needs. The group took a stocktake of services, talked to people with dementia and their carers as well as people looking after them, identified the gaps and priorities along with what new things we need to do differently. Our aim is to ensure that the population in County Durham and Darlington have the best possible services in place for those who have dementia, their carers and families, as well as those who have not yet been diagnosed with dementia along with a focus on prevention.

As part of developing this strategy, Healthwatch County Durham and Healthwatch Darlington have already spoken to nearly hundred and thirty people to ask them about their experiences in accessing dementia services. The lessons have helped focus the strategy, which will be updated annually.

What are the problem areas?

People are living longer and more people are expected to have dementia. But there are several challenges we need to focus upon :

- to screen all those who may have dementia or are at risk of developing it
- to support people who have dementia to reduce risk of hospital admission, timely discharge and not return to hospital unnecessarily because of a lack of support in the community
- to reduce the number of people with dementia who spend last days of their life in hospital rather than at home or at their preferred place of care
- to ensure that people with dementia and their carers get the best possible support at all points of their journey
- to give the most appropriate and clear information to people with dementia so they can be signposted to access as much support as possible
- to improve how we can reach out to and support more young people at risk of developing dementia early
- to ensure services work together and talk to each other so they are better joined up and can support different groups of people such as:
 - those who may develop dementia because of alcohol or substance misuse
 - those with learning disabilities who may have a higher risk of developing dementia early



- Black Asian and Minority Ethnic Groups who may not have the same access to dementia services
- prisoners who may develop young onset dementia or when they are older, and to ensure they get the same support as other people with dementia, especially when they leave prison

What are we planning to do to address these problems?

We have identified many actions that the implementation group will focus on over the next three years. We have developed a framework of priorities of what we will aim to do. We will:

- look at ways to make more people aware of what they can do to prevent dementia
- deliver improved dementia training more widely to all key staff including GPs and frontline staff
- look at developing new ways to avoid getting people with dementia admitted or readmitted to hospital,
- auditing the use of antipsychotics
- improve support to people with dementia who have challenging behaviour, and also the possibility of using dementia support workers in hospital
- look at all the pathways and make sure they are interlinked so that the highest quality compassionate care is provided, and where there are service gaps, aim to fill them
- develop a single point of knowledge/ information, such as a directory, that holds up to date information on all services, so people with dementia, their carers can have better control over their care and throughout all stages of their dementia. This information will be used by clinicians and commissioners too to help signpost people with dementia to a wide range of services
- implement plans for dementia support to be a part of end of life pathways and planning ahead by the person with dementia, so every person is treated with dignity and respect
- pilot projects to enable Dementia Friendly Communities to be rolled out over the next three years
- develop greater awareness of the research we do on dementia, and promote more opportunities for people with dementia to join the register as patients willing to take part in research
- carry out a Dementia Health Needs Assessment so that we have a better understanding of the needs of people with dementia in the region, and engage with various groups to obtain their views.

A six-week consultation consisting of public meetings and drop in sessions took place in advance of this strategy being approved by the Clinical Commissioning Groups in County Durham and Darlington, and Durham County Council and Darlington Borough Council.

Please note that the data gathered to produce reports generated by the map of dementia, is not complete, and is in some parts historical, so does not necessarily apply to actual performance by the providers at the time the data was accessed via the interactive map of



dementia. It is however the best available data that has been used to make deductions, rather than conclusions. As more data will be added to the map of dementia the reports will be revised accordingly.

An Implementation Group consisting of the group that drafted the strategy along with others and user representatives, will be established immediately, to drive this strategy forward. We will review the strategy annually and report out to the public on what improvements we make.



1. Introduction

A new drive to improve dementia care and support

The first strategy was a Joint Commissioning Strategy for Older People and Mental Health in 2009. That joint strategy incorporated objectives from the National Dementia Strategy for England which the Department of Health announced in 2009. It was not a blueprint for local services, but rather guidelines for local service providers to enable them to set priorities according to local needs. The joint strategy was reviewed when the Prime Minister's Challenge on Dementia came out in 2012, to become the second strategy with an implementation plan for 2012-2014. That Second strategy has been used during the last two years by commissioners and providers in County Durham and Darlington who as a dedicated working group made good progress in implementing the plan for the region.

This new document sets out the third strategy County Durham and Darlington for 2014-2017. It incorporates new information that has been announced during 2013 and 2014, as well as the new organisational arrangements we are now operating in.

There is an aspiration for the future that people with dementia must get the best support possible in the community so that unnecessary admissions to acute services can be avoided, and that those who are discharged from acute services are well supported in their communities closer to home.

In April 2013, NHS England set out a new mandate (see reference 1) with the Clinical Commissioning Groups which makes them legally responsible for ensuring that they commission healthcare services that are fit for the population. In the mandate, there are five priority areas and one of them focuses on making diagnosis, treatment and care for people with dementia, including support for carers, among the best in Europe by 2015. The mandate is being refreshed and a new addition will set a further ambition agreed by NHS England that by 2015 two thirds of the estimated number of people with dementia in England should have a diagnosis, with appropriate post diagnosis support.

NHS England has arrangements to establish a Strategic Clinical Network for Dementia covering the North East. This network looks for innovative ideas from clinicians to take steps to ensure that future services for dementia have improved outcomes for people with dementia which will be even better. So over time, the strategy will be influenced by the views of that network.

In December 2013 the Department of Health published a report, 'Dementia – a state of the nation report on dementia care and support in England'; (see reference 2). This report expands on the National Dementia Strategy that was published in 2012. The report has ten key priority aims for the future, some which are new. It says that society as a whole also has a role to play. It says that we now need the communities to be more aware of dementia and those who care for people with dementia are encouraged to seek help and support. In the



communities people must feel able to go about their daily lives safely and free of stigma. Our strategy will address this through a range of community based public health initiatives. Another priority aim is the need for more joined up research, which we have also addressed in the strategy. The need for more research in the future will grow. In December 2013, a G8 summit held in London focussed on dementia as well as the need for more research. All these countries agreed on a commitment to build an international effort to approach the problem of dementia together.

In February 2014 an announcement was made to support the ambition set out as part of the Prime Minister's Challenge on Dementia, NHS England will invest £90 million in diagnosing two thirds of people with dementia by March 2015 (see reference 3). It will focus on areas where the time taken to carry out diagnostic assessments is more than the average of six weeks.

This new strategy also gives attention to five new areas not previously addressed in the last strategy: prisoners with dementia; people with learning disabilities and those with young onset dementia; people with dementia belonging to Black, Asian and Minority Ethnic (BAME) groups, and people with dementia who frequently contact the police.

What have we done to develop the new strategy?

The strategy task group looked at the first strategy (for 2012-14) and did a stock take on its dementia projects to confirm what it has achieved and what we still needed to do. The group asked Healthwatch County Durham to work with Healthwatch Darlington, on a patient journey consultation with people with dementia and their family/carers. The results of this consultation have informed us where services and patient experiences can be further improved.

We also engaged directly with clinicians to ask them for their views on what should be a priority in our strategy.

The task group recognises that overview and scrutiny plays a key role in developing social care and health strategies and driving service improvement. In Durham, the Adults, Wellbeing & Health Overview and Scrutiny Committee has received a presentation on services in the County, development of the strategy and future plans. Further meetings are planned with the Overview and Scrutiny chair.

We are committed to maintaining an open and positive relationship with Overview and Scrutiny within both Durham and Darlington and welcome any future requests for further engagement.



Next steps

In this strategy, we have identified actions that set the direction of travel for an implementation group to implement, and report out to stakeholders on their progress.

We have agreed to initiate a Health Needs Assessment on Dementia for County Durham and Darlington. This has not happened ever before and the results will help us focus on areas that need improvement in the future. The results from this Health Needs Assessment will be available during 2014-2015. We will need to engage with some stakeholders when carrying out that assessment.

Every year we will refresh the strategy and make it clear what we did achieve and did not achieve. So, there will be the opportunity to incorporate the lessons learnt from the health needs assessment in the following year.

2. Our challenge in County Durham and Darlington

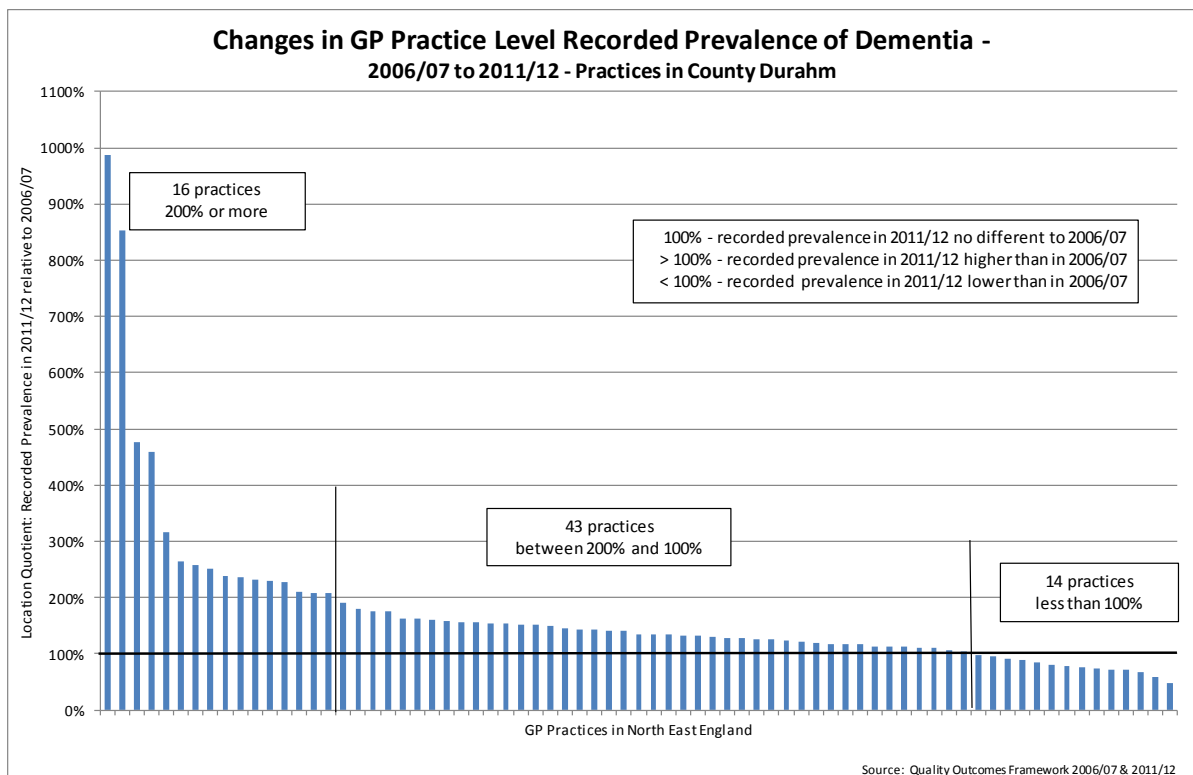
This section focuses on what we believe are the challenges we must address in our strategy:

- The increasing numbers of people with dementia in our area
- The need for more healthy living schemes to be promoted
- Challenges in the community from the State of the Nation Report
- Challenges at hospital from the State of the Nation Report
- Challenges on the future of care from the State of the Nation Report

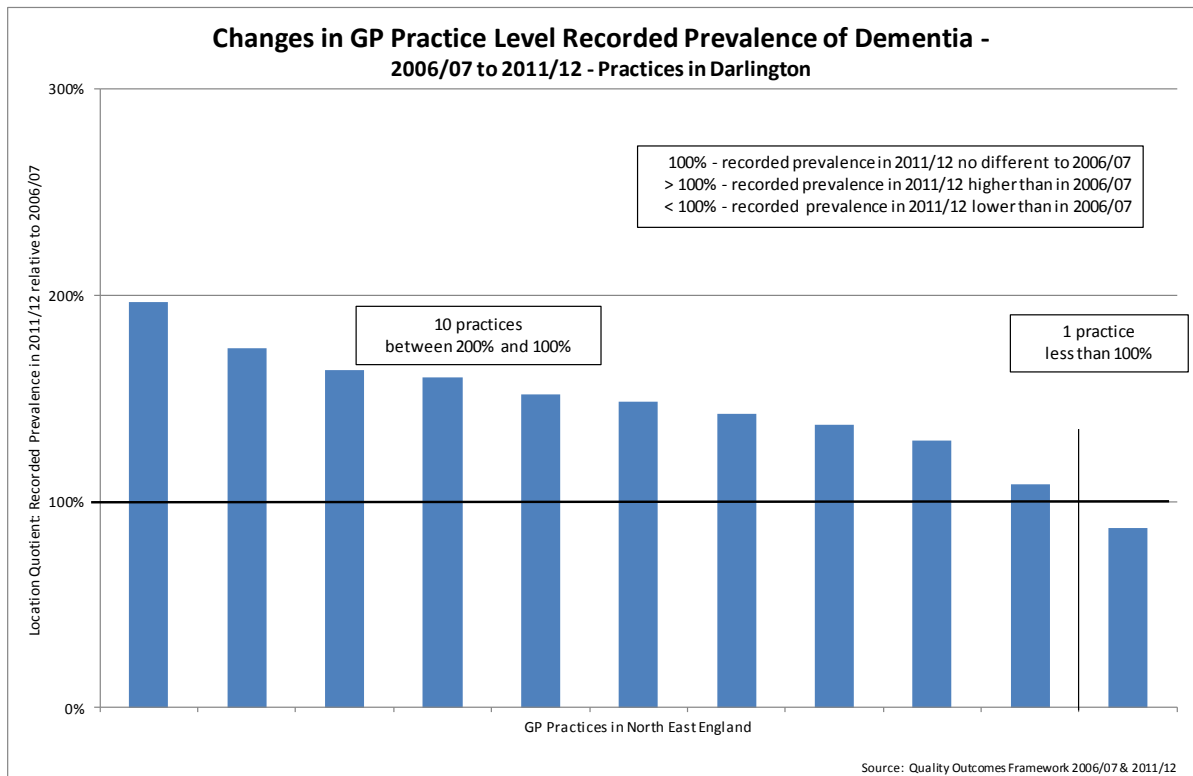
The number of people with dementia in County Durham and Darlington

Our population is living longer and the proportion of older people with dementia will increase. We know from information gathered by the North East Public Health Observatory, that most of the GP practices in County Durham have seen an increase in the proportion of their patients who have dementia over the past five years. Of all 73 practices, 59 of them have recorded at least two-fold (100%) increase in proportion of the population who have dementia during the past five years.

This increase supports the estimated prediction that the numbers of people with dementia in England is set to double in the next 30 years (Prime Minister’s Challenge on Dementia).



The situation is similar in Darlington. Information from North East Public Health Observatory also shows the prevalence of people with dementia has increased over the past five years. The table below shows that all but one of the GP practices has experienced at least a two-fold (100%) increase in the proportion of people with dementia.



Action: Capacity to meet diagnosis needs

We will strategically plan and communicate as to how we will meet the increasing demand in number of people with dementia who need screening and access to diagnostic services.

Prevention

The State of the Nation Report on dementia care and support in England reminds us that dementia can in some cases be delayed or prevented. Around 60 percent of people with dementia have Alzheimer’s disease. Approximately 20 percent have vascular disease and many people have a mixture of the two. Vascular dementia results from problems with the blood supply to the brain – without enough blood, brain cells can die. The effects of vascular dementia can be minimized or prevented altogether through a healthy lifestyle. Smoking and obesity, for example, affect many types of dementia, in particular vascular dementia.



Helping people to understand the impact of their lifestyle could help them to make better, more informed choices and reduce their risk of developing vascular dementia.

So far, the national focus has been around improving diagnosis of dementia. In our strategy we will take this further and focus on opportunities to prevent dementia through healthy lifestyle programmes. The implementation group will establish joint working relationships with public health and promote preventative projects through all primary and secondary care services (GP practices, alcohol services etc.)

Action: Prevention

We will take action to promote the benefits of healthy life style programmes to the public, making it clearer that the risks of developing vascular dementia (as well as other life threatening conditions like cancer, heart disease and stroke) can be reduced.

We will review opportunities for promoting dementia awareness through all possible contacts, such as substance misuse and alcohol teams as well as primary care.

Challenges in the community – waiting time and antipsychotics

The State of the Nation Report measures four areas in the table below and suggests where improvements need to be made by the Durham Dales, Easington and Sedgefield Clinical Commissioning Group (DDES CCG) and Darlington Clinical Commissioning Group (D CCG), and the main provider, Tees, Esk and Wear Valleys NHS Foundation Trust (TEWV).

Type	Measure	Comments
Checking for dementia (the percentage of people diagnosed)	DDES CCG 65.3%	Average for England
	D CCG 61.4%	Average for England
	North Durham 56.7%	Average for England
Waiting to be tested by TEWV	Durham Dales/Sedgefield area 1 week	Good
	Easington area 3 weeks	Should move to 1 week
	Darlington 1 week	Good
	North Durham 3 weeks	Should move to 1 week
Waiting for results from TEWV	Durham Dales/Sedgefield area 6 week	Above average
	Easington area 9 weeks	Should move to 6 weeks
	Darlington 7 week	Should move to 6 weeks
	North Durham 9 weeks	Should move to 6 weeks
Prescribing antipsychotics in dementia	No data available	Need to take steps to obtain and centralise the data and compare to baselines

Measures from interactive map of dementia, 08/04/2014, <http://dementiachallenge.dh.gov.uk/map/>



There are some 'Gold Standard' models where CT scanning for diagnosis takes place on the same day, such as at James Cook Hospital that significantly reduces the time taken to complete a diagnosis.

During 2012-2013 an audit looking at the use of antipsychotic drugs for patients was undertaken across County Durham and Darlington. The audit focused on data from 2011. The audit aimed to ascertain whether patients with a diagnosis of dementia who were prescribed antipsychotic medication were prescribed in line with recommended guidance e.g. they are prescribed an atypical antipsychotic, namely Risperidone, and for a period of less than 12 weeks. However, we acknowledge that some antipsychotic medication is prescribed appropriately.

The audit shows that the percentage of those patients who have been prescribed the medication for longer than the recommended 12 weeks had increased slightly for some localities covered by the Clinical Commissioning Groups in County Durham and Darlington. Recommendations were made in the report, and a further audit is recommended to find out what improvements have been made using 2012 and 2013 data.

Action: Waiting time and antipsychotics auditing

We will work with providers to monitor and review waiting times for tests and results, and agree on improving targets and bringing uniformity in waiting times across the areas covered.

We will explore how we can audit the prescribing of antipsychotics with appropriate resources.

Challenges at hospital

The State of the Nation Report measures four areas in the table below and suggests where improvements need to be made at hospitals by three main providers – North Tees and Hartlepool NHS Foundation Trust (NTH); City Hospital Sunderland NHS Foundation Trust (CHS) and County Durham and Darlington NHS Foundation Trust (CDDFT) for the population in Durham Dales, Easington and Sedgefield Clinical Commissioning Group (DDES CCG), Darlington Clinical Commissioning Group (D CCG) and North Durham Clinical Commissioning Group (ND CCG).

Area	Locality	Provider/measure	Comments
Looking for dementia in Hospital	DDES CCG	NTH 100%	Good
		CHS 96.73%	Average
		CDDFT 89.56%	Mixed results, needs improving
	D CCG	CDDFT 89.56%	Mixed results, needs



			improving
	ND CCG	CDDFT 89.56%	Mixed results, needs improving
Assessing dementia in hospital	DDES CCG	NHT 99.73%	Above average
		CHS 100%	Good
		CDDFT 96.15%	Above average
	D CCG	CDDFT 96.15%	Above average
	ND CCG	CDDFT 96.15%	Above average
Referring patient for further tests	DDES CCG	NHT 100%	Good
		CHS 100%	Good
		CDDFT 97.67%	Above average
	D CCG	CDDFT 100%	Good
	ND CCG	CDDFT 100%	Good
Length of stay in hospital	DDES CCG	NHT longer	Needs improving
		CHS longer	Needs improving
		CDDFT longer	Needs improving
	D CCG	CDDFT longer	Needs improving
	ND CCG	CDDFT longer	Needs improving
Going back to hospital	DDES CCG	NHT same	Average
		CHS more likely	Needs improving
		CDDFT more likely	Needs improving
	D CCG	CDDFT more likely	Needs improving
	ND CCG	CDDFT more likely	Needs improving
Dying in hospital	DDES CCG	NHT more likely	Needs improving
		CHS more likely	Needs improving
		CDDFT more likely	Needs improving
	D CCG	CDDFT more likely	Needs improving
	ND CCG	CDDFT more likely	Needs improving

Measures from interactive map of dementia, 08/04/2014, <http://dementiachallenge.dh.gov.uk/map/>

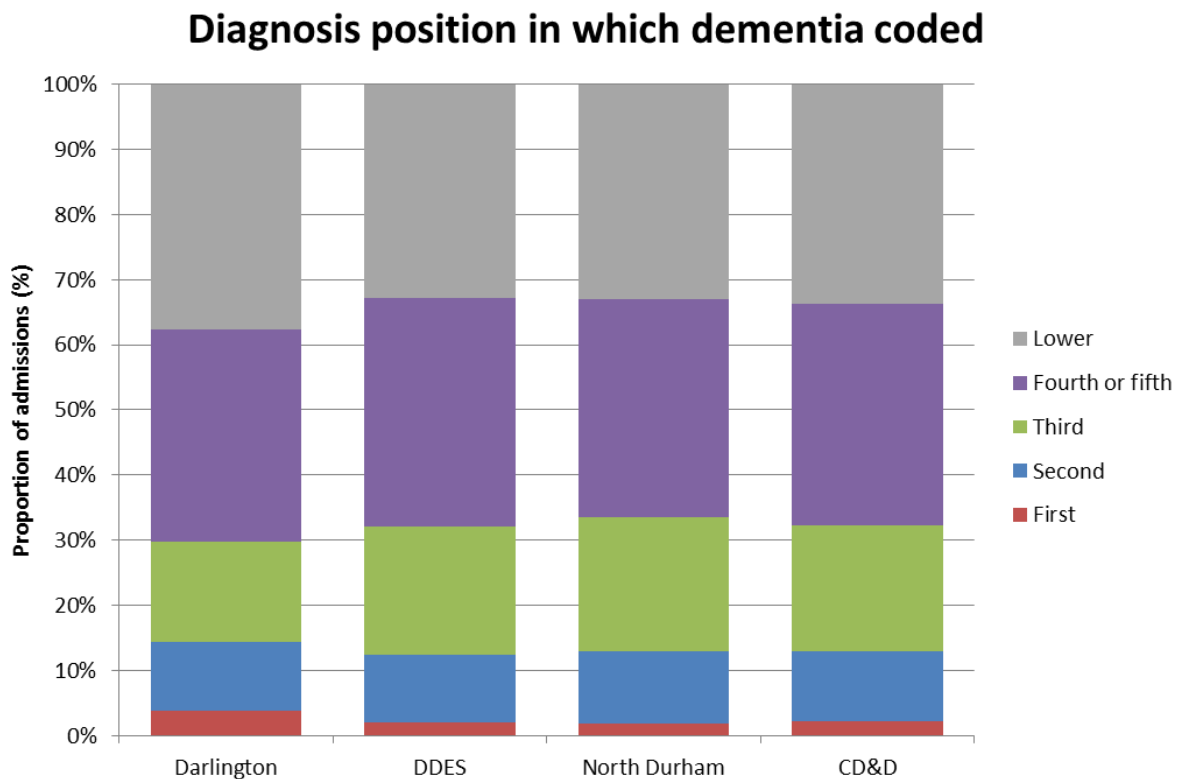
Action: Review dementia in hospitals and understand what can be done to keep dementia patients out of hospital

We will work together to review literature and examples of good practice, to identify suitable initiatives for development which we will jointly invest in, with the aim of reducing the need for people with dementia to stay in hospitals for longer than necessary and to reduce the likelihood of them dying in hospital.

Admissions of people with dementia

Admissions of people with dementia very often come with other conditions that require treatment, or are a factor which may influence the person with dementia's care or recovery. An analysis of data from April 2013-February 2014 showed very few patients are admitted to acute hospitals with a primary diagnosis of dementia (2.2%), however 32% of admissions was deemed of sufficient importance to causation / care that dementia is one of the first three

recorded diagnosis. 66% of admissions had dementia coded as one of the five most relevant diagnosis recorded. This is shown in the bar charts below:



This means, two thirds of all people admitted to acute hospitals who have dementia, will usually have the dementia recorded as a secondary condition. Where dementia is given as one of the first few recorded diagnosis, this should represent dementia being a significant contributor to causing admission or having a significant impact on the patient’s care.

We note that successful projects such as an acute liaison and care home liaison service has been working specifically for the past two years to improve the experience of people in hospitals or care homes who have dementia.

Readmission of people with dementia to non-mental health providers

A key focus for the strategy task group is around taking necessary steps to reduce the readmission of patients with dementia. As shown above, many admissions to non-mental health providers concern a co-morbidity of dementia with other conditions requiring treatment or where dementia is a factor which may influence the patient’s care or recovery. This presents a challenge for not only the community and acute providers, but for local services in taking steps to avoid unnecessary readmission to hospitals within 30 days and 90 days.

An analysis of data covering patients registered with a member practice of Durham Dales, Easington and Sedgefield Clinical Commissioning Group, North Durham Clinical Commissioning Group and Darlington Clinical Commissioning Group and unregistered



patients within their boundaries shows an average 12% patients with dementia are readmitted to non-mental health providers within 30 days of discharge from a prior admission, and 20% within 90 days of discharge from a prior admission.

Admissions within 30 days of discharge from a prior admission - May 2013 to Feb 2014

CCG / Point of Delivery	Admission within 30 days of discharge from prior admission	Admission NOT within 30 days of discharge from prior admission	Admission with readmissions status not known	Total	% of dementia related admissions in month that are 30 day readmissions
Darlington	43	364	2	409	10.5%
Acute	43	343	2	388	11.1%
Community Hospital		21		21	0.0%
DDES	147	1123	7	1277	11.5%
Acute	142	1061	6	1209	11.7%
Community Hospital	5	62	1	68	7.4%
North Durham	135	872	4	1011	13.4%
Acute	122	778	4	904	13.5%
Community Hospital	13	94		107	12.1%
CD&D	325	2359	13	2697	12.1%

Admissions within 90 days of discharge from a prior admission - May 2013 to Feb 2014

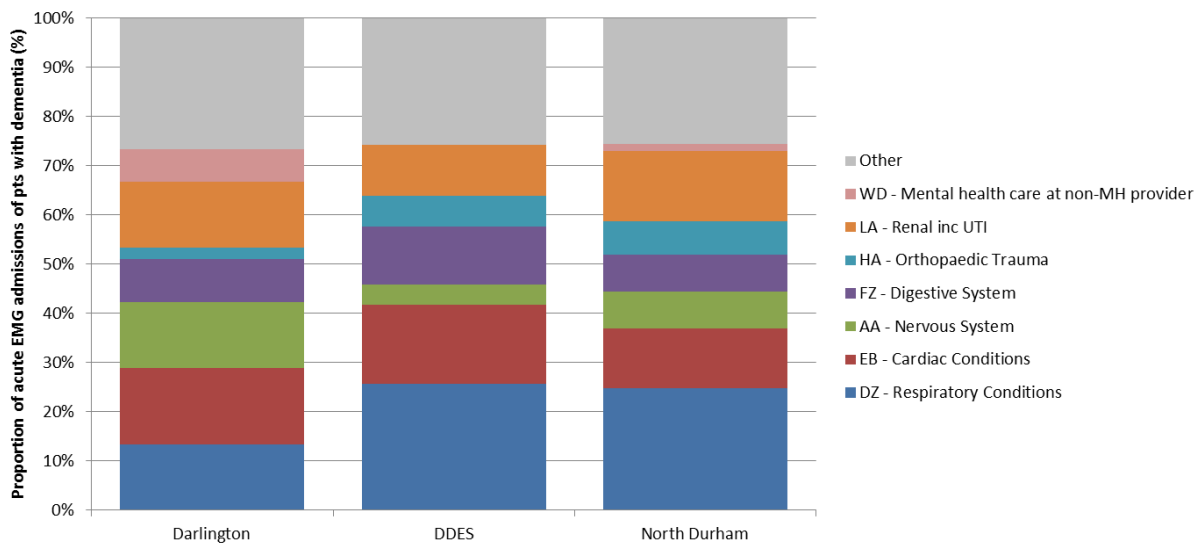
CCG / Point of Delivery	Admission within 90 days of discharge from prior admission	Admission NOT within 90 days of discharge from prior admission	Admission with readmissions status not known	Total	% of dementia related admissions in month that are 90 day readmissions
Darlington	72	335	2	409	17.6%
Acute	72	314	2	388	18.6%
Community Hospital		21		21	0.0%
DDES	248	1022	7	1277	19.4%
Acute	239	964	6	1209	19.8%
Community Hospital	9	58	1	68	13.2%
North Durham	229	778	4	1011	22.7%
Acute	205	695	4	904	22.7%
Community Hospital	24	83		107	22.4%
CD&D	549	2135	7	2697	20.4%

Readmission avoidance services and associated conditions

There are some generic admission and readmission avoidance services and pilot projects taking place at both primary care level and at care homes around County Durham and Darlington. In the Easington locality of Durham Dales, Easington and Sedgfield Clinical Commissioning Group a dementia dedicated admission / readmission avoidance pilot project has been taking place and will continue to do so during 2014-2015. It aims to see how the use of dedicated care coordinators giving reablement support people with dementia would reduce their risk of admission or readmission. To date, the pilot, although being short in duration and covering a limited geographical area, has demonstrated that people with dementia value highly the support of dedicated care coordinators around the time when they were discharged from hospital. Although not yet conclusive, this pilot scheme has to date brought the rate of readmission down from what is usually 12% within 30 days of a person being discharged from hospital, to 6%.

In trying to understand the reasons behind readmissions, a breakdown of data from May 2013-February 2014 covering County Durham and Darlington examined the grouping of conditions and procedures within the NHS payment system. This provides a useful summary of the main reason for a readmission and shows very few patients are readmitted with dementia being the primary diagnosis.

Comparison of 30 day readmission by HRG sub-chapter (2013/14 YTD)



This above chart is not population weighted across Durham Dales, Easington and Sedgefield Clinical Commissioning Group, North Durham Clinical Commissioning Group and Darlington Clinical Commissioning Group. It however indicates there is very little difference between Durham Dales, Easington and Sedgefield and North Durham Clinical Commissioning Groups as to the condition that require readmission for a patient with dementia. Darlington Clinical Commissioning Group however has a lower proportion of readmissions made up of respiratory conditions and a higher proportion of readmissions that the other clinical commissioning groups made up of nervous system conditions.

In conjunction with dementia friendly communities, people with dementia and their carers make it clear that they would prefer to remain living at home for as long as possible. This approach will delay or avoid the need for residential or nursing care. Alongside making the general community dementia friendly; suitable domiciliary care, day services and telecare initiatives will assist with this approach, as well as a more specialist forms of housing, such as extra care and dementia specific housing schemes.

Action – Develop dementia admission and readmission avoidance services

The implementation group for the strategy will:

- Share examples of good practice across the county where people with dementia are being discharged from hospital faster, and learn from those case studies.
- ‘Deep dive’ into readmission data to obtain a wider understanding of possible reasons



differences in conditions that require readmission for a patient with dementia, between the Clinical Commissioning Group areas, and take any necessary action to address those differences.

- Review the range of admission and readmission avoidance projects and services to ensure that they continue to reduce the likelihood of a patient with dementia being admitted to hospital following discharge from a prior admission, and take steps to strengthen the benefits of the services so they are more consistent across the region. Alongside this work, we will explore options for strengthening support for people at home, including housing options.

Future of Care

The table below shows the percentage of people expected to be living with dementia in the areas from what is known about the local population. It also shows those who have not signed up to 'Dementia Friendly Communities' initiatives, and the number of research projects taking place with memory clinics.

Type	Measure	Comments
<i>People expected to be living in the community with dementia</i>	DDES CCG 1.24%	Average for England
	D CCG 1.37%	More than average for England
	ND CCG 1.18%	Average for England
<i>Dementia Friendly Communities sign up</i>	Durham Dales/Sedgefield – nil	Need to sign up
	Easington - nil	Need to sign up
	D CCG -nil	Need to sign up
	ND CCG	Need to sign up
<i>Research studies into dementia treatment and care being run by memory clinics</i>	Durham Dales/Sedgefield –nil	Need to increase to five (average)
	Easington area – 1 study by TEWV	Need to increase to the average of five
	D CCG – 2 studies by TEWV	Need to increase to the average of five
	ND CCG – 2 studies by TEWV	Need to increase to the average of five

Measures from interactive map of dementia, 08/04/2014, <http://dementiachallenge.dh.gov.uk/map/>

The Prime Ministers Challenge on Dementia (launched March 2012, see reference 4) identified a series of commitments to action. Creating dementia friendly communities is one of the commitments in the challenge. The dementia friendly communities' programme focuses on improving the inclusion and quality of life of people with dementia. It is envisaged



that a dementia friendly community (which can be a village, town, city, borough or even an organisation) is one that shows a high level of public awareness and understanding so that people with dementia and their carers are encouraged to seek help and are supported in their community. Such communities are more inclusive of people with dementia, and improve their ability to remain independent and have choice and control over their lives.

All communities wishing to become accredited as dementia friendly must meet a set of foundation criteria specified by the Alzheimer's Society, who are responsible for the administration of the national programme. In Durham, plans are being developed to establish at least two town 'pilot sites' to follow the recognition process, within Barnard Castle in the South and Chester-le-Street in the north of the County identified at this stage.

In Darlington, similar plans are being developed in partnership with a care provider with experience in this area to establish dementia friendly communities within the extra care housing schemes across the borough.

Action: Roll out Dementia Friendly Communities programme and review arrangements for research studies at memory clinics

Durham and Darlington will complete pilot projects for the Department of Health Dementia Friendly Communities programme in 2014/15. We will use the lessons learnt from these projects to support further communities in Durham and Darlington to enter the accreditation process and become, and remain, recognised as dementia friendly, with the aim of rolling out accreditation across Durham and Darlington.

We will review access to services, including the making of reasonable adjustments (such as transport) to ensure people with dementia can benefit from a range of services.

The above actions set out in section 2 will be taken forward by a new implementation group for this strategy. There are additional actions in a Framework for Priorities set out in section 16, which will also be implemented.

Reinforcing the need for actions

Healthwatch County Durham and Healthwatch Darlington undertook a consultation in January to March 2014 (see Section 13). Members of the public identified all the above challenges in this section, and support the need for action to improve the experience from diagnosis to end of life care for carers, family members and patients with a diagnosis of dementia.



3. Ambition Map for Dementia Diagnosis Rates and Dementia Direct Enhanced Service

Improving rates of diagnosis

The diagnosis rate is planned nationally and there is a need to improve it. Diagnosis rates on average in England are just 48 per cent, which despite being a two per cent increase from 2012, means there are still around 416,000 people in England who are living with dementia but who are not diagnosed.

NHS England expects that by 2015 (in the refreshed mandate to CCGs) two thirds of the estimated number of people with dementia in England should have a diagnosis, with appropriate post diagnosis support.

Based on the Ambition Map for Diagnosis Rates (see reference 5) the following diagnosis rates are estimated using data from the year 2011/12 covering the localities of the new CCGs in the region. In the last two columns are the diagnosis rate ambitions for the next two years. The challenge for the CCGs is to ensure that appropriate steps are taken to meet those targets.

Clinical Commissioning Group	Diagnosis Rate (adjusted) 2011/2012	CCG Diagnosis Rate 2013/14 (as at Nov 2013)	CCG Diagnosis Rate Ambition 2014/15*	CCG Diagnosis Rate Ambition 2015/16*
Durham Dales, Easington and Sedgefield	56.99%	66.20%	66.53%	67.00%
Darlington	51.06%	62.20%	64.03%	67.06%
North Durham	52.05%	56.70%	62.03%	67.01%

**At the time of writing this strategy, those diagnosis rate ambitions were proposals to the Area Team (for Durham, Darlington and Tees area) and were awaiting approval.*

This target is dependent on the length of the pathway beginning with an assessment at GP practice level, leading to a full assessment by memory clinics including scans.

During 2013-2014 a new Dementia Direct Enhanced Service programme was released by NHS England (see reference 6). In County Durham and Darlington, 95% of all GP practices signed up to this programme. In signing up to the programme the GP practices agree to make an opportunistic offer of assessment for dementia to 'at-risk' patients and, where agreed with the patient, to provide that assessment. The GP practices will report on the numbers of at risk patients who are offered and receive an assessment, and who agree to be referred for an



assessment. As gateway keepers, the GP practices are expected to see an increase in patients being diagnosed for dementia. The data on the progress made is not presently available, however NHS England have agreed to extend the Dementia Direct Enhanced Service programme for 2014-2015. There will be a need to review the data and agree on any actions that can be taken to enhance the diagnosis rates so that the target of two thirds of the estimated number of people with dementia in County Durham and Darlington can be met by 2015.

Better coding

During 2013-2014 an exercise was taken to cross reference the dementia codes on the GP practices system against the codes on the acute system within the Mental Health Older People's Service at Tees, Esk and Wear Valley's NHS Foundation Trust (TEWV). This was done because there was evidence that some people with dementia registered (with the right codes) with the GP practice were not registered within the acute services, and vice versa. A significant number of 'mismatches' were identified and the coding was improved. This worthwhile exercise needs to be encouraged.

Action: Monitor and improve dementia diagnosis rate

The implementation group for the strategy will:

- Review activity data connected to the Dementia Direct Enhanced Service.
- Support practices that have not yet signed up to the Dementia Enhanced service or have a low uptake and share the best practice.
- Look for wider actions around engaging with other teams such as substance misuse/alcohol team.
- Be mindful about the future of Direct Enhanced Services for dementia and explore where local actions can be taken to increase the dementia diagnosis rate.
- Encourage and support improved coding and coding matching exercises on people with dementia between GP practices and secondary care dementia services.
- Consider piloting new screening tools that may be more effective and efficient.



4. Black, Asian and Minority Ethnic (BAME) Groups

In July 2013 the All-Party Parliamentary Group on Dementia found that many people from BAME communities did not receive a diagnosis of dementia, preventing them from having access to support and treatments that could help them live well with the condition (State of the Nation, page 8). Amongst those who did seek help, there was generally felt to be a lack of culturally sensitive dementia services.

In the North East, the BAME population is low in comparison to the rest of England. Nevertheless there will be BAME communities that will be at a disadvantage and be experiencing an inequality of outcomes when accessing dementia diagnosis and post diagnosis care. There is a need to understand what initiatives are currently in place to support BAME communities in County Durham and Darlington, and to compare case studies with good practices.

Action: Black, Asian and Minority Ethnic Groups

We will explore options for establishing a user led group or consultancy that will engage directly with the range of BAME groups to scope their needs, gaps and priorities for improving support for people with dementia, which the strategy group will consider implementing.



5. Learning Disabilities

The State of the Nation Report has highlighted that people with learning disabilities have an increased risk of developing dementia and usually develop the condition at a younger age. This is particularly true of people with Down's syndrome, one in three of whom will develop dementia in their 50s (see reference 7).

In County Durham and Darlington progress needs to be improved on the following areas:

- There needs to be a data exercise to establish the numbers of people with learning disabilities including those from GP practices that have not signed up to the Direct Enhanced Services for people with learning disabilities
- There are no defined pathways between GP practices and learning disabilities teams who can carry out specialised assessments on people with learning disabilities.
- There is a lack of knowledge/awareness among many carers about dementia in people with a learning disability. The symptoms are often unrecognised and therefore not brought to the attention of GPs in the first place.

Action: Learning disabilities and dementia

We will plan together how we will:

- Promote greater awareness to primary care services, of issues around the diagnosis of dementia of people with learning disabilities.
- Explore appropriateness of existing pathways to memory clinics and strengthen the interface between primary and secondary care services for people with learning disabilities.
- Focus on interacting with the learning disabilities teams who will undertake specialised assessments for dementia with people with learning disabilities.
- Establish the best pathways that will enable a clear interaction between primary care and the specialised learning disabilities teams.



6. Young Onset Dementia

Prevalence

The Alzheimer's Society (2002, see reference 7), estimates that there are about 18,500 younger people with dementia in the UK, suggesting that young onset dementia may occur in 1 in 1400 people between the ages of 40 and 65. However the Society states this is likely to be an underestimate and the true figure could be up to three times higher.

Figures below are based on LA mid-2006 estimates, using age range 40-64 to estimate prevalence rates against Alzheimer's Society suggested prevalence rates for this age range.

For County Durham and Darlington (mid 2006 Local Authority population estimates), this would equate to approximately 147 individuals, as follows:

Area	Population aged 40-64 years	Prevalence based on 1:1400
County Durham	171,500	123
Darlington	33,600	24
Total	205,100	147

There are currently 203 patients younger than 65 who are open to services within County Durham and Darlington Mental Health Service for Older People.

Young onset dementia services in County Durham and Darlington

Young people can develop dementia and this particular group require support from dedicated consultant sessions, dedicated and specialised psychological services, nursing and IT staff with skills in assessment and the management of Young Onset Dementia.

Tees Esk and Wear Valleys NHS Foundation Trust (TEWV) provide aspects of this service in County Durham and Darlington.

In South Durham and Darlington whilst dedicated resources are in place, there remains a gap in provision for neuropsychology. Whilst patients receive a range of required interventions, the full complement of recommended interventions needs to be expanded.

In North Durham, there is currently no dedicated resource and limited specialist interventions, and patients with suspected young onset dementia are seen within community teams by generic staff. Activity information shows considerably lower numbers than in South Durham



and Darlington where there is a dedicated resource. The current number of patients seen by the teams is also significantly lower than prevalence figures would suggest. It is recognised that the support offered to people with Young Onset Dementia could benefit from being connected to other services for rare conditions, such as Huntington's disease which has some symptoms of dementia. It is also recognised that staff providing Young Onset Dementia services would benefit from having access to a single point of information to enable them to support the person with dementia and their carers at the earliest opportunity.

Plans are in place to expand the range of support. It is understood from past experience that when a dedicated resource has been put into place, an increase in referral rates from GPs follows, as has been the case in South Durham and Darlington. This is largely owed to the fact that Young Onset Dementia is recognised as a gap by GPs and other service providers.

Action – Young Onset Dementia

The implementation group will review the services for Young Onset Dementia and consider actions to address gaps in provision and resources.



7. Prisoners with Dementia

Older prisoners are the fastest-growing section of the prison population. Care UK (working with TEVV as their sub-contractor for mental health services) is the current provider of prison healthcare services and is responsible for ensuring the provision of high quality mental health services to all prisoners in accordance with NICE Quality Standards and best practice. This include interventions for supporting self-help, provision of counselling services, nurse led services, general psychiatry and for those presenting with more complex mental health care needs access to Older Person, Psychiatry, Forensic Learning and Disability, Forensic Psychiatry and Clinical Psychology Services.

All those with a serious mental illness and/or a suicide risk will be identified at the initial reception screening led by a qualified nurse. Prisoners identified as having mental health and/or substance misuse problems, will be referred to the mental health team and will be seen within 5 days for a secondary screen where a more in-depth assessment will be undertaken to further understand mental health and substance misuse problems. The prisoner would then be assessed according to their level of need and sign posted appropriately. Care UK is responsible for the implementation and maintenance of robust pathways for older patients which comply with the Department of Health document “A pathway to care for Older Offenders (DH, 2007a). Care UK also regularly report achievement against a prison specific quality and outcomes framework which contains a specific clinical indicator in relation to Dementia. This requires Care UK to maintain and report monthly on a register of patients diagnosed with dementia, the percentage of patients diagnosed with dementia whose care has been reviewed in a face-to-face review in the preceding 12 months and the percentage of patients with a new diagnosis of dementia, with a record of FBC, calcium, glucose, renal and liver function, thyroid function tests, serum vitamin B12 and folate levels recorded within the last 6 months.

Below are figures confirming two identified cases for Durham for the year 2013-2014 to date.

Measure / location	HMP Frankland (High Security prison)	HMP-YOI Low Newton (Women’s prison)	HMP Durham (local prison)	HMP Holme House (local prison Stockton-on- Tees)
DEM001 – Register	1	0	1	1
DEM002 – Reviewed in previous 12 months	67.5%	70%	52.5%	100%
DEM003 – Tested within 6 months of new diagnosis	80%	80%	80%	-



Action: Prisoners with dementia

There is a pressing need to consider how to manage the health/social care interface and meet the needs of prisoners and others with social care needs. This is likely to require discussions with colleagues from Adult Social Care to negotiate and agree solutions, as this issue is likely to become more prominent as the prison population continues to age.



8. Living with dementia

In North of England, we have had the lowest percentage of patients with dementia (from GP Patient Survey data – a postal survey in 2012 and 2013) compared to the rest of England, who felt they did not have sufficient support from local services/organisations (State of the Nation Report, page 23). This is currently at just under 10% of those surveyed. Whilst this compares favourably with other regions in England, this percentage has risen between 2012 and 2013. Our challenge is to find out why this has been increasing, and what more we can do to stop it increasing, and to bring it down in the future.

We feel there is a growing need to support carers more widely, and for greater working in partnership. The critical time seems to be when someone is first diagnosed with dementia. The impact is profound, on the person as well as their family and others in their life. The State of the Nation Report cites two key reasons for this: it can be too late to get power of attorney when the diagnosis is given, causing problems and financial hardship for families; and secondly, earlier prior knowledge of a diagnosis could help families explore support networks and take advantage of them earlier.

We must ensure that carers do not have difficulties in obtaining a diagnosis for the person they care for. We presently do not know the extent of this possible problem for carers in County Durham and Darlington.

We must ensure carers are given information on legal issues and managing money. The Carers Trust (2013, see reference 8) found that many carers had learned about Lasting Power of Attorney too late. There is also a need to consider what should be done in situations when a person with dementia has the capacity to make decisions with healthcare staff and may wish to maintain a level of confidentiality from their own carers. In these situations, the carers will require support. Likewise, support for carers, who may hold Powers of Attorney, but feel their rights are not being heard or respected; needs to be considered.

There is currently no national measure of the provision of post diagnosis support. However work is underway by NHS England to develop an indicator for this which will be part of the NHS Outcomes Framework in the future.

Results from the consultation led by Healthwatch County Durham and Healthwatch Darlington identified the following needs:

- Carers would benefit from more support and intense support/counselling to be offered at the earliest point of diagnosis. This should extend to the families of patients as well as their primary carers. There is a need to ask, 'How will the diagnosis affect your family members?'
- Some carers have struggled to get an early diagnosis and have had to fight and push for further tests and investigation from the outset. Results have shown that an early



diagnosis and early treatment is vital in delaying the effects of dementia. The diagnosis of dementia can overlap with tests for other conditions such as depression and anxiety and this can make a clear diagnosis initially difficult to establish.

- Many carers have described not being informed of the help required to assist them manage their lives post diagnosis including any financial help, and legal issues they may need to address. Many have been unaware of any entitlements to benefits, or allowances and as such have been unable to get the help or support they require at the detriment of the independence and wellbeing of the dementia patient.

Action: Carer and Post diagnosis support

The implementation group for the strategy will appoint a carer representative on to the group. The group will identify what improvements to supporting people with dementia and carers can be made. The implementation group will consider improvements to the wider sharing of appropriate information, with a view to using tools such as patient passports to enable improvements to the implementation of care packages and referrals.

Develop a single knowledge base to access all types of information that people with dementia and their carers would benefit from, to cover all stages of dementia pathways.

Reinforcing the need for action

The actions set out in this section strongly correlate to the findings of Healthwatch County Durham and Healthwatch Darlington consultation during their interviews with dementia patients, family, carers and staff. It is absolutely imperative that carers are given more support and that intense support/counselling is offered at the earliest point of diagnosis and this support should extend to the families of patients as well as their primary carers.

There is a key concern around the quality of signposting of people with dementia and their carers to other support services. Many carers described not being informed of the help required to assist them manage their lives post diagnosis including any financial help, and legal issues they may need to address. Many have been unaware of any entitlements to benefits, or allowances and as such have been unable to get the help or support they require at the detriment of the independence and wellbeing of the dementia patient. This reinforces the need for a single point of access of information to assist with the signposting of people with dementia and their carers.

A central point of information will also help primary and secondary care staff consider pathway options that exist in the community, that people with dementia who are under their care, and their carers, may benefit from.



9. Carers

Carers play a critical role in supporting people with disabilities. Carers also have their health and wellbeing needs, which need to be supported. The current Direct Enhanced Service for dementia 2013-2015 focuses on people with dementia, it also places an expectation that health checks on carers are carried out. There will be opportunities to look closer at how widely the Direct Enhanced Service for dementia is being taken up by GP practices in respect to supporting carers and how this can be supported further,

Objective 7 of the National Dementia Strategy (2009) requires the implementation of a carer's strategy. It is recommended that unpaid carers need to be given access to a wide range of support to help them in caring for people with dementia. In particular, the carer's strategy should focus on people with dementia and ensure that effective assessment, support and short breaks (respite) packages are available.

Durham County Council and Darlington Borough Council, both offer a range of support to carers. It is critical that the carers are fully aware of all the services that are on offer, and providers are able to have up to date information to assist with signposting carers to the range of services on offer. A Joint Commissioning Strategy for Carers was prepared by Durham County Council and Darlington Borough Council for 2009-2013.

The consultation led by Healthwatch County Durham and Healthwatch Darlington confirms that there is scope for improvement for awareness and signposting for available services for their optimum utilisation. There is a signposting and information role for Healthwatch in this area that needs to be developed.

Action: Supporting Carers

A new generic Joint Carers Commissioning Group will deliver the actions of the Joint Health and Wellbeing Strategies for County Durham and Darlington.

We will monitor the Direct Enhanced Service for dementia to check the uptake of health checks for carers, and we will increase the awareness of this service to other groups who are also supporting the carers. We will explore ways to support services especially primary care for health checks for carers.



10. Supporting dementia carers and professionals to allow people with dementia to live well in last years of life

A growing number of the population are living longer with more co-morbidities, including dementia. Sadly, people with dementia do not fare well in hospital as the unfamiliar surroundings exacerbate their condition. Often, families/children live some distance from elderly parents and are unable to care for them as they would wish, which often results in care home admissions. This leads to feelings of guilt for family members/carers as well as distress to the person with dementia.

There is scope to improve communication between families and the people responsible for their care including their doctors. There is also significant scope to improve advanced care planning as currently, lack of plans is one of the major factors that may lead to hospital admissions some of which are avoidable.

NICE Dementia Guidance (see reference 9) recommends that dementia care should incorporate a palliative care approach from the time of diagnosis until death. The aim should be to support the quality of life of people with dementia and to enable them to die with dignity and in the place of their choosing, while also supporting carers during their bereavement, which may both anticipate and follow death.

In addition, there needs to be set an expectation that at the point of diagnosis, memory clinics initiate the use of 'This is Me' and encourage people with dementia and their carers to take it with them whenever they access health and social care services and ensure staff in those care settings ask to see it.

Not all of our workforce are skilled in looking after people with dementia and the end of life – neither are the end of life care processes, and documentation, reflective of accommodating end of life discussions in the last years of life for people with dementia.

To enhance the skills of mainstream services, and to bring focused and expert support for dementia carers in line with the national dementia strategy the Clinical Commissioning Groups in County Durham and Darlington have commissioned additional dementia practitioner expertise. Practitioners will support professionals, people with dementia in all patient settings, across the health and social care systems, regardless of the care or home setting.

Many Trusts across the North East including CDDFT have signed up to the 'Deciding Right' document (see reference 10) and as such this will hopefully improve the pathway and steps for patients at the end of life.

A new unplanned admissions Direct Enhanced Service scheme is available for 2014-2015. It has been introduced as part of a move to reduce unnecessary emergency admissions to



secondary care. With this scheme there would be scope to provide multidisciplinary support for patients with dementia who are at risk of admission.

Action: End of life/palliative care for people with dementia

We will take steps to promote awareness through education and pathway development/liaison with end of life groups, not only within primary and secondary care settings but develop enhanced awareness for people with dementia and their carers so that people with dementia will have the opportunity to be supported to plan ahead the last years of their life.

We will plan to have additional resources to enable practitioners specialising in end of life/palliative care to interact with and offer support into all parts of the health and social care systems.

We will also explore ways to encourage reviews of the emergency admissions data for people with dementia from all the CCGs involved.

We will consider how the new unplanned admissions Direct Enhanced Service can be used to provide greater multidisciplinary support for people with dementia who are at risk of admission.



11. People with Dementia and Police Services

It has been formally raised by Durham Constabulary that some people with dementia will make emergency calls to the police to report suspicious activity and concerns, such as a burglary or theft which have subsequently been classed as non-crime due to the complainant having dementia.

A search of the log for January to March 2014 showed 147 callers where 'dementia' was noted in the record covering both County Durham and Darlington. There is currently no accurate way of identifying all dementia related callers, and there is a need to compose a list of all incidents and create a map of the locations of where the calls came from.

Some people with dementia may live alone for the main part of the day and can make high numbers of repeated calls to the police, which cause a drain on resources. There has been a case where an average 6 calls per week have been made by one person over a period of several months concerning a single recurring matter. A significant concern is also that a person with dementia, who has a record of making regular calls, could be at risk should a real incident occur within their household.

Action: Review what can be done to handle callers who have dementia

The implementation group will engage with the appropriate steering group that will review what can be done to hold better data on people with dementia who make regular calls to the police, and to consider how they can be handled without putting the person with dementia at risk

12. Research and Innovation

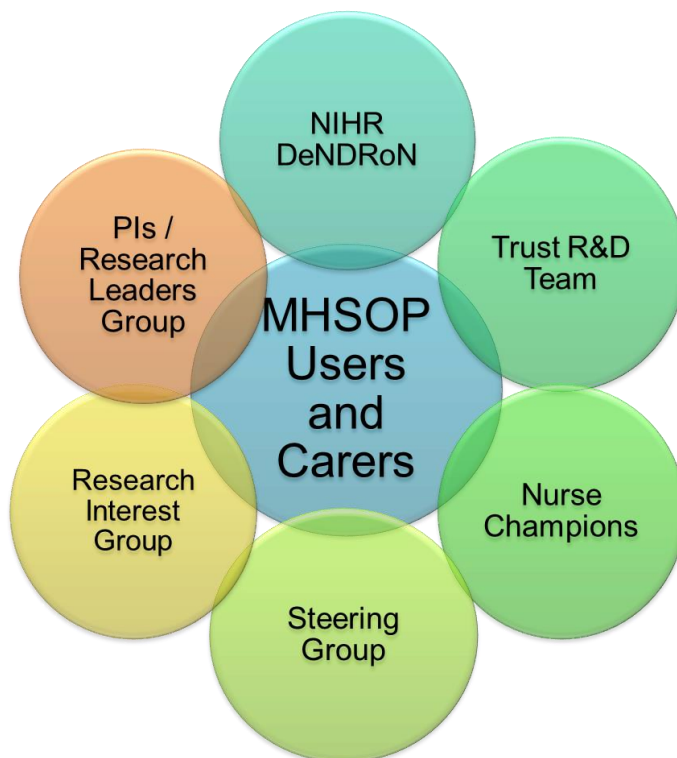
Research is vital to improve care in dementia and to improve mental health and wellbeing throughout the disease process.

The Call for Action (NHS England, July 2013, reference 11) highlights the need to support research amongst people with dementia. The State of the Nation report advocates that research has the potential to make a real difference to those with dementia and their families. It identifies the need for further research: towards faster diagnosis; towards new types of treatments; towards a cure; into how people with dementia can live well with the condition, around their decision-making ability and the reduced use of anti-psychotics in vascular dementia; understanding the disease and genetic factors; ways to tackle preventable dementia related disabilities.

DeNDRoN led research

Tees Esk and Wear Valleys NHS Foundation Trust (TEWV) is the main provider of dementia services in the Durham and Darlington. The majority of TEWV’s research is undertaken within the older people’s mental health services team and those people with dementia on the research register. The research projects are supported by DeNDRoN (Degenerative and Neurological Disease Research Network, reference 12) which is the main network which is part of the National Institute for Health Research (NIHR) Clinical Research Network (see reference 13).

The research arrangements at TEWV are outlined in the diagram below:





Within the above arrangement, the progress on research during the last year is such that:

- An MHSOP research interest group was set up and activity to date collated
- Collaborative relationships were established with Trust R&D team & DeNDRoN
- Governance structures were built and embedded to support rapid collective decision making
- A steering group recognised within Trust governing structures, was developed with new Terms of Reference.

There are currently 1078 research recruits associated to dementia research at TEWV, and this figure has increased year on year since 2009. NIHR has a wide portfolio of research at TEWV and the largest in terms for recruits, accounts for dementia research at 23%, a figure that has more than doubled in a year.

Of all research at TEWV, looking at the uptake in different service areas, the largest area is in dementia which has doubled in its volume of research projects during the last year.

As assessment of gaps and opportunities to strengthen research into dementia identified the following actions:

- Patients are given information about research opportunities
- There is an increase in the uptake of the DeNDRoN Dementia Research Register
- There is an increase in the number of patients with dementia that we refer to studies
- Increase the capacity of research skills by increasing the number of Principal Investigators for DeNDRoN studies; increasing research skills; undertaking more peer-reviewed research articles and hosting a research conference
- Consider how research studies can be devised within TEWV in parallel with DeNDRoN led studies.

Promoting dementia research in Primary Care

Whilst much dementia research takes place within the Mental Health Older People's Service, there should be opportunities for people with dementia to take part in diagnosis studies from the outset, such as in primary care settings. The promotion of the research register at primary care level should be encouraged. There should also be scope to include patients with other conditions in dementia research even when they may not yet be diagnosed with dementia, so that knowledge of preventative measures that can be taken in the future can be tested.

Early diagnosis

Early diagnosis is the first positive step in this process enabling decisions to be made and plans to be implemented whilst a good cognition is still evident and capacity is retained.



Current pathways of care show gaps in the evidence of robust pathways to provide support whilst minimising stigma during this post diagnostic period.

Innovation is required to ensure that patient empowerment at this early stage of the disease is retained appropriately through to end of life.

This process would encompass shared decision making to develop individualised care pathways and include medication management, planning for home care, financial physical and emotional carer support, advanced decision making records and end of life care.

Record sharing

Organisational innovation is necessary to improve timely cross care communication; of high priority is improvement in record sharing to enable swift, appropriate review and care with insight into co- morbidities and patient choice, this should include building a better understanding of each care provider's role for patient's, carers and other service providers.

Challenging behaviour

One of the most demanding areas of dementia care is the presentation of behaviour that challenges; some evidence shows that this can be a direct result of unmet needs. Development of joint psychosocial-medical understanding and communication is a priority to minimise the impact of BPSD (behavioural and psychological symptoms of dementia) and is a focus area for underpinning care of these patients.

Action: Research

We will scope all research studies and pilots and their timelines so that we can promote awareness of this work at both primary and secondary care levels, so the profile of research is raised more widely.



13. Healthwatch County Durham and Healthwatch Darlington Consultation on Dementia

The Dementia Strategy Task Group wanted to ensure that the strategy would be developed with local and up to date input from people with dementia and their carers from the outset.

Healthwatch County Durham and Healthwatch Darlington were commissioned to carry out a consultation with people with dementia and their carers, in a range of settings. The aim was to capture their experiences of having gone through a journey, from pre-diagnosis to diagnosis and leading to post diagnosis support.

Over 130 people were met at 18 meetings and 115 survey questionnaires were completed.

The consultation aimed to establish examples of good and poor practice. Examples of good practice would translate into outcomes that people with dementia and their carers should expect to experience when receiving health and care services at primary care, community and acute settings.

The consultation found that on the whole there seems to be room for improvement in the dementia pathway although there were some very good comments about dementia services which could possibly be rolled out throughout County Durham and Darlington.

Findings from the consultation are summarised below:

‘What are we doing well?’

- The time scale for diagnosis once the memory test is offered
- People who are offered access to groups and dementia cafes and use them value the support from these services and use them well
- Some Carers were offered a lecture and education on Dementia and this was found to be extremely helpful.

‘Areas for Improvement’

Signposting and information

- More educational information is needed to be provided at diagnosis
- More information to be available to carers regarding respite care
- Access to benefit advice and information on what financial help is available, prescriptions, other health needs
- Increased awareness regarding how dementia patients can make small lifestyle changes that can reduce risks of vascular dementia

Personalisation

- More choice in what services are available and how to access them.



- Services should be 'personalised' at the present time they are not individual enough for people at different stages of dementia. For example, a person with early stage dementia might benefit from a slightly different package of activities and integration compared with others.

Support

- The lack of free care available to patients and families – the care many people access has to be paid for
- The lack of support groups in some areas of the catchment area – most of the groups people attend are run by voluntary organisations and rely on family members to take the person with dementia to and from the groups
- More practical support for people to fill in forms
- More peer support
- More support for families - who asks the families as well as the primary carer as to how it is affecting them
- Respite care for carers.

Joined up service delivery

- The lack of knowledge surrounding dementia – comments regarding medical staff treating physical symptoms but not treating mental health symptoms
- Lack of home visits for patients who are housebound from GP, the need for regular contact from GPs and mental health services. Once a diagnosis is made the dementia patient and the carer/family member feel that they are 'left to cope'
- Health vs. social care argument – Patients need cognitive, stimulative and motivational activities/therapies to keep them from deteriorating, this is classed as a social care need and therefore not provided by health. Social care services appear not equipped or funded to take on this service.

“What is working well?”

- Support groups/memory cafes and singing for the brain, for those who can attend, are welcomed and talked about positively
- A few people we spoke to have been offered educational 'lectures' on dementia once a diagnosis has been made, this has helped them to understand dementia more. Very positive feedback on this was received
- Services are very good for certain people once access to them is obtained.

A report is being compiled at present to expand on the above points.

Action: Actions in response to findings

The implementation group will receive the report on the consultation and discuss the recommendations to determine what actions should be prioritised for 2014-2015 and 2015-2016.



14. Dementia Costs

As the population grows and ages there will be more people with dementia to care for, the cost of this care is expected to rise significantly. It is expected to cost more than the costs for cancer, heart disease and stroke services in the future. This section outlines the costs of dementia services that has been spend during 2013-2014, including the impact of admissions by people with dementia. It also outlines forthcoming steps that will take place to bring more acute services into the community, closer to home.

Current spend on acute and community based dementia services for County Durham and Darlington

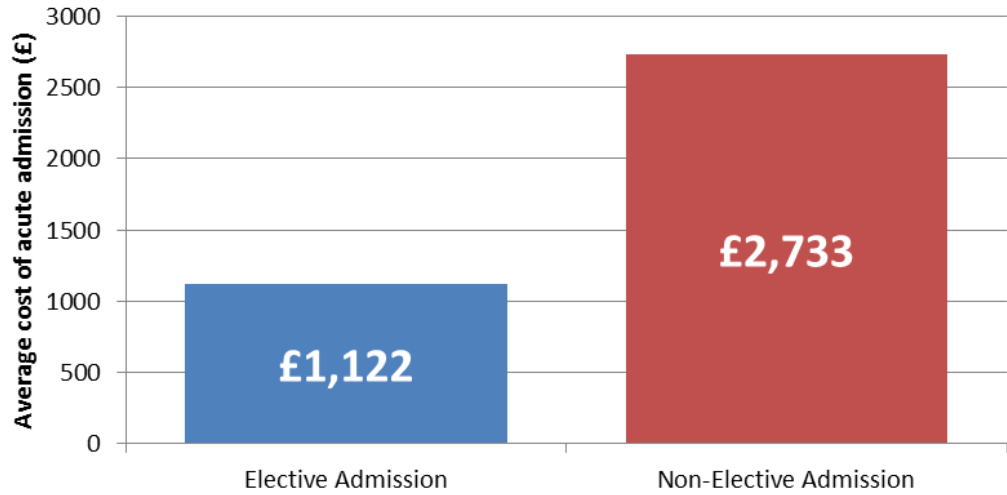
Location	Service	Spend in 2013/2014
Durham	Dementia Cafes	£10k
	Dementia Care Adviser Service	£240k
	Dementia Reablement Care Coordinators	£46k (part year)
	National Dementia Friendly Environment Pilot Programme – to be used across 8 separate pilot schemes	£1,024k (from Department of Health)
Durham and Darlington	Joint Carers Emergency Support Service (generic)	£10k for Durham £2k for Darlington £5k for Darlington CCG £31k for DDES and North Durham CCGs
Darlington	Dementia Adviser- includes the Dementia Cafes- funded by DBC Dementia Support Worker- funded by Alzheimer's Society	£64k
Durham and Darlington	Acute	Not currently available
	Memory Clinics	Not currently available
	Young Onset Dementia	Not currently available

Impact on Admissions by people with Dementia

One of the financial ‘burdens’ of dementia is that it increases the costs of an admission. This is the case when the dementia is not necessarily the first recorded diagnosis, but is a recorded diagnosis contributing to causing a patient’s admission or having a significant impact on their care.

The average cost of a non-reflective admission for a patient (any age) with dementia is significantly higher than the average cost for non-elective admissions of all patients aged 75 years and over (£2,310, 18% higher). Elective admissions of dementia patients are significantly more costly than the average for all elective admissions of patients aged 75 years and over (£934, 20.1% higher). Higher costs for acute admissions for dementia patients would be expected as for many admissions; the presence of dementia will trigger a higher tariff payment as a complicating co-morbidity, and are potentially more likely to attract excess bed day charges for very long admissions. This is demonstrated in the table below:

Average cost of acute admissions of a patient with dementia (2013/14)



Better Care Fund

From April 2015, through funding reallocations, councils and the NHS will pool £3.8 billion in the Better Care Fund (see reference 14), to work with each other and the voluntary sector and it is expected that local areas will use some of this to improve care for people with dementia, such as providing access to dementia advisers, reminiscence services and counselling. The best areas already do this and the Health Secretary is asking Health and Wellbeing Boards to make this a reality across the country.



Action: Securing future funds for dementia services

We will as a group consider carefully what priorities need to be commissioned in the future, and ensure that there are no duplications in projects and that all funding will be used as effectively as possible to bring more services closer to home.



15. Our current services and training programmes

Across County Durham and Darlington a range of dementia services are commissioned to support people with dementia and carers, as well as to train up the service staff providing the services. The services can be categorised into a number of types of services, and some of the services are being piloted at present for possible expansion in the future. Below are services currently being commissioned for 2014-2015. The services and projects have been aligned to the National Dementia Strategy (Appendix 1, and see reference 14).

Type of Service	Service name	Alignment to National Dementia Strategy Objectives	Locality		
			Durham Dales, Easington and Sedgefield	North Durham	Darlington
Primary care	GP screening with Direct Enhanced Service	2, 3	Yes	Yes	Yes
	Memory Clinics	2, 3,	Yes	Yes	Yes
Community	Therapeutic activities – Singing for the Brain	5, 6	Yes	Yes	Yes
	Dementia Advisers	4, 5, 6	Yes	Yes	Yes
	Dementia Cafes	5, 6	Yes	Yes	Yes
	CMHT	11	Yes	Yes	Yes
	Reablement Coordinators	9, 11	Part, pilot	No	No
	Just Checking Teleservice	10	Yes	Yes	Yes
	Walking Safe Telecare	10	Yes	Yes	No
	Floating Support Services for Users	6	Yes	Yes	No
	Community Intermediate Care Beds (generic)	9	Yes	Yes	Yes
	Carers	7	Yes	Yes	Yes



	Emergency Support				
	Carers Support Service	7	Yes	Yes	Yes
	Joint Carers Breaks	7	Yes	Yes	Yes
	Care First to Carers – Carers assessments	7	Review	Review	Yes
Residential	Dementia Awareness Care Home	11	Yes	Yes	Information not currently available
	Training to Nursing Home Staff	13	Yes	Yes	Yes
	Care Home Liaison within MHSOP Teams	11	Yes	Yes	Yes
	Care Homes Pilot for GP access to patients	9, 11	n/a	n/a	Subject to evaluation by CCG
	Dedicated Extra Care Scheme	11	Yes	No	Yes
Acute	Acute Hospital Liaison	8	Yes	Yes	Yes
	Training to staff	13	Information not currently available		
	Dementia environmental audit training	13	Information not currently available		

Note that in that the above list is not exhaustive and there are other services that are at present subject to funding.

Action: Current services

We will explore the need to develop a central model of care across County Durham and Darlington with which all pathways will align starting with the existing pathways we have for people with dementia, so that the efficiency and appropriateness of timely referrals will enable diagnosis and post diagnosis support to be provided at the earliest opportunity, reducing costs in the longer term. The implementation group will address existing gaps within the care pathways.



16. Framework of priorities - What we will aim to do

This framework sets out the actions the strategy implementation group will aim to implement in order to achieve the priorities set out in the 'State of the Nation' Report. The actions against each priority action have been informed through extensive engagement amongst the strategy task group for County Durham and Darlington. In November 2013 an event took place between the Clinical Commissioning Groups in Durham and Darlington; the providers and the councils, to agree on the steps we need to take to form the new strategy. The strategy group then carried out a stocktake to establish where we were with the previous strategy, and agree on the gaps. The strategy group then carried out an exercise to prioritise actions for the short term; long term and for continuation. Proposed actions were then shared with clinicians who may not have been part of the strategy task group. The clinicians added their views on projects and services that require improving to help prioritise which actions should be taken forward in the short term (2014-2015) and the long term (2014-2015) and also what is presently happening but needs to be continued. As a result we have ensured that our framework of priorities has been developed with the input of clinicians.

It should be noted that the priorities in this section may overlap with each other, and some of the short term actions are ones that should be initiated soon, but may take time (more than a year) to be fully implemented.

Prevention

Because the choices we make affect our risk of developing vascular dementia, we need to support people to make healthy choices to help them avoid getting the condition.
State of the Nation Report, 2013

Short term actions

- Identify three planned health and wellbeing projects and interact dementia awareness into them
- Plan to build dementia screening into the Health MOTs model
- Plan for training to raise dementia awareness in the substance misuse/ alcohol abuse teams.

Long term actions

- Making dementia part of other wellbeing programmes which will be reviewed over time

Alignments with the National Dementia Strategy Objectives: Objective 1



Diagnosis and support after diagnosis

Local NHS Clinical Commissioning Groups and local councils need to work together to ensure that, by 2015, two thirds of people with dementia have a proper diagnosis and get appropriate treatment.

State of the Nation Report, 2013

Dementia diagnosis will continue as Direct Enhanced Services during 2014-2015 and will enable more targeted screening across all GP practices and to review the list of those with suspected dementia or mild cognitive impairment regularly.

We should consider the high index of suspicion of dementia in people with falls, carer strain, with people not attending appointments and review those cases.

The standardising of codes and cross referencing between the GP practices and the providers has been to identify more people with dementia who may not have been registered with this condition. However, there is a need to consider the needs of the carers too.

There are concerns around patients who do not want to be referred to secondary care for assessment and reluctance from some professionals to refer patients to specialised service as there is controversy around potential benefits of diagnosis as debated in the national and medical media. There is an opportunity to discuss this matter with experts in primary and secondary care to decide what more can be done around education to debate this. Though it may be appropriate that some people do not need referral but many other factors including carer support as well as advanced care planning is still as important.

Short term actions

- Plan to standardise care home dementia awareness training
- Plan a strategic approach for rolling out dementia cafes
- Extend dementia reablement admission avoidance services and potential to pilot multi-disciplinary working as per the existing evidence base.
- Reflect on existing dementia services and supporting those with learning disabilities
- Reflect on offender health and what the prevalence of prisoners with dementia is, and what levels of support they receive
- Consider the need for dementia awareness to be part of other pathways such as stroke and diabetes
- Review gaps in services for people with Young Onset Dementia and what support should be put into place such as befriending schemes.

Long term actions

- Set a minimum level of understanding for frontline staff e.g. mandatory training and learning course
- Involve the foundation trusts educational point of view into educational training
- Plan on setting an improved target for diagnosis.
- Develop central service directory – easily accessible family/carers/ staff



- Standardise service across areas; make sure all involved link in with best practice/ pathways. Liaise with on the Northern Dementia Clinical Network to inform models of good practice and care
- More extensive roll out of “This is me” amongst wider teams
- Possible establishment of memory clinics run by memory nurses in primary care initially to review established cases as a step forward, progressing in time to reviewing new patients. Easington area is planning trials for this in local practices.

Action that need to be continued

- Continue and develop care home liaison service based on evaluations.
- Debate on the best way for clinicians and GPs to proactively lead screening and diagnosis of dementia
- Take steps to continue the emphasis on screening for dementia by GP
- Continued training for health care staff
- Roll out learning from Department of Health / Department for Education programme on dementia training – post April.

Alignments with the National Dementia Strategy Objectives: Objective 2, 3, 4

High quality, compassionate care everywhere

We need to give people with dementia and their carers care and support that is flexible, appropriate, timely and provided by skilled staff whether at home, in hospital or in a care home.

State of the Nation Report, 2013

The concerns identified are around lack of integrated information systems between acute and mental health services where the patient has to wait for results. There are also some issues around licences to access results remotely. There is a need to look closer into improving this because a large number of dementia patients end up in hospital and often for a long period.

At present, there are no penalties for discharge being delayed due to social reasons for mental health providers as opposed to patients admitted with acute medical problems. As a result some dementia patients have their discharge delayed unnecessarily due to a lack of funding arrangements being agreed. There is a need to consider the potential for a time bound target becoming a target for the provider.

In the new over-75 named GP enhanced service rolled out from 2014; the communication between GP's, AEs, paramedic staff as well as the 111 service should improve and hopefully, reduce some unnecessary admissions.



County Durham and Darlington NHS Foundation Trust have a Teesside based project with Newcastle College around specialist end of life training to reduce A&E and admissions. This project has the potential to be rolled out more widely.

Short term actions

- Agree on steps to develop clear path ways that all will sign up to and play a part
- Better links between the End of Life and Dementia strategies
- Consider role of a 'crisis team' for patients who are in residential care and may have challenging behaviour etc. could be used – with some flexibility for the team to deal with patients, who may need to be assessed for dementia at primary care level
- Plan to standardise care home dementia awareness training.

Long term actions

- Recruit and evaluate effectiveness of the workforce of the ISIS (Integrated Short Term Intervention Service In County Durham) and RIACT (Responsive Integrated Assessment Care Team in Darlington) teams to focus on supporting people with dementia
- To review the criteria for acceptance of referral amongst community matrons who presently do not accept patients with mental health needs.
- Housing for people with dementia to avert crisis care home admission
- Dementia workers in the hospital.

Actions that need to be continued

- Increase confidence of care homes to deal with people at End of Life – training, support and liaison
- Summary care records – sharing of patient records between primary and secondary care needs to be improved with information technology improving the interface
- Young Onset Dementia dedicated assessment and specialist support services based around memory clinics.

Alignments with the National Dementia Strategy Objectives: Objective 2, 3, 4, 5, 6, 7, 8, 9, 10, 11

Greater personal control

We need to enable people with dementia and their carers to exert control over their care and over their lives throughout all stages of their dementia.

State of the Nation Report, 2013

Healthwatch County Durham and Healthwatch Darlington carried out an engagement consultation and their high level findings are set out in section 13.



It has been identified that there is no single up to date centralised source of information on what services that support people with dementia in the region. Some information is available within generic directories. There is a widespread need for up to date centralised information to be made available to all stakeholders to enable signposting to be improved. Providers and commissioners need to work together to establish that a new directory of dementia services will be kept up to date, and made accessible to all.

Short term actions

- Guidance on identifying care & care registration
- Staff within Foundation Trusts' need to be more aware of carer services & how to refer to these
- Develop appropriate responses to managing delirium to maintain person at home
- Focus on fall prevention/physical health for individual – training, awareness, link with carers
- Review the availability and effectiveness of community related carer and befriending services and how well health and social care services are joined up when proactively offering information to people with dementia and carers i.e. direct payment.

Long term actions

- Develop comprehensive issues carers register
- Expand the reablement agenda with increased personal support and cover for people with dementia
- Carers to be able to access support in an emergency
- Describe and implement Care Act (2014) requirements for training on dementia
- Develop and deliver dementia housing scheme (Durham County Council) and associated services input
- More extreme care services housing scheme
- Nominate a Dementia Clinical Lead in each GP practice.

Actions that need to be continued

- 'Walking safe' scheme
- Joint Carers emergency support
- Dedicated Mental Health support for carers
- Dementia adviser service/ dementia café's providing important support to carers – need to embed these and have a consistent approach across area
- Consider specialist breaks/ holidays for individuals with carers. Build on the promised carer service to maintain leadership
- Increase awareness of telecare options/ services – invest in some.

Alignments with the National Dementia Strategy Objectives: Objective 3, 4, 5, 6, 7, 10



Reducing inappropriate medication

NHS and social care organisations must continue to reduce the inappropriate prescribing of antipsychotic medication for people with dementia.

State of the Nation Report, 2013

Managing antipsychotic medication is covered in section 2.

Short term

- Re-audit the information on the prescribing of Risperidone by GP practices across County Durham and Darlington against the NICE Guidance, compare against past audits and report out findings with actions.

Alignments with the National Dementia Strategy Objectives: Objective 11, 18

End of life care

Health and care professionals must be made aware of the alternatives to dying in hospital. Everyone with dementia and their families should have 'planning ahead' conversations with their doctor. End of life care should be excellent with every person treated with dignity and respect.

State of the Nation Report, 2013

Section 10 covers the need for end of life/palliative care services to be supported with resources and the need for the team to be supported by

Short term

- Implementation of plans for dementia to be included in end of life path way
- Standardised pathway for decisions on End of Life, within all teams
- Care home training should be a rewarded focus – Consider widening the approach.

Long term

- Commission additional dementia specialised staff to support end of life/palliative care pathways and interact this across all parts of the health and social care systems
- Focused training for care staff EOL and pathway
- Maintaining experience – Admiral Nurses – we need to know what they are.

Actions that need to be continued

- Training around advanced decisions



- Better planning around preferred place and death while individual has capacity.

Alignments with the National Dementia Strategy Objectives: Objective 12

Dementia education and training

All NHS and social care staff should be aware of the signs of dementia and how best to support people with the condition, their families and carers.

State of the Nation Report, 2013

So far 60,000 people have signed up to the Alzheimer's Society Dementia Friends programme. In February 2014 the Department of Health confirmed that leading British businesses have signed up to the cause which will see a further 190,000 people becoming Dementia Friends.

Short term

- Scope the range of training for dementia to assess where there are gaps and where efficiencies of provision of training can be made
- Organisations to proactively participate in dignity action days
- Seek to use the six C's approach (Care, Compassion, Competence, Communication, Courage, Commitment) in dementia services.

Long term

- All health and social care services have had training in recognising and dealing with dementia.
- Extension of The Gold Standards Framework (GSF) dementia programme -The GSF End of Life Care for People with Dementia Distance Learning Programme was introduced as a pilot programme to identify the level of need for bespoke dementia care for people nearing the end of their lives. The success of the programme is currently being evaluated with a view to further rollout – consideration should be made of extending this across the county.

To be continued

- Dementia modules/ training for staff
- Increase of dementia friends/ dementia champions across services and commissioners and public.



Alignments with the National Dementia Strategy Objectives: Objective 13

Dementia Friendly Communities

We need to create a dementia friendly society. We urge national businesses to become dementia friendly and to encourage their local branches to take this forward in their communities. We ask everyone to become a Dementia Friend so that more people know how they can help support people with dementia and their families.

State of the Nation Report, 2013

Section 2 -Our challenges, Future of Care, refers to the need for dementia friendly communities to be expanded. In County Durham and Darlington no Dementia Friendly Communities have yet been rolled out, however a pilot will commence in two locations and plans will be put into place for a regional roll-out of the programme.

Short term

- Chester-le-Street and Barnard Castle identified as Dementia Friendly Communities. Initial pilots will be implemented.

Long term

- To roll our dementia friendly communities initiatives over next three years with the Alzheimer's Society.

Alignments with the National Dementia Strategy Objectives: Objective 2, 3, 4, 5

Research

We need more dementia research and more people taking part in clinical trials. We ask those who fund research to strive ever harder to get the most from the excellent ideas, people and resources this country has to offer.

State of the Nation Report, 2013

Short term

- Tees Esk and Wear Valleys NHS Foundation Trust to review how awareness of research in dementia has increased amongst its staff and how they link in to this.
- Review the update of studies attached to memory clinics, to plan for more studies to be spread more consistently across the region
- To explore federating practices around research in mental health and dementia.

Long term

- Consider the need for highest level commitment from mental health trust as well as at the CCG level promoting the need for more research.



Alignments with the National Dementia Strategy Objectives: Objective 16

Better data and evidence

We call on national health and care organisations – such as NHS England, Public Health England, Health Education England, the Care and Quality Commission and the Health and Social Care Information centre – to work with the academic and research communities, the voluntary sector, industry and central government to improve the availability and quality of data on dementia

State of the Nation Report, 2013

There will be five actions for primary care which are around estimating the true prevalence and other actions.

A Health Needs Assessment on dementia will be initiated and the findings will enable the strategy to be refreshed in 2015. The improved data and information will inform the development of new actions.

Alignments with the National Dementia Strategy Objectives: Objective 17

Comments for Healthwatch County Durham and Healthwatch Darlington on Consultation

The over-arching theme coming from the consultation feedback (see Section 13) is the need to improve access and the availability of information. Giving dementia patients and their families this information at the point of diagnosis will help and equip them with the knowledge they need to manage the condition. This needs to be the main priority and the first step to supporting people to maintain their independence and to make informed choices.

There is an urgent need for a 'living' directory of up to date information on all services covering the whole care pathway for people with dementia and their carers to be implemented to enable effective signposting to support services.

The dementia strategy group appreciate Healthwatch County Durham and Healthwatch Darlington's involvement in the development of this strategy.

Action: Implementing the actions

We will review all the actions we have identified and realistically prioritise them for implementation. Some actions will happen in 2014-2015 and others will start in 2015-2016 and beyond. We will review all actions each year as we refresh our strategy.



17. How will we work to implement the strategy?

Implementation and Governance

The strategy task group will become the implementation group for this strategy. It will report to the Care Closer to Home Group of the Clinical Programme Board which is represented by the Clinical Commissioning Groups in County Durham and Darlington. The implementation group will escalate any issues to the Care Closer to Home Group. It will also report its progress to the Mental Health Implementation Group for County Durham, and the Mental Health Strategy Group at Darlington Borough Council.

What steps will we take to implement the strategy?

The implementation group will adopt all actions set out in this strategy. It will meet every month during the first 12 months of this new strategy. It will closely monitor its developments and plan collaboratively to prioritise all areas of work as well as identify new projects that need to be considered to improve the outcome of people with dementia and carers.

How will we know if we are achieving the aims of the strategy?

We will obtain data on the diagnosis rates, waiting times and antipsychotic medication, and other things such as research studies and compare them against past data to see where improvements are being made.

We will obtain user representatives to join the implementation group and ensure that they play a key role in informing the context and development of new priorities.

As a group we will take definitive steps to obtain the views of people with dementia and carers, as well as service providers, to do a reality check that their outcomes are being achieved.

We will publish our progress each year as we refresh the strategy and actions.



18. Summary Action plan for the next 12 months

This strategy captures a range of actions which the implementation group will focus on. The implementation group will meet monthly to plan in greater details how it will achieve the project outcomes.

The critical milestones for the next 12 months are:

- Establish communications task group to engage with stakeholders – April to September 2014
- Begin Health Needs Assessment on Dementia – April to October 2014
- Implementation Group is formed June 2014
- Appoint user representatives onto the implementation Group June 2014
- Refresh the strategy with new actions February 2015 to March 2015
- Communicate out the progress and refreshed actions April 2015 to June 2015



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Glossary

Organisational Abbreviations	
Abbreviation	Description
AEs or A&E	Accident and Emergency Departments
CDDFT	County Durham and Darlington NHS Foundation Trust
CHS	City Hospital Sunderland NHS Foundation Trust
DBC	Darlington Borough Council
DCC	Durham County Council
DCCG	Darlington Clinical Commissioning Group
DDES	Durham Dales, Easington and Sedgefield Clinical Commissioning Group
ISIS	Integrated Short Term Intervention Service In County Durham
LA	Local Authority
NDCCG	North Durham Clinical Commissioning Group
NICE	The National Institute for Health and Care Excellence (NICE) is a non-departmental public body of the Department of Health in the United Kingdom, serving both the English NHS and the Welsh NHS.
NIHR	National Institute for Health Research (NIHR)
NTH	North Tees and Hartlepool NHS Foundation Trust
RIACT	Responsive Integrated Assessment Care Team
TEWV	Tees, Esk and Wear Valleys NHS Foundation Trust
DeNDRoN	Degenerative and Neurological Disease Research Network

Terms:	
Abbreviation	Description
Alzheimer's Disease	Alzheimer's disease is the most common form of dementia. It was first described by German psychiatrist and neuropathologist Alois Alzheimer in 1906 and was named after him. Most often, Alzheimer's disease is diagnosed in people over 65 years of age, although the less-prevalent early-onset Alzheimer's disease can occur much earlier.
Antipsychotics	Are medicines designed to reduce the mental symptoms of people with a psychosis type of mental health problem. Symptoms, include delusions, hallucinations, or disordered thought. This group of medicines have a sedative property and are sometimes used to treat people with a dementia illness, to reduce the agitation, distress and trauma that the individual may be experiencing. They are carefully monitored to avoid over-sedation.
B12	Vitamin B12, a water-soluble vitamin with a key role in the normal functioning of the brain and nervous system, and for the formation of blood.
BAME	Black, Asian and Minority Ethnic (BAME) groups
BPSD	Behavioural and psychological symptoms of dementia
CT Scan	Computed Tomography (CT) is a technology that uses computer-processed x-rays to produce tomographic images (virtual 'slices') of specific areas of the scanned object, allowing the user to see what is inside it without cutting it open. This is a common head scan used to help the clinician form a diagnosis.
Dementia	A term used to describe a gradual deterioration in the brain caused by destruction of brain cells by disease factors. There are several described types of dementia and Alzheimer's Disease is the most commonly known form.
Dementia Register	A General Practice Register created within each General Practice to list patients with a diagnosis of a Dementia condition, regardless of the type. This list is used to help monitor and review patients with a Dementia at practice level.



Terms:	
Abbreviation	Description
Down's syndrome	Down syndrome (DS) or Down's syndrome, also known as trisomy 21, is a genetic disorder caused by the presence of all or part of a third copy of chromosome 21. It is typically associated with physical growth delays, characteristic facial features and mild to moderate intellectual disability.
EOL	End of Life
FBC	Full Blood Count – is a test panel requested by a doctor or other medical professional that gives information about the cells in a patient's blood. A scientist or lab technician performs the requested testing and provides the requesting medical professional with the results
GP or GPs	A General Practitioner (GP) is a medical practitioner who treats acute and chronic illnesses and provides preventive care and health education to patients in the community where they live.
Hospital	In the dementia strategy document, the references to a hospital admission or stay is usually referring to a General Hospital or Community Hospital and not a specialist Mental Health hospital designed to assess and treat people specifically with Dementia problems.
Huntington's disease	Huntington's disease (HD) is a neurodegenerative genetic disorder that affects muscle coordination and leads to cognitive decline and psychiatric problems. It typically becomes noticeable in mid-adult life. HD is the most common genetic cause of abnormal involuntary writhing movements called chorea, which is why the disease used to be called <i>Huntington's chorea</i> .
Neuropsychology	Neuropsychology studies the structure and function of the brain as they relate to specific psychological processes and behaviours.
Prevalence	Prevalence, in epidemiology (the study of disease), is the proportion of a population found to have a condition (typically a disease or a risk factor such as smoking or seat-belt use). It is arrived at by comparing the number of people found to have the condition with the total number of people studied, and is usually expressed as a fraction, as a percentage or as the number of cases per 10,000 or 100,000 people.
R&D	Research and Development
Vascular Dementia	Vascular dementia is the second most common form of dementia after Alzheimer's disease. It is caused by reduced blood flow to the brain because there is a problem with the blood vessels that supply it. Parts of the brain become damaged and eventually die from a lack of oxygen and nutrients. Unlike other forms of dementia, many cases of vascular dementia can be prevented. Vascular Dementia is sometimes described as "multi-infarct dementia", due to the fact that multiple blockages in blood vessels in the brain, cause infarcts (death to the brain tissue/cells).



Appendix 1 – National Dementia Strategy

The themes and objectives of the strategy

There are 17 objectives, which focus on four key areas for improving the quality of life for people with dementia and carers raising awareness and understanding, early diagnosis and support, living well with dementia and making the change (implementing the Strategy).

Objective 1: Public information campaign

A significant national awareness campaign is proposed that focuses on explaining what dementia is, the importance of diagnosis, help that is available, reducing stigma and promoting prevention. It suggests that local complementary campaigns should also be run.

Objective 2: Good quality early diagnosis and intervention

The Strategy proposes local commissioning of a good quality memory service which can provide early specialist diagnosis as well as appropriate intervention and support. [Memory services](#) might most appropriately be based in a community setting.

Objective 3: Good quality information

Good quality [information](#) should be available for people with dementia and their carers. A one year review of existing information is proposed, followed by the development and distribution of a set of good quality information on dementia and services. Information on [local service provision](#) should be tailored to that area.

Objective 4: A dementia adviser

Following diagnosis, all people with dementia should have access to a dementia adviser who can act as a point of contact for information and signposting to other services. The focus of work would be to help people with dementia to navigate the health and social care system. The DH proposes a series of demonstrator sites to examine which dementia adviser model works best and to evaluate impact on quality of life.

Objective 5: Peer support and learning networks

The Strategy proposes the development of peer support networks such as [support groups and dementia cafes](#) for people with dementia and their carers. The intention is to provide practical and emotional support, reduce social isolation and promote self-help. The Strategy proposes a demonstration and evaluation programme to evaluate peer support activity.

Objective 6: Improved community personal support services

It is recommended that an appropriate range of services needs to be put in place to support people with dementia and their carers in their own homes, with a range of options available from early intervention to specialist services. A dedicated programme will establish an evidence base on which specialist services are effective.

Objective 7: Implementing the Carers' Strategy

It is recommended that unpaid carers need to be given access to a wide range of [support](#) to



help them in caring for people with dementia. In particular work on the Carers' Strategy should focus on people with dementia and ensure that effective assessment, support and short breaks (respite) packages are available.

Objective 8: Improving care in hospitals

The Strategy proposes three key changes to dementia care practice in acute hospitals.

- Identifying a senior clinician who will be responsible for quality improvement in dementia
- Developing an explicit agreed care pathway for people with dementia in hospitals, explaining how people with dementia will be cared for, by whom and in what way
- The development of specialist older people's mental health liaison teams that can support staff throughout hospitals to care for people with dementia.

Objective 9: Improving intermediate care

Intermediate care services support people who have had a serious health incident. They allow these people to remain in their own homes without requiring hospital care, or to recover from a stay in hospital. Many intermediate care services currently wrongly exclude people with dementia. The DH issued new guidance on intermediate care in 2009, with explicit reference to people with dementia.

Objective 10: Housing and telecare

People with dementia should be included in locally developed housing options and should be able to take advantage of [assistive technology](#) and telecare.

Objective 11: Improving care in care homes

The Strategy recommends a number of steps be taken to improve quality of care in care homes:

- A named senior member of staff should take the lead for improving quality of dementia care in every home.
- This senior staff member should develop a local strategy for management and care of people with dementia.
- [Anti-psychotic medication](#) should only be used when appropriate.
- Specialist in-reach services should be commissioned to provide specialist advice and guidance on improving care.
- Other in-reach services such as primary care, pharmacy, dentistry should be available.
- Specialist guidance for care staff on best practice in dementia care should be provided.

Objective 12: Improving end of life care

Palliative care at the [end of life](#) needs to be improved. This objective suggests the involvement of people with dementia in planning end of life care in keeping with the principles of the [Mental Capacity Act](#). Local work on the [End of Life Care Strategy](#) needs to consider dementia. The Strategy proposes a programme of demonstration, piloting and evaluation projects to assist development of end of life care in dementia.

**Objective 13: Workforce competencies, development and training**

All health and social care staff involved in the care of people with dementia should have the skills to provide the best quality care to people with dementia and their families. The DH will work with representatives of all bodies involved in professional, vocational and continuing professional development to agree the core competencies required in dementia care. Those bodies will then consider how to adapt their curricula. Commissioners of services should specify dementia training as a requirement for service providers.

Objective 14: Joint local commissioning and World Class Commissioning

The Strategy recommends that local commissioning and planning mechanisms need to be established to determine how best to meet the needs of people with dementia and their carers. These should be informed by the Dementia World Class Commissioning guidance developed to support the Dementia Strategy.

Objective 15: Improved registration and inspection of care homes

Registration and inspection regimes should reflect the need for good quality dementia care. The Strategy includes a statement agreed with the [Care Quality Commission](#) setting out how they expect to regulate and inspect care homes.

Objective 16: Dementia research

The DH will work with the Medical Research Council to convene a summit of research funders and scientists interested in dementia research. This will be used to generate a plan for the development of dementia [research](#) in the UK.

Objective 17: National and local support for implementation

The DH will provide regional support to commissioners and providers implementing the Strategy to ensure progress.

Objective 18: Antipsychotic medication

There should be reductions in the prescribing of antipsychotic medication for people living with dementia.



Appendix 2 – Support in Developing the Dementia Strategy

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