

# Dementia 2014: A North East Perspective

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NORTH EAST  
DEMENTIA  
ALLIANCE

  
northern rock  
foundation

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# 1. Introduction

## Background to the report

In 2011 the Northern Rock Foundation commissioned Debbie Smith to produce the report '*Dementia: A North East Perspective*'. In that document Debbie Smith outlined "*the status of dementia care in the North East of England as of May 2011*".<sup>1</sup>

Since May 2011 a number of developments have resulted in a need to update the information contained in '*Dementia: A North East Perspective*.' These include:

- Changes to the groups and organisations in the North East of England
- Changes to the policy context influencing the provision of dementia care in the North East of England
- Continued progress towards increasing awareness of dementia and improving dementia care in the North East of England

## Aims of the report

This report will outline the status of dementia care in the North East of England as of July 2014. In particular, this report provides a summary of:

- The demographic position in the North East of England
- The relevant English policy context
- Dementia research in the North East of England
- The status of dementia care in the North East of England
- The development of dementia friendly communities in the North East of England

## Geographical area covered by the report

The phrase North East of England will be used in this report to refer to the geographical area covered by the localities of:

- Darlington
- Durham
- Gateshead

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<sup>1</sup> Smith, D. (2011) *Dementia: A North East Perspective* [Online] Available at: <http://www.nrfoundation.org.uk/wp-content/uploads/2011/08/Dementia-A-North-East-Perspective.pdf> (Accessed 17 May 2014) p.7

- Hartlepool
- Middlesbrough
- Newcastle
- North Tyneside
- Northumberland
- Redcar and Cleveland
- South Tyneside
- Stockton-on-Tees
- Sunderland

## Sources of information

The information for this report was drawn from both an in-depth literature review and semi-structured correspondence with key individuals in the North East.

## Structure of the report

Following this introduction the remaining sections of this report are organised into five parts. The five parts of report will address:

- Part A – The North East context (sections 2-4)
- Part B – Research in the North East (section 5)
- Part C – Care and support in the North East (sections 6-17)
- Part D – Dementia Friendly Communities in the North East (sections 18)
- Part E – Cross-cutting themes (sections 19-24)

## Acknowledgments

This report would not have been possible without those people who expended time and effort in order to share their knowledge and insights.

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Part A:

# The context

## 2. The North East context

### Key points

- The term 'dementia' is used to describe a collection of symptoms, including a decline in memory, reasoning and the ability to communicate and a gradual loss of the skills needed to carry out daily activities
- In 2014 an estimated 34,000 people in the North East of England are living with a form of dementia
- It is predicted that between 2014 and 2020 the overall number of people living with dementia in the North East will increase by 17% to 39,800
- Between 2008/09 and 2012/13 recorded prevalence in the North East increased by 35% from 496 people per 100,000 to 669
- In 2012/13 the prevalence of recorded dementia in North East England was higher than the national rate of 569 people per 100,000. The regional rate increased by 35% since 2008/09, marginally ahead of the national rate of 33%
- In 2013 the North East had a diagnosis rate of 54%, which was higher than the 48% rate for the whole of England
- A significant number of people from minority groups have dementia in the North East

This section of the report will set out the context for dementia and dementia care in the North East. It will outline:

- What is dementia?
- Relevant demographic information from the North East
- Conclusions and recommendations about the context of dementia in the North East

### 2.1 What is dementia?

The term 'dementia' is used to describe a collection of symptoms, including a decline in memory, reasoning and the ability to communicate and a gradual loss of the skills needed to carry out daily activities.<sup>2</sup>

According to '*The Dementia Guide*', published in August 2013:

- Approximately 800,000 people in the UK have dementia

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<sup>2</sup> London School of Economics. (2007) Dementia UK – The Full Report London: Alzheimer's Society

- The chance of developing dementia increases significantly with age. One in 14 people over 65 years of age and one in six people over 80, have dementia
- It is more common among women than men
- More than 17,000 younger people (under the age of 65) in the UK have dementia<sup>3</sup>

There are various sub-types of dementia, caused by different diseases of the brain. As these affect the brain in diverse ways, they produce different symptoms. The most common form of dementia is Alzheimer's, followed by vascular dementia, mixed dementias, dementia with Lewy Bodies and other, rarer, forms of dementia.

For further information see the websites of The Royal College of Psychiatrists or Alzheimer's Society.<sup>4</sup>

## 2.2 Demographic information

The data presented in the following three graphs are based on the most current information and assumptions, presented in the Dementia UK report.<sup>5</sup> The Department of Health and the Alzheimer's Society are expected to produce revised assumptions and figures in autumn 2014.

### Estimated number of people with dementia

#### Estimated numbers of people with dementia in the North East as of 2014

The estimated number of people with dementia or prevalence of dementia is the proportion of a given population estimated to have dementia, irrespective of whether they have a formal diagnosis or not. In 2014 an estimated 34,000 people in the North East of England are living with a form of dementia.

The localities within the North East with the largest estimated number of people living with dementia are County Durham (6,800) and Northumberland (4,845). The locality with the lowest estimated number of people living with dementia is Hartlepool (1,170). This reflects the overall distribution of the population and age patterns in the North East.

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<sup>3</sup> Alzheimer's Society (2013) The Dementia Guide: Living well after diagnosis [Online] Available at: <http://alzheimers.org.uk/dementiaguide> (Accessed 17 May 2014) p.10

<sup>4</sup> Royal College of Psychiatrists [Online] Available at: <http://www.rcpsych.ac.uk/healthadvice/problemsdisorders/dementiaandmemoryproblems.aspx> (Accessed 17 May 2014) and the Alzheimer's Society [Online] Available at:

<http://www.alzheimers.org.uk/site/scripts/documents.php?categoryID=200120> (Accessed 17 May 2014)

<sup>5</sup> King's College London and London School of Economics (2007) Dementia UK: Report to the Alzheimer's Society [Online] Available at: [http://www.alzheimers.org.uk/site/scripts/download\\_info.php?fileID=2](http://www.alzheimers.org.uk/site/scripts/download_info.php?fileID=2) (Accessed 17 May 2014)

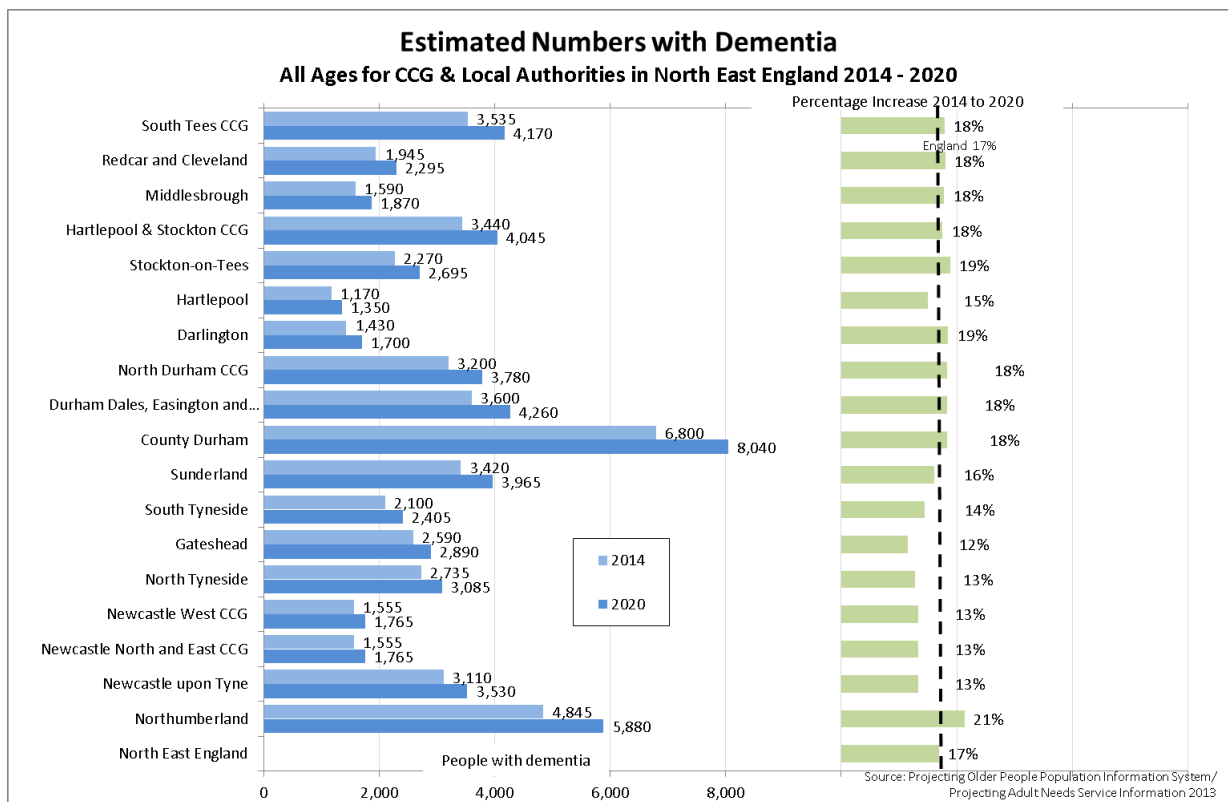


## Estimated increase in the number of people with dementia in the North East between 2014/20

It is predicted that between 2014 and 2020 the overall number of people living with dementia in the North East will increase by 5,750 to 39,750. This represents an increase of 17%. The increase in the number of people living with dementia in the North East between 2014 and 2020 is estimated to be comparable to the expected increase across the whole of England for the same period (17%).

The area in the North East with the lowest expected increase in the numbers of people living with dementia is Gateshead, which is expected to increase by 12%. The area in the North East with the highest expected increase in the number of people living with dementia is Northumberland, which is expected to increase by 21% over the 6 year period.

It is estimated that in six of the 12 local authorities in the North East there will be a greater percentage increase in the number of people living with dementia than the average for England as a whole. These areas are Darlington, Durham, Middlesbrough, Northumberland, Redcar and Cleveland and Stockton-on-Tees.



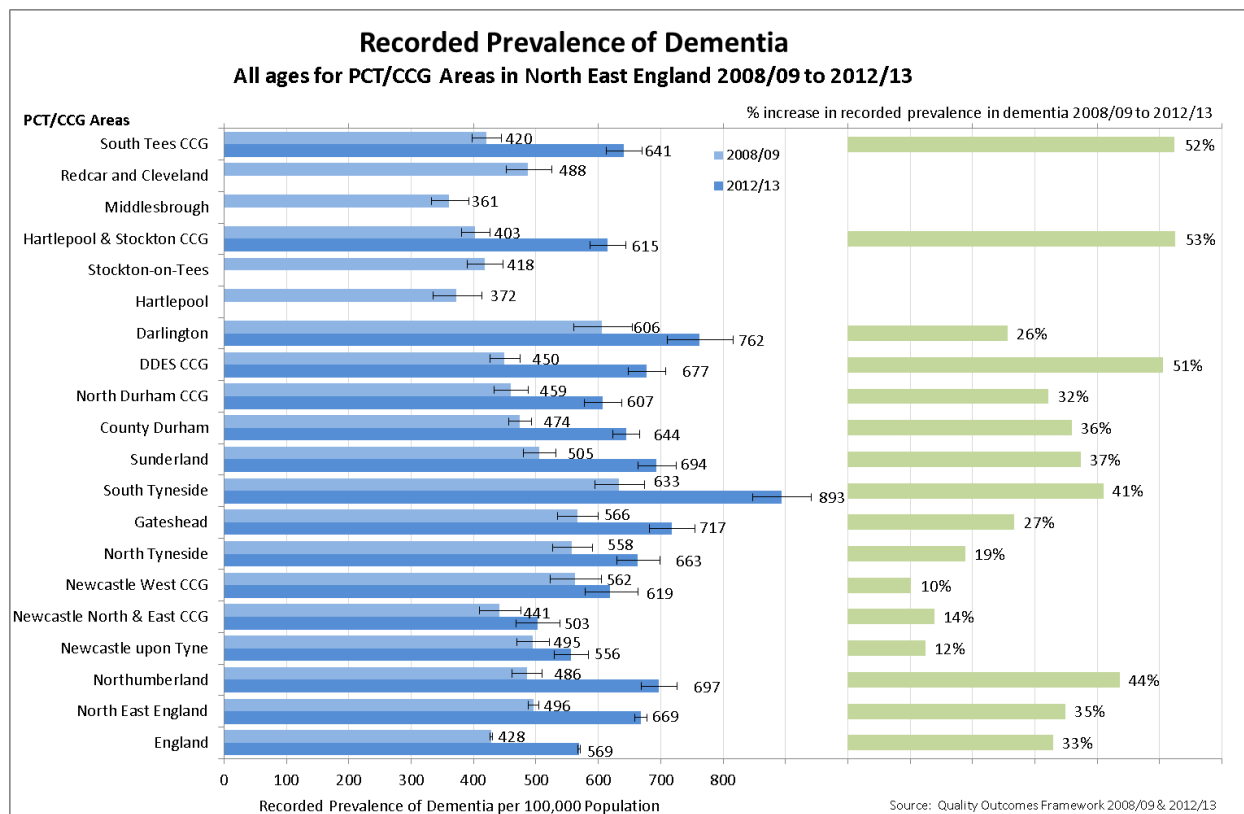
**Figure 1:** Estimated Numbers with Dementia: All Ages for CCG & Local Authorities in North East England 2012/20. Source: Projecting Older People Population Information System / Projecting Adult Needs Service Information 2013

In 2011 the North East Alliance published a report<sup>6</sup> which suggested that the number of people with dementia in 2030 was predicted to be 50,900. This figure is currently under review in light of emerging new assumptions that are expected to be released by the Department of Health and the Alzheimer’s Society in September 2014.

## Recorded prevalence

The recorded prevalence of dementia is the proportion of a given population with a formal diagnosis of dementia included on a GP practice dementia register. Figure 2 shows the recorded prevalence of dementia per 100,000 of the population. Between 2008/09 and 2012/13 recorded prevalence in the North East increased by 35%. The increase in recorded prevalence in the North East was slightly higher than the increase in recorded prevalence across England (33%).

The lowest increase in recorded prevalence was in Newcastle (12%). The highest increase in recorded prevalence was in Northumberland (44%).



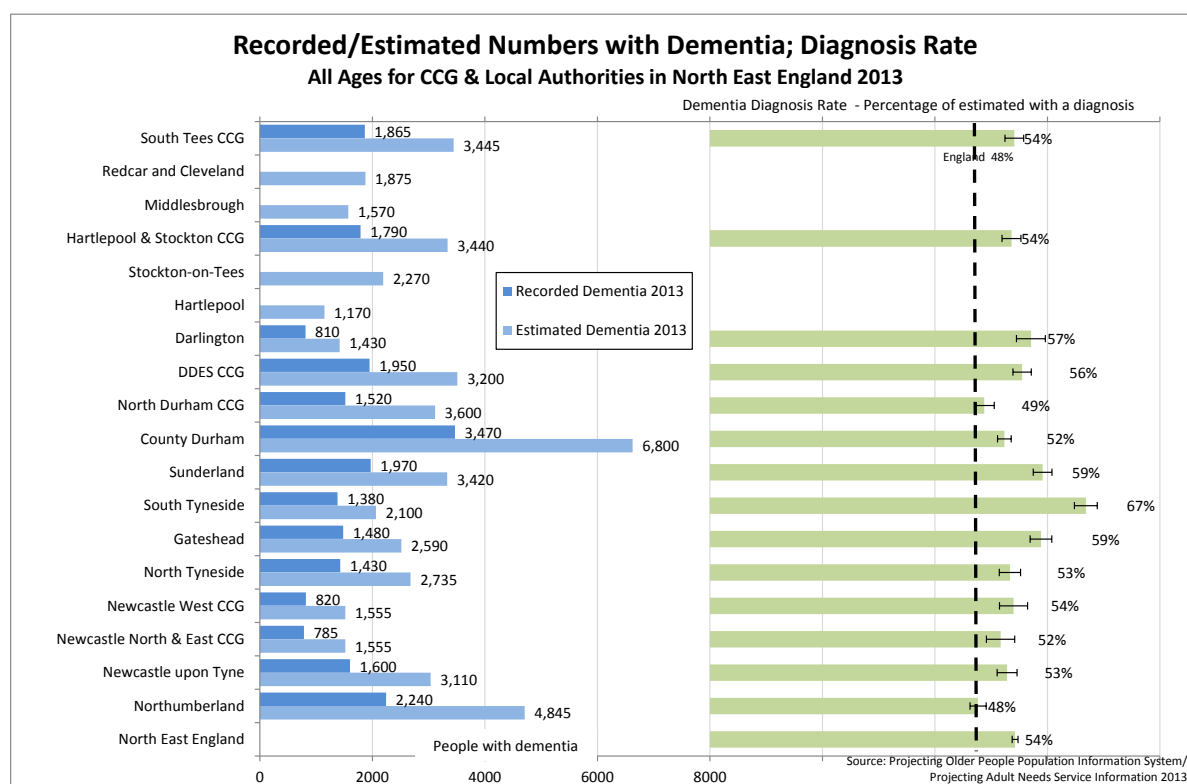
**Figure 2:** Recorded Prevalence of Dementia: All ages for PCT/CCG Areas in North East England 2008/09 to 2012/13. Source: Quality Outcomes Framework 2008/09 & 2012/13

<sup>6</sup> Cornsay Research (2011) Dementia North East England – 2011 Demographic Update [Online] Available at: <http://www.nr-foundation.org.uk/wp-content/uploads/2011/08/Dementia-North-East-England1.pdf> (Accessed 17 May 2014)

## Recorded prevalence against numbers with dementia

The recorded number of people with dementia is the number of people with a formal diagnosis entered on their GP's practice dementia register. The estimated number with dementia is generated by the application of the age and gender specific prevalence estimates to the population distribution for a locality. The diagnosis rate is the proportion of the estimated number of people with dementia who have a formal diagnosis.

The national ambition is to have a two thirds diagnosis rate by 2015. South Tyneside has achieved a 67% diagnosis rate. The lowest percentage diagnosis is in Northumberland (48%).



**Figure 3:** Recorded / Estimated Numbers with Dementia: Diagnosis Rate: All ages for PCT/CCG Areas in North East England 2013. Source: Projecting Older People Population Information System / Projecting Adult Needs Service Information 2013

The average percentage diagnosis in North East England is 54%, which is higher than the England average of 48%. For more detail about diagnosis rates see section 7 of this report.

## Minority Groups

It was estimated that in the North East in 2012 there were:

- 694 people of working age with dementia

- 353 people from a non-white ethnic background with dementia
- Between 540-756 lesbian, gay or bisexual people with dementia
- 5 transgender people with dementia
- 175 people with dementia with religious beliefs other than Christian and 781 who are likely to have no religious belief
- 16,560 individuals with dementia who have a longstanding illness, disability or infirmity and have significant difficulty with day-to-day activities<sup>7</sup>

For more details on minority communities see section 22 of this report.

## 2.3 Conclusions on the North East context

The term 'dementia' is used to describe a collection of symptoms. There are a number of subtypes of dementia, the most common being Alzheimer's disease.

As of 2014 an estimated 34,000 people in the North East of England are living with a form of dementia. By 2020 it is predicted this will increase to 39,800. This increase highlights the significant pressures on services and communities in the North East to ensure that care and support is right for people living with dementia and their carers.

The North East has a higher diagnosis rate than the average for England as a whole (54% compared to 48%). Despite this achievement 46% of people living with dementia in the North East do not have a diagnosis. It is essential that people are offered the opportunity to have a diagnosis and access the support which accompanies this.

It is clear from the statistics that dementia affects people from all communities. It is essential to consider peoples' individual needs and consider the needs of minority communities.

## 2.4 Recommendations on the North East context

- In September 2014 the Department of Health, with the Alzheimer's Society, is expected to produce revised assumptions and figures relating to the number of people living with dementia in England. In light of these changes the North East Dementia Alliance, working with the Mental Health, Dementia and Neurological Conditions Strategic Clinical Network Northern England, the Public Health England

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<sup>7</sup> Jackson, M (2012) Dementia in Minority Communities in North East England [Online] [http://www.nepho.org.uk/uploads/doc/vid\\_16758\\_Dementia%20in%20Minority%20Communities%20in%20North%20East%20England%20Aug%202012.pdf](http://www.nepho.org.uk/uploads/doc/vid_16758_Dementia%20in%20Minority%20Communities%20in%20North%20East%20England%20Aug%202012.pdf) (Accessed 17 May 2014)

Knowledge and Intelligence Team, should produce revised statistics for the North East.

## 3. Relevant English Policy

### Key points

- *'Living well with dementia: A National Dementia Strategy'*, published in February 2009, was a five-year strategy to enable improved care and support for people with dementia and carers
- 2014 marks the end of the formal implementation period of the National Dementia Strategy. However, as of May 2014, there is no evidence there will be an automatic refresh or update of the National Dementia Strategy
- The *'Prime Minister's Challenge on Dementia: Delivering major improvements in dementia care and research by 2015'*, published in 2012, aimed to build on the achievements of the National Dementia Strategy
- Other relevant policy includes:
  - The Care Act 2014
  - Everyone Counts: Planning for Patients 2014/15 - 2018/19  
Adult Social Care Outcomes Framework 2014/15
  - NHS Outcomes Framework 2014/15
  - Public Health Outcome Framework 2013/16
  - The National Dementia Declaration
  - Clinical Guidelines 42 Dementia: Supporting people with dementia and their carers in health and social care

This section will look at the general policy context for dementia care; policy relevant to specific aspects of dementia will be addressed in the relevant sections of this report. This section of the report will outline:

- Relevant English policy
- Conclusions and recommendations about the English policy context in the North East

## 3.1 Relevant English policy

### Living well with dementia: A National Dementia Strategy

The dementia strategy for England, '*Living well with dementia: A National Dementia Strategy*'<sup>8</sup> was published in February 2009 and the supporting implementation plan was published in July 2009.<sup>9</sup> This five-year strategy launched under the Labour Government, was endorsed by the Coalition Government, which published a second version of the implementation guidance in 2010.<sup>10</sup>

The National Dementia Strategy was produced to enable improved care and support for people with dementia and their carers. It defined a pathway, which runs from raising awareness about dementia amongst the public, through diagnosis and provision of appropriate support and care services, to good end of life care. It is relevant to all people with dementia and their carers no matter what support or services they receive.

The aim of the National Dementia Strategy was to ensure significant improvements in dementia services across three key areas: awareness, earlier diagnosis and intervention, and high quality of care. The Strategy has 17 key objectives, which are shown in Figure 3. It was anticipated that implementing the objectives would "*result in significant improvements in the quality of services provided to people with dementia and should promote a greater understanding of the causes and consequences of dementia*".<sup>11</sup>

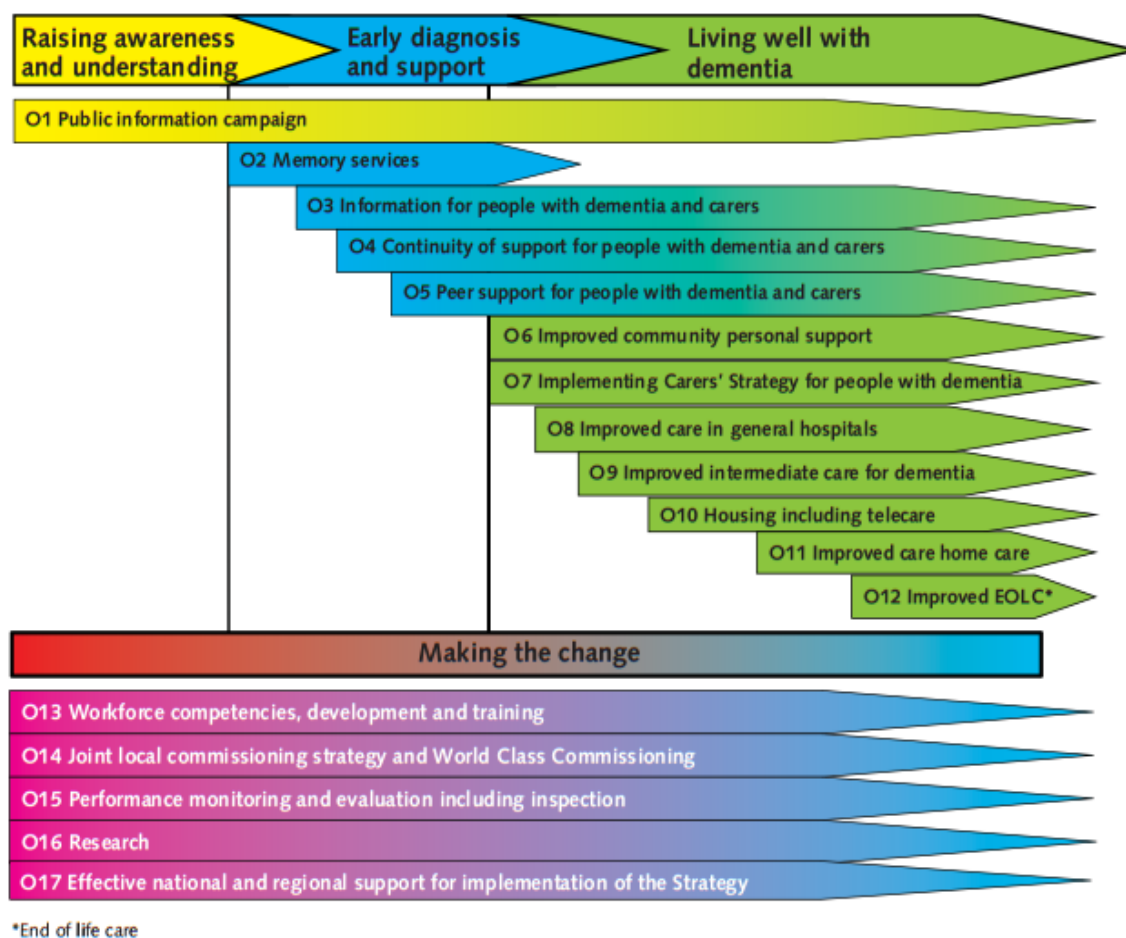
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<sup>8</sup> Department of Health (2009) *Living well with dementia: a National Dementia Strategy*. London: Department of Health

<sup>9</sup> Department of Health (2009) *Living Well With Dementia: A National Dementia Strategy – Implementation Plan* [Online] Available at: [http://www.thinklocalactpersonal.org.uk/\\_library/Resources/SouthEast/Legacy/OP\\_Dementia/Living\\_Well\\_with\\_Dementia\\_National\\_Dementia\\_Strategy\\_Implementation\\_Plan\\_OPD\\_Document.pdf](http://www.thinklocalactpersonal.org.uk/_library/Resources/SouthEast/Legacy/OP_Dementia/Living_Well_with_Dementia_National_Dementia_Strategy_Implementation_Plan_OPD_Document.pdf) (Accessed 17 May 2014)

<sup>10</sup> Department of Health (2010) *Quality outcomes for people with dementia: building on the work of the National Dementia Strategy*. London: Department of Health

<sup>11</sup> Department of Health (2009) *Living well with dementia: a National Dementia Strategy*. London: Department of Health



**Figure 4:** The 17 objectives of the National Dementia Strategy. Source: Department of Health (2009) *Living well with dementia: a National Dementia Strategy*. London: Department of Health

Following the publication, in October 2009, of *'The use of antipsychotic medication for people with dementia: Time for action - A report for the Minister of State for Care Services'* the need to reduce the inappropriate prescribing of antipsychotic medication for people with dementia was also recognised as a significant area in its own right.<sup>12</sup> As a result of this, the inappropriate prescribing of antipsychotic medication became, in effect, the "eighteenth objective".<sup>13</sup>

2014 marks the fifth anniversary of the National Dementia Strategy and the end of its formal implementation period. In February 2014, responding to a question about the National Dementia Strategy in the House of Commons, the Health Secretary, Jeremy Hunt, stated "*When I say that the strategy is here to stay, I mean that it is here to be refreshed and updated*".<sup>14</sup> As of May 2014 there is no evidence that there will be an automatic refresh or update of the National Dementia Strategy.

<sup>12</sup> Banerjee, S. (2009) *The use of antipsychotic medication for people with dementia: Time for action - A report for the Minister of State for Care Services*. London: The Stationary Office

<sup>13</sup> Ibid

<sup>14</sup> HC Deb 25 February 2014 vol 576 c142



As the Prime Minister's Challenge on Dementia is designed to build on the achievements of the National Dementia Strategy it is expected that the Prime Minister's Challenge will provide a focus for improvements and developments up until 2015.<sup>15</sup>

## Prime Minister's Challenge on Dementia: Delivering major improvements in dementia care and research by 2015

In March 2012 David Cameron, launched the '*Prime Minister's Challenge on Dementia: Delivering major improvements in dementia care and research by 2015*'.<sup>16</sup> The Prime Minister's Challenge aimed to build on the achievements of the National Dementia Strategy and outlined a number of ambitions in three key areas. These were:

- Driving improvements in health and care
- Creating dementia friendly communities that know how to help
- Better research

The key commitments outlined in relation to each of these three areas will be covered in more detail in the relevant sections of this report.

Progress reports on the Prime Minister's Challenge on Dementia were issued at both six months<sup>17</sup> and one year.<sup>18</sup>

Updates on progress are also available through the Department of Health's website, which includes the Dementia Map.<sup>19</sup> The Dementia Map geographically charts progress in relation to the three areas of the Prime Minister's Challenge on Dementia.

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<sup>15</sup> Department of Health (2012) Prime Minister's Challenge on Dementia: Delivering major improvements in dementia care and research by 2015. Department of Health: London p.5

<sup>16</sup> Department of Health (2012) Prime Minister's Challenge on Dementia: Delivering major improvements in dementia care and research by 2015. Department of Health: London

<sup>17</sup> Department of Health (2012) Prime Minister's Challenge on Dementia: Delivering major improvements in dementia care and research by 2015: A report on progress [Online] Available at: <http://media.dh.gov.uk/network/353/files/2012/11/The-Prime-Ministers-Challenge-on-Dementia-Delivering-major-improvements-in-dementia-care-and-research-by-2015-A-report-of-progress.pdf> (Accessed 17 May 2014)

<sup>18</sup> Department of Health (2013) Prime Minister's Challenge on Dementia: Delivering major improvements in dementia care and research by 2015: Annual report of progress [Online] Available at: <https://www.gov.uk/government/publications/the-prime-ministers-challenge-on-dementia-annual-report-of-progress> (Accessed 17 May 2014)

<sup>19</sup> [Online] Available at: <https://dementiachallenge.dh.gov.uk/map/> (Accessed 17 May 2014)

## Care Act 2014

The Care Bill was published in May 2013 and builds on the draft Care and Support Bill and the White Paper ‘*Caring for our future: reforming care and support*’,<sup>20</sup> which were both published in June 2012. The Bill went through the Commons report stage in March 2014. The Bill received Royal Assent on 14<sup>th</sup> May 2014. The Act consolidates existing legislation on care and support into a single statute. The Act is split into a number of parts covering:

### Care and Support

The Act sets out a vision for:

*“A modern system that promotes people’s well-being by enabling them to prevent and postpone the need for care and support and to pursue education, employment and other opportunities to realise their potential... It refocuses the law around the person not the service, strengthens rights for carers to access support, and introduces a new adult safeguarding framework”.*<sup>21</sup>

The Act also *“puts in legislation the changes recommended by the Commission on the Funding of Care and Support to introduce a cap on the costs that people will have to pay for care in their lifetime”.*<sup>22</sup>

### Care Standards

The Act includes provisions designed to deliver elements of the Government’s responses to the findings of the Francis Inquiry into events at the Mid Staffordshire Hospital Trust.<sup>23</sup> In particular, the Act includes a package of measures focusing on:

- Requirements for the Care Quality Commission (CQC) to develop a system of performance reviews and assessments
- Powers to allow the new Chief Inspector of Hospitals, appointed by the CQC, to instigate a new failure regime and allow the Secretary of State to impose changes on local health services with limited consultation
- Greater transparency and stronger accountability about the information providers produce on their own performance and outcomes, making it an offence for care providers to supply or publish certain types of false or misleading information and introducing additional legal sanctions<sup>24</sup>

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<sup>20</sup> Department of Health (2012) *Caring for our future: reforming care and support*. London: Department of Health

<sup>21</sup> Department of Health (2013) *The Care Bill explained: Including a response to consultation and pre-legislative scrutiny on the Draft Care and Support Bill*. London: The Stationery Office p.7

<sup>22</sup> Ibid

<sup>23</sup> Department of Health (2013) *The Care Bill explained: Including a response to consultation and pre-legislative scrutiny on the Draft Care and Support Bill*. London: The Stationery Office

<sup>24</sup> Ibid

## **Health Education England and the Health Research Authority**

The Act establishes Health Education England<sup>25</sup> and the Health Research Authority as Non-Departmental Public Bodies.<sup>26</sup>

## **Health and Social Care Act 2012**

In 2011 the Government introduced the Health and Care Bill, which sets out significant reforms to the way the NHS would commission health services. The bill was given Royal Assent in March 2012 and came into force in April 2013.

The reforms derived, at least in part, from a feeling that services were not responding to local need and were too often 'target driven' rather than evidence based. The main focus of the act was to create new commissioning arrangements and enshrine in law that the patient had to be at the centre of everything the NHS did.

The act created a number of new bodies:

### **The NHS Commissioning Board**

The NHS Commissioning Board is the central, directing authority of the health service in England. It also has responsibility for some commissioning; for example, specialist commissioning. The Commissioning Board sets national objectives for the NHS and has the power to direct commissioning decisions in certain circumstances. The Commissioning Board is represented in localities by Area Teams, which oversee the implementation of national objectives and support health service commissioners in their work.

For further information about Area Teams in the North East see section 4 of this report.

### **Clinical Commissioning Groups**

Clinical Commissioning Groups (CCGs) have been given control of more than half of the NHS budget. CCGs are 'clusters' of GP practices, which have been brought together to commission health services for their area using their knowledge of local health and care needs. Though the CCGs are led by GPs they are expected to include other clinicians, such as nurses, in their decision making bodies. Broadly speaking, the CCGs are now responsible for commissioning most community and secondary health care and some primary care services. CCGs have only been in operation for a little over a year and it is too soon to be able to offer an assessment of the changes they may have made to the nature of services provided by the NHS.

For further information about CCGs in the North East see section 4 of this report.

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<sup>25</sup> For further information see section 3 of this report

<sup>26</sup> Department of Health (2013) The Care Bill explained: Including a response to consultation and pre-legislative scrutiny on the Draft Care and Support Bill. London: The Stationery Office

## **Public Health England**

Public Health England has taken over responsibility for health protection, improving the nation's health and addressing health inequalities. Local authorities were given responsibility for public health in their areas.

For further information about Public Health England in the North East see section 4 of this report.

## **Health and Wellbeing Boards**

Health and Wellbeing Boards (HWB) were established at the level of upper tier local authorities. A HWB is comprised of elected local councillors, CCGs and other organisations involved in commissioning or delivering health and care services. The HWB should define what outcomes are important to their locality and lead on their delivery.

For further information about Health and Wellbeing Boards in the North East see section 4 of this report.

## **Healthwatch England**

Healthwatch England is the “national consumer champion in health care.” Its job is to ensure that the voice of those who use health and care services is heard by those who commission, deliver and regulate health and care services.

For further information about Healthwatch in the North East see section 4 of this report.

## **Commissioning Support Units**

Commissioning Support Units offer management and support services to commissioners; for example, providing IT systems and support, contract management and financial services. It is expected that, by 2016, Commissioning Support Units will be self standing bodies outside of the NHS.

## **Everyone Counts: Planning for Patients 2014/15 - 2018/19**

*'Everyone Counts: Planning for Patients 2014/15 - 2018/19'* sets out the aims for the NHS in England and how commissioners should plan to achieve those aims.<sup>27</sup>

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<sup>27</sup> NHS England (2013) *Everyone Counts: Planning for Patients 2014/15 - 2018/19* [Online] Available at: <http://www.england.nhs.uk/wp-content/uploads/2013/12/5yr-strat-plann-guid-wa.pdf> (Accessed 17 May 2014)

The guidance is published alongside financial allocations to CCGs and is accompanied by other documents intended to help local clinicians deliver more responsive health services, focused on improving outcomes for patients, addressing local priorities and meeting the rights people have under the NHS Constitution.

*'Everyone Counts: Planning for Patients 2014/15 - 2018/19'* states that a CQUIN (Commissioning for Quality and Innovation) scheme will be in place for 2014/15. One of the four national improvement goals for the 2014/15 CQUIN scheme is "improving dementia and delirium care, including sustained improvement in Finding people with dementia, Assessing and Investigating their symptoms and Referring for support (FAIR)".<sup>28</sup>

A Better Care fund (BCF) has been established (formerly the Integration Transformation Fund), to ensure a transformation in integrated health and social care. BCF is a single, pooled, budget to support health and social care services to work more closely together in local areas. The initial timetable is over five years. The first iteration of better care plans cover the next two financial years and early indications are that, in the North East, localities are looking to include a local performance metric of estimated diagnosis rate for people with dementia.<sup>29</sup> This metric would be in addition to the five national metrics that will contribute to the payment-for-performance element of the Fund. Final plans were due to be submitted on 4th April 2014 – too late to be considered fully in this report.

## Health and social care outcomes frameworks

Table 1 outlines the outcomes, overarching indicators and improvement areas from the *'Adult Social Care Outcomes Framework 2014/15'*,<sup>30</sup> *'NHS Outcomes Framework 2014/15'*<sup>31</sup> and *'Public Health Outcome Framework 2013-16'*<sup>32</sup> that could contribute to improved outcomes for people with dementia.

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<sup>28</sup> NHS England (2013) *Everyone Counts: Planning for Patients 2014/15 - 2018/19* [Online] Available at: <http://www.england.nhs.uk/wp-content/uploads/2013/12/5yr-strat-plann-guid-wa.pdf> (Accessed 17 May 2014)

<sup>29</sup> NHS England. Annex to the NHS England Planning Guidance: Developing Plans for the Better Care Fund (Formerly the Integration Transformation Fund) [Online] Available at: <http://www.england.nhs.uk/wp-content/uploads/2013/12/bcf-plann-guid.pdf> (Accessed 17 May 2014)

<sup>30</sup> Department of Health (2013) *Adult Social Care Outcomes Framework 2014/15* [Online] Available at: <https://www.gov.uk/government/publications/adult-social-care-outcomes-framework-2014-to-2015> (Accessed 17 May 2014)

<sup>31</sup> Department of Health (2013) *NHS Outcomes Framework 2014/15* [Online] Available at: <https://www.gov.uk/government/publications/nhs-outcomes-framework-2014-to-2015> (Accessed 17 May 2014)

<sup>32</sup> Department of Health (2012) *Public Health Outcomes Framework 2013-16* [Online] Available at: <https://www.gov.uk/government/publications/healthy-lives-healthy-people-improving-outcomes-and-supporting-transparency> (Accessed 17 May 2014)

Adult Social Care Outcomes Framework 2014/15	
<p><b>Domain 1:</b> Enhancing quality of life for people with care and support needs</p>	<p><b>Overarching measure</b></p> <p>1A. Social care related quality of life</p> <p><b>Outcome measures</b></p> <p><i>People manage their own support as much as they wish, so that they are in control of what, how and when support is delivered to match their needs.</i></p> <p>1B. Proportion of people who use services who have control over their daily life <i>Carers can balance their caring roles and maintain their desired quality of life.</i></p> <p>1D. Carer-reported quality of life <i>People are able to find employment when they want, maintain a family and social life and contribute to community life, and avoid loneliness or isolation.</i></p> <p>1I. Proportion of people who use services and their carers, who reported that they had as much social contact as they would like.</p>
<p><b>Domain 3:</b> Ensuring people have a positive experience of care and support</p>	<p><b>Overarching measure</b></p> <p><i>People who use social care and their carers are satisfied with their experience of care and support services.</i></p> <p>3A. Overall satisfaction of people who use services with their care and support</p> <p>3B. Overall satisfaction of carers with social services</p> <p><b>Outcome measures</b></p> <p><i>Carers feel that they are respected as equal partners throughout the care process.</i></p> <p>3C. The proportion of carers who report that they have been included or consulted in discussions about the person they care for <i>People know what choices are available to them locally, what they are entitled to, and who to contact when they need help.</i></p> <p>3D. The proportion of people who use services and carers who find it easy to find information about support <i>People, including those involved in making decisions on social care, respect the dignity of the individual and ensure support is sensitive to the circumstances of each individual.</i></p> <p>This information can be taken from the Adult Social Care Survey and used for analysis at the local level.</p>
NHS Outcomes Framework 2014/15	
<p><b>Domain 2:</b> Enhancing quality of life for people with long term conditions</p>	<p><b>Overarching indicator</b></p> <p>2 Health related quality of life for people with long term conditions</p> <p><b>Improvement area</b></p> <p><i>Ensuring people feel supported to manage their condition</i></p> <p>2.1 Proportion of people feeling supported to manage their condition <i>Enhancing quality of life for carers</i></p> <p>2.4 Health-related quality of life for carers <i>Enhancing quality of life for people with dementia</i></p>

	<p>2.6 i Estimated diagnosis rate for people with dementia</p> <p>2.6 ii A measure of the effectiveness of post-diagnosis care in sustaining independence and improving quality of life</p>
<p><b>Domain 4:</b> <b>Ensuring that people have a positive experience of care</b></p>	<p><b>Improvement area</b> <i>Improving people's experience of integrated care</i></p> <p>4.9 Indicator in development</p>
<p><b>Public Health Outcomes Framework 2013/16</b></p>	
<p><b>Domain 4:</b> <b>Healthcare public health and preventing premature mortality</b></p>	<p><b>Objective</b> Reduced numbers of people living with preventable ill health and people dying prematurely, while reducing the gap between communities.</p> <p>4.16 Estimated diagnosis rate for people with dementia</p>

**Table 1:** Outcomes, overarching indicators and improvement areas from the 'Adult Social Care Outcomes Framework 2014/15', 'NHS Outcomes Framework 2014/15' and 'Public Health Outcome Framework 2013/16'. Source: Based on the table produced by: National Institute for Health and Care Excellence (2013) QS30: Quality standard for supporting people to live well with dementia [Online] Available at: <http://publications.nice.org.uk/quality-standard-for-supporting-people-to-live-well-with-dementia-qs30> (Accessed 17 May 2014)

## National Dementia Declaration and Dementia Action Alliance

The 'National Dementia Declaration' was launched at a Department of Health conference in 2010 and described seven outcomes that people with dementia and their families and carers would like to see in their lives.<sup>33</sup> The seven outcomes were:

1. I have personal choice and control or influence over decisions about me
2. I know that services are designed around me and my needs
3. I have support that helps me live my life
4. I have the knowledge and know how to get what I need
5. I live in an enabling and supportive environment where I feel valued and understood
6. I have a sense of belonging and of being a valued part of family, community and civic life
7. I know there is research going on which delivers a better life for me now and hope for the future

<sup>33</sup> Dementia Action Alliance (2010) National Dementia Declaration. London: Dementia Action Alliance

The (national) Dementia Action Alliance came into being with the launch of the National Dementia Declaration in 2011 and is hosted by the Alzheimer's Society.<sup>34</sup> The aim of the Dementia Action Alliance is to transform the quality of life of people living with dementia in the UK by converting commitment into action.

More than 800 organisations, many of which operate in the North East, have signed up to the National Dementia Declaration. Each organisation has published an action plan setting out what it will do to secure the outcomes of the National Dementia Declaration by the end of the National Dementia Strategy in 2014.

Since the launch of the Prime Minister's Challenge on Dementia<sup>35</sup> the Dementia Action Alliance has worked to establish Local Dementia Action Alliances across the UK.

A Local Dementia Action Alliance is a collection of stakeholders brought together to improve the lives of people with dementia in its area. It can be established at any level, a village, a city or a region. Local Dementia Action Alliances usually include a range of organisations within a community including groups from the public, private and voluntary and community sectors. Members of Local Dementia Action Alliances each submit an action plan detailing what they will do in their community to help achieve the outcomes of the National Dementia Declaration.

As of April 2014 there were two Dementia Action Alliances in the North East. The North East Dementia Alliance is the regional action alliance for the North East (for further information see section 4 of this report). For further information on the Gateshead Dementia Action Alliance see section 18 of this report.

## Calls to action

The Dementia Action Alliance and partner organisations have issued a number of national 'calls to action' in order to bring about positive changes for people living with dementia and their carers. The 'calls to action' encourage people to come together to commit to coherent actions in a given area.

### **The Right Prescription: a call to action on the use of antipsychotic drugs for people with dementia**

In June 2011 the Dementia Action Alliance and the NHS Institute for Improvement and Development issued a joint call to action to ensure that *"all people with dementia who are receiving antipsychotic drugs should receive a clinical review from their doctor to ensure that their care is compliant with*

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<sup>34</sup> <http://www.dementiaaction.org.uk/>

<sup>35</sup> Department of Health (2012) Prime Minister's Challenge on Dementia: Delivering major improvements in dementia care and research by 2015. Department of Health: London



*current best practice and guidelines and that alternatives to medication have been considered by 31 March 2012”.*<sup>36</sup>

For further information see section 23 of this report or visit:

[http://www.institute.nhs.uk/qipp/calls\\_to\\_action/Dementia\\_and\\_antipsychotic\\_drugs.html](http://www.institute.nhs.uk/qipp/calls_to_action/Dementia_and_antipsychotic_drugs.html)

### **The Right Care: creating dementia friendly hospitals**

In October 2012 the Dementia Action Alliance, in partnership with the NHS Institute for Innovation and Improvement, launched a call to action for the improvement of care for people with dementia in acute hospitals. The aim of this call to action was to ensure that *“by March 2013 every hospital in England will have committed to becoming a dementia friendly hospital, working in partnership with their local Dementia Action Alliance”*.<sup>37</sup>

For further information see section 14 of this report or visit:

[http://www.dementiaaction.org.uk/joint\\_work/the\\_right\\_care](http://www.dementiaaction.org.uk/joint_work/the_right_care)

### **Carers’ Call to Action**

In November 2013 the Dementia Action Alliance issued the Carers’ Call to Action with the aim of ensuring that carers of people living with dementia:

- Have recognition of their unique experience
- Are recognised as essential partners in care
- Have access to expertise in dementia care for personalised information, advice, support and co-ordination of care for the person with dementia
- Have assessments and support to identify the on-going and changing needs to maintain their own health and well-being
- Have confidence that they are able to access good quality care, support and respite services that are flexible, culturally appropriate, timely and provided by skilled staff for both the carer and the person for whom they care

For further information see section 21 of this report or visit:

<http://www.dementiaaction.org.uk/carers>

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<sup>36</sup> Alzheimer’s Society [Online] Available at:

[http://www.alzheimers.org.uk/site/scripts/news\\_article.php?newsID=984](http://www.alzheimers.org.uk/site/scripts/news_article.php?newsID=984) (Accessed 17 May 2014)

<sup>37</sup> Dementia Action Alliance [Online] Available at: <http://www.dementiaaction.org.uk/therightcare> (Accessed 17 May 2014)

## Housing Call to Action

In February 2014 the Dementia Action Alliance and the Housing and Learning Improvement Network launched the Housing Call to Action in order to encourage housing providers to sign up the national Dementia Action Alliance and/or their Local Dementia Action Alliance.

For further information see section 11 of this report or visit:

<http://www.dementiaaction.org.uk/housing>

## Clinical Guidelines 42 Dementia: Supporting people with dementia and their carers in health and social care

The guidelines produced by the National Institute for Health and Care Excellence and Social Care Institute of Excellence make recommendations for the identification, treatment and care of people with dementia and the support of carers.<sup>38</sup>

## 3.2 Conclusions on the English policy context

Between 2009 and 2014 the key policy driving improvements in the care and support of people with dementia has been the National Dementia Strategy. This was supplemented in 2012 by the Prime Minister's Challenge on Dementia. Both policies take a holistic approach to ensure people with dementia are supported throughout their journey. The Dementia Strategy and the Prime Minister's Challenge have provided a structure and priorities for work within the North East. There is no indication that a further dementia strategy will be issued. The Care Act 2014 will update social care policy but is not condition specific.

The Health and Social Care Act 2012 placed responsibility for health commissioning and care onto a number of organisations, established in March 2013. The work of these organisations is shaped by a number of outcome frameworks. Many of the outcomes and indicators set out in these frameworks are not specific to people living with dementia but would be inclusive of them. The '*NHS Outcomes Framework 2014/15*' and the '*Public Health Outcomes Frameworks 2013/16*' do, however, contain indicators and outcomes relating to the diagnosis and post-diagnosis care of people with dementia. The outcomes frameworks have led to the direct involvement of Public Health England and Health Education England in the regional work led by the North East Dementia Alliance.

Supporting national drivers have been the 'calls to action' and NICE guidelines, which focus on improving quality of experience for the person living with dementia and their carers.

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<sup>38</sup> National Institute for Health and Clinical Excellence and the Social Care Institute for Excellence (2006) CG42Dementia: Supporting people with dementia and their carers in health and social care. London: National Institute for Health and Clinical Excellence

There is a danger that, if a further holistic dementia strategy is not issued, dementia may become less of a priority for those organisations for which it is not a sole area of work.

Furthermore, the lack of a holistic dementia strategy could result in disjointed work focusing on individual sections of the pathway rather than a person's journey as a whole.

### 3.3 Recommendations on the English policy context

- The National Dementia Strategy implementation period has come to an end. However, dementia still needs to remain a high priority. The North East Dementia Alliance should seek to influence Government to develop policy based on an integrated holistic pathway approach.
- The '*NHS Outcomes Framework 2014/15*' and the '*Public Health Outcomes Frameworks 2013/16*' include dementia as a priority. Key organisations, including the Mental Health, Dementia and Neurological Conditions Strategic Clinical Network Northern England and the North East Dementia Alliance, need to support but, ultimately, call to account the organisations responsible for the delivery of these objectives in the North East.
- There are four dementia specific 'calls to action' and key organisations need to act upon the calls and use them to deliver positive outcomes for people living with dementia.

## 4. Groups and organisations in the North East

### Key points:

- Six groups and organisations have a key role in improving the care and support of people with dementia across the whole of the North East. These are:
  - o The North East Dementia Hub
  - o The North East Dementia Alliance
  - o The Mental Health, Dementia and Neurological Conditions Strategic Clinical Network Northern England
  - o The North East Association of Directors of Adult Social Services
  - o Health Education England
  - o Public Health England
- The improved care and support for people living with dementia in the North East is supported by a number of sub-regional and local groups and organizations, including:
  - o Local area teams
  - o Collaboratives
  - o Clinical commissioning groups
  - o Locality based groups and structures

This section of the report will outline:

- Regional groups and organisations in the North East
- Sub-regional and local groups and organisations in the North East
- Conclusions and recommendations regarding the groups and organisations in the North East

### 4.1 Regional groups and organisations

Six regional groups and organisations have a key role in implementing the National Dementia Strategy in the North East. Three groups are specifically dedicated to dementia, while the other groups have wider remits that include, but are not specific to, dementia. There is some common membership between the groups which maximises joint working. Outlined below are details relating to the regional groups and organisations, their roles and their membership.

## North East Dementia Hub

In spring 2014 the contract to provide a North East Dementia Hub was awarded to Newcastle University. The purpose of the Dementia Hub will be to support improvements in dementia care across the North East of England. It is anticipated the hub contract will run for 18 months from July 2014. The Hub will have specific responsibility for supporting the North East Dementia Alliance and the Dementia Themed Network of the North East Association of Directors of Adult Social Services (ADASS).

## North East Dementia Alliance

The North East Dementia Alliance was formed in 2008 and is a partnership of key organisations and individuals concerned with improving the care and support of people living with dementia and carers.

Key to the Alliance is involving people with dementia in every aspect of their work. The Alliance has six key priorities:

- Good quality timely diagnosis
- Improved quality of care in general hospitals
- Living well with dementia in care homes
- Reducing the inappropriate prescribing of antipsychotic medication
- Developing dementia friendly communities
- Improving care and support to people with dementia from minority communities

There is funding to support the structure of the North East Dementia Alliance for 18 months from July 2014.

In spring 2014 the North East Dementia Alliance signed up to the National Dementia Declaration and became a Regional Dementia Action Alliance<sup>39</sup> (see section 3 of this report for further information on Dementia Action Alliances).

For further information contact [neda@newcastle.ac.uk](mailto:neda@newcastle.ac.uk)

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<sup>39</sup> [http://www.dementiaaction.org.uk/local\\_alliances/6390\\_north\\_east\\_dementia\\_alliance](http://www.dementiaaction.org.uk/local_alliances/6390_north_east_dementia_alliance)

## The Mental Health, Dementia and Neurological Conditions Strategic Clinical Network Northern England

The Mental Health, Dementia and Neurological Conditions Strategic Clinical Network Northern England was established in 2013 in response to national policy changes outlined in the documents *Strategic Clinical Networks: The way forward*<sup>40</sup> and *Strategic Clinical Networks: Single Operating Framework*.<sup>41</sup>

Strategic Clinical Networks bring together professionals from across different NHS organisations to improve outcomes for a particular disease or patient group by making improvements in complex patient pathways. These include:

- Reducing unwarranted variation in health and wellbeing service
- Improving patient outcomes
- Encouraging innovation in the way in which services are provided now and in the future
- Providing clinical advice and leadership to support decision making and strategic planning

Strategic Clinical Networks have been established to work in areas where there are major challenges to health and well-being. There are four nationally determined Strategic Clinical Networks, one of which is Mental Health, Dementia and Neurological Conditions.

The Mental Health, Dementia and Neurological Conditions Strategic Clinical Network Northern England covers North East England (the remit of this report) as well as north Cumbria (which has patient flows into Newcastle and Northumbria Hospitals) and the Hambleton and Richmondshire area of North Yorkshire (which has patient flows into Teesside).

There is a Clinical Lead for Dementia (Secondary Care) – Dr Louise Allan. As of May 2014 there was a vacancy for the Clinical Lead for Dementia (Primary Care).

The Mental Health, Dementia and Neurological Conditions Strategic Clinical Network Northern England held two events in the winter of 2013/14 in order to identify the priorities for its work around dementia. As of April 2014 priorities were being identified under the themes of:

- Pre-disease and prevention
- Very early and uncertain disease
- Established disease
- End of life care

Initially, two task and finish groups will look at dementia and delirium and the CQUIN, and the dementia enhanced services.

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<sup>40</sup> NHS Commissioning Board (2012) *The Way Forward: Strategic Clinical Networks* [Online] Available at: <http://www.england.nhs.uk/wp-content/uploads/2012/07/way-forward-scn.pdf> (Accessed 17 May 2014)

<sup>41</sup> NHS Commissioning Board (2012) *Strategic Clinical Networks: Single Operating Framework* [Online] Available at: <http://www.england.nhs.uk/wp-content/uploads/2012/11/scn-sof.pdf> (Accessed 17 May 2014)

For further information see [www.nescn.nhs.uk](http://www.nescn.nhs.uk)

## North East Association of Directors of Adult Social Services

The North East Association of Directors of Adult Social Services (NE ADASS) is the regional branch of the Association of Directors of Adult Social Services. As directors of adult services their remit covers the full breadth of adult social care including dementia. The North East ADASS structure includes a number of themed networks, one of which focuses exclusively on dementia while six others are not client specific but address issues relevant to people with dementia. The themed networks within the North East ADASS structure focus on:

- Sector-led improvement
- Carers
- Safeguarding
- Dementia
- Think Local Act Personal
- Learning Disability
- Health Education North East Local Government Group
- Performance Leads

The Dementia Network provides strategic leadership for three of the National Dementia Strategy objectives (community and personal support: objective 6, housing and telecare: objective 10, and care homes: objective 11).

The North East ADASS has welcomed presentations on dementia at other themed networks including the carers leads group in 2013, partially funded a person centred care programme in care homes (being implemented in 2014) and supported regional dementia events for example, on housing and dementia.

The Dementia Themed Network is chaired by a regional Dementia ADASS lead, Jacqui Old and is made up of the dementia leads from each local authority in the North East, who are primarily service commissioners. This group acts as a forum for sharing good practice and information, assessing the pace of implementation and progressing identified areas of work.

The group currently has four work streams, these are:

- Timely diagnosis
- Care homes
- Dementia friendly communities
- Maximising care at home

For further information contact [ian.hall@northeastcouncils.gov.uk](mailto:ian.hall@northeastcouncils.gov.uk)

## Health Education England

Health Education England is responsible for leading and coordinating the education, training, and workforce development of the NHS and public health workforce in England.

Health Education England's mandate, outlined in '*Delivering high quality, effective, compassionate care: Developing the right people with the right skills and the right values*'<sup>42</sup> aligns Health Education England's work with national NHS priorities to:

- Tackle preventable deaths
- Empower and support people living with long-term conditions
- Introduce a culture of caring
- Ensure the diagnosis, treatment and care of people with dementia in England to be among the best in Europe

This was refreshed in May 2014 covering the period April 2014 to March 2015.<sup>43</sup>

The work of Health Education England is supported through 13 Local Education and Training Boards (LETBs), responsible for the training and education of NHS staff.

Health Education North East is the regional presence for the organisation. It supports Health Education England to deliver its objectives by working to meet local workforce requirements and by ensuring the supply of a competent workforce to provide high quality health and patient care.<sup>44</sup>

To improve the care of people with dementia, Health Education England's mandate set out a national target of ensuring "*that 100,000 staff have foundation level training by March 2014*".<sup>45</sup> The refreshed mandate sets out a new target to "*provide Tier 1 training to a further 250,000 staff by March 2015, ensuring that the tools and training opportunities are available to all staff by the end of 2018*".<sup>46</sup>

For further information about the work undertaken by Health Education England in the North East please see section 19 of this report or contact <http://ne.hee.nhs.uk/>

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<sup>42</sup> Department of Health (2013) *Delivering high quality, effective, compassionate care: Developing the right people with the right skills and the right values: A mandate from the Government to Health Education England: April 2013 to March 2015* [Online] Available at: [http://hee.nhs.uk/wp-content/uploads/sites/321/2013/05/29257\\_2900971\\_Delivering\\_Accessible.pdf](http://hee.nhs.uk/wp-content/uploads/sites/321/2013/05/29257_2900971_Delivering_Accessible.pdf) (Accessed 17 May 2014)

<sup>43</sup> Ibid

<sup>44</sup> Health Education North East [Online] Available at: <http://ne.hee.nhs.uk/> (Accessed 17 May 2014)

<sup>45</sup> Department of Health (2013) *Delivering high quality, effective, compassionate care: Developing the right people with the right skills and the right values: A mandate from the Government to Health Education England: April 2013 to March 2015* [Online] Available at: [http://hee.nhs.uk/wp-content/uploads/sites/321/2013/05/29257\\_2900971\\_Delivering\\_Accessible.pdf](http://hee.nhs.uk/wp-content/uploads/sites/321/2013/05/29257_2900971_Delivering_Accessible.pdf) (Accessed 17 May 2014)

<sup>46</sup> Department of Health (2014) *Delivering high quality, effective, compassionate care: Developing the right people with the right skills and the right values: A mandate from the Government to Health Education England: April 2014 to March 2015* [Online] Available at: [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/310170/DH\\_HEE\\_Mandate.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/310170/DH_HEE_Mandate.pdf) (Accessed 17 May 2014) p.16



## Public Health England

Public Health England (PHE) is the national public health agency which fulfils the statutory duty of the Secretary of State for Health to protect and promote the health and well-being of the nation and address health inequalities.

PHE works with national and local government, the NHS, industry, academia, the public and the voluntary and community sector to protect and improve the nation's health and to address health inequalities.

The work of Public Health England focuses on five high-level enduring priorities and two supporting priorities. Included among the five high-level enduring priorities is the need to *“reduce the burden of disease and disability in life by focusing on preventing and recovering from the conditions with the greatest impact, including dementia, anxiety, depression and dependency”*.<sup>47</sup>

In addition the *‘Public Health England Outcomes Framework 2013/16’*<sup>48</sup> states that estimated diagnosis rates for people with dementia will be used as an outcome measurement for the objective *‘Reduced numbers of people living with preventable ill health and people dying prematurely, while reducing the gap between communities’*.

To achieve this priority the programme of work for Public Health England includes working with partners across the NHS, local government and voluntary and community sector to:

- Develop a coordinated national approach to preventing dementia
- Maximising the contribution of NHS Health Checks
- Focus on reducing the burden and stigma of dementia on families by supporting dementia friendly communities

The delivery of these objectives in the North East is supported by the PHE Centre for North East England.

The PHE Knowledge and Intelligence Team (Northern and Yorkshire) supports local authorities with the provision of public health information and data in North East England.

PHE Knowledge and Intelligence Team (Northern and Yorkshire) has representation on the national Public Health mental health, dementia and neurological conditions intelligence network and representatives from the Centre for North East England and the Public Health Knowledge and Intelligence attend the North East Dementia Alliance.

For further information about Public Health England's work in the North East contact [claire.sullivan@phe.gov.uk](mailto:claire.sullivan@phe.gov.uk)

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<sup>47</sup> Public Health England (2013) Our priorities for 2013/14 [Online] Available at: [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/192676/Our\\_priorities\\_final.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/192676/Our_priorities_final.pdf) (Accessed 17 May 2014)

<sup>48</sup> Department of Health (2012) Public Health Outcomes Framework 2013-16 [Online] Available at: <https://www.gov.uk/government/publications/healthy-lives-healthy-people-improving-outcomes-and-supporting-transparency> (Accessed 17 May 2014)

For further information about PHE Knowledge and Intelligence Team (Northern and Yorkshire) contact [NorthernAndYorkshireKIT@phe.gov.uk](mailto:NorthernAndYorkshireKIT@phe.gov.uk)

## 4.2 Sub-regional and local groups and organisations

Outlined below are a number sub-regional and local groups and organisations with a key role in implementing the National Dementia Strategy in the North East.

### Local Area Teams

NHS England (North) is one of four regional teams in England supporting the commissioning of high quality health services and directly commissioning primary care (GP services, dental practitioners, opticians and pharmacy) and specialised services.

There are two area teams within the North East:

- Durham, Darlington and Tees
- Cumbria, Northumberland, Tyne and Wear

Their combined geographical foot print is larger than the North East region as defined for the purposes of this report (see section 1 of this report for the geographical areas covered by this report); however, it corresponds with the areas covered by the Northern England Strategic Clinical Networks.

### Collaboratives

#### **Stockton and Hartlepool Dementia Collaborative**

Stockton and Hartlepool Dementia Collaborative aims to develop, implement and maintain large-scale system changes to improve patient-focused dementia services on behalf of North Tees & Hartlepool NHS Foundation Trust, Hartlepool and Stockton Clinical Commissioning Group, Tees, Esk & Wear Valleys NHS Foundation Trust, Stockton Borough Council and Hartlepool Borough Council.

Its intended high-level objectives are to:

- Deliver the National Dementia Strategy and the Prime Minister's Challenge on Dementia
- Improve existing, and develop new, pathways including earlier intervention
- Develop multi-level, system-wide training
- Support forward planning of services for people with dementia

For further information about the Stockton and Hartlepool Dementia Collaborative contact [corinne.walsh@nhs.net](mailto:corinne.walsh@nhs.net)

For further information about the achievements of the Stockton and Hartlepool Dementia Collaborative see sections 12, 13, 14 and 17 of this report.

### **Darlington Dementia Collaborative**

In early 2009 Chief Executives with responsibility for providing health and social care services in Darlington agreed to collaborate on a venture to deliver large scale change across organisational boundaries in order to commission and deliver health and social care of the highest quality. The initial focus of this joint venture was on improving services and outcomes for people with dementia.

The organisations involved were:-

- Tees, Esk and Wear Valleys NHS Foundation Trust
- County Durham and Darlington NHS Foundation Trust
- Darlington Borough Council
- County Durham and Darlington Community Health Services providers
- NHS County Durham and Darlington Commissioner

The work of the Darlington Dementia Collaborative included conducting Rapid Improvement Workshops (RPIWs) using the North East Transformation System (NETs),<sup>49</sup> focusing on:

- Preventing admissions to Darlington Memorial Hospital via 999/111 from care homes
- Improving the experience of patients attending the Emergency Department at Darlington Memorial Hospital
- Improving liaison psychiatry
- Improving intermediate care

Current work is focused on identifying how to carry forward the legacy of the service improvements delivered through the RPIWs.

### **Clinical Commissioning Groups**

In 2013, new structures for commissioning health services were introduced in England. Commissioning of Community and Secondary care was given to newly established bodies called Clinical Commissioning Groups (CCGs). CCGs replaced Primary Care Organisations (PCOs). Commissioning Support Units (CSUs) were also established to offer management and support services to commissioners: for example, providing IT systems and support, contract management and financial services. Until September 2014 CCGs have to buy commissioning support from CSUs but after that date they may commission support services from other organisations.

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<sup>49</sup> <http://www.nelean.nhs.uk/>

The following CCGs were established in the North East:

- South Tees
- Darlington
- Hartlepool and Stockton (HAST)
- Durham Dales, Easington and Sedgefield (DDES)
- North Durham
- Sunderland
- South Tyneside
- Gateshead
- Newcastle North and East
- Newcastle West
- North Tyneside
- Northumberland

The Newcastle and Gateshead CCGs have formed an Alliance, recognising that they have many health concerns in common and that patient flows are not restricted by the Tyne. The Newcastle CCGs have agreed to merge from April 2015 but, at the time of writing, the new body has yet to be authorised.

CCGs are led by clinicians, typically GPs and their aim is to commission quality health services for their local populations. There is no standard model for a CCG, but it must be led by clinicians. CCGs had to go through a rigorous assessment process before they could begin operating. Part of this process involved CCGs drawing up a five year strategy, which included national and local priorities. CCGs had then to publish a set of clear commissioning intentions and plans to for 2013/15.

An analysis of these commissioning intentions in relation to dementia care is summarised in Table 2.

	Identifies dementia as a challenge	Implement National Dementia Strategy and reduce the use of antipsychotics	NHS Operating Framework dementia priorities	Aims to improve diagnosis rates	Specific policies on dementia	Detailed areas
Northumberland	✓	✓	✓	✓		
North Tyneside	✓	✓	✓	✓	✓	Memory Services Jointly with Northumbria and NTW review diagnosis pathway Develop North Tyneside model to deliver NICE guidelines
Newcastle North and East	✓	✓	✓	✓	✓	Review dementia services as part of Older Persons' Services review
Newcastle West	✓	✓	✓	✓	✓	Increase access to memory services Reduce the use of antipsychotics Increase professional awareness of dementia Understand memory services Consider memory pathway and dementia adviser role Improve dementia information
Gateshead	✓	✓	✓	✓	✓	Implement memory services
South Tyneside	✓	✓	✓	✓	✓	Implement memory services
Sunderland	✓	✓	✓	✓	✓	Implement memory services
North Durham	✓	✓	✓	✓	✓	Reduce unnecessary hospital admissions Promote dignity in care Improve interface between physical and mental health services
Durham Dales, Easington and Sedgefield	✓	✓	✓	✓	✓	Easington locality to review community nursing Sedgefield to review community nursing and other support for older people and those with Long Term Conditions
Darlington	✓	✓	✓	✓	✓	Improve primary care dementia services to reduce hospital admissions for dementia Set up specific dementia workstream Review services for young onset dementia Promote dignity in care Improve interface between physical and mental health services
Hartlepool and Stockton	✓	✓	✓	✓	✓	Set up specific dementia workstream Implement 'Darlington Experience'
South Tees	✓	✓	✓	✓		Patient and public engagement have asked for more information and advice on dementia

**Table 2:** CCG commissioning intentions in the North East

The analysis shows all North East CCGs clearly identify dementia as a major health challenge in the coming years and have committed to implementing the National Dementia Strategy, including reducing the use of antipsychotic medication.

Most CCGs give some specifics of how they intend to meet the national and local priorities and these have been summarised in Table 2.

Commissioning intentions had to be refreshed in 2014 but these had not been published by the time of writing. The national priorities for 2014-15<sup>50</sup> still include improving care in hospitals for people with dementia and CCGs, though their longer term strategies remain committed to implementing the National Dementia Strategy.

In 2014, the Government changed the funding formula for CCGs. From 2014, the NHS funding allocations do not contain a weighting for deprivation; instead, it has been decided that age and gender of the patient are a greater determinant of their demand for health services. This means that more NHS funding goes to populations with higher numbers of children and older people. CCGs in the North East will receive less money than they would have done under the previous formula. The Association of North East Councils (ANEC) has estimated that CCGs in the North East will lose £166m in funding as a result of the change.<sup>51</sup>

It is too early to say what effect this change in funding will have on health services across the North East.

## Joint Strategic Needs Assessments

Since 2007, NHS Commissioners and local authorities have been under a legal obligation to provide a strategic needs assessment of their area. These documents are usually known as Joint Strategic Needs Assessments (JSNA) but recently some areas have produced a Single Needs Assessment (SNA) to try and link together all the determinants of health and well being.

The principal aim of the JSNA is to provide an analysis of the health and well being of the population of an area to enable the commissioning of health and care services which meet needs, both now and for the future. The JSNA is not a commissioning document, though it may make recommendations.

There is no standard format for a JSNA. As JSNAs are partnership documents they have been written at the level of upper tier local authorities so they can cover more than one Clinical Commissioning Group.

All the JSNAs highlight that ageing populations will inevitably bring greater incidence of long term conditions. Long Term Conditions (LTCs) are health problems that can not be cured but can be

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<sup>50</sup> NHS England (2013) Everyone Counts: Planning for Patients 2014/15 - 2018/19 [Online] Available at: <http://www.england.nhs.uk/wp-content/uploads/2013/12/5yr-strat-plann-guid-wa.pdf> (Accessed 17 May 2014) p. 50

<sup>51</sup> Association of North East Councils [Online] Available at : <http://www.northeastcouncils.gov.uk/curo/downloaddoc.asp?id=612> (Accessed 17 May 2014)

managed with medication and other therapies and which can seriously diminish a person's quality of life. All but one of the North East JSNAs list dementia as one of the long term conditions, which will become more prevalent in the future due to the ageing population. Only the Newcastle JSNA does not specifically mention dementia, but it does stress that, as people get older, they are more likely to suffer from complex health conditions.

All JSNAs say the aim of health services should be to enable people to live as independently as possible for as long as possible. To do this, the JSNAs say that health and welfare problems should be diagnosed as soon as possible so effective interventions can be made sooner to slow down deterioration in a person's health. The JSNAs also stress that, for these interventions to be truly effective, they must be collaborative between all services; for example a number of JSNAs mention the need for dementia specific housing, while North Tyneside's JSNA recommends it should aim to become a dementia friendly community.

All JSNAs cover the needs of carers, with a number making specific reference to carers of people with dementia. Those which do mention carers of people with dementia highlight the need to provide effective information and dementia specific emergency and crisis teams.

Overall, it appears all JSNAs indicate that dementia services remain a priority for health and social care in the immediate future.

## Health and wellbeing strategy

In 2011, Health and Wellbeing Boards were obliged to develop health and wellbeing strategies for their areas. The health and wellbeing strategy derives from the JSNA and is designed to enable the Health and Wellbeing Boards to take leadership in delivering integrated health and care services. They are documents written for their specific localities and should drive local health and care service commissioning decisions. The health and wellbeing strategy should set the health and care outcomes that are important for their locality.

All North East health and wellbeing strategy documents set firm, but achievable, goals for the kind of communities they wish to create; all of them want their citizens, whatever their circumstances, to live safe, secure lives as independently as possible. Even where a strategy does not mention dementia (6 out of 12 do not) there is still a clear emphasis on responding to the needs of individuals. A clear theme in the strategies is the need to get the basics right: early or timely diagnosis of health problems with appropriate services at each stage of the person's journey.

For those health and wellbeing strategies that do mention dementia, there are links back to the JSNA.

Overall, the Health and Wellbeing Boards have responded to their wide remit by producing strategies based on their local JSNAs.

## Local joint dementia plans

The operating framework for the NHS in England of 2011/12 required the publication of dementia action plans.<sup>52</sup> This was the responsibility of Primary Care Organisations and they were required to demonstrate how they were delivering, in particular, the four priorities of increased diagnosis, improving care in care homes, improving care in hospitals and reducing the use of antipsychotic medication.

The development and updating of local joint dementia plans has continued to a greater or lesser extent across the region. The latest joint dementia plans in localities in the North East are outlined in Table 3. Relevant details from these plans have been extracted and included in each of the sections throughout this report.

Area	Group with oversight and or steering the work	Latest local joint dementia plans
<b>County Durham</b>	Durham and Darlington Dementia Strategy Group.	Dementia Strategy for County Durham and Darlington Draft. Out for consultation until May 2014*. <sup>53</sup>
<b>Darlington</b>	Durham and Darlington Dementia Strategy Group.	Dementia Strategy for County Durham and Darlington Draft. Out for consultation until May 2014*. <sup>54</sup>
<b>Gateshead</b>	Older People's Mental Health Strategy Group (OPMHS). This group develops overarching strategic priorities for older people's mental health in. The Dementia Strategy and Action Plan are incorporated in the group's remit.	National Dementia Strategy Action Plan A Local Action Plan September 2012- September 2013.*  Currently rewriting action plan in view of an overview and scrutiny review.
<b>Hartlepool</b>		National Dementia Baseline Assessment Rating for Hartlepool (Position in 2010).
	Stockton and Hartlepool Collaborative Steering Group.	Stockton and Hartlepool Dementia Collaborative action plan to December 2014.*
<b>Middlesbrough</b>	Older People's Mental Health Group.	Mental Health Services for Older People in Middlesbrough Implementation Plan 2009-2014 Updated September 2012*.
<b>Newcastle</b>	Newcastle dementia steering group.	No plan to review archived. May 2014 redrafting a new action plan.
<b>North Tyneside</b>	Dementia sub group to the Older Persons Integration Board.	North Tyneside Joint Dementia Action Plan 2012-13. Plan is being updated / re written.*

<sup>52</sup> Department of Health (2010) NHS Operating Framework 2011–12. Department of Health: London. Section 3.21

<sup>53</sup> Dementia Strategy for County Durham and Darlington (Consultation Version): Draft version 8 (2014) [Online] Available at: <http://content.durham.gov.uk/PDFRepository/DementiaStrategyConsultation.pdf> (Accessed 17 May 2014)

<sup>54</sup> Ibid



<b>Northumberland</b>	Northumberland Strategic Partnership (Dementia).	Northumberland Joint Dementia Action Plan September 2011- March 2013.*  May 2014 - rewriting dementia strategy and action plan.
<b>Redcar &amp; Cleveland</b>		Service Delivery in Redcar and Cleveland against National Dementia Objectives. Updated April 2014*.
<b>South Tyneside</b>		Local Action Plan for Dementia in South Tyneside - version 3 - September 2012.*
<b>Stockton-on-Tees</b>	Stockton and Hartlepool Collaborative Steering Group.	National Dementia Strategy Implementation Group For Stockton-on-Tees Outstanding Actions November 2013*.  Stockton and Hartlepool Dementia Collaborative action plan to December 2014*.
<b>Sunderland</b>	Currently reviewing local arrangements.	National Dementia Strategy Action Plan. A Local Action Plan for Sunderland April 2008 to March 2013.*

Note The 10 plans marked with an \* are those used to inform the local joint dementia plans sections throughout this report. Note: County Durham has a joint draft strategy and Hartlepool and Stockton-on-Tees have a joint dementia collaborative action plan.

**Table 3:** Local joint Dementia Plans in localities across the North East

## Overview and scrutiny

### Overview and scrutiny committees

Overview and scrutiny committees were established in local authorities by the '*Local Government Act 2000*'.<sup>55</sup> Their role is to develop and review policy and make recommendations to the council. The current legislative provisions for overview and scrutiny committees are mostly contained in the '*Localism Act 2011*',<sup>56</sup> which added several new sections into the 2000 Act. The Localism Act allows 'external scrutiny,' where a council's committee(s) can look at issues which lie outside the council's responsibilities. Specific powers exist to scrutinise health bodies amongst others.

<sup>55</sup> Great Britain. Local Government Act: Elizabeth II. Chapter 22 (2000) London: The Stationery Office

<sup>56</sup> Great Britain. Localism Act: Elizabeth II. Chapter 20 (2011) London: The Stationery Office

Since April 2011 seven out of 12 overview and scrutiny committees<sup>57</sup> in the North East indicated that they had carried out reviews or had received reports relating to dementia. These ranged in the purpose and level of detail.

Those who stated they had received dementia related reports were:

**County Durham** - The Adults Wellbeing and Health Overview and Scrutiny Group received a report in December 2013 to consider the implications of TEWV changes to inpatient services within the Durham County Council area.<sup>58</sup> An update was subsequently received by the Group on 24<sup>th</sup> January 2014.

**Gateshead** - The Healthier Communities Overview and Scrutiny Committee agreed that the focus of its review in 2013/2014 should be to identify measures to improve dementia care within Gateshead. It received a report, in June 2013,<sup>59</sup> which set out the scope of the review. The Committee received updates on findings on 3<sup>rd</sup> December 2013 and an interim report with potential recommendations on 4<sup>th</sup> March 2014.<sup>60</sup> The final report was due in April 2014.

**North Tyneside** - The Adult Social Care, Health and Wellbeing sub-committee considered the Dementia Action Plan 2012/13 at its meeting in September 2012. This was a one-off exercise to review progress of actions rather than a review of dementia services. Minutes "*Agreed that Review of the Dementia Action Plan be noted*".<sup>61</sup>

**Northumberland** - The Care and Well-being Overview & Scrutiny Committee meeting on 21<sup>st</sup> March 2013<sup>62</sup> was presented with local data and information about the key issues and activity in relation to

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<sup>57</sup> Representatives of the 12 Scrutiny Groups in the North East were contacted via the Scrutiny Group email address or where this could not be identified via the general information web address identified on the Local Authority Website

<sup>58</sup> Durham County Council. Adults Wellbeing and Health Overview and Scrutiny Committee [Online] Available at: <http://democracy.durham.gov.uk/documents/s28033/Item%20No%209%20-%20TEWV%20Dementia.pdf> (Accessed 17 May 2014)

<sup>59</sup> Gateshead Council. Healthier Communities Overview and Scrutiny Committee (2013) Review of Dementia [Online] Available at: <http://online.gateshead.gov.uk/docushare/dsweb/View/Collection-4310> (Accessed 17 May 2014)

<sup>60</sup> Gateshead Council. Healthier Communities Overview and Scrutiny Committee (2014) Review of Dementia [Online] Available at: <http://online.gateshead.gov.uk/docushare/dsweb/View/Collection-4481> (Accessed 17 May 2014)

<sup>61</sup> North Tyneside Council. Health and Wellbeing sub-committee [Online] Available at: [http://www.northtyneside.gov.uk/browse-display.shtml?p\\_ID=537734&p\\_subjectCategory=1350](http://www.northtyneside.gov.uk/browse-display.shtml?p_ID=537734&p_subjectCategory=1350) (Accessed 17 May 2014)

<sup>62</sup> Northumberland County Council. Care and well-being Overview and Scrutiny Committee (2013) Minutes Thursday, 21st March, 2013 [Online] Available at: <http://committees.northumberland.gov.uk/aksnorthumberland/users/public/admin/kab12.pl?cmte=CWB&met=52&arc=1> (Accessed 17 May 2014) and Northumberland County Council. Care and well-being Overview and Scrutiny Committee (2013) Minutes Thursday, 21st February, 2013 [Online] Available at: <http://committees.northumberland.gov.uk/aksnorthumberland/users/public/admin/kab12.pl?cmte=CWB&met=51&arc=20>

the provision of community dementia services across Northumberland. The presentation was noted and a further update was requested in September.

**Redcar and Cleveland** - The Scrutiny Team reported that some work had taken place in early spring 2014 in relation to dementia but no report was available at the time of writing the report.

**South Tyneside** - People Select Committee received a report about dementia on 15th October 2013. The committee was presented with information about the key issues and activity in relation to dementia, including details of services, dementia friendly communities and diagnosis rates. Officers were asked to evaluate the information provided and use it to challenge appropriate individuals and request further information to fulfil the role of the select committee. A revisit to this report is due early in June/July 2014.

**Stockton-on-Tees** - The Scrutiny Committee received a report, in 2012, in response to a service reconfiguration proposal from Tees Esk and Wear Valleys NHS Foundation Trust (TEWV) to reduce the number of inpatient mental health beds located in the borough at the Lustrum Vale Older People's Mental Health Unit.<sup>63</sup>

In addition, the Committee was consulted on the North Tees and Hartlepool NHS Foundation Trust's Quality Account Report 2013/14, which identified a quality improvement priority to assist people with dementia. The committee supported the Trust's approach.

### **Scrutiny group plans for 2014/15**

Each scrutiny group contact was asked whether it had plans to include dementia in its programme of reviews in 2014/15. Seven out of 12 have not finalised their programme for 2014/15, four said they would be carrying out work in relation to dementia and it has not been possible to get information relating to one group. The Newcastle group said that, although its programme was not set, there was a realistic possibility dementia could be included as the Care Quality Commission would be reviewing dementia services in the city in spring 2014. The Stockton-on-Tees group said that, although no dementia specific reviews were planned, one potential area of review was older adults, which would, by default, cover people living with dementia.

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(Accessed 17 May 2014) and

Northumberland County Council. Care and well-being Overview and Scrutiny Committee (2013) Minutes Wednesday, 26th February, 2014 [Online] Available at:

<http://committees.northumberland.gov.uk/aksnorthumberland/users/public/admin/kab12.pl?operation=SUBMIT&meet=62&cmte=CWB&grpId=public&arc=1> (Accessed 17 May 2014)

<sup>63</sup> Tees, Esk and Wear Valleys NHS Foundation Trust (2012) Improving Mental Health Services for Older People in Stockton-on-Tees [Online] Available at:

<http://www.tewv.nhs.uk/Global/improving%20mental%20health%20services%20for%20older%20people%20in%20Stockton%20on%20Tees.pdf> (Accessed 17 May 2014)

## Healthwatch

Healthwatch is an independent consumer champion that gathers and represents the views of the public on health and social care services in England. It was launched in April 2013. Healthwatch England has a statutory duty to collate evidence of service shortfalls and issues nationally and to ensure the regulators, other arms length bodies and government departments, respond accordingly. Healthwatch England works both at a national and local authority level. There is a local Healthwatch organisation in all 12 local authority areas in the North East.

Local Healthwatch organisations:

- Have the power to enter facilities and view services
- Have a seat on the local health and wellbeing board and should influence how services are set up and commissioned
- Produce reports which influence the way services are designed and delivered
- Provide information, advice and support about local services
- Pass information and recommendations to Healthwatch England and the Care Quality Commission

All Healthwatch organisations in the North East were contacted and asked if, since 2013, they had carried out any work to support people living with dementia and their carers and whether they planned to undertake any dementia related work in 2014/15.

**Durham and Darlington** - Healthwatch Darlington and Healthwatch County Durham have completed consultation work on behalf of two CCGs in Durham and Darlington to gather patient, family, carer and staff feedback on dementia services in the area. A variety of information gathering methods were used, which included visiting people with dementia and carers and an online survey. This information has fed into a new dementia strategy for local services written by North of England Commissioning Support for the commissioning CCGs. The strategy is currently in draft format and a number of consultation and drop in events have been scheduled for members of the public to have their say on its content.

**Gateshead** - No dementia specific work had been completed by Gateshead Healthwatch since April 2013 and none is planned for 2014/15. It will, however, respond to any emerging evidence or trends which need investigating.

**Middlesbrough, Redcar and Cleveland and Stockton-on-Tees** - Middlesbrough, Redcar and Cleveland and Stockton-on-Tees have not had any specific work priorities relating to dementia nor do they plan to have during 2014/15. However, many of the areas identified in their current work will have an impact on people living with dementia. For example a) Middlesbrough and Redcar and Cleveland are looking at Improving Access to Psychological Therapies (IAPT) and b) Stockton-on-Tees is looking at discharge from North Tees Hospital and direct payments for people using adult mental health services.

**North Tyneside** - In 2014/15 the North Tyneside Health and Wellbeing Board has prioritised dementia as a key area of work and Healthwatch will be working with the Board to take this priority

forward. LINK, the predecessor body to Healthwatch, produced a report about Dementia Friendly North Tyneside in December 2012.<sup>64</sup>

**Northumberland** - Northumberland Healthwatch has consulted with carers of people living in residential care (including many with dementia) about their experiences and has shared their feedback with CQC and Northumberland County Council. Northumberland Healthwatch volunteers have been recruited and trained as Independent Observers in care homes as part of contract monitoring processes in 2014. Healthwatch volunteers are also being recruited to participate in Mystery Shopping of local health and social care services.

Northumberland Healthwatch has also investigated issues raised by members of the public regarding whether the development of the new Specialist Emergency Care Centre in Cramlington, would be a 'dementia friendly' hospital. Northumbria Healthcare NHS Trust confirmed the centre would be 'dementia friendly'.

The Alzheimer's Society has been invited to have a representative on the Healthwatch Northumberland Board to develop partnership working between the two organisations and the Board has identified mental health as a priority area for its work in 2014.

A Health and Social Care Liaison Group has been established with Northumberland Healthwatch to co-ordinate partnership working, share findings from consultation activity and identify any emerging trends.

**South Tyneside** - South Tyneside Healthwatch was involved in a Cabinet Office visit to review the Prime Minister's Dementia Challenge in September 2013. This visit involved people living with dementia and their carers.

In spring 2014 Healthwatch South Tyneside were involved in research with the local Alzheimer's Society and volunteers looking at the availability of respite care for people with dementia. This was in response to carer feedback. The report highlights a gap in the availability of respite care facilities across the borough.

At the time of writing this report no information was available on the work of Healthwatch in Hartlepool, Newcastle and Sunderland.

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<sup>64</sup> North Tyneside Link (2012) Dementia friendly North Tyneside[Online] Available at: [http://www.healthwatchnorthtyneside.co.uk/sites/default/files/dementia\\_reportfinal\\_dec12.pdf](http://www.healthwatchnorthtyneside.co.uk/sites/default/files/dementia_reportfinal_dec12.pdf) (Accessed 17 May 2014)

## 4.3 Conclusions on the groups and organisations in the North East

Six regional and numerous local groups and organisations have a key role in improving the care and support of people living with dementia and carers in the North East.

A number of groups and organisations are specifically dedicated to improving care and support for people living with dementia:

- Dementia specific groups and organisations at a regional level are the dementia hub, the North East Dementia Alliance and the ADASS dementia themed network
- Dementia specific groups and organisations at a sub-regional and local level include the North Tees Dementia Collaborative and four identified active local planning groups

Health Education England, Public Health England and the Mental Health, Dementia and Neurological Conditions Strategic Clinical Network have multiple objectives, but clear priorities, linked to dementia.

Dementia is specifically mentioned in the commissioning intentions of all CCGs but not in all health and wellbeing strategies. In more than 50% of the region overview and scrutiny groups and Healthwatch organisations have addressed issues relating to the care of people dementia.

At a local level dementia is coming though as a recurring theme and priority. However, while there are 10 joint local dementia plans, many cover only up to March 2013, though there are indications that these are to be refreshed. The existence, status and roles of joint local dementia planning groups vary across the region.

## 4.4 Recommendations on the groups and organisations in the North East

- Dementia Collaboratives are showing positive outcomes using the North East Transformation System (NETs) including rapid process improvement methodology. This is not being taken up across the region. There is a need to share learning and look at the feasibility of establishing Dementia Collaboratives across the North East. The Mental Health, Dementia and Neurological Clinical Network, North East Dementia Alliance and the ADASS themed network should consider how to take this forward.
- Funding to maintain the Dementia Hub and North East Dementia Alliance is available until November 2015. There is a need to consider obtaining resources to carry out project work and to maintain the structures after November 2015.
- In May 2014 the North East Dementia Alliance registered with the National Dementia Action Alliance. The North East Dementia Alliance needs to review its membership to ensure it is engaging with the appropriate stakeholders across the North East.

- Active joint action planning groups are not in every locality despite having the benefits of looking at the whole pathway and allowing agencies to bring their plans together. Local planning groups should be in each locality to develop and coordinate local joint dementia plans.
- All CCGs prioritise dementia. Some areas use scrutiny groups and Healthwatch as effective partners to drive up the quality of care and support. This priority should remain and scrutiny groups and Healthwatch should be seen as key partners in improving quality of care and support for people living with dementia.



Part B:

Better  
research:  
**A North East  
Perspective**



## 5. Research

### Key points:

- Promoting research is one of the key focuses of the Prime Minister's Challenge on Dementia and the importance of research at a national level can be seen in the funding announcements that accompanied the G8 summit on dementia
- Despite its national importance, research is only mentioned in four out of the 10 local joint dementia plans in the North East
- Key institutions supporting the delivery of dementia clinical research in the North East include:
  - The NIHR Newcastle Dementia Biomedical Research Centre (a partnership between Newcastle upon Tyne Hospitals NHS Foundation Trust and Newcastle University)
  - The NIHR Newcastle Dementia Biomedical Research Unit in Lewy body dementia (a partnership between Newcastle upon Tyne Hospitals NHS Foundation Trust and Newcastle University)
  - The NIHR Clinical Research Network: North East and North Cumbria, Dementias and Neurodegenerative Diseases Research Network (DeNDRoN)
  - The Newcastle Brain Tissue Resource and the national Brains for Dementia Research initiative
- DeNDRoN is linking care homes to the ENRICH (Enabling Research in Care Homes) initiative to involve them in research
- The region benefits from a number of universities conducting research to support improvements in the lives of people with dementia and carers including the Institute of Health and Society and the Institute for Ageing and Health at Newcastle University
- All memory services in the North East are registered as having an interest in supporting people with dementia to take part in research studies; however, there are substantial differences in the number of research studies to which memory services have recruited people

This section of the report will consider key issues relevant to the promotion of high quality research relating to dementia. In particular this section of the report will outline:

- The policy context
- How dementia research has been included in local plans
- The work of the National Institute for Health Research in the North East
- The role of the Newcastle Brain Tissue Resource
- Research conducted by universities in the North East

- Memory services that involve people in research in the North East
- Conclusions on dementia research in the North East
- Relevant recommendations

## 5.1 Policy context

Outlined below is the policy context specific to the promotion of high quality research relating to dementia. This should be read in conjunction with the more general policy review in section 3 of this report.

### National Dementia Strategy

Objective 16 of the National Dementia Strategy highlights the need for “*evidence to be available on the existing research base on dementia in the UK and gaps that need to be filled*”.<sup>65</sup>

### Prime Minister’s Challenge on Dementia

In relation to improving research The Prime Minister’s Challenge on Dementia outlines five key commitments. These are:

- **More than doubling overall funding for dementia research to more than £66m by 2015** - The combined value of the National Institute for Health Research (NIHR), Medical Research Council (MRC) and Economic and Social Research Council (ESRC) funding for research into dementia will increase from £26.6m in 2009/10 to an estimated £66.3m in 2014/15
- **Major investment in brain scanning** - The MRC will make a major additional investment in dementia research using the BioBank. The MRC anticipates piloting the brain scanning of a subset of this national cohort, with a view to rolling out to 50,000–100,000 participants
- **£13m funding for social science research on dementia (NIHR/ESRC)**
- **£36m funding over five years for a new NIHR dementia translational research collaboration to pull discoveries into real benefits for patients** - Four new NIHR biomedical research units in dementia and biomedical research centres, which include dementia themed research, will share their considerable resources and world-leading expertise to improve treatment and care
- **Participation in high-quality research** - Offering people the opportunity to participate in research will be one of the conditions for accreditation of memory services<sup>66</sup>

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<sup>65</sup> Department of Health (2009) Living well with dementia: a National Dementia Strategy. London: Department of Health p.13

This Prime Minister's Challenge on Dementia stated that the work to achieve these commitments will be led by "the Ministerial Advisory Group on Dementia Research (MAGDR)... The group itself will be co-chaired by Dame Sally C Davies and Sir Mark Walport".<sup>67</sup>

## The Ministerial Advisory Group on Dementia Research – Headline Report

The Headline 'Report from the Ministerial Advisory Group on Dementia Research' identified the main challenges facing dementia research and set out a range of actions designed to address them.<sup>68</sup>

The report recommends actions that aim to:

- Strengthen collaboration and coordination
- Embed research in treatment and care
- Grow capacity and capability
- Harness existing resources
- Engage the public

The report included a 'Route Map for Dementia Research,' which summarised the main proposals with a clear time lines for delivery.

## Join dementia research

'Join dementia research' is a national initiative enabling people with dementia, carers and control volunteers to sign up for dementia research. 'Join dementia research' is funded by the National Institute for Health Research in partnership with Alzheimer's Research UK and the Alzheimer's Society. The charities will operate 'Join dementia research' helpdesks. These helpdesks can be contacted through the Alzheimer's Society Helpline 0300 222 11 22 and Alzheimer's Research-UK Infoline 0300 111 5 111.

'Join dementia research' is starting in London, and will open in the rest of the country by the end of 2014.

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<sup>66</sup> Department of Health (2012) Prime Minister's Challenge on Dementia: Delivering major improvements in dementia care and research by 2015. Department of Health: London pp 6-7

<sup>67</sup> Department of Health (2012) Prime Minister's Challenge on Dementia: Delivering major improvements in dementia care and research by 2015. Department of Health: London p.16

<sup>68</sup> Department of Health (2011) The Ministerial Advisory Group on Dementia Research: Headline Report [Online] Available at:  
[https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/215558/dh\\_127904.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/215558/dh_127904.pdf)  
(Accessed 17 May 2014)

## G8 Summit on Dementia

The G8 Dementia Summit, held in London in December 2013, brought together health and science ministers, researchers, pharmaceutical companies and charities. The G8 Dementia Summit concluded with the publication of a declaration and communiqué setting out the commitment of the G8 countries to:

- Set an ambition to identify a cure, or a disease-modifying therapy, for dementia by 2025
- Significantly increase the amount spent on dementia research
- Increase the number of people involved in clinical trials and studies on dementia
- Establish a new global envoy for dementia innovation, following in the footsteps of global envoys on HIV and Aids and on Climate Change
- Develop an international action plan for research
- Share information and data from dementia research studies across the G8 countries to work together and get the best return on investment in research
- Encourage open access to all publicly-funded dementia research to make data and results available for further research as quickly as possible<sup>69</sup>

As part of the G8 summit UK Prime Minister David Cameron committed to doubling the annual funding available for dementia research.<sup>70</sup>

## 5.2 Local plans

### Local joint dementia plans

Research is mentioned in four out of the 10 local joint dementia plans in the North East. Three local joint dementia plans mention working with DeNDRoN to give people the opportunity to participate in research if they wish to, while two local joint dementia plans highlight the use of memory clinics as an opportunity to support people with dementia to participate in research. The Durham and Darlington plan sets out an aim to contribute to the development of research studies and of developing personnel to support this process.

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<sup>69</sup> Department of Health (2013) G8 Dementia Summit Declaration [Online] Available at:

<https://www.gov.uk/government/publications/g8-dementia-summit-agreements> (Accessed 17 May 2014)

<sup>70</sup> Prime Minister's Office, 10 Downing Street (2013) [Online] Available at:

<https://www.gov.uk/government/news/g8-dementia-pm-calls-for-uk-to-lead-world-in-research> (Accessed 17 May 2014)

## 5.3 National Institute for Health Research in the North East

Outlined below is information about the work of the National Institute for Health Research in the North East including details about:

- The National Institute for Health Research
- The Dementia Translational Research Collaborative
- The National Institute for Health Research Clinical Research Network

### National Institute for Health Research

The National Institute for Health Research (NIHR) was formed in 2006 to “*improve the health and wealth of the nation through research*”.<sup>71</sup> The NIHR is funded through the Department of Health, is part of the NHS and is a key means through which the Secretary of State discharges its statutory duty to promote health. The NIHR funds research programmes and projects and has increased dementia research through a dementia-themed call for research proposals in 2012.

The NIHR supports and trains researchers and has research establishments. It also comprises the Research Design Service and the Clinical Research Network, which promotes research in the NHS across the whole country and in 30 different medical specialties, including dementia and neurodegeneration.

### Dementia Translational Research Collaboration

The NIHR Dementia Translational Research Collaboration was established in 2012 following the launch of the Prime Minister’s Challenge on Dementia.<sup>72</sup>

The NIHR Dementia Translational Research Collaboration is comprised of four NIHR Dementia Biomedical Research Units and six NIHR Biomedical Research Centres with dementia-related research themes. The North East has both a Unit and a Centre with dementia research themes.

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<sup>71</sup> National Institute for Health Research (2013) A brief overview of the National Institute for Health Research [Online] Available at: [http://www.nihr.ac.uk/files/Publications/NIHR%20overview%20leaflet\\_master\\_June13.pdf](http://www.nihr.ac.uk/files/Publications/NIHR%20overview%20leaflet_master_June13.pdf) (Accessed 17 May 2014) p.2

<sup>72</sup> NIHR Office for Clinical Research Infrastructure (2012) Translational Research in Dementia [Online] Available at: [http://www.nocri.nihr.ac.uk/media/12474/nocri\\_-\\_translational\\_research\\_in\\_dementia\\_lr\\_-\\_october\\_2012.pdf](http://www.nocri.nihr.ac.uk/media/12474/nocri_-_translational_research_in_dementia_lr_-_october_2012.pdf) (Accessed 17 May 2014) p.5

## **NIHR Newcastle Biomedical Research Units**

Biomedical Research Units aim to enable researchers and clinicians to work together in order to develop new treatments for the benefit of patients.

There is one Biomedical Research Unit in the North East. The NIHR Newcastle Dementia Biomedical Research Unit is a partnership between Newcastle upon Tyne Hospitals NHS Foundation Trust and Newcastle University. The Unit focuses on Lewy body dementias, including dementia with Lewy bodies and patients with Parkinson's Disease who later develop dementia. Newcastle is a recognised world leader in research into Lewy body dementias.<sup>73</sup>

## **NIHR Newcastle Biomedical Research Centres**

Biomedical Research Centres aim to translate fundamental biomedical research in to clinical research that benefits patients and their carers and promote the adoption of new insights into technologies, techniques and treatments for improving health.

There is one Biomedical Research Centre in the North East. The NIHR Newcastle Biomedical Research Centre in Ageing & Chronic Disease is a partnership between Newcastle upon Tyne Hospitals NHS Foundation Trust and Newcastle University, formed in 2012. Its research is focused on eight programmes aimed at improving healthcare in an expanding ageing population.

One of the centre's work themes is 'The Ageing Brain: Dementia & Stroke'. The main research strands within the Ageing Brain theme focus on investigating key mechanisms and substrate underpinning cognitive decline and brain ageing with the aim of identifying new targets to assist with early diagnosis, including identification of those 'at risk', and for novel therapeutic intervention.<sup>74</sup>

## **NIHR Clinical Research Network**

The NIHR Clinical Research Network provides the health service infrastructure to support clinical research in the NHS in England. The Clinical Research Network aims to:

- Ensure that patients and healthcare professionals from all parts of England, and from all areas of healthcare, are able to participate in and benefit from clinical research
- Improve the quality, speed and co-ordination of clinical research by removing the barriers to research in the NHS
- Streamline and performance manage NHS support for eligible studies

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<sup>73</sup> National Institute for Health Research [Online] Available at: <http://www.nocri.nihr.ac.uk/research-expertise/dementia-translational-research-collaboration/nihr-dementia-translational-research-collaboration-members/> (Accessed 17 May 2014)

<sup>74</sup> Newcastle University [Online] Available at: <http://www.ncl.ac.uk/biomedicine/research/brc/brain/> (Accessed 17 May 2014)

- Unify and streamline administrative procedures associated with regulation, governance, reporting and approvals
- Strengthen research collaboration with life sciences industries and ensure that the NHS can meet the health research needs of industry
- Further integrate health research and patient care<sup>75</sup>

In 2014 the NIHR introduced a new High Level Objective (HLO) for the Clinical Research Network to increase the number of participants recruited into Dementias and Neurodegeneration (DeNDRoN) studies on the NIHR Clinical Research Network Portfolio. The introduction of this new dementia specific HLO demonstrates the Government's focus on the increased delivery of dementia research.

Four DeNDRoN specific objectives have been set for the Clinical Research Network for 2014/15, these are:

- Implementing local arrangements for the delivery of joint dementia research
- Increasing the global and psychometric rater capacity within the network
- Improving the access to research for those living in care homes
- Increasing the clinical leadership capacity and engagement for each of the DeNDRoN sub specialties of dementia, Parkinson's, Huntington's and motor neurone disease

### **The Clinical Research Network: North East and North Cumbria**

Hosted by the Newcastle upon Tyne Hospitals NHS Foundation Trust, the Clinical Research Network: North East and North Cumbria is one of 15 networks covering all of England. The Dementias and neurodegeneration (DeNDRoN) research specialty in the North East and North Cumbria works in all NHS trusts to increase research activity and maximise patient recruitment to research studies. The role of DeNDRoN is to ensure that research adopted to the NIHR portfolio is efficiently carried out in the NHS. DeNDRoN works to bring together patients, carers, the public, clinicians, researchers, and healthcare workers to provide better research in the region.

The Clinical Research Network: North East and North Cumbria maintains a DeNDRoN Case Register, collecting the names of patients with dementia or neurodegenerative diseases who are interested in clinical research. If there is a suitable research study, members of the Case Register can be invited to join it. As of April 2014, 750 people on the Case Register were receiving regular research newsletters. There have been 500 approaches to patients on the Case Register to join research studies.

DeNDRoN and the NIHR have developed a web-based tool kit and network to improve opportunities for clinical research in care homes. Enabling Research in Care Homes (ENRICH) is building personal

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<sup>75</sup> National Institute for Health Research (2014) Clinical Research Network [Online] Available at: <http://www.nihr.ac.uk/files/pdfs/Briefing%20documents/4.1%20Clinical%20Research%20Network.pdf> (Accessed 17 May 2014) pp 1-2

relationships with care homes and the Clinical Research Network to support the delivery of research. The target is to have 20% of our ENRICH registered care homes recruiting to NIHR portfolio research studies during 2014/15.

DeNDRoN has a Patient, Carer and Public Involvement (PPI) Panel in the region, which offers advice about what and how research is carried out. There are (as of April 2014) 78 members on the PPI Panel.

DeNDRoN is currently supporting 38 studies, including eight industry studies of new medications, and research for improved diagnosis, causes of symptoms, treatments, management and care (including end of life care). These include:

- The early and accurate diagnosis of dementia by blood test
- The treatment of moderate Alzheimer's disease with antihistamine medication
- The predictive value of biomarkers from blood and cerebrospinal fluids and brain imaging for the development of dementia with Lewy bodies
- The use of PET imaging to compare patient symptoms with the amount of amyloid in their brains
- The use of Acute and Chronic effects of Transcranial Direct Current Stimulation in the treatment of hallucinations in Lewy body dementia patients
- Whether solanezumab can slow mental decline in patients with mild Alzheimer's compared to placebo
- The efficacy of minocycline in people with mild Alzheimer's disease
- Finding out the cause of visual hallucinations among people with Lewy body dementias<sup>76</sup>

These initiatives will enable the DeNDRoN specialty to work towards the goals defined in the Prime Minister's Challenge on Dementia. DeNDRoN is working to achieve the Prime Minister's ambition of increasing the number of patients involved in dementia research to 10%, an aspiration stated in the list of actions to deliver better research.<sup>77</sup>

For further information contact about DeNDRoN contact [margaret.piggott@nhs.net](mailto:margaret.piggott@nhs.net)

## 5.4 Newcastle Brain Tissue Resource

Newcastle Brain Tissue Resource (NBTR) has supported major advances in the understanding of dementia and neurodegenerative disease and identifying therapeutic targets. "*Current cholinergic therapy for dementia was based in part on studies carried out on tissue from NBTR*".<sup>78</sup> The NBTR currently receives core funding from the Medical Research Council. NBTR works in co-operation with

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<sup>76</sup> <http://www.northeastdendron.org.uk/>

<sup>77</sup> Department of Health (2012) Prime Minister's Challenge on Dementia: Delivering major improvements in dementia care and research by 2015. Department of Health: London p.22

<sup>78</sup> Newcastle University [Online] Available at: [nbtr.ncl.ac.uk](http://nbtr.ncl.ac.uk) (Accessed 17 May 2014)



other brain banks in the UK and is part of the Brains for Dementia Research Network, which is funded by the Alzheimer's Society and Alzheimer Research UK.

## 5.5 Research conducted by universities in the North East

### Newcastle University

#### **Institute of Health and Society**

A key research interest of the Institute is how people respond to and cope with chronic diseases, including dementia, and how care services and technology can improve peoples' lives when coping with these diseases. The institute is particularly interested in how the impact of chronic disease varies with income and how diet and alcohol consumption affect the health of older people.

#### **Institute for Ageing and Health**

The institute's work has focussed on dementia with Lewy bodies, dementia in Parkinson's disease, dementia after stroke and vascular contributions to cognitive decline and depression in later life. Much of the Institute's work focuses on *"the longitudinal clinico-pathological study of patient cohorts both with and at risk of dementia, with serial clinical and imaging investigations together with correlative autopsy studies through the Newcastle Brain Tissue Resource"*.<sup>79</sup>

The institute led the International Lewy body consortium in defining and validating clinical and pathological criteria for Lewy body dementia diagnosis and have validated new imaging biomarkers for diagnosis and undertaken influential treatment studies for Lewy body dementia. Details of a series of research projects can be found at <http://www.ncl.ac.uk/iah/research/areas/neurodegenerative/>

#### **Ageing, Health and Society Research Group**

The Ageing, Health and Society Research Group comprises researchers from both the Institute of Ageing & Health and Institute of Health and Society at Newcastle University and was established to *"provide an interdisciplinary cross-faculty collaboration between clinical scientists, behavioural and social scientists"*.<sup>80</sup>

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<sup>79</sup> Newcastle University [Online] Available at: <http://www.ncl.ac.uk/iah/research/areas/neurodegenerative/> (Accessed 17 May 2014)

<sup>80</sup> Newcastle University [Online] Available at: <http://www.ncl.ac.uk/biomedicine/research/groups/ageinghealth.htm> (Accessed 17 May 2014)

The Research Group conducts applied health services and policy research relating to, among other things, cognitive impairment and dementia.

### **Dementia and Imagination – creating community connections through art**

Newcastle University, other partner universities and Equal Arts are part of a £1.2 million research study funded by the Arts and Humanities Research Council and the Economic and Social Research Council. The research will explore how the visual arts can increase connectivity and well-being for people with dementia and their families. The intervention programme will be delivered by artists in care homes in the North East from June 2014 – July 2015 and will run alongside the research in Derbyshire and North Wales.

For further information see <http://dscd.bangor.ac.uk/di-project.php.en>

### **Translational Professorship**

In 2012 Professor Louise Robinson (Newcastle University) won a National Institute for Health Research Translational Professorship to improve the quality of community care for people with dementia and their families. This programme work is focused on number of key areas of community dementia care including identifying the most effective non-drug approaches for clinical commissioners to commission in dementia care and improving information provision and knowledge exchange between GPs and families with dementia. In addition she is the national Clinical Champion for Dementia for the Royal College until at least 2015.

A key project from this work was launched nationally in May 2014. The GP Dementia Roadmap is a web-based platform to facilitate knowledge exchange between GPs and their patients living with dementia. The Roadmap will contain the most up to date information on best practice and also specific regional information.

For further information see section 8 of this report or visit [www.dementiaroadmap.info](http://www.dementiaroadmap.info)

## **Northumbria University**

Northumbria University has set out its vision for the whole university in '*Vision 2025*'.<sup>81</sup>

Its focus, relating to people living with dementia, is to apply research and improve their quality of life. It does this by carrying out research in partnership and through training staff, including health, social care and allied health professionals.

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<sup>81</sup> For further information see:

[https://www.northumbriauniteders.org/procontract/northumbria/attachment\\_1.nsf/dsp\\_frm\\_attachments/ATT-DNWA-97VCLU/\\$FILE/Vision%20Impact.pdf](https://www.northumbriauniteders.org/procontract/northumbria/attachment_1.nsf/dsp_frm_attachments/ATT-DNWA-97VCLU/$FILE/Vision%20Impact.pdf)

Research is carried out through partnership working within the health and social care sector and with industry including small and medium sized enterprises. The university also carries out creative engagement by working with partners beyond health and social care, such as those in housing and the creative arts.

Examples of Northumbria University's work have included:

- Enhancing sheltered housing services so their environments are more dementia friendly
- Exploring the use of technologies, such as telecare, to support independent living through collaborative research by an international partnership (MATSIQEL)
- Implementation of an emotional robot - the Paro seal – in care homes and challenging behaviour units
- Implementation of henkeeping – known as HENPOWER – in older people's communities
- Enhancing workforce development to include the creative arts in specialised dementia care homes

Development of the healthcare workforce has been facilitated through pre-registration nursing students on dementia friends sessions and having service user/carers participating in taught programmes. Often this work cuts across university departments and brings together otherwise seemingly disparate disciplines; for example, nursing, mathematics, design, social care and performing arts.

The university is looking to attain dementia friendly status.

## Teesside University

Teesside University does not have ongoing research relating to people with dementia. It does, however, have a body of research on pain in older people. The results of a major research study exploring the experience of older people with pain will be available after May 2014. This project has received £1.2m funding from the Joint Research Councils' Lifelong Health and Wellbeing initiative and has been conducted in collaboration with Dundee, Aberdeen, Northumbria and Greenwich Universities.

Other work on pain management includes the development and evaluation of resources to improve understanding of pain. Some of this research is directly focused on older people. The university is analysing large public databases to explore links and mitigating factors between chronic pain and other health conditions, with evidence so far suggesting a link between cardiovascular disease and chronic pain.

The university is also carrying out research on the use of insoles in footwear to improve balance and function. This has shown benefits for older people, though this research has not been extended to include people with dementia.

## FUSE

Teesside University hosts the knowledge exchange hub for Fuse, the Public Health Centre of Excellence that spans the five North East universities; Durham, Newcastle, Northumbria, Sunderland and Teesside.

The aims of FUSE are to:

- Build capacity in North East England to undertake world class public health research
- Work collaboratively across the universities of North East England in undertaking national, regional and local research, producing evidence that will ultimately lead to better, fairer access to good health for all
- Research and implement ways in which public health research knowledge can be translated effectively into policy and practice
- Work with policy and practice partners to understand and develop their role as co-producers of research agendas and collaborators in research, leading to improved public health delivery

Apart from undertaking research, Fuse is committed to ensuring evidence makes its way into practice and so has instituted at Teesside a Professor in Knowledge Exchange in Public Health, a Fuse Knowledge Exchange Broker and Communications Officer. FUSE has also set up the AskFuse service, which is a responsive facility handling research and evaluation requests and enquiries from service partners in the public and third sectors. Some requests brokered through Fuse have related to dementia (e.g. evaluation of a sensory garden project for dementia patients).

For further information contact [info@fuse.ac.uk](mailto:info@fuse.ac.uk)

## Other universities in the North East

While other universities in the North East may be conducting research relevant to people living with dementia it was not possible to identify any such research for this report.

## 5.6 Memory services that involve people in research in the North East

The Prime Minister's Challenge on Dementia highlighted the involvement of memory clinics in research as one of its key commitments. Offering people with dementia the opportunity to participate in research is one of the conditions for accreditation of memory services and the report of the English National Memory Services Audit sets out the expectation that "*memory services will*

*offer all people with dementia the opportunity to be involved in a research project, or to be added to a register for future researchers to access”.*<sup>82</sup>

The report also stated that across England the average number of research studies to which each memory clinic recruited patients in the 12 months prior to the audit was 3.55.

In the North East four memory services recruited more patients to research studies than the national average. These were Lustrum Vale Memory Clinic (10 studies), Northumberland, Tyne and Wear NHS Trust - Memory Protection Service (eight studies), North Shields Memory Clinic (five studies) and Newcastle Memory Assessment and Management Service (four studies).

Two memory services in the North East recruited no patients to research studies; these were Derwentside Community Mental Health Team and Durham Dales Community Mental Health Team.

The number of research studies that memory services in the North East recruited to can be seen in Table 4.

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<sup>82</sup> Royal College of Psychiatrists (2013) English National Memory Services Audit Report. London: Royal College of Psychiatrists p.22

Memory services in the North East	Number of studies to which the memory service has recruited
Darlington Community Mental Health Team	2
Derwentside Community Mental Health Team	0
Durham and CLS Community Mental Health Team	2
Durham Dales Community Mental Health Team	0
Easington Community Mental Health Team	2
Hartlepool Community Mental Health Team	1
Lustrum Vale Memory Clinic	10
Middlesbrough Community Mental Health Team	1
Newcastle Memory Assessment and Management Service	4
Northumberland Planned Care Group	-
Northumberland Tyne and Wear NHS Trust - Memory Protection Service	8
North Shields Memory Clinic	5
Redcar and Cleveland Community Mental Health Team	2

**Table 4:** The number of research studies that memory services in the North East recruited. Source: Royal College of Psychiatrists (2013) English National Memory Services Audit Report. London: Royal College of Psychiatrists with additional information from providers in the North East

For further information about memory services in the North East see section 7 of this report.

## 5.7 Conclusions on dementia research in the North East

The North East has made significant contributions to dementia research both nationally and internationally. This can be seen in the contributions that North East research has made to our understanding of Lewy body dementias and the current cholinergic therapy for dementia.

The North East benefits from strong infrastructure and networks to support the delivery of dementia research. Although DeNDRoN's team members support clinical research in all NHS trusts in the region, Newcastle particularly benefits from a clustering of research infrastructures (for example the Dementia Translational Research Collaborations at Newcastle University). This agglomeration of infrastructures helps give Newcastle a comparative advantage as a site for clinical research in the North East and presents an opportunity for further specialisation.

Other universities in the region, notably Northumbria and Teesside, tend to have a more practice based approach to research, which has delivered positive outcomes for people living with dementia in the North East; for example, Northumbria University's work around dementia friendly environments in sheltered accommodation or the use of emotional robots in care settings.

Findings from research must be disseminated nationally and locally to ensure people with dementia reap the benefits.

To May 2014 DeNDRoN reported that there are 750 people on the DeNDRoN Case Register, with 500 approaches for research. While DeNDRoN and the memory services provide useful routes through which people living with dementia may become involved in research there is a need to go further to achieve the target of having 10% of patients involved in research. There is also a need to reduce the disparities between memory services in terms of the number of research studies to which they recruit.

## 5.8 Recommendations on dementia research in the North East

- Only four out of the 10 joint dementia plans in the North East make reference to research, despite it being a national priority. Locally joint dementia groups could consider what contribution they could make to research, such as encouraging people living with dementia to become involved in research.
- DeNDRoN and memory services support the recruitment of people with dementia to research studies. This work needs to be built on and new initiatives, such as the ENRICH project, that engage care homes, need to be supported by care home providers and commissioners.
- Significant research is being carried out in the North East. It is important to ensure that research findings are disseminated and translated into practice across the region. The universities and the North East Dementia Hub should play key roles in this, with significant partners including the North East Dementia Alliance and the Mental Health, Dementia and Neurological Clinical Network.



Part C:

Driving  
improvements in  
health and care:  
**A North East  
Perspective**



## 6. Increasing public awareness and understanding of dementia

### Key points:

- Increasing professional and public awareness of dementia is objective 1 of the National Dementia Strategy, while commitment 8 of the Prime Minister's Challenge on Dementia states that *"from autumn 2012, we will invest in a nationwide campaign to raise awareness of dementia, to be sustained to 2015"*
- Increased awareness of dementia is mentioned in two Joint Strategic Needs Assessments in the North East, both of which highlight the need to increase understanding about how improved health can reduce the risk of dementia
- In May 2014 work was undertaken in the North East to support national awareness campaigns, including the campaign being led by Public Health and Alzheimer's Society and local events to support Dementia Awareness Week
- There is little large scale awareness raising outside of these national initiatives; however, as of April 2014, 336 friends information sessions had taken place in the North East of England creating 4,140 Dementia Friends

This section of the report will consider key issues relevant to increasing public awareness and understanding about dementia. In particular this section of the report will outline:

- The policy context
- Ways in which increasing public awareness and understanding of dementia have been included in local plans
- Examples of work undertaken to increase public awareness and understanding of dementia in the North East
- Conclusions and recommendations on increasing public awareness and understanding of dementia in the North East

This section will focus on initiatives designed to increase public awareness and understanding about dementia. Section 19 of this report will identify work to increase dementia awareness among the health and social care workforce.

Increasing public awareness and understanding is a key aim of the dementia friendly communities initiative. For further information on dementia friendly communities see section 18 of this report.

## 6.1 Policy Context

Outlined below is the policy context specific to increasing public awareness and understanding about dementia. This should be read in conjunction with the more general policy review in section 3 of this report.

### National Dementia Strategy

Objective 1 of the National Dementia Strategy highlights the need for:

*“Public and professional awareness and understanding of dementia to be improved and the stigma associated with it addressed. This should inform individuals of the benefits of timely diagnosis and care, promote the prevention of dementia, and reduce social exclusion and discrimination. It should encourage behaviour change in terms of appropriate help-seeking and help provision”*.<sup>83</sup>

### Prime Minister’s Challenge on Dementia

Commitment 8 of the Prime Minister’s Challenge on Dementia sets out the ambition that *“from autumn 2012, we will invest in a nationwide campaign to raise awareness of dementia, to be sustained to 2015. This will build on lessons learned from previous campaigns and will inform future investment”*.<sup>84</sup>

## 6.2 Local plans

### Joint Strategic Needs Assessments

Increased awareness of dementia is mentioned in two Joint Strategic Needs Assessments (JSNAs) in the North East both of which highlight the need to increase understanding about how improved health can reduce the risk of dementia.

Northumberland’s JSNA identifies dementia as a mental health problem and the increased risk of dementia when a person has high cholesterol and blood pressure.<sup>85</sup>

Darlington’s JSNA identifies a lack of physical activity as a risk factor in developing dementia.<sup>86</sup>

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<sup>83</sup> Department of Health (2009) Living well with dementia: a National Dementia Strategy. London: Department of Health p.11

<sup>84</sup> Department of Health (2012) Prime Minister’s Challenge on Dementia: Delivering major improvements in dementia care and research by 2015. Department of Health: London p.6

<sup>85</sup> Northumberland Joint Strategic Needs Assessment [Online] Available at: <http://www.northumberland.gov.uk/default.aspx?page=8119> (Accessed 17 May 2014) pp 122-123

## Local joint dementia plans

All 10 local joint dementia plans make reference to increasing awareness and provision of information. The most frequent actions in this area relate to increasing the general public's awareness (these are mentioned in seven out of 10 plans) two with the aim of reducing stigma. Three of these plans included a health promotion element "*what is good for your heart is good for your head*". Two plans highlighted making primary care staff more aware.

## 6.3 Examples of work undertaken in the North East to increase information and awareness about dementia

### National awareness campaign from Public Health England and the Alzheimer's Society

Public Health England worked with the Alzheimer's Society to launch a national multi-media campaign between 7<sup>th</sup> - 31<sup>st</sup> May 2014 with the aim of inspiring people to become a Dementia Friend.<sup>87</sup> The campaign built on the Alzheimer's Society's initiative to recruit one million Dementia Friends.<sup>88</sup>

Public Health England with the Alzheimer's Society developed an awareness raising advert which was shown on television between 7<sup>th</sup> - 31<sup>st</sup> May 2014. As part of this national campaign Public Health England worked with relevant bodies in the North East to maximise the impact of the campaign in the region.

### Dementia Friends in the North East

*"Dementia Friends is a national initiative that is being run by Alzheimer's Society. It's funded by the Government and aims to improve people's understanding of dementia and its effects".<sup>89</sup>*

Dementia Friends sessions are delivered for free to anyone who wants to understand more about living with dementia. Dementia Friends are encouraged to turn their knowledge into practical actions to help people living with dementia in their community. The initiative aims to have one million Dementia Friends by 2015.

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<sup>86</sup> Single Needs Assessment for Darlington 2011/12 [Online] Available at: [http://www.darlington.gov.uk/dar\\_public/documents/\\_People/ChildrenFamiliesLearning/Darlington\\_SNA-2012.pdf](http://www.darlington.gov.uk/dar_public/documents/_People/ChildrenFamiliesLearning/Darlington_SNA-2012.pdf) (Accessed 17 May 2014) p.94

<sup>87</sup> Alzheimer's Society [Online] Available at: <https://www.dementiafriends.org.uk> (Accessed 17 May 2014)

<sup>88</sup> <https://www.dementiafriends.org.uk/>

<sup>89</sup> [http://www.dementiafriends.org.uk/about#.Uv9JlVl\\_sbg](http://www.dementiafriends.org.uk/about#.Uv9JlVl_sbg)

The Alzheimer's Society also provides Dementia Champions training for individuals over the age of 18. A Dementia Friends Champion can deliver Dementia Friends sessions and will encourage others to "make a positive difference to people living with dementia in their community".<sup>90</sup>

As of 22<sup>nd</sup> April 2014 336 friends' information sessions had taken place in the North East of England.<sup>91</sup> These sessions created 4,140 Dementia Friends. At the same date a further 35 Dementia Friends sessions were planned to take place in North East.

As of 22<sup>nd</sup> April 2014 529 Dementia Friends Champions were registered on the Dementia Friends website covering the North East. 224 of those had attended training and converted into trained champions. In addition, as of the same date, 39 champions were booked on training in the future.

For more information about the project see <http://www.dementiafriends.org.uk/>

## Dementia Awareness Week

Each year, during Dementia Awareness Week, communities across the UK undertake a range of activities with the aim of increasing awareness and understanding about dementia. Listed below are some examples of activities undertaken in the North East during Dementia Awareness Weeks in May 2013 and 2014.

### Dementia Awareness Week: Northumbria University

In 2013 Northumbria University, in partnership with the Alzheimer's Society, ran workshops and 'bite-size' activities to raise awareness of dementia. The events were attended by nursing students, healthcare professionals, carers and people living with dementia and included:

- Information sessions that enabled more than 70 people to become dementia friends
- Information sessions on issues such as how the arts can be used to benefit people with dementia
- A drop-in café where people could discuss any concerns or find out more about the condition

In 2014 A dementia friendly communities workshop was run with a film of Jack and Jill and the Red Post Box.

For further information contact [sue.tiplady@northumbria.ac.uk](mailto:sue.tiplady@northumbria.ac.uk)

<sup>90</sup> Alzheimer's Society [Online] Available at: [http://www.dementiafriends.org.uk/article/about-champions/what-is-a-champion#.Uv9NwPI\\_sbg](http://www.dementiafriends.org.uk/article/about-champions/what-is-a-champion#.Uv9NwPI_sbg) (Accessed 17 May 2014)

<sup>91</sup> Post code areas: TD, NE, DH, SR, DL, TS.

## Dementia Awareness Week: Stockton-on-Tees

In 2014 Stockton-on-Tees hosted a range of activities to promote Dementia Awareness Week, including:

- Raising awareness of dementia through story time and games with school children (delivered by Stockton Library Services)
- Dementia Friends sessions and the promotion of the Dementia Friendly Stockton project
- The distribution of information at venues across Stockton-on-Tees (including information on what dementia is, how to live well with dementia and services available in Stockton)
- Health checks and advice on alcohol related dementia at various venues throughout the week carried out by Public Health
- A 'Busk for Dementia Awareness' session in the middle of Stockton
- An ecumenical church service to promote the idea of dementia friendly churches

For further information contact [dfc@clevearc.com](mailto:dfc@clevearc.com)

## Dementia Awareness Week: Sunderland

In 2013 and 2014 Sunderland residents were invited to a 'Memory Event' at the Virgin Active Health and Racquet Club. This event was organised by staff from Gentoo Group.

The Memory Event, in association with the national Alzheimer's Society, encouraged people to talk to each other about their concerns and attendees were able to get advice from experts from a range of organisations, including Action on Dementia Sunderland; Sunderland Carers; Sunderland Telecare and Age UK. Representatives from the NHS were also present at the event giving free NHS Health checks and advice about nutrition and healthy eating. PAT dogs (Pets As Therapy) were also invited to demonstrate this alternative therapy for those living with dementia.

## Dementia Awareness Week: Beamish Museum

In 2014 Beamish Museum, working with the Alzheimer's Society, supported Dementia Awareness Week by hosting a week of events. Local school pupils, Alzheimer's Society groups and local care home residents came together to take part in the Alzheimer's Society's 'Singing for the Brain' sessions and the refurbished 1940s farm house also hosted a dementia café. The museum has more than 70 members of staff and volunteers as Dementia Friends and more workshops were held during the week. The week rounded off with a 1950s style garden party with lots of music, games and entertainment for everyone to enjoy together.

For further details contact [MichelleBall@beamish.org.uk](mailto:MichelleBall@beamish.org.uk)

## Northumberland Leaflet Drop

In 2012 the Department of Health organised a targeted leaflet drop in Northumberland with the aim of supporting the timely diagnosis campaign. There is currently no public evidence relating to the effectiveness of this intervention.

## 6.4 Conclusions on increasing public awareness and understanding of dementia in the North East

Key drivers for public awareness raising in the North East are linked to national initiatives, particularly Dementia Awareness Week and the use of Dementia Friends sessions. In May 2014 work was undertaken in the North East to support the national campaign led by Public Health England and the Alzheimer's Society.<sup>92</sup> Generally, there is little evaluation of the effectiveness of any campaigns other than the number of people attending events or the number of Dementia Friends. Two Joint Strategic Needs Assessments refer to the need for increased understanding about how general health improvements can help reduce the chances of developing dementia.

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<sup>92</sup> Alzheimer's Society [Online] Available at: <https://www.dementiafriends.org.uk> (Accessed 17 May 2014)

## 6.5 Recommendations on increasing public awareness and understanding of dementia in the North East

- National awareness campaigns are providing a spring board for raising awareness in the region. North East organisations should continue to capitalise on national initiatives and consider how to evaluate their success. They should also consider what other awareness raising activities are taking place outside of these campaigns.
- There are more than 4,000 Dementia Friends in the North East. The North East Dementia Alliance and partners should work with the Alzheimer's Society to increase the number of Dementia Friends and see how they can be used to increase awareness of dementia and contribute to improved quality of life for people living with dementia in the region.
- There is an emerging drive to consider the impact of good general health on the prevention of dementia. Locally, this has been highlighted in Joint Strategic Needs Assessments. Any emerging evidence needs to be collated and shared with regional stakeholders and embedded in any awareness campaign and prevention strategies.

## 7. Identification, referral and timely diagnosis

### Key points:

- Good-quality early diagnosis and intervention for all is Objective 2 of the National Dementia Strategy, while Commitment 1 of the Prime Minister’s Challenge on Dementia is *“increased diagnosis rates through regular checks for over-65s”*
- There is a national ambition to achieve a two thirds diagnosis rate by 2015
- The importance of diagnosis is reflected in its frequent inclusion in local plans (e.g. diagnosis is mentioned in some form in the commissioning intentions of all CCGs in the North East and all local joint dementia plans)
- Some structures are in place to help improve the identification, referral and diagnosis of people with dementia in the North East, such as:
  - NHS Health Check programme
  - The GP Enhanced Services for facilitating timely diagnosis and support for people with dementia
  - The National Commissioning for Quality and Innovation (CQUIN) payment framework for finding people with dementia, assessing and investigating their symptoms and referring for support
- The North East has a good provision of memory services covering all localities within the region
- The average diagnosis rate for the North East (54%) is higher than the national average for England (48%); however, only one locality in the North East has achieved the ambition of a two thirds diagnosis rate

This section of the report will consider key issues relating to the identification, referral and diagnosis of people living with dementia. In particular this section of the report will outline:

- The policy context
- How the identification, referral and timely diagnosis of people with dementia has been included in local plans
- How national initiatives to improve the identification, referral and timely diagnosis of people with dementia have been implemented in the North East
- Examples of work undertaken to support the identification, referral and timely diagnosis of people with dementia in the North East



- Conclusions and recommendations on the identification, referral and timely diagnosis of people with dementia in the North East

Increasing awareness of dementia is a vital part of improving diagnosis rates. It is therefore useful to read this section in conjunction with section 6 of this report, which is about increasing public awareness and understanding of dementia.

## 7.1 Policy context

Outlined below is the policy context specific to the identification, referral and timely diagnosis of people with dementia. This should be read in conjunction with the more general policy review in section 3 of this report and the policy review in section 8, which relates to the provision of information and support at the time of a diagnosis.

### National Dementia Strategy

Objective 2 of the National Dementia Strategy highlights the need for:

*“All people with dementia to have access to a pathway of care that delivers: a rapid and competent specialist assessment; an accurate diagnosis, sensitively communicated to the person with dementia and their carers; and treatment, care and support provided as needed following diagnosis. The system needs to have the capacity to see all new cases of dementia in the area”.*<sup>93</sup>

### Prime Minister’s Challenge on Dementia

Commitment 1 of the Prime Minister’s Challenge on Dementia outlines an aim of having *“increased diagnosis rates through regular checks for over-65s”*. This will be achieved by ensuring *“GPs and other health professionals make patients aged 65 and older aware of memory clinics and refer those in need of assessment”*.<sup>94</sup>

The Prime Minister’s Challenge states that clinical commissioning groups and local health and wellbeing boards should be encouraged to work with wider local partners to improve diagnosis rates. The Prime Minister’s Challenge also sets out the need for incentives to improve diagnosis rates by including a new indicator in the NHS Outcomes Framework 2013/14.

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<sup>93</sup> Department of Health (2009) Living well with dementia: a National Dementia Strategy. London: Department of Health p.11

<sup>94</sup> Department of Health (2012) Prime Minister’s Challenge on Dementia: Delivering major improvements in dementia care and research by 2015. Department of Health: London p.8

## The Mandate: A mandate from the Government to NHS England: April 2014 to March 2015

The NHS Mandate outlines what the NHS will deliver. As part of its aim to improve the quality of life for people with long-term conditions the NHS mandate for 2014/15 says that “*NHS England have agreed a national ambition for diagnosis rates that by 2015 two-thirds of the estimated number of people with dementia in England should have a diagnosis, with post diagnosis support*”.<sup>95</sup>

## NHS Outcomes Framework 2014/15 and Public Health Outcome Framework 2013/16

The NHS outcomes frameworks highlighted diagnosis rates as an improvement area and an outcome indicator.

‘Estimated diagnosis rate for people with dementia’ has been identified as an improvement area within the NHS Outcomes Framework 2014/15 (2.6 i).<sup>96</sup>

‘Estimated diagnosis rate for people with dementia’ is also an indicator within the Public Health Outcome Framework 2013/16 (4.16).<sup>97</sup>

## Unlocking Diagnosis: The key to improving the lives of people with dementia. All-Party Parliamentary Group report 2012

‘*Unlocking Diagnosis: The key to improving the lives of people with dementia*’,<sup>98</sup> published in 2012, details the findings of the All Party Parliamentary Group on Dementia’s inquiry into improving the diagnosis rate for dementia across the UK. To improve diagnosis rates the report recommended:

- Investment in a sustained public dementia awareness campaign

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<sup>95</sup> Department of Health (2013) The Mandate: A mandate from the Government to NHS England: April 2014 to March 2015 [Online] Available at: [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/256406/Mandate\\_14\\_15.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/256406/Mandate_14_15.pdf) (Accessed 17 May 2014) p.13

<sup>96</sup> Department of Health (2013) NHS Outcomes Framework 2014/15 [Online] Available at: <https://www.gov.uk/government/publications/nhs-outcomes-framework-2014-to-2015> (Accessed 17 May 2014)

<sup>97</sup> Department of Health (2012) Public Health Outcomes Framework 2013-16 [Online] Available at: <https://www.gov.uk/government/publications/healthy-lives-healthy-people-improving-outcomes-and-supporting-transparency> (Accessed 17 May 2014)

<sup>98</sup> All-Party Parliamentary Group on Dementia (2012) *Unlocking Diagnosis: The key to improving the lives of people with dementia* [Online] Available at: [https://alzheimers.org.uk/site/scripts/download\\_info.php?downloadID=873](https://alzheimers.org.uk/site/scripts/download_info.php?downloadID=873) (Accessed 17 May 2014)

- A quantified ambition that increases the percentage of people with dementia who have a formal diagnosis should be embedded in the NHS and used to lever change
- Public health directors across the UK should make early dementia diagnosis a priority
- Primary care workers and other health and social care professionals in contact with people in groups with an established risk of dementia should routinely ask questions to identify symptoms of dementia
- UK-wide, all health and social care professionals working in a general capacity with people at risk of dementia should have pre- and post-registration training in identifying and understanding dementia
- Issues with the assessment tools used by UK GPs and other primary care professionals should be explored and addressed
- Across the UK, commissioners should invest in appropriate memory service resources to cater to the needs of their population
- Strengthen the role of the Memory Services National Accreditation Programme (MSNAP) UK-wide
- Adequate information and one-to-one support should be provided to patients and their families immediately following diagnosis

## Dementia Prevalence Calculator

The Dementia Prevalence Calculator has been developed to allow communities to identify the prevalence of dementia within their area. It is anticipated that the Dementia Prevalence Calculator will allow communities to develop local plans and trajectories to improve their diagnosis rate.

The Dementia Prevalence Calculator is *“accessible to registered users including GP practice staff, CCGs, area and regional teams of NHS England and other approved stakeholder organisations”*.<sup>99</sup>

To access the Dementia Prevalence Calculator visit

<http://dementiapartnerships.com/diagnosis/dementia-prevalence-calculator/>

Version three of the calculator was issued in spring 2014. In September 2014 it is expected that, as a result of recent research, the prevalence figures will be re calculated. It is expected there will be a very marginal drop in prevalence.

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<sup>99</sup> Dementia Partnerships (2014) Dementia: Improving Timely Diagnosis: Introduction to the Dementia Prevalence Calculator v3 [Online] Available at: <http://dementiapartnerships.com/wp-content/uploads/sites/2/DPC-introduction-v4.pdf> (Accessed 17 May 2014) p.5

## 7.2 Local Plans

### Clinical Commissioning Groups

All the Clinical Commissioning Groups (CCGs) have committed themselves to achieving the national objective of improving diagnosis rates and implementing the National Dementia Strategy. Newcastle West is the only CCG to commit to a defined increase in dementia diagnosis of 5%, though Darlington, North Durham and DDES CCGs say that they will monitor observed prevalence rates of dementia as a success measure. Gateshead, South Tyneside and Sunderland all say that they will examine the possibility of using magnetic resonance imaging (MRI) to improve dementia diagnosis rates. Northumberland CCG mentions commissioning a dementia assessment service for housebound patients.

Out of the 12 CCG plans in the North East, five specifically mention improvements in memory services.

### Joint Strategic Needs Assessments

A number of Joint Strategic Needs Assessments (JSNAs) in the North East reference the need to increase diagnosis rates and the importance of providing people with the opportunity to receive an timely diagnosis. These include:

- North Tyneside, which highlights the need to consider addressing low diagnosis rates<sup>100</sup>
- South Tyneside, which emphasises the need to progress early diagnosis<sup>101</sup> and identifies how the introduction of memory clinics have already had a positive impact on the rates of early diagnosis<sup>102</sup>
- Sunderland, which outlines the need to use diagnosis rates as an outcome measure<sup>103</sup>

### Health and Wellbeing Strategies

A number of Health and Wellbeing Strategies reference diagnosis for people with dementia.

Two Health and Wellbeing Strategies indicate a commitment to improving diagnosis, these were:

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<sup>100</sup> North Tyneside Council (2013) North Tyneside Joint Strategic Needs Assessment 2013 [Online] Available at: [http://www.northtyneside.gov.uk/pls/portal/NTC\\_PSCM.PSCM\\_Web.download?p\\_ID=550377](http://www.northtyneside.gov.uk/pls/portal/NTC_PSCM.PSCM_Web.download?p_ID=550377) (Accessed 17 May 2014) p.4

<sup>101</sup> South Tyneside Health and Wellbeing Board (2012) Joint Strategic Needs Assessment 2012-13 [Online] Available at: <http://www.southtyneside.info/CHttpHandler.ashx?id=16681&p=0> (Accessed 17 May 2014) p.63

<sup>102</sup> South Tyneside Health and Wellbeing Board (2012) Joint Strategic Needs Assessment 2012-13 [Online] Available at: <http://www.southtyneside.info/CHttpHandler.ashx?id=16681&p=0> (Accessed 17 May 2014) p.6

<sup>103</sup> Sunderland Joint Strategic Needs Assessment [Online] Available at: <http://www.sunderland.gov.uk/index.aspx?articleid=6789> (Accessed 17 May 2014) p. 21

- North Tyneside, which outlines a commitment to implementing its Dementia Strategy to ensure early diagnosis and quality care<sup>104</sup>
- South Tyneside, which outlines the need to increase identification of people with dementia as one of its key recommendations<sup>105</sup>

Three Health and Wellbeing Strategies stated they would use diagnosis rates as an outcome measure; these are the Health and Wellbeing Strategies for Gateshead<sup>106</sup>, Durham<sup>107</sup> and Hartlepool.<sup>108</sup>

## Local joint dementia plans

The most frequent actions in relation to timely diagnosis in the local joint dementia plans relate to the provision of the right information to both public and professionals and the need to develop or review pathways. Four out of the 10 plans highlight actions relating to case finding. Other areas for action include ensuring that coding in records was correct and that memory services were appropriately commissioned by having the right specifications and correct capacity.

## 7.3 Identification and referral – The implementation of national initiatives in the North East

Outlined below are details of the number of national initiatives which have been implemented in the North East. These initiatives contribute to the identification of people with dementia and support the referral of people so that they can receive a timely diagnosis. The initiatives addressed in this section are:

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<sup>104</sup> North Tyneside Council (2013) North Tyneside Joint Health and Wellbeing Strategy 2013-23 [Online] Available at: [http://www.northtyneside.gov.uk/pls/portal/NTC\\_PSCM.PSCM\\_Web.download?p\\_ID=547453](http://www.northtyneside.gov.uk/pls/portal/NTC_PSCM.PSCM_Web.download?p_ID=547453) (Accessed 17 May 2014) p.28

<sup>105</sup> South Tyneside Health and Wellbeing Board (2013) Our Better Health and Wellbeing Strategy 2013-16 [Online] Available at: <http://www.southtyneside.info/CHttpHandler.ashx?id=21002&p=0> (Accessed 17 May 2014) p.10

<sup>106</sup> Gateshead Health and Wellbeing Board (2013) Active, Healthy and Well Gateshead: A Health & Wellbeing Strategy for Gateshead (2013/14 to 2015/16) [Online] Available at: <http://www.gateshead.gov.uk/DocumentLibrary/CBS/health/Active-Healthy-and-Well-Gateshead.pdf> (Accessed 17 May 2014) p.31

<sup>107</sup> County Durham Health and Wellbeing Board (2014) County Durham Joint Health and Wellbeing Strategy 2014-2017 [Online] Available at: <http://www.durham.gov.uk/Pages/Service.aspx?ServiceId=8873> (Accessed 17 May 2014) p.17

<sup>108</sup> Hartlepool Shadow Health and Wellbeing Board (2012) Hartlepool Health and Wellbeing Strategy 2013-18 [Online] Available at: <http://www.teesjsna.org.uk/images/ckfiles/files/Core%20Strategies/Hartlepool%20H%26WB%20strategy%2013-18.pdf> (Accessed 17 May 2014) p.15

- The NHS Health Checks programme
- The GP Enhanced Services for facilitating timely diagnosis and support for people with dementia
- The Commissioning for Quality and Innovation payment framework for finding people with dementia, assessing and investigating their symptoms and referring for support

## NHS Health Check programme

The NHS Health Check programme aims to help prevent heart disease, stroke, diabetes, kidney disease and certain types of dementia. Everyone between the ages of 40 and 74 (who has not already been diagnosed with one of these conditions or does not have certain risk factors) will be invited to have a check once every five years. The check will be used to assess a person's risk of heart disease, stroke, kidney disease and diabetes and they will be given support and advice to help them reduce or manage that risk.<sup>109</sup> From April 2013 dementia awareness has been included within the NHS Health Check programme. This is targeted at people in the 65-74 age group and includes sign-posting to local dementia services and memory services as appropriate.

There are currently no statistics relating to the number of people who have been signposted in the North East as a result of the NHS Health Check programme as the approaches to the dementia component of the Health Check vary between localities.

For further information about the NHS Health Check programme see <http://www.healthcheck.nhs.uk/> or contact [Beverley.oliver@phe.gov.uk](mailto:Beverley.oliver@phe.gov.uk)

## GP Enhanced Services – Facilitation of timely diagnosis and support of people with dementia

The NHS Commissioning Board included the 'facilitation of a timely diagnosis and support of people with dementia' as an Enhanced Service for 2013/14. GP practices which sign up to deliver this service will receive additional payments for taking a proactive approach to the assessment of at-risk patients who may be showing the early signs of dementia.<sup>110</sup>

The aims of this Enhanced Service are to:

- Identify patients at clinical risk of dementia
- Offer an assessment to detect for possible signs of dementia in those at risk
- Offer a referral for diagnosis where dementia is suspected

<sup>109</sup> For further information see <http://www.healthcheck.nhs.uk/>

<sup>110</sup> NHS Commissioning Board (2013) Enhanced Service Specification: Facilitating timely diagnosis and support for people with dementia [Online] Available at: <http://www.england.nhs.uk/wp-content/uploads/2013/03/ess-dementia.pdf> (Accessed 17 May 2014)

- Support the health and wellbeing of carers for patients diagnosed with dementia

Table 5 shows the percentage of GP practices within each CCG area that have signed up for enhanced services.

CCG area	Percentage of practices within CCG area that have signed up for enhanced services
Darlington	100%
Durham Dales, Easington and Sedgefield	98%
Gateshead	85%
Hartlepool and Stockton	75%
Newcastle North East	94%
Newcastle West	89%
North Durham	100%
North Tyneside	97%
Northumberland	87%
South Tees	84%
South Tyneside	82%
Sunderland	96%

**Table 5:** The percentage of GP practices within each CCG area that have signed up for enhanced services. Source: Northern England Strategic Clinical Networks (2014) SCN Dementia Intelligence Report (Unpublished)

This enhanced service has been renewed for 2014/15.<sup>111</sup>

<sup>111</sup> NHS Employers (2014) General Medical Services Contract 2014/15: Guidance and audit requirements [Online] Available at: <http://www.nhsemployers.org/~media/Employers/Publications/PCC/GMS/GMS%20contract%20guidance%20and%20audit%20requirements%202014-15.pdf> (Accessed 17 May 2014)

## Commissioning for Quality and Innovation

The Commissioning for Quality and Innovation (CQUIN) payment framework enables commissioners to reward high quality or innovative services, by making a proportion of English healthcare providers' income conditional on demonstrating improvements in quality and innovation in specified areas of care.<sup>112</sup>

### **Dementia Assessment and Referral CQUIN 2013/14**

One of the four national CQUIN goals for 2013/14 was “*improving dementia care, including sustained improvement in Finding people with dementia, Assessing and Investigating their symptoms and Referring for support (FAIR)*”.<sup>113</sup> This CQUIN applies to acute foundation trusts.

Payment for the Dementia Assessment and Referral CQUIN for 2013/14 is triggered by meeting the threshold of at least 90 % in each of the three stages (identification, diagnosis and referral) in any three consecutive months in the first year. Payment is divided equally between the three stages or steps.

Table 6 outlines:

- The proportion of patients aged 75 and over admitted as an emergency to an acute trust for more than 72 hours, who were assessed for known dementia, delirium and asked the case finding question to identify those who potentially have dementia (step 1)
- Those without a known diagnosis of dementia, who either had delirium or responded yes to the case finding question, who went on to have a further assessment and investigation of possible dementia (step 2)
- Percentage of those who screened positively or inconclusively for possible dementia in step 2, who were either referred back to their GP for further review or referred directly to specialist services (step 3)

The data relates to the acute foundation trusts in the North East between October and December 2013.

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<sup>112</sup> NHS England (2013) Everyone Counts: Planning for Patients 2014/15 - 2018/19 [Online] Available at: <http://www.england.nhs.uk/wp-content/uploads/2013/12/5yr-strat-plann-guid-wa.pdf> (Accessed 17 May 2014)

<sup>113</sup> Department of Health (2013) Commissioning for Quality and Innovation (CQUIN): 2013/14 guidance [Online] Available at: <http://www.england.nhs.uk/wp-content/uploads/2013/02/cquin-guidance.pdf> (Accessed 17 May 2014) p.22



Organisation name	Step 1	Step 2	Step 3
CITY HOSPITALS SUNDERLAND NHS FOUNDATION TRUST	99.86%	100.00%	100.00%
COUNTY DURHAM AND DARLINGTON NHS FOUNDATION TRUST	90.03%	95.33%	92.86%
GATESHEAD HEALTH NHS FOUNDATION TRUST	93.13%	93.98%	98.46%
NORTH TEES AND HARTLEPOOL NHS FOUNDATION TRUST	91.31%	99.58%	97.92%
NORTHUMBRIA HEALTHCARE NHS FOUNDATION TRUST	94.92%	82.38%	100.00%
SOUTH TEES HOSPITALS NHS FOUNDATION TRUST	93.22%	93.58%	92.86%
SOUTH TYNESIDE NHS FOUNDATION TRUST	85.61%	33.13%	100.00%
THE NEWCASTLE UPON TYNE HOSPITALS NHS FOUNDATION TRUST	90.45%	96.79%	97.87%

**Table 6:** Dementia Assessment and Referral data collection – Quarter 3 – 2013/14. Source: <http://www.england.nhs.uk/statistics/statistical-work-areas/dementia/>

**Step 1 - Identification** - Between October and December 2013, for patients aged 75 or over admitted as an emergency for more than 72 hours, 87.5% of acute trusts in the North East completed step 1 in 90% or more of patients. This compares well to the England average, where this level of identification was achieved in 62% of acute trusts.

**Step 2 - Assess and Investigate** - Six of the eight (75%) acute NHS foundation trusts in the North East, compared to 69% of NHS foundation trusts across England, reported that 90% or more of the patients requiring step 2, between October and December 2013, had this completed.

**Step 3 - Referral** - Eight of the eight (100%) North East NHS foundation trusts reported that 90% or more of the emergency admissions requiring step 3 had this completed, between October and December 2013, compared to 71% of NHS foundation trusts across England.

While these statistics reflect positively on the North East it is important to note the data in Table 6 relates only to quarter 3 of 2013/14. Data for the fourth quarter of 2013/14 was not available at the time this report was being produced and therefore any comparison to the national picture would benefit from a longer timescale.

It is also unclear from this data alone what affect (if any) the CQUIN has on the diagnosis rates in the North East.

### **Dementia and Delirium CQUIN 2014/15**

*Everyone Counts: Planning for Patients 2014/15 to 2018/19* states that a dementia CQUIN scheme will be in place for 2014/15.

One of the four national improvement goals for the 2014/15 CQUIN scheme is “*improving dementia and delirium care, including sustained improvement in Finding people with dementia, Assessing and Investigating their symptoms and Referring for support (FAIR)*”.

For further information on the 2014/15 CQUIN scheme see ‘*Commissioning for quality and innovation (CQUIN): 2014/15 guidance*’.<sup>114</sup>

## **7.4 Timely diagnosis**

Outlined below are details relating to:

- The diagnosis rates in the North East
- Memory services in the North East
- Work to improve access to timely diagnosis in the North East

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<sup>114</sup> Department of Health (2013) Commissioning for Quality and Innovation (CQUIN): 2013/14 guidance [Online] Available at: <http://www.england.nhs.uk/wp-content/uploads/2013/02/cquin-guidance.pdf> (Accessed 17 May 2014)

## Diagnosis rates in the North East

The ambition of NHS England is that by 2015 two-thirds of people estimated to have dementia should have a diagnosis.<sup>115</sup> In 2013 less than half of those estimated to have dementia in England (48%) had a formal diagnosis.<sup>116</sup>

In the North East as of 2013:

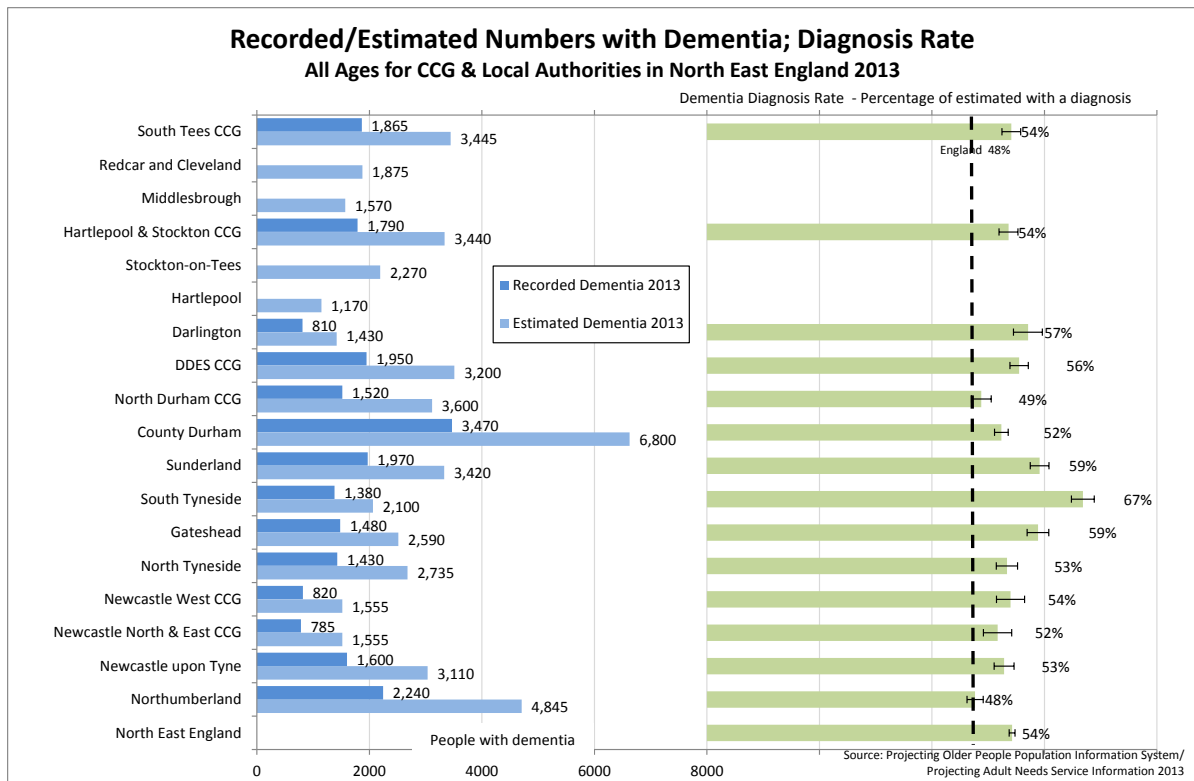
- Around 54% of people with dementia had a formal diagnosis for their condition. This was a higher diagnosis rate than the diagnosis rate for England as a whole
- Approximately 15,875 individuals in the region had dementia, but had no formal diagnosis
- South Tyneside was the only locality in North East England that achieved the ambition of a two-thirds dementia diagnosis rate (67% diagnosis rate)
- Across North East England the dementia diagnosis rate ranged from 48% (Northumberland) to 67% (South Tyneside)
- The diagnosis rate in all local areas was above the rate for England (48%), except in Northumberland (48%)

This information is shown in Figure 5.

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<sup>115</sup> Department of Health (2013) Dementia: A state of the nation report on dementia care and support in England [Online] available at: [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/262139/Dementia.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/262139/Dementia.pdf) (Accessed 17 May 2014) p.10

<sup>116</sup> Projecting Older People Population Information System/Projecting Adult Needs Service Information [Online] available at: <http://www.poppi.org.uk/> and <http://www.pansi.org.uk/>



**Figure 5:** Recorded/Estimated Numbers with Dementia; Diagnosis Rate: All Ages for CCG & Local Authorities in North East England 2013: Source Projecting Older People Population Information System/Projecting Adult Needs Service Information in 2013

## Memory services

Memory services play a key role in ensuring that people with dementia receive a diagnosis.

According to the Royal College of Psychiatrists “A *memory clinic/service* is defined as a multidisciplinary team (either NHS or private) that assesses and diagnoses dementia, and may provide psychosocial interventions for dementia. This can include Community Mental Health Teams for Older People”.<sup>117</sup>

## Memory Services National Accreditation Programme

The Memory Services National Accreditation Programme (MSNAP) is an initiative of the Royal College of Psychiatrist’s College Centre for Quality Improvement and was established in June 2009. MSNAP assess the standards of memory services for people with dementia and provides those

<sup>117</sup>Royal College of Psychiatrists (2013) English National Memory Services Audit Report. London: Royal College of Psychiatrists p.10

services that meet the necessary standards with accreditation from the Royal College of Psychiatrists.<sup>118</sup>

Accreditation is intended to assure staff, service users and carers, commissioners and regulators of the quality of the service being provided.

*'The Prime Minister's Challenge on Dementia: Delivering major improvements in dementia care and research by 2015: Annual report of progress'* sets out an intention to "promote the widespread implementation of useful interventions through national quality networks such as the Memory Services National Accreditation Programme (MSNAP). Increasing the number of memory services participating in MSNAP will lead to faster diagnosis and higher quality services".<sup>119</sup>

### **English National Memory Services Audit**

Between July and September 2013 the Royal College of Psychiatrists conducted an audit of 178 of the 214 memory clinics in England. The findings of this audit were released in November 2013.<sup>120</sup>

As part of the audit the Royal College of Psychiatrists produced an interactive map displaying waiting times, research involvement and MSNAP membership.

The interactive map can be accessed at: [www.rcpsych.ac.uk/memoryclinicsaudit](http://www.rcpsych.ac.uk/memoryclinicsaudit)

### **Memory services in the North East**

There are 14 memory services in the North East; these are shown in Table 7. Ten memory services are provided by Tees, Esk and Wear Valleys NHS Foundation Trust; three services are operated by Northumberland, Tyne and Wear NHS Foundation Trust and one by Northumbria Healthcare NHS Foundation Trust.

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<sup>118</sup> Royal College of Psychiatrists (2009) Memory Service National Accreditation Programme (MSNAP) Newsletter: Issue 1 [Online] Available at:

<http://www.rcpsych.ac.uk/PDF/MSNAP%20newsletter%20Dec%202009.pdf> (Accessed 17 May 2014)

<sup>119</sup> Department of Health (2013) Prime Minister's Challenge on Dementia: Delivering major improvements in dementia care and research by 2015: Annual report of progress [Online] Available at:

<https://www.gov.uk/government/publications/the-prime-ministers-challenge-on-dementia-annual-report-of-progress> (Accessed 17 May 2014) p.35

<sup>120</sup> Royal College of Psychiatrists (2013) English National Memory Services Audit Report. London: Royal College of Psychiatrists

Memory Services	Areas covered	Provider
<b>Darlington Community Mental Health Team</b>	Darlington	Tees, Esk and Wear Valleys NHS Foundation Trust
<b>Derwentside Community Mental Health Team</b>	Derwentside	Tees, Esk and Wear Valleys NHS Foundation Trust
<b>Durham and CLS Community Mental Health Team</b>	Durham and Chester le Street, County Durham	Tees, Esk and Wear Valleys NHS Foundation Trust
<b>Durham Dales Community Mental Health Team</b>	Durham Dales (in line with local authority and clinical commissioning group)	Tees, Esk and Wear Valleys NHS Foundation Trust
<b>Easington Community Mental Health Team</b>	Sedgefield	Tees, Esk and Wear Valleys NHS Foundation Trust
<b>Hartlepool Community Mental Health Team</b>	Hartlepool	Tees, Esk and Wear Valleys NHS Foundation Trust
<b>Lustrum Vale Memory Clinic</b>	Stockton-on-Tees	Tees, Esk and Wear Valleys NHS Foundation Trust
<b>Middlesbrough Community Mental Health Team</b>	Middlesbrough	Tees, Esk and Wear Valleys NHS Foundation Trust
<b>Newcastle Memory Assessment and Management Service</b>	Newcastle and West North Tyneside	Northumberland, Tyne and Wear NHS Foundation Trust
<b>North Shields Memory Clinic</b>	North Tyneside	Northumbria Healthcare NHS Foundation Trust
<b>Northumberland Planned Care Group</b>	Northumberland	Northumberland, Tyne and Wear NHS Foundation Trust
<b>Northumberland Tyne and Wear NHS Trust - Memory Protection Service</b>	Sunderland, South Tyneside and Gateshead	Northumberland, Tyne and Wear NHS Foundation Trust
<b>Redcar and Cleveland Community Mental Health Team</b>	Redcar and Cleveland	Tees, Esk and Wear Valleys NHS Foundation Trust
<b>Sedgefield Community Mental Health Team</b>	Sedgefield, Spennymoor, Ferryhill, Trimdon, Newton Aycliffe & Shildon	Tees, Esk and Wear Valleys NHS Foundation Trust

**Table 7:** Memory services in the North East with areas covered and providers. Source: Royal College of Psychiatrists (2013) English National Memory Services Audit Report. London: Royal College of Psychiatrists with additional information from providers in the North East

The Memory Service National Accreditation Programme (MSNAP) recommends that memory services should provide an assessment within six weeks of referral.<sup>121</sup> All but one of the memory services in the North East achieves this target. Eleven of the 14 memory services in the North East reported an average waiting time of three weeks or less from referral to assessment. Only the Newcastle Memory Assessment and Management Service failed to achieve the MSNAP recommendation of six weeks with the average reported waiting time for the service being 14 weeks.

The average waiting period between assessment and diagnosis for memory services in the North East is seven weeks; however, there are large disparities between services. The shortest waiting period between assessment and diagnosis in the North East was three weeks (Lustrum Vale Memory Clinic and Northumberland Planned Care Group) while the longest period is 18 weeks (Newcastle Memory Assessment and Management Service).

Table 8 outlines the waiting time between referral and assessment, the waiting time between assessment and diagnosis, whether the service offers home assessments and whether the service is registered with the Memory Services National Accreditation Programme. The information in the table is from the English National Memory Services Audit, with additional data from the service Northumberland, Tyne and Wear NHS Foundation Trust.

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<sup>121</sup> Royal College of Psychiatrists' Centre for Quality Improvement (2014) Memory Services National Accreditation Programme (MSNAP) Standards for Memory Services: Fourth Edition. Editors Hodge, S. Hailey, E. and Orrell, M. [Online] Available at: <http://www.rcpsych.ac.uk/PDF/MSNAP%20Standards%20Fourth%20Edition%202014r.pdf> (Accessed 17 May 2014) p.21 and Indicator 3 p. 48

	Waiting time for assessment (weeks)	Waiting time for diagnosis (weeks)	Home assessments	Memory services accreditation
<b>Darlington Community Mental Health Team</b>	1	7	Yes	No
<b>Derwentside Community Mental Health Team</b>	3	8	Yes	No
<b>Durham and CLS Community Mental Health Team</b>	3	9	Yes	No
<b>Durham Dales Community Mental Health Team</b>	1	6	Yes	No
<b>Easington Community Mental Health Team</b>	3	9	Yes	No
<b>Hartlepool Community Mental Health Team</b>	1	6	Yes	No
<b>Lustrum Vale Memory Clinic</b>	1	3	Yes	No
<b>Middlesbrough Community Mental Health Team</b>	3	5	Yes	No
<b>Newcastle Memory Assessment and Management Service</b>	14	18	Yes	Yes <sup>122</sup>
<b>Northumberland Planned Care Group</b>	3.5	3	Yes	No
<b>Northumberland Tyne and Wear NHS Trust - Memory Protection Service</b>	4	6	Yes	Yes <sup>123</sup>
<b>North Shields Memory Clinic</b>	4	6	No	Yes
<b>Redcar and Cleveland Community Mental Health Team</b>	2	4	Yes	No
<b>Sedgefield Community Mental Health Team</b>	2	11	Yes	No

**Table 8:** Memory services in the North East with information regarding waiting times, home assessments and accreditation with the Memory Services National Accreditation Programme. Source: Royal College of Psychiatrists (2013) English National Memory Services Audit Report. London: Royal College of Psychiatrists with additional information from providers in the North East

<sup>122</sup> Accredited with Psychosocial Interventions

<sup>123</sup> Accredited after the national audit with excellence and Psychosocial Interventions



\* The Northumberland, Tyne and Wear Planned Care Community Group also has additional Older Person's Community Mental Health Teams in South Tyneside, Sunderland, Newcastle and North Tyneside which also provide dementia diagnosis complex assessment and on-going case support.

## Work to improve access to timely diagnosis in the North East

### **North East Association of Directors for Adult Social Services - Dementia Themed Network**

The North East Association of Directors for Adult Social Services (NE ADASS) Dementia Themed Network has a series of work streams, one of which is based on improving the diagnosis process for people with dementia. In May 2014 the NE ADASS Dementia Themed Network conducted a survey with appropriate individuals from each locality in the North East. The survey identified what services and initiatives are currently in place across the region and the findings will be used to identify what interventions may help to improve diagnosis for people with dementia across the North East.

### **Public Health**

As of May 2014 Public Health England's Knowledge and Intelligence Team Northern and Yorkshire was undertaking research to evaluate the capacity for new assessments in memory services in the North East. This research will be used to determine whether memory services have sufficient capacity to meet the diagnosis gap.

For further information contact [Michael.Jackson@phe.gov.uk](mailto:Michael.Jackson@phe.gov.uk)

### **Speeding up the diagnosis process in North Tees**

To minimise delays in the diagnosis process the Old Age Psychiatry Services at Lustrum Vale in Stockton have negotiated a contract with South Tees Radiology Department. The arrangement will allow patients to receive a CT scan at South Tees Radiology Department during any working day without appointment. This arrangement is intended to avoid delays that result from sending requests or waiting for appointments.

To further reduce delays the Old Age Psychiatry Teams in the North Tees area are able to access the results of CT scans electronically so there is no need to wait for a postal copy.

For further information contact Dr M Santhana Krishnan FRCPsych, via Lustrum Vale, on 01642 358593

## 7.5 Conclusions on identification, referral and timely diagnosis in the North East

There is a national ambition that, by 2015, two thirds of people with dementia should have received a diagnosis. As of 2013, the diagnosis rate in the North East was 54%: higher than the rate for England as a whole (48%).

The drive to improve diagnosis rates appears consistently across North East CCGs priorities and other plans.

There are a number of nationally developed systems to support increased identification, referral and diagnosis. These initiatives are being implemented in the North East and include Health Checks, Enhanced Service contracts for GPs (Facilitation of timely diagnosis and support of people with dementia) and the national dementia CQUIN. At the time of writing the report little information was available regarding the impact of Health Checks or the GP Enhanced Service. There are also only limited indicators regarding the success the CQUIN scheme (i.e. the percentage of patients identified, diagnosed and referred).

Fourteen memory services cover the whole geography in the North East however there are variations between the services in terms of waiting times and diagnosis rates. Further work is planned for spring 2014 to evaluate the performance of memory services in the North East and their capacity to close the diagnosis gap in the region. This work will be undertaken by Public Health England.

## 7.6 Recommendations on identification, referral and timely diagnosis in the North East

- The average North East diagnosis rate at 2013 was 54%. In September 2014, on release of the national revised dementia prevalence figures, partners in the North East will need to recalculate the diagnosis rate and develop plans to achieve the ambition of a two-thirds diagnosis rate.
- There needs to be continued work towards achieving a two-thirds diagnosis rate across the North East. This work could be supported by learning from South Tyneside, which has already achieved a two-thirds diagnosis rate and other areas, including Scotland, where dementia diagnosis rates are high.
- A number of key groups in the North East have timely diagnosis as a priority work area. The Mental Health, Dementia and Neurological Conditions Strategic Clinical Network, ADASS and the North East Dementia Alliance need to ensure their plans complement each other, with the overall objective of improved care for people with dementia.

- Information about the GP enhanced services is due in the autumn 2014. As information about the outputs and outcomes from the health checks and GP enhanced service emerges any learning needs to be used to bring about change.
- Work is planned to assess efficiency of the memory services in the North East and their capacity to close the dementia diagnosis gap. The Clinical Network for Mental Health, Dementia and Neurological Conditions needs to consider any recommendations and take appropriate action.
- There is little information about the quality of the diagnosis experience from the perspective of the person with dementia and their carer. There is a need to explore any information available in order to ensure that work around diagnosis is not limited to just quantitative measurements of diagnosis rates, but also includes work on improving the quality of the experience.

## 8. Post diagnosis information and support

### Key points:

- The National Dementia Strategy includes the following objectives:
  - o Good-quality information for those diagnosed with dementia and their carers (Objective 3 )
  - o Enabling easy access to care, support and advice following diagnosis (Objective 4)
  - o Development of structured peer support and learning networks (Objective 5)
- All 10 local joint dementia plans make reference to the provision of information and support at the time of diagnosis
- Following a diagnosis, 12 out of the 14 memory services in the North East offer Cognitive Stimulation Therapy
- There are advice and support services available in most localities across the North East; however, there is no evidence to assess the effectiveness of the information and support service in terms of accessibility or outcome
- Many of the services offering post-diagnosis support are provided by third sector organisations
- Data from 2011 suggests that the prescribing of anti-dementia medication in the North East was at a lower level than the national average. However, data from 2013 shows that, where appropriate, all 14 memory services in the North East initiate the use of anti-dementia medication following a diagnosis

This section of the report will consider key issues relating to the provision of post diagnosis information and support. In particular this section of the report will outline:

- The policy context
- How post diagnosis information and support has been included in local plans
- Examples of work undertaken in the North East to improve post diagnostic information and support
- Examples of work to improve the prescribing of anti-dementia drugs in the North East
- Conclusions and recommendations on the provision of post diagnosis information and support in the North East

## 8.1 Policy context

Outlined below is the policy context specific to the provision of post diagnosis information and support. This should be read in conjunction with the more general policy review in section 3 of this report.

### National Dementia Strategy

Objective 3 of the National Dementia Strategy includes *“providing people with dementia and their carers with good-quality information on the illness and on the services available, both at diagnosis and throughout the course of their care”*.<sup>124</sup>

Objective 4 of the National Dementia Strategy highlights the importance of having *“a dementia adviser to facilitate easy access to appropriate care, support and advice for those diagnosed with dementia and their carers”*.<sup>125</sup>

Objective 5 of the National Dementia Strategy addresses the need for peer support networks and outlines how the *“establishment and maintenance of such networks will provide direct local peer support for people with dementia and their carers. It will also enable people with dementia and their carers to take an active role in the development and prioritisation of local services”*.<sup>126</sup>

### Prime Minister’s Challenge on Dementia

The Prime Minister’s Challenge on Dementia emphasises the importance of providing appropriate information and support at the time of diagnosis. Commitment 5 of the Prime Minister’s Challenge on Dementia outlines an aim of *“promoting local information on dementia services”*.

To support this aim, the Prime Minister’s Challenge on Dementia sets out an intention to *“promote the information offer pioneered by the NHS South West... [so that]... similar information will be available in all other parts of the country”*.<sup>127</sup>

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<sup>124</sup> Department of Health (2009) Living well with dementia: a National Dementia Strategy. London: Department of Health p.11

<sup>125</sup> Ibid

<sup>126</sup> Department of Health (2009) Living well with dementia: a National Dementia Strategy. London: Department of Health p.12

<sup>127</sup> Department of Health (2012) Prime Minister’s Challenge on Dementia: Delivering major improvements in dementia care and research by 2015. Department of Health: London p.6

## The Mandate: A mandate from the Government to NHS England: April 2014 to March 2015

As part of its aim to improve the quality of life for people with long-term conditions, the NHS mandate for 2014-15 outlines that “NHS England have agreed a national ambition for diagnosis rates that by 2015 two-thirds of the estimated number of people with dementia in England should have a diagnosis, with **post diagnosis support**”.<sup>128</sup>

## Improving Access to Psychological Therapies (IAPT)

The Improving Access to Psychological Therapies (IAPT) programme is a national initiative to provide NICE approved interventions to treat people with depression and anxiety disorders. The Prime Minister’s Challenge on Dementia states that the NHS should ensure that a range of psychological therapies are commissioned and made available to carers of people with dementia in line with NICE/SCIE guidelines.<sup>129</sup>

In 2012 there was a drive to work out what the specific access issues were for people living with dementia in regard to accessing NICE approved therapies.<sup>130</sup>

For further details about carers accessing psychological therapies see section 21 of this report.

## Healthbridge: the national evaluation of peer support networks and dementia advisers

In response to objectives 4 and 5 of the National Dementia Strategy, the Department of Health funded 40 Dementia Adviser and Peer Support demonstration sites; these were established across the country within a range of organisational settings for a period of two years from 2010.<sup>131</sup>

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<sup>128</sup> Department of Health (2013) The Mandate: A mandate from the Government to NHS England: April 2014 to March 2015 [Online] Available at: [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/256406/Mandate\\_14\\_15.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/256406/Mandate_14_15.pdf) (Accessed 17 May 2014) p.13

<sup>129</sup> Department of Health (2012) Prime Minister’s Challenge on Dementia: Delivering major improvements in dementia care and research by 2015. Department of Health: London p.9

<sup>130</sup> Department of Health (2011) Talking therapies: A four-year plan of action: *A supporting document to No health without mental health: A cross-government mental health outcomes strategy for people of all ages* [Online] Available at: <https://www.gov.uk/government/publications/talking-therapies-a-4-year-plan-of-action> (Accessed 17 May 2014) p.10

<sup>131</sup> Clarke, C.L. Keyes, S.E. Wilkinson, H.et al (2013) Healthbridge: The National Evaluation of Peer Support Networks and Dementia Advisers in implementation of the National Dementia Strategy for England[Online] Available at: <https://www.gov.uk/government/publications/peer-support-networks-and-dementia-advisers-evaluation> (Accessed 17 May 2014) p.5

In the North East the Department of Health funded Dementia Advisers in North Tyneside (employed by the Alzheimer's Society)<sup>132</sup> and Redcar & Cleveland (employed by Carers Together).

No Peer Support Networks were funded by the Department of Health in the North East.

The Department of Health commissioned a national evaluation of the Dementia Advisers and Peer Support Networks. The findings of this evaluation were published in October 2013 in the report *Healthbridge: the national evaluation of peer support networks and dementia advisers in implementation of the national dementia strategy for England*.<sup>133</sup> The evaluation found that:

- People with dementia and carers saw dementia advisers and peer support networks as having a positive impact on their wellbeing and quality of life
- Demonstrator sites provided evidence that both dementia advisers and peer support networks filled a gap in service provision that often occurs after diagnosis but before there is a need for more intensive support
- Both initiatives were seen as having resource saving implications for the local health and social care economy

## 8.2 Local plans

### Local joint dementia plans

All 10 local joint dementia plans make reference to the provision of post diagnosis information and support. The most frequent actions in this area relate to the provision of peer support networks (these are mentioned in seven out of 10 plans) with particular reference to the development of dementia cafés. Four plans highlight the role of dementia advisers. In addition one local joint dementia plan highlights the need to commission advocacy while another mentions the use of information prescriptions.

## 8.3 Examples of work in the North East to improve post diagnosis information and support

Outlined below are examples of work undertaken in the North East to improve post diagnostic information and support. These include:

- Psychological therapies
- Dementia advisers

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<sup>132</sup> This service as of May 2014 is provided by Northumberland Tyne and Wear NHS Foundation Trust

<sup>133</sup> Clarke, C.L. Keyes, S.E. Wilkinson, H. et al (2013) Healthbridge: The National Evaluation of Peer Support Networks and Dementia Advisers in implementation of the National Dementia Strategy for England[Online] Available at: <https://www.gov.uk/government/publications/peer-support-networks-and-dementia-advisers-evaluation> (Accessed 17 May 2014)

- Peer support groups
- Educative programmes
- Use of the Dementia Guide
- The development of the Live Well Dementia website
- Dementia GP Road Map

## Memory services and access to psychological therapies in the North East

The use of psychological therapies may, in some situations, provide an alternative means of treating some of the symptoms that might otherwise result in the use of pharmacological interventions (for further information about the use of antipsychotic medication see section 23 of this report). Psychological therapies may also help people who have dementia and family carers to deal with the experiences of dementia (for further information see section 21 of this report).

Therapies include:

**Cognitive Stimulation Therapy (CST)** - Where people with mild or moderate dementia are encouraged to take part in *“activities and exercises designed to improve ..... memory, problem-solving skills and language abilities”*.<sup>134</sup>

**Specialist post-diagnostic counselling** - The Royal College of Psychiatrists, in its memory clinics audit, states that specialist post-diagnostic counselling *“should be provided by a trained counsellor, for people who have rarer diagnoses or a particularly adverse reaction to the diagnosis”*.<sup>135</sup>

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<sup>134</sup> NHS Choices [Online] Available at: <http://www.nhs.uk/Conditions/dementia-guide/Pages/dementia-treatment.aspx> (Accessed 17 May 2014)

<sup>135</sup> Royal College of Psychiatrists (2013) English National Memory Services Audit Report. London: Royal College of Psychiatrists p.19



## Case study: Cognitive stimulation therapy at Derwent Clinic

The Derwent Clinic, provided by Tees, Esk and Wear Valleys (TEWV) NHS Foundation Trust, runs a Cognitive Stimulation Therapy group for people living with dementia.

The TEWV Dementia Pathway outlines the diagnosis process and what interventions to offer after this. It includes offering the person living with dementia a post diagnosis appointment within 10 working days. At this follow up appointment the person living with dementia is given the opportunity to attend a Cognitive Stimulation Therapy group.

The Cognitive Stimulation Therapy group runs 14 sessions over seven weeks. The group has up to eight patients at one session with two facilitators. Sessions are based on the evidence based group programmes outlined in *'Making a Difference: An Evidence-based Group Programme to Offer Cognitive Stimulation Therapy (CST) to People with Dementia'*.

Indications from the service provider are that they find people who have a moderate dementia benefit from this type of intervention better than other groups. People with mild dementia often feel that they are not ready to attend, or do not like attending, a group with more cognitively impaired patients.

For further details contact Joanne Bell, Mental Health Services Older Persons, Derwent Clinic, Shotley Bridge Hospital at [Joannebell@nhs.net](mailto:Joannebell@nhs.net)

Data from the English National Memory Services Audit shows that all memory services in the North East provide access to cognitive stimulation therapy except Northumberland Planned Care Group and the Memory Protection Services which operate in Sunderland, South Tyneside and Gateshead. Only one memory service in the North East (North Shields Memory clinic) does not provide access to specialist post diagnosis counselling.

Data from the English National Memory Services Audit suggests that more than 500 people in the North East have accessed cognitive stimulation therapy in the 12 months prior to the audit; while more than 2,000 people in the North East received specialist counselling during the same time period. The average number of people receiving specialist counselling in the North East in the 12 months prior to the audit was 230 per memory service. This number is broadly in-line with the national average. It should be noted, however, that this figure over estimates the actual numbers receiving specialist counselling because, as stated by the Royal College of Psychiatrists, it *"is likely that responders interpreted this as meaning providing general support and advice following a diagnosis, as it is unlikely that such a high number of people would need this kind of specialist counselling"*.<sup>136</sup>

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<sup>136</sup> Royal College of Psychiatrists (2013) English National Memory Services Audit Report. London: Royal College of Psychiatrists p.19

Table 9 shows the numbers of people receiving cognitive stimulation therapy and specialist counselling through memory services in the North East.

Memory Services	Access to Cognitive Stimulation Therapy	Service usage in the 12 months before audit (individuals)	Access to post diagnosis counselling	Service usage in the 12 months before the audit (individuals)
Darlington Community Mental Health Team	Yes	30	Yes	-
Derwentside Community Mental Health Team	Yes	35	Yes	312
Durham and CLS Community Mental Health Team	Yes	24	Yes	-
Durham Dales Community Mental Health Team	Yes	34	Yes	416
Easington Community Mental Health Team	Yes	16	Yes	312
Hartlepool Community Mental Health Team	Yes	15	Yes	236
Lustrum Vale Memory Clinic	Yes	50	Yes	125
Middlesbrough Community Mental Health Team	Yes	60	Yes	367
Newcastle Memory Assessment and Management Service	Yes	0	Yes	24
North Shields Memory Clinic	Yes	96	No	73*
Northumberland Planned Care Group	No	-	Yes	-
Northumbria Tyne and Wear NHS Trust - Memory Protection Service	No	-	Yes	349
Redcar and Cleveland Community Mental Health Team	Yes	116	Yes	396
Sedgefield Community Mental Health Team	Yes	44	Yes	-

\* There is a discrepancy between the 'no' answer and the figure 73 however this information is based on the return submitted by North Shields Memory Clinic.

**Table 9:** Access to Cognitive Stimulation Therapy and counselling through memory services in the North East. Source: Royal College of Psychiatrists (2013) English National Memory Services Audit Report. London: Royal College of Psychiatrists with additional information from providers in the North East.

## Dementia advisers

**Durham** - As of February 2014 there was an intention to commission a dementia adviser service in Durham before the end of 2013/14.

**Middlesbrough** - Sanctuary Supported Living provides a dementia adviser service.

**Newcastle** - Dementia advisers, provided by Northumberland, Tyne and Wear NHS Foundation Trust, are located within the Memory Assessment Service. The advisers provide support for people with dementia and their carers following a diagnosis of dementia. All patients are given a post diagnosis information pack, which includes information on local services.

**North Tyneside** - A specialist Memory Support Service is provided by Northumberland, Tyne and Wear NHS Foundation Trust, which provides advice, information and emotional support.

**Northumberland** - Alzheimer's Society locality based dementia advisers are funded through the Ballinger Trust.

**Redcar and Cleveland** - Redcar and Cleveland Borough Council, jointly with the NHS, has commissioned a dementia adviser service from Carers Together. The dementia adviser service takes referrals from everyone who receives a diagnosis of dementia from the memory clinic. It undertakes a carer's assessment for the local authority and provides a pack of information about services and issues that people can consider.

**Stockton-on-Tees** – Building work on the Halcyon Centre LiveWell Hub was completed in May 2014. When it is operational the LiveWell Hub will provide people with dementia with the opportunity to attend support groups and access information and advice.

**Sunderland / South Tyneside / Gateshead** - The Memory Protection Service (provided by Northumberland, Tyne and Wear NHS Foundation Trust) provides signposting to local resources. It operates a membership model so that those with dementia can re-access help and support at any time. All patients are given information including a post diagnosis information pack. Newsletters including updates on dementia, local events activities and services are sent to those on the Membership Scheme four times a year.

## Peer support

**North Tyneside** - In spring 2014 the North Tyneside Memory Support Service stated it would be developing a peer support network.

**Redcar and Cleveland** - The Dementia Adviser Service commissioned by Redcar and Cleveland Borough Council and the NHS provides a peer support group, which offers social outings and practical support, such as legal advice and counselling.

## Educative programmes

**Stockton-on-Tees** - Through the memory service at Lustrum Vale, people with dementia and carers are offered the opportunity to attend a post diagnosis session and have access to a free, 12 session education programme.

**Newcastle** - Memory Assessment and Management Service provides a six week program of Memory Remediation.

**Sunderland, South Tyneside and Gateshead** - The Memory Protection Service provides a post diagnostic education session open to both people recently diagnosed with dementia, carers and family members.

For further information about the Carers Information and Support Programme (CrISP) education programme provided by the Alzheimer's Society see section 21 of this report.

## Information, support and advice provided by the Alzheimer's Society in the North East

The Alzheimer's Society provides a range of dementia advice and support services across the North East. As of May 2014 the Alzheimer's Society was providing information, advice and support in:

- Darlington and Teesside
- Durham and Chester-le-Street
- Gateshead
- Newcastle
- Northumberland (Berwick & District, Blyth Valley, Morpeth & District, Seahouses, Tynedale Wooler)
- South Tyneside
- Sunderland

In Gateshead the Alzheimer's Society provides a 'Living with dementia' information programme, which offers information on dementia, memory, health and emotional well-being and the support services that are available.

## The Dementia Guide

The Alzheimer's Society and the NHS have produced a Dementia Guide, which will be given to everyone who receives a dementia diagnosis. The guide provides information that will be useful to

those with dementia, their close friends and family or anyone taking on a caring role for someone with dementia.<sup>137</sup>

The Dementia Guide contains information about:

- What dementia is
- Treatments (including both drug and non-drug treatments to help lessen the symptoms of dementia)
- Options to support living well with dementia
- How to plan for the future (including advice regarding financial matters)
- What services and support may be available and how they can be accessed
- What support may be available for carers
- Information on how to get involved in research
- Useful organisations to contact for further information
- A checklist to help people plan ahead and live well

In the North East the Alzheimer's Society is distributing the Dementia Guide:

- When people receive a diagnosis
- At Community Dementia Forums
- At dementia cafés
- At Memory Support Services
- Through Dementia Support Workers and Dementia Advisers
- At hospitals
- At awareness raising sessions

As of May 2014, Northumberland, Tyne and Wear Foundation Trust had distributed 5,000 Dementia Guides to patients who have recently been diagnosed. These are routinely included in the post diagnosis packs.

The Dementia Guide can be ordered (or downloaded) from [www.alzheimers.org.uk/dementiaguide](http://www.alzheimers.org.uk/dementiaguide)

## Live Well Dementia website

The Live Well Dementia website was launched in March 2013 in response to Commitment 5 of the Prime Minister's Challenge on Dementia, which highlights the need to promote local information on dementia services.<sup>138</sup> The future of this site is uncertain and its local content relating to the North East is limited. The website:

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<sup>137</sup> Alzheimer's Society (2013) The Dementia Guide: Living well after diagnosis [Online] Available at: <http://alzheimers.org.uk/dementiaguide> (Accessed 17 May 2014)

<sup>138</sup> Department of Health (2012) Prime Minister's Challenge on Dementia: Delivering major improvements in dementia care and research by 2015. Department of Health: London p.6

- Explains what people and their carers should expect from local dementia services across all parts of the person's journey, with links to NICE quality standards
- Describes the specific local dementia services commissioned by the NHS and, where appropriate, at the local authority or clinical commissioning group level
- Provides a directory of local organisations delivering services throughout the person's journey and covering health, social care, independent sector and other public sector and voluntary sector providers
- Presents comparisons of the performance of local organisations enabling people to understand the performance of their health and social care services, with the opportunity for organisations to comment on their own results
- Provides opportunities for people to engage with each other and give feedback on services they have received<sup>139</sup>

The Live Well Dementia website can be accessed at <http://www.livewelldementia.co.uk/>

## GP Dementia Roadmap

The GP Dementia Roadmap, launched in May 2014, is an online tool to help people with dementia access care in their local area. It has been produced by the Royal College of General Practitioners (RCGP) and led by its clinical dementia champions; Dr Jill Rasmussen and Professor Louise Robinson.

Produced in collaboration with the Alzheimer's Society and funded by the Department of Health, the Dementia Roadmap provides a platform to help CCGs and other local organisations collate information for patients in their area for the first time, so GPs can refer them to the best care to meet their needs as quickly as possible.

To be used by doctors and providers of community care to share knowledge and information to patients and their families, the Dementia Roadmap is a comprehensive 'one stop shop' designed to reflect a patient's needs as they progress through the disease and signpost them to relevant local resources at the right time, from diagnosis onwards.

It provides information about understanding dementia, memory worries, the diagnostic process, post diagnosis support, living well with dementia, carer health and planning for the future. This is supplemented by details of local information and services for patients, such as memory clinics, hospitals, care homes and specialist residential housing.

The Dementia Roadmap project has been piloted in Devon, North Somerset and South Gloucester and will be updated for use in the North East by 2015, via funding won by Dr Lynne Corner and Professor Louise Robinson from Newcastle University.

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<sup>139</sup> Live Well Dementia Support in the North of England [Online] Available at: <http://www.livewelldementia.co.uk/about-this-site/> (Accessed 17 May 2014)

## 8.4 Examples of work to improve the appropriate prescribing of anti-dementia drugs in the North East

Although there is currently no known cure for dementia there are a number of drugs that can help to improve or slow the progression of some symptoms. If anti-dementia drugs are appropriate for a person then the type of drug they will be prescribed will be dependent on the form of dementia with which they have been diagnosed.

### North East statistics on the use of anti-dementia medication

Research conducted by Cornsay Research in autumn 2012<sup>140</sup> looked at the use of anti-dementia medication among nine primary care trusts (PCTs) in the North East.<sup>141</sup> The medications that formed the focus of this research were Donepezil, Galantamine, Rivastigmine and Memantine.

Over the study period between 9.7% and 10.3% of people with dementia were being prescribed anti-dementia medication nationally. Across the North East the reported prescribing levels for PCT areas in 2011 ranged from 2.32% to 31.03%. One PCT area had a prescribing rate three times higher than the national rate but *“no other PCT in North East England reported the proportion of dementia medication greater than the national rate in 2011. Furthermore seven of the reporting PCT areas [had] fewer than half the national rate of people with dementia in receipt of dementia medication prescriptions”*.<sup>142</sup>

The report concluded that further research was needed to identify whether the cause of such low usage rates was *“due to inappropriate cases, inhibitive costs, patient choice or poor clinical/drug knowledge”*.<sup>143</sup>

### Memory services and anti-dementia drugs

Data from the English National Memory Services Audit shows that, following a diagnosis, all 14 memory services in the North East initiate the use of anti-dementia medication where appropriate. The data also reveals that all memory services, except the Newcastle Memory Assessment and Management Service (serving Newcastle and West North Tyneside), provide ongoing medication reviews following a diagnosis.

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<sup>140</sup> Jackson, M (2012) National Dementia & Antipsychotic Prescribing Audit 2012: Findings for North East England (Unpublished)

<sup>141</sup> Findings based on the Primary Care Trusts who submitted returns

<sup>142</sup> Jackson, M (2012) National Dementia & Antipsychotic Prescribing Audit 2012: Findings for North East England (Unpublished) p.3

<sup>143</sup> Jackson, M (2012) National Dementia & Antipsychotic Prescribing Audit 2012: Findings for North East England (Unpublished) p.11

## 8.5 Conclusions on information and support at the time of diagnosis in the North East

Post diagnosis information and support is seen as a key plank of the two thirds diagnosis ambition; however, it can be overshadowed by the diagnosis process and the diagnosis rate.

There are advice and support services in most localities in the North East but it is difficult to assess the full coverage of the services or their effectiveness at meeting the needs of people who are living with dementia and their carers. Many of the services offering post diagnosis support are provided by the third sector.

Data regarding the prescribing of anti-dementia medication was last collated on a regional basis in 2011 when it indicated prescribing was below the national average. All 14 memory services initiate the use of anti-dementia medication.

## 8.6 Recommendations on post diagnosis information and support in the North East

- Post-diagnosis information and support is being provided across the region but it is not known if these services are effective with particular regard to outcomes for the individual. Locally joint dementia planning groups need to assess, with people living with dementia and their carers, if services are meeting the needs of their localities and any such evaluation should also consider the sustainability of local services, given that much of it is provided by the third sector.
- A North East audit of anti-dementia medication prescribing was last carried out in 2011. An updated audit of anti-dementia medication prescribing needs to be carried out. Any recommendations made should then be considered by groups including the Mental Health, Dementia and Neurological Clinical Network.



## 9. Personalisation

### Key points:

- Objective 6 of the National Dementia Strategy, Community Personal support, suggests this can be delivered in part for people with dementia through Putting People First personalisation of care changes
- The Prime Minister's Challenge highlights carers needs may be met through support as a personal budget and they should be encouraged to take a personal budget
- Four out of 10 local joint dementia plans make reference to use of personal budgets to give the individual more control over the care and support they receive
- Personal budgets, which can be taken in various forms, are a key plank of the personalisation programme
- A number of national reports indicate there are major barriers to people with dementia taking up personal budgets and the reports propose a number of recommendations
- The statistics show the take up of direct payments, one form of personal budget, is very low by people with dementia in the North East

This section of the report will consider key issues relating to the implementation of the personalisation agenda for people living with dementia. In particular this section of the report will outline:

- The policy context
- How the implementation of the personalisation agenda for people living with dementia has been included in local plans
- Statistics on the use of direct payments by people with dementia in the North East
- Examples of work undertaken in the North East to improve the implementation of the personalisation agenda for people with dementia in the North East
- Conclusions and recommendations on the implementation of the personalisation agenda for people with dementia in the North East

## 9.1 Policy context

### National Dementia Strategy

Objective 6 of the National Dementia Strategy highlights the need for “*an appropriate range of services to support people with dementia living at home and their carers*”. The strategy suggests that this can happen by implementing the “*Putting People First* personalisation changes for people with dementia, utilising the Transforming Social Care Grant”<sup>144</sup>.

### Personalisation

Personalisation has been described as a drive to put “*people at the centre of their own care so that they have independence, choice and control over the services they use, with a focus on supporting people to live independently through early intervention*”.<sup>145</sup>

In January 2008 the Department of Health issued a circular setting out information to support the transformations outlined in the 2006 White Paper, ‘*Our Health, Our Care, Our Say: A new direction for community services*’.<sup>146</sup> The circular describes a vision for “*the development of a personalised approach to the delivery of adult social care*”.<sup>147</sup>

To build on the vision of social care outlined in ‘*Our Health, Our Care, Our Say: A new direction for community services*’ the Department of Health published, in 2007, ‘*Putting People First: A shared vision and commitment to the transformation of Adult Social Care*’.<sup>148</sup> The key elements of the vision outlined in the document were:

- Prevention
- Early intervention and re-enablement
- Personalisation
- Information, advice and advocacy

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<sup>144</sup> Department of Health (2009) Living well with dementia: a National Dementia Strategy. London: Department of Health p.46

<sup>145</sup> Alzheimer’s Society (2011) Getting personal? Making personal budgets work for people with dementia [Online] Available at: <http://www.alzheimers.org.uk/personalbudgets> (Accessed 17 May 2014) p.12

<sup>146</sup> Department of Health (2006) Our Health, Our Care, Our Say: A new direction for community services. London: Crown

<sup>147</sup> Care Quality Commission. Policy briefing: Putting People First [Online] Available at: [http://www.thinklocalactpersonal.org.uk/\\_library/Resources/Personalisation/Personalisation\\_advice/Putting\\_people\\_first\\_briefing1.pdf](http://www.thinklocalactpersonal.org.uk/_library/Resources/Personalisation/Personalisation_advice/Putting_people_first_briefing1.pdf) (Accessed 17 May 2014)

<sup>148</sup> Department of Health (2007) Putting People First: A shared vision and commitment to the transformation of Adult Social Care. London: Department of Health

To promote the aim of increased personalisation, Putting People First set out a requirement for councils “to move to a system of personal budgets for everyone who is eligible for publicly-funded adult social care support”.<sup>149</sup>

Following the conclusion of the Putting People First programme in 2010 the Think Local, Act Personal (TLAP) partnership was established in 2011. The TLAP partnership is “a national partnership of more than 30 organisations committed to transforming health and care through personalisation and community-based support”.<sup>150</sup>

## Clinical Guidelines 42 Dementia: Supporting people with dementia and their carers in health and social care

The guidelines produced by the National Institute for Health and Care Excellence and Social Care Institute of Excellence state that good care for people with dementia and their carers should be underpinned by a person-centred approach and assert the following principles:

- The human value of people with dementia, regardless of age or cognitive impairment, and those who care for them
- The individuality of people with dementia, with their unique personality and life experiences among the influences on their response to the dementia
- The importance of the perspective of the person with dementia
- The importance of relationships and interactions with others to the person with dementia, and their potential for promoting well-being<sup>151</sup>

## Personal budgets

According to the Alzheimer’s Society’s report ‘Getting personal? Making personal budgets work for people with dementia’ “personal budgets are a key way of delivering the personalisation agenda in England: the coalition government has made a commitment that everyone receiving social care services will be in receipt of a personal budget by April 2013”.<sup>152</sup>

The report goes on to explain “a personal budget is the amount of money that a council decides to spend in order to meet the needs of an individual eligible for publicly funded social care. A personal budget can be taken by the eligible person as a managed option by the council or third party, which

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<sup>149</sup> Ibid

<sup>150</sup> Think Local, Act Personal[Online] Available at:  
[http://www.thinklocalactpersonal.org.uk/About\\_us/](http://www.thinklocalactpersonal.org.uk/About_us/)(Accessed 17 May 2014)

<sup>151</sup> National Institute for Health and Clinical Excellence and the Social Care Institute for Excellence (2006) CG42Dementia: Supporting people with dementia and their carers in health and social care. London: National Institute for Health and Clinical Excellence

<sup>152</sup> Alzheimer’s Society [Online] Available at:  
[http://alzheimers.org.uk/site/scripts/documents\\_info.php?documentID=1557](http://alzheimers.org.uk/site/scripts/documents_info.php?documentID=1557) (Accessed 17 May 2014)

means not having to take on direct budget management responsibilities. Alternatively it can be taken as a direct (cash) payment or as a combination of these options”.<sup>153</sup>

## Direct payments

The report ‘*Personalisation: A Rough Guide*’, which was produced by the Social Care Institute for Excellence, explains that:

*“A direct payment is one way of taking a personal budget. It is a means-tested cash payment made in the place of regular social service provision to an individual who has been assessed as needing support. Following a financial assessment, those eligible can choose to take a direct payment and arrange for their own support instead. People can use their budgets to access a wide range of support, as long as it is legal and meets agreed outcomes”.*<sup>154</sup>

In England in 2011 “direct payments were extended to people who lack capacity to consent and to people with mental health problems that are subject to mental health and certain criminal justice legislation”.<sup>155</sup>

## Managed personal budgets

‘*Personalisation: A Rough Guide*’, explains that managed personal budgets can be either where:

- The local authority places an individual’s personal budget with a third party, so that day-to-day business arrangements are between the service user and the third party provider (purchasing or commissioning) OR
- The local authority itself holds the personal budget and manages/arranges the services on behalf of the service user (providing in-house owned or managed services)<sup>156</sup>

## Individual service funds

Individual service funds (ISFs) offer the benefits of choice and control, but avoid the need for people who use services to become involved in managing the financial aspects of their care, or the implications of becoming an employer when engaging a personal assistant. The person uses a

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<sup>153</sup> Alzheimer’s Society (2011) Getting personal? Making personal budgets work for people with dementia [Online] Available at: <http://www.alzheimers.org.uk/personalbudgets> (Accessed 17 May 2014) p.12

<sup>154</sup> Social Care Institute for Excellence [Online] Available at <http://www.scie.org.uk/publications/guides/guide47/#topic-link-24> (Accessed 17 May 2014)

<sup>155</sup> Alzheimer’s Society (2011) Getting personal? Making personal budgets work for people with dementia [Online] Available at: <http://www.alzheimers.org.uk/personalbudgets> (Accessed 17 May 2014)

<sup>156</sup> Carr, S. (2010) SCIE Report 20: Personalisation: A Rough Guide [Online] Available at: <http://www.scie.org.uk/publications/reports/report20.asp> (Accessed 17 May 2014)

personal budget to buy support from a provider and the money is held by the provider on the individual's behalf. ISFs are, therefore, a model which falls between services arranged directly by a local authority and a cash-based personal budget. It creates the environment where the individual designs their service directly with their provider.

## Personal health budgets

The principles of personalisation and personal budgets have been extended to health services in England. Following a three year pilot the Government, in November 2012, announced the national roll out of personal health budgets.

*“Personal health budgets will initially be aimed at people who are eligible for NHS Continuing Healthcare, who will have a right to ask for a personal health budget from April 2014 and a right to have a budget from October 2014. Clinicians can also offer personal health budgets to others that they feel may benefit from the additional flexibility and control. The NHS Mandate commits to a further roll out of personal health budgets to people who could benefit from April 2015”.*<sup>157</sup>

## Personal budgets for people living with dementia

### Personal budgets for people with dementia: A report on challenges and solutions to implementation based on interviews with eight local authorities in England

In October 2011 the Mental Health Foundation published the report *Personal budgets for people with dementia: A report on challenges and solutions to implementation based on interviews with eight local authorities in England*.<sup>158</sup>

The report outlines challenges which may affect the ability of a person with dementia to access personal budgets. The key findings of the report suggested that:

- Data collection in local authorities is such that it is difficult to assess the number of people with dementia in receipt of a personal budget
- Systems to support personal budgets for people with dementia are not well developed
- Anecdotally local authorities report that, where they have supported the delivery of personal budgets to people with dementia, they have concentrated on younger onset rather than the majority of older people with dementia

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<sup>157</sup> NHS England [Online] Available at: <http://www.personalhealthbudgets.england.nhs.uk/About/faqs/> (Accessed 17 May 2014)

<sup>158</sup> Goodchild, C. (2011) Personal budgets for people with dementia: A report on challenges and solutions to implementation based on interviews with eight local authorities in England [Online] Available at: [http://www.mentalhealth.org.uk/content/assets/PDF/publications/Personal\\_budgets\\_for\\_people\\_living\\_with\\_dementia.pdf](http://www.mentalhealth.org.uk/content/assets/PDF/publications/Personal_budgets_for_people_living_with_dementia.pdf) (Accessed 17 May 2014) p.3

- Local authorities report a reticence on the part of older people in general and families to seek a personal budget
- Local authorities are aware more work is needed to engage mental health trusts in personal budgets
- The reasons for slow implementation are complex and multi-layered across the local authority culture, strategic planning, organisational infrastructure and operational systems

### **Getting personal? Making personal budgets work for people with dementia**

In November 2011 the Alzheimer’s Society published its report ‘*Getting personal? Making personal budgets work for people with dementia*’.<sup>159</sup>

This report made a number of recommendations to support people living with dementia to become involved with the personal budget agenda to a level appropriate to the individual. The report recommended that:

- This may be through access to direct payments, or another form of support that engages with the person with dementia as fully as possible. It should include a discussion about the amount of money available and possible care and support options, and be recorded in a care plan
- Personal budgets must not be seen as a cure-all for the social care system. Social care reform must address wider barriers – in particular a lack of funding and strict eligibility criteria – working against the personal budgets system
- Ensure that the market is fully developed to deliver a range of different types of dementia services
- Make sure the personal budgets system is adapted to meet the particular needs of people with dementia and their carers
- Provide timely and appropriate information for people with dementia and their carers
- Implement awareness raising and training for health and social care professionals
- Ensure an improved evidence base on dementia, including pilot sites to evaluate effective models of provision and accurate data on current use of personal budgets

### **Improving personal budgets for older people: A research overview**

In January 2013 the Social Care Institute for Excellence published the report ‘*Improving personal budgets for older people: A research overview*’. The report provides an “*overview of key pieces of UK*

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<sup>159</sup> Alzheimer’s Society (2011) *Getting personal? Making personal budgets work for people with dementia* [Online] Available at: <http://www.alzheimers.org.uk/personalbudgets> (Accessed 17 May 2014) p. vi

*research between 2007 and 2012, which focused on the implementation and uptake of personal budgets and direct payments for older people (including those with dementia) in England”.*<sup>160</sup>

The report highlighted that “*research on direct payments and personal budgets for people living with dementia in England strikingly revealed an absence of collected data*” and “*personal budgets can not be approached as a ‘one size fits all’ solution for older people living with dementia*”.<sup>161</sup>

## 9.2 Local plans

### Local joint dementia plans

Four out of 10 plans make reference to use of personal budgets to give the person with dementia more control over the care and support they receive.

## 9.3 North East statistics

The Adult Social Care Outcomes Framework (ASCOF) has two indicators relating to self-directed support: a) the number of people offered a personal budget and b) the number who have gone on to take a direct payment. The figures are reported from the Referrals, Assessments and Packages of Care (RAP) return. At the time of writing this report information was not available relating to the number of people with dementia who had been offered a personal budget.

### **Use of direct payments by people with dementia in the North East**

Table 10 outlines the number of people with dementia, aged 65 and over, who were receiving direct payments at 31<sup>st</sup> March 2013.

It has not been possible to compare these figures with those of other localities in England as no national average could be found during the research undertaken for this report.

These figures need to be viewed with caution as anyone who has not received a diagnosis but receives direct payments will not be included in these numbers and the figures depend on the local authority correctly recording the person’s diagnosis in their care records e.g. Care First.

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<sup>160</sup> Social Care Institute of Excellence (2013) Report 63: Improving personal budgets for older people: A research overview [Online] Available at: <http://www.scie.org.uk/publications/reports/report63.asp> (Accessed 17 May 2014) p.1

<sup>161</sup> Social Care Institute of Excellence (2013) Report 63: Improving personal budgets for older people: A research overview [Online] Available at: <http://www.scie.org.uk/publications/reports/report63.asp> (Accessed 17 May 2014) p.3

Local Authority	Numbers of people aged 65 and over with dementia that had a Direct Payment on 31st March 2013
Darlington	1
Durham	79
Gateshead	13
Hartlepool	5
Middlesbrough	19
Newcastle Upon Tyne	21
North Tyneside	4
Northumberland	30
Redcar and Cleveland	5
South Tyneside	43
Stockton-on-Tees	0
Sunderland	6

**Table 10:** Number of people aged 65 and over with dementia that had a Direct Payment on 31st March 2013, by local authority. Source: Data from the Referrals, Assessments and Packages of Care (RAP) returns submitted by local authorities to Information Centre NHS covering the period 1st April 2012 to 31st March 2013.

It should be noted that the number of direct payments in their own right does not necessarily indicate that personalisation has produced a more innovative service or better outcomes for the person with dementia. For example, a person may take a direct payment to keep their existing provider in the event of changed contracting arrangements.

## 9.4 Examples of work undertaken in the North East

### North East Association of Directors of Adult Social Services - 'Think local, act personal' themed network

There is a North East Association of Directors of Adult Social Services (NE ADASS) 'Think local, act personal' themed network, which meets quarterly. The work of this group does not focus exclusively on dementia but provides a network for personalisation leads from local authorities across the North East. The network provides strategic and operational oversight of policy developments relating to personalisation and shares good practice across the region. The network will have a key role in ensuring local authorities meet the duties in the Care Act 2014 in relation to personalisation.

In 2014 a workshop was held to share good practice in relation to personalisation. This was not specific to the needs of people with dementia but contained some ideas and principles that are applicable to people living with dementia.

For further details contact [ian.hall@northeastcouncils.gov.uk](mailto:ian.hall@northeastcouncils.gov.uk)



## Sector-Led Improvement Master Class

The 12 North East local authorities are working together to look at sector-led improvement work for 2014/15 and are planning a series of master class events across the region. The regional Sector Led Improvement Board wants to use this approach to look at personalisation for people with dementia in the North East. They are arranging a master class in Autumn 2014 to focus on ways in which people with dementia can be supported in the community and how, through the personalisation agenda, they and their carers can exercise choice over the services they receive. The event will draw on examples to highlight existing good practice and explore the barriers that impact upon effective multi-agency working, including information sharing, agreed joint outcome measures and effective community based support.

For further details contact [ian.hall@northeastcouncils.gov.uk](mailto:ian.hall@northeastcouncils.gov.uk)

## Gateshead direct payments in residential care trailblazer

Twenty local authorities (now reduced to 18) were selected, after self-nominating, to be trailblazers for a Department of Health initiative exploring whether and how direct payments for people in residential care could give them and their families control over their care. The trailblazer project is to run over a two-year period (2013/15).

Gateshead is the only trailblazer local authority in the North East. Updated reports on the findings will be available in December 2014 and December 2015.

## 9.5 Conclusions on the implementation of the personalisation agenda for people with dementia in the North East

Person centred support for people living with dementia and their carers is a key policy objective. One means of promoting personalisation is through the provision of personal budgets. The uses of personal budgets were mentioned in four out of the 10 local joint dementia plans in the North East. Research reports indicate there are many barriers to older people and people living with dementia using personal budgets and direct payments. These reports do, however, make recommendations for improvement.

Figures from the Referrals, Assessments and Packages of Care (RAP) indicate there is a very low take up of direct payments in the North East by people over 65 with dementia. At the time of writing this report there were no figures available relating to the use of other types of personal budgets or quality indicators. These figures, therefore, only provide us with headline information and do not provide any indication of quality or outcomes. Moreover, the representativeness of these figures is cast into further doubt due to anecdotal evidence which suggests that not every person with dementia, who is in receipt of social care service, has a coding on the social care computer system

indicating this. It is, however, clear that more work needs to be done to support people with dementia to have more control over their services.

To maximise personalisation we also need to consider how we support people who are carers of people living with dementia and who may be entitled to direct payments in their own right. As systems are being trialled there are opportunities to learn from these.

## 9.6 Recommendations on the implementation of the personalisation agenda for people with dementia in the North East

- The personalisation of social care has the potential to have a great impact on the lives of people with dementia and their carers. For this report, it has not been possible to analyse all of the available information on personalisation so it is not possible to give an accurate assessment of its effect on the lives of people with dementia and those who care for them. In order to provide this accurate assessment, the dementia themed network should lead on work to collate, analyse and review all of the available data on personalisation.
- Anecdotal information indicates data bases used to collect personalisation data don't always have a person's diagnosis of dementia recorded. There is a need to explore the accuracy of coding/classification activity with an aim of improving accuracy and, therefore, reliability of data. Key partners exploring this would be the 'Think local, act personal', dementia and performance ADASS themed networks.
- There are identified barriers to the take up of personal budgets but national reports provide some recommendations to help overcome these barriers. Partners in the North East need to consider the barriers and recommendations and improve the take up of personal budgets among people with dementia and their carers who wish to take advantage of them.
- Current data provides us with some information about the take up of personal budgets. Work needs to be done to look at outcomes for people with dementia who are using personal budgets with more emphasis on qualitative, as well as quantitative, measures.
- Some carers of people with dementia may be entitled to personal budgets in their own right. Any service developments around personalisation need to be inclusive of carers of people with dementia.
- New approaches to personalisation are being implemented and piloted e.g. the use of individual service funds (ISF) and direct payments, which can be used to purchase care home places. These approaches need to consider people with dementia and their carers in their evaluation and need to be implemented. Health budgets are emerging. While no specific examples of people with dementia using personal health budgets are presented in this

report, a watching brief needs to be kept to ensure people with dementia get the maximum benefits from these initiatives.

- A sector-led improvement master class on dementia and personalisation is planned for 2014. This master class needs to take account of the contents of this report.

## 10. Care in the community

### Key points:

- Objective 6 of the National Dementia Strategy highlights the need for “*an appropriate range of services to support people with dementia living at home and their carers*” and Commitment 4 of the Prime Minister’s Challenge on Dementia outlines an intention to create a “*Dementia Care and Support Compact signed by leading care home and home care providers*”
- 5 out of the 10 local joint dementia plans in the North East highlight the need for actions to review or up-skill domiciliary care workers providing support to people with dementia.
- As of May 2014 there were 191 unique providers of domiciliary care services delivering services from 253 registered locations
- There are dementia specific day centres in every locality across the North East
- The North East has a good range of community services supporting a person’s broader well-being. These include art, music and sport based activities and social groups, such as dementia cafés
- There is a need for further work to identify how ‘universal’ primary health care services can be delivered in a manner that is appropriate for people with dementia

This section of the report will consider key issues relating to the provision of care in the community for people living with dementia. In particular this section of the report will outline:

- The policy context
- How the provision of care in the community for people living with dementia has been included in local plans in the North East
- Statistics on the number of domiciliary care providers in the North East
- Examples of work undertaken to improve the provision of care at home in the North East
- Examples of day services for people living with dementia in the North East
- Examples of North East community services supporting a person’s broader well-being
- Conclusions and recommendations on the provision of care in the community for people with dementia in the North East

According to the report *'Dementia: A state of the nation report on dementia care and support in England'* an estimated one third of people with dementia live in residential care with two thirds living at home.<sup>162</sup>

## 10.1 Policy context

Outlined below is the policy context relating to the provision of care in the community for people living with dementia. This should be read in conjunction with the general policy review in section 3 of this report.

### National Dementia Strategy

Objective 6 of the National Dementia Strategy highlights the need for *"an appropriate range of services to support people with dementia living at home and their carers"*. This includes *"access to flexible and reliable services, ranging from early intervention to specialist home care services, which are responsive to the personal needs and preferences of each individual and take account of their broader family circumstances"*.<sup>163</sup>

### Prime Minister's Challenge on Dementia

Commitment 4 of the Prime Minister's Challenge on Dementia outlines an intention to create a *"Dementia Care and Support Compact signed by leading care home and home care providers. Ten leading organisations have set out their commitment to deliver high-quality relationship-based care and support for people with dementia, and to engage and involve the wider community in this work"*.<sup>164</sup>

The (national) Dementia Action Alliance has been leading this initiative and, as of April 2014, 2772 care providers had signed up to the compact (including providers based or operating in the North East).

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<sup>162</sup> Department of Health (2013) *Dementia: A state of the nation report on dementia care and support in England* [Online]  
[https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/262139/Dementia.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/262139/Dementia.pdf)  
(Accessed 17 May 2014) p.6

<sup>163</sup> Department of Health (2009) *Living well with dementia: a National Dementia Strategy*. London: Department of Health p.12

<sup>164</sup> Department of Health (2012) *Prime Minister's Challenge on Dementia: Delivering major improvements in dementia care and research by 2015*. Department of Health: London p.6

To become a signatory of the compact providers must commit to:

- Focus on quality of life for people with dementia, as well as quality of care
- Set a benchmark for high quality, relationship-based care and support for people with dementia; inspiring and encouraging their sector to take responsibility for delivering this aim, building on existing good practice
- Engage and involve the wider community to improve their support for people with dementia, including GPs and healthcare professionals
- Play their part in supporting the wider community, sharing the knowledge and skills of their staff, and inviting people into their care settings
- Work with commissioners of care for people with dementia to ensure they commission quality care services appropriately
- Clearly set out how they have delivered on this compact to make a difference for people with dementia, their carers and families<sup>165</sup>

For further information visit <http://www.dementiaaction.org.uk/dementiacompact>

## 10.2 Local plans

### Joint Strategic Need Assessments

Sunderland's Joint Strategic Needs Assessment (JSNA) recommends the commissioning of more support to enable people with dementia to remain in their homes.<sup>166</sup> The document also emphasises that home support for people with dementia and carers is especially important given that people living with dementia may be particularly at risk.<sup>167</sup>

### Health and Wellbeing strategies

South Tyneside's Health and Wellbeing Strategy (HWBS) lists a key action as being to develop and implement new models for delivering dementia services.<sup>168</sup>

Durham's HWBS commits to joint working to enable people with dementia to live in their own homes for longer.<sup>169</sup>

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<sup>165</sup> Dementia Action Alliance [Online] Available at: <http://www.dementiaaction.org.uk/dementiacompact> (Accessed 17 May 2014)

<sup>166</sup> Sunderland Joint Strategic Needs Assessment [Online] Available at: <http://www.sunderland.gov.uk/index.aspx?articleid=6789> (Accessed 17 May 2014) p.4

<sup>167</sup> Sunderland Joint Strategic Needs Assessment [Online] Available at: <http://www.sunderland.gov.uk/index.aspx?articleid=6789> (Accessed 17 May 2014) p.5 and p.29

<sup>168</sup> South Tyneside Health and Wellbeing Board (2013) Our Better Health and Wellbeing Strategy 2013-16 [Online] Available at: <http://www.southtyneside.info/CHttpHandler.ashx?id=21002&p=0> (Accessed 17 May 2014) p.10

## Local joint dementia plans

The most frequent actions in the local joint dementia plans, relating to care in the community, are to address the need to review or up-skill staff in domiciliary care supporting people with dementia (5 out of 10).

Other areas for action highlighted in the local joint dementia plans refer to the need to work with the voluntary and community sector, ensure pathways are inclusive of people with dementia and ensure there are peer support networks. One plan makes particular reference to ensuring care at home services support the prevention of unnecessary admissions of people with dementia to hospital. The Stockton-on-Tees plan includes an action about building on the Smarter Homes initiative.

## 10.3 Domiciliary care services and providers in the North East

Table 11 shows the number of domiciliary care services in the North East being provided to people with dementia and people aged 65 plus (not specifically registered as providing dementia services).

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<sup>169</sup> County Durham Health and Wellbeing Board (2014) County Durham Joint Health and Wellbeing Strategy 2014-2017 [Online] Available at: <http://www.durham.gov.uk/Pages/Service.aspx?ServiceId=8873> (Accessed 17 May 2014) P.16

Care in your home and supported living - Count of CQC Provider by LA	Provides services for people with Dementia	Provides services for people aged 65+, but not with Dementia	Total number of service providers
<b>North East</b>	<b>185</b>	<b>68</b>	<b>253</b>
Darlington	11	9	20
Durham	32	10	42
Gateshead	16	8	24
Hartlepool	7	3	10
Middlesbrough	6	5	11
Newcastle upon Tyne	26	6	32
North Tyneside	13	2	15
Northumberland	20	11	31
Redcar & Cleveland	3	1	4
South Tyneside	12	4	16
Stockton-on-Tees	18	7	25
Sunderland	21	2	23

**Table 11:** Providers of Home Care services on CQC care directory in North East England providing services to support people with dementia. Source: CQC Care Directory 10 April 2014  
[www.cqc.org.uk/cqcdata](http://www.cqc.org.uk/cqcdata)

There are 191 unique providers of domiciliary care services, delivering services from 253 registered locations.

The figures in Table 11 relate only to the number of services. It is not known how many people each service supports or how many people these services have the capacity to support. Consequently, it is not possible to comment on the capacity of current services to meet demand.

The two localities with the largest number of services (that are registered to provide services to people with dementia) are the same as the two localities with the highest estimated number of people with dementia; County Durham and Northumberland.



## 10.4 Examples of work undertaken to improve care at home in the North East

### North East Association of Directors for Adult Social Services - Dementia Themed Network

The dementia themed network for the North East Association of Directors for Adult Social Services (NE ADASS) is working to produce a 'Dementia at Home' report, encouraging a joined up approach to the provision of good quality services and interventions to allow people with dementia to be cared for and stay in their homes for as long as possible.

The project is being led by a sub-group of the dementia themed network for the NE ADASS. The responsible group will:

- Identify the best models of care which support people to stay out of hospital or to avoid readmission
- Explore "Making it Real"<sup>170</sup> and look to adapt a peer review approach to developing services for people with dementia and carers
- Explore options around action learning sets for maximising care at home for people with dementia

Using this information the project group will produce a report that outlines:

- The current regional position
- Best practice from evidence of 'what works'

The group will also identify and share throughout the region good practice within Health and Social Care.

For further information contact [ian.hall@northeastcouncils.gov.uk](mailto:ian.hall@northeastcouncils.gov.uk)

### Stockton Smarter Homes

The Smarter Homes for the Future Project in Stockton-on-Tees was launched in 2011 and is a partnership between Stockton Borough Council, Tees, Esk and Wear Valleys NHS Foundation Trust and local home care agencies.

The project aims to help support the implementation of objective 6 of the National Dementia Strategy by improving *"outcomes for people with dementia living at home, and their carers, using the principles of dementia-friendly design (including assistive technology) to help people remain at home for longer"*.<sup>171</sup>

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<sup>170</sup> For further information see <http://www.thinklocalactpersonal.org.uk/Browse/mir/aboutMIR/>

<sup>171</sup> Housing LIN [Online] Available at:

<http://www.housinglin.org.uk/HousingRegions/NorthEast/?parent=1019&child=8549> (Accessed 17 May 2014)

The first phase of the project was evaluated in March 2012 and concluded that *“the project has proved that relatively small changes can make a big difference to someone’s peace of mind and independence, as well as alleviating some of the pressures on family members”*.<sup>172</sup>

The project has received additional funding to continue for 2012/13 and 2013/14 *“with a view to developing a sustainable model for the future”*.<sup>173</sup>

In 2014 a second evaluation of the project was published and a group had been established to mainstream the principles of the project through key social care and health partners.

For further information contact [natalie.shaw@stockton.gov.uk](mailto:natalie.shaw@stockton.gov.uk)

## Shared Lives

Shared Lives is providing an alternative to residential care, for periods of respite for older people with dementia and their carers. The Shared Lives scheme offers people the opportunity to receive support from a Shared Lives carer in a home within the community, rather than a residential respite care placement.

The Shared Lives scheme offers a Shared Lives carer and a person with support needs the opportunity to get to know each other with the intention that, if a long-term bond can be formed, the individual with support needs can become a regular daytime or overnight visitor to the Shared Lives carer's household.

The report *‘The State of Shared Lives in England 2014’* indicates that there are a small number of people with dementia or other age related needs using the Shared Lives scheme in the North East.<sup>174</sup> During research for the project it was established that one person with dementia in the North East was believed to have benefited from the scheme.

As of May 2014 Shared Lives schemes were running in:

- Durham
- Gateshead
- Newcastle
- North Tyneside
- Northumberland
- South Tyneside

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<sup>172</sup> KD Consultation Solutions (2012) Smarter Homes for the Future Stockton on Tees: Evaluation Report [Online] Available at: <http://www.housinglin.org.uk/HousingRegions/NorthEast/?parent=1019&child=8549> (Accessed 17 May 2014) p.5

<sup>173</sup> Housing LIN [Online] Available at:

<http://www.housinglin.org.uk/HousingRegions/NorthEast/?parent=1019&child=8549> (Accessed 17 May 2014)

<sup>174</sup> Shared Lives Plus (2014) The State of Shared Lives in England: Report 2014 [Online] Available at: <http://sharedlivesplus.invisionzone.com/index.php?/files/file/244-the-state-of-shared-lives-in-england-2014/> (Accessed 17 May 2014) p. 3

- Sunderland

For further information see <http://www.sharedlivesplus.org.uk/>

## Ageing Well Programme

The Ageing Well Programme aims to support older people to live well in their own homes by linking them to activities and services in their community. The Ageing Well programme in Northumberland supports the Health and Wellbeing and the Stronger Communities and Families priorities in the Northumberland County Council Corporate Plan. The approach is consistent with the emphasis on “Lifetime neighbourhoods” and the recognition that where a person lives can have a significant role in keeping them well and independent as they grow older. The programme has a range of partnership arts, sport, leisure and support initiatives to help people living with dementia stay healthy, active and connected within their local community. These include Blooming Well gardening, golf activities and supported walks.

For further information contact [Ann.Brown@northumbria-healthcare.nhs.uk](mailto:Ann.Brown@northumbria-healthcare.nhs.uk)

## 10.5 Examples of day services provided for people with dementia in the North East

Day services are provided across the North East by both independent and public sector providers. As of May 2014 there were day services for people with dementia in all localities in the North East; this includes services specifically for people with dementia and day services that are accessible for people with dementia.

Listed below are a number of examples of day services that are provided for people with dementia or have taken steps to be inclusive of people with dementia. These are examples and this section does not intend to be a comprehensive list.

### Halcyon Centre/LiveWell Hub - Stockton Borough Council

The Halcyon Centre is a day service for adults and older people, including those living with dementia, managed by Stockton Borough Council. The centre offers service users a wide choice of activities and all staff are trained in the care of people with dementia. The Kitwood Unit, which is based in the Halcyon Centre, offers a specialised service to people living with more severe dementia and dementia like conditions. The Kitwood staff offer care and support in small groups or on an individual basis to ensure people’s needs are met within the larger day centre setting.

In July 2013 the Halcyon Centre received funding from the Department of Health as part of its scheme to promote the creation of dementia friendly environments. The funding is being used to

create a LiveWell Hub that will provide a single, 'one-stop shop,' offering assessment, information, training and consultation opportunities for people with dementia, carers and the wider public. The Centre has been redesigned and refurbished to ensure the hub's services are delivered in a showcase, dementia friendly environment.

For further information call 01642 528028

## Bradbury Centre Day Club, Dementia Care - Newcastle

The Bradbury Centre Day Club is provided by Dementia Care. The centre has been refurbished to offer dementia friendly facilities and a sensory garden.

The staff at the Centre are trained to provide activities for people with dementia and clients are encouraged to record their life stories with support from families. The Centre organises outdoor activities including theatre trips, swimming, golf and walks.

For further information contact [info@dementiacare.org.uk](mailto:info@dementiacare.org.uk)

## Minerva House Day Centre, Hospital of God - Horden

The Hospital of God provides day services for people living with dementia in the East Durham area. The day services at Minerva House, Horden, offer service users the opportunity to take part in group activities or to relax and spend time in a quiet or small group environment. The day service also provides personal care, including assistance with bathing and a variety of therapies.

In July 2013 Minerva House received funding from the Department of Health as part of its scheme to promote the creation of dementia friendly environments. This funding has been used to extend and refurbish the building.

For further information contact [minerva.house@hospitalofgod.org.uk](mailto:minerva.house@hospitalofgod.org.uk)

## Alzheimer's Society

As of May 2014, the Alzheimer's Society was providing day services at:

- Connie Lewcock Day Centre - Newcastle
- Princess of Wales Centre Day Centre - Sunderland
- Alexandra Lodge (Hebburn) and Garden Court (South Shields) - South Tyneside

## 10.6 Examples of community services that support a person's broader well-being

A number of services have been established across the North East that aim to support the broader well-being of people living with dementia. Listed below are a number of examples of community based activities that can support a person's broader well-being. These are examples and this section does not intend to be a comprehensive list of activities and projects.

### Music based activities

#### **Singing for the Brain**

The Alzheimer's Society hosts Singing for the Brain sessions across the North East. Singing for the Brain sessions use singing to bring people together and offer people with dementia and carers the opportunity to express themselves. As of May 2014, Singing for the Brain sessions were being held at:

- County Durham - Barnard Castle, Chester-le-Street, Spennymoor
- Darlington
- Hexham
- South Tyneside

#### **Mindful of Music**

Mindful of Music sessions take place at the ARC in Stockton-on-Tees. These sessions offer people with dementia and their carers a friendly environment in which to sing, socialise and have fun. Singing sessions also take place at Cleveland Alzheimer's Residential Centre Ltd and the Halcyon Centre.

### Sport based activities

#### **Sporting memories – Sunderland, South Tyneside and Newcastle**

Staff from Northumberland, Tyne and Wear NHS Foundation Trust are using archive pictures of sporting legends, memorabilia and reports, to help unlock memories and provide activities that can help to improve the mental and physical well-being of sports fans living with memory problems. Sporting Memories Network (SMN) trained staff and supplied resources to the Trust. The network has a number of city and county wide projects across England promoting the mental and physical well-being of older people, including those living with dementia and memory problems. SMN is chairing a new task and finish group on sport and leisure as part of the Prime Minister's Challenge on Dementia and was the winner of the Best National Initiative in the Dementia Friendly Awards, run by the Alzheimer's Society in May 2014.

For further information contact Tony Jameson-Allen at [tony@sportingmemoriesnetwork.com](mailto:tony@sportingmemoriesnetwork.com) or see <http://www.sportingmemoriesnetwork.com/>

### **Sports and exercise - Gateshead**

Sports sessions now form an integral part of the daily support provided to people using the Promoting Independence Centres and Domiciliary Care services from Gateshead Council. Between December 2013 and February 2014 38 people participated in sports sessions, such as bocchia, football, wheelchair football, table tennis, ten pin bowling and athletics.

## **Horticultural Projects**

### **Blooming Well - Northumberland**

The Blooming Well programmes are designed for people in the early stages of dementia and provide activities to help maintain cognitive functioning, stimulate memories and conversations and reduce social isolation. Sessions offer a wide range of gardening activities in a peaceful environment. People are given the opportunity to develop new skills and rekindle old ones. Activities help to support independence and allow people to connect with nature. Carers can also benefit from the programmes and enjoy meeting other carers, forming friendships and swapping ideas.

## **Arts based projects**

### **Shadon Timeslips project**

In the summer of 2013, Shadon House Dementia Resource Centre alongside Equal Arts and Beamish Museum, worked with 19 people with dementia on a 'Timeslips' project. The project took place within both Shadon House and Saltwell Park in Gateshead and used visual images as a means to stimulate the imagination of people with dementia and evoke thoughts on the meaning of the images. Using the expressions of participants, narratives were formed and created into stories. A book entitled 'The Shadon Sagas' was published containing each story.

### **Chrysalis**

Chrysalis is a volunteer led organisation, at Hexham, that brings together people with dementia, families, friends, professionals and volunteers to undertake activities from sport and singing to arts and crafts and general socialising.

For further information see <http://www.chrysalis-tynedale.org.uk/>

## Dementia cafés

Dementia cafés provide people with dementia and their carers with the opportunity to socialise and share experiences with others in an inviting and supportive environment. Dementia cafés often provide a form of entertainment along with the opportunity to access information that can help a person to live well with dementia.

As of May 2014 there were dementia cafés in every locality within the North East.

## Community services provided by the Alzheimer's Society

As well as providing the Singing for the Brain groups the Alzheimer's Society hosts a number of other community services supporting a person's broader wellbeing. As of May 2014, these services included:

- Blyth - tea dances
- Gateshead - befriending service and Marigold Court lunch group
- Hexham - social group
- North Tyneside - fun and friendship group, musical entertainment, dance, singing group, social group
- South Tyneside - Marine Park activity group
- Sunderland - befriending service, Greenside lunch club, Oakfield Court lunch club and Penshaw lunch club

As of May 2014, the Alzheimer's Society was running dementia cafés at:

- County Durham – Belmont, Chester-le-Street, Durham, Stanley, Wolsingham
- Darlington
- Gateshead
- Jarrow
- Newton Hall
- South Shields
- Sunderland

## 10.7 Conclusions on community care for people living with dementia in the North East

A number of services are supporting people to remain in their own home. These services vary across localities and include a range of services from practical support, primarily through domiciliary care agencies, to broader well-being activities including arts and sports. This report has not been able to provide a full audit of all such services or evaluate the effectiveness of these services.

It should be noted that the services highlighted in this section may not be the only support required to enable a person to remain in their own home (although they are critical for many people). It may, therefore, be appropriate to consider the extent to which other services, such as 'universal' primary healthcare services, are meeting the needs of people with dementia.

## 10.8 Recommendations on community care for people living with dementia in the North East

- Within each locality across the region varying services provide support to enable people to remain in their own homes. Each joint local planning group needs to consider the geographical spread and type of services which would best meet the needs of people living with dementia in their area. This analysis should be based on meaningful consultation with people living with dementia and carers within each locality. A gap analysis needs to take place and then an action plan needs to be implemented to fill the gaps.
- Many of the projects supporting a person's broader well-being are provided by the third sector. In the current time of financial austerity their long term feasibility needs to be assessed and these projects should be supported, where appropriate.
- The up-skilling of domiciliary care staff has been identified as a requirement in a number of local dementia action plans. Any development activity should take account of the Skills for Care guide for leaders and managers in the domiciliary care workforce working with people with dementia.<sup>175</sup>
- No analysis of 'universal' primary care health services has been included in this report. Appropriate provision of these services; including improved continence services, pharmacy, dental, optometry and audiology services, can help people living with dementia to remain in their own home. There is a need for further work to identify how these services can be delivered in a manner appropriate for people with dementia.

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<sup>175</sup> Skills for Care (2014) Better domiciliary care for people with dementia: Best practice case studies from domiciliary care employers developing their workforces to support people with dementia [Online] Available at: <http://www.skillsforcare.org.uk/Document-library/Skills/Dementia/Better-domiciliary-care-for-people-with-dementia.pdf> (Accessed 17 May 2014)



# 11. Housing and assistive technology

## Key points:

- Objective 10 of the National Dementia Strategy outlines the need to consider “*the potential for housing support, housing-related services and telecare to support people with dementia and their carers*”.
- In the North East 38 housing associations are members of the National Housing Federation. These associations provide 161,900 homes, including 19,924 designated properties for older people (including sheltered housing and extra-care schemes)
- Across the North East there are some examples of innovative work to improve the provision of appropriate housing for people with dementia; this includes private, public and charitable sectors initiatives. However, there is a need to share innovative practices across the region
- The North East has the potential to build on existing examples of successful cross-sector working between housing, health and social care, such as the 2014 conference ‘Transforming Dementia Care: The housing contribution’
- The use of assistive technology, such as telecare and telehealth, has become increasingly common and is becoming a mainstream service offered by housing providers

This section of the report will consider key issues relating to the provision of appropriate housing and assistive technology for people living with dementia. In particular this section of the report will outline:

- The policy context
- How the provision of appropriate housing and assistive technology for people living with dementia has been included in local plans
- Examples of work undertaken in the North East to improve the provision of appropriate housing for people with dementia
- Examples of work undertaken in the North East to improve the provision of assistive technology for people living with dementia
- Conclusions and recommendations on the provision of appropriate housing and assistive technology for people living with dementia in the North East

## 11.1 Policy context

Outlined below is the policy context specific to the provision of housing and telecare for people with dementia. This should be read in conjunction with the more general policy review in section 3 of this report.

### National Dementia Strategy

Objective 10 of the National Dementia Strategy states *“the needs of people with dementia and their carers should be included in the development of housing options, assistive technology and telecare. As evidence emerges, commissioners should consider the provision of options to prolong independent living and delay reliance on more intensive services”*.<sup>176</sup>

### Quality Standard 30 (Supporting people to live well with dementia)

Quality Statement 7 of the National Institute for Health and Care Excellence’s *Quality Standard 30* (Supporting People to live well with dementia) addresses the design and adaptation of housing for people with dementia.<sup>177</sup> The quality statement highlights the need for:

- Evidence of local arrangements to ensure staff are trained to recognise when adaptations to housing can help meet the specific needs of people with dementia
- Evidence of local arrangements to ensure that new housing for people with dementia is designed to meet their specific needs

### Extra Care Housing and Dementia Commissioning Checklist

The *‘Extra Care Housing and Dementia Commissioning Checklist’*<sup>178</sup> was produced in June 2011 by the Department of Health National Dementia Strategy Implementation Group. The checklist is designed to help stakeholders commission extra care schemes which meet the needs of people with dementia and their carers.

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<sup>176</sup> Department of Health (2009) *Living well with dementia: a National Dementia Strategy*. London: Department of Health p.12

<sup>177</sup> National institute for Health and Care Excellence (2013) *QS30: Quality standard for supporting people to live well with dementia* [Online] Available at: <http://publications.nice.org.uk/quality-standard-for-supporting-people-to-live-well-with-dementia-qs30> (Accessed 17 May 2014) Quality Statement 7

<sup>178</sup> Garwood, S. (2011) *Extra Care Housing and Dementia Commissioning Checklist* [Online] Available at: <http://www.housinglin.org.uk/Topics/browse/HousingandDementia/Commissioning/?parent=5048&child=7950> (Accessed 17 May 2014)

## Home Truths

The Alzheimer's Society's 2012 report '*Home Truths: Housing services and support for people with dementia*'<sup>179</sup> "reviews the evidence on the housing issues facing people with dementia".<sup>180</sup> The key findings of the report were:

- More needed to be done to link housing with health and social care services
- Many people with dementia and their carers wanted to be supported in their current homes, but others preferred the option of housing with care, where care is available on site. While housing with care may not be suitable for everyone, the Home Truths report says it could potentially fill a gap between mainstream homes and care homes for some people with dementia
- There are mixed experiences of accessing information and advice on housing and housing options and strong support for access to funding and support to make adaptations to the home
- More needed to be done to ensure homes were designed and built with the needs of people with dementia in mind

The report highlighted that people with dementia are more likely than not to be owner-occupiers and levels of ownership were reported to be higher among older households in the UK. Among the wider population (not specifically people living with dementia) 75% of over-65 households in England were owner-occupied and around a quarter of householders over the age of 65 live in rented accommodation.<sup>181</sup> These statistics further emphasise the need to develop housing solutions that support people with different types of tenure.

## Dementia: finding housing solutions

The report '*Dementia: finding housing solutions*' was published by the National Housing Federation, the Stirling University Dementia Services Development Centre, the Housing Learning and Improvement Network and Foundations in May 2013. The report explores how "*integrating housing into the dementia care pathway can deliver better outcomes for people with dementia*" and finds that "*specialist homes can help people with dementia meet their aspirations, and reduce hospital stays and care home admissions*".<sup>182</sup>

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<sup>179</sup> Alzheimer's Society (2012) Home Truths: Housing services and support for people with dementia [Online] Available at: <http://alzheimers.org.uk/hometruths> (Accessed 17 May 2014)

<sup>180</sup> Social Care Institute for Excellence [Online] Available at: <http://www.scie.org.uk/publications/dementia/resources/dementia-links.asp> (Accessed 17 May 2014)

<sup>181</sup> p.15

<sup>182</sup> National Housing Federation (2013) Dementia: finding housing solutions [Online] Available at: <http://www.housing.org.uk/publications/browse/dementia-finding-housing-solutions> (Accessed 17 May 2014)

## Housing Call to Action

In February 2014 the (national) Dementia Action Alliance and the Housing and Learning Improvement Network launched the Housing Call to Action in order to encourage housing providers to sign up to the national Dementia Action Alliance and/or their Local Dementia Action Alliance.

For further information visit <http://www.dementiaaction.org.uk/housing> or see section 3 of this report.

## Housing Learning and Improvement Network (LIN)

The Housing LIN acts as a “*knowledge hub*’ for a growing network of housing, health and social care professionals in England involved in planning, commissioning, designing, funding, building and managing housing with care for older people”.<sup>183</sup> The Housing LIN web page includes a wide range of information on meeting the housing and care needs of people with dementia.

For details of the North East Group contact Denise Gillie at [denise@dgconsult.co.uk](mailto:denise@dgconsult.co.uk) or visit <http://www.housinglin.org.uk/HousingRegions/NorthEast/>

## The National Housing Federation

The National Housing Federation represents housing associations in England and has more than 1,000 members, who own and manage more than 90% of the country’s housing association properties – providing around two million homes for five million people in total.

There are 38 associations, large and small, who are members of the National Housing Federation in the North East. Together, they provide 161,900 homes, including 19,924 designated properties for older people (including sheltered housing and extra-care schemes).<sup>184</sup>

The Federation has been selected to be one of the Department of Health’s strategic health partners to look at ways in which housing associations can help to reduce health inequalities, produce better health outcomes and deliver health and social care services in cost effective ways.<sup>185</sup> The Federation is a member of the national Dementia Alliance and has established a Health and Housing Working Group, which includes representation from the North East.

As part of the 2014/15 Strategic Partnership the Federation will work with members and Public Health England to explore ways of linking housing data to health to improve early intervention services for people with dementia.

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<sup>183</sup> Housing LIN [Online] Available at: <http://www.housinglin.org.uk/AboutHousingLIN/> (Accessed 17 May 2014)

<sup>184</sup> Based on 2013 member returns to the National Housing Federation

<sup>185</sup> National Housing Federation [Online] Available at: <http://www.housing.org.uk/policy/health-care-and-housing/health-hub> (Accessed 17 May 2014)

For further information about the work of the National Housing Federation in the North East contact [lynne.livsey@housing.org.uk](mailto:lynne.livsey@housing.org.uk)

## 11.2 Local plans

### Joint Strategic Need Assessments

Only the Gateshead Joint Strategic Needs Assessment (JSNA) addresses the need for appropriate housing for people living with dementia; it states that there is a need for new housing models of care and special housing models.<sup>186</sup>

### Health and Wellbeing strategies

There is national evidence that housing is not always identified in integrated health and wellbeing strategies. A King's Fund survey of 70 Health and Wellbeing Boards in October 2013<sup>187</sup> found that only 31% had a lead housing representative on the Board, leading to concerns that housing may not be included in discussions about integrated services.

In the North East only the Gateshead Health and Wellbeing Strategy (HWBS) addresses the need for appropriate housing for people living with dementia; it lists dementia as a Focus for Action (2013-2016), including an emphasis on accommodation.<sup>188</sup>

### Local joint dementia plans

Five out of the 10 local joint dementia plans reference the need to maximise the use of assistive technology to ensure a full range of housing options are available. The main reasons put forward in the plans for progressing the housing and assistive technology agendas were to avoid hospital admissions, create savings and maximise people's independence and quality of life.

Extra care housing featured strongly in three plans. Training of housing staff was referenced in two plans. Dementia friendly housing design was seen as key in only two plans.

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<sup>186</sup> Gateshead Council (2012) Gateshead Strategic Needs Assessment 2012-2017 [Online] Available at: <https://www.gateshead.gov.uk/DocumentLibrary/council/strategy/Gateshead-Strategic-Needs-Assessment-2012-17.pdf> (Accessed 17 May 2014) Key Issue 2 p.17

<sup>187</sup> Humphries, R. and A. Galea (2013). Health and Wellbeing Boards: one year on. London, The Kings Fund. [Online] Available at: <http://www.kingsfund.org.uk/publications/health-and-wellbeing-boards-one-year-on> (Accessed 17 May 2014)

<sup>188</sup> Gateshead Health and Wellbeing Board (2013) Active, Healthy and Well Gateshead: A Health & Wellbeing Strategy for Gateshead (2013/14 to 2015/16) [Online] Available at: <http://www.gateshead.gov.uk/DocumentLibrary/CBS/health/Active-Healthy-and-Well-Gateshead.pdf> (Accessed 17 May 2014)

## 11.3 Examples of work undertaken in the North East to improve the provision of appropriate housing for people with dementia

### Care and Support Specialised Housing Fund

In 2013 the Government created a new capital fund to stimulate the development of specialised housing for people with disabilities and older adults. The '*Care and Support Specialised Housing Fund*' was announced by the Department of Health in the White paper '*Caring for our future: reforming care and support*<sup>189</sup> published in July 2012. The fund will run for five years from 2013/14 and is administered through the Homes and Communities Agency. The first round of successful funding bids was announced in July 2013.

Thirteen grants were made for new developments in the North East, 12 of which are designed for older people. Of the 12 developments, 10 were for older people's extra care schemes with flexible care and support built into the care offer. While these developments are not dementia specific it is expected that they will be able to offer support and suitable accommodation for people with dementia.

Further details about the fund and links to other housing resources are available from the Homes and Communities Agency website: <http://www.homesandcommunities.co.uk/ourwork/care-support-specialised-housing-fund>.

### Transforming Dementia Care: The housing contribution

In January 2014 the National Housing Federation, the North East Association of Directors of Adult Social Services and the North East Dementia Alliance collaborated to organise a regional event aimed at encouraging effective integration between housing, health and social care, in order to meet the needs of people with dementia. The event shared learning and good practice from across the region and demonstrated how housing interventions can support early intervention and prevention, improve care pathways and deliver specialist accommodation and assistive technology that meets the needs of people with dementia.

The conference report and presentations can be accessed at:  
<http://www.housing.org.uk/events/presentations/transforming-dementia-care-the-housing-contribution/>

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<sup>189</sup> Department of Health (2012) *Caring for our future: reforming care and support*. London: Department of Health

## Gentoo Sunderland - Healthwise Project

Gentoo is a large housing and support provider in Sunderland. With funding from the North East Dementia Alliance, Gentoo has developed a software package that will help to identify people with a cognitive impairment, which may lead to a diagnosis of dementia. This software package will be used to record certain actions: e.g. lost keys or missed rent payments and appointments, which, when brought together, may indicate a cognitive impairment. The software will also allow Gentoo to identify and monitor trends and map the geographical areas in which there may be groups of people living with dementia.

Through the Healthwise project, Gentoo aims to:

- Increase the rate of diagnosis through a multi-agency approach and sharing of information
- Increase the number of people living with dementia who are supported to live independently
- Raise awareness and understanding of dementia across its neighbourhoods
- Reduce the number of people reaching crisis points, reduce unnecessary admissions to hospital and reduce early admissions to residential care
- Maximise the number of people who are supported to participate in community activities
- Reduce the incidence of tenancy breakdown and/or individuals losing their homes

Gentoo has a Wellbeing Team dealing with referrals through Healthwise via frontline staff, residents and partner agencies. Members of the Wellbeing Team have achieved an NVQ Level 2 in Dementia Awareness and are supervised by a Support Services Supervisor who has an NVQ Level 3 in Dementia Care. The team has received training from the Dementia Lead at the Sunderland Clinical Commissioning Group so that they are able to carry out General Practitioner Assessment of Cognition tests where tenants have raised concerns. This means that, where Gentoo staff come across a concern relating to memory loss, they have the expertise, knowledge and tools to ensure a resident accesses the correct support in a timely manner.

For further information contact [Lindsay.gibbins@gentoo.org.uk](mailto:Lindsay.gibbins@gentoo.org.uk)

## Dementia Care - Newcastle

The dementia charity, Dementia Care, provides shared houses for people with dementia. The accommodation offers people with dementia the opportunity to have a private bedroom but a shared house, bathroom, kitchen, living space and garden. Houses typically have four or five bedrooms and are open to people at any stage of their journey with dementia. Dementia Care provides support with personal care, administration of medicine, and domestic duties.

For further information see <http://www.dementiacare.org.uk/>

## St Anthony of Padua Community Association - Newcastle

St Anthony of Padua Community Association is developing a new housing project that will support older people with care and housing needs in Newcastle.<sup>190</sup> The project will specialise in meeting the needs of people with dementia but will not be exclusive to them. The development will provide 24 hours a day, on-site support, from St Anthony's Care Services.

The development will include 16 one bedroom flats and is expected to be completed by June 2014.

For further information see <http://www.anthonycare services.org.uk/>

## Middleton Hall - Darlington

Middleton Hall, at Middleton St George, Darlington, is a retirement village with a range of accommodation and services including a dementia community for up to 28 residents. The dementia community offers accommodation in domestic households and offers a 'domestic way of life' via group living within a community that includes vegetable gardens, chickens and a café/bakery, all of which are run with the involvement of residents.

For further information see <http://www.middletonhallretirementvillage.co.uk/>

## Sunderland City Council Design Guide

Sunderland City Council has developed the guide "*Enabling Independence: Design Guide for Independent Living*".<sup>191</sup> This guide is for developers of supported housing and there is an expectation that developers will sign up to the standards contained in the guide. The guide has extensive references to and a chapter about the requirements of people living with dementia.

The City's Long Term Housing Review published in April 2013 highlighted that, within an extra care scheme in Ford Estate, 17 apartments would be designed specifically for people with dementia: the redevelopment of a listed building in Hendon will provide extra care accommodation for people living with dementia and planning approval has been granted for an extra care scheme to include 20 specialist units for people with dementia in Southwick.<sup>192</sup>

For a copy of the guide see

<http://www.housinglin.org.uk/Topics/browse/HousingandDementia/Design/?parent=5091&child=6331>

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<sup>190</sup> St Anthony Care Services [Online] Available at: <http://www.anthonycare services.org.uk/services/extra-care-housing-scheme> (Accessed 17 May 2014)

<sup>191</sup> Sunderland City Council (2013) *Enabling Independence: Design Guide for Independent Living: Version 8* [Online] Available at: <http://www.housinglin.org.uk/Topics/browse/HousingandDementia/Design/?parent=5091&child=6331> (Accessed 17 May 2014)

<sup>192</sup> Ibid p.17



## 11.4 Examples of work undertaken in the North East in relation to assistive technology

Examples of assistive technology (AT) to support a people with dementia to live safely at home, include simple installations, from care alarm services to more sophisticated monitoring systems and devices, often referred to as 'telehealth' or 'telecare' services. There are also new advances in GPS tracking devices to ensure that people who are 'lost' can be quickly located. The technology is evolving all the time and, while it is no substitute for personalised care and support, it is one of a range of options that can help people to stay in their own home and community.

Further information on assistive technology for people with dementia can be accessed from: [http://www.atdementia.org.uk/listChildren.asp?page\\_id=17](http://www.atdementia.org.uk/listChildren.asp?page_id=17).

### Coast and Country Housing

Working across Redcar and Cleveland, Coast and Country Housing has developed an integrated service model called HomeCall Independent Living. This service model operates across different housing tenures and provides support and care that can enable people to live independently.

The service aims to:

- Promote and support independence
- Enable people to stay at home for longer
- Prevent hospital admission and re-admission
- Facilitate speedy and timely hospital discharge
- Delay admissions to residential care
- Improve quality of life
- Help manage risks and anxieties
- Provide support to families and carers

HomeCall Independent Living provides tenants with access to a range of services including personal care, practical support, social support, handyman and property repairs and assistive technology services.

HomeCall Independent Living also offers Telecare as one of the assistive technology services it can deliver to people with a wide range of support needs, including people living with dementia.

Through the use of intuitive lifestyle and environmental sensors Telecare helps manage and mitigate the risks that may arise when a person with dementia is living independently (e.g. falls, wandering, bogus callers and cooking). Environmental sensors can include fall detectors, bed/chair occupancy sensors, door entry/exit sensors, gas management sensors, extreme temperature sensors and flood sensors. These sensors can be placed in and around the home and are linked to Homecall's 24 hour monitoring and emergency response service.

For further information contact [jason\\_lowe@cchousing.org.uk](mailto:jason_lowe@cchousing.org.uk)

## 11.5 Conclusions on the provision of appropriate housing and assistive technology for people living with dementia in the North East

Housing associations have specialist expertise in working with people with complex needs and can play an important role in:

- Reducing, or delaying use of health and social care services for people with dementia
- Improving the rate of diagnosis of dementia through early intervention and support
- Delivering improved health and social care outcomes from early diagnosis to end of life care.

While the majority of people diagnosed with dementia will be living in their own homes, there is a higher risk that people will enter residential care if they can not be supported adequately at home. The North East has the potential to build on existing examples of successful cross-sector working between housing, health and social care such as the 2014 conference 'Transforming Dementia Care: The housing contribution'.

Local Housing Strategies were not reviewed as part of the research for this report.

A number of innovative housing solutions operate within the North East, notably at Gentoo. Not all people with dementia live in specialist housing and there is the need to consider the use of home improvement agencies to support home owners living in the community, and a need to recognise that a person's housing needs may change as their condition progresses.

Maximizing the use of assistive technology is the most frequently mentioned action in the joint dementia action plans in relation to housing and assistive technology. There are few dementia specific technology projects compared to those highlighted in the 2011 report '*Dementia: A North East Perspective*'.<sup>193</sup> It remains unclear if this is as a result of this type of equipment and service becoming mainstreamed.

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<sup>193</sup> Smith, D. (2011) *Dementia: A North East Perspective* [Online] Available at: <http://www.nrfoundation.org.uk/wp-content/uploads/2011/08/Dementia-A-North-East-Perspective.pdf> (Accessed 17 May 2014)

## 11.6 Recommendations on the provision of appropriate housing and assistive technology for people living with dementia in the North East

- Technology can support people with dementia to live in their own homes. Health, social care and housing providers need to work collaboratively - maximising opportunities for the appropriate use of technology to support people to live in their own homes.
- A growing number of case studies and an increasing amount of research highlights successful housing options for people with dementia in the social housing sector. The learning from this needs to continue to be disseminated among commissioners and housing providers.
- The evidence indicates that most people over the age of 65 are home owners and that two thirds of people with dementia live in their own home. Many of these people would prefer to be able to live in their own home for as long as possible. To help achieve this, a whole range of support services will be needed, from providing assistive technology, or adaptations to the fabric of the house to advice on mortgages, equity release schemes and what housing options might be most suitable for each individual.
- People already living in social rented housing are more likely to have better access to advice and information than owner occupiers and/or people in the private rented sector (the latter may be particularly vulnerable to living in poorly maintained housing).<sup>194</sup> Support and advice about housing issues needs to be given to people in the private rented housing sector.
- The North East has the potential to build on existing examples of successful cross-sector working between housing, health and social care. The first area of focus should be Gentoo Healthwise, working with the National Housing Federation, the North East Dementia Alliance, and Public Health England Knowledge and Intelligence Team to test out the learning from this project.

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<sup>194</sup> Rugg, J. and Croucher, K. (2010) Older people's experiences of renting privately. A report for Age Concern and Help the Aged. [Online] Available from: <http://www.york.ac.uk/chp/people/rugg/#publications> (Accessed 17 May 2014)

## 12. Intermediate care and reablement

### Key points:

- Improved intermediate care for people with dementia is Objective 9 of the National Dementia Strategy
- The most frequent actions in relation to intermediate care and reablement in the local joint dementia plans relate to the need to ensure that any of these generic services can be accessed and used by people living with dementia (mentioned in 5 out of the 10 plans).
- A regional ADASS reablement group was established in 2011 to offer the opportunity for local authority officers to share best practice (this group was not dementia specific)
- In February 2013 Peopletoo published their Regional Reablement Review which evaluated the reablement programmes in the 12 localities within the North East and found a difference in how services responded to the needs of people with dementia
- Some localities in the North East have taken steps to ensure generic reablement services are made more accessible to people with dementia while others have developed specialist reablement services for people with dementia, there is however a need for further work to evidence which approach provides the best outcomes for people with dementia

This section of the report will consider key issues relating to the provision of intermediate care and reablement services for people living with dementia. In particular this section of the report will outline:

- The policy context
- How intermediate care and reablement for people living with dementia has been included in local plans
- Examples of work undertaken in the North East to improve the provision of intermediate care and reablement services for people with dementia
- Conclusions and recommendations on the provision of intermediate care and reablement services for people living with dementia in the North East

In this section the term 'intermediate care' will be used to refer to *“a range of integrated services to promote faster recovery from illness, prevent unnecessary acute hospital admission and premature admission to long-term residential care, support timely discharge from hospital and maximise*

*independent living*".<sup>195</sup> The term 'reablement' will be used to describe services that "*help people accommodate illness or disability by learning or relearning the skills necessary for daily living*".<sup>196</sup>

## 12.1 Policy context

Outlined below is the policy context specific to the provision of appropriate intermediate care and reablement services for people with dementia. This should be read in conjunction with the more general policy review in section 3 of this report.

### National Dementia Strategy

Objective 9 of the National Dementia Strategy highlights the need for "*intermediate care which is accessible to people with dementia and which meets their needs*".<sup>197</sup> The strategy predated the policy and thinking around reablement.

### Intermediate Care - Halfway Home: Updated Guidance for the NHS and Local Authorities

The guidance, published in July 2009, updates the 2001 guidance on intermediate care from the Department of Health. Specific updates include guidance on:

- Inclusion of adults of all ages, such as young disabled people, managing their transition to adulthood
- Renewed emphasis on those at risk of admission to residential care
- Inclusion of people with dementia or mental health needs
- Flexibility over the length of the time-limited period for which intermediate care can be provided
- Integration with mainstream health and social care
- Timely access to specialist support as needed
- Joint commissioning of a wide range of integrated services to fulfil the intermediate care function, including social care reablement
- Governance of the quality and performance of services

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<sup>195</sup> Royal College of Physicians [Online] Available at: <https://www.rcplondon.ac.uk/press-releases/rcp-welcomes-audit-report-intermediate-care-services> (Accessed 17 May 2014)

<sup>196</sup> Social Care Institute of Excellence (2013) SCIE Guide 49: Maximising the potential of reablement [Online] Available at: <http://www.scie.org.uk/publications/guides/guide49/files/guide49.pdf> (Accessed 17 May 2014) p.2

<sup>197</sup> Department of Health (2009) Living well with dementia: a National Dementia Strategy. London: Department of Health p.12

Annex 3 of the report contains a number of 'Illustrative practice examples for mental health and dementia care.'<sup>198</sup>

## 12.2 Local plans

### Health and Wellbeing Strategies

Gateshead's Health and Wellbeing Strategy lists dementia as a Focus for Action for 2013/16 and this includes access to reablement and intermediate care services.<sup>199</sup>

### Local joint dementia plans

Five out of the 10 joint local dementia plans in the North East mention the need to ensure that generic intermediate care and reablement services are accessible to people living with dementia. Three local joint dementia plans highlight the need to develop a co-ordinated approach between different services including intermediate and reablement services. A number of the plans mentioned specific initiatives, which support intermediate care, or reablement, for people with dementia. These included the use of reablement apartments, short term care co-ordinators and support services.

## 12.3 Examples of work undertaken in the North East

### North East Reablement Group

In 2011 the North East Association of Directors of Adult Social Services established a regional reablement group to offer local authority officers the opportunity to share best practice, challenges and future development opportunities. This group was not dementia specific.

The North East Reablement Group commissioned Peopletoo Ltd to conduct an independent review of reablement services in the North East, which included information about the specific needs of particular customer groups, including people with dementia.

In February 2013 Peopletoo published its Regional Reablement Review, which evaluated the reablement programmes in each of the 12 localities within the North East. The report found a difference of approach in each locality stating "*each local authority has adopted different models for*

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<sup>198</sup> Department of Health (2009) Intermediate Care – Halfway Home Updated Guidance for the NHS and Local Authorities. London: Department of Health

<sup>199</sup> Gateshead Health and Wellbeing Board (2013) Active, Healthy and Well Gateshead: A Health & Wellbeing Strategy for Gateshead (2013/14 to 2015/16) [Online] Available at: <http://www.gateshead.gov.uk/DocumentLibrary/CBS/health/Active-Healthy-and-Well-Gateshead.pdf> (Accessed 17 May 2014)

*their re-ablement services based on local and sub-regional priorities. There is no single common model of re-ablement across the region in terms of skill mix, staffing numbers and service configuration.”<sup>200</sup>*

The review also concluded that *“there is an increased impact on the duration of re-ablement for people with dementia, mental health support needs, or learning disabilities. Authorities are all considering which is the most effective approach to re-abling these cohorts of service users, using extra care facilities and re-ablement flats as examples.”<sup>201</sup>* The report suggested that *“further work is necessary to evaluate which approaches are most effective.”<sup>202</sup>*

## North Tees and Hartlepool NHS Foundation Trust – Community Dementia Liaison Service

North Tees and Hartlepool NHS Foundation Trust provides a Community Dementia Liaison Service, which works with local authority reablement services and Tees, Esk and Wear Valleys NHS Foundation Trust. The team was set up to enhance care delivery to people with a confirmed dementia diagnosis within community and acute settings. The service aims to:

- Ensure people are able to access appropriate dementia services
- Reduce admission and readmission rates for people with dementia
- Provide a seamless, timely and safe discharge from acute providers
- Provide information for the person with dementia and carers
- Provide education and training for care staff from North Tees and Hartlepool NHS Foundation Trust

To achieve these aims the Community Dementia Liaison service:

- Screens patients in acute settings
- Provides support management plans during acute episodes
- Expedites early discharge in a safe and effective way and engages in the discharge planning process
- Provides a follow up service post discharge (irrespective of destination)
- Enables joint assessment with local authorities to ensure appropriate care and facilitate carer assessment and support
- Provides training, understanding and coping strategies to carers

The service team includes a dementia specialist nurse working within the acute setting (in both North Tees and Hartlepool) and a community team that includes a registered nurse, health occupational therapist and a mental health occupational therapist employed by Tees, Esk and Wear Valleys NHS Foundation Trust. As of May 2014, the community service was being provided in

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<sup>200</sup> Peopletoo (2013) NEPO Regional Re-ablement Review: Phase 1 Report (Unpublished) p.3

<sup>201</sup> Peopletoo (2013) NEPO Regional Re-ablement Review: Phase 1 Report (Unpublished) p.19

<sup>202</sup> Peopletoo (2013) NEPO Regional Re-ablement Review: Phase 1 Report (Unpublished) p.4

Hartlepool with the hope that, in future, it could be extended across the whole of the North Tees area.

The service has resulted in a 0% readmission rate where the first condition coded is dementia, a 35% increase in referrals to memory clinics and a 30% reduction in the need to go into long term care.

For further information contact [pauline.townsend@nth.nhs.uk](mailto:pauline.townsend@nth.nhs.uk)

## Specialist reablement practitioner for dementia - Hartlepool

In Hartlepool a specialist reablement practitioner for dementia is responsible for promoting timely diagnosis and ensuring that people with dementia have an equal opportunity to access mainstream services. The specialist reablement practitioner provides training and practical support to staff in mainstream services that provide support for people with dementia: for example, in intermediate care, social care and extra care housing).

The specialist reablement practitioner has strong links with the mental health services provided by:

- Tees, Esk and Wear Valleys NHS Foundation Trust mental health services,
- North Tees and Hartlepool NHS Foundation Trust's Community Dementia Liaison Service
- Hartlepool Borough Council's reablement service

To promote reablement in a wider capacity the practitioner has established a number of self-sustaining and socially inclusive community groups. These groups give people with dementia the opportunity to engage in meaningful activities and support the person's well-being. The groups also aim to promote positive interaction between people with and without dementia within the wider community.

For further information contact [caroline.ryder-jones1@nhs.net](mailto:caroline.ryder-jones1@nhs.net)

Hartlepool's reablement strategy can be accessed at  
[http://www.hartlepool.gov.uk/downloads/file/9746/our\\_reablement\\_strategy\\_2012-2015](http://www.hartlepool.gov.uk/downloads/file/9746/our_reablement_strategy_2012-2015)

## Improving access to reablement and intermediate care for people with dementia – North Tees

In June 2013 the Stockton and Hartlepool Dementia Collaborative undertook a five-day Rapid Process Improvement Workshop (RPIW) to make Stockton and Hartlepool Reablement and Intermediate Care services more responsive to the needs of people with dementia. The improvement workshop focussed on ways of increasing referrals into these services and tailoring them for people with dementia.



As a result of the workshop changes were made to the dementia care pathway allowing for support to people with dementia from the reablement and intermediate care teams. Changes to the process included:

- Agreeing standard access pathways into reablement service for Stockton and Hartlepool from various settings, including community and acute settings
- Agreeing a standard access route for reablement staff to obtain mental health advice and support
- Developing a common reablement guide for Stockton and Hartlepool
- Agreeing to pilot the introduction of a dementia screening tool
- Identifying the training needs for each staff group

After 30 days there was a 60% increase in the number of people with dementia accessing these services.

In order to further improve reablement services for people with dementia Stirling University was commissioned to deliver a three day 'train the trainers' programme. Amongst those receiving this training was the Reablement Coordinator in Stockton-on-Tees, who then delivered a number of sessions to all members of the reablement team.

## Reablement and prevention of unnecessary hospital admissions for people with dementia in East Durham

Greatham Hospital of God provides a home from hospital scheme. This scheme aims to provide people with dementia with emotional and practical support on admission into hospital, for the duration of their stay and upon discharge.

The home from hospital service supports the person with dementia and their family in order to minimise their stay in hospital and prevent readmission by providing practical support before, during and after their stay in hospital. The service provides support for up to six weeks after discharge and the service is free to people living with dementia.

The service can provide:

- One to one support on wards
- Practical support: e.g. shopping, prescriptions, preparation of the home, domestic duties
- Assisting and supporting with GP or hospital visits
- Medication administration

For further information contact [homefromhospital@hospitalofgod.org.uk](mailto:homefromhospital@hospitalofgod.org.uk)

## 12.4 Conclusions on the provision of intermediate care and reablement for people living with dementia in the North East

Since the launch of the National Dementia Strategy reablement has become a key mechanism for supporting people with dementia to maximise their independence following illness or injury. The actions contained within local joint dementia plans focus on the need to ensure that intermediate care and reablement services are delivered in a way that is inclusive of people with dementia. Within the North East a number of initiatives are designed to promote access to reablement service for people with dementia (e.g. employing specialist dementia reablement practitioners). In 2013 a region-wide reablement report found a difference of approach in each locality, including a difference in how services responded to the needs of people with dementia.

## 12.5 Recommendations on the provision of intermediate care and reablement for people living with dementia in the North East

- Case studies from the North East highlight different models to support the delivery of intermediate care and reablement services that are inclusive of people living with dementia. The evidence of their outputs and outcomes (against resource input) should be collated and shared. This work should include key organisations including the Dementia Hub, the Regional Reablement Group, CCGs, the Dementia Leads Group and the North East Dementia Alliance.

## 13. Care homes

### Key points:

- Living well with dementia in care homes is Objective 11 of the National Dementia Strategy and Commitment 4 of the Prime Minister’s Challenge on Dementia outlines an intention to create a *“Dementia Care and Support Compact signed by leading care home and home care providers”*
- Local plans focus on training and supporting staff through the use of liaison services. Improving services using regulation and contracts was also seen as a key action
- 397 care and nursing homes in the North East registered with the Care Quality Commission specialise in, or otherwise provide services for, adults with dementia
- As of May 2014, there were 18,599 beds in care and nursing homes registered with CQC providing services for people with dementia aged 65 years or over
- The North East ADASS Dementia Themed Network is undertaking a programme of work, during 2014/15, to improve the delivery of person-centred care for people with dementia in care homes in the North East
- Examples of specific initiatives aimed at improving the lives of people with dementia in care homes in the North East include arts and reading based projects and initiatives to make the physical environment of care homes more dementia friendly. As these initiatives were targeted within specific localities there is an opportunity for the North East Dementia Alliance to share learning from these projects across the North East

This section of the report will consider key issues relating to the care and support of people living with dementia in care homes. In particular, this section of the report will outline:

- The policy context
- How the care and support of people living with dementia in care homes has been included in local plans
- Statistics on the provision of care homes for people with dementia in the North East
- Examples of work undertaken in the North East to improve the care and support of people living with dementia in care homes
- Conclusions and recommendations on the care and support of people living with dementia in care homes in the North East

## 13.1 Policy Context

Outlined below is the policy context specific to the care and support of people living with dementia in care homes. This should be read in conjunction with the more general policy review in section 3 of this report.

### National Dementia Strategy

Objective 11 of the National Dementia Strategy highlights the need for *“improved quality of care for people with dementia in care homes by the development of explicit leadership for dementia within care homes, defining the care pathway there, the commissioning of specialist in-reach services from community mental health teams, and through inspection regimes”*.<sup>203</sup>

### Prime Minister’s Challenge on Dementia

Commitment 4 of the Prime Minister’s Challenge on Dementia outlines an intention to create a *“Dementia Care and Support Compact signed by leading care home and home care providers. Ten leading organisations have set out their commitment to deliver high-quality relationship-based care and support for people with dementia, and to engage and involve the wider community in this work”*.<sup>204</sup>

The (national) Dementia Action Alliance has been leading this initiative and, as of April 2014, 2,772 care providers had signed up to the compact (including providers based, or operating, in the North East).<sup>205</sup>

To become a signatory of the compact providers must commit to:

- Focus on quality of life for people with dementia, as well as quality of care
- Set a benchmark for high quality, relationship-based care and support for people with dementia; inspiring and encouraging their sector to take responsibility for delivering this aim, building on existing good practice
- Engage and involve the wider community to improve their support for people with dementia, including GPs and healthcare professionals
- Play their part in supporting the wider community, sharing the knowledge and skills of their staff and inviting people into their care settings

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<sup>203</sup> Department of Health (2009) Living well with dementia: a National Dementia Strategy. London: Department of Health p.12

<sup>204</sup> Department of Health (2012) Prime Minister’s Challenge on Dementia: Delivering major improvements in dementia care and research by 2015. Department of Health: London p.6

<sup>205</sup> Dementia Action Alliance [Online] Available at: <http://www.dementiaaction.org.uk/dementiacompact> (Accessed 17 May 2014)

- Work with commissioners of care for people with dementia to ensure they commission quality care services appropriately
- Clearly set out how they have delivered on this Compact to make a difference for people with dementia, their carers and families

For further information visit <http://www.dementiaaction.org.uk/dementiacompact>

## Dementia Care Audit Pilot

The Social Care Institute of Excellence (SCIE) and the Health Quality Improvement Partnership (HQIP) undertook a Dementia Care Audit pilot between February and March 2014. They recruited more than 300 care homes, for people over 65 in England, to take part. The pilot audit was based on the Quality Standards produced by the National Institute for Health and Care Excellence (NICE) and tested if the audit could be used nationally.

HQIP reported, in April 2014, that the pilot indicated that the care home sector would participate in a national care audit using a nationally agreed audit tool. The Department of Health will consider the findings from the pilot and will decide whether to implement this audit tool nationally. A decision is expected in June 2014.<sup>206</sup>

## 13.2 Local plans

### Joint Strategic Needs Assessment

Sunderland's Joint Strategic Needs Assessment (JSNA) states that 75% of people admitted to council-funded residential/nursing care in 2010/11 had dementia and highlights that this is a group with significant daily living support needs.<sup>207</sup>

### Local joint dementia plans

Six out of 10 local joint dementia plans mention the need to support care homes with the training and development of their care staff. In particular, a number of these plans highlight the importance of providing specialist staff to go into the care homes via inreach, liaison or challenging behaviour teams (this was mentioned in five out of 10 plans).

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<sup>206</sup> Healthcare Quality Improvement Partnership [Online] Available at: <http://www.hqip.org.uk/dementia-care-audit-pilot/> (Accessed 17 May 2014)

<sup>207</sup> Sunderland Joint Strategic Needs Assessment (Supporting People to Live Independently) [Online] Available at: <http://www.sunderland.gov.uk/index.aspx?articleid=6789> (Accessed 17 May 2014)

Five out of 10 local joint dementia plans identify the use of contracting and quality frameworks as a recognised method of improving care. One locality stated it would aim to work with the Care Quality Commission to develop appropriate contracting and quality frameworks.

Driving up the quality of care for people with dementia in care homes was a recurring theme in the local joint dementia plans. This included facilitating the sharing of good practice (two plans) and specific initiatives promoting person centred care, reminiscence and life story work.

The role of care homes in reducing hospital admissions and the need to get value for money was mentioned in three plans.

## 13.3 Statistics on the provision of care homes for people with dementia in the North East

According to the report '*Dementia: A state of the nation report on dementia care and support in England*' approximately two thirds of care home residents are thought to have dementia.<sup>208</sup>

### Care Quality Commission Registered Care Homes in the North East

Table 12 shows that, in the North East in May 2014, 397 care and nursing homes were registered with the Care Quality Commission (CQC) as providing services for people with dementia (of all ages).<sup>209</sup> A further 186 care and nursing homes are for people aged 65 and over but are not registered as providing services for adults with dementia. Although not registered as providing services for people with dementia it is possible these care/nursing homes provide services to people whose dementia has not been diagnosed.

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<sup>208</sup> Department of Health (2013) *Dementia: A state of the nation report on dementia care and support in England* [Online]

[https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/262139/Dementia.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/262139/Dementia.pdf) (Accessed 17 May 2014) p.6

<sup>209</sup> This is defined by the CQC as "Type of Service" and included in this figure are care homes that are listed as providing the "specialism / service" for people with dementia. This does not include homes where the primary purpose is rehabilitation. Care Quality Commission Registered Care Homes. [Online] Available at: <http://www.cqc.org.uk/> (Accessed April 2014)

	North East Total	Provides services for people with dementia <65	Provides services for people with dementia & 65+	Provides services for people aged 65+, but not with dementia
Care home with nursing	222	5	142	75
Care home without nursing	316	4	216	96
Care home that provides both nursing and non-nursing care	45		30	15
<b>Total</b>	<b>583</b>	<b>9</b>	<b>388</b>	<b>186</b>

**Table 12:** Providers of Home Care services on CQC care directory in North East England providing services to support people with dementia. Source: CQC Care Directory 10 April 2014

[www.cqc.org.uk/cqcdata](http://www.cqc.org.uk/cqcdata)

Table 13 shows that the greatest number of care homes, providing both dementia care and care for people over 65-years-old, can be found in County Durham (107) and Northumberland (98). These are the same local authorities with the highest numbers of people predicted to have dementia.<sup>210</sup> The lowest numbers of care homes (providing both dementia care and care for people over 65 years) are in Hartlepool (21) and Darlington (29) which are the authorities which have the lowest number of people predicted to have dementia.

<sup>210</sup> Durham, Northumberland, Newcastle and Sunderland

Care Home -Count of CQC Provider ID	Provides services for people with dementia	Provides services for people aged 65+, but not with dementia
<b>North East</b>	<b>397</b>	<b>186</b>
Darlington	18	11
Durham	73	34
Gateshead	28	16
Hartlepool	14	7
Middlesbrough	17	12
Newcastle upon Tyne	34	24
North Tyneside	27	14
Northumberland	68	30
Redcar & Cleveland	23	13
South Tyneside	27	3
Stockton-on-Tees	23	14
Sunderland	45	8

**Table 13:** Care homes on CQC care directory in North East England providing services to support people with dementia excluding rehabilitation services. Source: CQC Care Directory 10 April 2014 [www.cqc.org.uk/cqcdata](http://www.cqc.org.uk/cqcdata)

### Number of beds in Care Quality Commission Registered Care Homes in the North East

Table 14 shows that, as of May 2014, 18,599 beds in care and nursing homes are registered with CQC as providing services for people with dementia aged 65 or over.<sup>211</sup> In addition, a further 6,238 beds in care and nursing homes are for people aged 65 and over but are not registered as providing services for adults with dementia. Although not registered as providing services for people with dementia, it is possible these care/nursing homes provide services to people whose dementia has not been diagnosed.

The greatest number of beds in care and nursing homes (providing both dementia care and care for people over 65 years) can be found in County Durham (5,084) and Northumberland (3,392). These are the same local authorities with the highest numbers of people predicted to have dementia.<sup>212</sup> The lowest numbers of beds in care and nursing homes (providing both dementia care and care for people over 65 years) are in Hartlepool (947), which is the authority with the lowest number of people predicted to have dementia.

<sup>211</sup> This is defined by the CQC as “Type of Service” and included in this figure are care homes that are listed as providing the “specialism / service” for people with dementia. This does not include homes where the primary purpose is rehabilitation. Care Quality Commission Registered Care Homes. [Online] Available at: <http://www.cqc.org.uk/> (Accessed April 2014)

<sup>212</sup> Durham, Northumberland, Newcastle and Sunderland



Local Authority	Care homes that provide both nursing and non-nursing care		Care homes with nursing		Care homes without nursing		Total
	Dementia	Non-dementia	Dementia	Non-dementia	Dementia	Non-dementia	
Darlington	60	-	380	194	499	117	1,250
Durham	617	262	2,101	567	1,137	400	5,084
Gateshead	133	-	797	326	551	142	1,949
Hartlepool	183	-	143	49	427	145	947
Middlesbrough	-	44	414	239	634	175	1,506
Newcastle upon Tyne	138	47	790	580	617	294	2,466
North Tyneside	142	48	341	405	553	155	1,644
Northumberland	173	124	961	363	1,384	387	3,392
Redcar & Cleveland	-	-	365	97	492	179	1,133
South Tyneside	121	-	350	40	677	75	1,263
Stockton-on-Tees	-	48	561	409	666	91	1,775
Sunderland	197	146	1,010	76	985	14	2,428
<b>North East</b>	<b>1,764</b>	<b>719</b>	<b>8,213</b>	<b>3,345</b>	<b>8,622</b>	<b>2,174</b>	<b>24,837</b>

**Table 14:** North East England registered care home bed capacity for people aged 65 years and over. Source: CQC Care Directory 7 May 2014 [www.cqc.org.uk/cqcdata](http://www.cqc.org.uk/cqcdata)

## 13.4 Examples of work undertaken in the North East

### Implementing person-centred practices and personalisation in care homes across the North East

The dementia themed network of the North East Association of Directors of Adult Social Services and the North East Dementia Alliance are jointly undertaking a programme of work to improve the delivery of person-centred care for people with dementia in care homes in the North East. The project, which will take place during 2014/15, will engage 20 residential and nursing care homes that provide care for people living with dementia within each of the 12 localities in the North East.

Managers from participating care homes will be supported to complete a self-assessment tool entitled '*Progress for Providers: Checking your progress in delivering personalised support for people living with dementia*'.<sup>213</sup> This tool will allow care home providers to examine their practices, policies,

<sup>213</sup> Helen Sanderson Associates (2012) *Progress for Providers: Checking your progress in delivering personalised support for people living with dementia*[Online]Available at: <http://progressforproviders.org/checklists/delivering-personalised-support-for-people-living-with-dementia/> (Accessed 17 May 2013)

knowledge and skills and measure their progress in delivering personalised support for people living with dementia. In addition, managers will receive specialised training and support.

Once practice is assessed this tool will highlight areas of strength as well as development needs for each participating care home. The tool will also assist teams to produce action plans to improve practice detailing what each care home should aspire to achieve.

This work will be delivered by The Tyne and Wear Care Alliance in conjunction with Helen Sanderson Associates.

## Room for the Imagination Project

Equal Arts was commissioned by NHS South of Tyne and Wear to implement a training programme that would develop the capacity of the care home workforce to deliver arts-based approaches beyond sessional activities. Equal Arts is a registered charity that works with professional artists to improve the access of older people to high quality arts activity. The programme included weekly art-based training sessions in nine care homes in Gateshead, South Tyneside and Sunderland over an eight month period to May 2013.

The programme was evaluated by a research team at Northumbria University. One of the main findings of the evaluation was that a key way in which care staff learn is by engaging with work-based artists that can lead to positive 'cultural change.'

For further information see <http://www.equalarts.org.uk/>

## Get into Reading Project

The Get into Reading Project has trained volunteers in Stockton-on-Tees to read out loud to people with dementia. The sessions are based on carefully selected literature and can be delivered either as a group or on a one-to-one basis. From October 2012 to June 2013 the project trained 32 volunteers and established reading groups at a number of venues including care homes and a day service. During the project 85 people with dementia were beneficiaries.

The project aims to achieve a number of therapeutic outcomes for people with dementia, including improved social interaction, mood and concentration for people with dementia, while also reducing agitation. Achievement of these aims was measured using questionnaires. The responses to these questionnaires indicated positive outcomes for those living with dementia who attended the sessions. The questionnaires also suggested that there were beneficial effects for carers and volunteers.

## Dementia Friendly Environments in Care Homes

In October 2012 the Department of Health announced that *“up to £50 million will be available to NHS Trusts and local authorities working in partnership with social care providers to help tailor hospitals and care homes to the needs of those with dementia”*.<sup>214</sup>

In the North East 13 projects were successful in receiving funding through this source. The successful projects included a number of care homes. These were:

**Durham County Council** - Improving the environments in local care homes (Abigail Lodge, Barrington Lodge, Langley Park, Stanley Park, Brockwell Court, Bishopsgate Lodge and Redwell Hills)

**Redcar & Cleveland Borough Council** - Brookfields Care Home in Lazonby secured £237k to provide four additional en suite rooms for people with dementia and to adapt its internal and external facilities to improve the quality of life for people with dementia. The work will be evaluated nationally and the learning from Brookfields will be shared with other care homes in the area.

For further information on North East projects which received funding through the Department of Health, see section 18 of this report.

## Reducing unnecessary attendance at Accident and Emergency

In 2013 the Stockton and Hartlepool Dementia Collaborative organised a Rapid Process Improvement Workshop (RPIW) to explore ways of preventing unnecessary attendance at Accident and Emergency for people living with dementia in care homes. The event resulted in a significant reduction in 999 calls from pilot homes. As a result of this, Hartlepool and Stockton CCG agreed to fund the rollout of these changes to all care homes across Stockton-on Tees and Hartlepool in 2014. The training programme, which is being rolled out in Stockton-on Tees during spring 2014, is being delivered by Care Plus in conjunction with Newcastle College and will ensure:

- All care home residents receive regular physical health monitoring and have the opportunity to complete the ‘Deciding Right’ documentation
- Care home staff use a standard communication tool to report health deterioration to GPs, nurses, 111 and 999 services, to enable them to make a more informed decision
- All care home residents have the appropriate information needed ready in advance to accompany them on the ambulance and for use in hospital to provide person centred care, if hospital admission is required
- Documentation is updated and returned back to the care home with the resident on discharge

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<sup>214</sup> Department of Health [Online] Available at: <https://www.gov.uk/government/news/50-million-investment-to-give-people-with-dementia-specially-designed-care-homes-and-wards> (Accessed 17 May 2014)

Once all homes have received training the number of residents admitted to hospital will be monitored.

For further information contact [corinne.walsh@nhs.net](mailto:corinne.walsh@nhs.net)

## The Newcastle, Northumberland County and South of Tyne Challenging Behaviour Teams

Northumberland NHS Foundation Trust hosts three specialist teams supporting the treatment of behaviours that challenge. The teams work with staff in care homes, specialist mental health wards and in the community in Newcastle, Northumberland and Sunderland and South Tyneside. The Newcastle team developed a framework of care known as the Newcastle Model, which is now recognised as one of the premier person-centred approaches in the UK.<sup>215</sup> National Education Scotland has adopted the approach and provided staff training programmes to apply the model throughout Scotland.<sup>216</sup>

## INTERACT

Northumbria University has facilitated an action learning project to develop the INTERACT<sup>217</sup> framework. The framework provides a model to support care home staff to think through strategies that can be adopted in a care home to support the development of social relationships. The INTERACT model includes:

- a) Auditing the home against each dimension of the INTERACT framework
- b) Using the INTERACT learning resource for staff to consider the evidence in relation to social interaction and reflect on practice
- c) Staff development and implementing practices that address the barriers to social interaction in care homes and enhance the development of social relationships

The INTERACT model is complemented by the use of technologies. As part of the service development care staff are encouraged to utilise robot technology to promote social interaction in the context of facilitated group discussion. The PARO, developed by AIST in Japan, is an artificial

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<sup>215</sup> James, I.A. (2011). Understanding Behaviour in Dementia that Challenges: A guide to assessment and dementia. London: Jessica Kingsley

<sup>216</sup> <http://www.nes.scot.nhs.uk/education-and-training/by-discipline/psychology/multiprofessional-psychology/psychology-and-psychological-interventions-in-dementia/training-programmes.aspx>

<sup>217</sup> Cook, G. Clarke, C. and Cowie, B. Maintaining and developing social interaction in care homes: A workbook for care home, health and social care staff (2009) [Online] Available at: [http://www.dhcarenetworks.org.uk/\\_library/resources/dementia/regions/northeast/maintaining\\_and\\_developing\\_social\\_interaction\\_in\\_care\\_homes.pdf](http://www.dhcarenetworks.org.uk/_library/resources/dementia/regions/northeast/maintaining_and_developing_social_interaction_in_care_homes.pdf) (Accessed 17May 2014)

emotional response companion robot in the form of a harp seal. It was designed to interact with and develop an emotional attachment to human beings. PARO facilitated group discussions focus on human-robot interaction. Weekly sessions commence with orientation, followed by familiarisation with PARO and, eventually, discussions concerning PARO and the participants' stories and experiences of pets and animals. The latter stages of the group discussions give care home residents the opportunity to reflect on the experiences of interacting with the PARO. It is also a failure free activity in which individuals with severe cognitive problems and disabilities can participate.

For further information contact [glenda.cook@northumbria.ac.uk](mailto:glenda.cook@northumbria.ac.uk)

## Quality in Care Homes Event

In October 2013 the Northern CCG Forum hosted an event to look at how quality in care homes could be assured. The event was not specific to the needs of people with dementia living in care homes. The event aimed to:

- Increase understanding of the current quality and monitoring systems for care homes
- Map variations in the ways local authorities and CCGs work together on performance and quality in care homes
- Examine what works well and what current gaps exist locally
- Identify how gaps could be rectified locally

A number of suggestions were made which could be taken forward regionally including the use of the 'Tees Tool', development of a clinical network for care homes and the use of integrated funding (health and social care) for care homes.

It was not possible to assess the outcomes of this event before this report was published, due to staff changes in the NHS.

## 13.5 Conclusions on the provision of care and support for people living with dementia in care homes in the North East

The geographic distribution of nursing and care homes in the North East appears to reflect demographic trends, with localities that are estimated to have the highest expected numbers of people living with dementia also containing the greatest number of care homes providing services for people with dementia. As of May 2014, 18,599 beds in care and nursing homes were registered with CQC as providing services for people with dementia aged 65 or older.

External systems are being used to improve the quality of care delivered in care homes. These include the use of audits, liaison services and contract management.

A number of care homes in the North East have received funding from the Department of Health to make environmental improvements to make the homes more dementia friendly. A major project between North East ADASS and the North East Dementia Alliance is delivering training on person centred approaches to staff in 240 homes out of 343 (70%) in the region during 2014/15.

## 13.6 Recommendations on the provision of care and support for people living with dementia in care homes in the North East

- The information available does not tell us what occupancy levels are in care homes, or the triggers for admission to a care home. This information would support commissioners to deliver better services and it needs to be identified and, where possible, sourced.
- The North East ADASS and North East Dementia Alliance have commissioned person centred training for 240 care and nursing homes in the region in 2014/15. An evaluation of the outcome of this work needs to be completed and appropriate actions need to be taken as a result of this review.
- A statistical care home report was published in November 2011.<sup>218</sup> This needs to be revised and updated.
- A regional workshop in 2013 brought together professionals from health and social care with the aim of improving the quality of care delivered in care homes across the North East. This approach needs to be built on to improve care for people living with dementia in all care homes in the North East.

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<sup>218</sup> Jackson, M. (2011) Report on the Profile of Care Homes in North East England Licensed to Support Older People & People With Dementia [Online] Available at:  
[http://www.nepho.org.uk/securefiles/140527\\_2140//Profile%20of%20Care%20Homes%20in%20the%20North%20East%20-%20July%202011.pdf](http://www.nepho.org.uk/securefiles/140527_2140//Profile%20of%20Care%20Homes%20in%20the%20North%20East%20-%20July%202011.pdf) (Accessed 17 May 2014)

## 14. General hospitals

### Key points:

- Objective 8 of the National Dementia Strategy sets out the need for *“improved quality of care for people with dementia in general hospitals”* while Commitment 2 of the Prime Minister’s Challenge on Dementia outlines the need for *“financial rewards for hospitals offering quality dementia care”*
- All but one of the Strategic Plan Documents for 2013/14 for the eight acute NHS foundation trusts in the North East included an explicit reference to meeting the needs of people with dementia, while five out of the eight trusts have either a dementia strategy or action plan
- Across the North East the number of people being admitted to hospital as an emergency where the primary diagnosis was recorded as dementia, has decreased by 34.1% between 2006/07 and 2011/12
- All the acute NHS foundation trusts in the North East have committed to the call to action ‘The Right Care: creating dementia friendly hospitals’
- Initiatives designed to improve the care of people with dementia in hospitals in the North East include work to make the physical environment of hospitals more dementia friendly and the implementation of ‘Forget me not’, ‘This is me’ and ‘All about me’ schemes

This section of the report will consider key issues relating to the provision of general hospital care for people living with dementia in the North East. In particular, this section of the report will outline:

- The policy context
- How the care of people with dementia in general hospitals has been included in local plans in the North East
- North East statistics relating to emergency admissions to general hospitals
- Examples of work undertaken to improve the care of people with dementia in general hospitals in the North East
- Conclusions and recommendations on the care of people with dementia in general hospitals in the North East

## 14.1 Policy context

Outlined below is the policy context specific to the care of people living with dementia in general. This should be read in conjunction with the more general policy review in section 3 of this report.

### National Dementia Strategy

Objective 8 of the National Dementia Strategy sets out the need for *“improved quality of care for people with dementia in general hospitals”*. Objective 8 particularly highlights the importance of *“identifying leadership for dementia in general hospitals, defining the care pathway for dementia there and the commissioning of specialist liaison older people’s mental health teams to work in general hospitals.”*<sup>219</sup>

### Prime Minister’s Challenge on Dementia

Commitment 2 of the Prime Minister’s Challenge on Dementia outlines the need for *“financial rewards for hospitals offering quality dementia care”*. The Prime Minister’s Challenge on Dementia states that *“from April 2012, £54m will be available through the Dementia CQUIN to hospitals offering dementia risk assessments to all over-75s admitted to their care. From April 2013, this will be extended to the quality of dementia care delivered. Also for April 2013, access to CQUIN rewards will be dependent on delivering support for carers in line with NICE/SCIE guidelines”*.<sup>220</sup>

For further information on the CQUIN for hospitals and its application in the North East see section 7 of this report.

### National Audit of Dementia (care in general hospitals)

The National Audit of Dementia (care in general hospitals) was initiated in 2008 to *“examine the quality of care received by people with dementia in general hospitals”*.<sup>221</sup>

The first round of the National Audit of Dementia was carried out in 2010/11 and the follow up report concluded that *“hospitals needed to design and implement an integrated approach to the care of people with dementia and highlighted improvements to be made at all levels”*.<sup>222</sup>

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<sup>219</sup> Department of Health (2009) Living well with dementia: a National Dementia Strategy. London: Department of Health p.12

<sup>220</sup> Department of Health (2012) Prime Minister’s Challenge on Dementia: Delivering major improvements in dementia care and research by 2015. Department of Health: London

<sup>221</sup> Royal College of Psychiatrists (2013) National Audit of Dementia care in general hospitals 2012-13: Second round audit report and update. Editors: Young J, Hood C, Gandesha A and Souza R. London: HQIP p.6



Following the first national audit a bespoke report was produced outlining the findings of the audit in relation to the North East.<sup>223</sup>

The second round of the audit collected data between April and October 2012. The report '*National Audit of Dementia Care in General Hospitals 2012/13: Second Round Audit Report and Update*' was released in 2013 and contained the findings of the audit, along with a number of recommendations to improve the care of people with dementia in general hospitals.<sup>224</sup>

## Dementia Assessment and Referral CQUIN 2013/14

The Commissioning for Quality and Innovation (CQUIN) payment framework enables commissioners to reward high quality or innovative services, by making a proportion of English healthcare providers' income conditional on demonstrating improvements in quality and innovation in specified areas of care.<sup>225</sup>

One of the four national CQUIN goals for 2013/14 was "improving dementia care, including sustained improvement in **Finding** people with dementia, **Assessing** and **Investigating** their symptoms and **Referring** for support (FAIR)".<sup>226</sup>

*Everyone Counts: Planning for Patients 2014/15 to 2018/19* states that a CQUIN scheme will be in place for 2014/15. Although similar to the 2013/14 CQUIN this has been broadened to include delirium with one of the four national improvement goals for the 2014/15 CQUIN scheme being: "improving dementia and delirium care, including sustained improvement in **Finding** people with dementia, **Assessing** and **Investigating** their symptoms and **Referring** for support (FAIR)".

For further information on the 2014/15 CQUIN scheme see *Commissioning for quality and innovation (CQUIN): 2014/15 guidance*.<sup>227</sup>

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<sup>222</sup> Royal College of Psychiatrists (2011) National Audit of Dementia Care in General Hospitals in 2011. Editors: Young J, Hood C, Wolley R, Gandesha A and Souza R. London: HQIP

<sup>223</sup> Royal College of Psychiatrists (2010) Regional Report: North East [Online] Available at: [http://www.phine.org.uk/securefiles/140527\\_2146//Royal%20College%20of%20Psychiatrists%20North%20East%20Report.pdf](http://www.phine.org.uk/securefiles/140527_2146//Royal%20College%20of%20Psychiatrists%20North%20East%20Report.pdf) (Available at 17 May 2014)

<sup>224</sup> Royal College of Psychiatrists (2013) National Audit of Dementia care in general hospitals 2012-13: Second round audit report and update. Editors: Young J, Hood C, Gandesha A and Souza R. London: HQIP

<sup>225</sup> NHS England (2013) Everyone Counts: Planning for Patients 2014/15 - 2018/19 [Online] Available at: <http://www.england.nhs.uk/wp-content/uploads/2013/12/5yr-strat-plann-guid-wa.pdf> (Accessed 17 May 2014)

<sup>226</sup> Department of Health (2013) Commissioning for Quality and Innovation (CQUIN): 2013/14 guidance [Online] Available at: <http://www.england.nhs.uk/wp-content/uploads/2013/02/cquin-guidance.pdf> (Accessed 17 May 2014) p.22 also

Department of Health (2012) Using the Commissioning for Quality and Innovation (CQUIN) payment framework: Guidance on new national goals for 2012-13 [Online] Available at: [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/215049/dh\\_133859.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/215049/dh_133859.pdf) (Accessed 17 May 2014)

See section 7 of this report for further information on how the CQUIN has been implemented in the North East.

## Care update report Issue 2 - March 2013 - Care Quality Commission Report

The care update report (Issue 2) outlined the Care Quality Commission's review of the performance of care services in England during the nine-month period to 31st December 2012. The following issues were highlighted in relation to hospital care:

- In more than half of all PCT areas, people with dementia living in a care home were more often admitted to hospital with avoidable conditions than those who did not have dementia
- In almost a third of hospital admissions of people with dementia there was no record of the person's dementia
- People with dementia have longer stays in hospital, more readmissions and higher mortality rates than similar people without dementia
- The impact on outcomes for patients with dementia was greater in relation to elective admissions
- The impact on outcomes for patients with dementia was greater in younger age groups<sup>228</sup>

## 14.2 Local plans

### CCG Commissioning intentions

All the Clinical Commissioning Groups (CCGs) must agree to implement the national priorities on improving care in hospitals for people with dementia. Some of the North East CCGs set these objectives out in detail, some do not. All the CCGs say they will be offering the national CQUIN scheme to their local acute trusts.

North Durham and Darlington CCG plans specifically mention their aim to reduce unnecessary hospital admissions of people living with dementia.

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<sup>227</sup> NHS England (2014) Commissioning for quality and innovation (CQUIN): 2014/15 guidance [Online] Available at: <http://www.england.nhs.uk/statistics/wp-content/uploads/sites/2/2013/09/CQUIN-Guidance-2014-15-PDF-751KB.pdf> (Accessed 17 May 2014)

<sup>228</sup> Care Quality Commission (2013) Care Update: Issue 2: March 2013 [Online] Available at: [http://www.cqc.org.uk/sites/default/files/media/documents/cqc\\_care\\_update\\_issue\\_2.pdf](http://www.cqc.org.uk/sites/default/files/media/documents/cqc_care_update_issue_2.pdf) (Accessed 17 May 2014)

## Local joint dementia plans

Six out of the 10 local joint dementia plans in the North East mention the importance of staff training and development. Five out of the 10 plans refer to the review or development of liaison services which support staff and patients. Five out of the 10 plans have actions to improve the environment of hospitals using existing resources such as the Stirling University best practice guidance.<sup>229</sup>

National initiatives, including the delivery of the FAIR CQUIN<sup>230</sup> (3 plans) and the use of the Royal College of Psychiatrists Audit of General Hospital Care (3 plans),<sup>231</sup> feature in local joint dementia plans.

Areas for further work identified in local joint dementia plans include readmissions, use of A&E and length of stay (3 plans). South Tees NHS Foundation Trust highlights it will use social media to progress its work.<sup>232</sup>

## Strategic plans of acute NHS Foundation Trusts in the North East

All but one of the Strategic Plan Documents for 2013/14 of the North East's eight acute NHS foundation trusts included an explicit reference to meeting the needs of people with dementia.

Table 15 outlines the areas of improvement (in relation to people with dementia and their carers) highlighted in the eight Strategic Plan Documents for 2013/14.

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<sup>229</sup> Stirling University [Online] Available at: <http://dementia.stir.ac.uk/>

<sup>230</sup> NHS England (2014) Commissioning for quality and innovation (CQUIN): 2014/15 guidance [Online] Available at: <http://www.england.nhs.uk/statistics/wp-content/uploads/sites/2/2013/09/CQUIN-Guidance-2014-15-PDF-751KB.pdf> (Accessed 17 May 2014)

<sup>231</sup> Royal College of Psychiatrists (2013) National Audit of Dementia care in general hospitals 2012-13: Second round audit report and update. Editors: Young J, Hood C, Gandesha A and Souza R. London: HQIP

<sup>232</sup> See for example <https://twitter.com/steesdementia>

Area of improvement	Number of Strategic Plan Documents referring to area of improvement
Improved care/personalised care (using Forget me Not or equivalent)	5
Support for carers	5
Patient safety (including preventing falls and serious injuries and reducing the risk of malnutrition and dehydration)	3
Diagnosis (Identification, assessment and referral)	3
Appropriate training of staff	3
Making environments dementia friendly	3
Reducing avoidable (re)admissions	2
Providing off site support	2
Improved care pathways	2
Reducing the length of stay	1

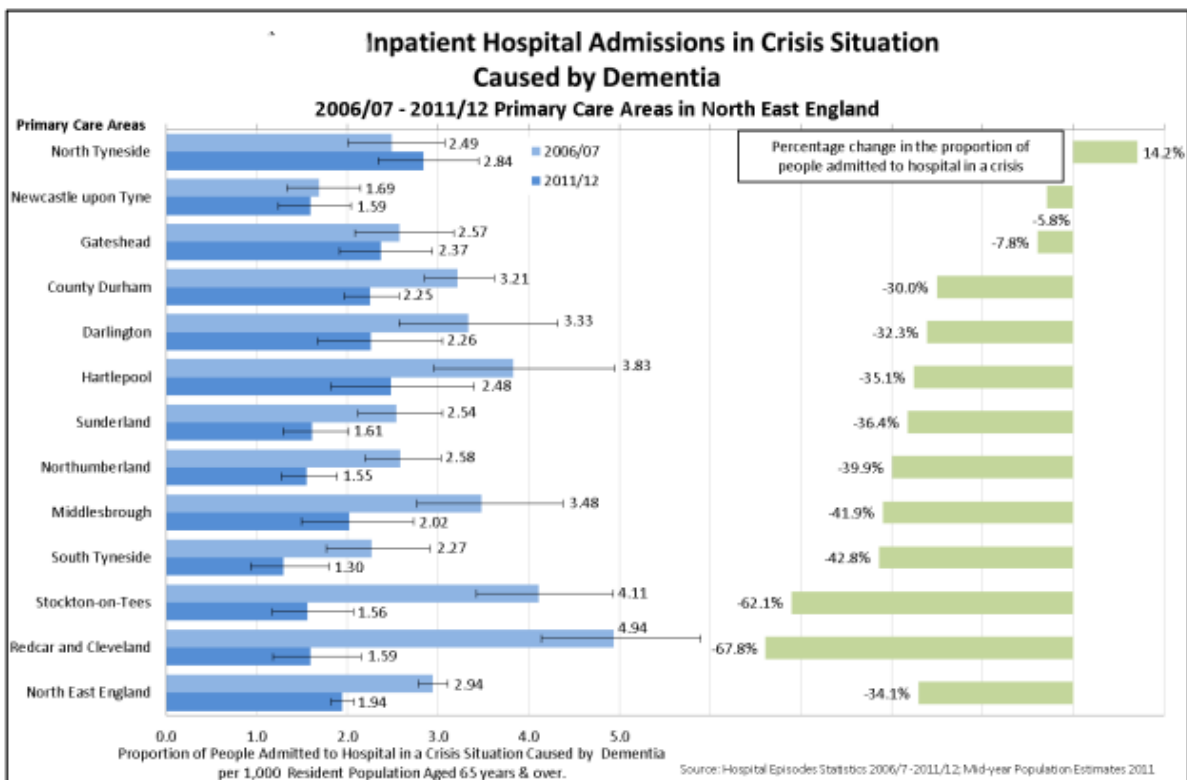
**Table 15:** Areas of improvements outlined in the Strategic Plan Documents for 2013/14 of the eight acute NHS foundation trusts in the North East (in relation to people with dementia and their carers)

## 14.3 North East statistics relating to the care of people living with dementia in general hospitals

### Emergency hospital admissions where the primary diagnosis is dementia

Research by Public Health England Knowledge and Intelligence Team Northern and Yorkshire found that, across the North East:

- The number of people admitted to hospital as an emergency, where the primary diagnosis was recorded as dementia, had decreased by 34.1% between 2006/07 and 2011/12
- This represented a reduction from 2.94 individuals per 1,000 population estimated with dementia aged 65 years and over, to a rate of 1.94
- All primary care areas in the region recorded a fall in the rates of admissions, ranging from 5.8% to 67.8% (except in North Tyneside where the rate of admissions increased by 14.2%)
- The largest reductions in rates were in Redcar & Cleveland and Stockton-on-Tees (62.1%)
- The lowest rate of admissions in 2011/12 was in South Tyneside (1.30 individuals per 1,000 aged 65 years and over estimated with dementia) while in North Tyneside the rate was the highest (2.84)<sup>233</sup>



**Figure 6:** Inpatient Hospital Admissions in Crisis Situations Caused by Dementia: 2006/07 – 2011/12 Primary Care Areas in North East England. Source: Public Health England (2013) Improving the dementia diagnosis rate in North East England 2013: An update on prevalence rates; diagnosis rates; crisis related hospital admissions.

<sup>233</sup> Public Health England (2013) Improving the dementia diagnosis rate in North East England 2013: An update on prevalence rates; diagnosis rates; crisis related hospital admissions [Online] Available at: [http://www.nepho.org.uk/securefiles/140511\\_2202/Improving%20the%20Dementia%20Diagnosis%20Rate%20in%20North%20East%20England%202013.pdf](http://www.nepho.org.uk/securefiles/140511_2202/Improving%20the%20Dementia%20Diagnosis%20Rate%20in%20North%20East%20England%202013.pdf) (Accessed 17 May 2014) p.14

## Mortality among those with dementia, compared with similar people without dementia

The Care Quality Commission's thematic review of 2012/13 stated that mortality rates in hospitals in England, were more than a third higher (36%) among those with dementia when compared to similar people without dementia. The review also found that, among people with dementia, mortality rates were higher among elective admissions (148%) than emergency admissions (36%).<sup>234</sup>

## 14.4 Examples of work undertaken in the North East

### Groups, leads and strategies in general hospitals

Trust name	Dementia strategy	Action plan	Action group	Dementia lead	Comments
<b>County Durham and Darlington NHS Foundation Trust</b>	✓	✓	-	✓	
<b>North Tees and Hartlepool NHS Foundation Trust</b>	✓	-	✓	-	Dementia sits in the 'Integrated Care Pathway Group for Dementia and the Older Person Pathway.' Dementia strategy is in development.
<b>South Tees Hospitals NHS Foundation Trust</b>	✓	✓	✓	✓	
<b>Gateshead Health NHS Foundation Trust</b>	✓	✓	✓	✓	Pathway for dementia care introduced to all wards. <sup>235</sup> There are 4 work streams under the Dementia Steering Group.
<b>Newcastle upon Tyne Hospitals NHS Foundation Trust</b>	-	✓	✓	✓	Dementia pathway in place.
<b>South Tyneside NHS Foundation Trust</b>	✓	-	✓	-	Strategy out for consultation. Refreshing action group. May include pathway development.

<sup>234</sup> Care Quality Commission (2013) The state of health care and adult social care in England in 2012/13: Technical Annex 3: Dementia thematic review. London: The Stationery Office p. 4

<sup>235</sup> Gateshead Health NHS Foundation Trust (2012) Forward Plan Strategy Document for 2012-13 [Online] Available at: <http://www.monitor.gov.uk/home/news-events-publications/our-publications/browse-category/reports-nhs-foundation-trusts/reviews-3> (Accessed 17 May 2014) p.15

<b>Northumbria Healthcare NHS Foundation Trust</b>	-	-	✓	✓	Responsibility for leading on dementia sits with the 'Person Centred Care Group.' Plans regarding a dementia strategy and training are to be confirmed in spring 2014.
<b>City Hospitals Sunderland NHS Foundation Trust</b>	✓	✓	-	✓	Carers group to be started in July 2014.

**Table 16:** Dementia strategies, action plans and dementia leads in general hospitals in the North East. Source: Table based on responses from acute trust representatives

## The Right Care: creating dementia friendly hospitals

All eight NHS acute hospital trusts in the North East have committed to the call to action 'The Right Care: creating dementia friendly hospitals'. As of May 2014, four acute trusts in the North East had submitted plans outlining what they will do to become more dementia friendly. These were:

- City Hospitals Sunderland NHS Foundation Trust
- Northumbria Healthcare NHS Foundation Trust
- South Tees Hospitals NHS Foundation Trust
- South Tyneside NHS Foundation Trust

For further information on 'The Right Care: creating dementia friendly hospitals,' see section 3 of this report.

The drive to create more dementia friendly hospitals in the North East was bolstered by the Dementia Friendly Hospital conference held in Durham during December 2012. The event, which was organised by NHS North East, featured best practice examples, a presentation by Angela Rippon and was attended by more than 100 healthcare workers from across the North East.

## Stirling University training for hospitals in the North East

In June 2012 the North East Strategic Health Authority funded Stirling University to deliver a training course to representatives from each of the hospital and mental health trusts in the North East. The training course outlined the principles of dementia friendly design. Following the training sessions each trust completed an audit of its environment and completed an action plan. Each trust then received £5k funding from the Strategic Health Authority to support the implementation of their action plans. This process was followed by a number of workshops that allowed trusts to share ideas and learning. Examples of environmental changes resulting from these workshops included decoration in wards and corridors to help with orientation, the purchase of day and night time orientation clocks, coloured crockery and dark coloured, contrasting, toilet seats.

## Dementia friendly environments in hospitals

In October 2012 the Department of Health announced that *“up to £50 million will be available to NHS Trusts and local authorities working in partnership with social care providers to help tailor hospitals and care homes to the needs of those with dementia”*.<sup>236</sup>

In the North East a total of 13 projects were successful in receiving funding through this source. Three successful projects included plans to make hospitals more appropriate for people with dementia. These were:

**County Durham & Darlington NHS Foundation Trust** - £1,034k was awarded to improve the environment of care for people with dementia in the general outpatient department of Darlington Memorial Hospital.

**Newcastle Hospitals** - £380k was awarded to enhance the acute care environment and to reduce the distress, disorientation and anxiety that admission to hospital can mean for some people with dementia. The Trust has redesigned and refurbished the day areas on all eight of the wards in the Directorate of Older People’s Medicine. This redesign is based on specialist advice from Stirling University. The environments have been made more ‘homely and welcoming’ with the use, among other things, of: colour contrast, to facilitate understanding and independence; traditional features, which look and feel familiar (such as fireplaces and curtains); specialist, bespoke signage, which incorporates a picture alongside words and lighting, that can be set to reflect the changes in natural light throughout the day. Each of the wards has ‘My Life Software,’ which can be used for group and individual reminiscence as well as for building Life Stories and simple relaxation.

**Gateshead Foundation Trust** - £158k was awarded for the development of a dementia friendly waiting area within the outpatient department, to provide a gym for young people with dementia in Dunstan Hill Day Hospital and the development of outdoor space for a gardening scheme.

These projects will be evaluated as part of a national evaluation commissioned by the Department of Health.

For further information on the other projects in the North East that received funding through the Department of Health and more detail about the evaluation process, see section 18 of this report.

## ‘Shared Purpose’ Project – Northumbria Healthcare

The ‘Shared Purpose’ Project<sup>237</sup> is run by Northumbria Healthcare in partnership with Age UK and Northumberland Carers. The project aims to provide dignified, compassionate and safe care to their

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<sup>236</sup> Department of Health [Online] Available at: <https://www.gov.uk/government/news/50-million-investment-to-give-people-with-dementia-specially-designed-care-homes-and-wards> (Accessed 17 May 2014)

<sup>237</sup> Northumbria Healthcare NHS Foundation Trust [Online] Available at: <https://www.northumbria.nhs.uk/quality-and-safety/shared-purpose> (Accessed 17 May 2014)



elderly patients. On identified 'Shared Purpose' wards environmental audits have led to dementia friendly improvements, such as the provision of dignity crockery and nutritional assistants have been trained and recruited to provide mealtime support.

Northumbria Healthcare has also developed information for people living with dementia and their families on its website.<sup>238</sup> This includes information about the signs and symptoms of dementia, patients and carers' frequently asked questions and health and social care services the Trust provides in its hospitals, people's homes and in the community.

Values Based Recruitment methods were implemented across the Trust in March 2014.

For more information contact [Ann.Brown@northumbria-healthcare.nhs.uk](mailto:Ann.Brown@northumbria-healthcare.nhs.uk)

## Identifier, information and carer response schemes

Hospitals in the North East have adopted various schemes to identify patients living with dementia and to record key information about them.

Information and carer response schemes adopted in the North East include 'Forget me not',<sup>239</sup> 'This is me'<sup>240</sup> and 'All about me.' The resources for these schemes have been designed to record the preferences of patients with dementia who have limited communication skills or are unable to communicate information themselves. The documents record the information that health and ancillary staff will be able to use to provide person centred support. The documentation is completed by the person with dementia, the patient's family and other key people.

The amount and level of information recorded varies between schemes. The 'Forget me not' card is one A4 sheet compared to the three sheets of the 'This is me' scheme.

Focus groups conducted by Dr Louise Allan (Newcastle Hospitals NHS Foundation Trust) in April 2012, with support from the North East Dementia Alliance, indicated that patients and carers favoured the use of the 'Forget me not' resource; however, it was felt that in some situations this could be supplemented with the 'This is me' resource. 'Forget me not' was felt to be particularly useful in A & E departments and short stay wards. Information and carer response schemes are used in North East hospitals as follows:

**Newcastle Hospitals NHS Foundation Trust, Northumbria Healthcare NHS Foundation Trust and South Tyneside NHS Foundation Trust** have been introducing and using 'Forget me not.'

**Northumbria, South Tees Hospitals and Gateshead NHS Foundation Trusts** are using both the 'Forget me not' and 'This is me' resources to deliver personalised care. Northumbria Healthcare Foundation Trust was a partner in the development of 'This is me.' **Gateshead NHS Foundation**

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<sup>238</sup> [www.northumbria.nhs.uk/dementia](http://www.northumbria.nhs.uk/dementia)

<sup>239</sup> Royal College of Nursing [Online] Available at: [http://www.rcn.org.uk/development/practice/dementia/best\\_practice\\_examples/jill\\_cunliffe](http://www.rcn.org.uk/development/practice/dementia/best_practice_examples/jill_cunliffe) (Accessed 17 May 2014)

<sup>240</sup> Alzheimer's Society[Online] Available at: <http://alzheimers.org.uk/thisisme> (Accessed 17 May 2014)

Trust has introduced a blue wrist band for patients with communication problems, which will include some people living with dementia. City Hospitals Sunderland NHS Foundation Trust have implemented 'This is me'.

**North Tees and Hartlepool** NHS Foundation Trust is implementing a locally developed 'All about me' scheme. This scheme was created during a Rapid Process Improvement Workshop conducted by the Stockton and Hartlepool Dementia Collaborative.<sup>241</sup> The document is based on 'This is me' and incorporates learning from the Learning Disability hospital passport. The document was created for patients with dementia to inform professionals involved in their care of their needs, preferences, likes, dislikes and interests.

## 14.5 Conclusions on the care of people with dementia in the general hospitals in the North East

The Royal College of Psychiatrists' national audit of dementia (care in general hospitals) 2010/11 made both national and local recommendations for improvement. The findings of the audit and its recommendations provide a useful guide for considering factors that need to be addressed in order to improve the care of people with dementia in general hospitals.

Across the North East there are examples of on-going work to enhance the quality of care for people with dementia in general hospitals. All acute trusts have indicated a commitment to improving services for people with dementia by signing up to the call to action 'The Right Care: Creating Dementia Friendly Hospitals.' A number of initiatives have been taken forward to improve the care of people with dementia in hospitals, These include environmental improvements, the use of dementia champions and schemes and identifier and information recording schemes such as 'This is me.'

Not all North East acute hospital trusts have indicated that they have dementia strategies, action plans, working groups or a dementia lead.

This report contains limited data regarding emergency admissions where the primary diagnosis is recorded as dementia. Further detailed data needs to be compiled to gain a more comprehensive understanding of the care of people with dementia in general hospitals in the North East. The standards outlined in the '*National Audit of Dementia (Care in General Hospitals) 2010/11*' could provide a useful starting point in terms of identifying what further information is required. For example, areas where further data is needed could include re-admission rates, length of stay and mortality in hospitals. It is, however, important to note that the standards contained in the '*National Audit of Dementia (Care in General Hospitals) 2010/11*' cover a wide range of factors and it would not be practical to gather region wide information relating to each standard contained in the national audit. It is, therefore, likely that preliminary work would have to be undertaken to prioritise information and identify key areas where further information is needed.

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<sup>241</sup> For further information on the Stockton and Hartlepool Dementia Collaborative see section 4 of this report

## 14.6 Recommendations on the care of people with dementia in the general hospitals in the North East

- Not all hospital trusts have identifiable structures to support improvements in hospital care for people with dementia. Hospital trusts should work to develop dementia strategies, action plans and working groups and appoint identified dementia leads.
- Some initiatives have been taken forward to improve care in general hospitals in the North East. These interventions need to be shared and implemented across all trusts. This work could be supported by the regional Dementia Hub and the Mental Health, Dementia and Neurological Conditions Strategic Clinical Network.
- This report includes limited data relating to emergency hospital admissions. Further detailed data needs to be compiled to gain a more comprehensive understanding of the care of people with dementia in general hospital. The Mental Health, Dementia and Neurological Conditions Strategic Clinical Network should identify the key indicators and should access these data sets. Where actions are needed, the Mental Health, Dementia and Neurological Conditions Strategic Clinical Network needs to lead on these changes.

# 15. Liaison services

## Key points:

- Objective 8 of the National Dementia Strategy (improved quality of care for people with dementia in general hospitals) highlights the need for “the commissioning of specialist liaison older people’s mental health teams to work in general hospitals”
- Five out of the 10, local dementia plans highlight an intention to review or develop liaison services
- The Rapid Assessment, Interface and Discharge (RAID): an economically evaluated psychiatric liaison service model developed in Birmingham, is being replicated, in part or in full, across the North East
- The Royal College of Psychiatrists has an accreditation programme for psychiatric liaison services (PLAN). In the North East the Older Person’s Mental Health Liaison service working in the Queen Elizabeth Hospital in Gateshead is the only older person’s liaison team with accreditation
- A business case for the use of the psychiatric liaison model has been developed for the area served by Northumberland Tyne and Wear NHS Foundation Trust
- Evaluations indicate liaison services could lead to considerable resources being released
- There has been investment in liaison services across the region; however, it is unclear if coverage is comprehensive and what the full benefits have been, particularly for people living with dementia

This section of the report will consider key issues relevant to the provision of liaison services for people with dementia. In particular, this section of the report will outline:

- The policy context
- How liaison services have been included in local plans
- Examples of liaison services in the North East
- Conclusions and recommendations on liaison services for people with dementia in the North East

## 15.1 Policy context

Outlined below is the policy context specific to provision of liaison services for people with dementia. This should be read in conjunction with the more general policy review in section 3 of this report.

## National Dementia Strategy

Objective 8 of the National Dementia Strategy (improved quality of care for people with dementia in general hospitals) highlights the need for *“the commissioning of specialist liaison older people’s mental health teams to work in general hospitals”*.<sup>242</sup>

## Clinical Guidelines 42 Dementia: Supporting people with dementia and their carers in health and social care

The guidelines produced by the National Institute for Health and Care Excellence and Social Care Institute of Excellence advocating the use of specialist liaison older people’s mental health teams.<sup>243</sup>

## Rapid Assessment, Interface and Discharge (RAID) mental health team

The Rapid Assessment, Interface and Discharge (RAID) service was introduced in the Birmingham and Solihull Mental Health NHS Foundation Trust in December 2009. The RAID service offers *“a comprehensive range of mental health specialities within one multi-disciplinary team, so that all patients over the age of 16 can be assessed, treated, signposted or referred appropriately regardless of age, address, presenting complaint, time of presentation or severity”*.<sup>244</sup>

The RAID service operates 24 hours a day, seven days week and *“has a target time of one hour within which to assess referred patients who present to A&E and 24 hours for seeing referred patients on the wards.”*<sup>245</sup> The service provides formal teaching and informal training on mental health difficulties to acute staff throughout the hospital.<sup>246</sup>

In 2012 an independent economic evaluation of the RAID service found that *“the service generates significant cost savings and is excellent value for money”*.<sup>247</sup>

The RAID model has served as an example for other localities to follow. As described in the report *‘Outline Strategic Business Case for Development of Psychiatric Liaison Services: Across the geographical area served by Northumberland, Tyne and Wear NHS Foundation Trust’*

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<sup>242</sup> Department of Health (2009) Living well with dementia: a National Dementia Strategy. London: Department of Health p.12

<sup>243</sup> National Institute for Health and Clinical Excellence and the Social Care Institute for Excellence (2006) CG42 Dementia: Supporting people with dementia and their carers in health and social care. London: National Institute for Health and Clinical Excellence

<sup>244</sup> Parsonage, M. and Fossey, M. (2011) Economic evaluation of a liaison psychiatry service. London: Centre for Mental Health p.7

<sup>245</sup> Ibid p.7

<sup>246</sup> Ibid p.7 p.7-8

<sup>247</sup> Ibid p.7 p. 3

*“The RAID model was identified in the NHS Operating Framework<sup>248</sup> for 2012/13 as an example of good practice.... to support delivery of the Quality, Innovation, Productivity and Prevention (QIPP) agenda... which requires the continued improvement of quality whilst reducing overall costs by 20% over a 5-year period. Commissioners are encouraged to examine the RAID model as an effective and efficient use of resources”.*<sup>249</sup>

For further information see <http://www.bsmhft.nhs.uk/our-services/rapid-assessment-interface-and-discharge-raid/>

## Psychiatric Liaison Accreditation Network (PLAN) – Royal College of Psychiatrists

The Royal College of Psychiatrists has an accreditation programme for psychiatric liaison services (PLAN). Each service has to assess its services against a series of standards and then be subject to a peer review.<sup>250</sup> In the North East, the Older Person’s Mental Health Liaison service at the Queen Elizabeth Hospital in Gateshead is the only older person’s liaison team with accreditation.

## 15.2 Local Plans

### Local joint dementia plans

Five out of the 10 North East local joint dementia plans mention the need to review or develop liaison services that support staff and patients.

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<sup>248</sup> Department of Health. (2011) The Operating Framework for the NHS in England 2012/13. London: Department of Health

<sup>249</sup> North of England Mental Health Development Unit (2013) Outline Strategic Business Case for Development of Psychiatric Liaison Services: Across the geographical area served by Northumberland, Tyne and Wear NHS Foundation Trust [Online] Available at: <http://www.nemhdu.org.uk/publications/> (Accessed 17 May 2014) p.3

<sup>250</sup> Royal College of Psychiatrists (2014) Quality Standards for Liaison Psychiatry Services 4th Ed. Editors: Palmer, L. Cawdron, R. Pollock, E. Bolton, J. and Spink, J. [Online] Available at: <http://www.rcpsych.ac.uk/workinpsychiatry/qualityimprovement/qualityandaccreditation/liaisonpsychiatry/plan/membersarea/resources.aspx> (Accessed 17 May 2014)

## 15.3 Examples of liaison services in the North East

### Northumberland Tyne and Wear NHS Foundation Trust

The Northumberland Tyne and Wear NHS Foundation Trust provides liaison nurse support, with medical sessions providing psychiatric liaison services into all acute hospital sites in Newcastle, Northumberland and South Tyneside.<sup>251</sup>

#### **Outline Strategic Business Case for Development of Psychiatric Liaison Services: Across the geographical area served by Northumberland, Tyne and Wear NHS Foundation Trust**

In August 2013 the North of England Mental Health Development Unit was commissioned to write a report to “*demonstrate the wider economic and systems benefits of investment, in Psychiatric Liaison Services, and to share knowledge of their potential impact, across the geographical footprint served by Northumberland, Tyne and Wear NHS Foundation Trust*”.<sup>252</sup>

The report suggested that the use of a Psychiatric Liaison Service, that builds on the RAID model across each of the acute/general hospitals would “*enable the release of significant resources within the health economy locally*”. The report describes investing in such a service as being an investment to save money in the long run concluding that the “*strategic business case offers a unique opportunity to improve services and reduce cost*”.<sup>253</sup>

### City Hospitals Sunderland

Since 2010 Northumberland Tyne and Wear NHS Foundation Trust has provided an Older Persons Mental Health Hospital Liaison Service at City Hospital Sunderland. From 2013/14 there are plans to provide a whole mental health liaison service at City Hospital Sunderland. This service will operate 24 hours a day, seven days a week and will have a particular focus on identifying mental health needs among those attending A&E or admitted to general hospital beds. The service will offer training to general hospital staff to help them identify dementia, delirium and other mental health needs and offer a specialist assessment and management function.<sup>254</sup>

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<sup>251</sup> Northumberland Tyne and Wear NHS Foundation Trust [Online] Available at: <http://www.ntw.nhs.uk/section.php?l=2&p=275> (Accessed 17 May 2014)

<sup>252</sup> North of England Mental Health Development Unit (2013) Outline Strategic Business Case for Development of Psychiatric Liaison Services: Across the geographical area served by Northumberland, Tyne and Wear NHS Foundation Trust [Online] Available at: <http://www.nemhdu.org.uk/publications/> (Accessed 17 May 2014) P.3

<sup>253</sup> North of England Mental Health Development Unit (2013) Outline Strategic Business Case for Development of Psychiatric Liaison Services: Across the geographical area served by Northumberland, Tyne and Wear NHS Foundation Trust [Online] Available at: <http://www.nemhdu.org.uk/publications/> (Accessed 17 May 2014) p.5

<sup>254</sup> Information taken from the audit conducted by the North East Association of Directors of Adult Social Services – Dementia Themed Network as part of their work stream around diagnosis. For further information on the Dementia Themed Network see section 4 of this report.

## South Tees team at James Cook University Hospital and North Tees team at University Hospital of North Tees and University Hospital of Hartlepool

The liaison psychiatry services provides an *“assessments and a signposting service for patients aged 18 and over, who present with mental health problems at any of the acute general hospitals in Teesside”*. The service is provided by Tees, Esk and Wear Valleys NHS Foundation Trust and is operational 24 hours a day, seven days a week.

## County Durham and Darlington mental health liaison services

County Durham and Darlington mental health liaison services *“respond to and provides a comprehensive psychosocial assessment of people (aged 16 years and over) who present at or are admitted into the acute general hospitals across the County Durham and Darlington area. This includes accident and emergency departments, wards and departments and into community hospitals.”* The service operates seven days a week, from 8am until 10pm.

The service supports staff in acute hospitals to increase their competencies in the early detection of mental health problems and the management of people with mental health needs. The acute liaison teams also provide a link to the community and inpatient mental health services.<sup>255</sup>

## Northumbria Healthcare Foundation Trust Psychiatry of Old Age Liaison Team

A liaison team provides psychiatric support to older patients with mental health needs, such as dementia, delirium and depression, who have been admitted to North Tyneside General Hospital for a physical health problem. The team also provides regular education sessions, including dementia care, to the general hospital staff. The team consists of a part time consultant psychiatrist, three nurses and a health care assistant.

In addition, the team provides psychiatric input to older patients with mental health needs who have been transferred to the Kielder Unit on the North Tyneside General Hospital site.<sup>256</sup>

## Gateshead liaison service

Gateshead Health NHS Foundation Trust provides specialist Older Person's Mental Health services at the Queen Elizabeth Hospital (QEH) in Gateshead. The Mental Health Liaison service provides

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<sup>255</sup> Tees, Esk and Wear Valleys NHS Foundation Trust [Online] Available at: <http://www.tewv.nhs.uk/Our-services1/County-Durham-and-Darlington/Adult-services/Liaison-services/> (Accessed 17 May 2014)

<sup>256</sup> Northumbria Healthcare NHS Foundation Trust [Online] Available at: <https://www.northumbria.nhs.uk/our-services/hospital/psychiatry-of-old-age> (Accessed 17 May 2014)



routine and urgent assessments for any patient over the age of 65 years within the QEH. This includes cognitive assessments, mood related assessments as well as management of challenging psychiatric situations and urgent assessments of acute psychiatric conditions such as self-harm or acute psychosis. The Team also provides support for the acute hospital wards and departments with regards to the management of mental health patients while in a hospital setting. The Mental Health Liaison staff service provides on-going support to the dual care ward (WD 23) as well as providing mental health training and education to acute hospital staff. The service provides cover seven days a week. This service has been accredited by the Royal College of Psychiatrists as part of the PLAN programme.

## 15.4 Conclusions on the provision of liaison services in the North East

The evaluation of the RAID model and the business case produced for Northumberland Tyne and Wear NHS Foundation Trust provide compelling evidence to support the provision of liaison services into hospitals and care homes. There are a number of liaison services across the North East; however, the models vary in terms of staffing levels and client group supported. These differences make it unclear whether coverage is comprehensive and what the full benefits have been, particularly for people living with dementia.

## 15.5 Recommendations on the provision of liaison services in the North East

- It is unclear if the cover of psychiatric liaison services is comprehensive and whether the provision of liaison services extends into care homes. A comprehensive mapping exercise of the liaison services in the North East should take place, including staffing levels and mix and times of operation. The Mental Health, Dementia and Neurological Conditions Strategic Clinical Network and CCGs would be key partners in this.
- In conjunction with a full mapping of psychiatric liaison services, an evaluation of the full benefits, particularly for people living with dementia, needs to be completed. The Mental Health, Dementia and Neurological Conditions Strategic Clinical Network and CCGs would be key partners in this.

# 16. Specialist mental health services

## Key points

- In the North East there are two dedicated NHS specialist mental health service providers and two additional trusts providing mental health services. The four trusts give full geographical coverage of the North East
- The average number of beds available for mental illness has slightly reduced between 2011 and 2014 (ranging from 1,881 to 1,591). It has not been possible to identify how many beds are used by people with dementia
- Specialist mental health services also provide memory services (see section 7 of this report), psychiatric liaison teams (see section 15 of this report) and community teams. These are not explored in this section of the report

This section of the report will consider the provision of specialist mental health services for people living with dementia. In particular, it will outline:

- The provision of specialist mental health services for people living with dementia in the North East
- The average number of beds available for people with mental illness (including dementia)
- Conclusions and recommendations relating to specialist mental health services for people living with dementia in the North East

There are two dedicated NHS mental health providers in the North East. They are Tees, Esk and Wear Valleys NHS Foundation Trust (TEWV) and Northumberland, Tyne and Wear NHS Foundation Trust (NTW). In addition, Northumbria Healthcare NHS Foundation Trust and Gateshead Health NHS Foundation Trust provide mental health services.

## 16.1 Specialist mental health providers in the North East

### Tees, Esk and Wear Valleys NHS Trust

Tees, Esk and Wear Valleys NHS Foundation Trust (TEWV) provides mental health services for older people. The Trust covers County Durham and Tees Valley and some areas in North Yorkshire.

Working in partnership with local authority social care teams and the voluntary and independent service sectors, the Trust provides in-patient, day and out-patient assessment and treatment services (including acute intensive care and rehabilitation services). The Trust also provides a wide range of community-based services, including in-reach care home teams and general in-reach hospital teams.

## Northumberland, Tyne and Wear NHS Foundation Trust

The Northumberland, Tyne and Wear NHS Foundation Trust (NTW) provides services to older people through both urgent care (inpatients / crisis services) and planned care (community). The Trust covers Northumberland, Newcastle and the Longbenton area of North Tyneside. In addition, the Memory Support Service extends to all of North Tyneside, South Tyneside and Sunderland, while the Memory Protection Service also covers Gateshead.

The Trust provides assessment, treatment, rehabilitation and ongoing care to older people with organic and/or functional mental illness. This includes services for older people with complex mental health problems and/or challenging behaviour. At May 2014 the Trust was reviewing its dedicated services for younger people with dementia and its wider community services model as part of the Principle Community Pathways work. The Trust also provides in-reach services to other local NHS and independent providers when they require specialist mental health input or psychological therapies.

## Northumbria Healthcare NHS Foundation Trust

The Northumbria Healthcare NHS Foundation Trust is a hospital trust providing secondary care services; however, the Trust also delivers a 'Psychiatry of Old Age' service. The service is for older people with mental health problems and can provide an early assessment. To reduce the need for hospitalisation the Trust provides patients with the option of receiving treatment and care within their home environment. The Trust provides services for Gateshead and North Tyneside (excluding Longbenton).

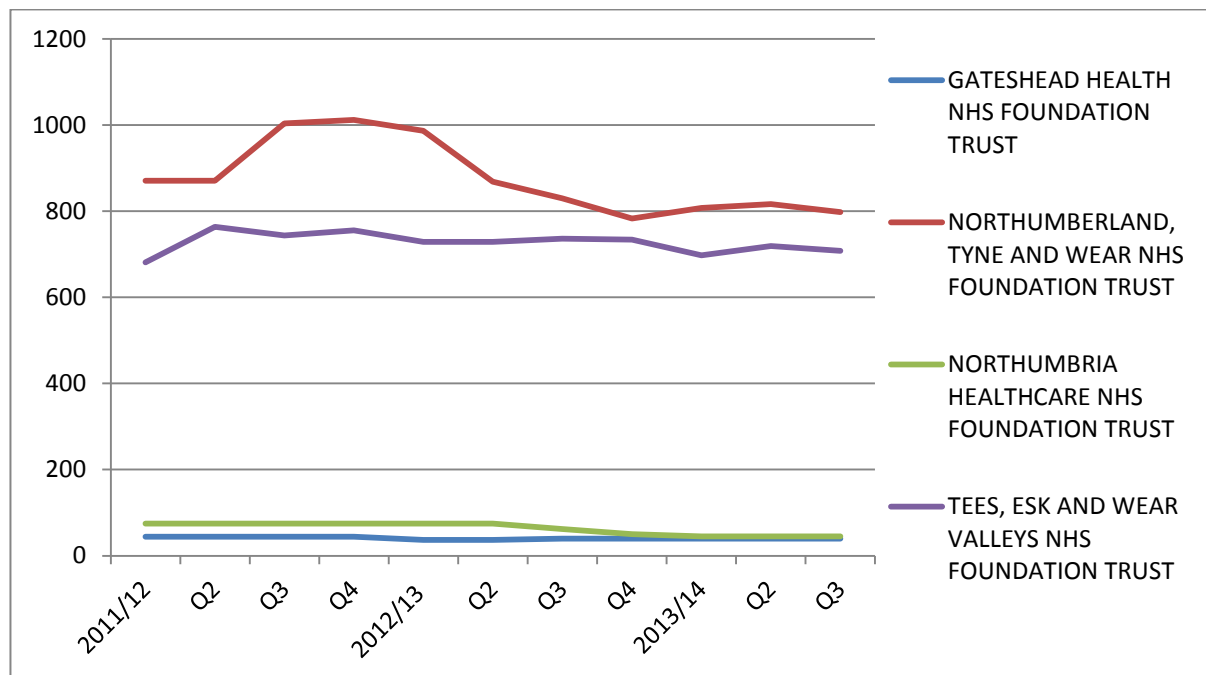
## Gateshead Health NHS Foundation Trust

Gateshead Health NHS Foundation Trust provides specialist Older Person's Mental Health services in Gateshead. These services are provided at a number of sites and via outreach services. The Trust has an admission and assessment unit for older people with organic mental illness and two units for continuing care and palliative care services. The Trust also provides outreach services for people requiring assessment and for younger people with dementia; a seven day, nurse led day hospital providing assessment, treatment, rehabilitation and monitoring of people over the age of 65 with organic and functional mental health problems and a Community Psychiatric Nursing Service visiting clients in their own home. The Trust has an anti-dementia team and Community Resource Team for Older People (CROP).

## 16.2 Average daily number of beds available (mental illness)

During the research for this report it was not possible to identify figures relating to the number of beds available for people with dementia within the specialist mental health providers listed in this section. The statistics in Table 17 and Figure 7 outline the average number of beds available daily for mental illness in the North East. Mental illness in this context includes Adult Mental Illness, Child and Adolescent Psychiatry, Forensic Psychiatry, Psychotherapy and Old Age Psychiatry. These figures are, therefore, inclusive of beds available for people with dementia but also include beds available for other service user groups.

The figures suggest that in the time period from 2011/2012 to 2013/14 there has been a slight reduction in the number of beds available for mental illness. Further research is needed to identify whether the reason for this reduction is an increased focus on the provision of community mental health services or whether there is an alternative reason for the reduction in the number of beds available.



**Figure 7:** Average daily number of beds available for mental illness in North East England. Source: NHS England [Online] Available at: <http://www.england.nhs.uk/statistics/statistical-work-areas/bed-availability-and-occupancy/> (Accessed 17 May 2014)

Trust	2011/12				2012/13				2013/14		
	Q1	Q2	Q3	Q4	Q1	Q2	Q3	Q4	Q1	Q2	Q3
<b>TEES, ESK AND WEAR VALLEYS NHS FOUNDATION TRUST</b>	681	764	744	756	729	729	736	734	698	719	708
<b>GATESHEAD HEALTH NHS FOUNDATION TRUST</b>	44	44	44	44	37	37	40	40	40	40	40
<b>NORTHUMBRIA HEALTHCARE NHS FOUNDATION TRUST</b>	75	75	75	75	75	75	62	50	45	45	45
<b>NORTHUMBRIA, TYNE AND WEAR NHS FOUNDATION TRUST</b>	871	871	1,004	1,012	987	869	830	783	808	817	798
<b>Total in North East</b>	<b>1671</b>	<b>1754</b>	<b>1867</b>	<b>1887</b>	<b>1828</b>	<b>1710</b>	<b>1668</b>	<b>1602</b>	<b>1591</b>	<b>1621</b>	<b>1591</b>

**Table 17:** Average daily number of beds available for mental illness in North East England. Source: NHS England [Online] Available at: <http://www.england.nhs.uk/statistics/statistical-work-areas/bed-availability-and-occupancy/> (Accessed 17 May 2014)

## 16.3 Conclusions on the provision of specialist mental health services for people living with dementia in the North East

There are two dedicated NHS mental health providers in the North East. These are Tees, Esk and Wear Valleys NHS Foundation Trust (TEWV) and Northumberland, Tyne and Wear NHS Foundation Trust (NTW). In addition, Northumbria Healthcare NHS Foundation Trust and Gateshead Health NHS Foundation Trust provide mental health services. Together these services provide full geographical cover for the North East.

The provision of beds available for mental illness in the North East has slightly reduced between 2011 and 2014. From the available information it was not possible to identify the number of beds available specifically for people with dementia or how the overall reduction in beds has affected the number of beds available for people living with dementia. Indications from scrutiny reports show that Tees, Esk and Wear Valleys NHS Foundation Trust have made some reductions in the number of beds available for older people (for further information on scrutiny reports in the North East see section 4 of this report).

## 16.4 Recommendations on the provision of specialist mental health services for people living with dementia in the North East

- Indications are that the number of beds for people with mental health needs in the North East, including those which would be used by people with dementia, has reduced. Further work needs to be undertaken to establish the bed provision for people with dementia and any changes in provision across the North East.
- In light of the reduction in beds provided by specialist mental health providers, there is a need to look at whether people with dementia are receiving appropriate support. Alternative support may be provided through specialist mental health community services. A review of community mental health services (for people with dementia) should be considered alongside an assessment of the number of beds.
- During the research for this report no information was identified relating to the outcomes of any service changes for people with dementia and their carers. If changes are found to have taken place a retrospective review of the impact on people with dementia needs to be undertaken.

# 17. End of life care

## Key points

- Improved end of life care for people with dementia is Objective 12 of the National Dementia Strategy
- Eight out of the 10 joint dementia plans in the North East focus on advanced care, planning referencing advance directives and 'Deciding Right'
- In 2012 the number of deaths in the North East, where Alzheimer's disease or other dementia are listed as either the underlying cause of death or as a contributory cause of death, was 2,242
- Based on 2008/10 figures, 48% of deaths in the North East, where Alzheimer's disease, dementia or senility are listed, took place in care homes, 46% in hospitals, 6% at home and fewer than 1% in hospices
- SEED, a significant national research project about end of life care and dementia, is being led from Newcastle University
- There are examples of work to improve end of life care for people with dementia in the North East including regional approaches to replacing the Liverpool Care Pathway, and employment of an Admiral Nurse in Durham

This section of the report will consider key issues relating to end of life care for people living with dementia. In particular this section of the report will outline:

- The policy context
- How end of life care for people living with dementia has been included in local plans
- End of life statistics
- Examples of work undertaken in the North East to improve end of life care for people living with dementia
- Conclusions and recommendations on end of life care for people living with dementia in the North East

## 17.1 Policy Context

Outlined below is the policy context specifically relevant to the provision of end of life care for people living with dementia. This should be read in conjunction with the more general policy review in section 3 of this report.

## National Dementia Strategy

Objective 12 of the National Dementia Strategy includes an ambition for “*people with dementia and their carers to be involved in planning end of life care which recognises the principles outlined in the Department of Health End of Life Care Strategy.*”<sup>257</sup> The objective also highlights the need for “*local work on the End of Life Care Strategy to consider dementia.*”<sup>258</sup>

## Prime Minister’s Challenge on Dementia

End of life care is referred to once in the Prime Minister’s Challenge. This is in the Care and Support Compact, which states that, if asked, people with dementia should be able to say “*I am confident that my end-of-life wishes will be respected. I can expect a good death.*”<sup>259</sup>

## End of Life Care Strategy: Promoting high quality care for all adults at the end of life

The End of Life Care Strategy was launched in 2008 and, though not specific to people with dementia, the strategy sets out an intention that all people at the end of life will have:

- The opportunity to discuss personal needs and preferences with professionals who can provide support and the opportunity for these preferences to be recorded in a care plan so every service involved in providing support will be aware of a person’s priorities. These preferences and choices will be taken into account and accommodated wherever possible
- Coordinated care and support: ensuring that needs are met, irrespective of who is delivering the service
- Rapid specialist advice and clinical assessment wherever it is needed
- High quality care and support during the last days of life
- Services which treat people with dignity and respect both before and after death
- Appropriate advice and support for carers at every stage<sup>260</sup>

Since 2008 a number of updates have been issued in relation to the End of Life Care Strategy. The fourth update report includes a reference to the North East work on developing a Good Death

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<sup>257</sup> Department of Health (2009) Living well with dementia: a National Dementia Strategy. London: Department of Health p.13

<sup>258</sup> Ibid

<sup>259</sup> Department of Health (2012) Prime Minister’s Challenge on Dementia: Delivering major improvements in dementia care and research by 2015. Department of Health: London p.24

<sup>260</sup> Department of Health (2008) End of Life Care Strategy: Promoting high quality care for all adults at the end of life. London: Department of Health



Charter for People with Dementia and their Carers, which was developed by the North East Good Death Charter Group in consultation with the North East Dementia Alliance.<sup>261</sup>

## Clinical Guidelines 42 Dementia: Supporting people with dementia and their carers in health and social care

The guidelines produced by the National Institute for Health and Care Excellence and Social Care Institute of Excellence state 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*”.<sup>262</sup>

### My life until the end: dying well with dementia

In October 2012 the Alzheimer’s Society released the report ‘*My life until the end: dying well with dementia*’.<sup>263</sup> Based on interviews with people with dementia, carers and former carers the report sought to identify the key issues regarding end of life care for people with dementia and outlined a number of recommendations to improve end of life care for people with dementia. The main issues outlined in the report were:

- Public awareness, care planning and proxy decision making. A lack of public discussion around death and dying means the wishes of people with dementia are often unknown
- Dignity, pain, withholding and withdrawing treatment - people in later stages of dementia are sometimes treated without dignity as they are less able to communicate their needs and wishes; this causes particular problems in cases where pain, discomfort, hunger and thirst are present
- Emotional and spiritual concerns - dementia is progressive and it can be difficult for people to make decisions towards the end, meaning end of life planning in the early stages is essential
- Place of care and death - the report revealed that most people with dementia want to die at home but many die in hospital

The report recommended that:

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<sup>261</sup> Department of Health (2012) End of Life Care Strategy: Fourth Annual Report [Online] Available at: <https://www.gov.uk/government/publications/end-of-life-care-strategy-fourth-annual-report> (Accessed 17 May 2014) p.42

<sup>262</sup> National Institute for Health and Clinical Excellence and the Social Care Institute for Excellence (2006) CG42 Dementia: Supporting people with dementia and their carers in health and social care. London: National Institute for Health and Clinical Excellence

<sup>263</sup> Alzheimer’s Society (2012) My life until the end: Dying well with dementia [Online] Available at: <https://www.alzheimers.org.uk/endoflife> (Accessed 17 May 2014)

*“There should be greater recognition of dementia as a terminal illness and greater support for people to plan for their future in formal as well as informal ways. This could be achieved if there was more training for clinicians and care home staff especially around initiating and conducting conversations about end of life care planning. There should also be more research into understanding the detection of pain in people with advanced dementia. People should be supported in the different models of care and in the different settings that they have chosen to die in”.*<sup>264</sup>

## More care, less pathway: a review of the Liverpool Care Pathway

In July 2013 the Department of Health published the report ‘*More care, less pathway: a review of the Liverpool Care Pathway*’.<sup>265</sup> This report sets out recommendations regarding the Liverpool Care Pathway (LCP) and end of life care following an independent review chaired by Baroness Julia Neuberger.

The report’s recommendations include:

- Phasing out the LCP and replacing it with an individual end of life care plan
- A general principle that a patient should only be placed on the LCP, or a similar approach, by a senior responsible clinician in consultation with the healthcare team
- Unless there is a very good reason, a decision to withdraw or not to start a life-prolonging treatment should not be taken during any ‘out of hours’ period
- An end to incentive payments for use of the LCP and similar approaches

A new system-wide approach to improving the quality of care for the dying

Following the recommendations of the report the Department of Health stated “*the Liverpool Care Pathway will no longer exist from July 2014*”.<sup>266</sup>

## 17.2 Local plans

### Health and Wellbeing Strategies

The Gateshead Health and Wellbeing strategy lists dementia as a Focus for Action during 2013-2016 with an emphasis which includes end of life care.<sup>267</sup>

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<sup>264</sup> Alzheimer’s Society [Online] Available at: <https://www.alzheimers.org.uk/endoflife> (Accessed 17 May 2014)

<sup>265</sup> Department of Health (2013) *More care, less pathway: A review of the Liverpool Care Pathway* [Online] Available at: <https://www.gov.uk/government/publications/review-of-liverpool-care-pathway-for-dying-patients> (Accessed 17 May 2014)

<sup>266</sup> Alzheimer’s Society [Online] Available at: [http://www.alzheimers.org.uk/site/scripts/documents\\_info.php?documentID=428](http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=428) (Accessed 17 May 2014)

<sup>267</sup> Gateshead Health and Wellbeing Board (2013) *Active, Healthy and Well Gateshead: A Health & Wellbeing Strategy for Gateshead (2013/14 to 2015/16)* [Online] Available at:

## Local joint dementia plans

Eight out of the 10 North East local joint dementia plans focus on advanced care planning and reference advance directives and 'Deciding Right'.

South Tyneside and Sunderland both reference a 2011/12 CQUIN agreement, through which Northumberland, Tyne and Wear NHS Foundation Trust were asked to offer all patients the opportunity to carry out advanced care planning where appropriate. Sunderland's plan sets out the aim of developing a co-ordination centre for the management of advanced care plans.

Training staff on end of life care appeared in four plans. One plan suggested awareness about dementia should be improved amongst end of life care staff,<sup>268</sup> while another plan aimed to improve skills around end of life care among the older people's mental health service staff.<sup>269</sup> Two areas suggested the employment of specialist dementia nurses – dementia voice nurse and an admiral nurse.<sup>270</sup>

## 17.3 End of Life Statistics

During the research for this report the most recent statistics regarding cause of death which have been sourced are from 2012 and relate to deaths in all England and Wales.

In England and Wales heart disease was the biggest cause of death in 2012, killing over 64,000 people, followed by dementia and Alzheimer's disease, which caused more than 43,000 deaths (13,984 men and 39,873 women).<sup>271</sup> In 2012 in the North East dementia and Alzheimer's disease were recorded as the cause of death for 2,242 people (675 men and 1,567 women).

For women over 80 dementia and Alzheimer's disease were the leading cause of death accounting for 16% of female deaths in that age group and 11.5% of all female deaths in 2012. Dementia and Alzheimer's disease were the second leading cause of death for men in this age group.<sup>272</sup>

More detailed figures, for the purposes of this report, relate to 2008/10. The figures in Table 18 show the numbers and percentage of all deaths where Alzheimer's disease, dementia or senility are

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<http://www.gateshead.gov.uk/DocumentLibrary/CBS/health/Active-Healthy-and-Well-Gateshead.pdf>  
(Accessed 17 May 2014) p.32

<sup>268</sup> Northumberland

<sup>269</sup> Stockton on Tees

<sup>270</sup> For further information on Admiral Nurses see <http://www.dementiauk.org/what-we-do/admiral-nurses>  
For further information on Dementia Voice nurses see

[http://alzheimers.org.uk/site/scripts/documents\\_info.php?documentID=2322&pageNumber=3](http://alzheimers.org.uk/site/scripts/documents_info.php?documentID=2322&pageNumber=3)

<sup>271</sup> Office for National Statistics [Online] Available at: <http://www.ons.gov.uk/ons/rel/vsob1/mortality-statistics--deaths-registered-in-england-and-wales--series-dr-/2012/sty-causes-of-death.html> (Accessed 17 May 2014)

<sup>272</sup> Ibid

listed as either the underlying cause of death or as a contributory cause of death. These figures are based on average annual statistics for 2008/10.<sup>273</sup>

Although Northumberland and Durham were the localities with the highest total number of deaths (where Alzheimer’s disease, dementia or senility were listed) the localities with the highest percentage of deaths (where Alzheimer’s disease, dementia or senility were listed) were Darlington (22.5%) and Middlesbrough (22.2%).

Locality	All deaths	Where Alzheimer’s disease, dementia or senility listed as underlying or contributory cause	
		Numbers	Percentage
<b>Darlington</b>	1,059	239	22.5%
<b>Durham</b>	5,293	985	18.6%
<b>Gateshead</b>	2,058	348	16.9%
<b>Hartlepool</b>	931	190	20.5%
<b>Middlesbrough</b>	1,385	308	22.2%
<b>Newcastle upon Tyne</b>	2,589	475	18.3%
<b>North Tyneside</b>	2,134	360	16.9%
<b>Northumberland</b>	3,290	640	19.5%
<b>Redcar and Cleveland</b>	1,387	263	18.9%
<b>South Tyneside</b>	1,693	286	16.9%
<b>Stockton-on-Tees</b>	1,863	337	20.0%
<b>Sunderland</b>	2,906	481	16.6%
<b>North East</b>	<b>26,588</b>	<b>4,912</b>	<b>18.5%</b>
<b>England</b>			<b>17.3%</b>

**Table 18:** Deaths in the North East where Alzheimer’s disease, dementia or senility are listed.  
Source: National End of Life Care Intelligence Network: End of Life Care Local Authority Profiles 2012 [Online] Available at: [http://www.endoflifecare-intelligence.org.uk/end\\_of\\_life\\_care\\_profiles/la\\_profiles\\_2012](http://www.endoflifecare-intelligence.org.uk/end_of_life_care_profiles/la_profiles_2012) (Accessed 17 May 2014)

The figures in Table 19 show the place of death for all deaths where Alzheimer’s disease, dementia or senility are listed as either the underlying cause of death or as a contributory cause of death. These figures are based on average annual statistics for 2008/10.

It should be noted that “these profiles use Office for National Statistics (ONS) data for place of death. The ONS categorises place of death by address. As a result, it is not possible to distinguish between hospital deaths and deaths in specialist palliative care units / hospices that are based in hospitals.

<sup>273</sup> National End of Life Care Intelligence Network: End of Life Care Local Authority Profiles 2012 [Online] Available at: [http://www.endoflifecare-intelligence.org.uk/end\\_of\\_life\\_care\\_profiles/la\\_profiles\\_2012](http://www.endoflifecare-intelligence.org.uk/end_of_life_care_profiles/la_profiles_2012) (Accessed 17 May 2014)

*This means that, in many areas, the indicator showing hospital deaths will be an over-count and hospice deaths an under-count”.*<sup>274</sup>

The figures indicate that approximately 48% of deaths in the North East (where Alzheimer’s disease, dementia or senility are listed) were in care homes and 46% of deaths were in hospitals. Only 6% of deaths in the North East (where Alzheimer’s disease, dementia or senility are listed) were in the person’s home.

Location	Place of death			
	Home	Care Home	Hospital	Hospice
<b>Darlington</b>	13	123	101	0
<b>Durham</b>	64	489	407	2
<b>Gateshead</b>	21	135	189	0
<b>Hartlepool</b>	11	105	71	0
<b>Middlesbrough</b>	15	149	139	1
<b>Newcastle upon Tyne</b>	30	220	207	2
<b>North Tyneside</b>	16	188	155	0
<b>Northumberland</b>	40	342	252	0
<b>Redcar and Cleveland</b>	14	123	124	0
<b>South Tyneside</b>	25	93	166	1
<b>Stockton-on-Tees</b>	20	158	158	0
<b>Sunderland</b>	35	196	246	0
<b>North East</b>	<b>304</b>	<b>2321</b>	<b>2215</b>	<b>6</b>

**Table 19:** Place of deaths in the North East (where Alzheimer’s disease, dementia or senility are listed). Source: National End of Life Care Intelligence Network: End of Life Care Local Authority Profiles 2012 [Online] Available at: [http://www.endoflifecare-intelligence.org.uk/end\\_of\\_life\\_care\\_profiles/la\\_profiles\\_2012](http://www.endoflifecare-intelligence.org.uk/end_of_life_care_profiles/la_profiles_2012) (Accessed 17 May 2014)

## 17.4 Examples of work undertaken in the North East

### End of Life Care – The Clinical Network

There is a North East-wide End of Life Group, which aims to support good end of life care for the whole population including people living with dementia.

Four overarching themes have been identified to improve end of life care. These are:

<sup>274</sup> National End of Life Care Intelligence Network: End of Life Care Local Authority Profiles 2012 [Online] Available at: [http://www.endoflifecare-intelligence.org.uk/end\\_of\\_life\\_care\\_profiles/la\\_profiles\\_2012](http://www.endoflifecare-intelligence.org.uk/end_of_life_care_profiles/la_profiles_2012) (Accessed 17 May 2014)

- To engage wider society through a public health approach
- To make best practice consistent across the region
- To develop staff to deliver high quality evidence-based practice
- To ensure planning, commissioning and delivery of care is better integrated to deliver seamless care

The work priorities for the End of Life Group in 2014 are to further extend 'Deciding Right' and to develop a regional approach to care following the phasing out of the Liverpool Care Pathway in July 2014.

For further information see [www.nescn.nhs.uk](http://www.nescn.nhs.uk) or contact [lynda.dearden@nhs.net](mailto:lynda.dearden@nhs.net)

## 'Deciding Right'

'Deciding Right' is a North East-wide initiative and the first in the UK to extend the principles of making advance care decisions to all age groups. The initiative brings together advance care planning, the Mental Capacity Act, cardiopulmonary resuscitation decisions and emergency healthcare plans.

Written by health and social care professionals, 'Deciding Right' identifies the triggers for making care decisions in advance. At its core is the principle of shared decision making to ensure that care decisions are centred on the individual and minimise the likelihood of unnecessary or unwanted treatment.

This initiative is not specific to people living with dementia, but it is important for people living with dementia to have the opportunity to make advanced plans while they have the capacity to do so.

For further information see <http://www.cnne.org.uk/end-of-life-care---the-clinical-network/decidingright>

## North East Charter for a Good Death

The North East was the first region in the UK to adopt a broad-based public health approach to end of life issues. The North East Charter for a Good Death was developed by a multi-agency advisory group with involvement from the North East Dementia Alliance. The charter sets out key principles for individuals and organisations in relation to good practice when dealing with people who are dying, their carers and families, and others bereaved.

The aim of this programme has been to stimulate a societal approach, which sees death, dying and bereavement as normal to life and which strengthens the role of local communities in supporting, caring for and respecting the wishes of dying people and their families.

For further information see <https://www.phine.org.uk/a-good-death/charter>

## Clinical Networks Northern England - Recommendations for commissioners on end of life care for people with dementia

In October 2012 the North East End of Life Clinical Network and the North East Dementia Alliance held an event to identify how the existing end of life care pathway could be enhanced to ensure it meets the needs of people with dementia and is consistent with the national end of life programme.<sup>275</sup>

A post event report was published in January 2013 '*Recommendations for commissioners on end of life care for people with dementia*'.<sup>276</sup> The recommendations in the report included:

- Ensuring appropriate training for providers
- Extending bereavement support
- Extending access to, use of and knowledge of 'This is me' and 'Deciding Right' documentation
- Improving links between GP palliative care registers and dementia registers
- Improving communication between agencies, staff and families
- Bringing forward discussions around end of life to the point of diagnosis
- Addressing issues necessary to facilitate successful multi-disciplinary team working
- Increasing the numbers and knowledge of end of life and dementia champions

## Supporting Excellence in End of life care in Dementia (SEED Programme)

The Supporting Excellence in End of life care in Dementia (SEED) Programme is being led by a multi-disciplinary team from Newcastle University, Marie Curie and DeNDRoN. The project has received £1.92 million of funding from the National Institute for Health Research (NIHR) under its Grants for Applied Research Programme for a five year programme starting in October 2013.

The overall aim of the programme is to support professionals, both commissioners and providers, to deliver good quality, community-based end of life care in dementia by:

1. Identifying which aspects of existing end of life care in dementia are effective and efficient
2. Developing, implementing and evaluating an evidence-based integrated care pathway (ICP), and associated educational resources, to support the provision of good quality end of life care in dementia
3. Determining how community-based end of life care in dementia should be organised and commissioned

The project will produce:

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<sup>275</sup> This programme has now closed however programmes as at May 2014 can be found at <http://www.nhsiq.nhs.uk/>

<sup>276</sup> Clinical Networks Northern England (2013) Recommendations for commissioners on end of life care for people with dementia [Online] Available at: <https://www.nepho.org.uk/publications.php5?rid=1166> (Accessed 17 May 2014)

- A series of tools to support the organisation and delivery of better quality care
- Evidence-based commissioning guidance
- Care pathways with accompanying educational resources to facilitate use in practice
- Person-centred outcomes to measure their impact

The SEED programme is funded by the National Institute for Health Research (NIHR) under its Programme Grants for Applied Research Programme (RP-PG-0611-20005).<sup>277</sup>

For further information see the project's website at <http://research.ncl.ac.uk/seed/>

## North East Health Education England

North East Health Education England has received funding to provide end of life care training for care home staff across the North East during 2014/15. The training will not be specific to the end of life care of people with dementia.

## St. Benedict's Hospice

St. Benedict's Hospice, in Sunderland, is providing training to its workforce within domiciliary care and independent supported living schemes to ensure they feel confident to hold the necessary conversations about end of life preferences with people with dementia. These consultations are enabling end of life preferences to be captured, recorded and, later, acted upon.

## St Cuthbert's Hospice

St Cuthbert's Hospice, Durham, has employed an admiral nurse (April 2014), believed to be the only one in the North East. Admiral nurses are mental health nurses specialising in dementia. They work with family carers and people with dementia, in the community and other settings. Working collaboratively with other professionals, admiral nurses seek to improve the quality of life for people with dementia and their carers. This post will establish how best they can support carers and people with dementia at end of life across Durham. This will be achieved by establishing current gaps in service provision and identifying opportunities for effective interventions. The admiral nurse's post is being funded by the hospice.

For more details on the work of the hospice see <http://www.stcuthbertshospice.com/home.aspx>

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<sup>277</sup> For further information see <http://www.nihr.ac.uk/Pages/default.aspx>



## Tees, Esk and Wear Valleys NHS Foundation Trust

Tees, Esk and Wear Valleys NHS Foundation Trust have produced a 'Guideline for the Use of the Dementia End of Life Care Plan'.<sup>278</sup>

The guide aims to:

- Ensure the delivery of evidence based, generalised, palliative care to patients with dementia at the end of life
- Use the care plan to deliver person centred care for the dying patient
- Provide an end of life care plan that can be used for any patient at the end of their life (though it has been developed specifically for people with dementia)

## Stockton and Hartlepool Dementia Collaborative

In March 2014 the Stockton and Hartlepool Dementia Collaborative undertook a Rapid Process Improvement Workshop (RPIW) to improve the delivery of end of life care to people with dementia in care homes.

Key issues identified during the RPIW included:

- The need for improved access to appropriate equipment
- The need to increase the number of residents that have an Advanced Care Plan in place
- The need to tackle inequalities in training among care home staff
- The need to reduce a person's length of stay in hospital so as to allow a person to return to their care home where appropriate

In response to these issues the members of the Stockton and Hartlepool Dementia Collaborative have produced the following:

- A resource to promote and record discussions with residents and families regarding end of life care planning. This will be trialled in the care home environment and then consideration will be given to rolling it out to other areas, such as memory clinics, dementia information centres and carers centres
- A flow chart to promote good practice when holding a multidisciplinary team meeting within a care home to consider the needs of a resident approaching end of life
- Visual prompts to track a resident's status
- A training matrix with suggested topics that can be tailored to the diverse needs of different staff involved in end of life care
- Information leaflets and a letter of support to be sent to bereaved carers

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<sup>278</sup> Tees, Esk and Wear Valleys NHS Foundation Trust (2013) Guideline for the Use of the Dementia End of Life Care Plan [Online] Available at: <http://www.tevv.nhs.uk/Global/Policies%20and%20Procedures/Clinical/CLIN-0061-v2%20Dementia%20End%20of%20Life%20Care%20Plan%20Guidelines.pdf> (Accessed 17 May 2014)

For further information contact [corinne.walsh@nhs.net](mailto:corinne.walsh@nhs.net)

## Specialist Palliative Care Team (SPCT) for nursing homes, North Tyneside

North Tyneside Clinical Commissioning Group and Northumbria Healthcare have initiated a project to provide education to assist GPs and nursing home staff in all aspects of end of life care, including the management of the complex needs of people with dementia at end of life.

The project uses a collaborative approach allowing nursing home staff to utilise expertise from palliative care specialists and improvements in anticipatory treatment decisions.

The project has resulted in avoidance of inappropriate admission to hospital at end of life through the increased use of 'Emergency Health Care Plans' for patients with dementia.

For further information contact Pam Ransom at [Pamela.ransom@nhs.net](mailto:Pamela.ransom@nhs.net)

## 17.5 Conclusions on the provision of end of life care for people living with dementia in the North East

Improved advanced planning, including the use of 'Deciding Right,' is identified as an action in more than half of the North East's joint dementia plans.

The most recent data available in this report relates to deaths caused by dementia in 2012. This is limited as it only identifies the total number of deaths in the North East with no trend or supplementary data. More detailed data is available relating to deaths where Alzheimer's disease, dementia or senility are listed as either the underlying cause of death or as a contributory cause of death. This data is, however, from 2010. While the 2010 data provides some indication that a high percentage of deaths take place in hospitals, there is a need for more up to date data to identify more contemporary trends.

Prestigious national research into improving end of care for people with dementia is being led by Newcastle University and provides the opportunity to highlight and accelerate improvements in end of life care. Regional work by the North East End of Life Group during 2014/15 focuses on the use of 'Deciding Right' and the development of a regional approach following the phasing out of the Liverpool Care Pathway. There are some good, local, initiatives, which have produced resources and included staff employed specifically to support people with dementia at end of life.

## 17.6 Recommendations on the provision of end of life care for people living with dementia in the North East

- Giving people with dementia the opportunity to consider and record their end of life wishes is a key area of work. Any work which is carried out by the End of Life Regional Group needs to engage with people living with dementia and those working with people with dementia.
- 'Deciding Right' is a regionally recognised system. The Mental Health, Dementia and Neurological Clinical Network needs to support the implementation of this with people with dementia.
- The most detailed data about numbers of people dying from dementia and place of death in this report are from 2010. This also includes people dying with senility as a cause. Key data sets need to be identified to give the most useful data and then it needs to be sourced. This may include place of death and length of stay in location before death. The End of Life Regional Group and the Mental Health, Dementia and Neurological Clinical Network would be key partners in identifying and sourcing this data.
- Statistics on the place of death for people for whom Alzheimer's disease, dementia or senility are listed, show 46% are dying in hospital. Work needs to be undertaken to ensure people with dementia are dying in their place of choice, where possible.
- The SEED project is a significant research project. Newcastle University needs to consider the support that can be provided by other groups in the North East. Findings from the project need to be shared with key groups in the North East including the North East Dementia Alliance and the Mental Health, Dementia and Neurological Conditions Strategic Clinical Network.
- A number of small scale projects are leading to better outcomes for people living with dementia. The findings from these projects need to be shared with partners.



Part D:

Creating  
dementia friendly  
communities  
that understand  
how to help:  
**A North East  
Perspective**

# 18. Dementia Friendly Communities

## Key points:

- The initial driver for the creation of dementia friendly communities was the Prime Minister's Challenge, which included the aim that *"by 2015, up to 20 cities, towns and villages are to have signed up to become more dementia-friendly"*
- There is a National Recognition Process for Dementia Friendly Communities
- Seven out of 10 joint local dementia plans make reference to the development of dementia friendly communities
- In 2012 the North East Dementia Alliance published *'Knowing the Foundations of Dementia Friendly Communities'* for the North East and held two regional conferences
- The North East Dementia Alliance funded seven dementia friendly communities projects
- Stockton-on-Tees and Corbridge are registered with the national recognition process for dementia friendly communities

This section of the report will outline the work that has been undertaken to develop dementia friendly communities in the North East. In particular this section of the report will outline:

- The policy context
- How the development of dementia friendly communities has been included in local plans
- Examples of work undertaken to develop dementia friendly communities in the North East
- Conclusions and recommendations on the development of dementia friendly communities in the North East

A dementia friendly community has been defined as *"a city, town or village where people with dementia are understood, respected and supported and confident they can contribute to community life"*.<sup>279</sup>

## 18.1 Policy context

Outlined below is the policy context specific to the development of dementia friendly communities in England. This should be read in conjunction with the more general policy review in section 3 of this report.

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<sup>279</sup> Alzheimer's Society (2013) Guidance for communities registering for the recognition process for dementia-friendly communities [Online] Available at: <http://alzheimers.org.uk/recognitionprocess> (Accessed 17 May 2014) p.2

## Prime Minister's Challenge on Dementia

In relation to developing dementia friendly communities The Prime Minister's Challenge on Dementia outlines four key commitments. These are:

- **Dementia-friendly communities across the country** - By 2015, up to 20 cities, towns and villages are to have signed up to become more dementia friendly
- **Support from leading businesses for the Prime Minister's Challenge on Dementia** - Leading national organisations have already pledged to look at how they and others can play a part in creating a more dementia friendly society and raise awareness of dementia
- **Awareness-raising campaign** - From autumn 2012, there is to be investment in a nationwide campaign to raise awareness of dementia, to be sustained to 2015. This will build on lessons learned from previous campaigns and will inform future investment
- **A major event over the summer 2012, bringing together UK leaders from industry, academia and the public sector**, to take forward the Prime Minister's Challenge on Dementia<sup>280</sup>

To support the creation of dementia friendly communities a Dementia Friendly Communities Champion Group was established with the launch of the Prime Minister's Challenge on Dementia.

## National Recognition Process for Dementia Friendly Communities

In September 2013 the Alzheimer's Society launched a process to publicly recognise communities that are working to become more dementia friendly and show that they are working towards common criteria.<sup>281</sup>

The guide '*Foundation criteria for the dementia-friendly communities recognition process*' outlines the seven foundational criteria that communities registered with the recognition process will be expected to be working towards. These are:

- Make sure the right local structures are in place to maintain a sustainable, dementia friendly community
- Identify a person or people to take responsibility for driving forward the work to support a community to become more dementia friendly and ensure that individuals, organisations and businesses are meeting their commitments
- Have a plan to raise awareness about dementia in key organisations and businesses within the community that support people with dementia
- Develop a strong voice for people with dementia living in the community

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<sup>280</sup> Department of Health (2012) Prime Minister's Challenge on Dementia: Delivering major improvements in dementia care and research by 2015. Department of Health: London p.6

<sup>281</sup> Alzheimer's Society [Online] Available at: <http://alzheimers.org.uk/recognitionprocess> (Accessed 17 MAY 2014)

- Raise the profile of their work to increase reach and awareness to different groups in the community
- Focus their plans on a number of key areas that have been identified locally
- Have in place a plan or system to update the progress of their community after six months and one year

Communities that are registered with the recognition process for dementia friendly communities will be given the right to issue the 'Working to become dementia friendly' symbol to any organisation within their community that outlines what actions it will take to improve the lives of people living with dementia.<sup>282</sup>

## Relationship between Local Dementia Action Alliances and Dementia Friendly Communities

A dementia friendly community may be understood as an ideal to work towards. By comparison Dementia Action Alliances can be thought of as a model of organisation that can be used to achieve certain goals. It has been argued that Local Dementia Action Alliances are a useful vehicle for delivering dementia friendly communities given their emphasis on bringing together organisations from across a community and translating commitment into practical actions and change.

For further information on Dementia Action Alliances and the National Dementia Declaration see section 3 of this report.

## 18.2 Local plans

### Joint Strategic Needs Assessments

The joint strategic needs assessment for North Tyneside says that the borough aims to become a dementia friendly community.<sup>283</sup>

### Local joint dementia plans

Seven out of the 10 local joint dementia plans in the North East referenced actions in relation to developing dementia friendly communities. Most actions were linked to particular communities

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<sup>282</sup> Alzheimer's Society (2013) Foundation criteria for the dementia-friendly communities recognition process [Online] Available at: <http://alzheimers.org.uk/recognitionprocess> (Accessed 17 May 2014)

<sup>283</sup> North Tyneside Council (2013) North Tyneside Joint Strategic Needs Assessment 2013 [Online] Available at: [http://www.northtyneside.gov.uk/pls/portal/NTC\\_PSCM.PSCM\\_Web.download?p\\_ID=550377](http://www.northtyneside.gov.uk/pls/portal/NTC_PSCM.PSCM_Web.download?p_ID=550377) (Accessed 17 May 2014) p. 4

within the localities: for example, Skelton in East Cleveland or Bernard Gilpin School in Houghton-le-Spring.

Other actions identified how change would be made for example, through a series of pilots,<sup>284</sup> sharing and spreading the design principles from the Smarter Homes project,<sup>285</sup> using local authority quality monitoring payments in care homes<sup>286</sup> or ensuring community support staff have sufficient capacity and skills to implement dementia friendly communities.<sup>287</sup> The Darlington and Durham plan highlights an intention to register with the national recognition process for dementia friendly communities. South Tyneside emphasises the need to ensure that communities are dementia friendly and inclusive of people with sight loss and those with various religious beliefs.

## 18.3 Examples of work undertaken to develop dementia friendly communities in the North East

### North East dementia friendly communities on-line forum

The Northern Rock Foundation has developed an online forum for people from the North East and Cumbria who are developing dementia friendly communities. The forum provides a space for projects to network and share best practice and up-to-date information.

Any individuals or organisations interested in joining the forum should contact [generaloffice@nr-foundation.org.uk](mailto:generaloffice@nr-foundation.org.uk)

### Dementia friendly community project commissioned by the North East Dementia Alliance

#### **Knowing the Foundations of Dementia Friendly Communities for the North East**

In the summer of 2012 the North East Dementia Alliance commissioned the report '*Knowing the Foundations of Dementia Friendly Communities for the North East*'.<sup>288</sup>

The aim of the report was to inform the North East Dementia Alliance's programme of work on dementia friendly communities for 2012/13 as well as the work of interested parties both within and outside of the region.

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<sup>284</sup> Durham and Darlington

<sup>285</sup> Stockton-on-Tees

<sup>286</sup> North Tyneside

<sup>287</sup> Gateshead

<sup>288</sup> Prior, P. (2012) *Knowing the Foundations of Dementia Friendly Communities for the North East* [Online]

Available at:

[http://www.phine.org.uk/uploads/doc/vid\\_16756\\_Dementia\\_Friendly\\_Communities\\_Report\\_Final.pdf](http://www.phine.org.uk/uploads/doc/vid_16756_Dementia_Friendly_Communities_Report_Final.pdf)

(Accessed 17 May 2014)



The report identified existing knowledge and practice relating to dementia friendly communities from both local and national sources. The particular areas of knowledge that the project sought to identify were:

- How to define what dementia friendly communities are, including;
  - What aims do dementia friendly communities seek to achieve?
  - What factors need to be addressed in order to achieve these aims?
- What is known about how to bring dementia friendly communities in to being?

### **‘Joining the Dots’ Conferences**

In December 2012 the Northern Rock Foundation and the North East Dementia Alliance organised two half-day conferences called ‘Joining the Dots’.<sup>289</sup> The conferences were designed to disseminate learning from the report ‘*Knowing the Foundations of Dementia Friendly Communities for the North East*’ and brought together people from across the North East to discuss how dementia friendly communities could be developed across the region.

Following these conferences the North East Dementia Alliance invited applications for funding from organisations working to make their community more dementia friendly. The North East Dementia Alliance funded seven projects, detailed below.

### **Dementia Friendly Stockton**

Cleveland Alzheimer’s Residential Centre Ltd (Cleavearc) received funding to develop the borough of Stockton-on-Tees as a recognised dementia friendly community. The funding was used to recruit a Dementia Friendly Communities Link Worker, who would support local businesses and other organisations to meet the needs of people living with dementia and their carers.

Since receiving the funding, Cleavearc has worked collaboratively with Public Health in Stockton-on-Tees and other organisations to form the Dementia Friendly Stockton Working Group to support the delivery of the project. The Dementia Friendly Stockton Working Group has undertaken substantial consultation with people living with dementia and their carers in Stockton to identify local priorities.<sup>290</sup>

Based on the findings of the consultation the Dementia Friendly Stockton project produced a six step guide to becoming a dementia friendly organisation. It also collated existing resources to produce a guide to help organisations become more dementia friendly, easily and at a low cost. These resources are available in different formats and media. Public Health in Stockton-on-Tees is

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<sup>289</sup> For further information see: <http://www.nr-foundation.org.uk/resources/dementia-reports/dementia-friendly-communities/>

<sup>290</sup> The findings of this consultation can be accessed at <http://dementiafriendlystockton.co.uk/wordpress/wp-content/uploads/2013/11/What-people-told-us.pdf>

commissioning bespoke training which can be delivered for free to organisations wishing to become more dementia friendly.

In November 2013 Stockton-on-Tees successfully registered with the national recognition process for dementia friendly communities and is issuing the national 'working to become dementia friendly' symbol to organisations in Stockton-on-Tees, which outline what they will do to become more dementia friendly.

For further information see [www.dementiafriendlystockton.co.uk](http://www.dementiafriendlystockton.co.uk)

### **Dementia Friendly Skelton**

The Dementia Friendly Skelton project received funding to build on the work already undertaken to make Skelton in East Cleveland the prototype for an active dementia friendly community.

Since receiving the funding the project has worked to increase awareness about the initiative and consulted with people living with dementia and their carers in Skelton to identify changes people believe would make Skelton more dementia friendly.

The findings of the consultation revealed a number of activities people living with dementia in Skelton wanted to attend and the project is now looking at what is available and how to develop further the activities people want. A guide is being produced to inform people with dementia about available activities.

The project has coordinated the delivery of awareness raising sessions to individuals from the voluntary and public sector and is looking at how to engage further with organisations in Skelton.

For further information contact [susan.renvoize@redcar-cleveland.gov.uk](mailto:susan.renvoize@redcar-cleveland.gov.uk)

### **Cleveland Fire Brigade**

Cleveland Fire Brigade received funding to deliver training to staff within each of its four locality areas (Hartlepool, Stockton-on-Tees, Middlesbrough and Redcar and Cleveland). The training was designed to enable the members of Cleveland Fire Brigade to identify people with dementia and their carers who require additional support. It was also intended that the training would allow Cleveland Fire Brigade to assess vulnerable individuals in their own home. They would be able to collect information, which people living with dementia may not wish to share with other agencies but which would assist them to help people with dementia minimise fire and other risks.

Cleveland Fire Brigade has recruited the Alzheimer's Society to deliver in-depth training to specialist advocates in each locality. This knowledge is now being cascaded to all front line staff, both operational and support, to ensure all members of staff engaging with vulnerable people have received training and advice on dementia.

For further information contact [jrafferty@clevelandfire.gov.uk](mailto:jrafferty@clevelandfire.gov.uk)

## **Bernard Gilpin School, Houghton le Spring**

The school has been testing and evaluating a range of curriculum materials and activities as part of the Prime Minister's Dementia Challenge pioneer schools programme. The school is engaging with the wider community to enable intergenerational learning and understanding and provide supportive mechanisms for those living with dementia in the local community.

All the staff at the school have become dementia friends and a community room has been constructed to host weekly activities for people living with dementia and their carers. These activities, which include Singing for the Brain, a dementia café, intergenerational choir and 50s/60s dance, run on a four week rota. The school reached the final of the national Alzheimer's Society's 'Dementia Friendly Awards 2014'.<sup>291</sup>

For further information contact [andrew.bainbridge@schools.sunderland.gov.uk](mailto:andrew.bainbridge@schools.sunderland.gov.uk)

## **Drivers for Change: dementia friendly bus transport in Northumberland**

This project aimed to develop a sustainable method of training for bus drivers dealing with passengers with dementia and their carers and to increase awareness of the needs of passengers with dementia and how they can be supported using public transport.

The project has developed a 'train the trainer' model and has delivered a regional session to training providers from Arriva, Go North East, Stagecoach, Capital4 and Adapt. The project is also providing mentoring to support the trainers to cascade the training out to drivers.

As part of the Customer Service Apprenticeship, Capital4 training delivers 35 hours training for the Certificate of Professional Competency (CPC). Capital4 has agreed to include the dementia awareness training as part of the Customer Service CPC session; Northumbria Healthcare NHS Foundation Trust has trained some Capital4 trainers in dementia awareness and will be training more in 2014. The plan is to ensure that all bus and coach companies dealt with by Northumberland County Council and Capital4 have their dementia awareness training before September 2014.

Northumberland has a network of forums across the county involving people with different needs and stages of dementia and their families. The forums are where the idea for the bus drivers scheme originated. These forums continue to inform and support the development of material which is of practical use to the project: from users' experience in piloting training and developing proposals to rolling them out with transport providers in the county.

The next phase of the project aims to continue discussions to progress the model of delivery and put a programme in place for the numerous small independent and community transport operators in Northumberland. The training is also transferable to other groups of public service workers.

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<sup>291</sup> Alzheimer's Society [Online] Available at: <http://alzheimers.org.uk/dementiafriendlyawards> (Accessed 17 May 2014)

For more information contact Ann Brown, Operational Manager, Involvement & Service Development Team, Northumbria Healthcare NHS Foundation Trust  
Email: Ann.Brown@northumbria-healthcare.nhs.uk

### **Making our city dementia friendly - Newcastle**

The project aims to improve the level of dementia awareness within the Elders Council of Newcastle and identify ways in which, working with partners, it can use its resources to understand what it is like to live with dementia and to respond in a more supportive way.

For further information contact [info@qualityoife.org.uk](mailto:info@qualityoife.org.uk)

### **Involving local communities in meeting the spiritual needs of people with dementia across care settings in the North East**

Northumbria University received funding to host a workshop and produce a resource guide to help raise awareness of the spiritual needs of people with dementia. The workshops brought together key stakeholders including faith leaders, care providers and academics. Through the workshops Northumbria University examined how local communities could be more involved in meeting the needs of people with dementia and enabling them to maintain their spirituality. This project uncovered a range of valuable information including guides, websites and film clips, which have now been brought together in one publication: *'Dementia Friendly Communities Resource Guide Involving local communities in meeting the spiritual needs of people with dementia across care settings in the North East'*.<sup>292</sup> This resource will be useful to signpost people to materials to raise awareness and help take this forward at a local level.

For further information contact [isabel.quinn@northumbria.ac.uk](mailto:isabel.quinn@northumbria.ac.uk)

## **Gateshead Dementia Action Alliance**

Gateshead Council has established a Local Dementia Action Alliance as part of its work to make Gateshead a more dementia friendly community.

Members of the Alliance are required to submit action plans outlining what they will do to achieve the outcomes of the National Dementia Declaration. The Alliance has been working to encourage

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<sup>292</sup> Quinn, I. (2013) Dementia Friendly Communities Resource Guide: Involving local communities in meeting the spiritual needs of people with dementia across care settings in the North East [Online] Available at: <http://www.ncl.ac.uk/changingage/assets/documents/DementiaFriendlyResource-Spirituality.pdf> (Accessed 17 May 2014)

key organisations from the private, voluntary, community and public sectors to submit action plans and become members of the alliance.

An Alliance Steering Group is being established to oversee the project and ensure continued development of action plans. The Alliance will be developing or accessing a website to share information, good practice and celebrate achievements and will produce a newsletter every six months to promote information and good practice.

For further information contact [LeanneDouglas@gateshead.gov.uk](mailto:LeanneDouglas@gateshead.gov.uk)

## Dementia friendly communities work in Northumberland

With funding from the Ballinger Trust the Alzheimer's Society is leading the Northumberland Dementia Initiative, which aims to improve the lives of people living with dementia and carers in Northumberland.

As part of the Wellbeing stream of the initiative the Alzheimer's Society is working to develop dementia friendly communities across Northumberland.

As a result of this work the village of Corbridge has successfully registered with the national recognition process for dementia friendly communities. Following a presentation to the local traders association, businesses from across the village signed up to attend a dementia friends session. All local businesses that commit to becoming more dementia friendly will display the national 'working to become dementia friendly' symbol.

Corbridge is also providing information about dementia through its tourist information centre, drop-in sessions are being held at the Florence Hope activity club and health walks are offered for people living with dementia and carers.

The initiative is currently working with other communities in Northumberland, including Berwick, East Chevington and Hexham, to identify how they also can become more dementia friendly.

For further information contact [amy.syron-mallenby@alzheimers.org.uk](mailto:amy.syron-mallenby@alzheimers.org.uk)

## Dementia friendly hospitals

All eight NHS Acute Hospital Trusts in the North East have signed up to the call to action 'The Right Care: creating dementia friendly hospitals'. For further information on 'The Right Care: creating dementia friendly hospitals' see sections 3 and 13 of this report.

For further information on the support and care of people living with dementia in hospitals see section 13 of this report.

## Dementia friendly environments

In October 2012 the Department of Health announced that *“up to £50 million will be available to NHS Trusts and local authorities working in partnership with social care providers to help tailor hospitals and care homes to meet the needs of those with dementia”*.<sup>293</sup>

In the North East 13 projects were successful in receiving funding through this source. The successful projects were:

- **County Durham & Darlington NHS Foundation Trust** - Improving the environment of care for people with dementia in the general outpatient department of Darlington Memorial Hospital.
- **Newcastle Hospitals** - Enhancing the acute care environment to reduce the distress, disorientation and anxiety that admission to hospital can mean for people with dementia.
- **Durham County Council** - Improving the environments in local care homes (Abigail Lodge, Barrington Lodge, Langley Park, Stanley Park, Brockwell Court, Bishopsgate Lodge and Redwell Hills) and day services (Hospital of God).
- **Gateshead County Council and Gateshead Foundation Trust** - Improve the environment of care for people with dementia including:
  - The Chesters Care Home - New woodland walkway and amenity area, replacement of highly patterned carpet in communal areas and fitting of new red toilet seats
  - Wallace House - Food and drink stations to promote independent access to hot and cold drinks and finger foods as well as the creation of a sensory garden
  - Addison Court/Covent House - Replacement flooring, developing social spaces, providing opportunities for rest and creating focal points to assist people in finding their way, interior signage, lighting and the creation of a sensory garden
  - Hawksbury House Extension - To provide more space for meaningful activities, French windows from the lounge area to the garden, redesign of the garden, suitable flooring, signage and lighting
  - Promoting Independence Centres - Providing audio systems to reaffirm life stories, and a social area in Shadon House to promote integration and social interaction
  - St Joseph’s Day Centre - Improvements to bathing facilities.
- **Stockton-on-Tees Borough Council & Tees, Esk & Wear Valleys NHS Foundation Trust** - The Halcyon Centre LiveWell Dementia Hub Project (for further information on the Halcyon Centre and LiveWell Dementia Hub see section 10 of this report).

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<sup>293</sup> Department of Health [Online] Available at: <https://www.gov.uk/government/news/50-million-investment-to-give-people-with-dementia-specially-designed-care-homes-and-wards> (Accessed 17 May 2014)

- **Redcar & Cleveland Borough Council** - Improving the environment in Brookfield Care Home.

These projects will be evaluated as part of national evaluation commissioned by the Department of Health. Data will be collected until September 2014 with a national evaluation report expected in the autumn / winter of 2014.

## Northumbria University

Northumbria University has committed to becoming a dementia friendly university and, in partnership with the Central England University, is looking at dementia friendly design and how to help care homes to become more dementia friendly. The university has committed to delivering dementia friends sessions to all nursing students.

The university reached the final of the national Alzheimer's Society's national 'Dementia Friendly Awards 2014'.<sup>294</sup>

## North East Association of Directors of Adult Social Services – Dementia Themed Network

The Dementia Themed Network of the North East Association of Directors of Adult Social Services is currently undertaking work to support the development of dementia friendly communities in the North East. The group carried out consultation with 46 individuals from Durham, North Tyneside and Sunderland. The group has been developing resources that can be used to help organisations become more dementia friendly.

## 18.4 Conclusions on the development of dementia friendly communities in the North East

The Prime Minister's Challenge provided the national drive for the development of dementia friendly communities. Since 2012 a number of tools and resources that can help organisations become more dementia friendly have been developed, both in the North East and outside of the region. There have also been a number of innovative and successful projects in the region which have followed different approaches. There is now a need to review which approaches have been effective in making communities more dementia friendly and what this might mean for individual communities. This should take account of the Department of Health's evaluation of the Dementia Friendly Environments projects.

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<sup>294</sup> Alzheimer's Society [Online] Available at: <http://alzheimers.org.uk/dementiafriendlyawards> (Accessed 17 May 2014)

## 18.5 Recommendations on the development of dementia friendly communities in the North East

- There are a number of tools and resources to help to develop dementia friendly communities. These need to be shared to prevent duplication.
- A number of dementia friendly communities projects have been sponsored by the North East Dementia Alliance and others in the North East. There is a need to establish what is successful and how we measure success.
- In the North East two communities have registered with the national recognition process. Other towns and communities need to register and commit to becoming more dementia friendly.





Part E:

# Cross-cutting themes

# 19. Workforce

## Key points:

- An informed and effective workforce for people with dementia is objective 13 of the National Dementia Strategy and is included in the Prime Minister's Challenge
- All the local joint dementia plans in the North East include actions relating to workforce development
- In 2012 there were an estimated 85,200 adult social care jobs in the North East, with workers who provide direct care making up nearly 65,000 of these jobs
- More than 83% of the adult social care workforce in the North East in 2012 were in the independent sector
- The percentage of the North East's adult social care workforce (working with people with dementia) that had no qualification was smaller than the percentage for the whole of England (30.5% compared to 40.5%)
- A number of national initiatives support workforce development, including the 'Core Principles for Supporting People with Dementia' and the Health Education England's targets to increase dementia awareness across the health workforce
- The North East Dementia Alliance has produced two reports on the dementia workforce in the North East. The first provides recommendations for North East Dementia Alliance and the second provides information on values based recruitment
- There are currently changes to the Care Alliances in the North East

This section of the report will consider key issues relating to the development of an informed and effective workforce to meet the needs of people living with dementia. In particular this section of the report will outline:

- The policy context
- How workforce has been included in local plans
- Examples of work undertaken in the North East to improve the workforce
- Conclusions and recommendations on workforce in the North East

## 19.1 Policy context

Outlined below is the policy context specific to the development of an informed and effective workforce to deliver high standards of care and support for people living with dementia. This should be read in conjunction with the more general policy review in section 3 of this report.

## National Dementia Strategy

An informed and effective workforce for people with dementia is objective 13 of the National Dementia Strategy. Objective 13 highlights the need for *“health and social care staff involved in the care of people who may have dementia to have the necessary skills to provide the best quality of care in the roles and settings where they work”*. The strategy goes on to state that this is *“to be achieved by effective basic training and continuous professional and vocational development in dementia”*.<sup>295</sup>

## The Prime Minister’s Challenge on Dementia

The Prime Minister’s Challenge on Dementia states: *“We will work with the profession to identify how best to improve early diagnosis of dementia through improvements in awareness, education and training and through potential improvements to the GP contract”*.<sup>296</sup>

## Common Core Principles for Supporting People with Dementia: A guide to training the social care and health workforce

The guidance was commissioned by the Department of Health as part of the implementation of the National Dementia Strategy. The guidance, which was produced jointly by Skills for Care and Skills for Health, outlines eight core principles for supporting people with dementia.

The guidance is designed to support *“workforce development for any member of staff, in any health or social care setting, working with people at any stage of dementia. They can also be used to inform the content of curricula and training courses”*.<sup>297</sup>

The eight core principles it outlines are:

1. Know the early signs of dementia
2. Early diagnosis of dementia helps people receive information, support and treatment at the earliest possible stage
3. Communicate sensitively to support meaningful interaction
4. Promote independence and encourage activity
5. Recognise the signs of distress resulting from confusion and respond by defusing a person’s anxiety and supporting their understanding of the events they experience
6. Family members and other carers are valued, respected and supported just like those they care for and are helped to gain access to dementia care advice

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<sup>295</sup> Department of Health (2009) Living well with dementia: a National Dementia Strategy. London: Department of Health p.13

<sup>296</sup> Department of Health (2012) Prime Minister’s Challenge on Dementia: Delivering major improvements in dementia care and research by 2015. Department of Health: London p.20

<sup>297</sup> Skills for Care and Skills for Health (2001) Common Core Principles for Supporting People with Dementia: A guide to training the social care and health workforce. Leeds: Skills for Care and Skills for Health

7. Managers need to take responsibility to ensure members of their team are trained and well supported to meet the needs of people with dementia
8. Work as part of a multi-agency team to support the person with dementia

## Supporting People in the Advanced Stages of Dementia: A case study-based manager's guide to good practice in learning and development for social care workers supporting people in the advanced stages of dementia

Published in May 2013, the guidance was commissioned by the Department of Health and produced by Skills for Care.<sup>298</sup> The guidance aims to support leaders and managers to develop their workforces so they can provide high standards of care and support for people in the advanced stages of dementia.

The guide:

- Considers how reminiscence can be used by workforces to support people with dementia
- Provides examples of meaningful activity that the workforce can use to engage people with dementia
- Highlights dementia-specific qualifications, which can be used to develop the knowledge and skills of a workforce
- Provides a number of case studies and examples, as well as links to further resources to support workforce development

## 19.2 Local plans

### Health and Wellbeing Strategies

Gateshead's Health and Wellbeing Strategy lists dementia as a focus for action during 2013-2016. This includes the development of the health and care workforce.<sup>299</sup>

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<sup>298</sup> Skills for Care (2013) Supporting People in the Advanced Stages of Dementia: A case study-based manager's guide to good practice in learning and development for social care workers supporting people in the advanced stages of dementia [Online] Available at: [http://www.skillsforcare.org.uk/Document-library/Skills/Dementia/Advance-stages-of-dementia-guide-\(May-2013\)vfw.pdf](http://www.skillsforcare.org.uk/Document-library/Skills/Dementia/Advance-stages-of-dementia-guide-(May-2013)vfw.pdf) (Accessed 17 May 2014)

<sup>299</sup> Gateshead Health and Wellbeing Board (2013) Active, Healthy and Well Gateshead: A Health & Wellbeing Strategy for Gateshead (2013/14 to 2015/16) [Online] Available at: <http://www.gateshead.gov.uk/DocumentLibrary/CBS/health/Active-Healthy-and-Well-Gateshead.pdf> (Accessed 17 May 2014)

## Local joint dementia plans

All local joint dementia plans in the North East have actions relating to the training of the local workforce.

Four plans make reference to the use of the Tyne and Wear Care Alliance, which provides training to domiciliary and care home staff providing services in their localities. This includes the provision of training for dementia champions.

The need to map training, evaluate effectiveness, identify gaps and develop a clear strategic approach, is contained in four local joint dementia plans.

Two plans highlight a requirement for care home providers to have appropriate training in place as part of their contract with the local Authorities.

The plans highlight the need to provide specialist training in relation to deprivation of liberties, challenging behaviours and targeted dementia training for substance and alcohol misuse teams and GPs.

## 19.3 Local statistics relating to the workforce in the North East

The Skills for Care report '*North East Report, 2013: From the National Minimum Data Set for Social Care (NMDS-SC)*' stated that in 2012 there were estimated to be more than 85,000 adult social care jobs in the North East.<sup>300</sup> Workers who provided direct care made up nearly 65,000 (76%) of these jobs.<sup>301</sup> These figures included members of the adult social care workforce working with all service user groups and are not restricted to members of the workforce working with people with dementia.

As shown in Table 20, the largest adult social care workforce in the North East was in County Durham (14,500), while the lowest adult social care workforce was in Hartlepool (3,300).

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<sup>300</sup> Skills for Care (2013) North East report, 2013: From the National Minimum Data Set for Social Care (NMDS-SC) [Online] Available at: <http://www.skillsforcare.org.uk/Document-library/NMDS-SC,-workforce-intelligence-and-innovation/NMDS-SC/NorthEastregionalreport2013vweb.pdf> (Accessed 17 May 2014)

<sup>301</sup> Ibid

Locality	Total
Darlington	3,700
Durham	14,500
Gateshead	6,100
Hartlepool	3,300
Middlesbrough	4,200
Newcastle upon Tyne	9,800
North Tyneside	5,500
Northumberland	8,500
Redcar and Cleveland	4,600
South Tyneside	4,800
Stockton-on-Tees	5,600
Sunderland	8,500
<b>North East</b>	<b>85,200</b>

**Table 20:** Skills for Care's estimates of the number of jobs in the adult social care sector in the North East by locality as at 2012. Source: Skills for Care National Minimum Data Set for Social Care [Online] Available at <https://www.nmds-sc-online.org.uk/ReportEngine/Dashboard.aspx> (Accessed 17 May 2014)

More than 83% of the adult social care workforce in the North East in 2012 was in the independent sector (including those working for people who receive direct payments). This is shown in Table 21.

	Total Numbers	Percentage
<b>Total</b>	85,200	
<b>Local authority</b>	8,700	10.2 %
<b>Direct payments recipients</b>	12,100	14.2 %
<b>Voluntary</b>	14,600	17.1 %
<b>Private</b>	43,800	51.4 %

**Table 21:** Skills for Care's estimates of the number of jobs in the adult social care sector in the North East by sector as at 2012. Source: Skills for Care National Minimum Data Set for Social Care [Online] Available at <https://www.nmds-sc-online.org.uk/ReportEngine/Dashboard.aspx> (Accessed 17 May 2014)

As shown in Table 22, a smaller percentage of the North East adult social care workforce (working with people with dementia) had no qualification compared to the percentage for all of England (30.5% in the North East compared to 40.5% for England as a whole).

A smaller percentage of the North East adult social care workforce (working with people with dementia) held a level 4 qualification compared to the percentage for all of England (7.5% in the North East compared to 8.0% for England as a whole).

Highest qualification held	Percentage of Adult Social Care Workforce for England working with older people with dementia	Percentage of Adult Social Care Workforce for the North East working with older people with dementia
<b>No qualification held</b>	40.5%	30.5%
<b>Entry Level or Level 1</b>	0.7%	0.3%
<b>Level 2</b>	28.9%	32.1%
<b>Level 3</b>	14.3%	19.5%
<b>Level 4 or above</b>	8.0%	7.5%
<b>Other relevant social care qualification(s)</b>	5.9%	8.8%
<b>Any other qualifications(s)</b>	1.7%	1.4%

**Table 22:** The highest qualification level of social care workers recorded in the NMDS-SC across all job roles, service types, and sectors. Source: Skills for Care National Minimum Data Set for Social Care [Online] Available at <https://www.nmds-sc-online.org.uk/ReportEngine/Dashboard.aspx> (Accessed 17 May 2014)

## 19.4 Examples of work undertaken in the North East

### North East Dementia Alliance – Workforce Report

The North East Dementia Alliance commissioned a report to detail the issues, challenges and opportunities for the health and social care workforce in the North East of England in relation to

dementia care.<sup>302</sup> The report, published in March 2012, outlines “*the numbers, roles and characteristics of the dementia care workforce across the region, concentrating on the skills and knowledge that already exist, where it needs improving, and the educational and training resources available*”.<sup>303</sup>

The report provides:

- Information on the key leadership and management forums relevant to the dementia workforce in the North East
- Supporting information in annexes 1 - 5:
  - Workforce data, roles and numbers for the North East
  - A dementia learning resource catalogue
  - Values based recruitment case studies and sample person specifications
  - Examples of innovative dementia learning programmes
  - Key briefing notes for a range of leaders
- Seven priority themes for dementia care in the North East, with a supporting narrative and examples of good practice for each
- A summary and recommendations for action by the North East Dementia Alliance

## Working with people with dementia and their carers: Values Based Recruitment

In spring 2013 the North East Dementia Alliance commissioned the North of England Mental Health Development Unit to produce a 'Values Based Recruitment Toolkit' for service providers working with people with dementia. The aim of this work was to improve the quality of care for people with dementia and to reduce staff turnover and recruitment costs for employers.

The report ‘*Working with people with dementia and their carers: Values Based Recruitment*’<sup>304</sup> provides:

- A values based recruitment toolkit (based on evidence from research and practical examples from the North East and other areas of the country)
- A universal business case for developing and supporting a workforce which has the right values when working with people with dementia

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<sup>302</sup> Norman, H. and Rippon, S. (2012) The Implementation of the National Dementia Strategy: Objective 13. Workforce, Competencies, Development and Training. *The North East Position*. [Online] Available at: <http://www.phine.org.uk/group.php?gid=173&resources&collection=1476> (Accessed 17 May 2014)

<sup>303</sup> North of England Mental Health Development Unit (2013) Working with people with dementia and their carers: Values Based Recruitment [Online] Available at: <http://www.nemhdu.org.uk/publications/> (Accessed 17 May 2014) p.4

<sup>304</sup> North of England Mental Health Development Unit (2013) Working with people with dementia and their carers: Values Based Recruitment [Online] Available at: <http://www.nemhdu.org.uk/publications/> (Accessed 17 May 2014)



- A contract insert to be used by commissioners to ensure providers use values based recruitment and have values in their specification

The North East Dementia Alliance is making links with the NHS Employers Organisation to assist with the dissemination of the concept of values based recruitment as part of NHS Employer's 'recruiting to values' programme.<sup>305</sup>

## Skills for Care

Improving the quality of care for people living with dementia is a key priority in Skills for Care's 2013/14 business plan and is allied to the Government's agenda. It will continue to be a priority in its 2014/15 business plan.

Skills for Care has a national programme to ensure that personnel who provide care and support to those living with dementia have the right values, knowledge and skills to provide a high quality service.

Skills for Care gathers workforce intelligence, including levels of dementia qualifications, via its National Minimum Data Set – Social Care (NMDS-SC). The NMDS - SC is used by the Department of Health as the primary source of data for the Adult Social Care workforce.

As part of the national programme of work for 2013/14, Skills for Care has delivered a series of workshops in the North East, including:

- Common Core Principles for Supporting People with Dementia
- Supporting People in the Advanced Stages of Dementia

As part of its activity for 2014/15 Skills for Care will support the domiciliary care workforce to enable it to provide high standards of care for people living with dementia. During June and July 2014, Skills for Care will deliver a number of workshops based on its guide '*Better domiciliary care for people with dementia: Best practice case studies from domiciliary care employers developing their workforces to support people with dementia*'.<sup>306</sup> These workshops will be aimed at leaders and managers in the domiciliary care workforce and the North East Area event took place on 19<sup>th</sup> June 2014.

For further information contact [northern@skillsforcare.org.uk](mailto:northern@skillsforcare.org.uk)

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<sup>305</sup> NHS Employers [Online] Available at: <http://www.nhsemployers.org/your-workforce/recruit/employer-led-recruitment/recruiting-for-values> (Accessed 17 May 2014)

<sup>306</sup> Skills for Care (2014) *Better domiciliary care for people with dementia: Best practice case studies from domiciliary care employers developing their workforces to support people with dementia* [Online] Available at: <http://www.skillsforcare.org.uk/Document-library/Skills/Dementia/Better-domiciliary-care-for-people-with-dementia.pdf> (Accessed 17 May 2014)

## Skills for Health

Skills for Health works to meet the skills and workforce needs of the health workforce in the NHS and independent sector.<sup>307</sup>

Dementia is one of Skills for Health's services areas. Skills for Health has worked with Skills for Care to scope the education and training needs of the workforce and has developed an action plan for education and training that supports the National Dementia Strategy.

In 2014/15 Skills for Health will work with partners to:

- Develop an eLearning dementia awareness tool with modules for paramedics and primary care staff. This is in partnership with Worcester University
- Develop a Dementia Skills Framework defining outcomes linked tier 1, 2 and 3. This is being developed in partnership with Health Education England.

Skills for Health is part of the North East Local Education and Training Board (LETB).

## Health Education North East

To improve the care of people with dementia, Health Education England's 2013/14 mandate set out a national target of ensuring *"that 100,000 staff have foundation level training by March 2014"*.<sup>308</sup> This target was achieved in November 2013.

Although local targets were not set Health Education North East reported that at the end of December 2013 8,259 staff in the North East had been trained at Tier 1 (equivalent of foundation level), 1,157 at Tier 2 and 276 at Tier 3. The health workforce in the North East is estimated to be 73,000 people. Health Education North East is aiming to train all patient-facing staff to foundation level, which is estimated to be around about 58,000 staff members (80% of the health workforce in the North East).

The 2014/15 refreshed mandate sets the national target for *"tier 1 training [foundation] to [be delivered to] a further 250,000 staff by March 2015, ensuring that the tools and training opportunities are available to all staff by the end of 2018"*.<sup>309</sup> This translates into a regional target of 21,358. Between 2014/16 it will be expected to expand this work to support Tier 2 developments in dementia training to ensure NHS staff continue to receive the most advanced support available.

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<sup>307</sup> <http://www.skillsforhealth.org.uk/service-area/dementia/>

<sup>308</sup> Department of Health (2013) Delivering high quality, effective, compassionate care: Developing the right people with the right skills and the right values: A mandate from the Government to Health Education England: April 2013 to March 2015 [Online] Available at: [http://hee.nhs.uk/wp-content/uploads/sites/321/2013/05/29257\\_2900971\\_Delivering\\_Accessible.pdf](http://hee.nhs.uk/wp-content/uploads/sites/321/2013/05/29257_2900971_Delivering_Accessible.pdf) (Accessed 17 May 2014)

<sup>309</sup> Ibid p. 41

In conjunction with the Department of Health, Health Education England is expected to work with education providers and regulators to ensure that newly qualified staff, looking after patients with dementia, receive Tier 1 dementia training. It is also expected to work with bodies that set curricula to ensure all undergraduate courses include training in dementia by September 2015.

Health Education North East will provide leadership in the North East to support the development of training programmes enabling health staff to diagnose the early symptoms of dementia and deliver safe, dignified and compassionate care for people with dementia and their key people.

Health Education North East has an identified lead for dementia and a baseline review of training in secondary care providers has been carried out across the North East.

Health Education England is prioritising the development of GP skills to ensure they are able to identify and provide appropriate help to patients with dementia. Developing GP skills will be led from a national level.

For further information see <http://ne.hee.nhs.uk/> or contact [jill.smith@ne.hee.nhs.uk](mailto:jill.smith@ne.hee.nhs.uk)

## Health Education North East Local Government Group

The Health Education North East Local Government Group is a local authority sub group of Health Education North East. Members are made up of workforce leads from local authorities in the North East. The purpose of the group is to look for and develop opportunities for joint and integrated working with NHS colleagues. The network will have a key role in ensuring local authorities meet the duties in the Care Act 2014 in relation to workforce planning and development.

For further information contact [jill.smith@ne.hee.nhs.uk](mailto:jill.smith@ne.hee.nhs.uk)

## Care Alliances

Until spring 2014 there were four care alliances in the North East. The care alliances provided support and training to improve the care workforce in their respective localities. The four care alliances in the North East were:

- Durham Employer Care and Health Alliance - now closed
- Northumberland Care Alliance - fully operational
- Tees Valley Social Care and Health Alliance - operating until July 2014
- Tyne and Wear Care Alliance - fully operational

Outlined below are examples of the work undertaken by the care alliances prior to May 2014.

## **Tyne and Wear Care Alliance**

In 2011 the Tyne and Wear Care Alliance secured funding to facilitate the delivery of a Dementia Liaison and Coordination Champion (DLCC) programme across the South of Tyne area (Gateshead, Sunderland and South Tyneside). The programme aims to ensure that health and social care providers have Dementia Champions, who are trained to provide best practice person centred dementia care for people with dementia. Dementia Champions will also play a key role in supporting other staff to achieve an effective level of dementia awareness.

The programme supports members of care home/domiciliary care teams to complete a Level 3 Certificate in dementia using the awarding bodies of either City and Guilds or Edexcel.

The programme hosts bi-monthly 'Best Practice Forums' to maintain regular contact with the Dementia Champions. The bi-monthly forums also provide an opportunity for the DLCCs from care providers to study collectively all aspects of qualitative dementia care.<sup>310</sup>

The Tyne and Wear Care Alliance has been commissioned by the North East Dementia Alliance in conjunction with North East Association of Directors of Adult Social Services to co-ordinate person centred care training in care homes across the region (for further information see section 13 of this report).

## **Tees Valley Social Care and Health Alliance**

In July 2013 Skills for Care awarded a Workforce Development Innovation Fund contract to Tees Valley Care Alliance. This funding is being used to support 60 activity coordinators to undertake two Qualifications and Credit Frameworks (QCF) units in:

- Understanding the process and experience of dementia
- Co-ordinating activities in the provision of care

Each learner completing the programme has been awarded an over-arching Dementia Champion certificate.

## **Northumberland Care Alliance CIC**

In 2013 the Northumberland Care Alliance CIC ran Dementia Care Management training courses.

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<sup>310</sup> Tyne and Wear Care Alliance [Online] Available at:  
<http://www.twca.org.uk/documents/Generic%20Documents/Dementia/The%20Role%20of%20the%20Dementia%20Liaison.pdf> (Accessed 17 May 2014)

## Nurses training at Northumbria University

Northumbria University is training all undergraduate nurses in dementia care and offering nursing students the opportunity to take part in Dementia Friends sessions. The university will be extending the Dementia Friends session to the public health and allied health care departments. A creative writing project was run to assist students to evaluate the friends training, carry out reflective practice and to widen the sphere of influence.

For further information on the Dementia Friends initiative see section 6 of this report.

## Training at Northumbria Healthcare NHS Foundation Trust

As part of its 'Shared Purpose'<sup>311</sup> project Northumbria Healthcare NHS Foundation Trust is delivering one and two day comprehensive courses on dementia, delirium and depression. The training promotes person centred care that focuses on the individual not the condition and allows staff members to access online trust-wide dementia resources. The training includes sessions delivered by doctors, specialist nurses and patients and their carers. Since 2010, 32 teams have received this training.

The course has resulted in staff becoming more motivated to change their practice and make the wards they work in more dementia friendly, with staff members reporting an increased confidence in providing person centred care, involving carers and understanding their role.

## 19.5 Conclusions on workforce

In the North East approximately 65,000 adult social care workers provide direct care and there are 58,000 patient facing health staff, with care responsibilities in the community, hospitals and care homes. National initiatives help to develop and support the workforce so that they can care for and support people living with dementia. These include 'common core principles for supporting people with dementia,' the dementia skills framework and targets for training for health staff.

The significant task of recruiting to, retaining and developing these staff groups can not be underestimated. The use of national initiatives is valuable but can not be solely relied on. Employers and commissioners have a key role in ensure the workforce they employ and commission is fit for purpose.

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<sup>311</sup> Northumbria Healthcare NHS Foundation Trust [Online] Available at: <https://www.northumbria.nhs.uk/quality-and-safety/shared-purpose> (Accessed 17 May 2014)

## 19.6 Recommendations on workforce

- There are national targets for the training of health care staff. Health Education North East needs to continue to work with providers to ensure these targets are met.
- A dementia skills framework is being developed as part of the NHS mandate. Once developed, the training provided in the North East needs to be delivered in line with this national framework.
- The North East Dementia Alliance has published a values based recruitment toolkit. Providers and commissioners need to consider its usefulness for their organisation. Health organisations can also link with the NHS Employers Organisation to be part of its 'recruiting to values' project.
- The North East Dementia Alliance is working with ADASS and the Tyne and Wear Care Alliance to deliver person centred training to 240 care homes in the North East. The evaluation of this work needs to be considered to assess additional training and support needs among care home staff.
- People living with dementia and carers have supported the delivery of training to nursing students at Northumbria University. Anecdotal evidence suggests this approach has resulted in positive outcomes. There is a need for a formal evaluation of the impact of this approach with the possibility of replicating this model of training in other workforce settings.

## 20. Involving, engaging and empowering people with dementia and their carers

### Key points:

- The National Dementia Strategy:
  - Highlights the need to involve people with dementia and carers in commissioning services for people with dementia
  - States that engagement should move beyond consultation to meaningful roles in priority setting, monitoring and service design
- Actions in the local joint dementia plans relating to involvement focus on people with dementia influencing their own care
- The North East Dementia Alliance has developed a participation and engagement course for people with dementia and family carers
- The research for this report identified only one user led organisation for people living with dementia in the North East
- There are a number of opportunities for people with dementia and carers to influence service development through forums
- The Clinical Research Network: North East and North Cumbria has a Patient, Carer and Public Involvement Panel for DeNDRoN, which is consulted about what and how clinical research in dementia is carried out

This section of the report will consider key issues relevant to the involvement, engagement and empowerment of people with dementia so they are able to influence and shape dementia services. In particular, this section of the report will outline:

- The policy context
- How involving, engaging and empowering people with dementia have been included in local plans
- Examples of work undertaken to involve, engage and empower people with dementia in the North East
- Conclusions and recommendations on the involvement, engagement and empowerment of people with dementia in the North East

## 20.1 Policy context

Outlined below is the policy context specific to involving, engaging and empowering people with dementia so they are able to influence and shape dementia services. This should be read in conjunction with the more general policy review in section 3 of this report.

### National Dementia Strategy

The National Dementia Strategy sets out the need for services to be commissioned in conjunction with people with dementia and carers, stating: *“it is crucial that people with dementia and their families must be fully engaged at all the phases of commissioning. This engagement should move beyond consultation to meaningful roles in priority setting, monitoring and service design”*.<sup>312</sup>

The National Dementia Strategy also outlines ‘World Class Commissioning competencies’ designed to promote the use of creative approaches to ensure that, where possible, people with dementia are included and that their voices are heard (as well as the voices of their family carers).<sup>313</sup>

### Dementia Engagement and Empowerment Project

The Dementia Engagement and Empowerment Project (DEEP) brings together groups of people with dementia from across the UK. DEEP supports these groups to try to change services and policies affecting the lives of people with dementia and is led by the Mental Health Foundation, Innovations in Dementia and the Alzheimer’s Society.

The first phase of the project aimed to:

- Undertake a mapping survey and follow-up interviews to collect information about the groups and projects across the UK led by or actively involving people with dementia, influencing services and policies
- Hold a national event to bring groups of people with dementia together to discuss the findings of the survey and the possibility of a national network
- Publish a report and film that captures the activities, learning and information gathered by the survey
- Bring together an extended reference group network of people with dementia to ensure that the key components of DEEP are relevant, meaningful and, as far as possible, shaped by people with dementia

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<sup>312</sup> Department of Health (2009) Living well with dementia: a National Dementia Strategy. London: Department of Health p.81

<sup>313</sup> Ibid



In October 2012 the findings of the first phase of the project were recorded in the Joseph Rowntree Foundation report: '*A stronger collective voice for people with dementia*'.<sup>314</sup> This report was supported by '*Ripple on the Pond: DEEP: The engagement, involvement and empowerment of people with dementia in collective influencing: Appendix to main report – A stronger collective voice for people with dementia*'.<sup>315</sup>

## Strengthening the Involvement of People with Dementia: A Resource for Implementation

In 2007 the Care Services Improvement Partnership (CSIP, 2007) produced the resource guide '*Strengthening the Involvement of People with Dementia: A Resource for Implementation*'.<sup>316</sup>

The resource contains "*advice and examples of positive practice which can facilitate the active and meaningful involvement of people who have dementia in the planning, delivery and evaluation of health, social care and other support services*".<sup>317</sup>

## Making involvement count resource cards

In 2011 the Involving People with Dementia Reference Group produced a set of resource cards to support the engagement and consultation of people with dementia, aiming to "*strengthen and directly involve people with dementia as well as their families and carers*".<sup>318</sup>

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<sup>314</sup> Williamson, T. (2012) *A stronger collective voice for people with dementia*. York: Joseph Rowntree Foundation

<sup>315</sup> Mental Health Foundation (2012) *Ripple on the Pond: DEEP: The engagement, involvement and empowerment of people with dementia in collective influencing: Appendix to main report – A stronger collective voice for people with dementia* [Online] Available at: [http://www.mentalhealth.org.uk/content/assets/PDF/publications/DEEP\\_report\\_appendix\\_2012.pdf?view=Standard](http://www.mentalhealth.org.uk/content/assets/PDF/publications/DEEP_report_appendix_2012.pdf?view=Standard) (Accessed 17 May 2014)

<sup>316</sup> CSIP Older Peoples Mental Health programme (2012) *Strengthening the Involvement of People with Dementia: A Resource for Implementation* [Online] Available at: [http://www.dhcarenetworks.org.uk/\\_library/Resources/Dementia/CSIPComment/strengthening-the-involvement-of-people-with-dementia.pdf](http://www.dhcarenetworks.org.uk/_library/Resources/Dementia/CSIPComment/strengthening-the-involvement-of-people-with-dementia.pdf) (Accessed 17 May 2014)

<sup>317</sup> Ibid p.1

<sup>318</sup> Involving People Living with Dementia Reference Group (2011) *Involving People Living with Dementia : Making Involvement Count* [Online] Available at: [http://www.inclusionlondon.co.uk/domains/inclusionlondon.co.uk/local/media/downloads/Dementure\\_making\\_involvement\\_count.pdf](http://www.inclusionlondon.co.uk/domains/inclusionlondon.co.uk/local/media/downloads/Dementure_making_involvement_count.pdf) (Accessed 17 May 2014)

## 20.2 Local plans

### Joint Strategic Needs Assessment

Sunderland's Joint Strategic Needs Assessment recognised that certain groups, including people with dementia who may have communication difficulties, may need specialist advocacy support to help them express their views about their options in care, support and daily living solutions.

### Local joint dementia plans

All local joint dementia plans in the North East contain actions that highlight an intention to increase the provision of information for people living with dementia so as to increase involvement and empowerment.

Within the local joint dementia plans there is recognition that individuals need to be in control of their own care through advanced care planning (mentioned in eight out of 10 plans) and that this can be helped by using personal budgets (mentioned by four out of 10 plans).

A number of plans report that they are specifically involving people with dementia in the development of policies; for example, housing,<sup>319</sup> the formation and evaluation of the dementia strategy<sup>320</sup> and grant monitoring.<sup>321</sup>

## 20.3 Examples of work undertaken in the North East

A number of project specific consultations have taken place; these include one off consultations or consultations for a fixed period of time. Examples of these consultations include those conducted around the use of the 'Forget me Not' scheme,<sup>322</sup> dementia friendly communities initiatives<sup>323</sup> and the provision of respite services in South Tyneside.<sup>324</sup> However, this section of the report will particularly focus on initiatives that aim to give people with dementia and carers the opportunity to shape and influence dementia services over a longer-term.

### Living well with dementia – participation and engagement programme

The North East Dementia Alliance commissioned the North of England Mental Health Development Unit and Karen Picking and Associates to deliver a pilot version of the Living Well with Dementia

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<sup>319</sup> Gateshead

<sup>320</sup> Durham and Darlington

<sup>321</sup> Sunderland

<sup>322</sup> For further information see section 14 of this report

<sup>323</sup> For further information see section 18 of this report

<sup>324</sup> For further information see section 4 of this report

programme. The programme aims to help people with dementia and their carers to develop the skills and confidence that will enable them to be involved in and plan their own care and shape services.

The programme has been developed by people with dementia, carers and service providers and is based on research previously commissioned by the North East Dementia Alliance.

The course will support people with dementia and their carers to:

- Gain a greater understanding of the services available for people with dementia, the networks and people involved in caring for people with dementia and the factors which might affect people with dementia
- Develop the skills that will allow them to shape services and challenge attitudes towards people with dementia
- Increase self-confidence to get involved
- Increase the awareness of wellbeing and how to develop a wellbeing plan

The first programme started in May 2014. A second programme will run in autumn 2014. Following the initial pilots the programme will be evaluated.

For further information contact [paul.johnson@nemhdu.org.uk](mailto:paul.johnson@nemhdu.org.uk)

## Service User Led Groups

### **Young at Heart – Stockton-on-Tees**

Young at Heart is a user led group, which people with dementia and their carers can attend together. The group takes place in Stockton-on-Tees and supports people with dementia to undertake a range of activities of interest to them while carers have the opportunity to meet and chat. The group also provides feedback and opinion to help health and social care service development and the development of a dementia friendly community in Stockton-on-Tees.

For further information about Young at Heart contact [ggtweed.clevarc@btinternet.com](mailto:ggtweed.clevarc@btinternet.com)

### **Dementia Engagement and Empowerment Programme (DEEP) and the North East**

The North East Dementia Alliance is currently working with the Dementia Engagement and Empowerment Programme (DEEP) to support the further development of user led groups across the North East.

## Dementia forums

Dementia forums provide an opportunity for people with dementia and their carers to express their thoughts and opinions on issues and services that affect them. Dementia forums provide a

mechanism through which people with dementia and their carers can inform and shape the development of services and policy.

As of May 2014, dementia forums were running in the following localities in the North East:

- Alnwick
- Bedlington
- Blyth
- Gateshead
- Hexham
- South Tyneside

Older people's forums, open to people with memory problems, were, as of May 2014, running in:

- Ashington (through the Golden Age Forum)
- Berwick
- Hexham

In addition, the Northumberland Older People's Partnership Board includes various older people's and carers' representatives.

## Stockton and Hartlepool Advisory Group

The Stockton and Hartlepool Advisory Group gives people with dementia and their carers the opportunity to have their say on initiatives which will affect their lives.

The group meets regularly with the local authority to share its opinions on proposed improvements in dementia services. Representatives from organisations involved in delivering the proposed improvements also attend the sessions to discuss their initiatives. People with dementia and carers are able to contribute their opinion in a number of ways, such as attending group meetings or submitting their opinions by telephone, e-mail or post.

There have been direct changes in service delivery as a result of concerns expressed by carers in the Advisory Group. For example, carers' views were presented at the Stockton and Hartlepool Dementia Collaborative's Rapid Process Improvement Workshop on end of life care. This resulted in the production of a standard discharge letter from social workers to carers following bereavement.

For further information contact Kate Hogan on 01429 283095

## Patient, Carer and Public Involvement Panel – DeNDRoN

The Clinical Research Network: North East and North Cumbria has a Patient, Carer and Public Involvement Panel (PPI Panel) for DeNDRoN which is consulted about what and how clinical research in dementia is carried out. PPI Panel members have become involved in research by joining study

management groups, as co-applicants, in developing grant applications, and consulted about memory clinic organisation. There are (as of April 2014) 78 members on the PPI Panel.

For further information contact [margaret.piggott@nhs.net](mailto:margaret.piggott@nhs.net)

## 20.4 Conclusions on the involvement, engagement and empowerment of people living with dementia and carers in the North East

The National Dementia Strategy highlights the need to involve people living with dementia and carers in the commissioning of services. The strategy states this engagement should move beyond consultation to meaningful roles in priority setting, monitoring and service design. The action plans from three localities aim to achieve this level of engagement.

DEEP is a national initiative, which can support increased user involvement.

The North East Dementia Alliance has developed a course to support people with dementia and their carers to develop the right skills to engage with the process of planning and implementing changes to services. The establishment of forums and ongoing project specific consultations have helped to set involvement, engagement and empowerment in the regional agenda.

There is only one user led organisation for people with dementia and carers in the North East.

There are a number of meaningful engagement and empowerment initiatives; however, these are not fully spread across the North East and, therefore, only give limited opportunities to people living with dementia. This needs to be redressed.

## 20.5 Recommendations on the involvement, engagement and empowerment of people living with dementia and carers in the North East

- The Dementia Engagement and Empowerment Project (DEEP) provides opportunities to support groups of people with dementia to try to change services and policies affecting the lives of people with dementia. The North East Dementia Alliance should work with this project to see what benefits can be brought to people living with dementia in the North East.
- A minority of local action plans contain a commitment to improve the engagement and empowerment of people living with dementia by supporting people to take on meaningful roles in priority setting, monitoring and service design. All local plans should reflect a similar level of commitment.

- The North East Dementia Alliance has commissioned the development and delivery of a participation and engagement programme for people with dementia and their carers. If the evaluation of the pilot finds the course to be successful, resources should be sought to run it on a regular basis, across the region, taking into account any recommendations from the evaluation.
- There is only one user led organisation recorded in the North East for people with dementia and carers. The North East Dementia Alliance should continue to work with the Dementia Engagement and Empowerment Programme (DEEP) to support the further development of user led groups across the North East.
- Many consultation and involvement activities are responding to a predetermined agenda. Consideration needs to be given to how people with dementia can be meaningfully engaged. This applies to service providers and commissioners.
- People with dementia and their carers have been consulted and involved with the facilitation of Healthwatch. All engagement routes and methods need to be considered.
- No examples of engaging and empowering people with dementia in the North East, who also have limited communications skills, have been included in this section. Examples of how this can be carried out effectively need to be identified and shared. Key to this would be the North East Dementia Alliance, the Alzheimer's Society, the Mental Health, Dementia and Neurological Conditions Strategic Clinical Network and care home providers and commissioners.

## 21. Carers

### Key points:

- The legislative framework to support all carers is provided by the Carers Equal Opportunities Act 2004
- The National Dementia Strategy and the Prime Minister's Challenge both have extensive references to support for carers and there has been a National Carers' Call to Action
- Joint dementia plans all have actions in relation to supporting carers of people with dementia
- Carers assessments are provided through a number of different service providers
- There are education and support services for carers across the region including CrISP, support provided by the memory clinics, dementia advisors and access to psychological therapies
- There are more specialised projects for carers of people with dementia; for example, the Family Carers Matter project, which supports people to develop records of life stories with the person with dementia
- Improving Access to Psychological Therapies (IAPT) services are available in all localities in the North East; however, there is no data on the extent to which they are being used by the carers of people with dementia

This section of the report will consider key issues relevant to the provision of services for carers of people with dementia. In particular, this section of the report will outline:

- The policy context
- How support for carers of people with dementia has been included in local plans
- Examples of work undertaken to provide services for carers of people with dementia the North East
- Conclusions and recommendations on the provision of services for carers of people with dementia in the North East

This section of the report contains information relating specifically to the needs of carers however many other sections contained in this report outline information that is relevant to helping both people with dementia and carers to live well with dementia.

According to the report '*Dementia: A state of the nation report on dementia care and support in England*', an estimated 42% of the population (21 million people) in England knows of a close friend or family member with dementia. The report also states that around 550,000 people in England care

for a person with dementia and it is estimated that one in three people will care for a person with dementia in their lifetime.<sup>325</sup>

## 21.1 Policy context

Outlined below is the policy context specific to the provision of services for carers of people with dementia. This should be read in conjunction with the more general policy review in section 3 of this report.

### The Carers Equal Opportunities Act 2004

The Carers *'Equal Opportunities Act 2004'* is the most recent carers act and was implemented from April 2005.<sup>326</sup> The Act places a duty on social services departments to inform carers of their right to an assessment of their needs as a carer. The purpose of the assessment is not only to help the carer to continue to care, but should also include a discussion about the carers' aspirations to do other things, such as any wishes to continue or start paid work, go into further education and /or to engage in leisure pursuits.

Social service departments can ask other public bodies, including local health organisations, to provide services to carers; such a request must be considered and a formal response must be made. In the past carers and their needs have previously only been a duty for social service departments.

### Recognised, valued and supported: next steps for the Carers Strategy

Following consultation, the carers strategy was reviewed in 2010. The Government's updated priorities for carers for the next four years were set out in *'Recognised, valued and supported: next steps for the Carers Strategy'*. The updated priorities were:

- Supporting those with caring responsibilities to identify themselves as carers at an early stage, recognising the value of their contribution and involving them from the outset, both in designing local care provision and in planning individual care packages
- Enabling those with caring responsibilities to fulfil their educational and employment potential
- Personalised support both for carers and those they support, enabling them to have a family and community life

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<sup>325</sup> Department of Health (2013) Dementia: A state of the nation report on dementia care and support in England [Online]

[https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/262139/Dementia.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/262139/Dementia.pdf) (Accessed 17 May 2014) p.7

<sup>326</sup> Great Britain. Carers (Equal Opportunities) Act: Elizabeth II. Chapter 15 (2004) London: The Stationery Office



- Supporting carers to remain mentally and physically well<sup>327</sup>

## National Dementia Strategy

Although many of the provisions set out in the National Dementia Strategy aim to meet the needs of both people with dementia and carers, implementing the Carers' Strategy is objective 7 of the strategy. Objective 7 states that *"family carers are the most important resource available for people with dementia. Active work is needed to ensure that the provisions of the Carers' Strategy are available for carers of people with dementia"*.<sup>328</sup>

## Clinical Guidelines 42 Dementia: Supporting people with dementia and their carers in health and social care

The guidelines produced by the National Institute for Health and Care Excellence and Social Care Institute of Excellence state that *"carers of people with dementia who experience psychological distress and negative psychological impact should be offered psychological therapy, including cognitive behavioural therapy, conducted by a specialist practitioner"*.<sup>329</sup>

## Prime Minister's Challenge on Dementia

Many of the provisions outlined in the Prime Minister's Challenge on Dementia are intended for the benefit of people with dementia and carers; however, the document also includes commitments specifically aimed at supporting carers.

Key commitment 2 of the Prime Minister's Challenge on Dementia (financial rewards for hospitals offering quality dementia care) states that *"for April 2013, access to all CQUIN rewards will be dependent on delivering support for carers in line with the National Institute for Health and Clinical Excellence (NICE)/Social Care Institute for Clinical Excellence (SCIE) guidelines"*.<sup>330</sup> The Prime Minister's Challenge on Dementia also highlights that the NHS should ensure that a range of psychological therapies are commissioned and made available to carers of people with dementia in

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<sup>327</sup> Department of Health (2010) Recognised, Valued and Supported: Next steps for the Carers Strategy [Online] Available at: <https://www.gov.uk/government/publications/recognised-valued-and-supported-next-steps-for-the-carers-strategy> (Accessed 17 May 2014)

<sup>328</sup> Department of Health (2009) Living well with dementia: a National Dementia Strategy. London: Department of Health p.12

<sup>329</sup> National Institute for Health and Clinical Excellence and the Social Care Institute for Excellence (2006) CG42 Dementia: Supporting people with dementia and their carers in health and social care. London: National Institute for Health and Clinical Excellence

<sup>330</sup> Department of Health (2012) Prime Minister's Challenge on Dementia: Delivering major improvements in dementia care and research by 2015. Department of Health: London p.6

line with NICE/SCIE guidelines, as well as ensuring services are made available to support those relationships where one person is caring for a partner with dementia.<sup>331</sup>

To improve support for carers the Prime Minister's Challenge on Dementia also states "*the NHS is now required to work closer than ever before with local carers' organisations and councils to agree plans, pool their resources and make sure that carers get the support and break they deserve. We have provided an additional £400m to the NHS between 2011 and 2015 to provide carers with breaks from their caring responsibilities to sustain them in their role*".<sup>332</sup>

## Carers' Call to Action

In November 2013 the Dementia Action Alliance issued the Carers' Call to Action with the aim of ensuring that carers of people living with dementia:

- Have recognition of their unique experience
- Are recognised as essential partners in care
- Have access to expertise in dementia care for personalised information, advice, support and co-ordination of care for the person with dementia
- Have assessments and support to identify their on-going and changing needs to maintain their own health and well-being
- Have confidence that they are able to access good quality care, support and respite services that are flexible, culturally appropriate, timely and provided by skilled staff for both the carer and the person for whom they care

For further information visit <http://www.dementiaaction.org.uk/carers>

## Commissioning for Quality and Innovation

As part of the national dementia CQUIN acute providers must undertake a monthly audit of carers of people with dementia and report the findings to their Board at least twice per year. The content of this audit is for local determination (agreed between commissioner and provider) but must include a question on whether carers of people with dementia feel adequately supported.<sup>333</sup>

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<sup>331</sup> Department of Health (2009) Living well with dementia: a National Dementia Strategy. London: Department of Health P.10 and p.21

<sup>332</sup> Department of Health (2012) Prime Minister's Challenge on Dementia: Delivering major improvements in dementia care and research by 2015. Department of Health: London p.10

<sup>333</sup> Department of Health (2013) Commissioning for Quality and Innovation (CQUIN): 2013/14 guidance [Online] Available at: <http://www.england.nhs.uk/wp-content/uploads/2013/02/cquin-guidance.pdf> (Accessed 17 May 2014) p.22

## 21.2 Local action plans

### Joint Strategic Needs Assessments

All Joint Strategic Needs Assessments (JSNAs) in the North East cover the needs of carers, with a number making specific reference to carers of people with dementia. JSNAs that mention carers of people with dementia (Gateshead, Sunderland and Durham) highlight the need to provide effective information and dementia specific emergency and crisis teams.

### Health and Wellbeing Strategies

Durham's Health and Wellbeing Strategy (HWBS) states there is an increasing number of people with long term conditions and dementia who need more care. The HWBS goes on to identify that this may put an additional care burden on family members.<sup>334</sup>

### Local joint dementia plans

All 10 local joint dementia plans suggested that improving carers' services was a key area of work. The most frequently mentioned areas of work related to the provision of respite or breaks for carers and the need to provide the right information for carers. A number of plans highlighted the need to provide or develop peer support, including dementia cafés. Four plans specifically mentioned the need to improve carers' access to psychological therapies. Health checks and carers assessments were mentioned in two plans. Throughout the plans there is reference to the support provided to carers via the third sector through organisations such as Age UK, the Alzheimer's Society and Carers Centres.

## 21.3 Examples of work undertaken in the North East

### North East Association of Directors of Adult Social Services

The North East Association of Directors of Adult Social Services (ADASS) has a Carers Themed Network, which is a regional multi agency network covering carers issues for both adults and children's services. The network provides strategic oversight of policy developments which will impact upon carers, shares good practice across the region and will have a key role in ensuring local authorities meet the duties in the Care Act 2014 in relation to carers.

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<sup>334</sup> County Durham Health and Wellbeing Board (2014) County Durham Joint Health and Wellbeing Strategy 2014-2017 [Online] Available at: <http://www.durham.gov.uk/Pages/Service.aspx?ServiceId=8873> (Accessed 17 May 2014) p.15

The Carers Themed Network of the North East ADASS has received a presentation on dementia and the needs of carers for people with dementia. To help inform the work of the Carers Themed Network a representative from the group attends the meetings of the North East Dementia Alliance.

## Carers' assessments

It is the duty of social service departments to inform carers about their right to have a carers' assessment. The assessment and follow up support do not, however, have to be met only by the social service department. A number of initiatives have been commissioned to ensure carers are offered an assessment:

- Lustrum Vale Stockton-on-Tees - There is a dedicated nurse within the Memory Service who carries out carer assessments, arranges support and can advise on the value of life story work
- Northumberland - Has developed a Northumberland Carers Health and Wellbeing Checklist, which includes useful information for those caring for someone with dementia<sup>335</sup>
- South Tyneside - Carers Assessments are available to identify the need for carer breaks services

## Education and support for carers provided by memory service in the North East

Data from the English National Memory Services Audit shows that all but two of the 14 memory services in the North East provide access to education and support for carers.<sup>336</sup> The memory services that do not provide education and support for carers following a diagnosis are Easington Community Mental Health Team and Newcastle Memory Assessment and Management Service.

## Carers' centres

The Carers Trust describes carers' centres as "*independent charities that deliver a wide range of local support services to meet the needs of carers in their own communities. All carers' centres provide, either by telephone, drop-in or outreach surgeries, the following core services:*

- *Information and advice*
- *Emotional support*

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<sup>335</sup> Northumberland County Council [Online] Available at:  
<http://www.northumberland.gov.uk/default.aspx?page=327> (accessed 17 May 2014)

<sup>336</sup> Royal College of Psychiatrists (2013) English National Memory Services Audit Report. London: Royal College of Psychiatrists

- *Community consultation*<sup>337</sup>

Non-dementia specific carers centres in the North East that are part of the Carers Trust's networks are:

- Carers Association South Tyneside
- Carers' Centre Newcastle
- Carers Northumberland
- Derwentside Carers' Centre
- Durham County Carers Support (operating at Bishop Auckland, Barnard Castle, Chester-le-Street, Peterlee and Newton Aycliffe)
- Gateshead Carers
- Hartlepool Carers
- North Tyneside Carers' Centre
- Sunderland Carers' Centre<sup>338</sup>

Non-dementia specific carer services in localities not listed by the Carers Trust include:

- Carer services in Middlesbrough<sup>339</sup> and Stockton-on-Tees provided by Sanctuary Supported Living<sup>340</sup>
- Carers Together (Redcar and Cleveland)<sup>341</sup>
- Darlington Carers' Centre<sup>342</sup>

Carer services are also provided by non-carer specific organisations, such as the Alzheimer's Society, Age UK, Mind and others.

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<sup>337</sup> Carers Trust [Online] Available at: <http://www.carers.org> (Accessed 17 May 2014)

<sup>338</sup> Ibid

<sup>339</sup> For further information contact [wendy.collins@sanctuary-housing.co.uk](mailto:wendy.collins@sanctuary-housing.co.uk)

<sup>340</sup> For further information contact [Stockton.carers@sanctuary-housing.co.uk](mailto:Stockton.carers@sanctuary-housing.co.uk)

<sup>341</sup> For further information see <http://www.carerstogether.org.uk/>

<sup>342</sup> For further information see <http://www.darlingtondisability.org/carer/carer.htm>

## Examples of work undertaken by carers' centres in the North East

**Carers' Centre Newcastle** - The Carers' Centre offers support for carers of people with dementia through the provision of information and signposting, advice and advocacy, access to training, access to support groups, complementary therapies, counselling and the offer of activities and events. The Carers' Centre is working in collaboration with other organisations to raise the profile of carers for people with dementia and to develop an understanding of how services for carers can work together with trusts for the benefit of people with dementia and carers.

**Sunderland Carers' Centre** - The Carers Centre is funded to provide short breaks and training for carers of people with dementia .

**Durham County Carers Support (DCCS)** - DCCS employ a specific mental health carer development worker who covers dementia carers liaison. DCCS also provide a range of services for carers including carer breaks, which are available to carers of people with a diagnosis of dementia.

## Carers support groups and carers support services provided by the Alzheimer's Society

As of May 2014 The Alzheimer's Society was running support groups for carers in the following areas:

- Darlington
- Durham
- Gateshead- Gateshead and Whickham
- Newcastle
- Northumberland - Ashington, Bedlington, Hexham and Morpeth
- South Tyneside - Jarrow and South Shields
- Sunderland

The support groups provide an opportunity to meet with others in similar situations and to share experiences, knowledge and concerns in a confidential setting. The groups also give carers an opportunity to relax, socialise and have time to themselves. Guest speakers are invited from time to time to talk about topics of interest to the group.

## Carers Information and Support Programme – Alzheimer's society

The Alzheimer's Society has developed a Carers Information and Support Programme (CrISP), which provides information sessions in a group environment. The programmes give carers for people with dementia the opportunity to share experiences and identify what local services are available.

There are two CrISP courses:

- CrISP1 – “A four session programme aimed at family members and friends who support a person with a recent diagnosis of dementia. The topics covered include; understanding dementia, legal and money matters, providing support and care and coping day to day”
- CrISP2 – “A three session programme covering issues that arise as dementia progresses. Topics covered include; understanding change as dementia progresses, living with change as more help is needed, and living well as dementia progresses”<sup>343</sup>

As of May 2014 the Alzheimer’s Society was running CrISP sessions in:

- County Durham (operating in Barnard Castle, Chester-le-Street, Consett and Stanley)
- Northumberland (operating in Ashington)

## Family Carers Matter

The Life Story Network is working with Hartlepool Carers to train family carers of people with dementia in life story work. This project has initially been funded by Northern Rock Foundation. To ensure this training is sustainable the project aims to embed the necessary skills and resources within the Carers Centre so it can continue to provide individual support to family carers of people living with dementia.

Training will be given in the ‘Family Carers Matter’ programme for local, current and former carers, identifying future volunteers, providing them with enhanced skills and mentoring support so they can deliver this work in the community. The Life Story Network will continue to provide an ‘anchor’ for them to share good practice, updates, research and peer support.

For further information contact [jean@lifestorynetwork.org.uk](mailto:jean@lifestorynetwork.org.uk) or [kate.hogan@hartlepoolcarers.org.uk](mailto:kate.hogan@hartlepoolcarers.org.uk) or visit [www.lifestorynetwork.org.uk](http://www.lifestorynetwork.org.uk)

## Emergency response service - Newcastle

In Newcastle the British Red Cross has been commissioned to provide an emergency response service for carers in crisis.<sup>344</sup>

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<sup>343</sup> Alzheimer’s Society [Online] available at:

[http://alzheimers.org.uk/site/scripts/documents\\_info.php?documentID=1710](http://alzheimers.org.uk/site/scripts/documents_info.php?documentID=1710) (Accessed 17 May 2014)

<sup>344</sup> Red Cross [Online] Available at: <http://www.redcross.org.uk/Where-we-work/In-the-UK/Northern-England/County-Durham-and-Teesside-Northumbria-and-Cumbria/LocalServices/Support-at-home?dpid=6a9a7d80-34ff-40d2-8962-87fd26b15900> (Accessed 17 May 2014)

## Coffee morning for carers – North Tyneside

The coffee morning takes place in Killingworth on the second Tuesday of every month and provides carers of people with dementia the opportunity to get specialist advice and support from professionals, to be listened to, to take a break from their caring role and receive information about available help.

For further information contact Alison Neill at North Tyneside Carers' Centre on 0191 6432298

## Improving Access to Psychological Therapies

The Improving Access to Psychological Therapies (IAPT) service is a national initiative to provide NICE approved interventions to treat people with depression and anxiety disorders. The Prime Minister's Challenge on Dementia states that the NHS should ensure a range of psychological therapies is commissioned and made available to carers of people with dementia in line with NICE/SCIE guidelines.<sup>345</sup>

There are 16 IAPT services in the North East covering all localities within the region. There is also a North East IAPT provider forum and Health Education North East hosts a psychological therapies sub group. IAPT services do not routinely record the number of service users that care for a person living with dementia. It is, therefore, not possible to identify whether the services are being targeted at carers of people with dementia or the extent to which carers of people with dementia are using these services.

For further information on Cognitive Stimulation Therapy see section 8 of this report.

### Example IAPT Service - Sunderland

In Sunderland the IAPT services are integrated with the Primary Care Mental Health teams and are delivered in partnership between Northumberland Tyne and Wear NHS Foundation Trust, Sunderland Counselling Services, Washington Mind and Sunderland Mind.

The IAPT team in Sunderland includes psychological wellbeing practitioners, Cognitive Behavioural Therapy therapists and community psychiatric nurses, who offer a wide range of services including counselling or Cognitive Behavioural Therapy. This service can be used by carers of people with dementia, aged 16 or over, who need support to get through times when they feel low, depressed, anxious or stressed.

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<sup>345</sup> Department of Health (2012) Prime Minister's Challenge on Dementia: Delivering major improvements in dementia care and research by 2015. Department of Health: London p.9



## 21.4 Conclusions on the provision of services for carers of people living with dementia in the North East

There is a legislative framework for the protection and support of all carers but nationally there is also recognition in policy that carers of people living with dementia do need support and to be listened to. The Prime Minister's Challenge highlights the provision of £400m to the NHS between 2011 and 2015 to provide carers with breaks from their caring responsibilities.

In the North East all local joint dementia plans have reference to actions to support carers of people with dementia.

This report has not been able to provide a full audit of all carers services and need; however, there appears to be a good variety of support available for carers across the North East (although there are variations in terms of the services provided in each locality). Respite is needed for carers to continue in their role. The gaps in respite services for carers and people with dementia were highlighted in a report about provision in South Tyneside in 2014.<sup>346</sup>

Despite IAPT services being available in all localities within the North East it is not possible to identify whether the services are being targeted at carers of people with dementia or the extent to which carers of people with dementia are using these services.

## 21.5 Recommendations on the provision of services for carers of people living with dementia in the North East

- There appears to be a spread of different services for carers within each locality across the region; however, each locality group needs to undertake consultation to identify local need. Locality groups should also review existing service provision to identify the geographical spread and type of services being provided to ensure needs are being met.
- Respite is one of the key areas highlighted in the joint dementia action plans; however, little reference is made to respite provision in this section due to the limited research time for the project. Locality groups should give particular attention to respite services when carrying out an audit of services for carers of people with dementia.
- The Carers' Call to Action has been launched. This could provide a useful catalyst to highlight issues relating to carers of people with dementia and could influence change. Organisations and individuals in the North East should consider signing up.
- The North East ADASS has a carers themed network. Any work considered by the themed network needs to be inclusive of carers of people with dementia and their specific needs must be considered.

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<sup>346</sup> For further information see section 4 of this report

- Although IAPT services are available in all localities within the North East it is not possible to identify whether these services are being targeted at carers of people with dementia, or the extent to which carers of people with dementia are using these services. To gain a clearer understanding it would be useful if services delivering IAPT routinely monitored and reported on the numbers of carers for people with dementia who use the service. The North East Dementia Alliance should work with the North East IAPT provider forum and Health Education North East psychological therapies sub group to encourage and implement this.

## 22. Minority communities

### Key points:

- There is a general legislative and policy framework to promote equality including access to health and social care services
- Many local areas have improved care and support for people with dementia from minority communities as a priority in their local plans
- It is estimated that in the North East:
  - 694 people with dementia will be of working age
  - 353 people with dementia will have a non-white ethnic background
  - Between 540-756 people with dementia will be lesbian, gay or bisexual
  - 5 people with dementia will be transgender
  - 175 people with dementia will have religious beliefs other than Christian, while 781 are likely to have no religious belief
  - 16,560 individuals with dementia will have a longstanding illness, disability or infirmity and have significant difficulty with day-to-day activities
- The North East Dementia Alliance has undertaken some work to improve the support and care of people from minority communities living with dementia in the North East. This includes:
  - A statistical analysis to identify the potential number of people with dementia from minority communities in the North East
  - A research report to identify good practice relating to the support and care of people with dementia from minority communities in the North East
  - A DVD to support awareness and training on the issues faced by people with dementia

This section of the report will consider key issues relevant to the provision of support and care for people living with dementia from minority communities. In particular this section of the report will outline:

- The policy context
- How the care and support of people living with dementia from minority communities has been included in local plans
- Statistics on the number of people living with dementia from minority communities in the North East
- Examples of work undertaken to improve the support and care of people living with dementia from minority communities in the North East
- Conclusions and recommendations on the provision of support and care for people living with dementia from minority communities in the North East

The definition of minority communities used in this report is taken from ‘*Dementia in Minority Communities in North East England*’ where the term is used to mean “*those groupings... that are identified through their age, ethnicity, their sexual orientation, their gender reassignment, their religious beliefs or their level of disability*”.<sup>347</sup> These categories are based on the classifications employed by the ‘*Equality Act 2010*’<sup>348</sup> and enforced by the Commission for Equality & Human Rights in the UK.<sup>349</sup>

On the basis of this definition, this section focuses on information relating to the care and support of people with dementia from:

- Black and minority ethnic communities
- Gypsy and Traveller communities
- Lesbian, gay and bisexual communities
- Trans communities
- Religious minority communities
- Individuals with disabilities (including learning disabilities)
- Younger people with dementia

## 22.1 Policy context

Outlined below is the policy context specific to the provision of support and care for people living with dementia from minority communities. This should be read in conjunction with the more general policy review in section 3 of this report.

### The National Dementia Strategy

The National Dementia Strategy emphasises that it is “*designed to address the needs of all people with dementia, no matter of what type, age, ethnic origin or social status*”.<sup>350</sup>

### The Equality Act 2010

The ‘*Equality Act 2010*’ replaces previous discrimination laws and makes it illegal to discriminate (both directly and indirectly), harass or victimise people on the grounds of their:

- Age

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<sup>347</sup> Jackson, M (2012) *Dementia in Minority Communities in North East England* [Online] [http://www.nepho.org.uk/uploads/doc/vid\\_16758\\_Dementia%20in%20Minority%20Communities%20in%20North%20East%20England%20Aug%202012.pdf](http://www.nepho.org.uk/uploads/doc/vid_16758_Dementia%20in%20Minority%20Communities%20in%20North%20East%20England%20Aug%202012.pdf) (Accessed 17 May 2014) p.5

<sup>348</sup> Great Britain. *The Equality Act: Elizabeth II. Chapter 15* (2010) London: The Stationery

<sup>349</sup> [www.legislation.gov.uk/ukpga/2010/15/contents](http://www.legislation.gov.uk/ukpga/2010/15/contents)

<sup>350</sup> Department of Health (2009) *Living well with dementia: a National Dementia Strategy*. London: Department of Health p.16

- Disability
- Gender reassignment
- Marriage or civil partnership
- Pregnancy and maternity
- Race
- Religion or belief
- Sex
- Sexual orientation<sup>351</sup>

The ‘Equality Act 2010’ also brought the public sector equality duty into force. The public sector equality provision imposes an obligation on public bodies to:

*“consider all individuals when carrying out their day to day work – in shaping policy, in delivering services and in relation to their own employees. It requires public bodies to have due regard to the need to eliminate discrimination, advance equality of opportunity, and foster good relations between different people when carrying out their activities.”<sup>352</sup>*

In May 2012 the Home Secretary announced that a review would be undertaken of the public sector equality duty. In September 2013 the Independent Steering Group tasked with reviewing the Public Sector Equality Duty found that it was too early to make a final judgement about the impact of the Public Sector Equality Duty and the Government should consider a formal review in a further three years.<sup>353</sup>

## Dementia: Supporting people with dementia and their carers in health and social care

The clinical guidelines produced by the National Institute for Health and Clinical Excellence (NICE) and the Social Care Institute for Excellence (SCIE) affirm the need for health and social care staff to *“identify the specific needs of people with dementia and their carers arising from diversity, including gender, ethnicity, age (younger or older), religion and personal care”<sup>354</sup>* and should *“accommodate the preferences of people with dementia and their carers, including diet, sexuality and religion.”<sup>355</sup>*

In relation to younger people living with dementia the guidelines recommend that *“younger people with dementia have special requirements, and specialist multidisciplinary services should be*

<sup>351</sup> Great Britain. The Equality Act: Elizabeth II. Chapter 15 (2010) London: The Stationery

<sup>352</sup> [Online] available at: <https://www.gov.uk/equality-act-2010-guidance> (Accessed 17 May 2014)

<sup>353</sup> H M Government (2011) Advancing transgender Equality: A Plan for action [Online] Available at: <http://www.homeoffice.gov.uk/publications/equalities/lgbt-equality-publications/transgender-action-plan?view=Binary> (Accessed 17 May 2014)

<sup>354</sup> National Institute for Health and Clinical Excellence and the Social Care Institute for Excellence (2006) CG42 Dementia: Supporting people with dementia and their carers in health and social care. London: National Institute for Health and Clinical Excellence p.12

<sup>355</sup> Ibid p.13

*developed, allied to existing dementia services, to meet their needs for assessment, diagnosis and care”.*<sup>356</sup>

## Dementia does not discriminate: The experiences of black, Asian and minority ethnic communities

In July 2013 the All-Party Parliamentary Group on Dementia published the report '*Dementia does not discriminate: The experiences of black, Asian and minority ethnic communities*'.<sup>357</sup> The report outlines a number of recommendations based around the themes of:

- Raising awareness
- Undertaking preventative work and tackling modifiable risk factors
- Ensure local areas are aware of the needs to support people with dementia from BAME groups in their communities
- Share good practice in commissioning and support
- Improve access to high-quality services for people with dementia from BAME communities
- The use of Alzheimer's Society programmes
- Improve staff knowledge and skills

## Services for younger people with Alzheimer's disease and other dementias

In 2005 the Royal college of Psychiatrists and Alzheimer's Society jointly published the document '*Services for younger people with Alzheimer's disease and other dementias*'.<sup>358</sup> The paper outlines the needs of younger people living with dementia and sets out detailed recommendations of how services could be developed to meet the particular needs of younger people living with dementia.

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<sup>356</sup> National Institute for Health and Clinical Excellence and the Social Care Institute for Excellence (2006) CG42Dementia: Supporting people with dementia and their carers in health and social care. London: National Institute for Health and Clinical Excellence p.13

<sup>357</sup> All-Party Parliamentary Group on Dementia (2013) Dementia does not discriminate: The experiences of black, Asian and minority ethnic communities [Online] Available at: [http://alzheimers.org.uk/site/scripts/documents\\_info.php?documentID=1583&pageNumber=2](http://alzheimers.org.uk/site/scripts/documents_info.php?documentID=1583&pageNumber=2) (Accessed 17 May 2014)

<sup>358</sup> Royal College of Psychiatrists and Alzheimer's Society (2005) Services for younger people with Alzheimer's disease and other dementias [Online] Available at: <http://www.rcpsych.ac.uk/files/pdfversion/cr135.pdf> (Accessed 17 May 2014)

## Working for Lesbian, Gay, Bisexual and Transgender Equality: Moving Forward

In 2011 the Home Office set out the actions that the Government will take in order to attain its commitment of achieving equality for people from Lesbian, Gay, Bisexual and Transgender (LGB&T) communities in the report '*Working for Lesbian, Gay, Bisexual and Transgender Equality: Moving Forward*'.<sup>359</sup> To improve equality of access to health and social care services the document outlined the following actions:

- Work with the NHS to increase awareness of LGBT health issues and how medical staff can work more sensitively with their LGBT patients and their carers
- Develop a national network of LGBT 'champions'
- Support NHS providers to appropriately collect data on sexual orientation
- In partnership with LGBT groups, ensure that evidence on LGBT health issues is used to influence public health strategies and policies
- Consider what further action could be taken to support the health and social care needs of older LGBT people
- Engage with transgender communities to identify specific health issues faced by this group
- Work with the Equality and Human Rights Commission to analyse the current process for commissioning and service provision for gender identity services and identify best practice

## Advancing Transgender Equality: A Plan for action

In 2011 the Home Office published *Advancing transgender Equality: A Plan for action*.<sup>360</sup> This document outlines the actions that the Government will take to improve equality in a number of areas of public life including health and social care.

## Valuing People Now: a new three-year strategy for people with learning disabilities

In 2001 the Government published the white paper '*Valuing People: A new strategy for learning disabilities for the 21st century*'.<sup>361</sup> The paper sets out what the Government aimed to do in order to enable people with learning disabilities to "*live full and independent lives as part of their local*

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<sup>359</sup> H M Government (2011) *Working for Lesbian, Gay, Bisexual and Transgender Equality: Moving Forward* [Online] Available at: <http://www.homeoffice.gov.uk/publications/equalities/lgbt-equality-publications/lgbt-action-plan?view=Binary> (Accessed 17 May 2014)

<sup>360</sup> H M Government (2011) *Advancing transgender Equality: A Plan for action* [Online] Available at: <http://www.homeoffice.gov.uk/publications/equalities/lgbt-equality-publications/transgender-action-plan?view=Binary> (Accessed 17 May 2014)

<sup>361</sup> Department of Health (2001) *Valuing People: A new strategy for learning disabilities for the 21st century* London: The Stationery Office

communities”<sup>362</sup>. In particular, the paper outlines a commitment to promoting the rights, independence, choice and inclusion of people with learning disabilities.

The paper recognises the specialist needs of people with learning disabilities who develop dementia and states the Government’s desire for “*learning disability services to work with the specialist mental health services to ensure that, between them, appropriate supports are provided for younger people with learning disabilities suffering from dementia*”<sup>363</sup>.

‘*Valuing People: A new strategy for learning disabilities for the 21st century*’ was updated in the document ‘*Valuing People Now: a new three-year strategy for people with learning disabilities*’<sup>364</sup> which set out the Government’s three year plan to improve the lives of people living with learning disabilities and their families. Valuing People Now stresses the importance of ensuring that the Valuing People agenda works for everyone including those people with more specialist needs and emphasises the importance of providing “*high-quality specialist health services where these are needed*”<sup>365</sup>.

## 22.2 Local plans

### Joint Strategic Needs Assessments

A number of Joint Strategic Needs Assessments (JSNAs) make reference to minority communities. The most frequent reference is to the increased risk of people with Down’s syndrome developing dementia.<sup>366</sup> Early onset dementia is mentioned in the JSNAs for Northumberland, County Durham and Darlington. Durham and Darlington make reference to the higher percentage of early onset dementia amongst the BME communities compared to the wider population. Reference is also made to the difficulties of younger people accessing care.<sup>367</sup>

### Local joint dementia plans

Eight out of the 10 local joint dementia plans in the North East mention actions in relation to people with dementia from minority communities. The majority of actions relate to the Black and Asian Minority Ethnic communities including, the provision of information to carers in the BME community (1 plan), raising awareness (2 plans) and exploring the issues for the community and then responding appropriately (2 plans).

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<sup>362</sup> Ibid p.2

<sup>363</sup> Department of Health (2001) *Valuing People: A new strategy for learning disabilities for the 21st century* London: The Stationery Office p.104

<sup>364</sup> Department of Health (2009) *Valuing People Now: a new three-year strategy for people with learning disabilities*. London: Department of Health

<sup>365</sup> Ibid

<sup>366</sup> Including Northumberland, Sunderland, Darlington, Durham, North Tyneside

<sup>367</sup> Durham and Darlington.



Four plans include actions in relation to people with learning disability: exploring the issues, ensuring pathways and services are inclusive and developing specific resources for the person with a learning disability. South Tyneside has an action to include a person from the learning disability partnership on the board responsible for the dementia strategy.

Young onset dementia is referenced in three plans, including the need to look at service provision.

South Tyneside's plan highlights the need to consider the needs of the LGBT community.

## 22.3 Statistics on the number of people living with dementia from minority communities in the North East

In summer 2012 the North East Dementia Alliance commissioned research to identify the potential numbers of people with dementia in minority communities across the North East of England.

The findings of the study estimated that in the North East:

- 694 people with dementia will be of working age
- 353 people with dementia will have a non-white ethnic background
- Between 540-756 people with dementia will be lesbian, gay or bisexual
- 5 people with dementia will be transsexual
- 175 people with dementia will have religious beliefs other than Christian, while 781 are likely to have no religious belief
- 16,560 individuals with dementia will have a longstanding illness, disability or infirmity and have significant difficulty with day-to-day activities

The research also suggested that over the next 15 years *“the number of people with dementia from non-white ethnic backgrounds is likely to increase more rapidly than the numbers with white ethnic backgrounds due to the demographic structure of the communities. However the total numbers with non-white ethnic background will remain a relatively small proportion of the total population with dementia in North East England”*.<sup>368</sup>

As population numbers and demographic distribution are not routinely collected in relation to Gypsy and Traveller communities the research was not able to estimate the number of individuals within this community likely to have dementia.

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<sup>368</sup> Jackson, M (2012) Dementia in Minority Communities in North East England [Online]

<http://www.ncl.ac.uk/changingage/assets/documents/DementiaInMinorityCommunitiesInNorthEastEnglandAug2012.pdf> (Accessed 31 May 2014)

## 22.4 Examples of work undertaken in the North East

### Support and Care for People Living with Dementia from Minority Communities

In February 2013 the North East Dementia Alliance commissioned the report '*Support and Care for People Living with Dementia from Minority Communities*'.<sup>369</sup>

The aim of '*Support and Care for People Living with Dementia from Minority Communities*' was to make suggestions and recommendations for the North East Dementia Alliance to further develop and influence the support and care to people with dementia from minority communities in the North East.

In order to develop these suggestions and recommendations, the project aimed to identify information relating to:

- The support and care services valued by people living with dementia from minority communities
- The issues, if any, affecting the support and care of people living with dementia from minority communities
- The organisations best able to deliver support and care to people living with dementia from minority communities
- Existing services for people living with dementia from minority communities in the North East

The findings of the report are outlined in Table 23.

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<sup>369</sup> Prior, P. (2013) Support and Care for People Living with Dementia from Minority Communities [Online] Available at: <https://www.phine.org.uk/social-care-north-east/resources/1842> (Accessed 17 May 2014)

Community	Particular issues regarding the community's support and care	Support and care already available in the North East
<b>BME, religious minority and Gypsy and Traveller communities</b>	<ul style="list-style-type: none"> <li>• More likely to receive no diagnosis or receive a diagnosis at a later stage</li> <li>• Lack of awareness about dementia and the services that are available</li> <li>• Stigma attached to dementia in some communities</li> <li>• Services need to be delivered in a culturally appropriate manner</li> <li>• There is a need to provide support to unpaid carers</li> </ul>	<ul style="list-style-type: none"> <li>• Non-dementia specific community groups that support specific BME or religious communities</li> <li>• Support worker for hard to reach groups in Stockton-on-Tees</li> </ul>
<b>Younger people living with dementia</b>	<ul style="list-style-type: none"> <li>• Difficulties and delays experienced during the diagnostic process</li> <li>• Difficulty in identifying who is responsible for on-going care and support and what services are available to young people living with dementia</li> <li>• The need to meet the specialist care and support needs of younger people living with dementia, including: <ul style="list-style-type: none"> <li>• Age appropriate activities</li> <li>• Support with the particular financial and legal issues faced by younger people living with dementia</li> <li>• Practical and emotional support for family members including dependent children and older relatives</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• Tees, Esk and Wear Valleys NHS Trust young onset dementia team</li> <li>• Northumberland, Tyne and Wear NHS Trust young onset dementia services</li> <li>• Alzheimer's Society roaming day club *</li> </ul>
<b>Lesbian, gay and bisexual communities and Transgender communities</b>	<ul style="list-style-type: none"> <li>• Previous experiences of discrimination can shape how people from LGBT communities engage with care and support services</li> <li>• To provide appropriate care and support services it is necessary that services: <ul style="list-style-type: none"> <li>• Recognise that people from LGBT communities are using support and care services</li> <li>• Make it clear that they are respected and work to accommodate the needs of people living with dementia from LGBT communities</li> <li>• Develop appropriate policies and procedures to prevent discrimination and protect confidentiality</li> <li>• Employ appropriately trained staff</li> <li>• Recognise the family and other social relationships of people from LGBT communities</li> <li>• Ensure that services are informed by people from LGBT communities</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• A number of community groups are providing advice, support and information to people from LGBT communities</li> <li>• There are some community groups specific to older people but not specific to people living with dementia</li> </ul>
<b>People with learning disabilities and dementia</b>	<ul style="list-style-type: none"> <li>• Issues around diagnosis including: <ul style="list-style-type: none"> <li>• Recognising the early symptoms of dementia among people with learning disabilities</li> <li>• The specialist assessment process often required to deliver a diagnosis</li> <li>• Providing post-diagnostic information and support in an appropriate manner</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• Middlesbrough learning disabilities dementia groups</li> <li>• Specialist residential units for people with learning disabilities and dementia in Ponteland, Blyth and</li> </ul>

<ul style="list-style-type: none"> <li>• Issues relevant to on-going support and care including: <ul style="list-style-type: none"> <li>• The effect of the person’s dementia on people around them including other service users</li> <li>• Issues relating to the physical design of support and care services</li> <li>• Staff training to develop appropriate knowledge and skills</li> </ul> </li> </ul>	Coulby Newham
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\* This will be decommissioned in June 2014

**Table 23:** Summary of ‘Support and Care for People Living with Dementia from Minority Communities’. Source: Prior, P. (2013) Support and Care for People Living with Dementia from Minority Communities [Online] Available at: <https://www.phine.org.uk/social-care-north-east/resources/1842> (Accessed 17 May 2014)

The report found a particular lack of information relating to the care and support needs of people living with dementia from Gypsy and Traveller communities.

## Embracing Difference: Dementia Care for Minority Communities

In summer 2013 the North East Dementia Alliance commissioned the theatre company Open Clasp to produce the DVD ‘*Embracing Difference: Dementia Care for Minority Communities*’.

The DVD was produced as a training resource to help community groups, care providers, carers and health or social care professionals to think through some of the issues relating to the support and care of people living with dementia from minority communities.

The DVD outlines three scenarios; ‘Gloria’s Story’ (which addresses the care of a person from the LGBT community living in a residential setting); ‘Henna Night’ (which addresses the care of a person from the BME community) and ‘Flowers - the care plan’ (which addresses the care of a person from the Gypsy and Traveller Community living in a residential setting).

An evaluation of the DVD was published in June 2014, which indicated respondents had often shown the DVD to other professionals and had placed it in resource libraries. 370 respondents expressed a high level of satisfaction with the DVD and this applied equally to all three scenarios.

Recommendations include:

- Further and continued promotion of the DVD through a marketing plan
- Possible conversion of the DVD into a format such as YouTube to enable downloading
- The development of additional accompanying material

<sup>370</sup> Rodger, E. (2014) North East Dementia Alliance Evaluation of Embracing Difference: Dementia Care for Minority Communities DVD (Unpublished)

- Additional research to inform further drama-based videos focusing on other minority groups living with dementia

The DVD is free to organisations in the North East. There are, however, only a limited number of DVDs available. To order a copy please contact [NEDA@newcastle.ac.uk](mailto:NEDA@newcastle.ac.uk)

## Dementia training for people with learning disabilities

Durham County Council supported the production of the 'Supporting Derek' training. This training aimed to support staff working with people who have a learning disability and dementia and was delivered by a Health Facilitation Lead for Tees, Esk and Wear Valleys NHS Foundation Trust. A free half day session was put on for independent learning disability service providers in spring 2014.

The training package focused on practical strategies to improve the care and support of this client group, including:

- Understanding client behaviour
- Responding to pain
- Developing supportive environments
- Techniques for effective communication
- Delivering meaningful activities
- Improving nutrition
- Delivering night time care and palliative care

## Tees, Esk and Wear Valleys NHS Foundation Trust

Tees, Esk and Wear Valleys NHS Foundation Trust has adopted a dementia screening questionnaire for people with intellectual disabilities (DSQIID). The screening tool is used to identify people with learning disabilities who may be developing dementia.

Tees, Esk and Wear Valleys NHS Foundation Trust has also produced a leaflet for people with a learning disability who may need an assessment for dementia. This is written in an accessible format and is called '*Dementia Screening Information for individuals, families and carers*'.

In 2011 Tees, Esk and Wear Valleys NHS Foundation Trust piloted a person centred pathway of care for dementia in learning disabilities.

## Aapna Services

Aapna Services Ltd is a registered charity, based in Middlesbrough and founded in 2006. Its aim is to promote social inclusion. The organisation works closely with people from ethnic minority backgrounds. It provides and supports local BME network groups that encourage and enable people

to participate more effectively with the wider community. In spring 2014 Aapna developed services for people from the BME community who live with dementia. These services can include:

- Support to be referred to the memory clinic
- Support to participate in culturally appropriate services
- Life story work
- Support for carers
- Workshops and group sessions to raise awareness about dementia
- Telephone advice and referral to appropriate agencies.

For further information contact <http://www.aapnaservices.org.uk/index.html>

## 22.5 Conclusions on the care and support of people living with dementia from minority communities in the North East

Region-wide work, led by the North East Dementia Alliance, has taken place to deliver improved care and support for people living with dementia from minority communities. This has included research to identify the potential number of people with dementia from minority communities in the North East and research to identify good practice relating to the support and care of people with dementia from minority communities in the region. In addition, a DVD has been produced and has been evaluated. The DVD is a training resource to help community groups, care providers, carers or health or social care professionals to think through some of the issues relating to the support and care of people living with dementia from minority communities.

The region has moved forward in understanding the needs of people with dementia since 2011; however, these are just the foundations and additional work is needed to deliver further improvements.

## 22.6 Recommendations on the care and support of people living with dementia from minority communities in the North East

- The Embracing Difference DVD has been evaluated. In order to inform future work the North East Dementia Alliance needs to consider the recommendations that came out of the DVD's evaluation.
- In relation to minority communities, the main focus of local plans is to improve services and support for people from Black and Asian Minority Ethnic communities. It is critical that this continues; however, work needs to be undertaken to consider and support other groups as

well. For example, the estimated number of people from the LGBT community with dementia could be as high as one and a half times that of the BME community and little action is being taken in relation to this group.

- Four local joint dementia plans have included actions to improve the support and care of people with a learning disability and dementia. Opportunities to work with long established learning disability groups need to be utilised.
- In the North East there are few examples of services which are particularly sensitive to the needs of people with dementia from minority communities. Services which are for people with dementia from minority communities, or which are particularly sensitive to the needs of people from minority communities (from both the North East and in other parts of the country), need to be showcased to encourage the wider adoption of these practices.
- There is a lack of information about the number of people living with dementia from Gypsy and Traveller communities in the North East. There is also little information about how to improve the support and care of people living with dementia from Gypsy and Traveller communities. The North East Dementia Alliance should support further research to identify the number of people with dementia from Gypsy and Traveller communities in the North East to establish what steps could be taken to improve the support and care of people living with dementia from this community.

## 23. Antipsychotic medication

### Key points

- *“The use of antipsychotic medication for people with dementia: time for action”*, published in 2009, highlighted the need for a reduction in antipsychotic medication for people with dementia
- Between 2006 and 2011 there was a reduction in the use of antipsychotic medication across North East England for people with dementia and most reporting primary care trusts were below the national prescribing rate
- Approaches to reducing the inappropriate prescribing of antipsychotic medication in the North East were considered as part of a regional stakeholder event in 2011
- Financial awards were made via the North East Dementia Alliance of funding to support small scale projects
- Some services in the North East offer non pharmacological interventions to support people with dementia

This section of the report will consider key issues regarding the reduction of the inappropriate prescribing of antipsychotic medication to people with dementia. In particular this section of the report will outline:

- The policy context
- How reducing the inappropriate prescribing of antipsychotic medication has been included in local plans
- Statistics relating to the prescribing of antipsychotic medication in the North East
- Examples of work undertaken in the North East to reduce the inappropriate prescribing of antipsychotic medication
- Conclusions and recommendations on the use of antipsychotic medication in the North East

### 23.1 Policy context

Outlined below is the policy context specific to the appropriate use of antipsychotic medication. This should be read in conjunction with the more general policy review in section 3 of this report.



## The use of antipsychotic medication for people with dementia: time for action

The Department of Health commissioned Professor Sube Banerjee to examine the use of antipsychotic medication for people with dementia in the NHS in England. The findings of his investigation were outlined in the 2009 report *'The use of antipsychotic medication for people with dementia: time for action'*.<sup>371</sup>

The report recorded that antipsychotics appear to have only a limited positive effect in treating behavioural and psychological symptoms but can cause significant harm to people with dementia. The report did acknowledge that *"some people do benefit from these medications and there are groups (e.g. where there is severe and complex risk) where...there may be particular value in using these medications. However, it appears that they are too often used as a first-line response to behavioural difficulty in dementia rather than as a considered second-line treatment when other non-pharmacological approaches have failed"*.<sup>372</sup>

The report concludes that *"the high level of use of antipsychotics means that the potential benefit of their use in specific cases is likely to be outweighed by the adverse effects of their use in general"*.<sup>373</sup>

The report outlined 11 recommendations that could lead to an improvement in the way that antipsychotic medication is used to help people with dementia.

## Always a last resort: Inquiry into the prescription of antipsychotic drugs to people with dementia living in care homes

In 2008 the All-Party Parliamentary Group on Dementia published its report on the use of antipsychotic drugs among people with dementia in care homes.

The Group found that over-prescribing is clearly a significant problem in many care homes and raised concerns that *"there is widespread inappropriate prescribing, for example, antipsychotics are being used for people with dementia who have mild behavioural symptoms and prescribing is often continued for long periods of time"*.<sup>374</sup> The Group recommended that the use of antipsychotics should always be a last resort, used at times of severe distress or critical need.

The Group reported that, despite the existence of good practice guidelines, there were a number of barriers, such as a lack of training and support from external services, preventing good practice from being implemented. The report noted a number of alternatives to antipsychotic drugs that it suggested should be more widely used.

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<sup>371</sup> Banerjee, S. (2009) *The use of antipsychotic medication for people with dementia: Time for action - A report for the Minister of State for Care Services*. London: The Stationary Office

<sup>372</sup> Ibid P.5

<sup>373</sup> Ibid P.6

<sup>374</sup> All Party Parliamentary Group on Dementia (2008) *Always a last resort: Inquiry into the prescription of antipsychotic drugs to people with dementia living in care homes*. London: Alzheimer's Society p.ix

The Group further recommended that:

- The National Dementia Strategy for England should include an action plan to reduce the number of prescriptions of antipsychotics
- Dementia training should be mandatory for all care home staff
- Care homes must receive effective support from external services, including GPs, community psychiatric nurses, psychologists and psychiatrists, which should involve regular, active visits to the care home
- The use of antipsychotics for people with dementia must be included in Mental Capacity Act training for all care home staff
- Protocols for the prescribing, monitoring and review of antipsychotic medication for people with dementia must be introduced
- There should be compulsory regulation and audit of antipsychotic drugs for people with dementia

## The Right Prescription: a call to action on the use of antipsychotic drugs for people with dementia

In June 2011 the Dementia Action Alliance and the NHS Institute for Improvement and Development issued a joint call to action to ensure that *“all people with dementia who are receiving antipsychotic drugs should receive a clinical review from their doctor to ensure that their care is compliant with current best practice and guidelines and that alternatives to medication have been considered by 31st March 2012”*.<sup>375</sup>

For further information visit

[http://www.institute.nhs.uk/qipp/calls\\_to\\_action/Dementia\\_and\\_antipsychotic\\_drugs.html](http://www.institute.nhs.uk/qipp/calls_to_action/Dementia_and_antipsychotic_drugs.html) or see section 3 of this report.

## National dementia and antipsychotic prescribing audit

In 2010, the Department of Health commissioned the NHS Health and Social Care Information Centre (HSCIC) to carry out an audit to generate baseline data on the use of antipsychotic medication for people with dementia in each primary care trust in England.<sup>376</sup>

According to the report *‘Dementia: A state of the nation report on dementia care and support in England’* *“The Department of Health is re-running the national audit to monitor the level of*

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<sup>375</sup> Alzheimer’s Society [Online] Available at:

[http://www.alzheimers.org.uk/site/scripts/news\\_article.php?newsID=984](http://www.alzheimers.org.uk/site/scripts/news_article.php?newsID=984) (Accessed 17 May 2014)

<sup>376</sup> Health and Social Care Information Centre [Online] Available at: <http://www.hscic.gov.uk/dementiaaudit> (Accessed 17 May 2014)

*prescribing and regional variation. The audit results are expected to be available in spring 2014".*<sup>377</sup>  
At the time of publication of this report no further information was available.

## Clinical Guidelines 42 Dementia: Supporting people with dementia and their carers in health and social care

The guidelines produced by the National Institute for Health and Care Excellence and Social Care Institute of Excellence outline when the prescribing of antipsychotic medication is inappropriate for people living with dementia and the criteria that must be established in order for the prescribing of antipsychotic medication to be a possible option.<sup>378</sup>

## The Prime Minister's Challenge on Dementia

The Prime Minister's Challenge on Dementia states "*the NHS and Social Care working together with wider partners should continue to reduce inappropriate prescribing for people with dementia to improve quality of life with a view to achieving overall a two-thirds reduction in the use of antipsychotic medication*".<sup>379</sup>

## 23.2 Local plans

### Local joint dementia plans

Four out of the 10 local joint dementia plans in the North East mention an aim of developing and implementing best practice guidance and protocols around the prescribing of antipsychotics. In the South of Tyne area pharmacy reviews were to be conducted to provide a basis for planning future actions around dementia prescribing.

Three local joint dementia plans mentioned the use of a 2012/13 CQUIN to promote change within Northumberland Tyne and Wear NHS Foundation Trust.

Other actions to support the reduction in the inappropriate prescribing of antipsychotic medication included the use of liaison teams (mentioned in two plans) and the development of a patient passport (mentioned in two plans).

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<sup>377</sup> Department of Health (2013) Dementia: A state of the nation report on dementia care and support in England [Online] pg 58

<sup>378</sup> National Institute for Health and Clinical Excellence and the Social Care Institute for Excellence (2006) CG42 Dementia: Supporting people with dementia and their carers in health and social care. London: National Institute for Health and Clinical Excellence

<sup>379</sup> Department of Health (2012) Prime Minister's Challenge on Dementia: Delivering major improvements in dementia care and research by 2015. Department of Health: London p.10

## 23.3 North East statistics

In autumn 2012 the North East Dementia Alliance commissioned Cornsay Research to analyse the findings of the National Dementia and Antipsychotic Prescribing Audit. The aim was to identify key trends and statistics relating to the prescribing of antipsychotic medication among people with dementia in the North East.

The report revealed that, over the study period (2006/11), there was a decline in the use of antipsychotic medication across North East England for people with dementia. Seven of the nine Primary Care Trusts (PCT) for which data was available reported that the proportion of people with dementia being prescribed antipsychotic medication was below the national rate of 6.8%, with four reporting usage of less than 2%.<sup>380</sup>

The report did however show that *“in the majority of PCT areas in 2011, there were higher proportions of newly diagnosed people on antipsychotic medication compared to all people with dementia in the areas”*.<sup>381</sup>

## 23.4 Examples of work undertaken in the North East

### Development of a stepped care model

In 2013 a group of psychologists was commissioned by the British Psychological Society to write a report specifying alternative treatments to avoid the unnecessary use of antipsychotic medication for people with dementia.<sup>382</sup> Three of the four authors are based in the North East, working in the NHS. The report outlines a stepped-care model, stating which psychosocial treatments should be used in a phased manner prior to the use of antipsychotics medication. The report was launched at Westminster in March 2013. The Newcastle Challenging Behaviour team is working alongside the Tyne and Wear Care Alliance to incorporate this into training models to deliver in Newcastle.

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<sup>380</sup> Jackson, M (2012) National Dementia & Antipsychotic Prescribing Audit 2012: Findings for North East England (Unpublished)

<sup>381</sup> Ibid p.3

<sup>382</sup> Brechin, D. Murphy, G. James, I. and Codner, J. (2013) Alternatives to Antipsychotic Medication: Psychological Approaches on Managing Psychological and Behavioural Distress in People with Dementia [Online] Available at: [http://www.psige.org/public/files/BPS%20FPoP%20-%20Alternatives%20to%20Anti-Psychotic%20Medication%20-%20report%20-%20March%202013\(1\).pdf](http://www.psige.org/public/files/BPS%20FPoP%20-%20Alternatives%20to%20Anti-Psychotic%20Medication%20-%20report%20-%20March%202013(1).pdf) (Accessed 17 May 2014)

## North East Dementia Alliance Funding to reduce the inappropriate prescribing of antipsychotic medication

In January 2013 the North East Dementia Alliance allocated £70k to projects that aimed to reduce the inappropriate prescribing of antipsychotic medication.

Funding was awarded to the following projects:

- **Hadrian Primary Care Alliance** - A primary care model service improvement guide to improve patient outcomes for people with dementia
- **Green Care in Northumberland** - Branching Out: Living well with dementia through horticulture
- **Durham County Council with Durham Employers Health and Care Alliance** - Development of dementia training units linked to Qualification and Credit Framework
- **South Tees** - Development of checklist akin to the warfarin checklist
- **Newcastle Psychology and Challenging Behaviour Team** - Developing Structural and Functional Treatment Pathways on Inpatient Wards
- **Training in Gateshead Care Homes** - Revising workbooks which support improved care of people with dementia in care homes and delivery of five workshops
- **South Tees** - Audit of General Hospital prescribing in South Tees
- **Northumbria Health Care** - Reviewed ways of reducing prescribing of antipsychotic medication within general hospitals by use of non-pharmacological approaches and appropriate documentation

## Mental Health Clinical Innovation Team - stakeholder event

In March 2011 the Mental Health Clinical Innovation Team held a regional stakeholder event to consider how to reduce the inappropriate prescribing of antipsychotic medication. The event considered a number of projects in the region and across the country, which had led to a reduction in the prescription of antipsychotic medication.

A summary of the ideas generated during the event can be seen in Table 24. A comprehensive stocktake of progress against implementing these ideas has not been undertaken.

Area of work	Time scale			
	3 months	6 months	12 months	18 months
Reducing initial prescription	Develop a shared care guideline for the pharmacological treatment of behavioural and psychological symptoms of dementia	Shared care guideline for pharmacological treatment of behavioural and psychological symptoms of dementia agreed across agencies	Shared care guideline implemented across agencies	Achieve instant access to all relevant health care documents and information systems
Stopping existing prescriptions	Improved discharge planning from acute care	Care homes to prompt review for residents		
	Ensure no one exceeds 12/52 treatment without clinical review  Plan to stop prescribing at point of starting			
Preventing need for prescriptions	Crisis prevention; review education etc, availability of 24 hour support (help line for dementia)	Early diagnosis of dementia  Improved long term care of people at home	Improved long term care in institutions  Delirium prevention programmes in all care centres	
	Mandatory training programme	Publicity campaign  Challenging behaviour team developed/implemented	Implementation of 'confusion control'	Addressing challenging behaviour by ongoing debrief – identifying unmet needs
Changes in the system	Joint contractual development	General public awareness raising	Jointly commissioned education and training strategy support in/to care homes to enable people to live well with dementia in care homes	

**Table 24:** A summary of the ideas generated in the Mental Health Clinical Innovation Team - Stakeholder Event. Source: Mental Health Clinical Innovation Team (2011) Fast Focus: Mental Health: Improving the quality of life for people with dementia through the reduction of inappropriate prescribing of antipsychotic medication [Online] Available at:

## 23.5 Conclusions on the use of antipsychotic medication in the North East

Data from 2011 suggested the number of people with dementia, who were being prescribed antipsychotic medication, was reducing. The same data also suggested that the number of people with dementia in the North East being prescribed antipsychotics was below the national average. We do not know the position as of 2014.

To continue reducing the number of people with dementia being prescribed antipsychotic medication a regional stakeholder event was held in 2011 to develop actions to progress the agenda. In addition the North East Dementia Alliance funded a number of projects across the North East in order to reduce the inappropriate prescribing of antipsychotics. Non-pharmacological interventions, such as the use of the stepped care model, have been implemented to address some of the symptoms that might otherwise result in the use of antipsychotic medication.

## 23.6 Recommendations on the use of antipsychotic medication in the North East

- Regional statistics are available from 2011 regarding the prescribing of antipsychotic medication. There is a need for more up to date statistics and supporting analysis. The Mental Health, Dementia and Neurological Clinical Network would be a key partner in leading this.
- A regional event was held in 2011. The actions developed from the event need to be revisited and, where necessary, completed. Outcomes and learning need to be shared across the region.
- The North East Dementia Alliance has funded a number of small scale projects to help reduce the inappropriate prescribing of antipsychotic medication. The outcomes of these projects need to be shared.

## 24. Safeguarding

### Key points:

- No Secrets, Statement of Government Policy on Adult Safeguarding and Deprivation of Liberty Safeguards provide the operational framework for safeguarding people with dementia
- The Care Act 2014 has introduced new safeguarding measures
- Safeguarding issues are mentioned in five out of the 10 local joint dementia plans
- Some statistics are available nationally for safeguarding alerts and regionally for deprivation of liberty of people living with dementia
- In 2012/13 742 deprivation of liberty applications were made in relation to people living with dementia in the North East, this shows an increase on 2009/10 when there were 451 applications relating to people living with dementia in the North East
- There is a regional safeguarding oversight board which is a themed network of the North East ADASS

This section of the report will consider key issues relevant to the safeguarding of people with dementia. In particular this section of the report will outline:

- The policy context
- How the safeguarding of people with dementia has been included in local plans
- Statistics relating to the safeguarding of people living with dementia in the North East
- Examples of work undertaken to improve the safeguarding of people with dementia in the North East
- Conclusions and recommendations on the safeguarding of people with dementia in the North East

### 24.1 Policy context

#### No Secrets

Published in 2000, 'No Secrets' provides guidance on developing and implementing multi-agency policies and procedures to protect vulnerable adults from abuse.<sup>383</sup>

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<sup>383</sup> Department of Health (2000) No Secrets: Guidance on developing and implementing multi-agency policies and procedures to protect vulnerable adults from abuse. London: Department of Health



## Statement of Government Policy on Adult Safeguarding

The '*Statement of Government Policy on Adult Safeguarding*'<sup>384</sup> was issued to bridge the gap between '*No Secrets*' and the finalising of the '*Health and Social Care Bill*'. It includes the statement of principles to be used by local authority social services and housing, health, the police and other agencies when developing and assessing the effectiveness of their local safeguarding arrangements. It also describes, in broad terms, the outcomes for adult safeguarding, for both individuals and organisations.

## Deprivation of liberty

The Deprivation of Liberty Safeguards (DoLS) are part of the '*Mental Capacity Act 2005*'<sup>385</sup> but were introduced as an amendment under the '*Mental Health Act 2007*'.<sup>386</sup> DoLS have been developed to protect people in care homes and hospitals from having their freedom inappropriately restricted. The safeguards require staff in care homes or hospitals to ensure restrictions on a person's liberty are conducted in a safe manner and only when it is in the best interests of the person and there is no other alternative.

## Care Act 2014

The Act sets out the local authority's responsibility for protecting adults with care and support needs. In particular, the Act covers:

- The principles of safeguarding which should underpin all work to protect people from abuse and neglect
- Types of abuse and neglect
- Local authorities' responsibilities to carry out safeguarding enquiries where it is suspected someone is suffering or at risk of abuse or neglect
- Creating Safeguarding Adults Boards (SABs) in every area to bring together the key local partners to focus on safeguarding strategy and practice
- Conducting Safeguarding Adults Reviews where there is a cause for concern about a particular case: to learn lessons for the future
- Sharing information between local and national organisations to support reviews and enquiries

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<sup>384</sup> Department of Health (2011) *Statement of Government Policy on Adult Safeguarding* [Online] Available at: <https://www.gov.uk/government/publications/adult-safeguarding-statement-of-government-policy> (Accessed 17 May 2014)

<sup>385</sup> Great Britain. *Mental Capacity Act: Elizabeth II. Chapter 9* (2005) London: The Stationery Office

<sup>386</sup> Great Britain. *Mental Health Act: Elizabeth II. Chapter 12* (2007) London: The Stationery Office

- Providing independent advocates to enable some people, who would otherwise have difficulty, to take part in an enquiry or review<sup>387</sup>

## 24.2 Local plans

### Joint Strategic Needs Assessments

The North Tyneside Joint Strategic Needs Assessment highlights as a concern for the future “*the quality of care and the safety of those most vulnerable in our community*”.<sup>388</sup>

### Local joint dementia plans

The Tees joint dementia plans refer to a Tees wide safeguarding policy and procedure, which provides a framework for responding to vulnerable adult’s issues. Gateshead’s plan highlights that Gateshead NHS Foundation Trust will ensure that Mental Capacity and Deprivation of Liberty training is available to staff within the Trust and that deprivation of liberties are fully understood by care home staff.<sup>389</sup> In an update to their plan Redcar and Cleveland state training about the Mental Capacity Act for care at home staff is provided free of charge to the providers through the Tees wide Training Alliance, funded by the local authorities and the NHS.

## 24.3 Safeguarding statistics

### Safeguarding

During the research for this report it was not possible to identify any comprehensive statistics relating to safeguarding referrals affecting people living with dementia in the North East. During 2012/13 a total of 5,340 safeguarding referrals, relating to all adult groups, were made in the North East.<sup>390</sup>

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<sup>387</sup> Department of Health (2014) The Care Act 2014: Consultation on draft regulations and guidance for implementation of Part 1 of the Act in 2015/16 [Online] Available at: [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/317820/CareAct\\_cons\\_040614.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/317820/CareAct_cons_040614.pdf) (Accessed 15 June 2014)

<sup>388</sup> North Tyneside Council (2013) North Tyneside Joint Strategic Needs Assessment 2013 [Online] Available at: [http://www.northtyneside.gov.uk/pls/portal/NTC\\_PSCM.PSCM\\_Web.download?p\\_ID=550377](http://www.northtyneside.gov.uk/pls/portal/NTC_PSCM.PSCM_Web.download?p_ID=550377) (Accessed 17 May 2014) p.45

<sup>389</sup> Gateshead Council and NHS South Tyne and Wear - National Dementia Strategy Action Plan: A Local Action Plan for Gateshead: September 2012 – September 2013 p. 22

<sup>390</sup> Health & Social Care Information Centre (2014) Abuse of Vulnerable Adults in England 2012-13, Final Report [Online] Available at: <http://www.hscic.gov.uk/catalogue/PUB13499> (Accessed 17 May 2014) p. 23

The report “*Abuse of Vulnerable Adults in England 2012-13, Final Report*”<sup>391</sup> outlines data regarding the safeguarding of people living with dementia (under the primary client group of mental health). However, the report does not present the data by region. Outlined in Table 25 are the numbers (for the whole of England) of alerts, referrals, repeat referrals and completed referrals where the alleged injured party is a person with dementia.

	Alerts	Referrals	Repeat referrals	Completed Referrals
<b>18-64</b>	600	410	80	310
<b>65-74</b>	2045	1485	335	1190
<b>75-84</b>	6635	4715	995	3685
<b>85+</b>	6970	4970	940	4020
<b>Total</b>	<b>16250</b>	<b>11580</b>	<b>2350</b>	<b>9205</b>

**Table 25:** Numbers of alerts, referrals, repeat referrals and completed referrals for the whole of England where the alleged injured party is a person with dementia. Source: Health & Social Care Information Centre (2014) *Abuse of Vulnerable Adults in England 2012-13, Final Report* [Online] Available at: <http://www.hscic.gov.uk/catalogue/PUB13499> (Accessed 17 May 2014)

## Deprivation of Liberty

The report ‘*Health & Social Care Information Centre (2013) Mental Capacity Act 2005, Deprivation of Liberty Safeguards Assessments (England): Annual Report, 2012/13*’<sup>392</sup> shows that, in 2012/13 in England, 6,355 Deprivation of Liberty Safeguards (DoLs) applications were made, relating to people living with the dementia. This made up 53% of all applications.

In 2012/13 742 applications were made in relation to people living with dementia in the North East. 411 were authorised while 331 were not authorised. This shows an increase on 2009/10, when there were 451 applications relating to people living with dementia, of which 238 were authorised and 213 were not.

<sup>391</sup> Ibid

<sup>392</sup> Health & Social Care Information Centre (2013) *Mental Capacity Act 2005, Deprivation of Liberty Safeguards Assessments (England): Annual Report, 2012/13* [Online] <http://www.hscic.gov.uk/catalogue/PUB11379/DoLSAnnualReport201213v2.pdf> (Accessed 17 May 2014)

## 24.4 Examples of work undertaken in the North East

### North East Association of Directors of Adult Social Services

The North East Association of Directors of Adult Social Services has a region wide adult safeguarding themed network for adult safeguarding leads across the region. The network is not dementia specific but, instead, cuts across all client groups, including people living with dementia.

The network provides strategic and operational oversight on policy developments which will impact upon adult safeguarding, shares good practice across the region, leads on projects on behalf of ADASS and will have a key role in ensuring local authorities meet their safeguarding duties under the Care Act 2014.

## 24.5 Conclusions on the safeguarding of people living with dementia in the North East

Legislative structures exist to support the safeguarding of people with dementia with amendments expected as a result of the Care Act 2014. Issues regarding the safeguarding of people living with dementia are only included in some local plans. There is limited statistical or other information in this report to give us a comprehensive picture of what the issues may be in relation to the safeguarding of people with dementia. More research is needed to understand the safeguarding of people with dementia in the North East.

The research conducted as part of this report revealed little work being undertaken in the North East relating to the safeguarding of people living with dementia. This is particularly problematic given the vulnerable position of some people living with dementia.

## 24.6 Recommendations on the safeguarding of people living with dementia in the North East

- The Care Act 2014 has amended the legislative framework governing safeguarding. Providers and safeguarding leads need to consider the impact on these changes for people living with dementia. A key group to consider this will be the ADASS Adult Safeguarding Themed Network.
- Not all local joint dementia plans have safeguarding as part of their actions. All localities need to ensure that the safeguarding of people living with dementia is included in their plans.
- Limited statistical information regarding safeguarding was presented in this report. More statistical information, in the first instance, needs to be brought together to explore the

positive aspect as well as issues regarding the safeguarding of people with dementia in the North East.

- There is an ADASS Safeguarding Themed Network in the North East. Joint working needs to take place between the North East Dementia Alliance and the Mental Health, Dementia and Neurological Conditions Strategic Clinical Network to ensure people with dementia are appropriately safeguarded.

# Moving Forward Together in the North East - note from the authors

The North East Dementia Alliance wants the North East of England to be the best place in the United Kingdom for people to live well with dementia. This not only requires the public sector to be responsive to the needs of people with dementia; it requires every part of our society to respond to this challenge together. We each have a part to play and actions to take.

This dementia report, with the supporting papers, has shown a variation in services across the North East where the number of people with dementia is set to rise significantly. In some areas the services seem comprehensive and have some clearly demonstrated outcomes; in other areas the services are not available, or we have been unable to assess what they are achieving, for people with dementia. This illustrates we have to move forward and fast.

This report also highlights that the provision of dementia care can be hampered by inadequate information, with decisions sometimes being taken using out of date, or incomplete, information. We need more and better data, which can be used by key groups, including local authorities, CCGs, people with dementia and the public. Only by having adequate data will we be able to deliver better services and enable people with dementia to access the right support and information.

The North East Dementia Alliance wants to encourage a dialogue between health, social care, people with dementia and their carers. The aim would be to work in partnership to develop and deliver the right services for people with dementia in their local area. We want to support people with dementia and carers to call to account local health commissioners and services for the quality of local dementia care. We also want to support the sharing of good practice to improve services and support across the public, private and voluntary sectors.

This report and the supporting papers will inform the priorities and work plan of the North East Dementia Alliance for the 18 months following July 2014. The report also provides information and recommendations for other key groups in the North East.

Key areas for consideration include:

**Timely diagnosis and support after diagnosis:** Local NHS Clinical Commissioning Groups, local authorities and the third sector need to work together to deliver the ambition that, by 2015, two thirds of people with dementia will have a diagnosis and get appropriate support.

**End of life care:** Where possible, people with dementia should be able to die in the place of their choice. There should be the opportunity to plan ahead using tools such as 'Deciding Right'.<sup>393</sup>

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<sup>393</sup> For further information see <http://www.cnne.org.uk/end-of-life-care---the-clinical-network/decidingright>

**Full shared decision making:** We need to support people with dementia and their carers to have control over the decisions which affect their life; from their own care to influencing policy.

**A workforce equipped to meet the needs of people with dementia:** All members of the North East workforce that come into contact with people with dementia need to be equipped to meet the needs of people with dementia. The workforce should be recruited on the basis of having the right values along with the right training, supervision and support.

**Dementia friendly communities:** We need to continue to develop a dementia friendly society. Working with localities we want to share what works well when developing a dementia friendly community. We want to see more communities in the North East registering for the Alzheimer's Society's Dementia Friendly Community Recognition Process.

**Research:** We need continued and more dementia research in the North East, with more people taking part in research.

**Better data and evidence:** We need to work with national and regional organisations such as NHS England, Public Health England, Health Education England, the Care Quality Commission and the Health and Social Care Information Centre, to improve the availability and quality of data on dementia care and support.

**Outcomes:** Everything we do to improve care and support for people living with dementia needs to be evaluated in terms of the qualitative effect and outcomes for people with dementia.

**Joined up working:** People with dementia and their carers want a seamless service. Service commissioners and service providers need to work together to ensure this happens.

**Safeguarding:** People living with dementia are some of the most vulnerable people in society. We need to ensure that there are adequate safeguards in place while supporting them to be as independent as possible.

With the strong North East Dementia Alliance we need to continue to drive up standards and fill gaps in dementia care. By working together we can continue to improve the quality of life for people with dementia in the North East.

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## More information

Full and summary copies of the '*Dementia 2014: A North East Perspective*' report by Debbie J Smith and Peter Otter can be downloaded from the Foundation's website at [www.nr-foundation.org.uk/resources/dementia-report](http://www.nr-foundation.org.uk/resources/dementia-report)

For more information about Northern Rock Foundation's work on dementia please contact Northern Rock Foundation at the address below.

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