PACEC

Public and Corporate Economic Consultants

In association with Dr Karen Harrison-Dening

directors of adass adult social services North West Region

North West Dementia Perspectives - State

TABLE OF CONTENTS

Appendices are in a separate report.

Appendix 1: Methodology for the Review

Appendix 2: Literature Review of National and International Best Practice

Appendix 3: Demographic Information for Geographical Areas covered in this Report

Appendix 4: Dementia Research in Universities in the North West and Recruitment to Research Studies by Memory Clinics in the North West

1 INTRODUCTION

1.1 Background to the Report

In 2016, Bury Council on behalf of 22 other councils in the North West of England, commissioned PACEC Ltd. to complete the 'North West Dementia Perspectives: State of the Region Report'. All Directors of Adult Social Services (DASS) in the North West of England have committed to the production of this report.

The purpose of the report is to outline the status of dementia care in the North West (NW) of England as of March 2015 by highlighting both progress made and gaps in service development and provision, and reviewing this against the relevant English policy context.

1.2 Aims of the Report

The report outlines the status of dementia care in the North West of England as of March 2015. In particular, the report outlines:

- The demographic position in the North West of England;
- The relevant English policy context;
- Dementia research in the North West of England;
- The status of dementia care in the region; and
- Dementia Friendly Communities in the North West of England.

It is hoped that this report will provide the following benefits for the region:

- The document provides a comprehensive 'state of the region' report in one place;
- The report highlights good practice and enables the sharing of good practice;
- The report does not criticise or compare one area against another area;
- The report will allow for the wider dissemination of plans and strategies and will encourage joint working across the wider regional area;
- The report highlights areas for improvement to inform future planning; and
- The report will be of use in assisting the development of future commissioning intentions.

1.3 Geographical Area Covered by the Report

For the purpose of this report, the North West of England refers to the geographical area covered by the localities listed below:

- Blackburn
- Blackpool
- Bolton
- Bury
- Cheshire East
- Cheshire West and Chester
- Oldham
- Rochdale
- Salford
- Sefton
- Stockport
- St Helens

- Cumbria
- Halton
- Knowsley
- Lancashire
- Liverpool
- Manchester
- Tameside
- Trafford
- Warrington
- Wigan
- Wirral

1.4 Sources of Information

The information for this report was drawn from a number of sources, including:

- An in-depth literature and policy review;
- Desk-based research of dementia statistics and services in the North West;
- Consultations with key individuals in the North West; and
- An information request which was sent to all twenty three councils, and which was designed in collaboration with our contact in Bury council; the information request aimed to collect the information and statistics requested in the terms of reference regarding local policy structures in each area, health scrutiny arrangements, dementia prevalence, and mortality and hospital admissions due to dementia in each area, care homes and dementia beds in CQC care homes, end of life care, dementia services in the community, dementia friendly communities, direct payments / personalisation, safeguarding, medication and prescribing, and the workforce.

A copy of the information request / survey that was issued to all twenty three councils in the North West is set out in Appendix 1.

Four councils did not respond to the information request. While there may therefore not be as comprehensive a picture of dementia care in these councils as in others, they are included in the report where relevant information was publicly available from other sources.

1.5 Structure of the Report

The report is structured as follows:

- Section 2: Context
- Section 3: National and Regional Dementia Policies
- Section 4: Review of Best Practice
- Section 5: Groups and Organisations in the North West
- Section 6: Dementia Research in the North West
- Section 7: Driving improvements in Health and Social Care
- Section 8: Cross cutting themes
- Section 9: Conclusions and Recommendation

2 CONTEXT

This section sets out an overview of what dementia is and the key statistics relating to the prevalence of dementia in the North West, as well as estimated future prevalence rates.

2.1 What is Dementia

According to the Alzheimer's Society[1], 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. These symptoms are caused by structural and chemical changes in the brain as a result of physical diseases such as Alzheimer's disease or a series of strokes. Dementia is a progressive condition, meaning that symptoms will only become more severe over time as the structure and chemistry of the brain becomes increasingly damaged. How quickly dementia progresses is dependent on the individual, and can be impacted upon by many individual factors such as physical make-up, emotional resilience, and the support that is available to them.

2.1.1 Forms of Dementia

There are many different forms of dementia (as illustrated in Table 2.1), and some are more common than others. The different types of dementia are often so-called according to the condition that has caused the dementia.

Table 2:1: Different Types of Dementia

Type of Dementia	Description	Number and percentage of people in the UK with this type of dementia[2]
Alzheimer's Disease	This is the most common cause of dementia. During the course of the disease, the chemistry and structure of the brain changes, leading to the death of brain cells.	Total Number = 505,813 % of total dementia cases = 62%
Vascular Dementia	This is the second most common type of dementia. It is caused by reduced blood supply to the brain due to diseased blood vessels. The most common cognitive symptoms in the early stages of vascular dementia are slower speed of thought, and problems concentrating, including short periods of sudden confusion.	Total Number = 138,691 % of total dementia cases = 17%
Dementia with Lewy bodies (DLB)	DLB is a type of dementia that shares symptoms with both Alzheimer's disease and Parkinson's disease. Lewy bodies are tiny deposits of protein in nerve cells. Their presence is linked to low levels of important chemical messengers and to a loss of	Total Number = 32,633 % of total dementia cases = 4%

[1] King's College London and the London School of Economics. (2007). Dementia UK – The Full Report. London: Alzheimer's Society.
[2] According to report by King's College London and the London School of Economics. (2014). Dementia UK Update. London: Alzheimer's Society.

Type of Dementia	Description	Number and percentage of people in the UK with this type of dementia[2]
	connections between nerve cells.	
Frontotemporal dementia	This is one of the less common forms of dementia. Damage is usually focused in the front part of the brain, and personality and behaviour are initially more affected than memory.	Total Number = 16,317 % of total dementia cases[3] = 2%
Rarer Causes of Dementia		
Creutzfeldt-Jakob Disease (CJD)	CJD is caused by an abnormally shaped protein called a prion infecting the brain. Early symptoms of CJD include minor lapses of memory, mood changes and loss of interest, with symptoms progressing to jerky movements, shakiness, stiffness of limbs, incontinence, and loss of ability to move or speak. People affected by CJD usually die within six months of their early symptoms developing.	According to Alzheimer's Society UK website, it is estimated that CJD affects about one out of every one million people each year.
Korsakoff's Syndrome	Korsakoff's Syndrome is a brain disorder that is usually associated with heavy drinking over a long period. Although it is not strictly speaking a dementia, people with the condition experience loss of short term memory.	Reliable figures of the number of people with alcohol-related brain damage are not available and the condition is likely to be under-diagnosed, partly due to the stigma associated with alcohol, which may prevent people from seeking help.
Mild cognitive impairment (MCI)	This is a relatively new term which is used to describe people who have some problems with their memory but who do not actually have dementia. However, people with MCI do have an increased risk of going on to develop dementia.	According to the Alzheimer's Society UK, it is estimated that between 5-20% of people over 65 have MCI, and that 10-15% of people who have MCI with gradual memory loss go on to develop dementia.

Source: Alzheimer's Society UK website:
https://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=167

2.2 Demographic Information

The data presented below is based on the most current information available at the time of writing this report.

2.2.1 Current Prevalence and Estimated Future Prevalence at a National Level

According to a report[4] by the House of Commons in 2015, it is estimated that almost 676,000 people in England have dementia[5], and that only a little over half of those have been formally diagnosed.

[3] The percentages don't total to 100% due to the presence of the rarer forms of Dementia that make up the remaining 15%
[4] Parkin, E., and Baker, C. (2015). Dementia – An overview of policy and services, and statistics on prevalence. House of Commons Library. Available at: http://researchbriefings.files.parliament.uk/documents/SN07007/SN07007.pdf

Health and Social Care Information Centre data recorded dementia prevalence[6] in the UK at 0.76% (one in every 132 people) as of 30th April 2015[7]. A 2014 report by the Alzheimer's Society forecasted that the total number of people with dementia in the UK will increase to over one million by 2025 and over two million by 2051[8].

2.2.1.1 Age

Dementia can affect people of any age, but is most common in older people. Health and Social Care Information Data from April 2015 clearly shows how dementia prevalence increases with age, as demonstrated in Table 2.2.

Table 2:2: Dementia Prevalence by Age and Gender

Age group (years)	Prevalence in males	Prevalence in females
60-64	0.3%	0.2%
65-69	0.6%	0.5%
70-74	1.5%	1.5%
75-79	3.6%	3.9%
80-84	6.9%	8.5%
85-89	10.8%	14.9%
90+	13.4%	20.8%

Source: Health and Social Care Information Centre. (2015). Patients in England with a record of dementia diagnosis on their clinical record: April 2015. Available at: http://www.hscic.gov.uk/media/19020/Dementia-Diagnosis-Summary-April-2015/pdf/qual-outc-fram-rec-dem-diag-apr-2015-sum.pdf

2.2.1.2 Gender

Statistics released by the Office for National Statistics in 2015 show that twice as many women die from dementia than men[9]. In England and Wales in 2014, dementia accounted for 13.4% of all female deaths. Table 2.2 above shows minor inequalities between genders up to the age of 80,

[5] This is the proportion of the population estimated to have dementia, irrespective of whether they have a formal diagnosis or not
[6] Recorded dementia prevalence = Number of patients with a formal diagnosis of dementia entered on their GP's practice dementia register
[7] Health and Social Care Information Centre. (2015). Patients in England with a record of dementia diagnosis on their clinical record: April 2015. Available at: http://www.hscic.gov.uk/media/19020/Dementia-Diagnosis-Summary-April-2015/pdf/qual-outc-fram-rec-dem-diag-apr-2015-sum.pdf
[8] King's College London and the London School of Economics. (2014). Dementia UK Update. London: Alzheimer's Society.
[9] Information available from: http://webarchive.nationalarchives.gov.uk/20160105160709/http://www.ons.gov.uk/ons/rel/vsob1/mortality-statistics--deaths-registered-in-england-and-wales--series-dr-/2014/sty-what-do-we-die-from.html

above which females experience markedly higher rates of dementia. It is not yet clear why females are at a greater risk of dementia; however it is possible that as female life expectancy is greater than that of males, women are therefore more likely to survive to older ages when they are at increased risk of developing dementia.

2.2.1.3 Ethnic Minorities

As of the time of writing this report, official statistics on dementia prevalence among individual ethnic groups did not exist. However, a study from North London[10] does suggest that there is a somewhat higher prevalence of dementia among people of African-Caribbean country of birth than among white UK people. A 2013 report from the All-Party Parliamentary Group[11] on dementia reported that there were nearly 25,000 people with dementia from Black, Asian and Ethnic Minority (BAME) communities. In 2015, Public Health England conducted a systematic review of international literature in order to examine the prevalence of dementia in population groups by protected characteristics[12]. The results of the review showed that while dementia was more common in people from African-American, Black-Caribbean or Hispanic backgrounds, no information was published on people from south-east Asian backgrounds.

> The Manchester Institute for Collaborative Research on Ageing at the University of Manchester is currently undertaking a research project which seeks to improve the recognition of symptoms of dementia among South Asian older people. (See Section 6 for more details).

2.2.1.4 LGB&T Groups

Alzheimer's UK estimate that around 35,000 of those diagnosed with a dementia-related illness are LGBT[13]. Compared to heterosexual people with dementia, LGBT individuals with dementia are: more likely to be single, two and a half times more likely to be living on their own, four and a half times more likely to have no children, and less likely to see family members regularly[14].

[10] Adelman, S., Blanchard, M., Rait, G., Leavey, G., & Livingston, G. (2011). 'Prevalence of dementia in African-Caribbean compared with UK-born white older people: two stage cross-sectional study', British Journal of Psychiatry, 199 (2), pp. 119-25.
[11] All-Party Parliamentary Group on Dementia. (2013). Dementia does not discriminate: The experiences of black, Asian and minority ethnic communities. London: House of Commons.
[12] Matrix Policy Solutions Ltd. (2015). Prevalence of dementia in population groups by protected characteristics: A systematic review of the literature. London: Public Health England.
[13] http://www.ageuk.org.uk/derbyandderbyshire/lgbt
[14] Alzheimer's Society. (2013). Supporting lesbian, gay and bisexual people with dementia. London: Alzheimer's Society.

2.2.1.5 Learning Disabilities

Research shows that individuals with intellectual disabilities have a higher risk of developing dementia compared to the general population, with a significantly increased risk for people with Down's syndrome and at a much earlier stage[15]. According to the Alzheimer's Society, about one in five people with a learning disability who are over the age of 65 will develop dementia[16].

2.3 Dementia Statistics in the North West

2.3.1 Recorded Prevalence

The recorded prevalence of dementia, as recorded on practice disease registers, is the proportion of a given population with a formal diagnosis of dementia included on a GP practice dementia register. Table 2.3 shows the recorded prevalence of dementia in the North West as of 2014/15.

Table 2:3: Dementia Prevalence in North West of England as of 2014/15

	Dementia recorded prevalence (%) (all ages) – 2014/15	Number	Dementia recorded prevalence (aged 65+) (%) – Sept 2015	Number
England	**0.74**	**419,073**	**4.27**	**413,339**
North West Region	**0.79**	**58,996**	**4.51**	**58,464**
Blackburn with Darwen	0.66	1,118	4.42	1,051
Blackpool	1.02	1,758	4.93	1,678
Bolton	0.73	2,187	4.57	2,173
Bury	0.91	1,806	5.13	1,729
Cheshire East	0.92	3,578	4.47	3,616
Cheshire West and Chester	0.78	2,780	4.00	2,757
Cumbria	0.96	4,910	4.29	4,871
Halton	0.70	893	4.19	870

[15] British Psychological Society Division of Clinical Psychology and the Royal College of Psychiatrists. (2015). Dementia and People with Intellectual Disabilities. Leicester: The British Psychological Society.
[16] http://www.ageuk.org.uk/derbyandderbyshire/lgbt

	Dementia recorded prevalence (%) (all ages) – 2014/15	Number	Dementia recorded prevalence (aged 65+) (%) – Sept 2015	Number
Knowsley	0.69	1,058	4.78	1,117
Lancashire	0.86	10,231	4.50	10,008
Liverpool	0.65	3,376	4.44	3,312
Manchester	0.48	2,819	4.76	2,762
Oldham	0.76	1,790	5.11	1,782
Rochdale	0.67	1,503	4.21	1,444
Salford	0.72	1,906	5.40	1,999
Sefton	0.95	2,540	4.39	2,554
St Helen's	0.79	1,508	4.81	1,814
Stockport	0.88	2,667	4.48	2,517
Tameside	0.72	1,609	4.25	1,573
Trafford	0.80	1,900	4.77	1,908
Warrington	0.75	1,591	4.30	1,563
Wigan	0.74	2,342	4.07	2,341
Wirral	0.94	3,126	4.61	3,025

Source: Public Health England. (2016). Dementia Profile: http://fingertips.phe.org.uk/profile-group/mental-health/profile/dementia/data

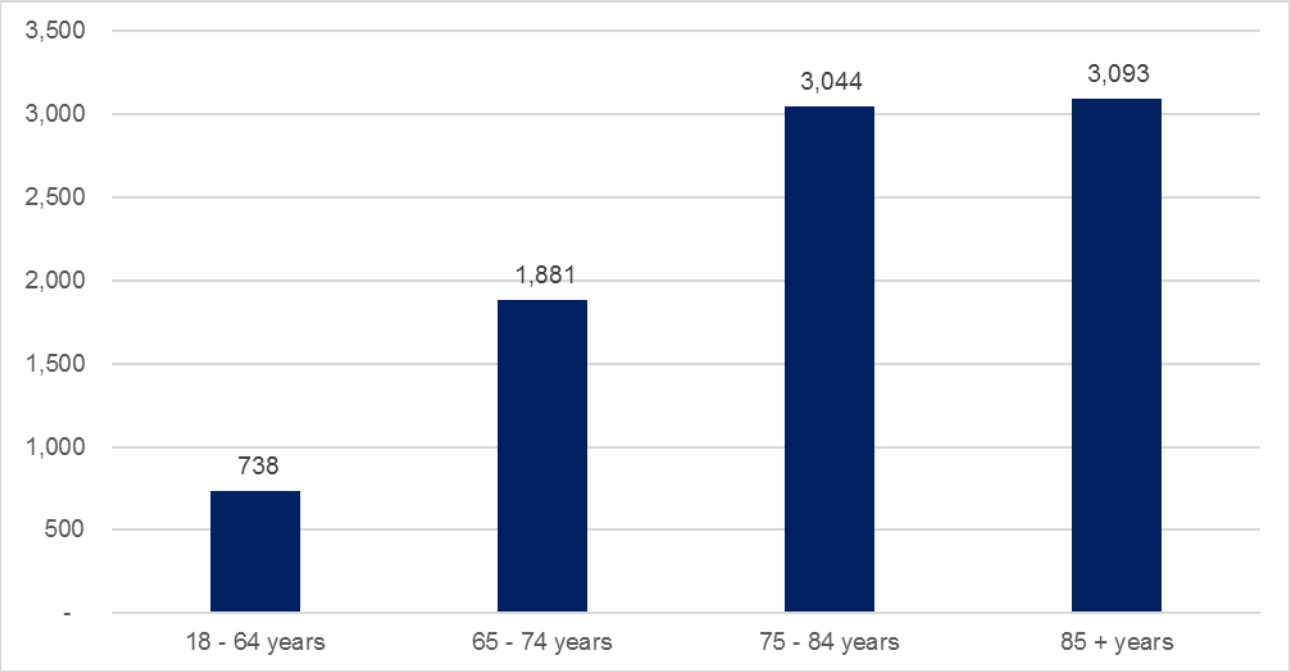
As can be seen in the Table above, dementia prevalence is slightly higher in the North West compared to the English average (0.79% compared to 0.74% for all ages; and 4.51% compared to 4.27% for over 65's).

As part of the information request that went to all councils, a question was asked regarding the numbers of individuals with dementia in their area as of March 2015 and by age group. A number of councils didn't respond to the information request; however the below graph was generated by

aggregating the figures[17] from the councils who responded and therefore provides a reflection of dementia by age group in the North West.

Unsurprisingly, the two age groups with the highest number of people with dementia overall are the two oldest age groups, 75-84 years and 85+ years, with 3,044 and 3,093 respectively. Looking at the individual area figures that were provided in the information request, Lancashire has the highest number of people with dementia for 16-64 and 65-74 age groups, which is likely due to their large population.

Figure 2.1: Dementia by Age Group in the North West as of March 2015



Source: Bury Council – North West Dementia Perspectives: State of the Region – Data Request for Councils (June 2016)

2.3.2 Estimated Future Prevalence Rates (2020)

It is estimated that between 2014 and 2020, the overall number of people living with dementia in the North West will increase by 10,029 to 69,025[18]. Table 2.4 below details the estimated future number of people that will be living with dementia, both for all ages and over 65's, in each area of the North West by 2020.

[17] Bury provided one figure for 18-64 years but not for any other age group and Lancashire provided data for 18-64 and 65-74 years but not for the remaining two age groups. These figures were included in the aggregate figures.
[18] For the purpose of this report, an increase of 17% was used to calculate estimated future prevalence rates of dementia for the North West. This was the expected whole of England percentage increase that was used for the North East Dementia Perspectives report in 2014.

Table 2:4: Estimated Increases in Numbers of People Living with Dementia in North West by 2020

	Estimated number of people of all ages who will be living with dementia by 2020	Estimated number of people of 65+ who will be living with dementia by 2020
England	**490,315**	**483,606**
North West Region	**69,025**	**68,402**
Blackburn with Darwen	1,308	1,229
Blackpool	2,056	1,963
Bolton	2,558	2,542
Bury	2,113	2,022
Cheshire East	4,186	4,230
Cheshire West and Chester	3,252	3,225
Cumbria	5,744	5,699
Halton	1,044	1,017
Knowsley	1,237	1,306
Lancashire	11,970	11,709
Liverpool	3,949	3,875
Manchester	3,298	3,231
Oldham	2,094	2,084
Rochdale	1,758	1,689
Salford	2,230	2,338
Sefton	2,971	2,988
St Helen's	1,764	2,122
Stockport	3,120	2,944
Tameside	1,882	1,840

	Estimated number of people of all ages who will be living with dementia by 2020	Estimated number of people of 65+ who will be living with dementia by 2020
Trafford	2,223	2,232
Warrington	1,861	1,828
Wigan	2,740	2,738
Wirral	3,657	3,539

Source: Public Health England. (2016). Dementia Profile: http://fingertips.phe.org.uk/profile-group/mental-health/profile/dementia/data, plus a project increase of 17% as per the National average and findings from the North East Dementia Perspectives report in 2014.

2.4 Conclusions

Dementia is an umbrella term that describes a wide range of symptoms associated with a decline in memory or other thinking skills severe enough to reduce a person's ability to perform everyday activities. The most common form of dementia is Alzheimer's disease.

As of 2014/15, in the North West of England there were an estimated 58,996 people living with dementia, 99% (58,464) of whom were aged 65 years or older. Dementia prevalence is slightly higher in the North West compared to the English average (0.79% compared to 0.74% for all ages; and 4.51% compared to 4.27% for over 65's). The areas with the highest prevalence of dementia for all ages in the North West are: Blackpool (1.02%), Cumbria (0.96%), Sefton (0.95%), Wirral (0.94%), Cheshire East (0.92%), and Bury (0.91%). However, Manchester has a significantly lower dementia prevalence rate for all ages compared to the North West average (0.48% compared to 0.79%).

It is estimated that based on prevalence rates and population projections, the number of individuals of all ages living with dementia in the North West is expected to rise to 69,025 by 2020. This is likely to place significant pressures on services and communities in the North West. It is estimated[19] that a little over half of those living with dementia will have a formal diagnosis.

While there are currently no official statistics on dementia prevalence among individual ethnic groups, research does suggest that there is a somewhat higher prevalence of dementia among people from BAME communities. Therefore, it is vital that the needs of minority communities are also considered in dementia care.

[19] http://www.hscic.gov.uk/media/19020/Dementia-Diagnosis-Summary-April-2015/pdf/qual-outc-fram-rec-dem-diag-apr-2015-sum.pdf

3 NATIONAL AND REGIONAL DEMENTIA POLICIES

3.1 Introduction

This section of the report sets out the key National and Local Policies that relate to the provision of dementia care in the North West. Policy that is relevant to specific aspects of dementia, such as dementia research, will be addressed in the relevant sections of this report.

3.2 National Policy

3.2.1 Living Well with Dementia: A National Dementia Strategy[20]

In February 2009, the Department for Health launched the first ever National Dementia Strategy for England. The aim of the Strategy is to ensure that significant improvements are made to dementia services across three key areas: improved awareness, earlier diagnosis and intervention, and a higher quality of care. The Strategy identifies 17 key objectives which, when implemented, largely at a local level, should result in significant improvements in the quality of services provided to people with dementia, as well as promote a greater understanding of the causes and consequences of dementia.

In July 2009, the supporting Implementation Plan[21] for the Strategy was published. This Plan sets out how the Department of Health intends to support delivery of the Strategy through its national and regional structures, with the aim that the potential described in the Strategy for improved services and support for people affected by dementia be realised.

April 2014 marked the end of the formal implementation period for the Strategy. In February 2014, Jeremy Hunt, the Health Secretary, stated that the Strategy would be "refreshed and updated"[22]. However, as of the time of this report, there is no evidence of any immediate plans for an update or refresh of the National Dementia Strategy.

3.2.2 Prime Minister's Challenge on Dementia 2020[23]

In March 2012, the Prime Minister launched the first Challenge on Dementia[24], which aimed to follow on from the achievements of the National Dementia Strategy, and set out improvements and ambitions that the Government aimed to achieve by 2015. In order to build on the progress made by the first programme of work, the Prime Minister launched his second challenge on dementia in February 2015. In this he states that by 2020, he wants England to be:

- "the best country in the world for dementia care and support and for people with dementia, their carers and families to live"; and

[20] Department of Health. (2009). Living Well with Dementia: A National Dementia Strategy. Available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/168220/dh_094051.pdf
[21] Department of Health. (2009). Living Well with Dementia: A National Dementia Strategy – Implementation Plan. Available at: http://www.laterlifetraining.co.uk/wp-content/uploads/2011/12/DoH-Dementia-Strategy-2009.pdf
[22] HC Deb 25 February 2014 vol 576 c142
[23] Department of Health. (2015). Prime Minister's Challenge on Dementia 2020. Available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/414344/pm-dementia2020.pdf
[24] Department of Health. (2012). Prime Minister's Challenge on Dementia: Delivering Major Improvements in Dementia Care and Research by 2015. London: Department of Health.

- "the best place in the world to undertake research into dementia and other neurodegenerative diseases".

18 key commitments that the Government wish to achieve by 2020 are outlined in the Challenge. These are related to issues such as improved public awareness and understanding; coordination and continuity of care; further development of Dementia Friendly Communities; and increased investment in dementia research, and are covered in more detail in the relevant sections of the report.

The associated Implementation Plan[25] was published in March 2016, and outlines how the commitments as set out in the 2020 Challenge will be met by setting out priority actions across four themes:

- Risk reductions;
- Health and Care;
- Awareness; and
- Social Action.

The majority of the actions require joint efforts from multiple organisations and bodies, such as Government, the NHS, research institutions, and the charity and voluntary sector.

3.2.3 Care Act 2014

The Care Act represents a significant reform of care and support, and places people and their carers in control. The Act pulls together information from over a dozen different Acts, into a "single, modern framework for care and support"[26]. The Act is split into three sections, namely:

Care and Support – The Act delivers the commitments in the Government's 2012 White Paper, 'Caring for Our Future: Reforming Care and Support'[27], which 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"[28]. As part of this, the Act defines the promotion of individual well-being as one of the primary responsibilities of local authorities, representing a shift from the duty to provide services to meeting needs. Under this Act, local authorities are therefore required to adopt a person-centred approach and a focus on preventing or delaying the need for support. The Act also requires local authorities to promote integration with the NHS and work with other key partners to improve services locally. Additionally, the Act puts in place legislation to introduce a cap on the costs that people will have to pay for care in their lifetime.

Care Standards – The Act delivers a number of elements in the Government's response to the finding of the Francis Inquiry, which identified failings across the health and care system. For example, the Act will allow for Ofsted-style ratings for hospitals and care homes that will enable patients and the public to compare organisations or services in a fair and balanced way. The Act will

[25] Department of Health. (2016). Prime Minister's Challenge on Dementia 2020 – Implementation Plan. Available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/507981/PM_Dementia-main_acc.pdf
[26] 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 Stationary Office (p.5).
[27] Department of Health. (2012). Caring for our future: reforming care and support. London: Department of Health.
[28] 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 Stationary Office (p.7).

also provide the new Chief Inspector of Hospitals the power to instigate a process to tackle unresolved problems, and will make it a criminal offence for providers to supply or publish misleading information.

Health Education England and the Health Research Authority – The Act establishes Health Education England as a statutory body which will assist local healthcare providers and professionals to educate and train their staff. The Act also establishes the Health Research Authority and strengthens its' ability to protect patients' interests in health and social care research. Both of these bodies will be independent of the Department of Health.

3.2.4 Health and Social Care Act 2012

The Health and Social Care Act was given Royal Assent in 2012, and came into force in April 2013. The Act set out significant reforms to the way that the NHS commissions health services, such as:

- Giving groups of GPs and other professionals (i.e. Clinical Commissioning Groups / CCGs[29]) budgets to commission care on behalf of their local communities; and
- Shifting a number of responsibilities that were historically located in the Department of Health to a new and politically independent NHS Commissioning Board, which has since been renamed NHS England[30].

Other new bodies created under the Health and Social Care Act include:

- Public Health England (which took over responsibility for health protection and promotion, and reducing health inequalities);
- Health and Wellbeing Boards (which act as forums where key leaders from the health and social care system work together to improve the health and wellbeing of the local population);
- Healthwatch England (the national consumer champion for health and social care); and
- Commissioning Support Units (which support commissioners by providing business intelligence, health and clinical procurement services, as well as back-office administrative functions).

The Act places new duties and powers for public health on local authorities, such as the duty to improve public health via research into health improvement, the provision of facilities for the prevention and treatment of illness, the provision of financial incentives to encourage individuals to adopt healthier lifestyles, and the provision of assistance to help individuals minimise risks to health arising from their accommodation or environment; and the duty to provide information about dementia to older people.

3.2.5 The Adult Social Care Outcomes Framework (ASCOF)[31]

ASCOF is the Department of Health's main tool for setting direction and strengthening transparency in adult social care. The Framework identifies four domains with associated outcomes and measures. The domains and outcomes are outlined in the table below.

[29] CCGs are clinically-led statutory NHS bodies responsible for the planning and commissioning of health care services for their local area.
[30] NHS England leads the National Health Service (NHS) and commissions health care services in England.
[31] Department of Health. (2014). The Adult Social Care Outcomes Framework 2015/16. Available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/375431/ASCOF_15-16.pdf

Table 3:1: Adult Social Care Outcomes Framework 2015/16

Domain	Outcomes
Enhancing quality of life for people with care and support needs.	• 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 meet their needs. • Carers can balance their caring roles and maintain their desired quality of life. • 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.
Delaying and reducing the need for care and support	• Everybody has the opportunity to have the best health and wellbeing throughout their life, and can access support and information to help them manage their care needs. • Earlier diagnosis, intervention and reablement means that people and their carers are less dependent on intensive services. • When people develop care needs, the support they receive takes place in the most appropriate setting, and enables them to regain their independence.
Ensuring that people have a positive experience of care and support.	• Carers feel that they are respected as equal partners throughout the care process. • People know what choices are available to them locally, what they are entitled to, and who to contact when they need help. • 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.
Safeguarding adults whose circumstances make them vulnerable and protecting them from avoidable harm.	• Everyone enjoys physical safety and feels secure. • People are free from physical and emotional abuse, harassment, neglect and self-harm. • People are protected as afar as possible from avoidable harm, disease and injuries. • People are supported to plan ahead and have the freedom to manage risks the way that they wish.

3.2.6 NHS Outcomes Framework 2015 -2016[32]

Alongside ASCOF, the NHS Outcomes Framework sits of heart of the health and care system. The NHS Outcomes Framework groups the high level national outcomes that the NHS should be aiming to improve into five domains. Of particular relevance to dementia is:

[32] Department of Health. (2014). The NHS Outcomes Framework 2015/16. Available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/385749/NHS_Outcomes_Framework.pdf

- Domain 2: Enhancing quality of life for people with long-term conditions – Outcomes under this domain include ensuring people feel supported to manage their condition; reducing time spent in hospital by people with long-term conditions; enhancing quality of life for carers; and enhancing quality of life for people with dementia; and
- Domain 4: Ensuring that people have a positive experience of care – Outcomes associated with this domain include improving people's experience of outpatient care; and improving the experience of care for people at the end of their lives.

3.2.7 Public Health Outcomes Framework 2013 – 2016[33]

The Public Health Outcomes Framework sets out the desired outcomes for public health and how they will be measured between 2013 and 2016. The Framework groups indicators into four domains that cover the full spectrum of public health, and reflect a focus not only on how long people live, but on how well they live at all stages of life. Of particular relevance to the condition of dementia is Domain 4: Healthcare and public health and preventing premature mortality. The objective of this domain is to reduce the 'numbers of people living with preventable ill health and people dying prematurely, while reducing the gap between communities'. One of the indicators for this outcome is 'estimated diagnosis rate for people with dementia'.

3.2.8 Everyone Counts: Planning for Patients 2014/15 – 2018/19[34]

Everyone Counts sets out the aims for the NHS in England and how commissioners should plan to achieve these aims. Under this guidance, it is noted that a Commissioning for Quality and Innovation (CQUIN) scheme was to be put in place in 2014/15, and that one of the national improvement goals for the scheme will be "improving dementia and delirium care, including sustained improvement in **F**inding people with dementia, **A**ssessing and **I**nvestigating their symptoms, and **R**eferring for support (FAIR)".

3.2.9 NICE Clinical Guidelines 42 – Dementia: Supporting People with Dementia and their Carers in Health and Social Care[35]

These guidelines make a number of recommendations based on the best available evidence for the identification, treatment and care of people with dementia and the support of their carers. The guidelines note that where possible, agencies should work together in an integrated way to maximise the benefit for people with dementia and their carers.

3.3 Local Policies & Strategies

3.3.1 Joint Strategic Needs Assessment

Under the Local Government and Public Involvement in Health Act 2007, Primary Care Trusts (PCTs) and local authorities are required to produce a Joint Strategic Needs Assessment (JSNA) of the health and wellbeing of their local community.

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[33] Department of Health. (2013). Public Health Outcomes Framework 2013-2016. London: Department of Health.
[34] NHS England. (2013). Everyone Counts: Planning for Patients 2014/15 – 2018/19. Available at: https://www.england.nhs.uk/wp-content/uploads/2013/12/5yr-strat-plann-guid.pdf
[35] National Institute for Health and Clinical Excellence. (2006). CG42 Dementia: Supporting people with dementia and their carers in health and social care. London: NICE.

17 of the 19 councils who responded to our information request stated that their Joint Strategic Needs Assessment covered specific issues relating to dementia.

For example, Halton has a specific JSNA for dementia[36], which sets out the policy context, estimated prevalence, risk factors and sub-groups of need, current service provision and national best practice in relation to dementia in Halton.

It identifies the following as key priorities for consideration by commissioners in relation to dementia:

- Prevention;
- Public and professional awareness;
- Pre-diagnosis support;
- Diagnosis;
- Increase awareness across hospital ward staff, as well as consideration of the approach to treatment where patients have suspected dementia or a diagnosis of dementia;
- Prescribing;
- Post-diagnosis;
- Quality and appropriateness of services;
- Respite; and
- Identifying and supporting carers.

Sefton's Strategic Needs Assessment for Older People (65 and over)[37] predicts that there will be a 49% increase in the number of people living with dementia between 2015 and 2030. This will lead to an increase in the numbers of people who are likely to need care or who will need support to live longer with the disease which will have a significant impact on the ability of services to cope with demand.

In January 2016, the Knowsley Council and CCG, along with partners of the Knowsley Health and Wellbeing Board prepared the JSNA for dementia report[38], an overarching strategic assessment which aims to identify the needs and gaps in provision for people with and at risk of dementia in Knowsley, and their carers to support future commissioning.

In 2015, the Age Well commissioning team at Lancashire County Council commissioned a study to fill a gap in intelligence about people with young-onset dementia. An assessment of population need was completed and information was gathered on prevalence, gender differences, geographical distribution, numbers receiving support, support costs, and a greater understanding of the link between learning disabilities and young-onset dementia. The results were used to inform commissioning decisions about dementia services for younger people in Lancashire[39].

[36] Halton Joint Strategic Needs Assessment Dementia 2015.
[37] Sefton Strategic Needs Assessment Older People Section (65 and over) 2014. Accessed via: https://www.sefton.gov.uk/media/728987/SSNA-2014-Older-People.pdf
[38] Knowsley Council. (2016). 'Dementia – JSNA Report – January 2016'.
[39] Jones, G. (2016). 'Young Onset Dementia in Lancashire-12: 2014-2030. An assessment of population need'.

3.3.2 Health & Well-being Strategies (focused on Early Identification and Supporting Independence)

All nineteen councils who responded to our request for information stated that they had a Health and Wellbeing Strategy for their area, and sixteen (84%) of these reported that their strategies set out actions or initiatives for dementia.

For example, Priority 5 of the Tameside Health and Wellbeing Strategy (2013-2016)[40] focuses on ageing well by **promoting independence and working together** to make Tameside a good place to grow old. As part of this priority, the Strategy commits to improving outcomes for people living with dementia through improved dementia care, which they hope to achieve by enhancing awareness of dementia, improving arrangements in primary care for early diagnosis and treatment, and ensuring older people with dementia have access to intermediate care services.

The Blackpool Joint Health and Wellbeing Strategy (2013-2015)[41] sets out 20 health and wellbeing priorities for Blackpool which were identified using evidence from the Joint Strategic Needs Assessment (JSNA) and other strategic needs assessments, as well as through consultations with local residents, patients and service users. Dementia is one of the identified priorities.

The Rochdale Borough 'Co-operating for better health and wellbeing plan for 2016-21'[42] highlights that emergency hospital admissions for dementia are currently high in Rochdale, and that projected increases in older people will likely see an increase in the prevalence of dementia. The Plan proposes a number of Transformation Initiatives that are relevant to dementia; for example under Programme 3: Getting More Help, Rochdale Borough Council, and Heywood, Middleton and Rochdale CCG have committed to focusing resources on people with dementia, recognising the impact that this will have on people's **ability to remain independent.** The plan sets a target of reducing the number of emergency admissions to hospitals for dementia by 2021[43].

Dementia also features in a number of the Strategic Priorities of the Manchester Health and Wellbeing Board Joint Health and Wellbeing Strategy (2013). For example, Strategic Priority 3 identifies the need to move more health provision into the community, especially for those with long-term conditions such as dementia. Those individuals living with dementia are also among the target groups for Strategic Priority 8 (Enabling older people **to keep well and live independently in their community**). Specifically under this priority, the Strategy hoped to achieve the following headline outcomes by 2015: 'People in the early stages of dementia and their families are aware of the symptoms and seek support, guidance and diagnosis', and 'People with dementia and their families / carers say that the support that is provided is enabling them to continue to participate in family and community life'.

Similarly, Bolton's Health and Wellbeing Strategy for 2013-2016[44] focuses on **early identification and effective management of dementia.** Outcome indicators used to measure success in this area

[40] Tameside Health and Wellbeing Strategy (2013-2016) – Making it happen together in Tameside: Our Vision for Health and Wellbeing.
[41] Blackpool Health and Wellbeing Board – Blackpool Joint Health and Wellbeing Strategy 2013-2015. Available at: https://www.blackpool.gov.uk/Your-Council/Documents/Blackpool-Joint-Health-and-Wellbeing-Strategy-2013-15.pdf
[42] Heywood, Middleton and Rochdale CCG and Rochdale Borough Council. Co-operating for better health and wellbeing – A plan for 2016-21.
[43] These targets are still under development and so the exact figure for reduced admissions has yet to be agreed.
[44] Bolton Health and Wellbeing Board – Health and Wellbeing Strategy 2013-2016.

were: 'permanent admissions to residential and care homes per 1,000 population', and 'identified vs. expected prevalence on GP dementia registers'.

The Knowsley Joint Health and Wellbeing Strategy for 2013-2016[45] identifies mental health, and within this **a dementia pathway** including support for carers, as an immediate / short term (up to 18 months) priority area. The Strategy states that success across all outcome areas will be measured by asking local people for their views on whether there has been an improvement in the quality of their care and treatment, and by monitoring the life course outcome success measures identified in the Strategy, such as 'more people with long term conditions experience a good quality of life', 'fewer unplanned hospital admissions and re-admissions', 'improved quality of life and experience for carers', 'more people living in the community independently for longer', 'more people dying at their preferred place of care', and 'improved quality of life for individuals with progressive conditions'.

Outcome 3 of the Joint Health and Wellbeing Strategy for the Population of Cheshire East (2014-2016)[46] is in relation to 'Ageing Well' and sets out a particular need to focus on '**improving the co-ordination of care around older people,** in particular those with dementia, and supporting independent living'. The Strategy also sets out partner priorities; for example, CEC Adult Social Services have a duty to ensure that people with dementia are supported to live safely in the community, while the 'Ageing Well' programme is tasked with developing dementia services and promoting dementia friendly communities.

Oldham's first Health and Wellbeing Strategy[47] sets out it's' aims and priorities in relation to the improvement of health and wellbeing for the period of April 2013 – April 2016. Among these aims and priorities, a number are specific or relevant to dementia, including: '**earlier detection of and treatment** *(of dementia)*'; and 'to focus on the impact of increasing prevalence of dementia and what can be done to achieve better care and outcomes for people with dementia'. Associated with this but not restricted to dementia, will be a focus on supporting carers, 'both in providing care to others and in looking after their own health'. In response to these challenges, the Health and Wellbeing Board required commissioners to work with providers and older people to 'ensure the right balance of services across the whole spectrum of need to support people as they age'.

Priority 8 of St. Helen's Health and Wellbeing Strategy (2013-2016)[48] focuses on older people and support for people with dementia, with Adult Social Care being the lead agency / partner in this area. Specifically under this Priority, the Strategy **sets a number of ambitions**, including:

- Work closely with GPs to ensure there is a consistent approach to supporting people with dementia and their carers and ensuring there is good quality information available to enable people to make informed choices or decisions;
- Increase people's understanding of how they can manage a diagnosis of dementia and understand where and how they can access services;
- Focus on preventative services that can avoid a crisis by providing timely support when required;
- Ensure there is clear information on how to access 24 hour and hospital care, and ensure that care providers will take account of the needs of people with dementia; and

[45] Knowsley Health and Wellbeing Board. Joint Health and Wellbeing Strategy 2013-2016.
[46] The Joint Health and Wellbeing Strategy for the Population of Cheshire East 2014-2016.
[47] NHS Oldham. Health and Wellbeing Strategy April 2013 – April 2016.
[48] St. Helen's Council and CCG. St. Helen's Health and Wellbeing Strategy 2013-2016. Available at: http://www.sthelensccg.nhs.uk/Library/your_health/1300145_health_and_wellbeing_strategy.pdf

- Review the current approach to End of Life care to ensure services support the individual and their family in receiving dignified and compassionate care.

This Strategy is currently under review.

Finally, the Halton Health and Wellbeing Strategy (2013-2016)[49] identifies an ageing population which will mean more people living with dementia as a challenge for the area. Mental Health is therefore a priority of the Halton Health and Wellbeing Strategy, with 'people with dementia would have good levels of support' highlighted as an indicator of success in this area.

In the majority of cases where dementia is mentioned in a Health and Wellbeing Strategy, there is often a link to findings of the Joint Strategic Needs Assessment (see section 3.3.1 above).

Other councils, such as Trafford, stated that while there is no separate section or aim dedicated to dementia in their Health and Wellbeing Strategy, they are focusing on areas such as increasing healthy life expectancy and ageing well which in itself will have an impact on dementia.

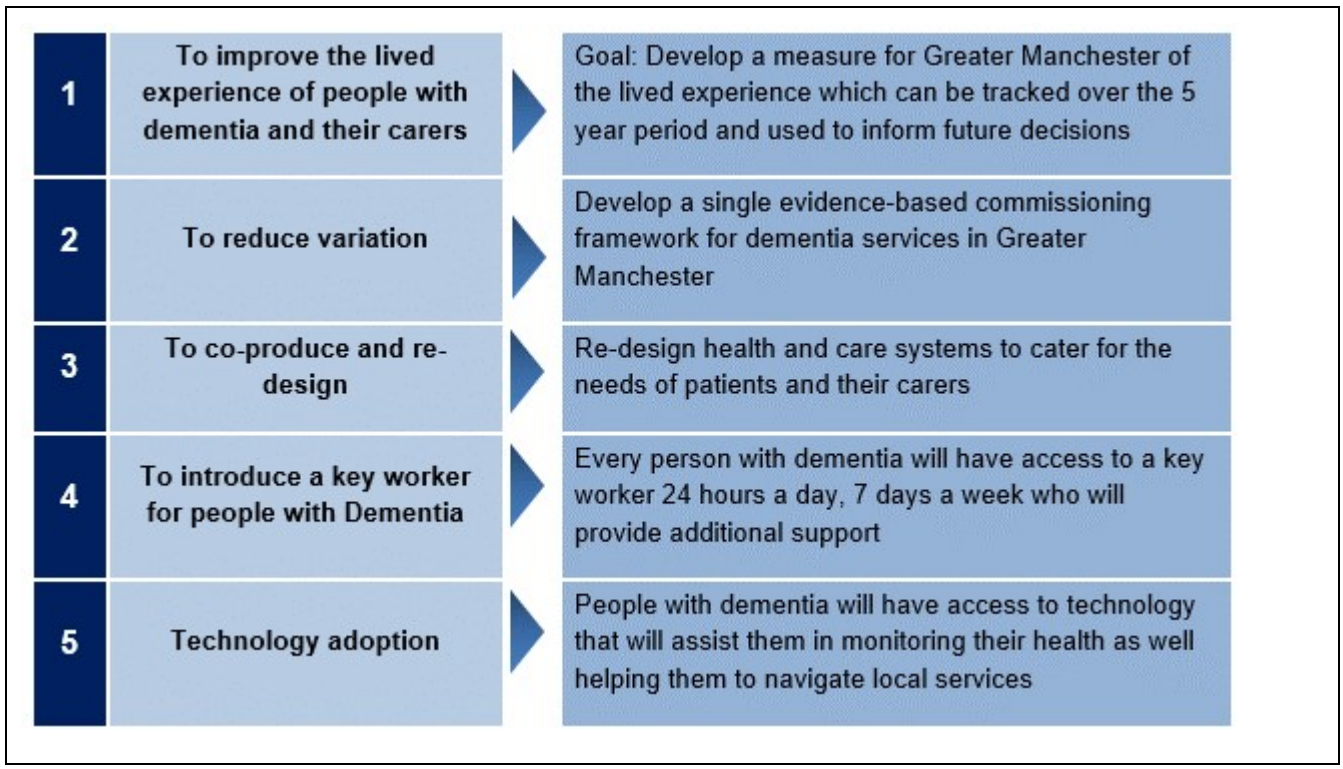
3.4 Local Dementia Strategies

The Greater Manchester Mental Health and Wellbeing Strategy produced by the Greater Manchester Combined Authority (GMCA) sets out a **whole system approach** with the aim of improving the mental health and wellbeing of individuals and their families. Through the development of already existing best practice initiatives and application of national and Greater Manchester standards relating to access and care delivery, the Greater Manchester strategy seeks to "make Manchester the best place in the world to live with dementia" (GMCA, 2016)[50].

In order to facilitate the delivery of this vision to make Manchester a better place to live with dementia, Greater Manchester has made 5 guarantees:

[49] Halton Health and Wellbeing Strategy 2013-2016.
[50] GMCA (2016) Greater Manchester Mental Health and Wellbeing Strategy (accessed at https://www.greatermanchester-ca.gov.uk/downloads/20031/health_and_social_care)

Figure 3.1: Greater Manchester 5 Guarantees



Source: GMCA (2016) Greater Manchester Mental Health and Wellbeing Strategy (accessed at https://www.greatermanchester-ca.gov.uk/downloads/20031/health_and_social_care)

Data collected in 2013 indicated that the number of people in Greater Manchester with dementia was 29,950, affecting 7.1% of people aged over 65. Health and social care costs associated with dementia currently equate to £221 million in Greater Manchester and the Greater Manchester Mental Health and Wellbeing Strategy points out that this figure would increase to £320 million if everyone with a suspected diagnosis was treated.

3.5 Dementia Commissioning Strategies

In 2015, the Local Government Association (LGA) and ADASS commissioned the University of Birmingham to develop a set of commissioning standards which would ultimately lead to improved outcomes for adults using social care, and their families, carers and communities[51]. In order to ensure that the standards reflected evidence about good practice in commissioning, a review of the available literature on effective commissioning was undertaken, as well as engagement with a wide range of stakeholders to identify challenges in commissioning. Nine standards for good commissioning were developed and were grouped into three domains as follows:

- Person-centred and outcomes focused:
  - Person-centred and focuses on outcomes; and
  - Coproduced with people, their carers and their communities.

[51] Local Government Association. (2015). 'Commissioning for better outcomes: a route map'. Available at: http://www.local.gov.uk/documents/10180/5756320/Commissioning+for+Better+Outcomes+A+route+map/8f18c36f-805c-4d5e-b1f5-d3755394cfab

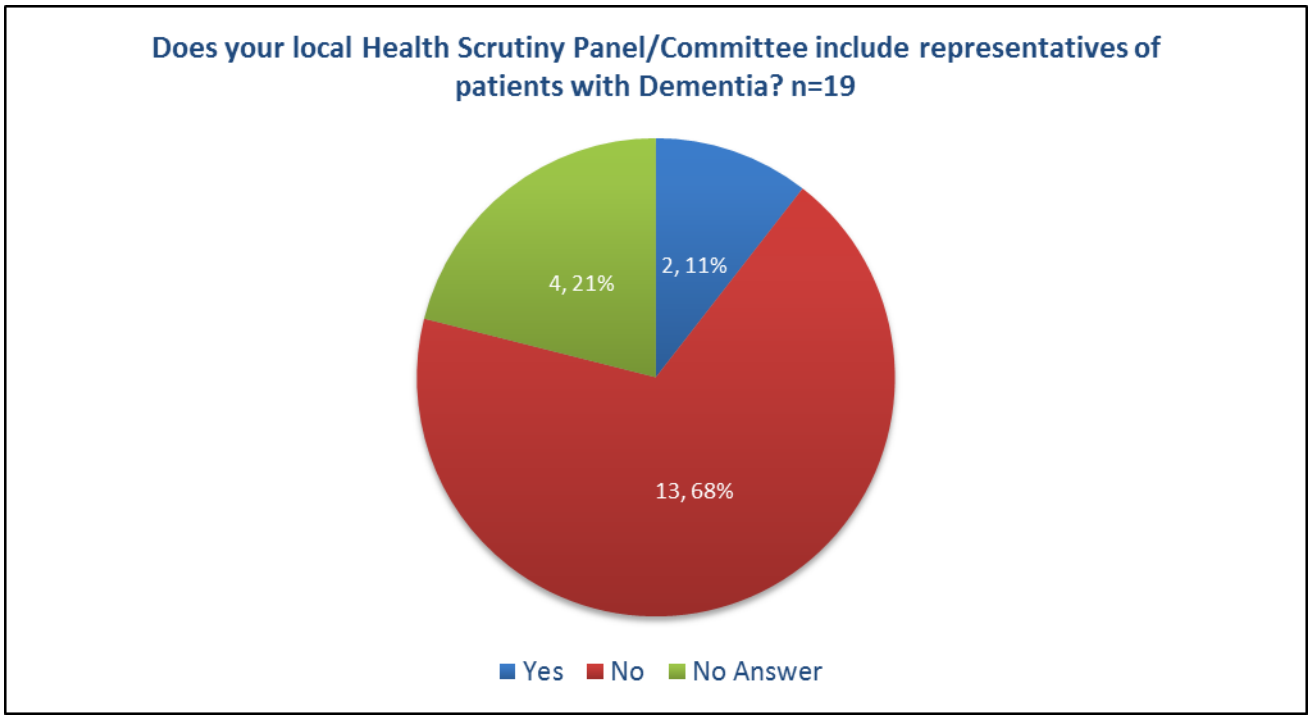
- Well led:
  - Well led by local authorities;
  - Demonstrates a whole system approach; and
  - Uses evidence about what works.
- Promotes a diverse and sustainable market:
  - Ensures diversity, sustainability and quality of the market;
  - Provides value for money;
  - Develops the commissioning and provider workforce; and
  - Promotes positive engagement with providers.

Thirteen of the nineteen councils (68%) have specific dementia commissioning strategies within their council area, either as a standalone document or one which was incorporated into other policies/ strategies. For example, St Helens noted that their JSNA and marketing position statement incorporates their commissioning intentions. Two council areas also highlighted the importance of ensuring that these strategies were aligned to other strategic policies. For example, Bury noted that their commissioning strategy was currently under development and will be aligned with the Greater Manchester Devolution framework and Lancashire noted that their refreshed strategy will take into account the actions required from the Prime Ministers Challenge on Dementia 2020.

Lancashire County Council and NHS Central Lancashire also produced a Joint Dementia Commissioning Strategy (2011 – 2015). This strategy notes the need to provide person centred, holistic services that can change to meet the needs of people living with dementia. It also highlights the need for better education and training for staff and carers. The strategy is also broadly consistent with the standards set out by ADASS and LGA as it was co-produced by people with dementia and their carers and also considers a wide range of issues including the needs of those with young onset dementia, people from ethnic minorities and the range for support and care required as dementia progresses.

3.6 Overview & Scrutiny panels

Figure 3.2: Health Scrutiny Panel

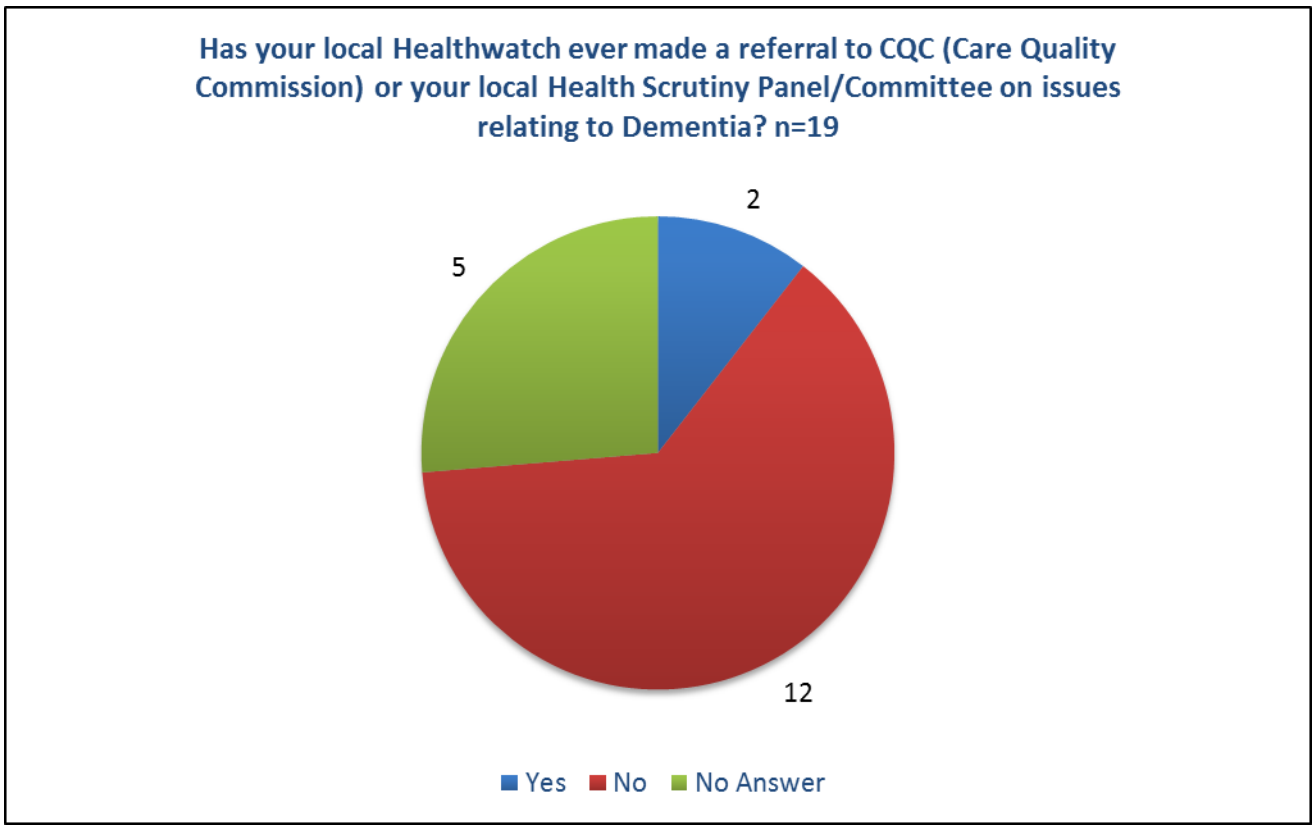


Source: NW Dementia Perspectives Information Request for Councils – June 2016

Two respondents (11%), St Helens and Knowsley, noted that there were representatives of people with dementia on their local health scrutiny panel. St Helens Council noted that they have a service user who is a member of their Dementia Action Alliance (DAA) group and a "good informant/advisor" to their members. Additionally, they have a Dementia sub group as part of the overview and a scrutiny agenda for Dementia where they have someone from Living Well with Dementia as a member. They also have someone from Living Well with Dementia as a member of their Health and Wellbeing Board (HWBB) Dementia sub group. Knowsley Council stated that the scrutiny committee (health) undertook an in depth review of mental health in 2015 and as part of this review, representatives of people with dementia were invited to give their views on services and support as well as raise any issues that they felt needed to be explored in the review.

Whilst thirteen (68%) council areas noted that they did not have representatives of people with dementia on their health scrutiny panel, two councils did highlight other ways of engaging with people with dementia on specific issues. For example, Bury Council noted that they have the facility to engage with representatives on specific themes as and when it is required. Blackpool Council also noted that while their committee does not currently consult directly with people with dementia, they are in the process of establishing a service user group who can be consulted with on a wide range of dementia related issues.

Figure 3.3: Referrals to CQC



Source: NW Dementia Perspectives Information Request for Councils – June 2016

Two (11%) councils noted that they had made a referral to either the CQC or the local Health Scrutiny Panel on issues relating to dementia. Cumbria stated that the Healthwatch has referred at least one individual case to CQC after they were contacted by a concerned person. They noted that dementia issues are more likely to be raised in the overall context of issues relating to certain groups, for example older people in care homes, both to the CQC and the Health Scrutiny Panel. Knowsley noted that Healthwatch suggested a review of mental health in the area which included dementia. Two recommendations relating to dementia emerged from this; firstly, that the CCG and the Council, working with other partners, develop a dementia strategy that sets out plans for dealing with likely increases in the number of older people living with dementia and their future care requirements; and secondly that the topic of dementia be put forward as a suggested scrutiny review to be considered as part of the 2016-2017 scrutiny work plan.

Twelve (63%) councils had not made referrals, including Liverpool Council who said that they had no knowledge of referrals relating to dementia. Blackpool Council noted that Healthwatch conducted 11 care home reviews in Blackpool in December, and that many of the care homes catered for residents with dementia. Blackpool also held a public consultation in 2015 and dementia services was one of the issues that came up as something which Healthwatch should look into.

3.6.1 Financial Challenges

Since 2010, there have been substantial cuts to the budgets that local authorities have across England to fund adult social services[52]. From 2010 to 2014 local authorities have delivered savings of £3.53 billion to adult social care budgets[53]. There is a range of reports that have highlighted how these budgetary cuts have had adverse impacts on adult social services, for example an ADASS report estimated that at least 24% of the required savings in 2016 will come from cutting services or reducing the personal budgets of people who receive care and support[54]. This will have negative impact on both service users and the acute hospital services.[55] In addition to the budget cuts, other factors including an increased demand on services and the introduction of the National Living Wage (2016) has also significantly increased the costs of delivering and commissioning adult social services across England.

Staff from Liverpool [56]noted that because of the efficiencies that have been required in Adult Social Services that have been required to cut preventative services for adults with early onset dementia, yet the Care Act 2014 places a statutory duty on local authorities to consider whether or how a person's needs can be reduced or prevented.

A number of councils in the North West have implemented strategies to deliver services even more efficiently, for example Cheshire East and Cheshire West and Chester are participating in Department of Health's Integration Pioneers Programme where services are planned, commissioned and in partnership with NHS Foundation Trusts and local CCGs. It is anticipated that this integrated approach will provide a "better standard of health and wellbeing and place less demand on more costly public services"[57] Specifically, the Cheshire West and Chester Joint Strategic Needs Assessment notes that "Dementia should not be viewed in isolation but as one part of several comorbidities. Integrated community care teams, therefore, should work collaboratively and ensure that care is person-centred and delivered in an holistic manner. Integrated community care teams should ensure that care can be provided to prevent unnecessary stays in hospital and long term care admissions". Therefore, in Cheshire it is recognised that integrated care is not only an efficient approach to deliver services but it is also the best way to ensure that care is person centred.

A review of the Adult Social Care Efficiency Programme[58] identified a range of activities that Councils across the North West were implementing in order to reduce the costs of adult social care, these included:

- Reducing the use of residential care;
- Increasing access to telecare;
- Increasing controls to access domiciliary care; and
- Re-structuring other services such as transport and day services.

It was also noted that whilst Lancashire County Council faced efficiency saving of £31m in 2015/16. It has also prioritized dementia services and in 2013 announced an investment of £5m on a new-

[52] Adult Social Care Funding: 2014 State of the Nation Report. Local Government Association. Association of Directors of Adult Social Services (2014)
[53] ADASS Budget Survey 2014
[54] ADASS Budget Survey 2016
[55] For example see: https://www.alzheimers.org.uk/site/scripts/news_article.php?newsID=2486
[56] http://www.communitycare.co.uk/2016/05/11/coming-face-face-impact-social-care-cuts-youve-made-directors-story/
[57] http://cheshirepioneer.co.uk/our-shared-vision/
[58] Adult Social Care Efficiency Programme: Final Report. Local Government Association 2014

build centre of excellence for dementia care, for people throughout the county in need of specialist care, and a further £250,000 programme to train county council employees in proving care for people with dementia[59]

3.7 Conclusions

In 2015 the prevalence rate of dementia in the North West was slightly higher than the national average, of 0.79 compared to 0.74. This equates to 58,000 people in the North West who are living with dementia. This is expected to increase to 69,000 by 2020.

The Prime Ministers Challenge on Dementia 2020 sets the national policy environment for services for people with dementia and their carers. A review of local plans, policies and supporting papers from the 23 local areas across the NW has demonstrated that dementia has been a priority in many areas. For example in Greater Manchester local authorities, health, private and voluntary and community sector bodies have formed a partnership (Dementia United) with the stated aim to make Manchester the best place to live for people with dementia and carers. Other local authorities (such as Knowsley and Halton) prioritised the care and support of people with dementia through the development of specific strategies and plans for people with dementia under their Joint Strategic Needs Assessments and Health and Well-being Strategies.

Seventeen of the 23 local authorities have a Joint Strategic Needs Assessments with actions specific to dementia, 16 local authorities have Health and Well-being Strategies with actions specific to dementia. This indicates that dementia is seen as a local priority across much of the North West as well as a national one. There were a number of common themes emerging from these local strategy documents, including the need to implement services and activities to increase the level of support to people with dementia (and their carers) in the community which will in turn return the need for other forms of care such as hospitals and nursing homes, the need for early diagnosis. The need for improved co-ordination in dementia care was highlighted as an objective for the majority of local authorities, this included improved integrated working and joint commissioning. In addition to this around one third of the local authorities also noted the need for accurate and timely data on those in their communities living with dementia, this data is needed to plan and effectively manage dementia services.

The budgetary cuts and financial pressures faced by local authorities in England is well documented. From 2010 to 2014 local authorities have delivered savings of £3.53 billion to adult social care budgets[60]. In addition to this some local authorities have also reported increased demand on services as the proportion of older people in the population increases. Local authorities across the North West have implemented a number of initiatives to enable the continued provision of services for people with dementia within these budgetary constraints including a reduction in domiciliary care and beds in nursing and residential homes, as well as an increase in integrated working.

[59] http://www3.lancashire.gov.uk/corporate/news/press_releases/y/m/release.asp?id=201302&r=PR13/0077
[60] ADASS Budget Survey 2014

4 REVIEW OF BEST PRACTICE

4.1 Introduction

The desk research methodology used for the literature review was a 'Rapid Evidence Assessment'[61], which is defined as being non-systematic (i.e. a quick overview of research undertaken on a (constrained) topic).

This type of assessments or 'map' of existing literature is undertaken with limited resources (particularly time), and is usually constrained by all or some of the following:

- Question (a delimited narrow focus);
- Search (use few search sources, and only key terms);
- Screen (use only electronically available abstracts and texts); and
- Map (use only easily available sources, provide only simple description with limited analysis).

The key themes emerging from the review of the literature relating to best practice in providing care for people with dementia in the community and international approaches to dementia care are summarised below. For further details on the studies sourced for this literature review, see Appendix 2.

4.2 Care in the Community

The review identified a number of key issues associated with self-directed care for people with dementia living at home. For example, Dawson *et al* (2015[62]) found that self-directed care and support, rapid response measures, day services and medication management are important services to address for those living at home with dementia. The monitoring and management of medication should especially be recognised as an integral part of dementia care, especially for those living at home with significantly limited cognitive function[63].

Starting in April 2013, a trial of the Admiral Nurse Service began in the Mid Norfolk area serving seven GP surgeries. Admiral Nurses work holistically with families and carers to deliver a range of interventions that will help people with dementia and carers lead a more positive lifestyle based on principles of improved communication, productive relationships and psychological support for carers[64]. An evaluation of the service in Norfolk was carried out with the use of both qualitative and quantitative data and showed that the Admiral Nurse Service delivered a positive impact in the seven areas that were investigated[65]. The service was described as being 'excellent and vital' as well as providing much-needed support to carers. The service was also found to be cost effective as over the 10 month period the pilot ran for, savings of approximately £440,000 were generated

[61] http://www.nfer.ac.uk/research/centre-for-information-and-reviews/rapid-evidence-assessments.cfm https://www.gov.uk/government/collections/rapid-evidence-assessments

[62] Dawson, A., Bowes, A., Kelly, F., Velzke, K., Ward R. (2015) Evidence of what works to support and sustain care at home for people with dementia: a literature review with a systematic approach, BMC Geriatrics 15:59.

[63] Jedenius, E., Johnell, K., Fasbom, J., Stromoqvist, J., Winblad, B., Andreasen, N. (2011) *Dementia management programme in a community setting and the use of psychotropic drugs in the elderly population*, Scandinavian Journal of Primary Health Care, 29(3):181-186 (accessed at http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3347957/pdf/pri-29-181.pdf)

[64] Pepper, A., Maio, L. (2015) Admiral Nursing Service End of Year Report, Sutton: NHS Sutton Clinical Commissioning Group. Available at https://www.dementiauk.org/wp-content/uploads/2016/04/Sutton-Report-FINAL.pdf

[65] Aldridge, Z., Findlay, N. (2014) Norfolk Admiral Nurse Pilot: Evaluation Report. Available at: http://dementiapartnerships.com/wp-content/uploads/sites/2/IDN412AdmiralNursePilotEvalReport.pdf

because of the team of three admiral nurses. These savings resulted from delayed admissions to care homes, a reduction in inappropriate hospital admissions and a reduction in referrals to psychological therapies. In terms of the Admiral Nurse's contribution to other health professionals' caseloads and their ability to manage the care of people with dementia and their carers, 94% of professionals who used the service stated that the contact they had with the Admiral Nurse Services improved their confidence in dealing with people living with dementia and their carers.

However, one 2015 systematic review[66] found that, overall, the evidence on community-based services supporting people with dementia living in their own homes is limited and there is a clear need for more UK specific research. However, literature examined as part of this review did suggest that the best outcomes for people with dementia are associated with services that are timely, responsive, flexible and tailored to individual need.

4.3 Therapeutic Interventions

Cognitive Stimulation Therapy (CST)[67] is a brief treatment for people with mild to moderate dementia. It was designed following extensive evaluation of research evidence, hence it is an evidence-based treatment. UK NICE guidance on supporting people with dementia and their carers[68] recommends the use of group CST for people with mild to moderate dementia, irrespective of drug treatments received. A 2016 study[69] aimed to assess the impact of a pragmatic CST course of 10 sessions on the cognitive function of people living with dementia, and also to ascertain whether attending a concomitant / associated support group was beneficial for carers. Qualitative data collected via semi-structured interviews with carers demonstrated that carers perceived CST to have some benefits for people living with dementia, especially social benefits. Carers also perceived that attending the carers support group was beneficial for them in terms of gaining a better understanding of dementia, developing coping skills, and having peer support.

Bury Cognitive Impairment Pathway

Dementia Clinical Leads in Bury are currently implementing the new, cognitive impairment pathway in 23 out of the 31 practices in the region, with at least five of these practices having devised or implemented their own processes and protocols. The effect of this new pathway has been significant in terms of the number of referrals, and reducing the waiting time until assessment or diagnosis. Comparing the pre-intervention period (April 2014 to March 2015), with the post-intervention period (April 2015 to June 2016), the new pathway has resulted in a 40% decrease in the average number of referrals per month, a 20% decrease in the length of time from referral to assessment and a 41% decrease in the length of time from referral to diagnosis. The Dementia Clinical Leads also reported that the new pathway allowed GPs to gain a broader understanding of their patients and that the ability to refer direct for diagnosis scans was very beneficial.

[66] Dawson, A., Bowes, A., Kelly, F., Velzke, K., Ward R. (2015) Evidence of what works to support and sustain care at home for people with dementia: a literature review with a systematic approach, BMC Geriatrics 15:59.
[67] For more info, see: http://www.cstdementia.com/
[68] National Institute for Health and Clinical Excellence. (2006). CG42 Dementia: Supporting people with dementia and their carers in health and social care. London: NICE.
[69] Bailey, J., Kingston, P., Alford, S., & Taylor, L. (2016). 'An evaluation of Cognitive Stimulation Therapy sessions for people with dementia and a concomitant support group for their carers', *Dementia,* Jan 18.

A literature review of approaches that achieve better outcomes for people with dementia, and which are also beneficial from an economic point of view, reviewed CST and found that it has positive effects on cognition and quality of life, and also has the potential to be more cost effective than usual care[70]. The review also found that physical exercise programmes, were shown to be effective as primary prevention measures for older people with good cognitive functioning, and as secondary prevention for older people with mild-to-moderate dementia; and that interventions targeted at carers, such as day care services, were shown to confer benefits that are similar or greater to those achieved through standard care. Other research (e.g. Erickson *et al*, 2011[71]) has shown that physical activity can improve memory as well as moderate the decline in ability to perform daily living activities associated with dementia.

Validation therapy is a type of 'psychosocial intervention', meaning that it doesn't involve the use of medication[72]. This type of therapy requires carers to provide people living with dementia the chance to express themselves, which can be done through understanding the world of the individual with dementia. One way of doing this is through life story work which is an activity that gets patients to recall and review previous life experiences, with the benefits being individualised care, stronger relationships between the care staff and the family, and greater communication[73].

Finally, Empathic Curiosity is a form of communication that can be used to interact with people with dementia[74]. It is a beneficial tool that can encourage people with dementia to elaborate on the emotional experiences they are having at the time of the interaction. In addition to its perceived benefits for those with dementia, it can also benefit carers who adopt an empathic and curious attitude when communicating with people with dementia, helping them to establish lines of communication and develop a relationship based on mutual understanding[75].

4.4 Creative Activities

A number of research studies have demonstrated the positive impact of taking part in creative activities such as arts and singing on individuals living with dementia and their carers, both in the UK and other countries. For example, one UK study which explored the impact of participating in a five-week creative arts leisure programme designed for family caregivers of people with dementia found that participants experienced the arts group as providing a sense of freedom and respite, strengthening identity through promoting achievement, offering social support through a collective focus on art and craft making, and increasing resilience for coping with caring[76]. Similarly, a study of

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[70] Knapp, M., Romeo, R., & Iemmi, V. (2011). *Dementia care costs and outcomes: Literature review.* London: Alzheimer's Society.
[71] Erickson, K. I, Voss, M. W., Prakash, R. S., Basak, C., Szabo, A., Chaddock, L., Kim, J. S., Heo, S., Alves, H., White, S. M., Wojcicki, T. R., Mailey, E., Vieira, V. J., Martin, S. A., Pence, B. D., Woods, J. A., McAuley, E., Kramer, A.F. (2011) *Exercise training increases size of hippocampus and improves memory*, Proceedings of the National Academy of Sciences, vol. 108, 7: 3017-3022
[72] Larsen, D. (2016) *Validation Therapy for Dementia*. http://www.aplaceformom.com/blog/2-18-16-validation-therapy-for-dementia/
[73] Thompson R. (2011) *Using life story work to enhance care*. Nursing Older People 23 (8): 16-21
[74] McEvoy, P., Baker, D., Plant, R., Hylton, K., Mansell, W. (2013) *Empathic Curiosity: resolving goal conflicts that generate emotional distress*, Journal of Psychiatric and Mental Health Nursing, 20; 3, 273-278.
[75] McEvoy, P., Pant, R. (2014) Dementia Care: using empathic curiosity to establish the common ground that is necessary for meaningful communication, Journal of Psychiatric and Mental Health Nursing, 2014, 21, 477-482
[76] Pienaar, L. & Reynolds, F. (2015). '*A respite thing':* A qualitative study of a creative arts leisure programme for family caregivers of people with dementia', *Health Psychology Open, Jan-June 2015,* pp. 1-11.

a Canadian arts-based programme, 'Artful Moments', for persons in the middle-to-late stages of dementia and their carers found that, following participation, carers observed improvements in participants creativity, communication, relationships, and task accomplishment, with some also reporting reduced stress[77].

Music therapy and singing have also been shown to have beneficial impacts for individuals with dementia and their carers. Singing for the Brain (SftB) was established by the Alzheimer's Society in 2003 and combines aspects of reminiscence therapy and music. A study of the programme in 2014 aimed to assess the impact of the intervention on family caregivers and individuals living with dementia who attended a group in the East Midlands[78]. Ten patient-carer interviews were conducted, and results showed that as well as enjoying the sessions, participants felt that attending SftB helped them in accepting and coping with dementia. Social inclusiveness and improvements in relationships, memory and mood associated with the programme were found to be especially important to the participants.

However, authors of these research studies have concluded that further research is needed into the long-term benefits of creative arts and singing groups for promoting the wellbeing of individuals living with dementia and carers. There also appears to be a need for more UK research on the topic, as well as more quantitative evaluations with larger sample sizes.

Singing with Dementia in Salford

Singing with Dementia is a Salford based charity set up in 2010 to support carers of individuals living with dementia or Alzheimer's disease. The charity uses music as a communication tool to stimulate the process of recalling past memories for people living with dementia or Alzheimer's disease.

For more information, see: http://www.singingwithdementia.co.uk/

4.5 Support for Carers

The caregiver plays a central role in the delivery of care at certain stages of Dementia and it is important they have the relevant skills and knowledge to carry out their role effectively. The psychological needs of family carers can be as disabling as the physical stresses of caring and in order to relieve some of the stress that is often associated with caring for people with dementia, supportive interventions should be implemented, such as establishing a telephone connection with health professionals and other experienced caregivers to assist informal caregivers in managing symptoms[79]. Implementations should be family centred as each family member as each family member has unique needs therefore an assessment of the family's needs should be carried out. Providing caregivers with an online community in which to communicate with other caregivers and

[77] Hazzan, A.A., Humphrey, J., Kilgour-Walsh, L., Moros, K.L., Murray, C., Stanners, S., Montemuro, M., Giangregoriol, A. & Papaioannou, A. (2016) Impact of the 'Artful Moments' Intervention on Persons with Dementia and Their Care Partners: a Pilot Study, *Canadian Geriatrics Journal, 19(2)*: 1-8

[78] Eldirdiry Osman, S., Tischler, V., & Schneider, J. (2014). 'Singing for the Brain': A qualitative study exploring the health and wellbeing of benefits of singing for people with dementia and their carers', *Dementia,* pp. 1-14.

[79] Mahoney, D.F., Tarlow, B.J., Jones, R.N. (2003) Effects of an automated telephone support system on caregiver burden and anxiety: findings from the REACH for TLC intervention study, Gerontologist, 43: 556-567

use as a platform for learning more about treating dementia has also shown potential to improve the quality of care and reduce some of the burden associated with caring for someone with dementia[80]. The easily accessible nature of an online resource centre is valuable to those family caregivers that cannot leave their home whenever they want.

Support groups are another tool that can provide family caregivers with the opportunity to share their experiences with other family caregivers and express their concerns and frustrations[81]. Diehl et al (2003)[82] identified therapeutic benefits associated with support groups designed to encourage caregivers to express their needs and how to deal with challenging emotions such as anger and aggression. Similarly an online chat forum can provide an opportunity for family caregivers to learn from others and develop relationships with experienced people who can give them useful advice and support[83].

Another key theme emerging from the review of the literature is that community-based care for people with dementia is a valuable service that not only improves the living standards and general wellbeing of those with dementia, but also the health and well-being of informal/family caregivers. Various studies have demonstrated the need for support structures for carers[84] and how this can create better outcomes for people with dementia. For example, a systematic literature review of support structures for people living with dementia at home and their carers found that, in relation to post-diagnostic support, the literature suggests that locally-based, multi-component interventions including education, cognitive stimulation, cognitive training and cognitive rehabilitation may be useful to support family carers to support people with dementia to live at home[85].

The 'Triangle of Care' model[86] also noted that meaningful involvement and inclusion of informal / family carers can lead to better care for people with dementia, as well as giving carers a more comprehensive overview of the person with dementia's needs.

4.6 Training for the Dementia Workforce

The review of the literature identified a number of key issues relating to health and social care staff who are caring for people with dementia. The need for a well-trained and supported team that can deliver care at a professional standard was a common theme. In their guide to training the health and social care workforce in the UK, Davies and Cross (2011)[87] acknowledge the necessity for a qualified and confident workforce who are capable of supporting individuals with dementia and delivering the most appropriate care. This is similar to a qualitative study in Sweden by Bökberg *et al*

[80] Pagán-Ortiz, M. E., Cortés, D. E., Rudloff, N., Weitzman, P., Levkoff, S. (2014) *Use of an Online Community to Provide Support to Caregivers of People With Dementia*, Journal of Gerontological Social Work, 57:6-7, 694-709
[81] Wang, L. Q., Chien, W. T., Lee, I. Y. M. (2012) An experimental study on the effectiveness of a mutual support group for family caregivers of a relative with dementia in mainland China, Contemporary Nurse, 40: 210-224
[82] Diehl, J., Mayer, T., Förstl, A. F., Kurz, A. (2003) *A support group for caregivers of patients with frontotemporal dementia*, International Journal of Social Research and Practice, 2: 151-161
[83] McKechnie, V., Barker, C., Stott, J. (2014) The effectiveness of an internet support forum for carers of people with dementia: a pre-post cohort study, Journal of Medical Internet Research, 16: 415-428
[84] Hannan, R., Thompson, R., Worthington, A., & Rooney, P. (2013). *The Triangle of Care. Carers Included: A Guide to Best Practice for Dementia Care.* London: Carers Trust.
[85] Dawson, A., Bowes, A., Kelly, F., Velzke, K., Ward R. (2015). Evidence of what works to support and sustain care at home for people with dementia: a literature review with a systematic approach, BMC Geriatrics 15:59.
[86] Hannan, R., Thompson, R., Worthington, A., & Rooney, P. (2013). *The Triangle of Care. Carers Included: A Guide to Best Practice for Dementia Care.* London: Carers Trust.
[87] Davies, K. & Cross, J. (2011). Common Core Principles for Supporting People with Dementia – A guide to training the social care and health workforce. Skills for Care / Skills for Health: Leeds / Bristol.

(2014)[88] of the chain of care for people with dementia that found highly trained staff with an extensive knowledge of the patient are essential to interpreting symptoms and behaviour in the most competent manner.

Staff training can also play a significant role in end of life care as dealing with dementia at its most advanced stage requires a higher degree of training with regards to appropriate medication, pain management and end of life plans[89]. Similarly important is staff training at the diagnosis stage. Providing access to support services at the early stage of diagnosis can be a valuable way of ensuring individuals are provided with the necessary understanding and knowledge to manage symptoms associated with dementia as demonstrated by the First Link initiative implemented in Canada[90].

Age UK also commissioned research[91] into workforce skills in the health and social care sector for older people that is also relevant to persons with dementia. This study noted that often the health care needs of older service users are more complicated that than of younger service users. Furthermore, despite strong policy directives towards person centred care, specific skills gaps were evident in the areas of joined-up team working, supporting service users (particularly when transitioning from one service to another) and providing clear communication about treatment.

4.7 Early-Onset Dementia

Whilst dementia is typically associated with older people, Alzheimer's disease is responsible for 30-40% of cases of dementia under the age of 65[92]. Jefferies and Agrawal (2009)[93] highlight the implications a diagnosis of early-onset dementia can have for younger patients. Given the lifestyle differences of younger patients and those who are diagnosed at an older age, it is important to identify the effect that a diagnosis of early onset dementia can have in relation to a young patient's psychological wellbeing.

A research study in America examined the effects of a volunteering programme for individuals living with early onset-dementia and their carers. The Get Out of the House (GOOTH) project provides men with early-onset dementia with a weekly opportunity to participate in supervised volunteer work at the local zoo, and respite for family caregivers. Face-to-face semi-structured interviews were undertaken with 6 participants, as well as a focus group with their spouses. The interviews with participants showed that they strongly identified with the programme, developed a bond with fellow participants, derived socialisation benefits, and had a shared understanding and insight about participation. The focus group results showed that the programme represented a break in the day-to-day routine for spouses and families, provided opportunities for social interaction and development of friendships, had benefits that extended beyond the actual time spent in the

[88] Bökberg, C., Ahlström, G., Karlsson, S., Hallberg, I. R., Janlöv, A. C. (2014) Best practice and needs for improvement in the chain of care for persons with dementia in Sweden: a qualitative study based on focus group interviews, BMC Health Services Research, 14:596. Available at http://bmchealthservres.biomedcentral.com/articles/10.1186/s12913-014-0596-z
[89] Dementia Care Homes Steering Group. (2015). *Examples of Good Practice in Dementia Care in Norfolk Care Homes.* Available at: http://www.healthwatchnorfolk.co.uk/wp-content/uploads/2015/11/15-04-Examples-of-Good-Practice-in-Dementia-Care-in-Residential-Homes.pdf
[90] McAiney, C.A., Hillier, L.M., Stolee, P., Harvey, D., & Michael, J. (2012). *'Throwing a Lifeline': the role of First Link in enhancing support for individuals with dementia and their caregivers.* Available at: http://www.alzheimer.ca/~/media/Files/national/For-HCP/for_hcp_McAiney_FL_outcomes_2012_e.pdf
[91] Healthcare Workforce Skills and Competencies for an Aging Society. Age UK (2010)
[92] Harvey, R. J., Skelton-Robinson, M., Rossor, M. N. (2003) *The prevalence and causes of dementia in people under the age of 65 years*, Journal of Neurology, Neurosurgery & Psychiatry, 74: 1206-1209
[93] Jefferies, K., Agrawal, N. (2009) *Early-Onset Dementia*, Advances in Psychiatric Treatment, vol. 15: 380-388

programme, and that there was very little that wives would change about the programme. The wives also reported that they now felt a sense of personal responsibility to inform the broader community about the challenges associated with, and the impact of, early onset dementia.

4.8 Dementia in the BME Community

Within the black and minority ethnic (BME) community, there are several factors that act as barriers for people living with Dementia in these communities and, as such, they don't take full advantage of the care services available. The Oldham Dementia Ethnic Minority (ODEM) reference group identified some of these factors to be awareness and knowledge of Dementia, language barriers and stigma, cultural confidence and the competence of staff[94]. The ODEM has been successful in building the understanding and awareness of Dementia within the BME community in Oldham, as well as building relationships with the community, providing staff and communities with training for the effective delivery of Dementia treatments and developing culturally appropriate support[95].

Early onset dementia is more prevalent among (BME) communities: 6 percent of BME people with dementia have the early onset form, compared to 2 percent for the UK population as a whole[96]. The susceptibility of some BME groups to risk factors for vascular dementia such as hypertension, diabetes and cardiovascular disease[97] contributes to a larger proportion of BME people being diagnosed with early onset dementia. Employing preventative measures to tackle modifiable risk factors and the implementation of strategies that improve access to high quality services for people with dementia in BME communities should form part of care providers' responsibility to tackle dementia in these communities[98]. Training for practitioners to overcome language and cultural differences is also an important step in affecting a positive change for dementia care services available to BME communities[99] as well as raising awareness among these communities about dementia and the services that are available.

However, the current UK evidence base on supporting BME people with dementia and their carers is very limited and reliant upon a small number of local studies[100]. Also, there is no regional data regarding BME and dementia prevalence available.

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[94] Oldham Dementia Ethnic Minority (ODEM) Reference Group: Draft terms of Reference
[95] Kaiser, P. (2016) BME – Highlight Report, NHS Foundation Trust
[96] Knapp, M., Prince, M., Albanese, E., Banerjee, S., Dhanasiri, S., Fernandez, J-L., Ferri, C., McCrone, P., Snell, T., Stewart, R. (2007) *Dementia UK. A report to the Alzheimer's Society on the prevalence and economic cost of dementia in the UK*. Available at https://www.alzheimers.org.uk/site/scripts/download_info.php?fileID=2
[97] Adelman, S. (2010) Prevalence and recognition of dementia in primary care: a comparison of older African-Caribbean and white British residents of Haringey, PHD thesis, University College London. Available at http://discovery.ucl.ac.uk/19622/1/19622.pdf
[98] All-Party Parliamentary Group on Dementia (2013) *Dementia does not discriminate: The experiences of black, Asian and minority ethnic communities*. Available at file:///C:/Users/chris.tate/Downloads/Alz_Soc_APPG_Report_2013_update.pdf
[99] Moriarty, J., Nadira, S., Robinson, J. (2011) *Black and minority ethnic people with dementia and their access to support and services*. Available at https://www.researchgate.net/profile/Jo_Moriarty/publication/233741268_SCIE_Research_Briefing_35_Black_and_Minority_Ethnic_People_with_Dementia_and_Their_Access_to_Support_and_Services/links/0fcfd50af852a5a3d3000000.pdf
[100] For example, see the All Party Parliamentary Group on Dementia 2013 report on 'Dementia does not discriminate: The experiences of black, Asian and minority ethnic communities' which contains a number of case studies of services for BME individuals with dementia and their carers

4.9 Conclusions

This Rapid Evidence Assessment of relevant academic, primary, secondary and grey literature identified a number of themes relating to best practice in providing care for people with dementia living in the community. The workforce has a crucial function in providing care for those individuals with dementia living at home who can no longer function with total independence. The literature reinforced the importance of caregivers and a prevalent feature was the need to support caregivers and provide them with resources to develop their knowledge and skills essential to provide high-quality care. The review also identified a number of areas where research is lacking, such as supporting BME people living with dementia and their carers, evidence on the effectiveness of community-based services that support people with dementia to live in their own homes, as well as large scale studies of the long-term impacts of creative activities on individuals living with dementia and their carers. These topics should be included in any future plans for dementia research in the North West, so as to grow the evidence base and knowledge in this area.

5 GROUPS AND ORGANISATIONS IN THE NORTH WEST

5.1 Introduction

This section provides an overview of the groups and organisations that have a role in providing care to people living with dementia and their carers. It includes an overview of the statutory bodies such as the Association of Directors of Adult Social Services (ADASS), as well an overview of Dementia Action Alliance and its status in each individual locality of the North West.

5.1.1 NW ADASS

The, North West (ADASS, NW), is the regional branch of the Association of Directors for Adult Social Services England. The aim of the association is to promote a high quality of care and to influence the development of social care legislation and policy. Their remit covers the full range of adult social services, and therefore dementia is one aspect of their role. The North West regions membership consists of representatives from each of the twenty three relevant council areas. NW ADASS has identified 12 key work streams, of which Dementia is one:

- Care Act;
- Carers;
- Dementia;
- Finance and Resources;
- IMT / AIN (informatics network);
- Learning Disabilities;
- Market Shapers;
- Mental Health;
- Performance;
- Personalisation;
- Safeguarding;
- Urgent Care;
- Workforce.

ADASS's Dementia Network was fully established by 2015. The ADASS Annual report for 2015 notes that the Network is encouraging all Directors of Adult Social care to deliver the actions attributed to ADASS under the Prime Minister's Challenge 2020 Implementation Plan, including dementia friendly communities, establishing best practice in patient pathways, tele-care and awareness raising. The role of the NW Network is to consider key issues concerning the services and support for people with dementia, their carers and families; promote the improvement of social care and health and to strengthen links with other organisations to promote joint objectives for improvement.

A number of workshops and presentations have been organised by the ADASS NW Dementia Network, including sessions on understanding the Prime Minister's Challenge, a user's perspective on personalisation and creating dementia friendly communities.

5.1.2 Health Education England

Health Education England's main objective is in workforce planning, to help deliver the highest quality of healthcare for patients and the public by providing the necessary staffing numbers as well as appropriate and adequate training possible. Health Education took over the Strategic Health Authorities in 2013 taking with it all accountability for workforce planning and education, which also helps ensure standardisation and consistency across England. The work of Health Education England is supported through 13 Local Education and Training Boards (LETBs). These Local Education and Training Boards are responsible for delivering the training and education to NHS staff. The North West is an LETB.

Health Education England is responsible for delivering excellent healthcare and improving health for patients and public. This is coordinated through developing a workforce for the present and future that can meet the need and quality required. 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[101].

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' aligns Health Education England's work with national NHS priorities to:

- Greater accountability of healthcare providers
- Enhance training for better simulation and outcomes
- Provide person-centred care
- Support the development of the workforce on a national level
- Support innovation, research and quality improvement
- Enhance transparency, fairness and efficient to investments in education and training
- Follow the explicit duty of the Secretary of State to secure an effective system for education and training.

Health Education North West is the regional presence for the organisation. It supports Health Education England to meet its objectives by focusing on developing the workforce of the North West, meeting requirements and providing high quality health and patient care[102].

The government provided a mandate to Health Education England for the period April 2015 to March 2016, published in March 2015. The Mandate announced the first national ambition to improve dementia diagnosis rates. This however can only be obtained through Local Training and Education Boards maintaining high standards and HEE reaching their set targets:

- 350,000 NHS staff reach tier 1 proficiency in dementia training followed by March 2015 followed by all staff reaching tier 1 by 2018; and
- Following all staff reaching tier 1 proficiency, look to develop tier 2 proficiency and ensure that education is best prepared in regards dementia training for bringing new NHS staff into the workplace fully trained in tier 1 proficiency.

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[101] *Health Education England (2015): https://hee.nhs.uk/about-us*

[102] *NHS (2016) North West | Health Education England: https://www.hee.nhs.uk/hee-your-area/north-west*

5.1.3 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 improve the nation's health and wellbeing, and reduce health inequalities[103].

The four core functions of Public Health England set out by an annual remit letter from Ministers are[104]:

- Protecting public's health from infectious diseases and other public health hazards;
- Improving public's health and wellbeing;
- Improving the population's health through sustainable health and care services; and
- Building the capacity and capabilities of the public health system.

To date the Public Health England with the cooperation of the UK Health Forum have released the Blackfriars Consensus specialising on promoting brain health and reducing the risk of dementia. Alongside this, Public Health England supported the Alzheimer Society's Dementia Friends programme which achieved more than 1 million people receiving education on helping people with dementia. The new target is to have 4 million Dementia friends by 2020.

Through several documents such as From Evidence into Action: opportunities to protect and improve the nation's health and NHS Five Year Forward View, seven priorities of Public Health England have been formed which includes "reducing dementia risk". In order to help reduce dementia risk Public Health England declares the action to raise awareness of steps people can take to reduce the risk of dementia through NHS Health Checks.

The delivery of these objectives in the North West is supported by the PHE Centre for North West England located in Manchester This centre provides local health protection services, expertise, response and advice to the local NHS, local authorities and other partners.

In 2014, PHE and the Alzheimer's Society jointly launched a major TV campaign, aimed at trying to create a more Dementia friendly society by raising awareness and understanding of Dementia[105]. One of the main focus points of this campaign was to encourage not only individuals, but also businesses to sign up to Dementia Friends, especially due to changing attitudes towards dementia by businesses, as they are more willing to be seen as becoming Dementia Friendly[106]. In terms of the North West specifically, dementia is being addressed by the PHE in Manchester assisting in the set-up of the Greater Manchester Aging Hub which supports age-friendly communities, scaling work on Dementia friendly communities and supporting people with Dementia[107].

[103] Public Health England (2016) Public Health England: https://www.gov.uk/government/organisations/public-health-england
[104] Public Health England (2015) Who we are and what we do: Annual Plan 2015/16. https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/452328/Annual_plan_2015-_Aug7-web.pdf
[105] Alzheimer's Society (2014) Alzheimer's Society and Public Health England launch Dementia Friends TV campaign: https://www.alzheimers.org.uk/site/scripts/news_article.php?newsID=2021
[106] Public Health England (2014) New dementia campaign launches as research reveals the true cost to business of dementia : https://www.gov.uk/government/news/new-dementia-campaign-launches-as-research-reveals-the-true-cost-to-business-of-dementia
[107] Public Health England (2015) Greater Manchester devolution – the public health revolution: https://publichealthmatters.blog.gov.uk/2015/08/14/greater-manchester-devolution-the-public-health-revolution/

5.1.4 Dementia United

In 2014[108], a devolution agreement was introduced for the Greater Manchester area which transferred powers from the national government to the Greater Manchester Combined Authority (GMCA). The main purpose of this agreement was to give the GMCA more power over policies and legislation for the area, allowing local needs to be addressed and also to have control over the spending decisions in the area[109].

The devolution agreement led to new priorities in areas including Health and Social Care, where the GMCA identified dementia as a major priority in this area. This led to the establishment of a Dementia transformation programme; 'Dementia United', in 2015[110]. The sole aim of which is to make Manchester the best place in the world for people living with dementia.

The programme recognises[111] that to be successful, involvement from a huge range of partners in the Manchester area was required including contribution of resources, knowledge and expertise, however several high profile partners have already signed up to help:

- Alzheimer's Society and Greater Manchester SCN;
- Bury, Manchester City, Salford & Tameside Councils;
- Manchester, Salford and Tameside & Glossop CCGs; and
- University of Manchester, Salford & Manchester Metropolitan University.

One of the first initiatives that has been introduced by Dementia United is the Salford Way Dementia app, launched by Salford CVS[112]. The app can help thousands of people with dementia and their carers, to navigate around Salford[113]. The app has a further benefit in that it shows dementia friendly businesses, meaning that they have an understanding of the disease, which will increase the amount of dementia friendly businesses in the area, contributing to the aim of Dementia United, especially since the app is available on both Apple and Android platforms which account for a significant proportion of the mobile phone market.

5.2 Healthwatch

Healthwatch England[114] is the national consumer champion in health and social care in England which was established through the health and social care reforms of 2012. As part of this every local authority across England has a Healthwatch. Locally each Healthwatch acts as a facilitator of concerns and provides feedback to service providers and commissioners. For 2016/17 Healthwatch has listed the follow priorities:

- Provide leadership, support and advice to local Healthwatch to deliver their statutory activities and be a powerful advocate for services that work for people;

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[108] Local Government Association (2016) Devolution Deals: http://www.local.gov.uk/devolution-deals
[109] Greater Manchester Combined Authority (2016) Devolution: https://www.greatermanchester-ca.gov.uk/homepage/59/devolution
[110] Macauley, A. (2015) Greater Manchester partners unite for dementia drive: http://www.localgov.co.uk/Greater-Manchester-partners-unite-for-dementia-drive/39829
[111] Dementia United (2016) Who's Involved: http://dementiaunited.net/what-is-it/stakeholders/
[112] GMHSC (2016) GM pledges support for Dementia Awareness Week: http://www.gmhsc.org.uk/news/gm-pledges-support-for-dementia-awareness-week/
[113] Salford Online (2016) Dementia app has been launched in Salford to help people in living with the disease: http://salfordonline.com/23835-dementia-app-launched-salford-help-people-living-disease.html
[114] Healthwatch (2016) Healthwatch: http://www.healthwatch.co.uk/

- Bring public views to the heart of national decisions about the NHS and social care; and
- Build and develop an effective learning and values foundation to Healthwatch.

Examples of recent activities undertaken by Healthwatch relating to dementia in the North West include:

- Healthwatch Liverpool arranged a Family Carers Matter Programme in June 2016. This was a programme for those involved with dementia getting to learn about life story work in caring for people with dementia. The programme is carried out by Life Story Network and it is a 2 day programme with 4 weeks difference between the 2 days to allow the participant to apply and then reflect on what they have learnt on the first day;
- Healthwatch Manchester recently held a one-off focus group to explore the views of over 60's and the best ways to involve the public. Furthermore, Healthwatch Manchester conducted a survey on dementia services in Manchester which they then shared their findings with Manchester Mental Health and Social Care Trust to respond to the feedback; and
- Healthwatch Wigan has facilitated a number of Enter and View Reports to organisations such as Barley Brook Care Home and St Georges Care Home who are home to people with dementia. Healthwatch sends trained volunteers to observe these homes, not to criticise but to get a perspective of what it is like.

5.2.1 Strategic Clinical Networks

SCNs are part of NHS England and receive their support and funding through network support teams, hosted by the NHS Commissioning Board, and cover 12 geographical areas[115], with the relevant NW SCNs are:

- North West Coast- Covering Cheshire, Merseyside, Lancashire and South Cumbria[116];
- Greater Manchester, Lancashire and Cumbria (GMLC)- Covering Greater Manchester, Lancashire and South Cumbria[117]; and
- Northern England- Covering the North East, North Cumbria and Hambleton & Richmondshire.

Strategic Clinical Networks (SNCs) are used to collate the users, providers and commissioners of health services in order to implement any improvements and have the national aim to provide improved quality of healthcare, in a more equitable manor so that those who need access to the service the most, receive the care that they need[118]. The Northern England SNCs were established in 2013[119] and use the knowledge and experience of several stakeholders, NHS clinicians, patient input and NHS staff so as to achieve the purpose, as stated on their website, of:

- Reducing the variation in the provision and quality of health and well-being services in the North of England;

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[115] *NHS Commissioning Board (2013) Strategic Clinical Networks- frequently asked questions (FAQ): https://www.england.nhs.uk/wp-content/uploads/2012/11/scn-faq.pdf*

[116] *North West Coast Strategic Clinical Networks (2016) About Us: http://www.nwcscnsenate.nhs.uk/strategic-clinical-network/about-us/*

[117] *GMLSC SCN (2016) Strategic Clinical Networks: http://www.gmlscscn.nhs.uk/*

[118] *NHS England (2016) Strategic Clinical Networks: https://www.england.nhs.uk/ourwork/part-rel/scn/*

[119] *Northern England SCN (2016) About Us: http://www.nescn.nhs.uk/about-us/*

- Facilitating innovation in terms of the provision of services at present, and in the future; and
- Assisting decision making and strategic planning by providing clinical advice and leadership.

The Strategic Network team are tasked with delivering projects that improve the quality of life of those living with dementia which they aim to achieve by promoting dementia friendly communities, providing training to care homes, visiting health and social care staff so that they can effectively care for people with dementia and construct pathways that improve the crisis management of people living with dementia in an attempt to reduce unnecessary hospital admissions[120].

The SNCs work in partnership with a number of institutions in order to achieve their goals, including the Academic Health Science Network, Health Education England, and local CCG's. Through partnerships, the SNCs gather information on the views of patients and carers through a number of channels that ensure they are introducing projects that account for the needs of patients with dementia.

The overall SCN is led by a clinical director and has three medical directors who are supported by an associate director. All SCNs have a network called Mental Health, Dementia, Neurological Conditions and Learning Disabilities, consisting of commissioners, patients and carers who work towards developing Dementia services. The mental health networks are supported by a Clinical Director[121] [122] [123] and other relevant clinical staff such as dementia leads.

The SCN has delivered a number of dementia focused projects in the NW, including:

- Dementia in Care Homes initiative[124] that was commissioned by the North West Coast SCN. This project is primarily focused on addressing the needs of staff and residents in care homes in relation to dementia and has the objective of equipping care assistants with the necessary skills so that they can use the Referral to GP tool (DeAR-GP). This tool assists workers in identifying people who are displaying signs of dementia and allows them to refer the person to their GP for review. The impact of this project will be to address the needs of care home staff so that they can identify potential patients with dementia earlier and quickly allow them to refer the patients to their GPs. Additionally, the project will provide support for the people living with dementia and their family, whilst assisting them to plan for the future;
- The Dementia Matters project was delivered in conjunction with The University of Manchester and aimed to inform young people in the Greater Manchester area on dementia[125]. It supported young people to talk about dementia and facilitated the exchange of key information regarding dementia between the young people and the staff involved with the delivery of the project (Dementia Matters staff and the researchers from Manchester University), and getting the young people involved in a discussion on future solutions about dementia. The first pilot session contained an information session at the beginning of the project as well as activities designed to increase dementia awareness. The stated outcomes of the project were that the young people

[120] *NHS (2016) Dementia: http://www.gmlscscn.nhs.uk/index.php/networks/mental-health-dementia-and-neurological-services/dementia*
[121] *Northern England SCN (2016) Networks and Senate Structure: http://www.nescn.nhs.uk/wp-content/uploads/2014/05/NetworkXteamXstructureXJulyX2016Xv.1.6.pdf*
[122] *GMLSC SCN (2016) Clinical Leads: http://www.gmlscscn.nhs.uk/index.php/clinical-leads*
[123] *North West Coast SCN (2016) Meet the Team: http://www.nwcscnsenate.nhs.uk/strategic-clinical-network/about-us/network-support-team/*
[124] *North West Coast SCN (2016) Dementia in Care Homes project: http://www.nwcscnsenate.nhs.uk/strategic-clinical-network/our-networks/mental-health-dementia-and-neurological-conditions/senate-news/dementia-care-homes-project/*
[125] *Central Manchester University Hospitals (2016) Dementia Matters: https://research.cmft.nhs.uk/case-studies/dementia-matters*

gained knowledge regarding dementia that they otherwise might not have learned. Staff reported that the questions asked by students were creative and they provided some solid research ideas. The Dementia Matters project is now being piloted in several secondary schools and colleges across Manchester and is seen as a vital project for increasing dementia awareness in young people; and

- Lancashire Dementia Voices (LDV)[126] is another project that the GMLSC SCN have helped to deliver. The LDV are a campaigning group with the sole objectives of raising awareness of dementia by educating professionals and organisations and campaigning for and promoting services for people with dementia in Lancashire. To achieve these objectives, the LDV works with a range of organisations, including the GMLSC SCN, but also The Dementia Engagement and Empowerment Project (DEEP), Innovations in Dementia and Lancashire care NHS Foundation Trust to name a few.

5.3 National Groups Providing Local services

There are a number of dementia specific national charitable organisations that provide service and support to people living with dementia and their carers in the North West. These include Dementia UK and the Alzheimer's Society.

5.3.1 Dementia UK

Admiral Nurses[127:] Dementia UK provide specialist nurses, known as Admiral Nurses, who assist people with Dementia by providing expert, practical, clinical and emotional support to those individuals as well as their families and carers. Not only do these nurses help people with dementia to deal with the everyday challenges, but they also provide support for the future of living with dementia to individuals and families.

5.3.2 Alzheimer's Society

5.3.2.1 Dementia Friends

This is an initiative that looks to build society's understanding of dementia and provide support to those people living with dementia and their families. Over 1.5 million people have signed up to become a Dementia Friend with 10,500 of those being voluntary Dementia Friend Champions. A target has been set to achieve a total of 4 million Dementia Friends by 2020. Dementia Friends have a partnership with the University of Manchester, being one of the University's Social Responsibility flagship programmes[128].

[126] *Lancashire Dementia Voices (2016) Home: http://lancashiredementiavoices.org/*
[127] *Dementia UK (2016) Admiral Nursing: https://www.dementiauk.org/how-we-help/admiral-nursing/*
[128] *The University of Manchester (2016) Dementia Friends: http://www.socialresponsibility.manchester.ac.uk/strategic-priorities/responsible-processes/dementia-friends/*

Dementia Friendly Workplace: This initiative aims to inform employers about how to make workplaces more Dementia friendly by providing a comprehensive guide that sets out several aspects of Dementia including how Dementia affects employees and customers[129]. The Dementia Friendly Business Pilot sets out a best plan of action for businesses on how to become Dementia friendly.

Case Study: Dementia Friendly Workplaces

Manchester introduced a new initiative in 2015 that was aimed to make the city more Dementia friendly due to estimates of 22,000 local people who will have Dementia by 2020 and has led to the formation of the new Dementia United partnership to help make the city more Dementia friendly. Sir David Dalton, Chief Executive of Salford Royal, has stated that for this initiative to work, drastic changes are needed including changes to workplaces.

In Lancashire, specifically the Rossendale community, mentioned that part of their action plan for building a more Dementia friendly community could involve providing guidance for employers on how to create a Dementia friendly workplace as part of their commitment to dealing with Dementia due to the relatively high, older population.

The 2015 Dementia Friendly Award Winners contained two winners from the North West region, both of which were from Liverpool. Liverpool SURF won the Best Dementia Friendly Involvement Initiative for delivering numerous awareness sessions at not just a national, but an international level. National Museums Liverpool- House of Memories also won an award for Best Dementia Friendly Partnership Working for expanding rapidly since their beginnings in 2012 to encompass a suite of national museum partners and resources.

5.3.2.2 Dementia Friendly Communities:

This initiative was established to correspond with the Prime Minister's Challenge on Dementia 2020. It seeks to create and facilitate Dementia friendly communities across the UK in which all parts of society have a shared responsibility for Dementia in the community. This is facilitated through Community Engagement Teams who seek to drive forward social inclusion through raising awareness and promoting learning[130]. By 2015 there were 12 communities classed as 'active dementia friendly' in the NW including Lancashire, Bury, Liverpool, Warrington and Blackburn with Darwen[131]. In order to create and facilitate Dementia friendly communities across the UK, a number of programmes have been established:

- The Dementia Friendly Communities Recognition Process;
- The Dementia Friendly Communities Champion Group; and
- The Dementia Friendly Business Pilot[132].

[129] *Alzheimer's Society (2015) Creating a dementia-friendly workplace - A practical guide for employers - Alzheimer's Society: https://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=2963*
[130] *Alzheimer's Society (2015) Community engagement - Alzheimer's Society: https://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=3160*
[131] *Alzheimer's Society (N.A) List of Active Dementia Friendly Communities: https://www.alzheimers.org.uk/site/scripts/download.php?type=downloads&fileID=2887*
[132] *Jacobs, B. (2015) New £35,000 a year project set to aid Blackburn with Darwen dementia patients: http://www.yorkpress.co.uk/news/11783564.New___35_000_a_year_project_set_to_aid_Blackburn_with_Darwen_dementia_patients/*

5.3.2.3 Dementia Connect:

This is the Alzheimer's Society Dementia services online which contains over 4,000 listings of local information, support and services across England, Wales and Northern Ireland. Users can enter their postcode or place name to find the nearest voluntary, statutory and private services.

5.4 Dementia Action Alliances

The Dementia Action Alliance (DAA) is a nation-wide movement committed to transforming the lives of people with dementia and their carers with input from organisations and local authorities. At a national level the DAA seeks to shape policy and attitudes, while locally they coordinate and support Local Dementia Action Alliances.

A Local Dementia Action Alliance brings together regional and local members to improve the lives of people with dementia in their area. Members have to sign up to a National Dementia Declaration. This declaration explains the challenges of dementia and targets that they are looking to meet. Local dementia action alliance groups are the primary factor in developing dementia friendly communities. DAAs in the North West are developing across the region at local levels, with some very established and others just getting started. Each region has its own regional lead whose role is to develop the Alliance in that area.

Table 5:1: Status of Dementia Action Alliances in the North West

Locality and start-up date[133]	Description	Alliance members
Blackburn and Darwen (Early 2014)	A more established alliance that has outlined dementia strategic priorities. In the next 15 months it aims to focus improvements of pre-diagnosis, living well and planning for the future and dementia care.	24
Blackpool (May 2015)	Wanting to make Blackpool a dementia friendly town. Looking to encourage organisations from the tourism and leisure industry to help with this aim.	12
Bolton (February 2016)	To bring local organisations, groups, and businesses together to improve the lives of people living with Dementia.	25
Bury (August 2013)	Made up of members working to radically improve the lives of people living with dementia and carers.	49
Cheshire East (November 2014)	Made up of members working to radically improve the lives of people living with dementia and carers.	30
Cumbria (Not formally launched)	County wide focus and welcomes organisations serving the whole area.	6

[133] Start-up dates are approximate dates of the first meetings for each of the areas

Locality and start-up date[133]	Description	Alliance members
Halton (November 2014)	Wanting members to share their experiences with each other and learn from others. New members also must show how they can make a difference to people living with dementia.	30
Lancashire (Established 2014, functioning with meetings from July 2016)	Made up of members working to radically improve the lives of people living with dementia and carers.	11
Liverpool (also covering Knowsley[134], May 2014)	Wanting members to share their experiences with each other and learn from others, complete action plans and follow the Liverpool Dementia Charter.	39
Manchester (2013, the DAA registered on the dementia friendly communities recognition process early in 2014)	Made up of members working to radically improve the lives of people living with dementia and carers.	56
Oldham	Made up of members working to radically improve the lives of people living with dementia and carers. Oldham also have several DAA supporters including NatWest Uppermill and Co-operative food.	45
Salford (November 2014)	Wanting members to share their experiences with each other and learn from others. Members have also identified the key priorities of access along with diagnosis and support.	60
Sefton (Also covering Southport, August 2015)	Made up of members working to radically improve the lives of people living with dementia and carers.	32
St Helens (July 2015)	Made up of members working to radically improve the lives of people living with dementia and carers	12
Tameside (Not formally launched)	Made up of members working to radically improve the lives of people living with dementia and carers. Looking to encourage organisations from the tourism and leisure industry to make Tameside dementia friendly.	3
Trafford	Made up of members working to radically improve the	18

[134] Knowsley are hoping to start their own DAA in the future, however this is still in the early stages

Locality and start-up date[133]	Description	Alliance members
(Not formally launched)	lives of people living with dementia and carers.	
Warrington (March 2014)	Made up of members working to radically improve the lives of people living with dementia and carers.	31
West Cheshire (Cheshire West and Chester, May 2014)	Working towards enabling and inspiring dementia friendly communities.	18
Wigan (October 2014, with meetings from February 2015)	Made up of members working to radically improve the lives of people living with dementia and carers.	45
Wirral (July 2016)	Members focusing on local areas and then coming together to share good practices.	5

Source: Dementia Action Alliance (2016) Dementia Action Alliance - North West. Available at: http://www.dementiaaction.org.uk/north_west (Accessed: 21 July 2016).

From the table above, there is a total of 551 combined members across all the areas. The Manchester area, of Salford, Manchester and Trafford, have 60, 56 and 18 members respectively meaning that combined, the Manchester area makes up just under 25% (134) of the amount of total alliance members across the North West, which could be due to Manchester being a major city in the North West and the population size in the area. In contrast to this, Lancashire, the biggest area by population, only has 11 alliance members (2%) which could indicate that the DAA was only recently established in the area. In 2016, there have been two areas to sign up to become local DAAs in the North West, Bolton and Wirral, accounting for 25 and 5 members respectively. The response to the Bolton DAA has been significant, managing to build up 25 members since start-up, which may be down to the fact that the closest DAA to people in this area is Manchester. Expanding the number of alliance members from a local view to the national picture, there are a total of 4,458 members of DAAs in the UK, which are part of 252 local alliances. This means that the North West area of England comprises 12% of the total number of members across the UK at a national level.

Across all the areas, the DAAs tend to share a common goal of working towards improving the lives of people living with Dementia and their carers/families within their respective areas whilst also coming up with strategies and initiatives that can make the local area more Dementia friendly, and then share this knowledge with other areas on a national level. The DAA as a whole states that it has one aim, to bring about a society-wide response to Dementia which is an aim followed at all local DAAs.

5.5 Summary

Key points emerging from the review of local groups and organisations include:

- The NW ADASS aims to establish a high standard of care in the NW and influence the development of social care legislation and policy. The Network is encouraging all Directors of

Adult Social care to deliver the actions outlined in the PM Challenge 2020, including Dementia friendly communities, best practice in patient pathways etc. Role of NW Network is to deal with key issues around Dementia including support, improvement of social care and strengthening of links with other organisations.

- Health Education England: Main objective is to assist in delivery of the highest quality of healthcare for patients by providing the necessary staffing numbers and training. Responsible for delivering excellent healthcare and improving general health. This is coordinated through developing a workforce for the present and future that can meet the needs and demand.
- Public Health England: The national public health agency with a duty to improve the nation's health and wellbeing and reduce health inequalities. Released the Blackfriars Consensus alongside the UK Health Forum which promotes brain health and reducing the risk of Dementia. Have also supported the Alzheimer's Society Dementia Friends programme
- Dementia United: Formed after the devolution agreement which granted the Greater Manchester Combined Authority (GMCA) powers to influence policy in local area. Having the sole aim of making Manchester the best place to live with Dementia in the world. Launched the Salford Way Dementia app- helps people with Dementia navigate around Salford and shows Dementia friendly businesses (those with an understanding of Dementia). May encourage more businesses to become Dementia friendly in Salford, especially as the app is available on both Apple and Android.
- Healthwatch: The national consumer champion in health and social care in England. Established through the health and social care reforms of 2012. Part of these reforms mean that every local authority in England has a Healthwatch. Local healthwatch's act as a facilitator of concerns and provides feedback to service providers and commissioners. Activities- Healthwatch Liverpool: Family Carers Matter Programme- programme for those involved with dementia getting to learn about life story work in caring for people with dementia, Healthwatch Manchester: Focus Group- to explore the views of over 60's and the best ways to involve the public, Healthwatch Wigan: facilitated a number of Enter and View Reports for Barley Brook Care Home, St Georges Care Home etc. who are home to people with dementia. Healthwatch sends trained volunteers to observe these homes, not to criticise but to get a perspective of what it is like.
- SCNs: Used to collate users, providers and commissioners of health services with the aim of implementing improvements, however have a national objective to improve the quality and equitable distribution of healthcare. Projects include: Dementia in Care Homes initiative, Dementia Matters project and Lancashire Dementia Voices (LDV)
- National Groups providing Local Services;

Dementia UK:

- Admiral Nurses
- Alzheimer's Society:
- Dementia Friends;
- Dementia Friendly Workplaces;
- Dementia Friendly Communities; and
- Dementia Connect
- Dementia Action Alliances: Brings together Organisations across England to transform the lives of people with Dementia and their carers. National objective is to shape policy and attitudes, locally, coordinate and support local Dementia Action Alliances. All DAAs share a common goal of working towards improving the lives of people with Dementia and producing

strategies/initiatives that make the local area more Dementia friendly plus share that knowledge with other areas. One aim is to bring about a society-wide response to Dementia. A review of members and activities suggests that the Dementia Action Alliances are at different stages of development in each area.

6 DEMENTIA RESEARCH IN THE NORTH WEST

6.1 Introduction

This section details the key issues relevant to the promotion of high quality research relating to dementia in the North West of England, including:

- The national policy context for dementia research, and national dementia research initiatives;
- How dementia research has been included in local plans in the North West;
- Research commissioned by councils in the North West;
- Research conducted by universities in the North West; and
- Memory services that involve people in dementia research in the North West.

6.2 Policy Context for Dementia Research

Outlined below is the national policy context for dementia research. This should be read alongside the more general policy review detailed in Section 3.

6.2.1 Living Well with Dementia: A National Dementia Strategy[135]

The Strategy notes that while there has been a growth in public, industrial and charity funding of dementia research, the level of funding for dementia research lags behind other major health priorities such as cancer and heart disease. The need for further research has been identified by stakeholders for all aspects of dementia (i.e. prevention, cause, care and cure). Therefore, Objective 16 of the Strategy calls for 'a clear picture of research evidence and needs' and 'evidence to be available on the existing research base on dementia in the UK and gaps that need to be filled'.

6.2.2 Prime Minister's Challenge on Dementia 2020[136]

In relation to dementia research, the Prime Minister's Challenge outlines eight key aspirations that the Government hopes to achieve by 2020:

- Dementia research as a career opportunity of choice with the UK being the best place for Dementia Research through a partnership between patients, researchers, funders and society;
- Funding for dementia research on track to be doubled by 2025;
- An international dementia institute established in England;
- Increased investment in dementia research from the pharmaceutical, biotech devices and diagnostics sectors, including from small and medium enterprises (SMEs), supported by new partnerships between universities, research charities, the NHS and the private sector;
- Cures or disease modifying therapies on track to exist by 2025, their development accelerated by an international framework for dementia research;
- More research made readily available to inform effective service models and the development of an effective pathway to enable interventions to be implemented across the health and care sectors;
- Open access to all public funded research publications; and

[135] Department of Health (2009). Living Well with Dementia: A National Dementia Strategy. London: Department of Health.
[136] Department of Health (2015). Prime Minister's Challenge on Dementia 2020. London: Department of Health.

- Increased numbers of people with dementia participating in research, with 25% of people diagnosed with dementia registered on 'Join Dementia Research', and 10% participating in research (up from the current baseline of 4.5%).

6.2.3 The Ministerial Advisory Group on Dementia Research – Headline Report[137]

The Ministerial Advisory Group was set up to find ways to increase the volume and impact of high quality research. Their Headline Report identifies the main challenges facing dementia research and sets out a range of actions designed to address them. These actions are summarised in a 'Route Map for Dementia Research', and are to be taken forward by a wide range of organisations with clear time lines for delivery. The actions aim to:

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

6.2.4 NICE Clinical Guidelines for Dementia[138]

The Guideline Development Group, on the basis of their review of the evidence, made the following recommendations for research, in order to improve NICE guidelines and the care of people with dementia:

- Research into the effectiveness of acetylcholinesterase inhibitors and memantine for the treatment of psychotic symptoms in dementia;
- Research into the effectiveness of cognitive stimulation and/or acetylcholinesterase inhibitors in Alzheimer's disease;
- Research into the cost effectiveness of psychological interventions for carers of people with dementia; and
- Research into the effect of staff training in dementia-specific person-centred care on behaviour that challenges and reduced prescription of medication.

6.2.5 James Lind Alliance Dementia Research Priorities

In 2013, the James Lind Alliance, along with the Alzheimer's Society, undertook a national priority setting exercise in order to identify the most salient research priorities for dementia. The following questions were prioritised by people with dementia, carers, and health and social care professionals to inform the future of dementia research. The priorities were launched at Alzheimer's Society's Research conference on 27th June 2013.

[137] Department of Health. (2011). The Ministerial Advisory Group on Dementia Research: Headline Report. Available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/215558/dh_127904.pdf [accessed 1 April 2016]
[138] National Institute for Health and Clinical Excellence (NICE). (2006). CG42: Dementia: Supporting people with dementia and their carers in health and social care. London: NICE.

Table 6:1: James Lind Alliance Dementia Research Priorities

No.	Priority
1	What are the most effective components of care that keep a person with dementia as independent as they can be at all stages of the disease in all care settings?
2	How can the best ways to care for people with dementia, including results from research findings, be effectively disseminated and implemented into care practice?
3	What is the impact of an early diagnosis of dementia and how can primary care support a more effective route to diagnosis?
4	What non-pharmacological and/or pharmacological (drug) interventions are most effective for managing challenging behaviour in people with dementia?
5	What is the best way to care for people with dementia in a hospital setting when they have acute health care needs?
6	What are the most effective ways to encourage people with dementia to eat, drink and maintain nutritional intake?
7	What are the most effective ways of supporting carers of people with dementia living at home?
8	What is the best way to care for people with advanced dementia (with or without other illnesses) at the end of life?
9	When is the optimal time to move a person with dementia into a care home setting and how can the standard of care be improved?
10	What are the most effective design features for producing dementia friendly environments at both the housing and neighbourhood levels?

Source: http://www.jla.nihr.ac.uk/top-tens/dementia-top-ten

6.3 National Dementia Research Initiatives

6.3.1 Join Dementia Research

'Join Dementia Research' is a national initiative which enables people with dementia, carers and control volunteers to sign up for dementia research, and be matched to suitable studies. The initiative is funded by the Department of Health, and delivered in partnership with the National Institute for Health Research, Alzheimer Scotland, Alzheimer's Research UK and Alzheimer's Society. To date, 4,921 volunteers have been enrolled in 62 dementia research studies, with 16,816 individuals registering their interest to take part in research[139]. Join Dementia Research activities are co-ordinated in the Greater Manchester area through the NIHR Clinical Research Network: Greater Manchester (CRN: GM).

[139] https://www.joindementiaresearch.nihr.ac.uk/

6.3.2 Dementia Discovery Fund[140]

The Dementia Discovery Fund (DFF) is a global investment, launched in 2015, and which aims to support the discovery and development of novel dementia treatments. $100 million has been invested in the fund from contributors such as the Department of Health, Alzheimer's Research UK, and major world-leading pharmaceutical companies such as Biogen, Johnson and Johnson, and Pfizer. The DFF has been established to deliver new drug approaches for dementia by 2025, and to diagnose and intervene early to modify the course of the disease while also improving symptoms and laying the foundations for effective therapies. The DFF will work collaboratively with universities, academic institutes, and the biotechnology and pharmaceutical industry internationally to identify novel dementia research projects and support these through the pre-clinical phase, enabling further development in clinical trials.

6.4 How Dementia Research Has Been Included in Local Plans in the North West

Dementia research is referred to in five local plans or strategies in the North West, as detailed in the table below.

Table 6:2: Dementia Research in Local Plans in the North West

Area	Relevant strategy	How dementia research is included in local plan:
St Helens	St Helens Health and Wellbeing Board – Dementia Project Group – 3 Year Action Plan 16/17 – 18/19	Objective 5 of the Plan relates to the development of further user led commissioning to influence dementia services, by: • Ensuring that people in St. Helens are given opportunities to participate in and contribute to dementia research; • Ensuring that people in St. Helens benefit from outcomes of national and international dementia research; and • Exploring the options of setting up a database that includes a register of service users interested in becoming involved with research into dementia.
Warrington	Warrington Dementia Strategy 2016-19	One of the key actions of this Strategy is to 'research and develop assessment tools that are relevant for minority ethnic communities and people for whom English is not a first language.
Trafford	Living Well with Dementia – A Strategy for Trafford 2016-2020, and Dementia Strategy	Research is one of the key priorities of this Strategy, and Trafford intend to contribute to the developing research and evidence base in relation to dementia. According to

[140] http://www.theddfund.com/

Area	Relevant strategy	How dementia research is included in local plan:
	Action Plan	the Strategy Action Plan, Trafford aims to achieve this through Greater Manchester West (GMW)[141] ensuring that people who are given a diagnosis of dementia are provided with information on the national Join Dementia Research campaign.
Manchester	Manchester: JSNA In-Depth Report on Dementia 2013	The Manchester JSNA on dementia proposed that they would explore and maximise the use of dementia research and academic insight to inform the emerging Dementia Strategy for 2014-2018.
Cheshire East	Joint Dementia Commissioning Work Plan 2014-2017	Objective 10 of the Joint Dementia Commissioning Work Plan relates to 'future research', specifically that 'individuals' experiences and those of their carers and families are captured and inform future research at local and national level'.

6.5 Research Commissioned by Councils in the North West

Local councils were asked had they commissioned or completed any research in their area regarding dementia or the needs of those living with dementia as of March 2015. Six councils reported that they had commissioned or completed research in their area regarding dementia or the needs of people living with dementia as of March 2015 (namely Salford, Liverpool, Bury, Cumbria, Knowsley, and Lancashire).

- In Salford, this research takes the form of a dementia needs assessment commissioned by Salford Public Health and which is due to report this year (2016).
- In Liverpool, Public Health have commissioned a Dementia Profile, which details key dementia statistics for the Liverpool CCG area.
- In Bury, research has been commissioned into the development of an end of life care pathway.
- Cumbria County Council have commissioned the University of Stirling to undertake two pieces of research regarding dementia: in 2012/13, a survey and report of the experiences of people living with dementia and their carers; and in 2014, an evaluation of the Dementia Home Care Environments project[142].
- In Knowsley, a JSNA on dementia was completed in January 2016, and a review of mental health which considered the needs of people living with dementia, took place during 2014.

[141] Provides a range of mental health services for adults across Trafford, including a Dementia Crisis and Prevention Team
[142] This project sought to evaluate the Home Care Environment (HCE) project through engagement with service users, their carers and staff delivering the project.

- Lancashire County Council have produced an intelligence report and assessment of population need (2014-2030) with regards to young-onset dementia in the county.

The Catalyst Programme

The NHS North West R&D (research and development) office delivers catalyst events across the North West, which brings together people from a wide range of healthcare and academic disciplines who have a shared interest in a particular topic. The aims of the Catalyst programme are to:

- Identify research questions which are of importance to policy makers, commissioners, service providers, clinicians, patients and the public;
- Create new and innovative collaborations to develop research funding;
- Improve links with the NHS and other organisations, and with universities to facilitate research and support changes in practice;
- Contribute to the economic agendas of the North of England and EU regional partners, through the attraction of additional research and development funding; and
- Give colleagues in the North of England and the EU an idea of strengths and potential gaps in research in the region.

In 2014, the Catalyst Programme held an event on 'identifying the gaps in dementia research', which brought together prominent individuals from diverse backgrounds across the North West of England and who had an interest in dementia research. The main themes emerging from group discussions at the event with regards to research gaps included support for family and carers, training for care staff, treatment interventions and evaluation of these interventions, stigma, and maintaining dignity.

For more information on the programme, and the 'identifying gaps in dementia research' event, see: http://www.research.northwest.nhs.uk/work/catalyst-programme/

6.6 Clinical Research Conducted by Universities in the North West

Ten universities in the North West were identified through desk-based research, and telephone calls / emails with relevant individuals from the universities as conducting research into dementia. The following table summarises the key relevant research activities[143] identified in each university, with further detail on the research activities provided in the sections below. This information was collected between April and June 2016, and is up to date as of this point in time. As can be seen, there is a wide variation in the scale of dementia research that is being undertaken. Please note that this is not an exhaustive list, and other research activities may be ongoing at universities in the North West and that are not listed below. For further detail on some of the individual research projects, see Appendix 4.

[143] This includes both current and recently completed research studies / activities.

Table 6:3: Dementia Research Conducted by Universities in the North West

University	School / research centre	Research areas	Start / end date	Principal investigator	Funder and funding
Liverpool Hope University	Health and Well-being Research Team	Metabolic disease with a focus on diabetes and dementia	*Not specified*	Professor Ebrahim Naderali	*Not specified*
Liverpool John Moore University	Centre for Collaborative Innovation in Dementia	Innovate Dementia Transnational Living Lab	April 2012 – Sept 2015	Grahame Smith	INTERREG IVB – Approx. £5.5m (note 1)
		Evaluation of dementia reablement	May 2015 – May 2016	Grahame Smith	Cheshire East Council - £*Not specified*
University of Liverpool	Institute of Psychology, Health and Society	Evaluation of Dementia Care Home Liaison Intervention in 5 Boroughs NHS Trust	March 2013 – December 2014	Professor Richard Whittington	5 Boroughs NHS Trust - £*Not specified*
		Palliative care for dementia	*Not specified*	Professor Mari-Lloyd Williams	*Not specified*
		Embedding a human rights based approach to dementia care	May 2014 – April 2017	Professor Peter Kinderman	National Institute of Health Research (NIHR) - £408,411
	Institute of Integrative Biology	Altered Heparan Sulfate in Ageing and Dementia: a Potential Axis for Dysregulation of BACE-1 in Alzheimer's Disease	October 2013 – September 2016	Professor Jerry Turnbull	Alzheimer's Society - £90,000
		Drug discovery for dementia	2003 – ongoing	Professor Jerry Turnball	Various agencies including

Table 6:3: Dementia Research Conducted by Universities in the North West

University	School / research centre	Research areas	Start / end date	Principal investigator	Funder and funding
					Alzheimer's Society and Medical Research Council - £500,000
Edge Hill University	Evidence Based Practice Research Centre	Effective home support in dementia care (in collaboration with University of Manchester)	September 2013 – September 2018	Professor David Challis (University of Manchester)	NIHR- £1,998,981
Manchester Metropolitan University	School of Art	Dementia and imagination / visual arts	2013 - 2016	Lead Investigator: Dr. Gill Windle (Bangor University) Co-Investigator: Clive Parkinson (School of Art, Manchester Met)	Arts and Humanities Research Council Connected Communities programme - £1.2m
		Exploration of temporary art spaces to evaluate primary responses in older people living with dementia – detail	*Not specified*	Stacey Coughlin (PhD student)	*Not specified*
University of Manchester	Personal Social Services Research Unit (PSSRU)	Effective home support in dementia care	September 2013 – September 2018	Professor David Challis	NIHR - £1,998,981
	Dementia@Machester	Investigating a cellular mechanism for	October 2013 - September	Professor Nigel Hooper	Alzheimer's Research UK -

Table 6:3: Dementia Research Conducted by Universities in the North West

University	School / research centre	Research areas	Start / end date	Principal investigator	Funder and funding
		Alzheimer's - A cell surface, lipid raft based signalling complex links amyloid-b to tau via Fyn	2016		£327,075
		European Medical Information Framework – Alzheimer's Disease: Alzheimer's Disease biomarkers study in cognitively normal advanced elderly	2014-2017	Professor Karl Herholz	Innovative Medicines Initiative - £56,317,001 (note 2)
		INVEST in Parkinsonian Dementias / A psychosocial intervention to benefit people with Parkinsons-related Dementia	2014-2017	Dr Iracema Leroi	NIHR Research for Patient Benefit - £342,000
		Neighbourhoods and Dementia Programme: A Mixed Methods Study (note 3)	May 2014 – April 2019	Professor John Keady	Economic and Social Research Council (ESRC) & NIHR - £20m
	School of Nursing, Midwifery and Social Work – Dementia and Ageing Research Team (DART)	CAN-DO' – research into cancer-related information needs and decision making preferences in people with dementia, their carers and	*Not specified*	Professor Janelle Yorke	Age UK - £*Not specified*

Table 6:3: Dementia Research Conducted by Universities in the North West

University	School / research centre	Research areas	Start / end date	Principal investigator	Funder and funding
		cancer clinicians			
		Developing dementia awareness training for dementia researchers	*Not specified*	Dr. Caroline Swarbrick	*Not specified*
		Exploring the experiences of caring for someone living with dementia in Salford	July 2014 – June 2016	Dr. Caroline Swarbrick	Salford Clinical Commissioning Group - £*Not specified*
		The 'Changing Face of our Neighbourhoods'	*Not specified*	Dr. Caroline Swarbrick	Funded as part of the Neighbourhoods and Dementia programme - £*Not specified*
	Manchester Institute for Collaborative Research on Ageing (MICRA) / PSSRU	Recognition of symptoms of dementia in South Asian elders	July 2011 – December 2013	Professor David Challis	NIHR - £205,161
	Faculty of Life Sciences	Does zinc deficiency lead to faster decline in Alzheimer's Disease?	*Not specified*	Dr. Catherine Lawrence	Alzheimer's Society - £258,801
University of Salford	Salford Institute for Dementia	Evaluation of dementia friendly communities training	July 2015 – July 2016	Dr. Tracey Williamson	Alzheimer's Society - £5,000
		Living well with young onset dementia	April 2015 – ongoing	Dr. Tracey Williamson	Booth Charities, Salford - £325,000
		Dementia and Diversity /	Multiple –	Dr. Anya	Several including

Table 6:3: Dementia Research Conducted by Universities in the North West

University	School / research centre	Research areas	Start / end date	Principal investigator	Funder and funding
		Experiences of dementia among ethnic minorities	Ongoing	Ahmed	telephone funding (internal university funding) - £2,500; Camden London Borough Council - £8,700; Salford CCG - £19,200
		Digital games for dementia care	July 2015 – ongoing	Dr. Claire Dormann	*Not specified*
		Co-designing augmented board games in ageing and dementia care	September 2015 – ongoing	Sam Ingleson & Dr. Claire Dormann	*Not specified*
		Investigating alterations in autophagy in frontotemporal lobar degeneration / Exploring protein degradation deficits in Alzheimer's disease	October 2015 – October 2019 / October 2014 – October 2018	Dr. Gemma Lace-Costigan	Alzheimer's Research UK - £80,467 PhD studentship grant / Alzheimer's Research UK Local Network Equipment Grant (2014 - £1,400 2015/16 - £3,000)
		Acoustics of environments used by people affected by dementia	April – May 2015	Prof Marcus Ormerod, Rachel Russell, & Prof Bill Davies	Saint-Gobain Echophon - £5,046 (note 4)
		Dementia Friendly Flooring	March – December 2015	Prof Marcus Ormerod & Rita Newton	*Not specified*

Table 6:3: Dementia Research Conducted by Universities in the North West

University	School / research centre	Research areas	Start / end date	Principal investigator	Funder and funding
		Exploring free-living behaviour with people affected by frontotemporal dementia using body-worn activity monitors	*In development*	Dr. Chris Pickford & Prof Malcolm Granat	*Not yet awarded*
		Activity monitoring of people with dementia using the activPAL and a home sensor network	*In development*	Dr. Chris Pickford & Prof Malcolm Granat	*Not yet awarded*
		Investigation of technological applications that enhance the well-being of caregivers and people living with dementia	June 2015 – ongoing	Dr. Richard Talbot & Dr. Claire Dormann	Submitted funding proposals: British Academy - £9,600 Abbeyfield Society - £19,802
		Evaluation of dementia friendly environments in Salford	October 2013 – March 2015	Dr. Tracey Williamson	Salford County Council - £29,000
		Evaluation of dementia friendly environments (University Hospital of South Manchester – UHSM)	March 2014 – August 2015	Natalie Yates-Bolton & Dr. Tracey Williamson	University Hospital of South Manchester - £30,000
		Evaluation of Empathic Curiosity communication	August 2015 – August 2018	Dr. Tracey Williamson, Natalie Yates-Bolton &	Innovate UK - £165,000

Table 6:3: Dementia Research Conducted by Universities in the North West

University	School / research centre	Research areas	Start / end date	Principal investigator	Funder and funding
		training for carers of people with dementia		Elizabeth Collier	
		Human rights of people with dementia	April 2015 – ongoing	Dr. Nicolas Kang-Riou	*Not specified*
		Designing community exercise groups for people with dementia and carers	December 2015 – December 2016	Dr. Chris Pickford & Prof Malcolm Granat	*Not specified*
		Evaluation of Salford Community Christmas project	April 2015 – September 2015	Dr. Tracy Collins	The Wellcome Trust - £4,845
		Metrics Project: Establishing the current evidence-base for the holistic model of environments of dementia	February 2015 – February 2018	Monika Sharma	Dowager Countess Eleanor Peel Trust - £*Not specified*
University of Central Lancashire	School of Art, Design and Fashion	Housing choices and care home design for people with dementia	January – December 2013	Prof Karim Hadjri	University of Central Lancashire - £3,000
University of Chester	Centre for Ageing Studies	Evaluation of cognitive stimulation therapy for people living with dementia and a concomitant support group for	*Not specified*	Dr. Jan Bailey	Alzheimer's Society - £*Not specified*

Table 6:3: Dementia Research Conducted by Universities in the North West

University	School / research centre	Research areas	Start / end date	Principal investigator	Funder and funding
		their carers			
		Intimate and sexual relationships after a diagnosis of dementia	*Not specified*	Rumandeep Tiwana (full-time doctoral student)	Tom Mason Scholarship - £*Not specified*
Lancaster University	Centre for Ageing Research	'Ageing Playfully' - Creative activities and quality of life in people with dementia	January – July 2015	Dr. Emmanuel Tsekleves	Creative Exchange / The Arts and Humanities Research Council - £6,000 (note 5)
	Department of Biomedical and Life Sciences	Development of biomarkers for dementia in old age	*Not specified*	Prof David Allsop	*Not specified*
		Getting a promising drug ready for clinical trials	*Not specified*	Prof David Allsop	Alzheimer's Society - £149, 164
		Testing type-2 diabetes drugs as potential treatments for Alzheimer's Disease	2013 – ongoing	Prof Christian Holscher	Alzheimer's Society & Alzheimer's Drug Discovery Foundation - $248,000
	Collaboration between the Centre for Ageing Research and AgeUK Lancashire	The Spatial Social and Social Dynamics of Public Inclusion for People with Dementia	October 2014 – ongoing	Prof Katherine Froggatt	*Not specified*

Source: Information obtained from universities websites and via phone calls and emails with relevant contacts at the universities between April and June 2016

Note 1: This is the amount of funding that is available for the whole project, and is shared across the 10 European partners.

Note 2: Please note this is across the whole project.

Note 3: There are ten investigator organisations involved in this study. The University of Manchester is the lead partner, and the others are: University of Liverpool, Lancaster University, University of Salford, University of Stirling, University College London, Greater Manchester West Mental Health NHS Foundation Trust, Pennine Care NHS Foundation Trust, British Deaf Association, and the Centre for Dementia Research at Linkoping University, Sweden.

Note 4: Manufacture and sell acoustic ceilings, wall panels and screens that contribute to a good indoor environment, for more info see: http://www.ecophon.com/uk#

Note 5: The Creative Exchange is a collaboration between Lancaster University, Newcastle University, and the Royal College of Art, who bring expertise in designing experiences, digital prototyping and communication innovation. They are one of four Knowledge Exchange Hubs funded by the Arts and Humanities Research Council to bring together creative sector businesses and academics. For more info see here: http://thecreativeexchange.org/

6.6.1 Research Gaps and Areas of Overlap

Dementia research undertaken by universities in the North West is focused on a wide range of issues from **young onset dementia**[144] to **end-of-life care**[145], as well as **drug research**[146] and the links between **creative activities and dementia**[147]. The majority of research identified for this study is focused on the theme of '**dementia care**' or '**living well with dementia'** (i.e. interventions or processes that could be implemented straight away or in the very near future). For example, the Centre for Collaborative Innovation in Dementia at Liverpool John Moore University is currently evaluating a pilot dementia reablement service, while the Institute of Psychology, Health and Society at the University of Liverpool have been involved in the evaluation of a dementia care home liaison intervention in the 5 Boroughs NHS trust. The Personal Social Services Research Unit (PSSRU) at the University of Manchester, alongside the Evidence Based Practice Research Centre at Edge Hill University are also conducting research into effective home support in dementia care.

The Alzheimer's Society Drug Discovery programme is an innovative approach which focuses on 'drug repurposing'. This approach takes drugs that are already being used to treat other conditions and tests their potential as a treatment for dementia. Current clinical trials being funded under the programme test the potential of drugs for conditions such as diabetes and rheumatoid arthritis. For more information, see: https://www.alzheimers.org.uk/drugdiscovery

Research in the North West is also examining the potential of **creative activities** and **elements of housing or care home design** to improve the quality of life of individuals living with dementia. For example, the School of Art at Manchester Metropolitan University is currently investigating how taking part in visual arts can contribute to the health and well-being of people with dementia, while the Salford Institute for Dementia is undertaking research into digital games for dementia care, and

[144] For example, see 'Living well with young onset dementia' at Salford Institute for Dementia,
[145] For example, see 'Palliative care for dementia' at University of Liverpool
[146] For example, see 'Getting a promising drug ready for clinical trials' and 'Testing type-2 diabetes drugs as potential treatments for Alzheimer's Disease' at Lancaster University
[147] For example, see research undertaken by the School of Art at Manchester Metropolitan University, as well as 'Digital games for dementia care' at Salford Institute for Dementia, and the 'Ageing Playfully' project at Lancaster University

the co-design of board games for people living with dementia. The Salford Institute for Dementia are also involved in research into the acoustics of environments used by people affected by dementia as well as dementia friendly flooring.

Both the University of Liverpool and the University of Salford are examining **human rights** in relation to dementia. The research undertaken by the University of Liverpool focuses on whether embedding a human rights based approach to dementia care will lead to improvements in the care and wellbeing of people with dementia in an inpatient / care home setting, while research at Salford is focused on determining how the law (especially with regard to legal capacity, rights in residential care, and employment rights) can improve the enjoyment of human rights of people with dementia.

With regards to specific groups, the Salford Institute for Dementia are conducting a three year project which will explore the needs of people living with **young-onset dementia**. Salford are also conducting research into **dementia and diversity**, examining BME (black or minority ethnic) communities experiences of dementia services. This is similar to research being undertaken by the University of Manchester which is examining the recognition of symptoms of dementia in South Asian elders.

A number of research projects are also examining the **experience of carers** of people living with dementia and services for them. For example, the Dementia and Ageing Research Team (DART) at the University of Manchester are examining the experiences of caring for someone living with dementia in Salford, while the Salford Institute for Dementia are evaluating Empathic Curiosity communication training for carers (which is discussed in Section 4 as a beneficial communication tool for individuals living with dementia and carers), as well as conducting research into the development of community exercise groups for people living with dementia and their carers. The University of Chester are also involved in the evaluation of a cognitive stimulation therapy for people living with dementia and a concomitant support group for their carers.

Universities in the North West are also involved in a number of **clinical trials** which test the potential of **new drug treatments** for Alzheimer's disease and dementia, or examine biomarkers for dementia or the biological processes by which Alzheimer's disease, and subsequently dementia, develops. Such research aims to further knowledge so as to lead to the development of disease-modifying drugs in the future.

The research that is being conducted by universities and research centres in this region therefore appears to be well linked to the NICE Guidelines Research Recommendations (see section 6.2.4) and the James Lind Alliance Dementia Research Priorities (see section 6.2.5). However, there does appear to be some gaps in the dementia research of the North West, namely:

- A lack of research regarding the most effective ways to encourage people with dementia to eat, drink and maintain nutritional intake (a James Lind Alliance Dementia Research Priority);
- A lack of research around when is the best / optimal time to move a person with dementia into a care home setting (a James Lind Alliance Dementia Research Priority); and
- A lack of research into possible 'cures' for dementia (a goal of the Prime Minister's Challenge on Dementia 2020) – the majority of the research undertaken by universities in the North West appears to focus on the treatment of dementia, and how best to live well with the disease.

6.6.2 Sharing Knowledge and Research

There appears to be some evidence of universities in the North West of England sharing knowledge, innovation and research findings in order to enhance capacity in this sector. For example, in October 2015, the Centre for Ageing Research at Lancaster University showcased the newest and most innovative research around dementia being undertaken by the university as part of the 'Dementia Futures' event. This also included work by public, private and third sector partners with whom the university works. An array of topics were examined during the event including: the latest software for tracking cognitive health; the emotional impact of dementia on care staff; dementia care training; and developments in drugs and health technology.

More recently, in January 2016, the University of Manchester hosted the 'Joint Dementia Research Showcase' in which it showcased dementia research activity alongside the University of Salford and Manchester Metropolitan University. At this half-day event, a series of brief presentations from each institution highlighted the breadth of the work of key research groups. Structured networking time around particular themes was also part of the programme on the day. The Showcase was attended by more than 140 academics from the three institutions, and was the result of a series of exploratory meetings aimed at fostering collaboration among the three universities.

The Alzheimer's Research UK Manchester and North West Network Centre unites researchers across the universities of Manchester, Salford, Liverpool and Lancaster, and supports dementia research through the funding of collaborative science and networking to share findings and resources. Through the Network Centre, there are opportunities for pump-priming funds, equipment grants, and travel awards[148].

There are also examples of partnerships / collaborative working on particular research projects among universities in the North West. For example, alongside the Personal Social Services Research Unit (PSSRU) at the University of Manchester, the Salford Institute for Dementia at the University of Salford are undertaking research into 'Effective home support in dementia care: components, impacts and costs of tertiary care'. The 'Neighbourhoods and Dementia' study also involves collaboration between the University of Manchester (lead partner), and experts from the universities of Liverpool, Salford and Lancaster.

6.6.3 Other Universities in the North West

For the purpose of this report, it was not possible to identify any dementia relevant research being conducted at other universities in the North West (such as the University of Cumbria, the University of Bolton, and University Campus Oldham/University of Huddersfield)[149].

[148] For more information, see: http://www.alzheimersresearchuk.org/for-researchers/network-centres/manchester-and-north-west-network-centre/whos-who/

[149] Through online research and phone calls with research administrators at these universities between April and June 2016, we were able to determine that there is no dementia research currently being undertaken at the University Campus Oldham / University of Huddersfield, and that while ageing research is being conducted at the University of Cumbria, currently none of this research is related to dementia. We were unable to make contact with anyone from the University of Bolton, however, we were unable to source any dementia related research here through our online searches.

6.7 Memory Services that Involve People in Dementia Research in the North West

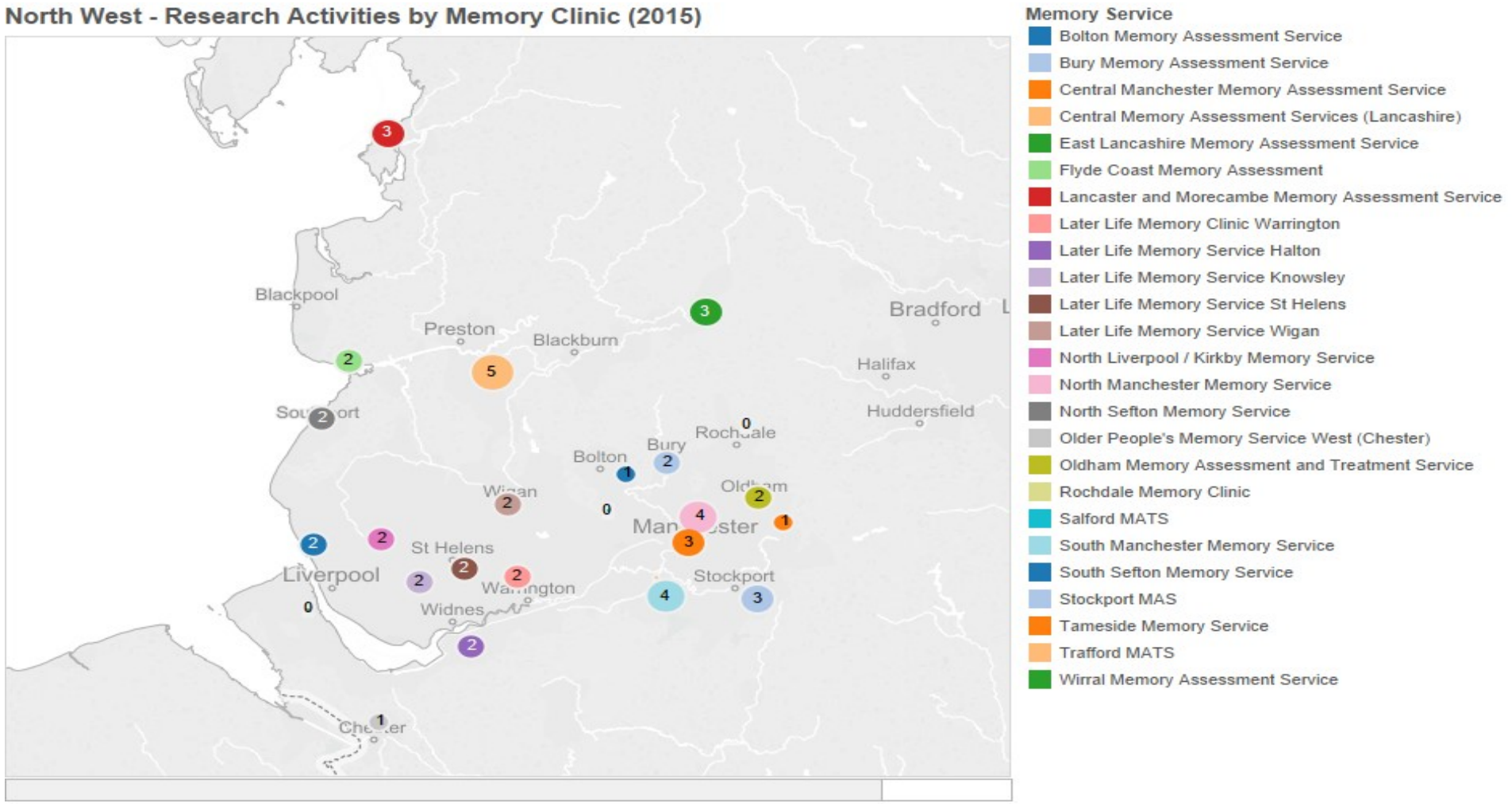
Memory services have an important role to play in the assessment, diagnosis, and treatment of individuals with dementia. However, the Memory Services National Accreditation Programme (MSNAP) Standards for Memory Services[150] also state that memory services in the UK should demonstrate a commitment to ongoing quality improvement and research. In 2015, the Royal College of Psychiatrists published the second English national memory clinics audit report[151], which documents the findings of an audit of memory clinics in England conducted between 15 September and 31 October 2014. The audit showed that overall in 2014, 153 memory clinics in England recruited individuals to at least one research study, and that the national average number of research studies each memory clinic recruited participants into was 2.98.

In the North West, seven memory services recruited individuals to more research studies than the national average. These were: South Manchester Memory Service (4 studies); Central Manchester Memory Assessment Service (3 studies); North Manchester Memory Service (4 studies) Stockport MAS (3 studies); East Lancashire Memory Assessment Service (3 studies); Lancaster and Morecombe Memory Assessment Service (3 studies); and Central Memory Assessment Services (Lancashire) (5 studies). Four memory services recruited no individuals to studies (Trafford MATS; Rochdale Memory Clinic; Salford MATS; and Wirral Memory Assessment Service), and for some areas, such as Blackpool, Cheshire East, Cumbria, and Blackburn, no data was available at the time of the audit.

Figure 6.1 shows the number of research studies that memory services in the North West recruited to in 2014 (see also Appendix 4 for table documenting the number of research studies recruited to by memory services in the North West).

[150] Memory Services National Accreditation Programme. (2014). Standards for Memory Services. Available at: http://www.rcpsych.ac.uk/pdf/MSNAP%20Standards%20Fourth%20Edition%202014r.pdf
[151] The Royal College of Psychiatrists. (2015). Second English National Memory Clinics Audit Report. London: Royal College of Psychiatrists.

Figure 6.1: Number of Research Studies that Memory Services in the North West Recruited Participants to



6.8 Conclusions

Research was identified as a key priority in the Prime Minister's Challenge on Dementia. Six of the 23 Councils in the North West noted that they commissioned research as part of their local policies or plans.

Ten of the 13 universities in the North West of England are involved in research that is relevant to individuals living with dementia and their carers, and many have dedicated research centres / institutes that aim to further knowledge and innovation in this area.

Universities in the North West also undertake a range of activities and events to raise awareness and knowledge of dementia and other related disorders. For example, in November 2015, Liverpool Hope University hosted an event on behalf of Liverpool Dementia Action Alliance which gave local businesses the opportunity to learn about dementia. The University of Manchester also funded a unique arts and science collaboration in September 2015 entitled 'Portraits of a Place'. This involved service users from Manchester Mental Health and Social Care Trust's Young Onset Dementia Service teaming up with artists, composers and musicians from Manchester Camerata to work on songs and artwork in weekly sessions. The aim of this project is to use learning from this work to develop similar activity with others who have young onset dementia, locally, regionally, and nationally. Cumbria University, despite not being involved in dementia research, is one of 53 universities in the Higher Education for Dementia Network (HEDN), and in January 2014, launched a new curriculum to improve dementia education in the UK.

While the universities in the North West undertake activities in order to share research and learning with other universities / academics in the area, a wider dissemination plan would be beneficial (i.e. aimed at practitioners and lay people) in order to ensure that the research can have as much impact as possible. However, universities in the North West do make efforts to include people with dementia and their carers in research (e.g. see Neighbourhoods and Dementia research study).

The involvement of memory clinics in research is also one of the key commitments in the Prime Ministers Challenge. In 2014, 25 memory clinics in the North West recruited participants to 50 studies, which is an average of two studies per clinic. Seven of these memory clinics recruited participants to more studies than the national average (3 studies), while four had not recruited individuals to any research studies.

7 DRIVING IMPROVEMENTS IN HEALTH AND SOCIAL CARE

7.1 Introduction

This section provides detail on services and activities to improve care and support for people with dementia in the North West.

7.2 Increasing Public Awareness and Understanding of Dementia

Increasing awareness of dementia is an important aspect to increasing care and support. This section considers:

- How increasing public awareness and understanding of dementia in the North West is included in local plans;
- Examples of work undertaken in the North West to increase public awareness and understanding of dementia in line with National Strategies (Living Well with Dementia: A National Dementia Strategy[152]and the Prime Minister's Challenge on Dementia 2020)[153]; and
- Conclusions and recommendations on increasing public awareness and understanding of dementia in the North West.

7.2.1 Local Plans

Increasing awareness and understanding of dementia is noted in 11 of the local plans. For example, the Wirral Health and Wellbeing Strategy (2013-2015) notes the need to improve public and professional awareness and understanding of dementia through the Wirral Well website by making use of national materials and taking into account individuals who are often missed by mainstream services such as certain ethnic groups or people with learning disabilities. The St Helen's 3 year Dementia Action Plan (2016-2019) also notes the need to 'ensure a co-ordinated approach to registration and participation in a number of national schemes to improve the awareness of dementia within the St Helens community and to develop a systematic communications and engagement strategy which will include a series of co-ordinated local awareness raising events'.

Priority 3 of the Blackpool Commissioning Strategy (2009-2019) is 'to provide support & raise awareness and understanding; and to promote early intervention and prevention', while the Central Lancashire Commissioning Strategy (2011-2015) notes the need to ensure better knowledge about dementia, to remove the stigma that still surrounds dementia, and for better education and training for all who come into contact with people with dementia and their carers.

The Warrington Dementia Strategy (2016-2019) also notes the need for prevention and promotion through raising awareness and understanding. Stockport's Dementia Strategy – Joint Commissioning Strategy (2010 – 2015) seeks to increase awareness of dementia the provision of information and advice, campaigns, training and recruitment of dementia champions. Similarly, the

[152] Department of Health. (2009). Living Well with Dementia: A National Dementia Strategy. Available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/168220/dh_094051.pdf
[153] Department of Health. (2015). Prime Minister's Challenge on Dementia 2020. Available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/414344/pm-dementia2020.pdf

Sefton Dementia Strategy (Living Well with Dementia, 2014-2019) highlights the importance of increasing awareness, particularly through the use of 'champions'.

The Bury Locality Plan (2016-2021) details how Bury will continue to raise awareness of dementia by ensuring that all staff receive the appropriate level of training required to carry out their responsibilities and by working with schools and within communities.

Cumbria Dementia Pathway (Version 3, 2016: Due for revision in June 2019) is a resource that targets people living with dementia. The pathway sets out useful information to patients as to what Dementia is, diagnosis & early signs of dementia, medical interventions, dementia friendly communities & environments, accommodation and end of life care. The pathway gives details on every aspect of dementia that is relevant to patients and is a vital, easily accessible source of information that is available to individuals with dementia which helps them to understand their condition.

7.2.2 Examples of work undertaken in North West to increase information and awareness about dementia

7.2.2.1 Dementia Friends[154]

Dementia Friends is a national initiative run by the Alzheimer's Society, and which aims to change people's perceptions about dementia. Dementia Friends Information Sessions are freely available to individuals of all ages across England and Wales and who wish to learn more about dementia and how they can help to create dementia friendly communities. Alternatively, individuals can become a Dementia Friend by watching an online video where you learn from one individual what it is like to live with dementia, and by signing up for the 'Little Book of Friendship', a resource pack which contains more information and tips on how to support those living with dementia to better feel a part of the community. The initiative has set a target of creating four million Dementia Friends by 2020.

Dementia Friends in St Helens

In St Helen's, a number of people have been trained as Dementia Champions to spread the 'Dementia Friends' awareness messages. St Helens Council's Public Health Team have promoted the Dementia Friends scheme not only within the Council but across the borough as a whole.

In April 2015, a Dementia Friends Champion training session took place at St Helens Town Hall, in which 25 champions were trained. Participants included officers from St Helens Council / CCG, as well as people from local organisations and people from outside St Helens. Since then efforts have been made to create a St Helens Dementia Friends Champion working group in which local champions could support each other and coordinate efforts to deliver information sessions in St Helens. As of April 2016, there had been two meetings of this group.

In December 2015, St Helens Council partnered with St Helens Star (newspaper) to deliver a campaign to increase the number of dementia friends and the membership of the Dementia Action Alliance. Each month an article was released with a personal story of a St Helens resident who had been affected by dementia in one way or another. At the start of the campaign, approximately 3,000 residents were registered as Dementia Friends (accumulated since 2013); as of April 2016, the figure was just over 7,000.

[154] https://www.dementiafriends.org.uk/

As of July 5th 2016, there were 1,620,075 Dementia Friends across the UK[155].

Through the initiative, individuals can also become a Dementia Friends Champion, a volunteer who encourages others to make a positive difference to people living with dementia in their community. Dementia Friends Champions will attend an induction session, which usually lasts for one day, and which provides volunteers with information and resources to help them better understand dementia and how it affects people, as well as sources of further information and support which they can direct individuals living with dementia to. Once trained, Dementia Friends Champions can deliver a Dementia Alzheimer's Society Dementia Awareness Week.

Each year in May, the Alzheimer's Society runs a Dementia Awareness Week, in which communities across the UK undertake a range of activities that aim to increase awareness and understanding of dementia. In 2016, the week ran from 15-21 May, and in 2015, the 17-23 May.

Provided below are some examples of the activities undertaken in the North West during Dementia Awareness Weeks in 2016 and 2015.

Blackpool – Dementia Awareness Week May 2016

A number of activities and events took place over the course of Dementia Awareness Week in Blackpool in May 2016. These included:

- A range of activities by Blackpool Victoria Hospital such as vintage tea parties, music, and Dementia Corridor Tours;
- A Memory Lane café;
- A Carers Day at Clifton Hospital with Radio Lancashire and which included stalls, music, vintage tea parties and information stands;
- A Dementia Awareness event to close the week, and which included information stalls, memory testing, entertainment, and a charity bike-ride.

[155] https://www.dementiafriends.org.uk/

Salford – Dementia Awareness Week May 2016

A number of activities and events took place over Dementia Awareness Week 2016 in Salford that aimed to help people learn more about how to live well with dementia. These included:

- Embracing the Dementia Challenge in Salford – This innovative engagement event was co-designed and co-produced by the Dementia Champions Group, and was aimed at people living with dementia, carers, family members, and anyone with an interest in dementia. The event provided an opportunity to meet various organisations, participate in activities over lunch, and celebrate the great improvements that have been in Salford, while also looking to the future.
- The Swim for Dementia Challenge – To raise awareness of dementia in Salford, Salford Community Leisure challenged the people of Salford to collectively swim a length for all the approximately 2,000 people in Salford who have dementia. The Challenges concluded with an intergenerational swimming relay where people living with dementia, family and friends were joined by members of the public to swim together.
- Dementia Arts Project – Through this project, which was funded through the Salford Health and Wellbeing board and Salford CCG as a pilot to show the benefits of using creative arts with people living with dementia, Start in Salford Creative Arts and Wellbeing Centre was commissioned to work with two venues (Humphrey Booth Resource Centre and Age UK) and to provide an artist to deliver weekly sessions to participants over the course of a year. The project culminated in two exhibitions during Dementia Awareness week.

7.2.2.2 Halton Dementia Week[156]

Following on from the 2016 National Dementia Awareness Week, Halton ran a Dementia Week from 23-27 May 2016 at the 'Changing Minds'[157] unit at Runcorn shopping centre. The event aimed to provide the public with an opportunity to meet local dementia support services and voluntary organisations that can help individuals with dementia to live well. By providing people visiting the shopping centre with the opportunity to seek out information in a way which is comfortable for them, the event helped to de-stigmatise dementia, educated people about the condition, and promoted local services. The café style setting of the 'Changing Minds' unit encouraged discussion and provided a friendly and informal setting for people to engage. The unit hosted a range of providers and services[158] giving out information over the course of the week, as well as drop-in surgery sessions (including the Admiral Nurse Service), sensory activities, reminiscence sessions, relaxation, and sing-alongs.

[156] https://www.haltonsthelensvca.org.uk/event/halton-dementia-week
[157] A month-long pop-up shop, which was part of a Mental Health Awareness campaign in Halton – local support workers from organisations such as The Samaritans were on hand at the shop for anyone who wished to discuss any issues, and there was a seating area with free refreshments available for anyone who wanted to drop in for a chat
[158] Organisations who took part in the Halton Dementia Week included: Alzheimer's Society, Admiral Nurses, Halton Carers Centre Safe in Town, Halton Health and Wellbeing team (Falls Awareness), Helping Hands Extra, Halton Library Service, Halton Trading Standards, Lunch Bunch, Helping Hands, and Wellbeing Enterprises.

7.2.2.3 Oldham Dementia Awareness Month[159]

In 2015, Oldham Dementia Action Alliance, in partnership with Oldham Council and Oldham Clinical Commissioning Group (CCG), ran a number of activities to celebrate the lives of people living with dementia, running from May 5th to June 8th. Such activities included:

- An event for people of Asian heritage to find out more about dementia and what support is available in Oldham;
- A Reminiscence Walk – a guided walk around a park which was suitable for people of ages. Each walk started with a film about dementia, and participants were then given a guided tour of the park, and informed of its' history. At the end of the walk, each participant received a potted sensory plant as a lasting memory from the walk;
- Dementia Friends sessions;
- Making Memories – creative reminiscence activities for older people and their carers including 'The Dementia Friendly Trail' which provided an activity sheet for people to use while visiting the Oldham Art Gallery and which provided conversation starters based on collections to encourage interaction and reminiscence; and
- Coffee mornings and information sessions.

7.2.2.4 'Hidden Voice' Liverpool

In November 2015, a music-with-film composition by John McHugh was hosted in St. Barnabas Church on Penny Lane in order to raise awareness of dementia. 'Hidden Voice' is based on the speech patterns of people living with dementia and their families, and was performed by the Royal Liverpool Philharmonic Orchestra at this free event. A Dementia Friends information session also took place at the event , focusing on the message that it is possible to live well with dementia.

7.2.2.5 St Helen's Chamber Dementia Awareness Workshops

St Helen's Chamber provide a number of seminars and workshops for their members throughout the year in order to transfer knowledge and expertise into businesses. Seminars are delivered for a number of areas such as Information Technology, Health and Safety and Health and Social Care. One such workshop run by the Chamber is concerned with Dementia Awareness, which aims to provide participants with a better understanding of dementia and its' associated behaviours. It will give participants an awareness of the main forms of dementia, knowledge of the common symptoms, and an understanding of resulting behaviours, as well as person-centred approaches.

7.2.3 Liaison and RAID (Rapid Assessment Interface and Discharge)

The information request asked respondents if there is a Dementia Liaison Service[160] in their area, if this service has any specific accreditations, if the local Dementia plan highlights an intention to develop such a service if there isn't one present already, if any of the services follow the RAID[161]

[159] http://www.oldham.gov.uk/info/200941/dementia/1488/dementia_awareness_month
[160] In line with the National Dementia Strategy (2009), Dementia Liaison Services is defined as providing 'assessment and diagnosis of those with suspected and/or known Dementia in acute and general hospitals inpatient and/or emergency departments'.
[161] The RAID model was evaluated in Birmingham and was found to improve the quality of care of older people by reducing their length of stay, avoiding their admission to acute hospital beds, and discharging them in increased numbers

model and if not, is there an intention to do so. Sixteen councils responded that there was a Dementia Liaison Service in place within their council area.

Five of the Liaison services' have specific accreditations. For example, in Liverpool the service is accredited by the Royal Liverpool University Hospital Psychiatric Liaison Accreditation Network. For those councils who do not currently have accreditation, some indicated that they are currently looking into this.

For those three councils who do not currently have a Dementia Liaison Service, all indicated that they had an intention to develop one in the near future.

In eight of the councils, dementia services follow the RAID model (Rapid Assessment Interface and Discharge.)[162] For example, in Salford the local liaison service was commissioned against a service specification based on the RAID model. Trafford Council also state that their hospital services follow this model, while Bury have a RAID Older People's inpatient service in place that takes referrals and supports in patients. This service helps in reducing delayed discharges by providing appropriate care and signposting. Tameside noted that Pennine Care FT has an Older People's RAID team which provides assessment, advice and support to patients within an acute setting with suspected and/or known mental health problems, including dementia.

Seven Council areas reported that their services do not follow the RAID model, including St Helens where the CCG have instead commissioned a transport service (in conjunction with Whiston A&E), which accompanies individuals with dementia home if they present at A&E but do not require admission. The service ensures that the person gets home safely and that their property is safe and warm before they leave them.

7.3 Personalisation

Eight councils provided information regarding the number of people with Dementia who have direct payments as of March 2015. Lancashire had the highest number of people with Dementia who had used direct payments (77) followed by Liverpool (46). Data from Skills for Care indicates that there are in the region of 35,000 older people in the North West receiving Direct Payments[163], although it is not known how many of these people have a Dementia diagnosis.

For the previous period (2014), Liverpool had the highest number of people with direct payments, at 45. The Council area with the second highest figure for 2014 was Bolton with 38, who also had the highest figure for the 2013 period with 36. None of the local authorities in the Council areas were one of the 18 "trailblazer" pilot sites for personalised budgets in residential settings.

7.4 Care at home and in the community

Councils were asked to provide information on the number of **day services for people with Dementia** in their area as well as the total number of people with Dementia who make use of these

back to their original place of residence, rather than an institution or care home. In addition, the RAID model has been shown to reduce the readmission rate after discharge by 65% in comparison with a pre-RAID group.

[162] The councils that do have dementia services that follow the RAID model are Salford, Tameside, Bury, Trafford, Wigan, Rochdale, City of Manchester and Knowsley.

[163] SCIE note that a direct payment is one way of taking a personal budget. It is means tested and those who are eligible can take a direct payment and arrange their own support.

services in a year. Eleven Councils provided this information. It is important to note that consultations with staff from three council areas highlighted that it can often be difficult to establish the exact number of service users with specific conditions such as dementia, as services are often provided under generic older people's services and records are not necessarily maintained in a format that would allow this type of analysis.

As shown below Lancashire has the highest number of total day services with 18 and Bury has the second highest, at 18 and 328 service users. Whereas Liverpool, who responded that they have three day services for people with dementia, have a total of 319 people using their services. Oldham recorded 130 people using 3 services.

Table 7:1: Day Services for People with Dementia

Council Area	Total number of day services for people with dementia in your area	Total number of people with dementia who use these services in a year
Liverpool City Council	3	319
Tameside Metropolitan Borough Council	3	0
Metropolitan Borough of Bury	12	-
Blackpool Council	1	77
Warrington Borough Council	1	38
Wigan Borough Council	2	73
Rochdale Metropolitan Borough Council	2	75
City of Manchester	2	128
Knowsley Metropolitan Borough Council	6	40
Lancashire County Council	18	328
Oldham Metropolitan Borough Council	2	130
St Helens Metropolitan Borough Council	2	85

Source: NW Dementia Perspectives Information Request for Councils, June 2016

Both Liverpool Council and Blackpool Council noted that the way in which service user data is collated does not allow them to provide an accurate figure of the number of people who are living with dementia using these services. For example, the Blackpool figure of 77 people using the services relates to a specific Dementia day service in the area which is for moderate to advanced Dementia. However, Blackpool have a further two day generic older people's services that they have commissioned and an additional community day provision through the third sector (e.g. Age Concern) which will also support people living with dementia (typically early onset to moderate)

which is not specifically recorded. Therefore, the official recorded statistic of people with dementia who use day services in these areas will be understatement.

Cheshire East – Dementia Reablement Service (DRS)

The DRS was set up in response to the Prime Minister's Dementia Challenge 2020. Cheshire East has the highest percentage of over 65s in England, making the area especially susceptible to burdens placed on the local health services as a result of Dementia care. The DRS was launched as a pilot scheme with the objective of providing support to individuals with early stage Dementia and their families. The service has the vision of helping individuals with Dementia live independently for as long as possible, which not only improves their quality of life, but also relieves the pressure on formal health care services. An evaluation of DRS found that the service reduced the strain on health services and prevented a significant decline in the wellbeing and quality of life of those living with dementia. Evidence showed that both service users and carers benefited from the service as a result of allowing patients to live at home for longer and the provision of information regarding the future. Health care professionals have also highlighted the positive impact of the DRS, with particular attention on the ease of referrals and the integrated working and linking of services. There has been over 650 referrals to the DRS since it was launched in May 2015, with a Dementia coordinator being appointed to work with providers, local organisations and individuals to make Cheshire East a Dementia friendly borough. As Cheshire East has a high over 65s population, the scheme has been successful and as a result of this, has been extended for a further 12 months.

Table 7.2 (below) provides aggregate data for the type and number of day services for individuals with Dementia that are available in the Council areas. Day services include: day centres, social activities, psychological therapies, cognitive stimulation therapies, dementia cafes, advocacy, dementia advisors, patient peer support groups, support for carers, carer peer support groups, carer education programmes, memory services, online advice / education portals, and patient education programmes.

Blackpool Council noted the most day services in the North West with 194 day services offered to people with Dementia. Lancashire have the second highest number of day services for people with Dementia with 184, while four Council areas were unable to provide figures for this. In terms of the total number of people with Dementia who use these services, of the Council areas who were able to provide information, Oldham had the most people with Dementia using their services with a total of 3,347 service users. Oldham also noted that they commission a wide range of support and activity focused services for people living in the community with dementia, ranging from dementia cafes to music groups and support services for carers. The services are delivered in partnership with the local DAA, the voluntary and community sector and faith based groups.

Cumbria - CHESS (Care Home Education and Support Service)

CHESS is a service, provided by Cumbria Partnership NHS Foundation Trust that works with people living with Dementia. The service aims to improve the quality of life and mental wellbeing of those individuals with Dementia while also acting as a programme for mental health education for care home staff. The CHESS service aims to improve the skills and abilities of care home staff so that they better equipped to deal with individuals with Dementia, or other mental health difficulties. The primary result of this service is a reduction in the amount of unnecessary hospital admissions, however the service also allows individuals with Dementia to remain in their placement of choice for a longer period of time, which improves the quality of life for people living with dementia.

Table 7:2: Type and Number of Day Services

Council Area	Total number of day services for people with dementia	Total number of people with dementia who use these services in a year
Salford City Council	26	-
Liverpool City Council	23	319
Tameside Metropolitan Borough Council	19	Not available at present
St Helens Metropolitan Borough Council	15[164]	N/A[165]
Metropolitan Borough of Bury	41	2,647
Trafford Metropolitan Borough Council	-	-
Cheshire West and Chester Council	-	-
Cumbria County Council	32	-
Blackpool Council	194	1,793[166]
Warrington Borough Council	9	1,130
Wigan Borough Council	42	2,879[167]
Rochdale Metropolitan Borough Council	10	75
Halton Borough Council	21	1,898
City of Manchester*	37	-
Knowsley Metropolitan Borough Council	17	39
Metropolitan Borough of Bolton	-	-
Lancashire County Council**	124	328

[164] St Helens Council stated they had 352 but do not have the breakdown
[165] 1560 Dementia Carers Registered. Approx. 200 new Carers registered in 15-16
[166] Plus a further estimate by the Council of 800-1,000
[167] Wigan Council stated that they had 4,486 not broken down to people living with dementia and their carer's, 603 people living with dementia and 754 carers

Council Area	Total number of day services for people with dementia	Total number of people with dementia who use these services in a year
Cheshire East Council	-	-
Oldham Metropolitan Borough Council	23	3,347[168]
St Helens Metropolitan Borough Council	2	157

Source: NW Dementia Perspectives Information Request for Councils – June 2016

The table below shows the number of people with Dementia that are **living at home with support**. Lancashire have aggregated their figure across all six of their CCGs.

Eleven councils noted that they provide support services to people living at home with dementia, five of whom were able to provide data on the number of people being supported. Of these Lancashire supported the most people living at home with support with a total of 506 people.

Table 7:3: Dementia Support at Home

Council Area	CCG	No. of people with dementia living at home with support
Salford City Council	-	-
Liverpool City Council	Liverpool	496
Tameside Metropolitan Borough Council	Tameside & Glossop	Figures Not Available
St Helens Metropolitan Borough Council	St Helens CCG	*[169]
Metropolitan Borough of Bury	Bury	298
Trafford Metropolitan Borough Council	-	-
Cheshire West and Chester Council	-	-
Cumbria County Council	Cumbria	Figures Not available
Blackpool Council	Blackpool	-
Warrington Borough Council	Warrington	167
Wigan Borough Council	Wigan	**[170]
Rochdale Metropolitan Borough Council	-	-
Halton Borough Council	-	-
City of Manchester	-	-
Knowsley Metropolitan Borough Council	Knowsley	141

[168] Oldham have additional people who use their services, however in their answer they provided estimates and not exact figures. They gave three figures that said 100+.
[169]St Helens Council stated that Dom care packages are provided based on Assessed need, not Diagnosis and that they do not have a breakdown of diagnosis.
[170]Wigan Council stated that 1,399 People registered with AS services in Wigan who are still at home up to last contact (max. 12 months ago). Also 115 clients still using their services who are in sheltered accommodation.

Council Area	CCG	No. of people with dementia living at home with support
Metropolitan Borough of Bolton	-	-
Lancashire County Council	all	506
Cheshire East Council	-	-
Oldham Metropolitan Borough Council	Oldham	Figures not available

Source: NW Dementia Perspectives Information Request for Councils – June 2016

Councils were also asked to supply information on the providers of home care and supported living services for those with Dementia in their area. Liverpool had the most providers (55) out of all the council areas.

Table 7:4: Home Care and Support Living Services[171]

Council Area	No. of providers of services for people with dementia	No. of providers of services for people aged 65+ but not with dementia	Total number of service providers
Salford City Council	-	-	-
Liverpool City Council	55	-	-
Tameside Metropolitan Borough Council	Not Available	Not Available	Not Available
St Helens Metropolitan Borough Council	-	-	-
Metropolitan Borough of Bury	16	16	16
Trafford Metropolitan Borough Council	-	-	-
Cheshire West and Chester Council	-	-	-
Cumbria County Council	9	9	9[172]
Blackpool Council	8	8	8
Warrington Borough Council	13	13	-
Wigan Borough Council	27	24	27

[171] Some local authorities have used the term “supported living” while others use “extra care housing”. In this context, supported living refers to the provision of homes to people with Dementia, in order to provide them with care and allow them to remain independent: http://www.dementiacare.org.uk/services/independent-supported-living/

[172] Cumbria used to have 47 providers of home care, however a recent retendering now means that they have a total of 9 providers covering 17 zones.

Council Area	No. of providers of services for people with dementia	No. of providers of services for people aged 65+ but not with dementia	Total number of service providers
Rochdale Metropolitan Borough Council	20	44	44
Halton Borough Council	-	-	-
City of Manchester	-	9	9
Knowsley Metropolitan Borough Council	5	5	5
Metropolitan Borough of Bolton	16	-	16
Lancashire County Council	-	-	-
Cheshire East Council	-	-	-
Oldham Metropolitan Borough Council	15	15	15

Source: NW Dementia Perspectives Information Request for Councils – June 2016

Wigan Council reported that they have 24 providers of home care services for people aged 65+ but who do not necessarily have dementia, as well as three home care providers that cater specifically for people with early onset Dementia.

St Helens offer what they call 'Dom Care' (a personal care service) which is provided on the basis of assessed need. Examples of services that St Helens Council provide to people in their own home include The Falls Service, Speech and Language, Memory Services, and Dementia Advisors.

Thirteen Councils reported that they have specific processes in place to ensure that Dementia services are implemented in their area **in line with NICE standards and guidelines**. This generally took the form of incorporating NICE guidelines in service specifications and contracts. For example, Cumbria noted that 'NICE standards are written into service specifications when contracts are renewed, and are integral to in-house services', while Wigan noted that 'all extra care provision and home care providers are expected to ensure their processes are in line with NICE standards and guidelines'. Knowsley reported that NICE guidelines have been used by the council and the CCG to support improvements in nursing and residential homes with regards to the quality of care they provide to patients with dementia.

Councils were also asked in the information request whether there were any specific **examples of services in their area that they believed to be good practice or in line with the Care Act 2014**. Liverpool responded by describing their SURF (Service User Reference Forum), which was established in 2014, and won the Best Engagement Initiative in the National Alzheimer's Society Awards 2015.

Bury Council described the Bury GP Dementia Pathway 2014, where GPs work in partnership with social care to diagnose and care-manage people with non-complex Dementia. All practices in Bury have a Dementia lead who have access to regular training and peer support forums.

7.5 Housing and Assistive Technology

The majority of councils (82%) provide assistive technology to those with Dementia living at home. For example, Liverpool Council state that they provide trackers, bathing and ADL (activities of daily living) equipment and telecare available to patients with dementia and that the average number of these technologies per patient varies based on individual need. Warrington provide smoke alarms, property exit alarms, bed sensors, natural gas detectors, carbon monoxide detectors, and bogus caller buttons, while Tameside provides also provides 'smoke detectors, wander alerts, possible pill dispensers, then any other peripheral devices as deemed appropriate'. Bolton provides 'falls detectors, bed and chair exit sensors, temperature extreme sensors, PIRs (passive infrared sensors), Door Exit sensors, Epilepsy sensors, and "buddi" systems[173].

As shown in the table below, of the eleven Councils that could collate this data, Bolton has the highest number of people with dementia using assistive technology with a total of 7,180.

Table 7.5: Number of Patients with Dementia Living at Home with Assistive Technology

Council Area	Number of patients with assistive technology
Salford City Council	3,025
Liverpool City Council	difficult to access data
Tameside Metropolitan Borough Council	221
St Helens Metropolitan Borough Council	-
Metropolitan Borough of Bury	23
Trafford Metropolitan Borough Council	-
Cheshire West and Chester Council	-
Cumbria County Council	1,969
Blackpool Council	-
Warrington Borough Council	899
Wigan Borough Council	77
Rochdale Metropolitan Borough Council	300
Halton Borough Council	117
City of Manchester	65

[173] https://www.buddi.co.uk/

Council Area	Number of patients with assistive technology
Knowsley Metropolitan Borough Council	12
Metropolitan Borough of Bolton	7,180
Lancashire County Council	Not available
Cheshire East Council	-
Oldham Metropolitan Borough Council	-

Source: NW Dementia Perspectives Information Request for Councils – June 2016

7.5.1 Specialist Housing for People with Dementia

Seven councils reported that they provide specialist housing for people with Dementia; however only five were able to provide information regarding the number of specialist housing units in their areas, while four provided information on the number of people with dementia using these housing units. As with other services some respondents noted that the specific condition of service users is not always recorded in a way that will facilitate an analysis by type of service user.

Table 7.6 Specialist Housing Units for People with Dementia

Council Area	Number of specialist housing units	Number of people with dementia using specialist housing units
St Helens Metropolitan Borough Council	2	23
Metropolitan Borough of Bury	20	23
City of Manchester	10	10
Knowsley Metropolitan Borough Council	101	11
Lancashire County Council	101	Dementia only stats Not available

Source: NW Dementia Perspectives Information Request for Councils – June 2016

Cumbria Dementia Home Care Environments project

In 2014, Cumbria County Council commissioned the University of Stirling to evaluate the Home Care Environments (HCE) service which ran in Allerdale and Copeland in 2013. The HCE service provided people with dementia and their families and carers with advice and resources to make simple changes to the design features of their homes to create a more dementia-friendly environment. The evaluation showed that a wide range of equipment and adaptations had been provided including: orientation boards, new carpets and other flooring, garden fences, night lights, adapted cutlery and crockery, easy use microwaves, movement sensors, medication reminder devices, raised flower beds, alterations to bathrooms and signs. Outcomes for people with dementia and their carers as a result of these adaptations or equipment included: delayed move to residential care, increased sociability, improved orientation for people with dementia, reduced work and stress for carers, reduced use of health and social care services at home, reduced risks of falling, and increased well-being.

Belong Villages

Belong is a values-based organisation, founded on the vision that older people have the right to enjoy the same community belonging and richness of experience that they have always known.

Belong Villages are designed to offer four key services:

- Households offering 24 hour care for people who need some degree of personal, dementia or nursing care;
- Apartments which can be bought or rented and where people continue to live independently;
- A village centre with a range of facilities open to the public, and where a specialist day care service – Belong Experience Days – is provided; and
- The Belong at Home domiciliary care, which goes out into the wider community to support people in their own homes.

The Belong Village is designed to offer the most supportive and calming environment possible to residents experiencing dementia. All staff are trained in dementia care, and the Villages also offer a free Admiral Nurse Service which provides specialist dementia support and advice to residents who have been diagnosed with dementia.

Belong operates a number of villages across the North West, including in Greater Manchester, Cheshire, Wigan and Warrington.

https://www.belong.org.uk/

7.5.2 Care and Nursing Homes and Beds

Table 7.7: Number of Care Homes per Area (2015)

Council Area	Total Number of CQC registered Care Homes	Total number of CQC registered Care homes providing dementia services	Number of CQC registered Care homes providing dementia services without Nursing	Number of CQC registered Care homes providing dementia services with Nursing	Number of CQC registered Care homes providing dementia services with Nursing (both Nursing and Non-Nursing Care)
Blackburn and Darwen	38	13	7	5	1
Blackpool	83	34	26	8	0
Bolton	48	24	13	10	1
Bury	64	21	13	7	1
Cheshire East	100	47	16	29	2
Cheshire West and Chester	84	39	18	17	4
Cumbria	179	98	70	24	4
Halton	31	15	8	4	3
Knowsley	30	14	10	4	0
Lancashire	449	185	111	70	4
Liverpool	111	45	19	26	0
Manchester	100	32	15	17	0
Oldham	46	41	28	13	0
Rochdale	59	18	11	7	0
Salford	49	15	8	7	0
Sefton	143	40	22	17	1

Council Area	Total Number of CQC registered Care Homes	Total number of CQC registered Care homes providing dementia services	Number of CQC registered Care homes providing dementia services without Nursing	Number of CQC registered Care homes providing dementia services with Nursing	Number of CQC registered Care homes providing dementia services with Nursing (both Nursing and Non-Nursing Care)
St Helen's	38	17	11	5	1
Stockport	73	39	27	12	0
Tameside	44	35	22	13	0
Trafford	60	25	14	10	1
Warrington	48	23	10	12	1
Wigan	56	27	13	14	0
Wirral	134	39	18	19	2
North West	**2067**	**886**	**510**	**350**	**26**

Source: CQC Care Directory April 2015

Table 7.8: Number of Dementia Beds per Area (2015)

Council Area	Total Number of Dementia Beds	Total number of dementia beds in CQC registered Care homes providing dementia services	Number of dementia beds in CQC registered Care homes providing dementia services without Nursing	Number of dementia beds in CQC registered Care homes providing dementia services with Nursing	Number of dementia CQC registered Care homes providing dementia services with Nursing (both Nursing and Non-Nursing Care)
Blackburn with Darwen	1101	554	201	284	69

Council Area	Total Number of Dementia Beds	Total number of dementia beds in CQC registered Care homes providing dementia services	Number of dementia beds in CQC registered Care homes providing dementia services without Nursing	Number of dementia beds in CQC registered Care homes providing dementia services with Nursing	Number of dementia CQC registered Care homes providing dementia services with Nursing (both Nursing and Non-Nursing Care)
Blackpool	1815	863	539	324	0
Bolton	1697	1092	341	724	27
Bury	1877	1056	365	642	49
Cheshire East	3950	2290	496	1626	168
Cheshire West and Chester	2857	1702	517	970	215
Cumbria	4875	3648	2180	1284	184
Halton	910	677	318	191	168
Knowsley	1169	673	323	350	0
Lancashire	12585	7291	3525	3540	226
Liverpool	3900	2321	750	1571	0
Manchester	2828	1397	426	971	0
Oldham	1832	1750	911	839	0
Rochdale	1690	757	365	392	0
Salford	1362	742	238	504	0
Sefton	3650	1619	669	914	36
St Helen's	1382	810	423	334	53
Stockport	2383	1636	941	695	0

Council Area	Total Number of Dementia Beds	Total number of dementia beds in CQC registered Care homes providing dementia services	Number of dementia beds in CQC registered Care homes providing dementia services without Nursing	Number of dementia beds in CQC registered Care homes providing dementia services with Nursing	Number of dementia CQC registered Care homes providing dementia services with Nursing (both Nursing and Non-Nursing Care)
Tameside	1928	1565	870	695	0
Trafford	1507	928	359	486	83
Warrington	1880	1380	378	897	105
Wigan	2238	1339	469	870	0
Wirral	3646	1628	502	1063	63
North West	**63062**	**37718**	**16106**	**20166**	**1446**

Source: CQC Care Directory April 2015

Table 7.9: Number of Dementia Beds per Area by Dementia Prevalence

Council Area	Total number of care home beds in CQC registered Care homes providing dementia services	Dementia recorded prevalence[1] (aged 65+)	Number of beds per person with dementia diagnosis
Blackburn with Darwen	554	1,051	0.53
Blackpool	863	1,678	0.51
Bolton	1,092	2,173	0.50
Bury	1,056	1,729	0.61
Cheshire East	2,290	3,616	0.63
Cheshire West and Chester	1,702	2,757	0.62

Council Area	Total number of care home beds in CQC registered Care homes providing dementia services	Dementia recorded prevalence[1] (aged 65+)	Number of beds per person with dementia diagnosis
Cumbria	3,648	4,871	0.75
Halton	677	870	0.78
Knowsley	673	1,117	0.60
Lancashire	7,291	10,008	0.73
Liverpool	2,321	3,312	0.70
Manchester	1,397	2,762	0.51
Oldham	1,750	1,782	0.98
Rochdale	757	1,444	0.52
Salford	742	1,999	0.37
Sefton	1,619	2,554	0.63
St Helen's	810	1,814	0.45
Stockport	1,636	2,517	0.65
Tameside	1,565	1,573	0.99
Trafford	928	1,908	0.49
Warrington	1,380	1,563	0.88
Wigan	1,339	2,341	0.57
Wirral	1,628	3,025	0.54
North West	**37718**	**58,464**	**0.65**

Source: CQC Care Directory April 2015

Councils were also asked how they ensure dementia care homes/beds are in line with NICE standards, Salford Council responded by saying that they use the contract and specification to make sure that their care homes/beds meet the NICE standards. Liverpool Council say they do this through their inspection and monitoring team, while Bolton do this through contract specifications and monitoring. St Helens care homes are subject to regular quality monitoring visits by St Helens Council Contracts and Quality Monitoring Team. These visits check compliance against regulatory

and contractual requirements with clinical aspects being monitored by a nurse who is a member of the team. The team also work closely with CQC especially if areas of concern have been identified as part of the inspection. Bury Council ensure that they meet the NICE standards by making references to duties in relation to NICE standards for each individual specification or contract as well as having their internal quality assurance team check compliance. The CQC also checks compliance.

In St Helens, good practice is promoted via regular provider forums and by the involvement of a number of health professionals from the care homes support team, meds management etc. Feedback from care managers, family members, service users or others who indicate a concern around a service users care or the setting in which they are placed are used to inform targeted focus visits which look to raise the standard across the sector. The care home staff also attend council training on dementia and other courses relating to their role.

7.6 Hospitals and Dementia Friendly Hospitals

Half of the consultees highlighted that they provide dementia training to staff in homes with and without nursing. The purpose of this is to increase dementia awareness and to ensure that people with dementia (with and without a diagnosis) receive appropriate support and care.

Nine councils provided data on emergency admissions to hospital with a primary diagnosis of dementia. Salford Council specifically noted that they were unable to provide this data as they don't code their data in a way that will allow this kind of extrapolation. The average number of admissions per annum across all nine respondents was 1,833. Lancashire recorded the highest number of admissions caused by dementia with 10,329, which equated to 2% of all admissions. This compares to Liverpool City Council who recorded 144 emergency admissions due to dementia, equating to 0.12% of all emergency admissions.

Nine councils also provided data on the average length of stay in hospital for patients with dementia. An average length of stay in a Liverpool hospital for a patient with dementia is 12.5 days, which is significantly longer than the average length of stay for all patients (2.9 days). Cumbria had the longest length of stay for people with dementia with patients stay, at an average stay of 30 days, whilst Bury had the lowest average length of stay at 1.4 days.

Seventeen (89%) councils noted that they have schemes and processes in place to identify people with dementia in hospital, as summarised below.

Five Councils (Salford, Liverpool, Cumbria, Warrington and City of Manchester) had more than one hospital scheme in place with Cumbria having the most out of all Council areas with four hospital schemes in place.

Five Council areas also noted that they followed the Butterfly scheme (Liverpool, Cumbria, Blackpool, Lancashire and Knowsley[174]). The Butterfly scheme[175] was developed by a former carer and it aims to improve the safety and wellbeing of hospital patients with Dementia by training hospital staff to identify patients living with Dementia and other memory impairment related conditions through a discreet butterfly symbol on the patients notes. The staff training involves informing staff to be positive and offer the most appropriate response to people who fall under the Butterfly scheme.

Rochdale- Oasis Unit

The Oasis Unit is a five-bed facility, commissioned by NHS Heywood, Middleton and Rochdale CCG (HMR CCG), which is dedicated to management of acute medical illness in those people who are living with dementia. The unit creates a dementia friendly evironment for tpeople living with dementia, as well as providing them with greater nursing staff ratios to receive a better quality of treatment, and input from specialist, Registered Mental Nurses. HMR CCG has invested around £1 million into this unit, with the service being provided by a skilled team of doctors, nurses and heatlhcare professionals from The Pennine Acute Hospitals NHS Trust and Pennine Care NHS Foundation Trust as well as a social worker from Rochdale Council Social

Tameside Council work in partnership with Dementia UK (the charity that provides Admiral Nurses), and after listening to the needs of family carers of people with dementia, they appointed the first Admiral Nurse in an acute hospital in the North of England. The Chief Admiral Nurse and Chief Executive of Dementia UK applauds Tameside Hospital for its foresight in becoming the first hospital in the North to make this appointment: “Having Admiral Nurses in an acute hospital environment is proven to minimise the stress and distress that some patients with a diagnosis of dementia, and their family, feel when they are in a hospital environment. Admiral Nurses in hospitals also help to reduce costs for the Trust by reducing the length of stay and the needs for costly agency or 1:1 staff to manage the distress signs exhibited by the person living with dementia. “They also provide health and social care staff with training and coping strategies to empower them to work confidentially and effectively with patients with dementia. In addition, they work with families to equip them to be able to continue with the caring and support role, to build resilience and to prevent future crises and unnecessary admissions.”

In the Cheshire East Council area, all people over 75 years who are admitted in an emergency are screened during their hospital stay for memory difficulties. If issues are detected their GP is asked to visit them once back at home and refer for specialist memory assessment as required. They also have an identifier in place on their electronic system to alert them that the person is living with dementia so that they know on admission that the person might require additional support. Finally, they use a dementia care bundle which contains a personal support plan, information that is

[174] Knowsley employ a slightly different version of the Butterfly scheme but still use signs and logos to ensure that staff are aware which patients have Dementia.
[175] http://butterflyscheme.org.uk/

essential for them to know about the person during their stay in hospital and ward staff use an electronic handover which will have information about diagnoses and needs.

7.7 End of Life Care

Improved end of life care is an objective within the National Dementia Strategy. Nice guidelines[176] also note that, "The care team should make sure that palliative care is available to people with dementia from the time they are diagnosed until the end of life. The team should consider the person's needs so they can maximise their quality of life"

This section collates information about the specific plans in each council area relating to the end of life care for patients with dementia.

Table 7:5: Specific End of Life Plan Strategies

Council Area	Health and well-being strategy	Local dementia plan	Joint strategic needs assessment
Salford City Council	Yes	No	No
Liverpool City Council	Yes	Yes	Yes
Tameside Metropolitan Borough Council	No	Yes	No
St Helens Metropolitan Borough Council	Yes	Yes	Yes
Metropolitan Borough of Bury	No	Yes	Yes
Trafford Metropolitan Borough Council	Yes	Yes	Yes
Cheshire West and Chester Council	No	Yes	No
Cumbria County Council	No	Yes	Yes
Wigan Borough Council	No	Yes	Yes
Rochdale Metropolitan Borough Council	Yes	-	No
City of Manchester	Yes	Yes	Yes
Knowsley Metropolitan Borough Council	No	No	Yes
Metropolitan Borough of Bolton	Yes	Yes	Yes
Lancashire County Council	Yes	Yes	No
Cheshire East Council	-	Yes	Yes
Oldham Metropolitan Borough Council	No	No	No

Source: NW Dementia Perspectives Information Request for Councils – June 2016

As set out in the table above, sixteen Councils noted that they had dementia specific end of life care plans. Eight Councils indicated that their Health and Well-being Strategy did contain specific plans for end of life care. Twelve reported that they had an end of life plan in place within their local Dementia plan, and ten councils' noted that end of life plans were covered in their Joint Strategic Needs Assessments.

Salford Council noted that their CCG is developing new End of Life Care standards for Primary Care and that these standards will follow NICE guidelines and standards. Bury Council also noted that

[176] https://www.nice.org.uk/guidance/cg42/ifp/chapter/palliative-care-and-care-for-people-nearing-the-end-of-life

the Bury Locality Plan contains a reference to the development of End of Life Care planning and that End of Life Care will be included in their H&WB Strategy refresh. Trafford and Cumbria both indicated that their plans followed best practice/guidance, while Warrington developed their end of life care plan with guidance from Leadership Alliance for the Care of Dying People (June, 2014)[177].

In Cheshire West and Chester, while the Council does not currently have a specific strategy on end of life care, this issue is built into all of their contracts. In Manchester, work is being led by Making Space to deliver training to identify EMI nursing homes regarding End of Life Care as part of a training package that was commissioned by the CCG.

7.8 Dementia Friendly Communities

Creating Dementia Friendly Communities is a key objective of the Prime Minister Challenge on dementia. Dementia Friendly Communities are defined as a "city, town or village where people with dementia are understood, respected and supported, and are confident that they can contribute to community life" (Alzheimer's Society, 2013). This section sets out information on the work that councils in the North West are undertaking to make their community more Dementia Friendly.

Thirteen councils noted that they have created Dementia Friendly Communities between 2013. Examples of activities undertaken include; Wigan Council who created fifteen Dementia friendly communities within the borough by 2015, providing funding for dementia friendly activities across the Borough. Awareness raising through the creation of Dementia Friends, events such as Dementia Awareness Week and local Memory walks and the creation of Wigan Dementia Action Alliance.

Bolton Council noted that they are currently undertaking a pilot within the Horwich area and have plans for a borough wide roll out. Nine Dementia Friendly communities in the North West, are registered with the Alzheimer's Society's Dementia Friendly Communities Programme, by 2015, including Wigan who have been highlighted as best practice by the Alzheimer's Society.

'There is a need to create dementia friendly communities where people with dementia and their carers will be encouraged to seek help and will be supported by their communities. People with dementia need to feel included in their community, be more independent and have more choice and control over their life. This can be achieved by raising awareness around dementia, building stronger communities and re-orientating the model of care from a deficit-based to an asset-based model' (Cheshire West and Chester, Integrated Strategic Needs Assessment)

Five councils have set out plans to develop Dementia Friendly Communities in the future within their JSNA. Four of whom (Liverpool, St Helens, Bury and Warrington), provided details on which CCG areas will be covered (Liverpool CCG, St Helens CCG, Bury CCG and Warrington CCG respectively). In terms of when the plans will be implemented, Bury provided an estimation of 2016/17 while St Helens noted that work is ongoing and they are having regular meetings with the Chair regarding the plans.

In 2015, Blackburn with Darwen, specifically the Borough 50+ Partnership, received £35,000 in funding to be used to assist those living with dementia living in the area. The project specified that they have two aims, to create a Dementia friendly community in the borough and to identify

[177] https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/323188/One_chance_to_get_it_right.pdf

patients early and provide them with support from when they are diagnosed to when they need later care and support.

Dementia Friendly Swimming (Manchester)

Manchester joined the Amateur Swimming Association (ASA) Dementia Friendly Swimming project at the beginning of 2015, as one of the pilot cities of the project. The aim of the project is to create a network of dementia friendly pools across the city, providing people living with dementia and their carers and families the opportunity to go swimming in a safe and supportive environment. This will help people to live well with the condition and stay engaged in their local communities. All sessions provided are free.

http://www.swimming.org/dementiafriendly/manchester-city-council/

7.9 Conclusions

This section of the report set out the range of key services available to people with dementia across the North West. Many respondents to the information request and those who were consulted with highlighted that it is often difficult to determine the actual number of service users with dementia, unless it is a dementia specific service. Given the difficulty in accessing accurate data on services for people with dementia it is therefore not possible to identify specific gaps in services.

Almost half of the councils in the North West noted that they have specific plans to increase awareness of dementia in their area, in line with the National Dementia Strategy and the Prime Minister's Challenge. There are a number of examples of local authorities working with Alzheimer's Society (through Dementia Friends and Dementia Action Alliance) to deliver a wide range of initiatives to make those in the community more aware of dementia and the needs of people living with dementia.

Sixteen councils noted that they provide a hospital liaison service, eight of which follow the RAPID model. RAPID services have been implemented and evaluated in other areas of England and were assessed as being highly effective at supporting people with dementia in acute hospitals.

The majority of Councils (82%) noted that they provide assistive technology to people with dementia in their area. The technologies include a wide range of alarms, detector and sensors. There is a wide range of reports noting that technology can help people with dementia maintain their independence and live in the own home for longer.[178]

Data from CQC showed that there are 886 care homes in the North West providing services for people with dementia, with over 37,000 beds. The number of beds per person with dementia varied considerably across each council area, ranging from 0.37 in Salford to 0.98 in Oldham. However, the number of beds in each area to indicate the level of occupancy or the level of care required.

The Dementia Friendly Communities initiative is continuing to develop across the North West with thirteen Council areas being involved and five further councils noting that they are planning dementia friendly community activities. Consultations with staff from local authorities and the

[178] *Dementia-friendly technology charter. Alzheimer's Society 2014.*

voluntary and community sector highlighted that there are a number of areas where staff are considering new ways to increase dementia awareness and to get other sectors involved (such as small businesses).

8 CROSS CUTTING THEMES

8.1 Introduction

There are a number of key themes which impact on all aspects of dementia care. This section sets out information relating to the dementia workforce, engaging and empowering, minority communities, medication and safeguarding.

8.2 Workforce

The following paragraphs summarise the statistics on the dementia workforce in the NW, including highest qualification held for health and social care staff, percentage of the workforce working for people with dementia, and a comparison with national statistics.

Table 8:1: Estimated Numbers of the Health & Social Care Workforce in the North West

Area	Total social care workforce	Workforce working with older people	Workforce working with people with dementia	% of Older people workforce working with dementia
England	**710,783**	**523,027**	**396,194**	**75.8%**
North West	**102,091**	**73,450**	**55,905**	**76.1%**
Bolton	3,637	2,873	2,252	78.4%
Bury	3,013	2,328	2,150	92.4%
Cheshire East	5,025	3,726	2,611	70.1%
Lancashire	17,996	12,751	9,995	78.4%
Trafford	2,807	2,103	1,568	74.6%
Cumbria	8,835	6,675	5,050	75.7%
Rochdale	3,125	2,060	1,595	77.4%
Sefton	4,910	3,055	1,995	65.3%
Halton	1,595	1,125	1,021	90.8%
Wigan	4,737	3,817	3,089	80.9%
Blackpool	2,646	2,175	1,470	67.6%
Tameside	2,409	2,288	1,822	79.6%

Area	Total social care workforce	Workforce working with older people	Workforce working with people with dementia	% of Older people workforce working with dementia
Knowsley	3,083	2,161	1,548	71.6%
Liverpool	7,197	3,875	3,022	78.0%
Manchester	4,455	3,138	1,962	62.5%
Stockport	3,983	3,189	2,459	77.1%
Cheshire West and Chester	4,993	3,664	2,476	67.6%
Oldham	2,995	2,620	1,991	76.0%
Salford	2,674	1,547	1,214	78.5%
St Helens	2,428	1,862	1,639	88.0%
Wirral	4,240	2,541	1,940	76.3%
Blackburn	1,819	1,033	893	86.4%
Warrington	3,489	2,844	2,143	75.4%

Source: Skills for Care, Open Access NMDS-SC Dashboards, Data as at June 26 2016.

As set out above, Lancashire has the greatest number of workers (17,996) and also the highest number of workers working with older people and workers working with older people with Dementia with 12,751 and 9,995 respectively. Lancashire have the highest numbers in each of these categories compared to the other areas, as the population of the area is significantly higher than the other regions that provided information. Cumbria have the second highest number of workers for each of these categories with 8,835, 6,675 and 5,050 respectively. The area with the smallest workforce numbers was Halton, while Blackburn had the fewest workers working with older people and people with Dementia.

Looking at the statistics for the proportion of older people with Dementia compared to the total number of older people for the North West and England as a whole, the North West has higher than the England average (75.8%) with a proportion of 76.1%. Interestingly, when looking at proportion, Bury and Halton have the highest percentage figures with 92.4% and 90.8% respectively while Lancashire had only 78.4%. The lowest proportion came from Manchester where the percentage figure was 62.5%

The following table sets out the latest statistics relating to the qualifications of the social care workforce of those working with people with dementia.

Table 8:2: Highest Qualification Level of Adult Social Care Workforce for Areas in the North West Working with Older People with Dementia (NMDS-SC)

Area	No qualification held	Entry level/ Level 1	Level 2	Level 3	Level 4 or above	Other qualification(s)	Number of staff
England	**32.8% (30,859)**	**0.6% (559)**	**24.8% (23,301)**	**15.8% (14,867)**	**13.5% (12,721)**	**11675 (12.4%)**	**93,982**
Bolton	18.5% (191)	0.0% (0)	27.2% (280)	13.8% (142)	16.9% (174)	244 (23.7%)	1,031
Bury	15.3% (101)	0.0% (0)	50.1% (331)	14.7% (97)	15.4% (102)	30 (4.5%)	661
Cheshire East	32.0% (114)	0.0% (0)	18.8% (67)	25.0% (89)	17.4% (62)	24 (6.7%)	356
Lancashire	20.7% (681)	2.7% (88)	24.5% (806)	13.5% (444)	15.7% (515)	750 (22.8%)	3,284
Trafford	31.3% (196)	0.5% (3)	30.9% (194)	17.9% (112)	16.3% (102)	6 (1.0%)	627
Cumbria	50.0% (702)	1.2% (17)	18.4% (258)	13.1% (184)	10.3% (145)	98 (7.0%)	1,404
Rochdale	30.5% (114)	0.3% (1)	21.1% (79)	11.5% (43)	21.7% (81)	56 (15.0%)	374
Sefton	31.2% (64)	0.0% (0)	23.4% (48)	30.2% (62)	10.7% (22)	9 (4.4%)	205
Halton	9.2% (11)	0.0% (0)	16.0% (19)	23.5% (28)	16.0% (19)	42 (35.3%)	119
Wigan	42.2% (294)	0.0% (0)	29.9% (208)	17.1% (119)	6.9% (48)	27 (3.9%)	696
Blackpool	20.8% (151)	1.0% (7)	15.0% (109)	23.1% (168)	25.3% (184)	107 (14.7%)	726
Tameside	40.7% (161)	0.8% (3)	22.2% (88)	20.7% (82)	6.1% (24)	38 (9.6%)	396
Knowsley	29.6% (123)	0.0% (0)	24.8% (103)	18.5% (77)	13.0% (54)	59 (14.2%)	416
Liverpool	28.6% (348)	0.0% (0)	32.6% (396)	18.9% (230)	18.8% (229)	13 (1.1%)	1,216

Area	No qualification held	Entry level/ Level 1	Level 2	Level 3	Level 4 or above	Other qualification(s)	Number of staff
Manchester	14.1% (136)	2.1% (20)	21.9% (211)	7.7% (74)	18.3% (176)	345 (35.9%)	962
Stockport	36.3% (284)	0.0% (0)	20.7% (162)	9.2% (72)	27.6% (216)	46 (5.9%)	783
Cheshire West and Chester	36.8% (204)	0.2% (1)	27.0% (150)	16.4% (91)	11.4% (63)	46 (8.3%)	555
Oldham	32.2% (194)	0.0% (0)	18.4% (111)	22.7% (137)	17.9% (108)	53 (8.8%)	603
Salford	55.9% (62)	0.0% (0)	30.6% (34)	9.9% (11)	3.6% (4)	0 (8.8%)	111
St Helens	27.0% (124)	3.5% (16)	31.3% (144)	21.1% (97)	10.9% (50)	29 (6.3%)	460
Wirral	27.6% (118)	0.5% (2)	26.7% (114)	23.0% (98)	12.9% (55)	40 (9.4%)	427
Blackburn	41.8% (167)	0.8% (3)	26.5% (106)	16.8% (67)	8.8% (35)	22 (5.5%)	400
Warrington	41.9% (75)	0.0% (0)	14.5% (26)	12.8% (23)	5.6% (10)	45 (25.1%)	179

Source: Skills for Care. Open Access NMDS-SC Dashboards, Data as at June 26 2016

The above table shows the highest level of qualification achieved by the adult social care workforce working with older people with dementia in the areas of the North West. Stockport had the highest percentage of workers with a level 4 or above qualification, at 216 or 27.6%. On the other hand, Salford had the highest percentage of the workforce holding no qualifications with 55.9% (62 workers) not holding a qualification.

In three areas, more than 2% of the workforce had a level 1 or entry level qualification: Lancashire, Manchester and St Helens with 2.7%, 2.1% and 3.5% respectively.

The table below shows the level of qualifications that members of the adult social care workforce in the North West are currently working towards. As can be seen, across the North West as a whole, 8.8% of the workforce are currently in the process of achieving a qualification at Level 2, 3, 4 and above (in comparison to 8.4% of the English workforce). Tameside has the highest percentage of its' workforce working towards a Level 4 or above qualification at 3.3%, while Blackpool have the highest percentage of workers in the process of obtaining other relevant social care qualifications, at 6.4%.

Table 8:3: Qualifications Being Worked Towards (in progress)

Area	No qualifications being worked towards	Entry level or Level 1	Level 2	Level 3	Level 4 or above	Other relevant social care qualification(s)	Any other qualification(s)
England	**89.6% (64,148)**	**0.1% (52)**	**4.1% (2,902)**	**3.4% (2,454)**	**0.9% (629)**	**0.4% (320)**	**1.5% (1,054)**
North West	**88.1% (9,444)**	**0.0% (5)**	**5.2% (562)**	**2.7% (293)**	**0.9% (101)**	**0.9% (92)**	**2.1% (225)**
Bolton	85.3% (244)	0.0% (0)	3.1% (9)	6.6% (19)	1.0% (3)	0.0% (0)	3.8% (11)
Bury	98.0% (675)	0.0% (0)	1.3% (9)	0.4% (3)	0.3% (2)	0.0% (0)	0.0% (0)
Cheshire East	82.3% (693)	0.0% (0)	12.4% (104)	3.6% (30)	1.0% (8)	0.1% (1)	0.7% (6)
Lancashire	85.3% (1,093)	0.0% (0)	4.4% (57)	3.0% (39)	1.4% (18)	3.5% (45)	2.3% (29)
Trafford	83.4% (316)	0.0% (0)	7.1% (27)	2.9% (11)	1.8% (7)	0.5% (2)	4.2% (16)
Cumbria	87.5% (1,158)	0.2% (2)	4.5% (60)	2.6% (35)	1.2% (16)	0.4% (5)	3.6% (48)
Rochdale	95.6% (217)	0.0% (0)	0.9% (2)	0.0% (0)	1.3% (3)	0.4% (1)	1.8% (4)
Sefton	85.4% (187)	0.0% (0)	3.2% (7)	8.7% (19)	2.7% (6)	0.0% (0)	0.0% (0)
Halton	100.0% (161)	0.0% (0)	0.0% (0)	0.0% (0)	0.0% (0)	0.0% (0)	0.0% (0)
Wigan	91.8% (595)	0.0% (0)	5.2% (34)	1.7% (11)	0.6% (4)	0.3% (2)	0.3% (2)
Blackpool	82.7% (91)	0.0% (0)	0.0% (0)	5.5% (6)	2.7% (3)	6.4% (7)	2.7% (3)
Tameside	84.5% (229)	0.0% (0)	3.0% (8)	5.9% (16)	3.3% (9)	1.1% (3)	2.2% (6)
Knowsley	80.9% (55)	0.0% (0)	10.3% (7)	7.4% (5)	0.0% (0)	1.5% (1)	0.0% (0)
Liverpool	84.1% (159)	0.0% (0)	12.2% (23)	2.1% (4)	0.0% (0)	0.0% (0)	1.6% (3)
Manchester	92.3% (168)	0.0% (0)	0.5% (1)	1.1% (2)	2.2% (4)	1.6% (3)	2.2% (4)

Area	No qualifications being worked towards	Entry level or Level 1	Level 2	Level 3	Level 4 or above	Other relevant social care qualification(s)	Any other qualification(s)
Stockport	93.0% (917)	0.0% (0)	1.1% (11)	1.3% (13)	0.4% (4)	1.0% (10)	3.1% (31)
Cheshire West and Chester	79.4% (466)	0.0% (0)	10.9% (64)	4.1% (24)	0.7% (4)	0.3% (2)	4.6% (27)
Oldham	90.8% (643)	0.0% (0)	3.1% (22)	3.2% (23)	0.3% (2)	0.0% (0)	2.5% (18)
Salford	99.1% (229)	0.0% (0)	0.9% (2)	0.0% (0)	0.0% (0)	0.0% (0)	0.0% (0)
St Helens	90.9% (482)	0.0% (0)	3.2% (17)	2.1% (11)	0.2% (1)	1.1% (6)	2.5% (13)
Wirral	84.3% (183)	0.9% (2)	7.8% (17)	4.6% (10)	0.9% (2)	0.0% (0)	1.4% (3)
Blackburn	83.7% (216)	0.4% (1)	10.9% (28)	2.3% (6)	1.2% (3)	1.6% (4)	0.0% (0)
Warrington	81.2% (267)	0.0% (0)	16.1% (53)	1.8% (6)	0.6% (2)	0.0% (0)	0.3% (1)

Source: Skills for Care. Open Access NMDS-SC Dashboards, Data as at June 26 2016

With regards to training undertaken by the adult social care workforce in the North West (as represented in the table below), training in Dementia Care has been completed in all 23 areas. Knowsley have the highest percentage of their workforce trained in Dementia Care at 63%, followed by Liverpool at 58.5%, and Blackburn at 52.3%. In Liverpool, health staff are required to complete dementia training tier 1, 2 or 3 depending on their area of work.

Table 9:4: Workforce Training Profile

Area	Dementia care	Dignity, respect and person centered care	Equality, diversity and human rights training	Mental capacity act and deprivation of liberty safety	Palliative / end of life care	Safeguarding adults
Bolton	34.1%	11.2%	5.9%	30.5%	15.8%	45.4%
Bury	38.3%	38.3%	33.7%	51.7%	21.9%	69.9%
Cheshire East	41.5%	13.8%	23.9%	24.4%	6.7%	63.4%

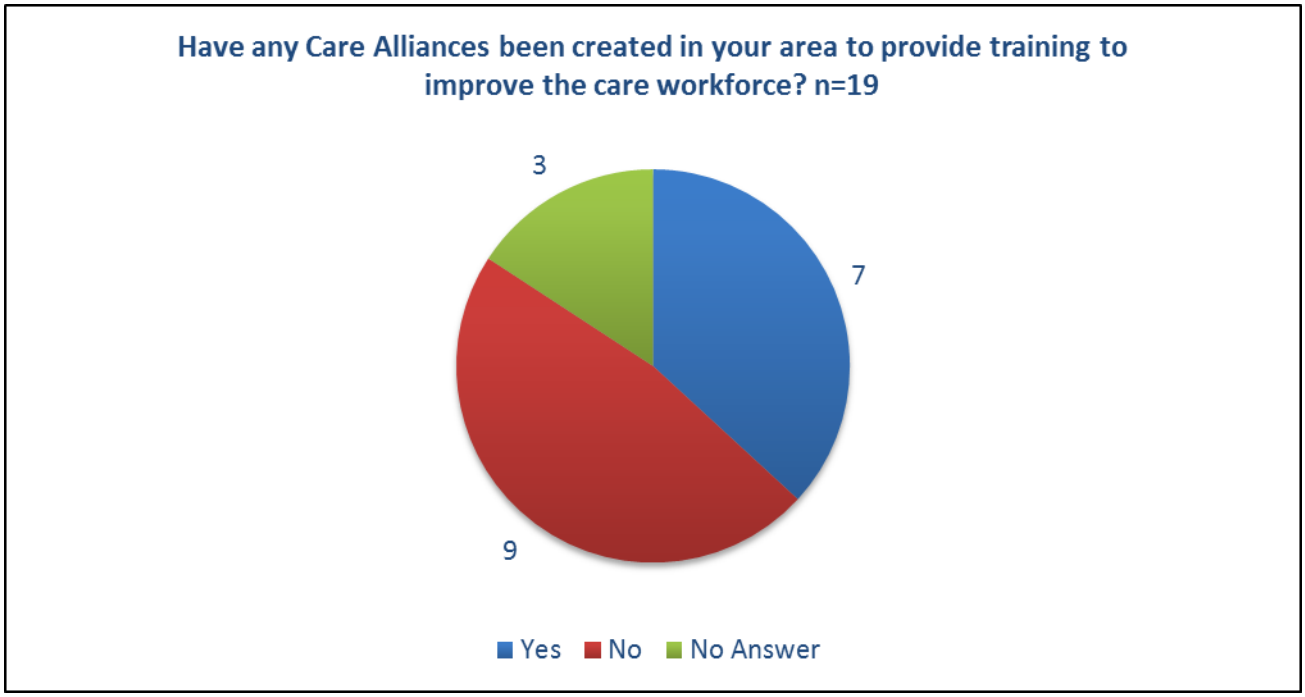
Area	Dementia care	Dignity, respect and person centered care	Equality, diversity and human rights training	Mental capacity act and deprivation of liberty safety	Palliative / end of life care	Safeguarding adults
Lancashire	35.6%	16.6%	15.3%	31.9%	12.7%	60.7%
Trafford	44.4%	17.4%	13.7%	28.8%	14.2%	45.2%
Cumbria	26.6%	12.6%	13.1%	15.7%	9.9%	69.1%
Rochdale	29.0%	23.8%	12.7%	28.9%	10.7%	47.3%
Sefton	40.5%	6.5%	19.0%	20.4%	8.5%	74.4%
Halton	36.8%	0.0%	0.0%	10.5%	32.6%	15.8%
Wigan	38.3%	17.5%	33.3%	41.6%	9.9%	71.7%
Blackpool	30.4%	14.1%	10.4%	37.4%	8.7%	68.5%
Tameside	45.0%	20.1%	27.0%	35.0%	11.6%	71.4%
Knowsley	63.0%	37.3%	37.6%	37.0%	22.0%	51.8%
Liverpool	58.5%	46.7%	48.7%	56.0%	38.4%	70.3%
Manchester	37.5%	4.5%	12.3%	27.0%	9.6%	53.9%
Stockport	31.4%	10.8%	2.6%	23.5%	7.5%	54.4%
Cheshire West and Chester	28.2%	23.0%	25.7%	38.4%	19.2%	60.5%
Oldham	33.3%	5.7%	17.0%	27.9%	9.4%	72.2%
Salford	14.6%	4.9%	12.9%	16.3%	4.6%	50.3%
St Helens	52.0%	11.5%	7.6%	37.5%	18.8%	55.9%
Wirral	50.5%	39.8%	34.7%	45.2%	25.6%	73.2%
Blackburn	52.3%	15.1%	7.7%	15.6%	24.6%	65.9%
Warrington	35.3%	25.5%	23.4%	27.0%	7.1%	45.3%

Source: Skills for Care. Open Access NMDS-SC Dashboards, Data as at June 26 2016

Care Alliances have also been created in seven councils in order to provide training to improve the care workforce.

St Helens are currently reviewing their workforce and training strategy so that they will have a more integrated approach to training provision, while Blackpool's Care Home Training Team has supplied free training to care homes over the past few years. Finally, in Oldham, there is an Oldham Training Partnership which is made up of care at home organisations, care homes, the Council, the CCG, Skills for Care, Oldham College and Age UK Oldham.

Figure 9.1: Care Alliances



In Bury, Dementia Friends has been rolled out to all front line staff in Bury Council and face-to-face training is provided for those who come into direct contact with customers. SCIE modules have also been made available to all staff, while those who work directly with people with dementia are trained to standards in the Skills for Care Framework. Contracts with providers in Bury state that all staff must undergo Care Certificate training and, if providing specialist dementia services, must be trained to the level indicated in the Skills for Care Framework.

In Knowsley, dementia awareness training and a City and Guilds level 3 certificate in dementia is offered to all staff.

8.3 Involving, Engaging and Empowering People with Dementia and their Carers

The following paragraphs provide examples of activities and initiatives in the North West to involve, engage and empower people with dementia and their carers.

Empowerment

Empowerment was formed in March 2013 from the merger of Blackpool Advocacy and Lancaster and District Women's Aid. The service operates across Lancashire, working to empower people affected by domestic abuse, health and social care problems, and dementia.

Empowerment provides a range of dementia services across Blackpool such as:

- Dementia Advisor Service, which provides free, independent and confidential support to

Empowerment

people who have a diagnosis of dementia or dementia related concerns;

- Dementia Friendship and Support Network, which provides opportunities for people living with dementia in Blackpool to meet each other, make friends, and take part in a range of activities including lunch clubs, arts and crafts and day trips; and
- Memory Screener, which provides free memory screening for people in Blackpool aged 50-90, to identify people with memory problems early so they can get the support they need at an earlier stage of their condition and plan for their future.

For more information on Empowerment and their dementia services, see: http://www.blackpooladvocacy.co.uk/

The Dementia Engagement and Empowerment Project (DEEP)

The DEEP is a nationwide project that aims to facilitate collaboration between groups of people with Dementia across the UK, whilst also having a regional aspect. In the North West, Lancashire Dementia Voices (LDV) is just one of the projects present in the region. The LDV is a voluntary independent group of people living with dementia and carers who aim to educate, raise awareness and challenge service providers on post diagnosis support. The group meets monthly to share and contribute stories, and discuss how they can influence service providers[179].

DEEP also supports the following groups in the North West Region with the aim of changing services and policies to have a positive effect on the lives of people with Dementia:

- Fabulous Forgetful Friends, Manchester;
- The Liverpool Service User Reference Forum (SURF);
- Chinese Wellbeing on behalf of Liverpool DAA Diversity Sub Group;
- Weekend Day Centre for Dementia Care (Stockport);
- Oldham Dementia Carers Group: Springboard;
- Open Doors Project, Salford; and
- EDUCATE (Early Dementia Users Co-operative Aiming To Educate) Stockport.

House of Memories in Liverpool

House of Memories is an award-winning training programme, developed and delivered by National Museums Liverpool, and which targets the carers of people living with dementia and health and social care professionals. The free day-long workshop sessions use artistic interpretation, curatorship, museum education, and reminiscence therapy techniques to provide participants with information about dementia and equip them with the practical skills and knowledge to facilitate a positive quality of life experience for people living with dementia.

The programme has also developed an innovative My House of Memories app, which allows

[179] For more information, see: http://lancashiredementiavoices.org/

House of Memories in Liverpool

individuals living with dementia and their carers to explore objects from the past and share memories together.

The programme also offers a free 'memory suitcase loan service' which contain objects, memorabilia and photographs to help carers engage with the individuals they are looking after. General and themed suitcases are available to loan for up to two weeks at a time, and contain a range of topics relating to the past such as music and fashion memorabilia, and picture books and games. Themed suitcases are available for particular minority groups with dementia such as the Liverpool Irish community, and those of LGBT or BME heritage.

In 2013, the House of Memories training programme was extended to other venues in the North West of England, including workshops at Salford Museum and Art Gallery, and Bury Art Museum. An evaluation of the programme in these areas found that House of Memories*:

- Significantly improved levels of understanding of dementia, including complexities in how dementia is presented and implications for those directly affected including carers and family members;
- Enhanced capacity for considered, empathetic, interpersonal care that is responsive to individual circumstance;
- Improved professional conscientiousness on individual and collective bases; and
- Encouraged openness to creative, inclusive, alternative approaches to care that are responsive to individual needs.

For more information on the programme and its' evaluations, see: http://www.liverpoolmuseums.org.uk/learning/projects/house-of-memories/

*Source: *National Museums Liverpool. (2013). An evaluation of House of Memories Dementia Training Programme: Northern Model. Available at: http://www.liverpoolmuseums.org.uk/learning/documents/HoM-evaluation-Northern-model-2013.pdf*

8.4 Minority Communities

Four (21%) Council areas noted specific policies to address the needs of those living with dementia and their carers from ethnic minorities.

- Bury, noted that their strategy is currently in development but will have policies that will address these needs of people living with dementia and their carer's.
- Trafford, stated that they have contact with a local voluntary sector organisation regarding BME people with Dementia in the area and also have a BME development worker within the Trafford CCG.
- Wigan noted that while they don't have specific policies in place, all their policies are assessed against the nine domains of the Equality Act 2010 to ensure appropriate access and adjustments.

Rochdale Befriending Service

Rochdale has a large South Asian population, as well as a substantial Polish community. In the past, the Alzheimer's Society had set up a Dementia Café for people from BAME communities. However, these were not found to be very successful, partly due to the stigma attached to dementia among South Asian communities which meant that people with dementia were not comfortable attending a service with other people from their own or other communities.

Therefore, with the help of funding from local health commissioners, Alzheimer's Society staff in the Rochdale area set up a new befriending service in January 2013, which had a specific focus on befriending people from BME communities. The service works collaboratively with and receives referrals from several organisations, including the local memory service and South Asian community groups. The Befriending manager attends events for the BME community to help build relationships with people from all communities, and will recruit volunteer befrienders who have the cultural awareness to work with people from BME communities.

Source: All-Party Parliamentary Group on Dementia. (2013). Dementia does not discriminate: The experiences of black, Asian and minority ethnic communities.

A review of literature (see section 4) also highlighted that training for practitioners to overcome language and cultural differences is also an important step in affecting a positive change for dementia care services available to BME communities[180] as well as raising awareness among these communities about dementia and the services that are available.

8.5 Anti-psychotic Medication Prescribing

Three Council areas provided information on the number of individuals with Dementia who received prescriptions in 2015, only one of which was also able to provide information for 2014 and 2013. Tameside and Cumbria area Councils stated that the information to answer the question was not available and several other Council areas stated that the difficulty obtaining information was due to the CCG not collecting this type of data, other organisations/boroughs carrying out annual audits on the prescribing of anti-psychotic prescriptions that make getting this type of data difficult etc.

Lancashire Council didn't provide figures, however they did mention that they have made good progress over the last two years in reducing the number of anti-psychotic prescriptions for people living with dementia. The data that was available is set out in the following table.

[180] Moriarty, J., Nadira, S., Robinson, J. (2011) *Black and minority ethnic people with dementia and their access to support and services*. Available at https://www.researchgate.net/profile/Jo_Moriarty/publication/233741268_SCIE_Research_Briefing_35_Black_and_Minority_Ethnic_People_with_Dementia_and_Their_Access_to_Support_and_Services/links/0fcfd50af852a5a3d3000000.pdf

Table 8:3: Individuals Receiving Prescriptions

Council Area	Number of individuals with dementia who received prescriptions in 2015	Number of individuals with dementia who received prescriptions in 2014	Number of individuals with dementia who received prescriptions in 2013
Liverpool City Council	12% of those diagnosed	-	-
Tameside Metropolitan Borough Council	Not Available	Not Available	Not Available
Trafford Metropolitan Borough Council	6% of those diagnosed	-	-
Cumbria County Council	Not available	Not available	Not available
Blackpool Council	-	-	-
Warrington Borough Council	6% of those diagnosed	122	105

Therefore, due to the very limited amount of data available it was not possible to identify any trends in the prescription of anti-psychotics across the North West.

Non-Pharmaceutical Intervention Project

The Non-Pharmaceutical Intervention (NPI) project was an 18 month project to deliver a range of group based activity services for people living with dementia and their carers in Merseyside. The project was commissioned and funded in part by the Primary Care Trusts of Liverpool, Knowsley and Sefton, and additional funds were contributed by Alzheimer's Society. The programme of services delivered under the programme included:

- **Visual Arts**: Participants were invited to attend two hour sessions twice a month with an accompanying carer or family member who was also invited to take part in the artistic activities. As part of the sessions participants were introduced to a range of different art techniques and materials and encouraged to create a final piece of artwork of their choice;
- **Dance and Movement**: At these sessions, dance facilitators utilised a number of engagement and movement techniques including improvisation, games, reminiscence, song and music, partner work, touch and mirroring. Participants were encouraged to contribute to the content and structure of the sessions;
- **Maintaining Skills**: Activities included games, cognitive activities, arts and crafts, and reminiscence activities such as facilitated discussions around books, and photographs etc.
- **Music and Well-being**: Music facilitators supported participants through a range of different musical activities such as playing as part of a group, experimenting with different instruments,

Non-Pharmaceutical Intervention Project

and working together to compose and rehearse a final piece;

- **Reading Together**: During these sessions, the facilitator would lead discussions around poems or short stories;
- **Singing for the Brain**: The principal aims of Singing for the Brain are to provide a facilitated structured group session for people with dementia and their carers designed around the principles of music therapy and singing; and
- **Carers Information and Support programme**: Within these sessions, participants were encouraged to ask questions and engage with one another through sharing experiences and challenges.

An evaluation of the programme showed that the services had a positive impact on participants' well-being and quality of life, with particularly positive impacts on levels of social integration. Four key messages were developed from the results:

1. The importance of process over product;
2. The impact of a communal spirit;
3. Facilitating the enjoyment of activities for the person with dementia and carer together; and
4. The potential for improving quality of life.

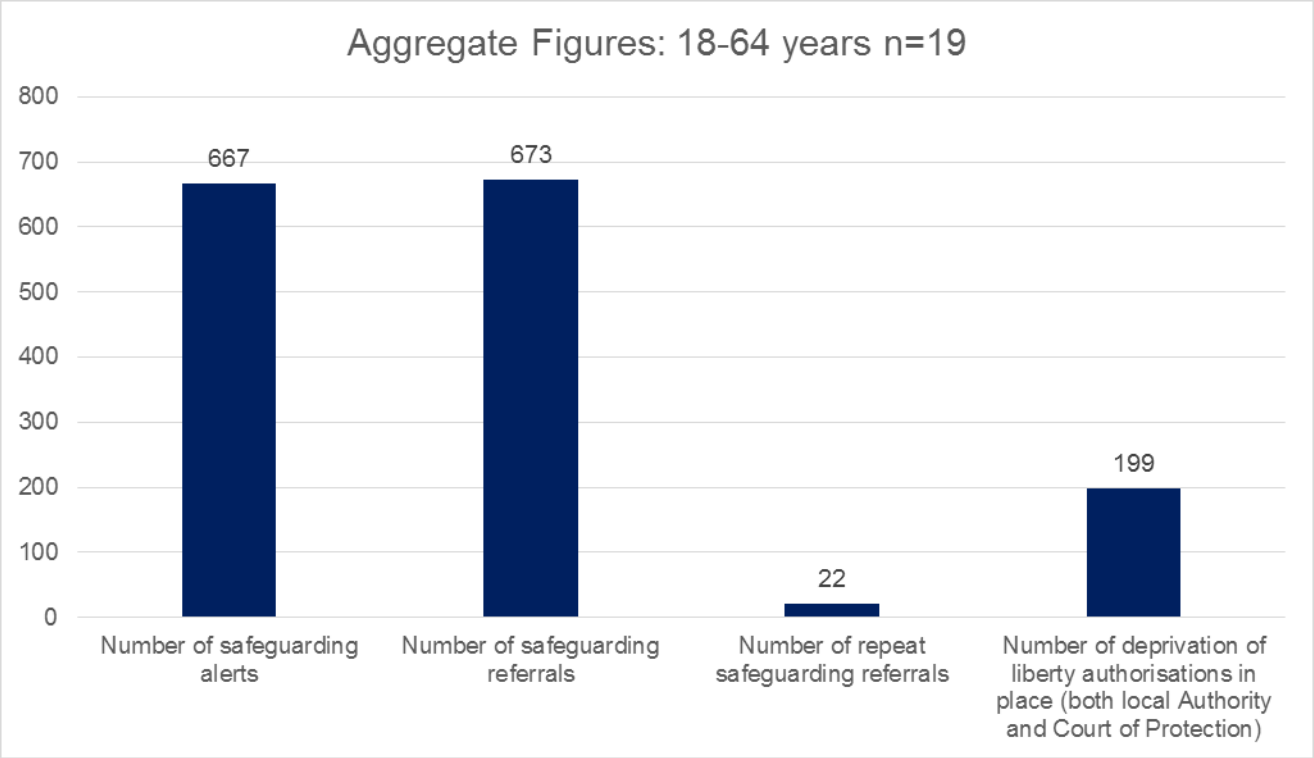
For more information on the project and the evaluation, see: http://www.mdi.org.uk/content/files/NPI_final_reportsmallpdf.com.pdf

8.6 Safeguarding

This section shows data[181] relating to safeguarding and the deprivation of liberty for people with Dementia within Council area (as of March 2015) and by age group.

[181] St Helens data for both number of safeguarding alerts and referrals may be skewing the results, therefore data may need to be validated.

Figure 8.2: Safeguarding for the 18-64 Age Group

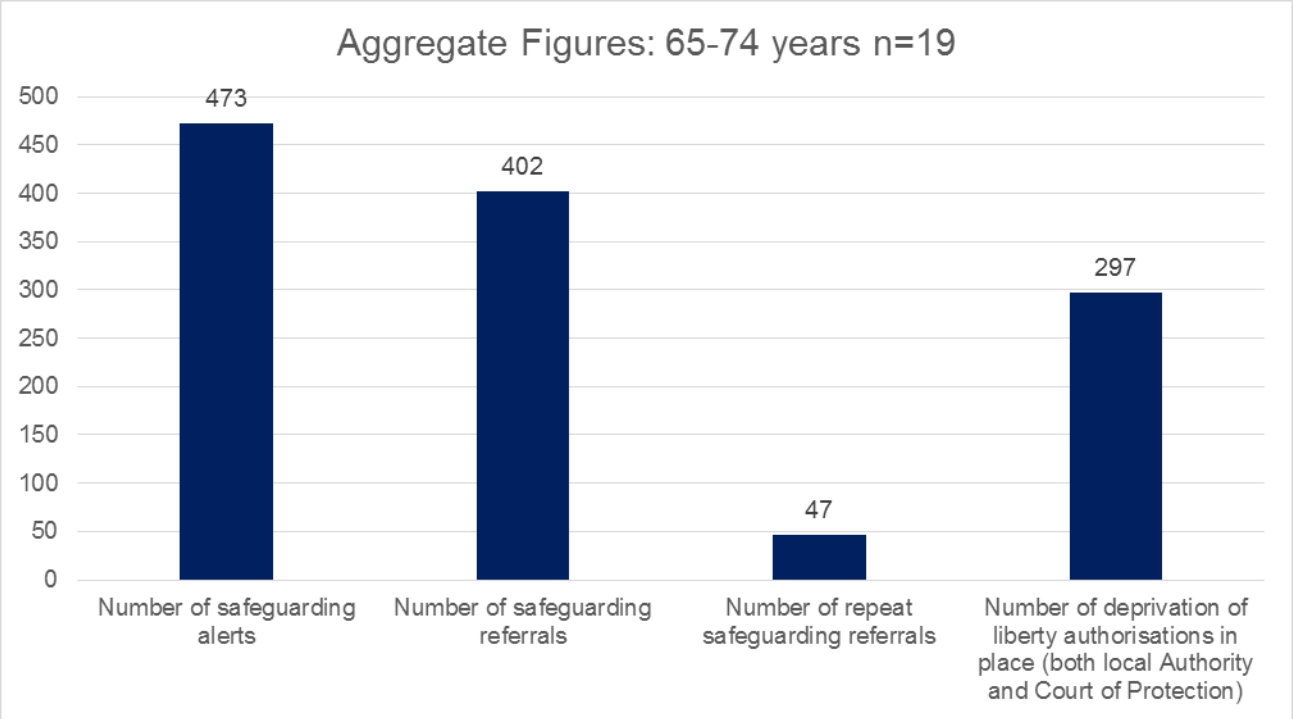


The above data shows the aggregated figures for the 18-64 year group in terms of the number if safeguarding alerts and referrals, the number of repeat safeguarding referrals and the number of deprivation of liberty authorisations in place (both local Authority and Court of Protection.) The first two figures appear to be distorted by the information that St Helens provided and it is likely that these figures are incorrect.

Lancashire Council represent the highest number of safeguarding alerts with 33 (excluding St Helens.) Both Halton and Cheshire East Council areas make up the highest number of safeguarding referrals as they both have 27 (again, excluding St Helens.) There was only eight figures provided for the number of repeat safeguarding referrals, but of these seven, Cheshire East had the most amount of repeat referrals with 14.

Both Cheshire West & Chester Council and Cheshire East Council make up a significant proportion of the total number of deprivation of liberty authorisations with 50 and 44 respectively.

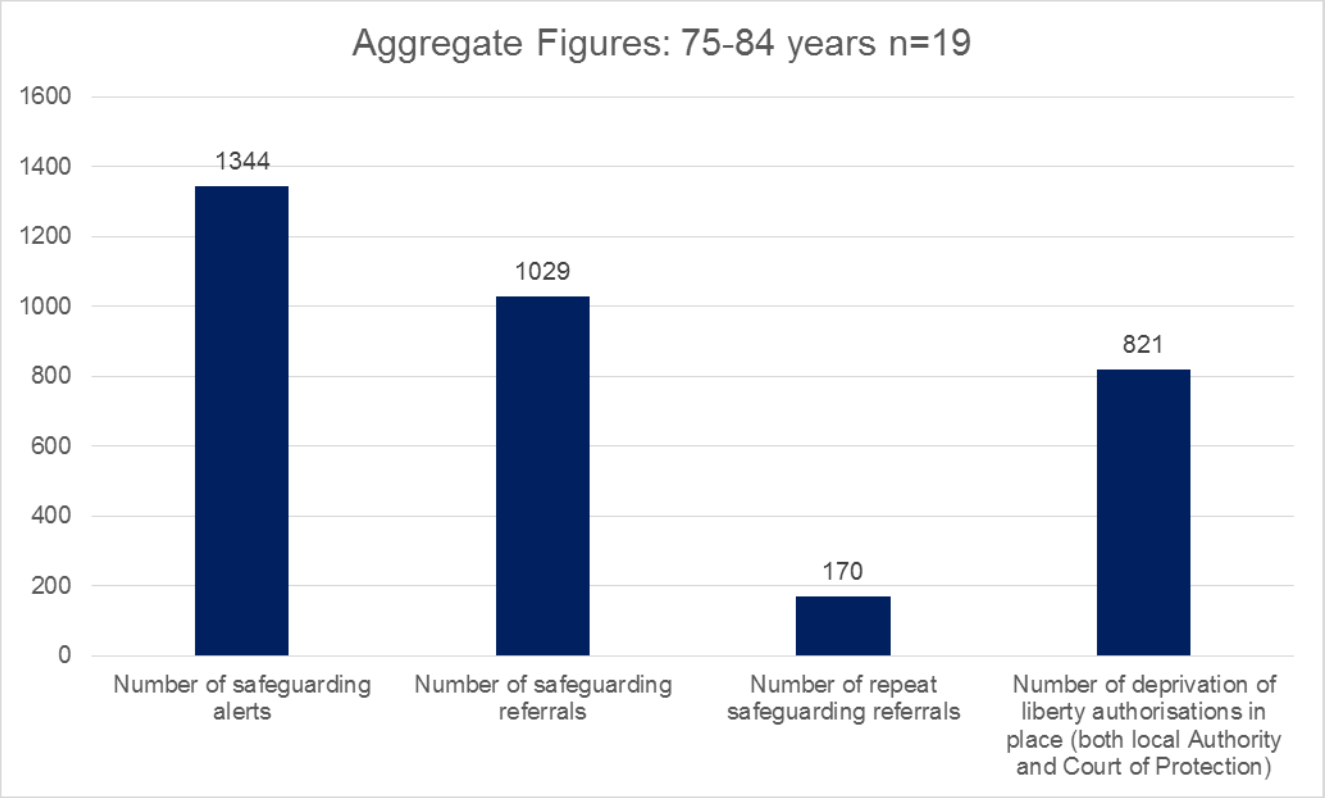
Figure 9.3: Safeguarding for the 65-74 Age Group



For the 65-74 age group, St Helens make up the biggest proportion of safeguarding alerts and referrals with 172 for both of these[182]. Lancashire have the second highest number of alerts with 109, while Liverpool have the second highest number of referrals with 72. Lancashire have the highest number of repeat safeguarding referrals with 24 while Liverpool have the highest number of deprivation of liberty authorisations in place with 87.

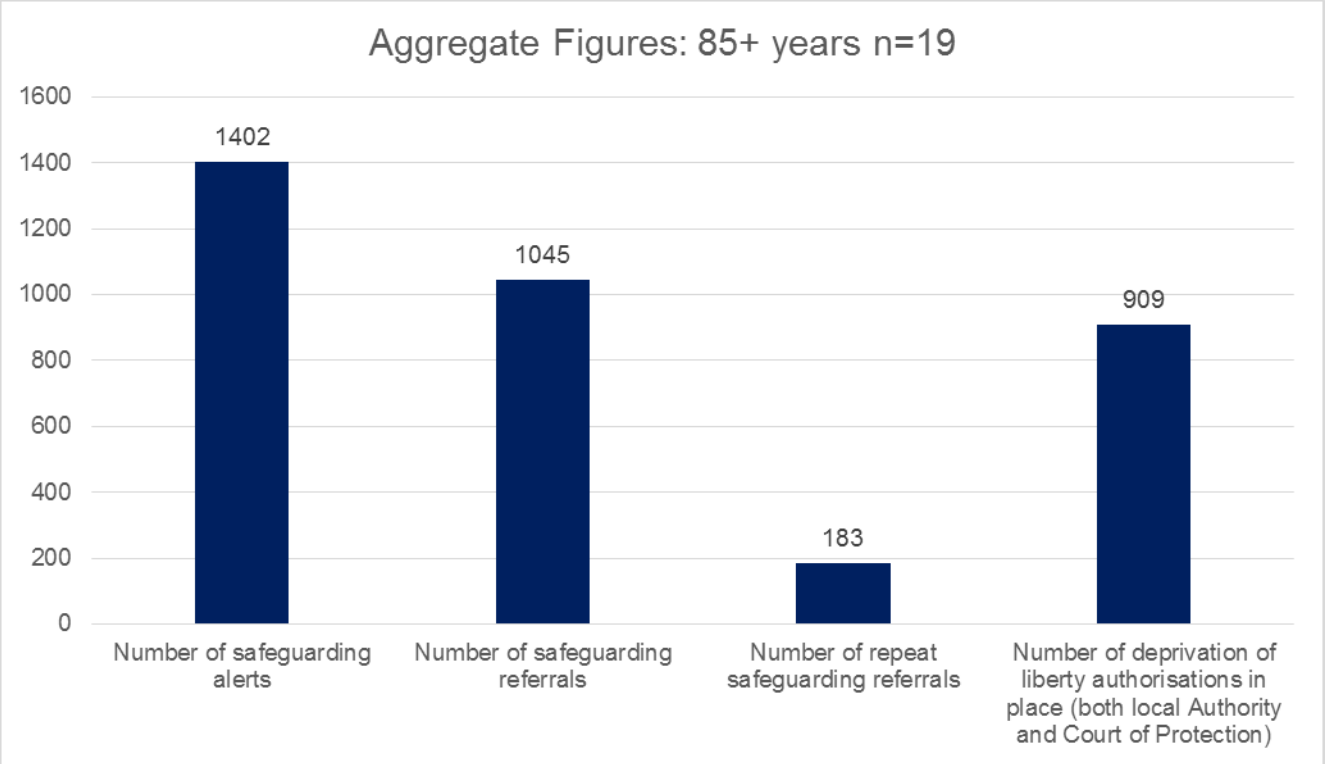
[182] Data from St Helens may need to be validated due to high value that may skew the results.

Figure 9.4: Safeguarding for the 75-84 Age Group



With the 75-84 age group, Lancashire have the highest number of alerts with 385 while St Helens have the highest number of referrals with 275. Liverpool have the second highest number of referrals with 228. Again, Lancashire have the highest number of repeat safeguarding referrals with 104 while Liverpool have the highest number of deprivation of liberty authorisations in place with 221.

Figure 9.5: Safeguarding for the 85+ Age Group



Finally, for the 85+ age group, Lancashire again have the highest number of alerts with 453, while St Helens have the highest number of referrals with 277. Liverpool have the second highest number of safeguarding referrals, 213, and Lancashire has just marginally less with 211. With repeat referrals, Lancashire has 141 and also has the same number for deprivation of liberty authorisations in place with Liverpool having the highest number with 184 and Cheshire East being joint with Lancashire for the second highest with 141.

9 CONCLUSIONS AND RECOMMENDATIONS

9.1 Introduction

The section summarises the key findings from the previous sections of the reports and sets out the recommendations that have emerged from this review.

9.2 National and Local Context

The 2015 dementia prevalence data shows that the North West has a higher prevalence rate than the national average, at 0.79 compared to 0.74. This equates to 58,000 people with dementia in the region which is expected to rise to 69,000 by 2020.

The Prime Ministers Challenge on Dementia 2020 sets the national policy for services for people with dementia and their carers. A review of local plans, policies and supporting papers from the 23 local areas across the NW has demonstrated that dementia has been prioritised by the majority of Councils through the development of specific strategic and dementia focused actions in JSNAs, Health and Well-being Strategies and Commissioning Strategies.

There were a number of common themes emerging from these local strategy documents, including the need to implement services and activities to increase the level of support to people with dementia (and their carers) living in the community, which will in turn reduce the need for other forms of care such as hospitals and nursing homes. The need for improved co-ordination in dementia care was also highlighted as an objective for the majority of local authorities, this included improved integrated working and joint commissioning. In addition to this around one third of the local authorities also noted the need for accurate and timely data on people in the community living with dementia, this data is required to plan and effectively manage dementia services. For example, in 2015, the Lancashire County Council commissioned work to fill a gap in intelligence about people with young-onset dementia. The results were used to inform commissioning decisions about dementia services for younger people in Lancashire[183].

The financial pressures faced by local authorities in England are well documented. From 2010 to 2014 local authorities have delivered efficiency savings of £3.53 billion to adult social care budgets[184]. In addition to this some local authorities have also reported increased demand on services as the proportion of older people in the population increases. Local authorities across the North West have implemented a number of initiatives to enable the continued provision of services for people with dementia within these budgetary constraints including a reduction in domiciliary care and beds in nursing and residential homes, as well as an increase in integrated working in order to provide services more efficiently.

9.2.1 Policy & Strategy Recommendations

There are strong national and regional policy drivers to prioritise dementia. All local Authorities within the North West should ensure that the planning and delivery of dementia services is prioritised and documented within key strategic documents, such as Joint Strategic Needs Assessments, Health

[183] Jones, G. (2016). 'Young Onset Dementia in Lancashire-12: 2014-2030. An assessment of population need'.
[184] ADASS Budget Survey 2014

Well-being Strategies and Commissioning Strategies. Local Authorities may also wish to consider if separate Dementia Strategies are required for their area.

Gaps in knowledge and data were identified in a number of areas, particularly in relation to the provision and uptake of services such as assistive technology, specialist housing and care in the community. At the moment the Short and Long-term Support (SALT) and Adult Social Care Outcomes Framework (ASCOF) data returns state that the only mandatory data collection set is Autism and Asperger's, therefore dementia specific data collection is at the discretion of each local authority. Up to date, validated dementia specific data is required in each area in order to plan and deliver dementia services effectively. All local authorities should work closely with their CCG colleagues to ensure that they have access to the most up to date statistical data relating to people living with dementia. Detailed demographical information is required to ensure that services are relevant and sensitive to the needs of local populations. ADASS should consider if a regional approach to the data collection can be implemented in order to ensure that data is collected in a consistent manner, to facilitate regional and comparative analysis.

9.3 Regional Groups and organisations

The NW ADASS Network is responsible for the commissioning and delivery of adult social care and support services across the North West. Dementia is one of sixteen themes of ADASS's work and the ADASS Dementia Network works with members to encourage implementation of the plans and priorities set out for then within the Prime Minister's Challenge. ADASS noted that the voluntary and community sector are crucial to the effective delivery of services and initiatives both nationally, and in the North West. National bodies such as the Alzheimer's Society and Dementia UK deliver and co-ordinate a wide range of activities in the UK and the North West.

The recent development of Dementia United brings a co-ordinated, sub-regional approach to planning and delivering dementia services across the Greater Manchester area. This standardised approach and partnership working at a sub-regional was recognised as good practice within the Prime Minister's Challenge on Dementia 2020 Implementation Plan[185].

A review of relevant policy documents at a local level and the review of dementia groups and organisations indicates that the level of partnership working and integration varies considerably across the North West. The Prime Minister's Challenge on Dementia notes that a wide range of stakeholders are required to support people with dementia and their carers.

9.3.1 Recommendations

The standardised approach to dementia services that is being implemented in the Greater Manchester area through Dementia United provides the opportunity to develop and deliver dementia services and share good practice at a sub-regional level. This sub-regional level of partnership working should be considered in other areas of the North West.

There are a number of organisations that have already been established that can provide access to people with dementia and their advocates (e.g. Dementia Action Alliance and Healthwatch). Statutory health and social care organisations should ensure that they engage with these

[185] Prime Minister's Challenge on Dementia 2020 Implementation Plan (2016).

organisations when consulting with people with dementia and their carers, for example in the development of dementia strategies.

Information from the Prime Minister's Challenge on Dementia and a review of the groups and organisations involved in dementia in the North West suggests that there may be low levels of awareness of dementia in minority communities and therefore potentially low numbers of people accessing early intervention dementia services. Furthermore, a review of the literature suggests that people from certain ethic groups may be more susceptible to dementia[186] and prevalence statistics indicate that the rates of dementia amongst those from ethnic minority groups is expected to increase steadily[187]. At a local level, partnership organisations such as Dementia Action Alliance should engage with local ethnic minority representative groups to encourage their participation and to determine the most effective way of engaging with people with dementia from minority ethnic groups.

9.4 Research on dementia

There is a strong national policy directive supporting dementia research in England, the Prime Minister's Challenge on Dementia, National Dementia Strategy and NICE all advocate the need for research to identify effective treatments and support for people with dementia. Additionally, there is a vast range of research relating to dementia that is conducted by the Universities in the NW, covering both the clinical and social aspects of dementia. These universities also coordinate activities and events designed to raise awareness and knowledge of dementia, as well as other, related disorders. In November 2015, Liverpool Hope University hosted an event on behalf of the Liverpool DAA that educated local businesses on dementia. Additionally, the University of Manchester funded an arts and science collaboration in 2015 with the aim of using the learning from the collaboration to inform other, similar activities for people with young onset dementia on a local, regional and national basis. Finally Cumbria University are one of the 53 universities in the Higher Education for Dementia Network (HEDN) and launched a new curriculum to improve dementia education in the UK.

A review of the relevant literature, along with consultations with key stakeholders, highlighted potential gaps concerning the knowledge and understanding of dementia that could benefit from further research. These gaps include:

- Early on-set dementia;
- End of life care; and
- Dementia amongst ethnic minority groups.

9.4.1 Recommendations

There is considerable dementia research activity taking place across the North West and it is important that research findings are disseminated to those who are responsible for planning and delivering dementia services. Relevant staff / research groups from the Universities should be

[186] Knapp, M., Prince, M., Albanese, E., Banerjee, S., Dhanasiri, S., Fernandez, J-L., Ferri, C., McCrone, P., Snell, T., Stewart, R. (2007) *Dementia UK. A report to the Alzheimer's Society on the prevalence and economic cost of dementia in the UK.* Available at https://www.alzheimers.org.uk/site/scripts/download_info.php?fileID=2

[187] Department of Health (2009) Living well with dementia: a national dementia strategy, London: Department of Health

encouraged to participate in partnership groups such as Dementia Action Alliances and any other sub-regional groups that may be established to support the dissemination of research findings in order to ensure that the research can have as much impact as possible.

In order to address some gaps in knowledge about dementia service providers (local authorities and health Trusts) should engage with researchers and research networks. This may provide the opportunity to influence research projects at an early stage, for example by shaping research questions.

9.5 Services

Councils provided information which highlighted the wide range of services in their area for people living with dementia and their carers. Feedback from consultations highlighted that, in many areas, the actual diagnosis or condition of service users was not always recorded, meaning that unless the services were dementia specific, usage data was difficult to determine.

Sixteen councils noted that there is a Dementia Liaison Service in their area, nine of which follow the RAID model (Rapid Assessment Interface and Discharge). Rapid Assessment and Liaison services are specialist, multi-disciplinary teams working in acute hospitals to support adults attending A&E who may have mental health problems. The RAID model was evaluated in Birmingham and was found to improve the quality of care of older people by reducing their length of stay, avoiding their admission to acute hospital beds, and discharging them in increased numbers back to their original place of residence, rather than an institution or care home. In addition, the RAID model has been shown to reduce the readmission rate after discharge by 65% in comparison with a pre-RAID group[188]

Seventeen (89%) councils noted that they have schemes and processes in place to identify people with dementia in hospital. This is an important aspect of ensuring that they have access to appropriate care and support. However, not all areas were able to provide data on the number of people with a primary diagnosis of dementia who had been admitted to hospital.

Assistive technology is reportedly being used more frequently by local councils to support those with dementia to live at home for longer. Sixteen councils reported providing assistive technology to at least 13,800 service users (five council areas were unable to provide the total number of people using assistive technology with dementia). The technologies provided included a wide range of sensors and trackers to help keep people with dementia safe in their own homes and to make them comfortable. Seven Councils also reported that they provide specially adapted housing for people with dementia. Cumbria noted that they have been working with Stirling University to implement a dementia friendly design for the homes of people with dementia. They noted that an evaluation of this service increased health and well-being, reduced falls and delayed admissions to nursing homes.

The CQC datasets identified 886 dementia nursing and care homes in the North West in 2015, with a total of 63,062 dementia beds. The number of beds per person with dementia varied considerably across each council area, ranging from 0.37 in Salford to 0.98 in Oldham, with an average of 0.65 across the Region. However, the level of occupancy within each care home or the level of care

[188] *Singh, I. et al The Rapid Assessment Interface and Discharge service and its implications for patients with dementia. Clinical Interventions in Aging. 2013; 8: 1101–1108*

provided is not known, therefore it is not possible to undertake a comparative analysis by council area.

Improved end of life care is an objective within the National Dementia Strategy. Nice guidelines[189] also note that palliative care planning should begin from the time a dementia is made. Sixteen councils noted that they have dementia specific end of life care plans, three councils noted that they are in the process of developing new end of life care plans.

Twelve Councils reported the development of Dementia Friendly Communities and consultees noted interesting cases studies and examples of activities and strategies that have been implemented to make life easier for people with dementia living in their community. Five further councils noted that they are planning to implement dementia friendly community projects.

9.5.1 Recommendations

Given the reported effectiveness of RAID services for people with dementia in hospital, all council areas and acute hospitals in the North West should ensure that effective dementia liaison services are provided within acute hospitals. ADASS should engage with Health Trusts and CCGs in order to ensure that the most effective liaison services are delivered in the areas.

Councils should consider the most effective and efficient way to ensure that health and social care staff have received dementia awareness training, it is likely that to ensure appropriate coverage and to reduce any potential for duplication this should be done in co-ordination with the local CCG.

In line with NICE guidelines and the Prime Minister's Challenge all Council areas should have dementia specific end of life care plans. These should allow people with dementia to make decisions about their end of life care and place of death and planning should take once dementia has been diagnosed.

Work should continue to develop Dementia Friendly Communities across the North West. These initiatives should be implemented in consultation with people with dementia to understand how and where the initiative would have the most impact for them.

9.6 Cross Cutting themes

Data from Skills for Care indicates that there are around 55,000 people in the adult health and social care workforce in the North West working with people with dementia and that only 12% of these jobs are with local authroirties[190]. Therefore, this shows that local authorities employ a small percentage of the dementia workforce and would be required to work with others such as private and voluntary sector providers to ensure that staff are appropriately trained.

A review of the literature in relation to dementia care highlighted that having a suitably trained workforce is key to the delivey of good quality services. Stockport has the highest percentage of staff with a qualification of NVQ level 4 or above (at 28%) in relevant social care qualifications.

[189] https://www.nice.org.uk/guidance/cg42/ifp/chapter/palliative-care-and-care-for-people-nearing-the-end-of-life
[190] http://www.skillsforcare.org.uk/Document-library/NMDS-SC,-workforce-intelligence-and-innovation/NMDS-SC/Regional-reports-2015/SFC-NWREGION-WEB.pdf

Furthermore, seven Councils noted that they have created Care Alliances in their Council area in order to provide training to improve the care workforce.

Four councils noted that they had undertaken specific activities to engage with people from ethnic minorities. These have included engaging with representative groups to raise dementia awareness and providing culturally sensative services and activities

9.6.1 Recommendations

Staff training is a key aspect to providing good quality care to people with dementia. Local Authorities and ADASS should ensure that staff are trained appropriately and that staff from those commissioned services also have access to good quality training. There are a number of resources that local authorities could access to support this, for example Skills for Care provides a National Framework on training and Dementia Care Training Programme.